

Social Inclusion (ISSN: 2183–2803) 2023, Volume 11, Issue 4, Pages 291–302 https://doi.org/10.17645/si.v11i4.7105

Article

Halin ai: Intersectional Experiences of Disability, Climate Change, and Disasters in Indonesia

Desy Ayu Pirmasari and Katie McQuaid *

School of Geography, University of Leeds, UK

* Corresponding author (k.r.v.mcquaid@leeds.ac.uk)

Submitted: 29 April 2023 | Accepted: 3 October 2023 | Published: 5 December 2023

Abstract

Halin ai centres the lived experiences of climate change and disasters of people living with disabilities in two urban sites in Indonesia—Banjarmasin in South Kalimantan and Mataram in West Nusa Tenggara. We call for an intersectional and decolonial approach to better understand how disabilities intersect with social and structural injustices in urban settings to shape diverse responses to climate change and disasters. We highlight the economic, socio-cultural, and embodied challenges that increase vulnerability to—and ability to recover from—disasters including urban flooding and earthquakes. We draw on ethnographic and visual data from our research, including a comic illustrated by Ariel and Zaldi and sketches by Rizaldi, to centre diverse lived experiences of structural vulnerabilities and socio-cultural marginalisation, particularly concerning education and livelihoods. Foregrounding life stories in this way serves to challenge the absence of meaningful engagement of people with disabilities in disaster risk reduction and climate change actions and decision-making. Our article highlights disability as a site of both discrimination and critical embodied knowledge, simultaneously a product of structural, socio-cultural, political, and environmental injustice while also a source of innovation, resilience, and agency.

Keywords

climate change; decolonial; disability; disasters; hazards; Indonesia

Issue

This article is part of the issue "Disabled People and the Intersectional Nature of Social Inclusion" edited by Alexis Buettgen (McMaster University), Fernando Fontes (Universidade de Coimbra), Susan Eriksson (South-Eastern Finland University of Applied Sciences), and Colin Barnes (University of Leeds) as part of the (In)Justice International Collective.

© 2023 by the author(s); licensee Cogitatio Press (Lisbon, Portugal). This article is licensed under a Creative Commons Attribution 4.0 International License (CC BY).

1. Disasters and Disability in Indonesia

When an earthquake struck Lombok Island in West Nusa Tenggara, Indonesia, at night in 2018, Zainal (all names in this article are pseudonyms), who is blind, was working as a massage therapist. When the building began shaking all customers began fleeing the building in panic. Zainal and his colleagues did not know where to go. Even though they were finally able to find the door and exit the building, due to limited sensory ability they had no way of knowing if they were in a safe location:

We did not know if there were nearly falling rooves or walls around...it was near the main street as well and

people were running and driving all over the place as there was a rumour about tsunami at that time.

There were no railings or guiding blocks to help them, and no one offered any help or support, so all they could do was wait and hope that it would soon be over. Meanwhile, just outside the city of Mataram, Putri—who uses crutches and a wheelchair—and is an active member of a women's disability organisation in Lombok, explained how she and many others had been helped to flee during the same earthquake, but their mobility aids had been forgotten, reflecting a common lack of understanding by community agencies regarding the specific needs of people with disabilities during and in the



aftermath of disasters (see Lindsay et al., 2022). This led to increased difficulties in the immediate aftermath of the earthquake, exacerbating their discomfort and ability to recover. Once in the shelters, she reports, women with disabilities found themselves especially vulnerable to harassment when they were asleep, and we heard many examples of women being harassed when using the toilets and washing facilities.

Indonesia is situated in the "ring of fire," prone to hazards and disasters including volcanic eruptions, landslides, earthquakes, tidal waves and abrasion, and flooding. According to Indonesia's National Disaster Mitigation Agency, in 2022 there were a reported 3,542 disasters, displacing over 5.3 million people and killing over 850 (Aditya, 2023). Within the first three months of 2023, the country recorded 564 disasters, of which more than 40% were floods, followed by extreme weather, landslides, forest fires, and earthquakes (Annur, 2023). A disaster, Rydstrom and Kinnvall (2020, p. 2) remind us, "unfolds societal dynamics at the structural level and a community's relation to its environment," which further shapes their "capability to adapt and the extent to which local knowledge can be infused to reduce vulnerability and harm." It is therefore critical we address the disproportionate and unequal impacts of disasters on people as a result of geographic, structural, and social marginalisation including poverty, gender, age, colonialism, race, ethnicity, disability, and indigeneity (see Wisner et al., 2012), and the extent to which this further excludes their experiential knowledge from decision-making. To do so here, we centre the perspectives of people with disabilities.

Evidence on the experiences of people with disabilities during Indonesia's disasters remains scant and representations of disasters by people with disabilities continues to be neglected within planning and policy at multiple scales. Following Spivak (2003) and Gaillard (2022, p. 13) we understand "representation" as a call for spaces in which diverse people with disabilities can speak, write, and ultimately define what a disaster is, what it entails, and what needs to be done to reduce risks. In the process, this can challenge the ongoing colonisation (and lack of inclusivity) of both disaster and disability discourses.

This is an urgent issue. People with disabilities are four times more likely to die when a disaster strikes than those without disabilities (UNESCAP, 2014, 2017). Disasters can worsen pre-existing disabilities and create new disabilities (Kelman & Stough, 2015; Sheppard & Landry, 2016; UNESCAP, 2014), and people with disabilities are among those least able to access support or social assistance. Critically, this vulnerability is due not to their bodies and minds, but to multiple and reinforcing systemic (and normalised) socio-cultural, economic, and political barriers in daily life (Calgaro et al., 2020, p. 370; Gaskin et al., 2017; IFRC, 2007; Sheppard & Landry, 2016; World Health Organization, 2017); as well as "the hegemony of Western knowledge in disas-

ter studies," which supports "normative and standardised disaster risk reduction policies and actions, which in many instances fail to consider the diverse realities of very different local contexts around the world" (Gaillard, 2022, p. 2).

