10. Dis/ableism: Placing the Spotlight on the "Missing People": Unrecognized and Unthought Indonesian Women with Disabilities

Kristine Meneses and Megawati Naibaho

Disability, a shared human experience, can stem from different causes like traits present from birth, acquired conditions, accidents, or societal factors such as war, climate, or poverty. It is a complex issue that involves cultural, socio-economic, and political aspects, and sometimes connects with gender perspectives, given its significant focus on the body. Curiously, within feminist and theological discourses and conversations, disability remains notably at the periphery. Disability resembles a secondary consideration, akin to a "consolation prize," when acknowledged. The absence of disability within these conversations raises the question: what unique elements does disability offer that remain conspicuously absent from feminist theological discourse? Does the absence of disability in feminist discussions relate to its association with vulnerability and dependence? Could the visibility of disability challenge or cast doubt upon society's esteem for independence, control, or autonomy? These presumptions merit thorough examination, particularly in societies like Indonesia that prioritize performance, especially concerning women with disabilities. The diverse experiences of disability among the respondents in this study are deeply rooted in their respective contexts.

The onset of impairment and disability can occur unexpectedly, impacting lives at any juncture and thereby becoming an inevitable facet of the human experience. Understanding the narratives of Indonesian women with physical disabilities is crucial, given their perseverance in navigating a world that often proves unwelcoming and hostile toward them. Regrettably, contemporary society continues to operate within rigid binaries of us/them, male/female, hetero/homo, normal/abnormal, able/disabled, and other such dichotomies, perpetuating a cycle of discrimination and exclusion. For Indonesian women with disabilities, this societal bigotry has fostered an environment of dis/ableism, leading them to voluntarily withdraw from visibility to shield themselves from recurring anguish and harm.

Institutionalized and Internalized: Dis/Ableism as an Unrecognized "Normal"

Let us begin this section by posing several questions: Have we habitually perceived disability through a negative lens, characterizing it as an undesirable condition? Have we exalted technological advancements that promise independence for individuals with disabilities, not only for their potential autonomy but also to absolve them from feeling burdensome to society? To what extent have we idealized the concept of independence? Do we perceive disability as a predicament or a liability? Are individuals with disabilities automatically deemed incapable of fulfilling tasks? Is disability inherently seen as an imperfection necessitating repair, rehabilitation, or correction? How frequently have we averted our gaze from the realm of disability? Is the reluctance to decline requests rooted in the fear of being perceived as weak, incapable, or inadequate? Is there a tendency to exert extra effort to demonstrate one's capabilities? Are we adept at interacting with individuals with disabilities? Is assistance offered without seeking their consent? Does the notion of disabled individuals serving as inspiration arise from their resilience in accomplishing "remarkable" feats despite their disabilities?

These questions reveal how we subconsciously frame disability, potentially leading us to downplay or overlook its significance. They mark the beginning of acknowledging our inadvertent acceptance of widespread but often unnoticed oppression: dis/ableism. They offer an opportunity to highlight dis/ableism, prompting a reevaluation of our attitudes, behaviors, culture, and systems regarding disability and those affected by it.

Similar to racism, dis/ableism is a discriminatory force that oppresses and devalues persons with disabilities. Dis/ableism subtly pervades societal and religious structures, often overlooking its ethical and moral implications. Fiona Kumari Campbell, a feminist disability scholar, emphasizes how dis/ableism institutionalizes the negation of disability through compulsory normality. This normalization internalizes dis/ableism, shaping an inherently negative perception of disability entrenched in societal practices and consciousness, cultural norms, and structural frameworks.[1]

Dis/ableism manifests in beliefs, processes, and practices that produce and maintain the fictional ideal of the normal self and body, which contours what it means to be fully human. Hence, disability is considered a diminished/undesirable state of what it means to be human.[2] Similarly, Veronica Chouinard defines ableism as "ideas, practices, institutions and social relations that presume able-bodiedness, and by so doing, construct persons with disabilities as marginalized . . . and largely invisible 'others.'"[3] In addition, Chouinard rightly observes that what seems amiss in this concept of ableism is its operation as the norm. According to Bruno Latour, "The disabled body induces a fear as being a body out of control because of its appearance of uncontainability"[4]; thus, society promotes the necessity and desirability of repairing a disabled body.

Dis/ableism also takes a patronizing form known as "inspiration porn," a term used by disability rights advocate Stella Young.[5] This phenomenon, seen in memes and social media, highlights the resilience of disabled individuals, but it objectifies them for the temporary upliftment of able-bodied individuals. Young argues this narrative diminishes the daily reality

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[1] Fiona Kumari Campbell, *Contours of Ableism: The Production of Disability and Abledness* (Palgrave Macmillan, 2009), 166.