We thus understand disability as socially contingent and relative (Eriksen et al., 2021); as a site of discrimination and a product of structural, political, socio-cultural, and environmental injustices and violence (Belser, 2020; Lawson & Beckett, 2021; Oliver, 1996). Some bodies are more vulnerable to disabilities than others, and have different lived experiences of disability due to myriad intersecting factors, including the unequal impacts of environmental harms, social factors including gender, race and age, and the social and structural norms that standardise notions of in/ability to perform certain activities, communicate, and engage with society (Gaskin et al., 2017; Griffo, 2014). In this way, we recognise how ableism operates as a socio-political mechanism of marginalisation, systematically reinforcing the social differentiation of disability and vulnerability (S. Bell, 2019), and converging with other axes of oppression to manifest a "double invisibility" for many groups including, for example, women and children with disabilities (Jodoin et al., 2020). Increasingly popular among activists in Indonesia is the term difabel (diffability), derived by Mansour Fakih and Setiadi Purwanta, two blind people in Indonesia, from the English "differently-abled people" as a critique of the term disabilitas (disability), which perpetuates and re-produces the marginalisation of people with disabilities and fails to recognise (or normalise) the diversity of "ability" (Suharto et al., 2016; Thohari, 2011). Critically, we also recognise disability as a site of critical embodied and experiential knowledge and socio-political resistance (Belser, 2020). Thus, in this article, we will continue using the term "people with diffabilities." Diffabled people have the embodied knowledge, agency, and ability to strengthen decision-making processes and disaster risk reduction (DRR) strategies for the benefit of whole societies (Pertiwi et al., 2019).

We must adopt an intersectional approach to foreground embodied diversity and highlight how poverty, structural exclusion, social disadvantage, and other categories of difference disproportionately render people with diffabilities more vulnerable to climate change and disasters (C. M. Bell, 2011; Engelman et al., 2022; Erevelles & Minear, 2010; Priestley & Hemingway, 2006). This further serves to direct attention to "gender differences in perceptions, impacts, and responses" (MacGregor, 2010, p. 137) to better understand gendered impacts, for example how women and girls with diffabilities come to be at greater risk of violence, physical abuse, and sexual exploitation after disasters due to displacement and unsafe shelters and public spaces (Calgaro et al., 2020, p. 370; Smith et al., 2012). As Green et al. (2018) argue regarding the lived experience of First Nations diffabled people in Australia, an intersectional approach is necessary if we are to address cumulative



systems of social inequalities perpetuating the experience of multiple and intersecting barriers and discriminations, each of which work to amplify and compound the impact of each other (Cooms et al., 2022). Such systems shape the "set of diverse knowledge, skills and resources people can claim, access and resort to in dealing with hazards and disasters" (Gaillard, 2022, p. 31).

In Indonesia, the rights of diffabled people are protected under Law No. 8/2016 on Persons With Disabilities. This stipulates various rights for people with diffabilities from access to jobs and employment, disaster response, and support and help. On the international scale, legal frameworks and conventions (e.g., the UN Convention on the Rights of People With Disabilities, Sendai Framework for Disaster Risk Reduction 2015–2030, and the Incheon Strategy 2013-2022) recognise that inclusion in DRR processes is a human right and must be factored into DRR policy and practice to significantly reduce risk (UNESCAP, 2012; UNESCAP & UNISDR, 2012; UNISDR, 2015). People with diffabilities should therefore be afforded the same rights as any other citizen to both risk reduction and management measures and the right of equal participation in the design and implementation of DRR policies and practices. However, pathways to achieving inclusion and greater justice for diffabled people are unclear and fragmented, with very few documented cases of success (Calgaro et al., 2020, p. 369; Weibgen, 2015). In a 2013 report by the UN's Office for DRR, 85% of respondents living with diffability from 137 countries stated they were not involved in community disaster management and risk reduction processes and policies (UNISDR, 2014). As Calgaro et al. (2020, p. 373) note, diffabled people are "largely unseen, unheard and unaccounted for in all levels of disaster management due to normalised exclusionary policies and practices of communities, governments and disaster assistance organisations" (see IFRC, 2007; King et al., 2019).

People with diffabilities are routinely robbed of their agency and right to a public "voice" by normalised medical models of diffability within climate and development discourses that locate "problems" and "impairments" within individual non-conforming bodies, undermining rights-based approaches that recognise diffabled people as capable agents (Belser, 2015; Calgaro et al., 2020; Gartrell & Hoban, 2013). As the rate of disasters increases in many climate frontlines across the world, it is more important than ever that we centre the lived experiences of diffabled people. In doing so, we must situate their stories within broader postcolonial, political, socio-cultural, and geographic landscapes, and analyse "the specific historical and culture-specific meanings of disability, physical and mental differences" (Parekh, 2007, p. 150). We need to actively listen to diffabled people to better understand how interconnected systems of power work to create and reinforce systemic inequalities that increase vulnerability to—and capacities to recover from—disasters. We can then radically reconsider how we practice inclusion, representation,

and engagement in climate and disaster governance. A decolonising approach is therefore as critical as an intersectional one.

Contemporary diffability studies continue to risk constituting "a form of scholarly colonialism, and needs to be re-thought taking full account of the 400 million disabled people living in the global South" (Meekosha, 2011, p. 668; see also Connell, 2011, p. 1372). As Livingston (2006, p. 125) points out, "while four-fifths of the world's disabled persons live in developing countries, there is a relative dearth of humanities and social science scholarship exploring disability in non-Western contexts." We agree with Puar (2017), who highlights the uneven risks faced by certain bodies and populations, which is further exacerbated by the intersectionality of race, age, gender, sex, cultures, poverty, and healthcare inequalities.

A postcolonial lens is necessary to understand how power structures have—and continue to—manufacture diffability. Colonialism, as Connell (2011, p. 1374) reminds us, brought "crisis to the social orders in which embodiment had been organised...creating new hierarchies of bodies," and changing "the ways in which bodily difference, impairment and ability were socially constructed." Colonial regimes disrupted socio-cultural meanings (and often acceptance) of diffability through the imposition of new gendered and patriarchal social orders. Then, as local gender orders became "subsumed in a global economy, a modernised patriarchy has become internationally hegemonic" (Connell, 2011, p. 1376). This translates into particular gendered burdens differently experienced by men, women, and sexual and gender diverse people with diffability, disproportionately so for those living in poverty. As Meekosha (2011, p. 671) points out, "disability in the global South is firmly linked to northern imperialism, centuries of colonisation and globalisation." In pre-colonial Indonesia, the perception of diffabled people was not negative, and they were often considered to have supernatural powers (Widinarsih, 2018). However, white colonialism and the introduction of "Western" medicine introduced the perception of diffability as an affliction in need of treatment (Thohari, 2011). Widinarsih (2018, p. 76) highlights how the social exclusion that led to contemporary discrimination and abuse towards diffabled people is a legacy of this colonialism, in which they came to be seen as unproductive and in need of being "normalised" through nursing homes and rehabilitation agencies. To borrow Puar's (2017) term, this perpetuated a "right to maim," in which certain bodies were—and continue to be—contained and maintained in precarious conditions.

Postcolonial diffability studies increasingly highlight how diffability and poverty go hand-in-hand. We must therefore attend to "layerings of disadvantage," which create "unexpected barriers and unique priorities for an individual and family that can be described as a "wicked problem" that is resistant to conventional approaches of redress" (Cooms et al., 2022, p. 3). In recognition of



the historical, structural, and systemic manufacturing of diffabilities, we must consciously define people not by their dis—or in-ability, or their exclusion, but by diffability: adopting a "strength-based understanding of our differences" (Acker-Verney, 2016, p. 413) that directly leads from lived experience and embodied knowledge. To do so, in this article, we intentionally centre the lived experiences of diffabled people in two sites in Indonesia— Banjarmasin in South Kalimantan and Lombok in West Nusa Tenggara. Banjarmasin is situated on the third largest island in the world and located below sea level where floods regularly occur, while Lombok Island is vulnerable to coastal erosion and earthquakes. In 2018, Lombok was hit by a magnitude 7 earthquake causing over 555 fatalities. In the following section, we outline our feminist intersectional methodology before empirically exploring the experiences of those born with diffability and those who later acquire diffability. We aim to highlight the cumulative structural, socio-economic, and physical challenges that compound their vulnerability to—and ability to recover from—disasters including urban flooding and earthquakes, while simultaneously foregrounding the creativity, innovations, survival mechanisms, and activism of diffabled people.

2. Methodology

This article draws from a combination of ethnographic and applied arts methods conducted as part of a wider project adopting feminist, decolonial, and intersectional methodologies to investigate the gender-ageurban interface of climate change in Indonesia. To do so, our work explicitly focuses on marginalised urban communities including women, people with diffabilities, older and indigenous people, informal workers, and sexual- and gender-diverse communities. Conducted over nine months in 2022, our research comprised participant observation, in-depth ethnographic interviews, and 52 creative workshops that combined visual and applied arts including creative writing, drawing, digital storytelling, songwriting, and local arts.

Our creative sharing workshops involved over 15 civil society organisations led by (and serving) the communities participating in them as co-facilitators and research partners. We invited local artists to co-facilitate multiple workshops with the same group of participants to enable them to explore different perspectives on climate change and disasters in ways that embraced multiple ways of knowing including the embodied, sensory, and non-linguistic. This simultaneously served to build solidarity and raise critical consciousness of the structural injustices driving vulnerability to disasters. Artists provided training to participants in different art forms while also producing creative outputs that synthesised key experiences and perspectives.

As far as possible our research was designed and conducted in collaboration with the communities themselves to foreground local priorities and build ownership.

This served to resist and subvert historical and colonial power dynamics of research by enabling the community itself to determine how this research was produced, including shaping the research questions and how they were asked, what methods and art forms were used, and how to analyse and apply the knowledge co-produced. In many cases, ethnographic interviews were conducted with participants after creative workshops to provide a safe space in which they could reflect on the workshop material and share personal experiences in more depth, as well as to reach participants who could or did not want to attend group workshops. Conversations, interviews, and workshops were conducted in either Banjarese, Sasak, or Bahasa Indonesia, and where necessary translated by our local research assistants (including those with diffabilities). All interviews and workshops were recorded and transcribed in full and data was first analysed in the original languages to maintain a connection with local contexts and centre local values. All data was collected in adherence to strict ethical and safety protocols co-designed with communities to incorporate locally situated knowledge and expertise within the ethical frameworks of the University of Leeds and the Indonesia National Research and Innovation Agency.

3. Precarious Livelihoods, Gender, and Spatial Poverty Traps

In Indonesia, poverty and diffability are often deeply intertwined, exacerbated by social exclusion and discrimination across multiple scales, from homes to public spaces, which prevents people from achieving equal opportunities. Many diffabled people are caught within spatial poverty traps, where the physical, natural, social, political, and human capital of an area is low while the poverty rates are high (Bird et al., 2010). A lack of educational and livelihood opportunities forces many into precarious low-paid work, and poor-quality housing susceptible to disasters, as we will see below.

For Pirmasari, this has personal dimensions. Her oldest brother, Ali, now 45, was known as si bisu, which literally translates as "mute," but in their natal village in the heart of Kalimantan Island, and Banjarmasin too, many people define it as "the deaf." He could not hear nor speak the language of everyone else in their village and slowly began to communicate using informal sign language as their family grew and villagers started to try speaking to him. When Ali was a child his neighbours and some family members often mocked him by covering their mouths and ear at him, scornful of his being unable to hear and speak. He now recounts the feeling of always being treated as if he was unable to think or help his family and everyone else. People always felt sorry or pitied him for being "different." He could not go to a Sekolah Luar Biasa (SLB), which literally translates as "extraordinary school" (another translation could be "unusual school"). There was (and is) no SLB in his village, and while there were SLBs on Java Island, it would have cost



too much money just to travel there, let alone stay and study, so it was never viable for anyone from his village.

Ali, like many diffabled people we spoke to, has no formal education or skills training, and faces an impossible job search, with employers regularly discriminating against all diffability. He has been forced to remain dependent on family members: "I will not marry and I will never have a family of my own," he reflects. This burden of not meeting the pressure to have a family is even greater when we consider the broader context of a patriarchal society in which men are expected to be breadwinners and the heads of their own family, taking care of their own elderly parents in time. It also has ramifications for how both himself and his ageing parents will be affected by, and have the capacity to recover from, disasters. Ali's comments reflect dominant social norms in which bodies are regulated and contained as able (or not) to pursue independent livelihoods, perform agency, or fulfil masculine and feminine ideals and markers of social ageing including getting married and bearing children. Yet Ali does play a key role within his household. When floods hit his village, he actively helps, shifting electrical items out of the rising waters; when his and neighbours' houses caught fire he used the water pump engine to dowse the flames.