[2] Fiona Kumari Campbell, "Inciting Legal Fictions: Disability's Date with Ontology and the Ableist Body of the Law," *Griffith Law Review* 10 (2001): 44.

[3] Veronica Chouinard, "Making Space for Disabling Difference: Challenging Ableist Geographies," *Environment and Planning D: Society and Space* 15 (1997): 380.

[4] Campbell, *Contours of Ableism,* 8.

[5] Stella Young, "I am Not Your Inspiration, Thank You Very Much," TED Talk, June 2014, ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much.

of disabled lives, trapping them in a cycle that overlooks social barriers as well as their daily experiences.

Building upon Judith Butler's work, Robert McRuer argues that establishing the normativity of an abled body proves unattainable due to the unpredictable and unforeseen nature of impairment and disability. McRuer saw that Butler's gender performativity could be extended to disability studies, and he argues that "able-bodiedness offers normative . . . positions that are intrinsically impossible to embody, and the persistent failure to identify fully and without incoherence with these positions reveals [able-bodiedness] itself not only as a compulsory law, but as an inevitable comedy. Indeed, I would offer this insight into [able-bodied identity] as both a compulsory system and an intrinsic comedy, a constant parody of itself, as an alternative [disabled] perspective."[6]

The regime of able-bodiedness is indeed a parody, a comedy, because able-bodied status is transient, and disability is a singular identity category universally experienced if individuals live a sufficiently extended lifespan. Considerable aspects regarding the reality of disability remain obscured, disregarded, disavowed, and rejected because they upset and disrupt presumed bodily and ontological security. Reflecting on Michel Foucault's insights, it becomes evident that within this context, "fear has a target object"[7] wherein disability becomes the focal point. Disability is now perceived as a threat to the cherished ideals of independence, control, and autonomy, casting individuals with disabilities as disruptors, deviants, inherently different, and relegated to a diminished state. Fear operates as a potent force shaping societal convictions that the disabled body must either be rectified or concealed. Moreover, owing to this fear, disability

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[6] Robert McRuer, "Compulsory Able-Bodiedness and Queer/Disabled Existence," in *Disability Studies: Enabling the Humanities*, ed. Sharon L. Snyder, Brenda Jo Brueggemann, and Rosemarie Garland-Thomson (Modern Language Association of America, 2002), 93–94. McRuer has drawn this from Judith Butler, *Gender Trouble: Feminism and the Subversion of Identity* (Routledge, 2006), 155.

[7] Kristine Meneses, "L'Arche, a Radical Reversal: Fearless Dialogue between Foucault and Vanier with the New Testament," *Journal of Disability & Religion* 24, no. 2 (2020): 156, doi.org/10.1080/23312521.2020.1718571.

finds itself consigned to the "nether regions of the unthought," resulting in the erasure of disability. Yet individuals with disabilities persist as enduring realities.

Unpacking how ableism operates and is maintained is evident in the absence of narratives of women with physical disabilities or the scarcity of data on their demographic representation. Thus, it matters to search and provide a space for the narratives of disabled Indonesian because their assertions serve to relativise the absolute claims of the many non-disabled. Their voices, their narratives, and their visibility serve as a pathway towards a "third" space for these "missing people."

In Search of the Missing: Nanoscopic "Synodality" with Indonesian Women With Disabilities

As previously discussed, disability and persons with disabilities are placed in the nether regions of the unthought. Rosi Braidotti, a feminist post-humanist brings to light the "missing people" and elevates the voices and experiences of those often left unacknowledged in discussions about humanity. Braidotti argues for "actualization . . . enacted through collectively shared, community-based praxis . . . [and] recomposition of a missing people."[8] Case in point, Indonesian women with disabilities are among the "missing people" deserving prominence within this discourse.[9] Therefore, to fully comprehend the impact of dis/ableism, it becomes imperative to delve into the narratives of persons with disabilities, positioning this chapter as a "third" space to amplify their voices and experiences.

Dis/ableism, a form of discrimination, manifests notably through physical barriers, inaccessible ramps, inadequate public transit, and technology devoid of assistive features like voice descriptions or closed

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[8] Rosi Braidotti, *The Posthuman* (Polity Press, 2013), 100.