Hilman discusses his childhood and growing up blind in Lombok. He went to an SLB until secondary school and in 2018 applied for public school, where he was almost rejected due to his diffability. That year Lombok was hit by a huge earthquake. He was in class and did not know what to do and no one helped him. He just took cover under a table until the shaking stopped. The situation almost made him give up and return to the SLB, despite always ranking first in his class. Later, he received an offer from the university. However, the discrimination continued. On one occasion, when speaking of his ambitions, his lecturer told him that "an educator [teacher and lecturer] should not be diffabled, there is no deaf teacher right?" Hilman started to believe this was true, feeling hopeless in the face of constant discrimination. However, his ability to compete academically with the non-diffabled and his achievements to date always bring back hope.

Discrimination by employers as well as educators is widespread. In practice employers (both private and public) are hesitant to recruit people with what are known in Indonesia as "heavy diffabilities" (sensory and mobility impairments). As Misnah, a woman in Mataram explains, people often misjudge her ability to conduct work like "everyone else": "Last year I applied for culinary art training, but I was not accepted. So many businesses do not want to accept us. There are many deaf friends unemployed because no one wanted to accept them." Putri, who uses a wheelchair in Lombok, describes how a recent job requirement by a state-owned enterprise: "looked for people with handicapped diffability and the deaf, but the deaf ones should have a hearing aid so they can communicate and the handicapped ones

should not use a wheelchair." In her case, diffability and age discrimination intersect: "In my case, I could not apply because of my age [47]." Many of our participants cited recent job adverts that clearly stated applicants "should not be blind, fully deaf, limp or use a wheelchair." In Banjarmasin, Fajar spoke of how, "in 2017 or 2018 during civil servants' recruitment, one of the conditions required in the applications was "not blind and not using a wheelchair." He and his wife lead a local diffability support group and filed a formal complaint to the government; the following year these conditions were removed, but a person with diffabilities has yet to be recruited. Routine exclusion and invisibility of diffabled people within workplaces act to reinforce their othering. It highlights the visibility of their diffabilities and further convinces family members that the diffabled people they care for will always remain dependent on them. This is further exacerbated by gender hierarchies, placing undue burdens on men with diffabilities to marry and act as breadwinners, and relegating women to the domestic realm.

These cases illustrate an in/visibility paradox. Due to their diffabilities, people are often rendered hypervisible and thus become a target for stigma and discrimination, including gender-based violence and harassment, while also driving their invisibility within work and public places. For women in particular this fuels their confinement to private and domestic spaces. Fears about gender-based harassment of women with sensory and mobility issues lead many parents of daughters with diffabilities to restrict their mobility and keep them at home. Community leaders from the Banjarmasin Chapter of the Indonesia Disabled People's Association reported to us increased cases of women being kept home from a young age. This had several long-term impacts including reduced educational outcomes and livelihood opportunities, social isolation from peers, and women taking on increased domestic burdens within the family including cleaning, tidying, cooking, and washing clothes. Figure 1 is an excerpt from a comic illustrated by Ariel and Zaldi to highlight some of these multiple burdens faced by young women with diffabilities as shared with us during fieldwork.

Mira and Irma, two diffabled women in Lombok, recounted how their parents often asked them to stay at home in order to protect them. As Mira wryly commented: "If I stay home I can get knowledge about washing...and if I stay home I can also look after my parents when they are old." Hilman, the blind man mentioned above, observed the contingency of this "protection":

Usually blind women were protected more by their parents...because of the stigma in the society....Sometimes I felt really sad and cried to hear news that deaf women were raped by their closest relatives, which made me think how prone are women with disabilities...and we do not know how to protect ourselves in that situation.





Figure 1. Excerpt from a Banjarese comic (with English translation) illustrated by Ariel and Zaldi about the experiences of women with diffabilities facing harassment on the street.

The intersecting forces of poverty, gender, age, and stigma not only shape the lives of people born with diffabilities, but also increase the risks of people acquiring diffabilities. Informal work and accompanying precarious incomes often restrict people's access to quality healthcare and routine medication, intersecting with ageing to exacerbate medical conditions, often leading to permanent diffabilities. During the writing of this article alone, we heard the distressing news that one of our participants had become blind due to ongoing complex health issues and persistent stress, while another had lost his legs due to a traffic accident. When we met Ahmad, a fisherman in his late 50s in Lombok. He had been recently paralysed from a diving accident. He used to work as a compressor diver: a fishing technique where he dived down to 30 meters using a dive regulator with a hose connected to an air compressor machine on a boat. Ahmad, along with many other compressor divers across Indonesia, did not wear proper scuba equipment and had limited access to diving health and safety standards, making them prone to decompression sickness. At the same time, as fishing communities in Lombok explained to us, economic pressures placed on men as the heads of their households translated into burdens to provide more money to the family, often forcing fishermen to push their bodies to the limit and jeopardise their own

health (Rakhman, 2018). In March 2022 after a long dive in Bali Strait, Ahmad was taken to hospital and put in a hyperbaric chamber. He could only afford to pay for 2.5 hours, not enough time to treat his decompression sickness, and thus led to his permanent paralysis. He has since been forced to sell his boat and engines due to economic difficulty. His economic precarity continues to rob him of his dignity as well as his health. He is unable to afford catheters or ongoing medical treatment, and spends his days confined to bed, placing a plastic cup inside his shorts to capture his urine.

Ahmad's case is not uncommon in Lombok. Fishermen have long faced injury, paralysis, or even death at sea in the pursuit of their precarious livelihoods. Their bodies are thus maintained in a precarious condition by the layering of economic, social, and environmental burdens. Fishing is becoming ever riskier as fishermen are forced to go further out to sea to fish, with limited equipment and a lack of communication devices (see Stoltz et al., 2021). As the fishing communities in Mataram say: "aiq sere rapet, empaq sere jaoq" (the water is getting closer, the fish is getting further). Coastal abrasion is bringing the sea closer to their houses, with high seas and rising levels of sand shrinking the height of their houses, all serving to increase anxiety among the fishing communities who live by the beach,



increasingly trapping them in cycles of poverty, diffability, and disaster.

The disproportionate environmental burdens faced by diffabled people was most obviously reflected in their residence in poor neighbourhoods vulnerable to disasters. In Banjarmasin, for example, many of our participants were forced by precarious livelihoods to live in poor quality, semi-permanent wooden housing on the riverside, which are increasingly vulnerable to flooding. In some cases, their flooring was literally rotting away from repeated soaking from rising water levels. Nila, who had become blind due to old age, said all she can do when it floods is to close her door so that her plates, cups, and other precious belongings do not float away. She simply sits on the bridge in front of her house to wait for the waters to recede. Environmental burdens facing these neighbourhoods—poor water and sanitation, bad roads, informal housing, water, and air pollutionintersect with the impacts of poverty—poor education, precarious livelihoods, and inadequate healthcare—to exacerbate the impacts of disasters, especially fires and floods, reducing residents' capacities to plan for or sustainably recover. Such layers of disadvantage disproportionately affect those with diffabilities, as well as the family members who care for them.

Figure 2 was drawn by Rahimah, a woman who uses crutches to move around, during a creative workshop in Banjarmasin.

When flood waters suddenly enter their house, she and her daughter have to seek immediate refuge on the bed, as this is the driest place in their house. Fajar, her husband, who is blind, has tried to adapt all of their rental houses to cope with the floods by making stands—known in Banjarese as bakatil—to protect their bed, fridge, and other equipment from flood damage. The floods make the floor slippery and too dan-

gerous for her to move safely around, so her husband must do everything during flood events and clean up the house when the water recedes. She describes the indignity of flooding disasters as she is forced to urinate next to the bed as she cannot reach their toilet. When the water levels are really high, the polluted water is just three centimetres shy of reaching the mattress, so when a boat passes their riverside house, the wake can push the water up to soak their mattress. Sometimes the flood waters enter the house for a few hours every day, so it becomes a routine for the family. Through time, they slowly learnt the flood patterns: When it comes and when it will dry. However, they report worsening and more unpredictable floods over the past five years, reflecting statements from the River Agency ("Banjarmasin semakin sering," 2023), with the worst floods hitting in 2021.

Rahimah and Fajar have always lived in rental houses that were designed by and for non-diffabled people. It is rare in Banjarmasin to find rental houses that can aptly accommodate diffability. In 2022, Rahimah and Fajar were forcibly evicted from their previous rented accommodation (pictured in Figure 2) due to late rent payments. The prolonged Covid-19 lockdown and the floods that regularly hit their house had directly affected their livelihoods. Fajar, who works as a masseur—a common occupation for blind men in Indonesia, lost nearly all customers during the lockdowns, forcing the family to rely upon Rahimah, whose only income at that time was sewing and selling face masks. On a day-to-day basis, they survived on people's generosity, both during the pandemic and in the aftermath of floods.

This community social support system plays a central role in enabling many people in their neighbourhoods to survive and "recover" from shocks and ongoing crises. Fajar and Rahimah lead a social support network for

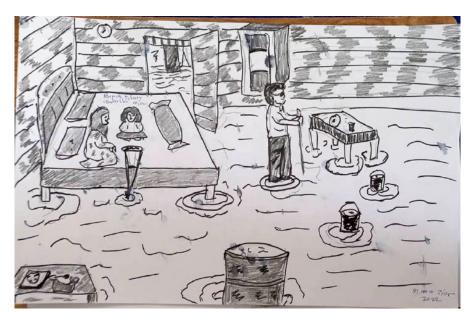


Figure 2. Rahimah draws her situation during flooding in Banjarmasin: She and her daughter sit on the bed while her husband makes tea.



diffabled people in Banjarmasin, playing an active role in helping those excluded from formal and informal support in their neighbourhoods. As Rahimah recounts:

There was a paralysed couple in Kampung Melayu. They did not receive any help or support. They were missed out when people did surveys to receive support. They contacted us. We did not know how to help as we were in the same situation [flooded], so we contacted the fire brigade we knew, who were then willing to check on them, and only after that, people and local authorities there were aware that there were people who had been missed out in the neighbourhood. Even though the communal kitchen was situated close to their house...they said they were always being missed out. They said they saw people distributing support and help [in the neighbourhood] but they do not open the door of their house during floods, worried that rubbish [in the water] will enter their house.

Rahimah and Fajar are also active in collecting data about diffabled people living in the city. There is no formal data available on the population with diffabilities, so they work voluntarily at the grassroots to identify people across the city, then leverage their networks in the private sector or government to try and source necessary support. During the worst floods, they help mobilise and distribute food donations. Rahimah rides a three-wheeled motorcycle (see Figure 3) that she and her husband personally modified so she can drive it with just



Figure 3. Rahimah and her a three-wheeled motorcycle, drawn by Rizaldi.

one leg and her husband can ride in the purpose-built sidecar. It cost them IDR 5 million (US\$ 340) in 2012, representing more than four times the monthly minimum wage in South Kalimantan that year. They have had to adapt the motorcycle at their own cost to accommodate their needs, and they spoke of recently having to draw on precious savings to fix the motorcycle after it was submerged by prolonged flood waters.

There is a critical lack of data about diffabled people in both Banjarmasin and Lombok, often driven by social invisibility within the communities that surround them. This invisibility often actively excludes people from social assistance, support, and help (Lindsay et al., 2022). Nila, an older blind woman who lives on her own, has never received social assistance from the government. She lives in a leaning house by the river in Banjarmasin, prone to regular flooding, and has no access to clean water in her kitchen or toilet. She relies on her neighbour for immediate assistance to escape flooding and lock her house. During disasters, people reported that their social support networks of families and neighbours were the most active. The government was always considered late in responding, too mired in bureaucracy, and the help they gave was much less than private or personal support from neighbours and other citizens. In some cases, people said it felt "like begging" to get some assistance from the government, even when they needed "help

In the absence of the state, people come together to help each other in the face of disasters. For Fajar and Rahimah, as well as Dina—their friend, another woman living in Banjarmasin—it is their embodied knowledge of what it feels like to endure difficulty in the face of disaster that drives their own motivation to build solidarity with—and mobilise support for—diffabled people. The most active social support networks are led from within the community but encompass a growing network of government and civil society actors.

Yet despite the active roles played by Rahimah and Fajar and their networks, and the data they have gathered, they speak with frustration of being judged for their diffabilities and thus routinely excluded from policyand decision-making about their experiences and needs. Their embodied knowledge is routinely neglected in urban and disaster planning. Even when it comes to the implementation of accessibility measures across the city, non-diffabled authorities tend to decide and enact their own visions of what is needed by diffabled people, and in both sites we have struggled to identify any disaster planning measures responding to the needs or barriers of diffabled people. In one of the only examples, Zainal, in Mataram, described how during a training on what to do during an earthquake, a small-magnitude quake hit and the non-diffabled trainer fled the room, leaving the diffabled participants to find their own way out of the building. This state of disaster planning represents an ongoing form of colonisation over diffabled bodies, with non-diffabled authorities creating knowledge about



and actions on the needs of diffabled people, echoing Spivak's (2003) key work "Can the Subaltern Speak?" When it comes to disaster planning in Indonesia, people with diffabilities are repeatedly rendered a subaltern voice, unheard and silenced (Cameron, 2022). This reflects the global scale, where diffabled people are routinely excluded from DRR processes (Gartrell et al., 2020). Their needs are defined by persistent framings of diffability as inability. The ongoing biopolitics of disaster planning and diffability define diffabled people as both subaltern and other, justifying their exclusion and representation by non-diffabled actors who speak on their behalf.

4. Halin ai: Conclusion and Recommendations

Halin ai in Banjarese translates to "well, what can I do?" This term is frequently evoked by diffabled people and is used to describe the feeling of "what else can I do?" when everything is happening out of your control. Banjar and Lombok societies are in Muslim-majority regions, as Indonesia is in general. Disaster is frequently understood as something that happens to one's life and is often seen as destiny from God, as with one's fortune and luck (Samuels, 2016). Thus, instead of fighting it or holding a grudge about it, people respond by creating a space to negotiate with or adapt to disasters. Fajar and Rahimah do not fight the floods that come regularly; instead, they learn to understand the patterns so they are prepared for the waters when they come. Their creativity and resolve to adapt to disasters and to help others build on lifetimes of adapting to a world that favours the non-diffabled and continues to speak on their behalf. When disaster strikes they mobilise and lead community responses within a vibrant support network of people with diverse diffabilities, regularly advocating for inclusive change and stronger political representation. Fajar and Rahimah's experiences highlight the key roles diffabled people are playing as they perform agency, resist marginalisation, lead social change, and practice ongoing adaptation to precarious and rapidly evolving conditions.

However, they do so in a hostile landscape and in the face of unpredictable disasters. As we have demonstrated, the vulnerability of diffabled people to disasters is a socio-political product of systemic exclusion and continuous (re)production of prejudice and discrimination (Nario-Redmond, 2019; Priestley & Hemingway, 2006). Their perspectives and experiences should be at the forefront of DRR processes and knowledge production about disasters. A decolonial, intersectional, and critical diffability lens is therefore paramount if we are to meaningfully include the knowledge, rights, and equal opportunities of diffabled people within global climate and disaster discourses. This would foster DRR and climate strategies that promote dignity, respect embodied diversity, more fully recognise people's capacities and skills, and open safe constructive spaces for contesting prevailing perspectives and systemic exclusion (S. Bell et al., 2020; Barclay et al., 2019).

The able-bodied dis-ability to hear and/or understand the experiences of diffabled people has often led to a homogenisation of diffability experiences within one single category that is equated with inability and dependence. This neglects abilities in favour of dis-abilities and negates the diversity of individual experiences, or the multiple ways in which ableism intersects with gender, age, race, class, poverty, and so on. It serves to depoliticise and take the focus off structural problems exacerbating vulnerability; and is at risk of "inclusive marginalisation," partially accommodating diffabilities at an individual rather than socio-structural level (Grue, 2019). This distances communities from holding those accountable for climate change and disasters to account. Furthermore, why must diffabled people be forced to find the resources within themselves to challenge these structural problems and inequities?

So, halin ai? What can we do? Diffability must be normalised and put at the heart of climate and DRR decision-making. Our public spaces, workplaces, homes, research teams, and decision-making tables as well as our policies and actions to prepare for climate change and disasters, must be transformed through the inclusion of the embodied and experiential knowledge of diffabled people as part of a new status quo. We must identify and directly tackle structural barriers, increase visibility, and actively work to make prejudice and discrimination towards disabilities unacceptable. Our climate actions must demand social, environmental, and disaster justice for diffabled people, directly challenge systemic and intersecting inequalities, and be designed from the ground up by those who live, embody, and resist these injustices every day. In Banjarmasin, for example, we are beginning such work with our Kayuh Baimbai Project, translating the research we describe here into creative interventions led by diffabled people to shape new inclusive disaster preparedness processes and knowledge production at multiple scales, from engaging with the City Government and disaster practitioners and firefighters, to working collaboratively in communities amongst leaders, neighbours, and extended and immediate families. Kawa baucap, kawa manggawi, kawa manyandang: If we can say it, we can do it, and we can handle it. Words without action mean nothing.

Acknowledgments

We are indebted to the diffabled communities of South Kalimantan and West Nusa Tenggara who so generously shared their time, perspectives, and life worlds with us. In particular, we honour the work of the Banjarmasin chapters of the Indonesia Disabled People's Association and Indonesia Disabled Women's Association, Inspirasi NTB, Maulani Furi Fajarini, and Lalu Faris Naufal Makhroja in Lombok, West Nusa Tenggara. This work was supported by a UKRI Future Leaders Fellowship (MR/S015299/1).



Conflict of Interests

The authors declare no conflict of interests.

References

- Acker-Verney, J. M. (2016). Embedding intersectionality and reflexivity in research: Doing accessible and inclusive research with persons with disabilities. *Third World Thematics: A TWQ Journal*, 1(3), 411–424.
- Aditya, N. (2023, January 18). BNPB: Terjadi 3.542 bencana selama 2022 [BNPB: There were 3.542 disasters in 2022]. *Kompas*. https://nasional.kompas.com/read/2023/01/18/14322181/bnpb-terjadi-3542-bencana-selama-2022
- Annur, C. (2023, March 8). BNPB catat ada 564 kejadian bencana alam di Indonesia hingga awal maret 2023 [BNPB recorded there were 564 natural disasters in Indonesian until early 2023]. *Katadata*. https://databoks.katadata.co.id/datapublish/2023/03/08/bnpb-catat-ada-564-kejadian-bencana-alam-di-indonesia-hingga-awal-maret-2023#:~: text=Menurut%20data%20Badan%20Nasional% 20Penanggulangan,terjadi%20dengan%20total% 20233%20kejadian
- Banjarmasin semakin sering dilanda banjir rob, PR Bagi Pemko [Banjarmasin is increasingly being hit by tidal floods: A homework for the City Government]. (2023, April 14). *KlikKalsel*. https://klikkalsel.com/banjarmasin-semakin-sering-dilanda-banjir-rob-pr-bagi-pemko
- Barclay, J., Wilkinson, E., & White, C. (2019). Historical trajectories of disaster risk in Dominica. *International Journal of Disaster Risk Science*, 10, 149–165.
- Bell, C. M. (Ed.). (2011). *Blackness and disability: Critical examinations and cultural interventions* (Vol. 21). LIT Verlag.
- Bell, S. (2019). Experiencing nature with sight impairment: Seeking freedom from ableism. *Environment and Planning E: Nature and Space*, *2*, 304–322.
- Bell, S., Tabe, T., & Bell, S. (2020). Seeking a disability lens within climate change migration discourses, policies and practices. *Disability & Society*, *35*, 682–687.
- Belser, J. W. (2015). Disability and the social politics of 'natural' disaster: Toward a Jewish feminist ethics of disaster tales. *Worldviews: Environment, Culture, Religion*, 19(1), 51–68.
- Belser, J. W. (2020). Disability, climate change, and environmental violence: The politics of invisibility and the horizon of hope. *Disability Studies Quarterly*, 40(4). https://doi.org/10.18061/dsq.v40i4.6959
- Bird, K., Higgins, K., & Harris, D. (2010). *Spatial poverty traps: An overview* (Working Paper). Overseas Development Institute; Chronic Poverty Research Centre.
- Calgaro, E., Villeneuve, M., & Roberts, G. (2020). Inclusion: Moving beyond resilience in the pursuit of transformative and just DRR practices for persons with disabilities. In A. Lukasiewicz & C. Baldwin (Eds.),

- Natural hazards and disaster justice challenges for Australia and its neighbours (pp. 319–348). Palgrave Macmillan.
- Cameron, C. (2022). Disability studies as a subaltern discipline. In A. Vatansever & A. Kölemen (Eds.), *Academic freedom and precarity in the Global North* (pp. 59–76). Routledge.
- Connell, R. (2011). Southern bodies and disability: Re-thinking concepts. *Third World Quarterly*, *32*(8), 1369–1381.
- Cooms, S., Muurlink, O., & Leroy-Dyer, S. (2022). Intersectional theory and disadvantage: A tool for decolonisation. *Disability & Society*. Advance online publication. https://doi.org/10.1080/09687599.2022.2071678
- Engelman, A., Craig, L., & Iles, A. (2022). Global disability justice in climate disasters. Mobilizing people with disabilities as change agents: Analysis describes disability justice in climate emergencies and disasters, mobilizing people with disabilities as change agents. *Health Affairs*, 41(10), 1496–1504.
- Erevelles, N., & Minear, A. (2010). Unspeakable offenses: Untangling race and disability in discourses of intersectionality. *Journal of Literary & Cultural Disability Studies*, 4(2), 127–145.
- Eriksen, S., Grøndahl, R., & Sæbønes, A. (2021). On CRDPs and CRPD: Why the rights of people with disabilities are crucial for understanding climate-resilient development pathways. *The Lancet Planetary Health*, *5*(12), E929–E939.
- Gaillard, J. C. (2022). The invention of disaster: Power and knowledge in discourses on hazard and vulnerability. Routledge.
- Gartrell, A., & Hoban, E. (2013). Structural vulnerability, disability and access to nongovernmental organization services in rural Cambodia. *Journal of Social Work in Disability and Rehabilitation*, 12(3), 194–212.
- Gartrell, A., Calgaro, E., Goddard, G., & Saorath, N. (2020). Disaster experiences of women with disabilities: Barriers and opportunities for disability inclusive disaster risk reduction in Cambodia. *Global Environmental Change*, 64, Article 102134. https://doi.org/10.1016/j.gloenvcha.2020.102134
- Gaskin, C., Taylor, D., Kinnear, S., Mann, J., Hillman, W., & Moran, M. (2017). Factors associated with the climate change vulnerability and the adaptive capacity of people with disability: A systematic review. Weather, Climate, and Society, 9, 801–814.
- Green, A., Abbott, P., Davidson, P. M., Delaney, P., Delaney, J., Patradoon-Ho, P., & Digiacomo, M. (2018). Interacting with providers: An intersectional exploration of the experiences of carers of aboriginal children with a disability. *Qualitative Health Research*, 28(12), 1923–1932.
- Griffo, G. (2014). Models of disability, ideas of justice, and the challenge of full participation. *Modern Italy*, 19(2), 147–159.
- Grue, J. (2019). Inclusive marginalisation? A critical analysis of the concept of disability, its framings and their



- implications in the United Nations Convention on the Rights of Persons with Disabilities. *Nordic Journal of Human Rights*, *37*, 3–17.
- IFRC. (2007). World disasters report 2007: Focus on discrimination. https://www.ifrc.org/PageFiles/99876/WDR2007-English.pdf
- Jodoin, S., Lofts, K., & Ananthamoorthy, N. (2020). A disability rights approach to climate governance. *Ecology Law Quarterly*, 47, 73–116.
- Kelman, I., & Stough, L. (Eds.). (2015). *Disability and disaster: Explorations and exchanges*. Palgrave Macmillan.
- King, J., Edwards, N., Watling, H., & Hair, S. (2019). Barriers to disability-inclusive disaster management in the Solomon Islands: Perspectives of people with disability. *International Journal of Disaster Risk Reduction*, 34, 459–466.
- Lawson, A., & Beckett, A. (2021). The social and human rights models of disability: Towards a complementarity thesis. *The International Journal of Human Rights*, 25, 348–379.
- Lindsay, S., Hsu, S., Ragunathan, S., & Lindsay, J. (2022). The impact of climate change related extreme weather events on people with pre-existing disabilities and chronic conditions: A scoping review. *Disability and Rehabilitation*. Advance online publication. https://doi.org/10.1080/09638288.2022.2150328
- Livingston, J. (2006). Insights from an African history of disability. *Radical History Review*, 2006(94), 111–126.
- MacGregor, S. (2010). A stranger silence still: The need for feminist social research on climate change. *Sociological Review*, *57*, 124–140.
- Meekosha, H. (2011). Decolonising disability: Thinking and acting globally. *Disability & Society, 26*(6), 667–682.
- Nario-Redmond, M. R. (2019). *Ableism: The causes and consequences of disability prejudice*. John Wiley & Sons.
- Oliver, M. (1996). *Understanding disability: From theory to practice*. Macmillan Education.
- Parekh, P. (2007). Gender, disability and the postcolonial nexus. Wagadu: A Journal of Transnational Women's & Gender Studies, 4(1), 142–161.
- Pertiwi, P., Llewellyn, G., & Villeneuve, M. (2019). People with disabilities as key actors in community-based disaster risk reduction. *Disability & Society*, *34*, 1419–1444.
- Priestley, M., & Hemingway, L. (2006). Disability and disaster recovery: A tale of two cities? *Journal of Social Work in Disability & Rehabilitation*, 5(3/4), 23–42.
- Puar, J. K. (2017). *The right to maim: Debility, capacity, disability*. Duke University Press.
- Rakhman, F. (2018, September 27). In an Indonesian village, compressor diving for fish is a dangerous business. *Mongabay*. https://news.mongabay.com/2018/09/in-an-indonesian-village-scubaspearfishing-is-a-dangerous-business
- Rydstrom, H., & Kinnvall, C. (2020). Introduction: Climate hazards, disasters, and gender ramifications. In C. Kin-

- nvall & H. Rydstrom (Eds.), *Climate hazards, disasters, and gender ramifications*. Routledge.
- Samuels, A. (2016). Hikmah and narratives of change: How different temporalities shape the present and the future in post-tsunami Aceh. In R. M. Feener, D. Kloos, & A. Samuels (Eds.), *Islam and the limits of the state* (pp. 24–55). Brill.
- Sheppard, P., & Landry, M. (2016). Lessons from the 2015 earthquake(s) in Nepal: Implication for rehabilitation. *Disability and Rehabilitation*, *38*(9), 910–913.
- Smith, F., Jolley, E., & Schmidt, E. (2012). *Disability and disasters: The importance of an inclusive approach to vulnerability and social capital*. Melksham. https://www.preventionweb.net/publications/view/34933
- Spivak, G. C. (2003). Can the subaltern speak? *Die philosophin*, 14(27), 42–58.
- Stoltz, A. D., Shivlani, M., & Glazer, R. (2021). Fishing industry perspectives on sea-level rise risk and adaptation. *Water*, *13*(8), Article 1124. https://doi.org/10.3390/w13081124
- Suharto, S., Kuipers, P., & Dorsett, P. (2016). Disability terminology and the emergence of 'diffability' in Indonesia. *Disability & Society*, *31*(5), 693–712.
- Thohari, S. (2011). Contesting conceptions of disability in Javanese society after the Suharto regime: The case of Yogyakarta, Indonesia. University of Hawaii.
- UNESCAP. (2012). Incheon strategy to 'make the right real' for persons with disabilities in Asia and the Pacific. http://www.unescap.org/sites/default/files/Incheon%20Strategy%20%28English%29.pdf
- UNESCAP. (2014). Message on disability-inclusive disaster risk reduction delivered at the 6th AMCDRR. http://www.unescap.org/announcement/message-disability-inclusivedisaster-risk-reduction-delivered-6th-amcdrr
- UNESCAP. (2017). Disability in Asia and the Pacific: The facts—2017 midpoint review edition. http://www.unescap.org/sites/default/files/Disability_ The_Facts_2.pdf
- UNESCAP, & UNISDR. (2012). The Asia-Pacific disaster report 2012: Reducing vulnerability and exposure to disasters.
- UNISDR. (2014). Living with disability and disasters: UNISDR 2013 Survey on living with disabilities and disasters—Key findings. https://www.unisdr.org/ 2014/iddr/documents/2013DisabilitySurvery Report 030714.pdf
- UNISDR. (2015). *Sendai framework for disaster risk reduction 2015–2030*. http://www.preventionweb.net/files/43291 sendaiframeworkfordrren.pdf
- Weibgen, A. (2015). The right to be rescued: Disability justice in an age of disaster. *Yale Law Journal*, 124(7), 2406–2469.
- Widinarsih, D. (2018). *Creating welcoming communities: Indonesian people with disabilities speak out* [Unpublished doctoral dissertation]. Curtin University.
- Wisner, B., Gaillard, J. C., & Kelman, I. (2012). *Handbook of hazards and disaster risk reduction*. Routledge.



World Health Organization. (2017, December 1). Disaster risk management for health: People with disabilities and older people [Fact Sheet]. https://cdn.who.int/

media/docs/default-source/disaster-mngmt/risk-management-disabilities-december2017.pdf? sfvrsn=77b44e28_1&download=true

About the Authors



Desy Ayu Pirmasari is an indigenous Dayak from Indonesia, a feminist ethnographer, and a scholar-activist at the University of Leeds, UK. Desy works on gender, climate, and diffability justice; feminist postcolonial and decolonial studies. Prior to her academic roles, Desy worked as a journalist covering major global political events and disasters, including the Arab Spring in Libya, Egypt, and Tunisia, the conflict in Mindanao (the Philippines) and Southern Thailand, the North Korea Rocket Launch, Padang earthquake 2009, and Merapi volcano 2010.



Katie McQuaid is an anthropologist and associate professor of gender and climate at the University of Leeds, UK. Katie works on the gender-age-urban interface of climate change and disasters in Uganda and Indonesia. Her research and scholar-activism combine ethnographic, feminist, and creative decolonial methodologies in collaboration with communities including women, people with diffabilities, refugees and asylum-seekers, and sexual- and gender-diverse people. She holds a UKRI Future Leaders Fellowship for her work towards building inclusive and climate-resilient cities.