[9] Indonesia, primarily a Muslim nation with a minority Catholic population, experiences a degree of religious freedom under the Joko Widodo regime. However, despite this religious plurality, the invisibility of women with physical disabilities persists.

captions. Though these are blatant forms of discrimination, the roots lie deeper. Additionally, dis/ableism permeates attitudes and behaviours, framing persons with disabilities as inherently dependent or incapable, further marginalizing women with disabilities who face a double bind of prejudice.

Patriarchal attitudes compound pre-existing prejudice, amplifying the vulnerability of Indonesian women with disabilities and aggravating their suffering and indignity. As expressed by one respondent:[10] "The suffering and humiliation of our dignity as women and disabled become even more severe for us." This harsh synergy reinforces societal perceptions that cast disabled individuals, especially women, as "*sampah masyarakat*" or social trash. When questioned about the impact of the Catholic Church's treatment of Indonesian women with disabilities and their connection with the church, their answers were:

For Anne:[11]

> *Orang cacat seperti saya diabaikan Gereja, sehinggasaya ragu untuk berpartisipasi aktif. Pengabaian initelah menyebabkan banyak dari kami menarik diri dari gereja dan keterlibatan sosial yang lebih luas. Pengalaman pengucilan mengakibatkan keterputusan yang mendalam.* (Disabled members like myself feel neglected by the church, leading to hesitancy in active participation. This neglect has caused many of us to withdraw from both the church community and broader social engagement, leaving a profound sense of exclusion and disconnection.)

She further expressed her sentiments in these words:

> *Ketika saya mengikuti kegiatan gereja sering menghadapi tatapan simpatik atau merendahkan. Hal ini menimbulkan ketidaknyamanan*

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[10] Retroactive approval of this study was granted by the Ethics Review Board of the Sekolah Tinggi Pastoral Dian Mandala Gunungsitoli, North Sumatra-Indonesia (henceforth STP Dian Mandala), which confirms that this study was conducted in full compliance with the standard ethics protocol.

[11] The names of the respondents in this study are pseudonyms to protect their identity.

> *dan semakin rendah diri. Menjadi seorang perempuan dan cacat membuka pintu lebar pada diskriminasi dan marginalisasi.* (When I attend church, I often encounter sympathetic or condescending looks, fostering discomfort and feelings of inferiority. Being a woman with a disability seems to amplify experiences of discrimination and marginalization.)

She recounted distressing mistreatment from her former job at a Catholic school, under a religious congregation (notably from a nun), significantly affecting her self-worth. Despite facing discrimination in the church and being unemployed, she serves as the treasurer of her prayer group, and like other parishioners, she is expected to contribute to parish expenses.

Another respondent, Elly, has this to say:

> *Saya tidak pernah mengikuti kegiatan doa di lingkungan atau komunitas basis Gerejawi. Saya kesulitan beradaptasi dengan tempat baru dan tidak ingin menjadi pusat perhatian. Saya tidak mampu untuk bergerak bebas.* (I've never engaged in prayer activities within the neighborhood or the church community due to some challenges I face in adjusting to new environments. I prefer not to draw attention or rely on assistance as my mobility is significantly limited.)

One of the authors of this chapter, Megawati Naibaho, who understands the plight of those considered "dis-abled," shares her feeling in the light of from her lived experiences:

> *Saya merasa sedih saat berdoa karena tidak mampu membuat tanda salib dengan tangan kananku. Namun lebih menyakitkan, Ketika kumenyalam dengan menyodorkan tangan kananku yang ditopang tangan kiriku berbagairaksispontan, adamemandang dengan wajah heran, kasihan dan ada juga yang seakan-akanmengejek.* (Sometimes, I feel sad knowing I cannot use my right hand to make the sign of the cross in prayer. It's tough when I extend my right hand, supported by my left, for a greeting, and people react with disbelief, pity, or even mockery.)

Encountering dis/ableist attitudes poses significant challenges. Frustration with the Catholic Church arises from its consistent oversight and exclusion of persons with disabilities. Dis/ableist structures persist in society, particularly affecting those from non-affluent backgrounds. Respondents highlighted the high cost of quality education as a barrier, rendering formal education inaccessible. This lack of access hinders skill development, limits opportunities for permanent employment and a secure future, and ultimately renders them unemployable, exacerbating their marginalization.

Indonesian women with disabilities share narratives of societal and church-level exclusion, impacting their dignity both on a larger societal scale and in their everyday encounters of ableism within their social circles. Despite claims of cultural openness, unchallenged dis/ableism persists within ecclesiastical spheres, revealing society's discomfort with disability and vulnerability. These women's "missing" presence from society reflects the need to acknowledge and address the framing of disability, as it shapes perceptions of valuable, meaningful, and mournable lives, both on an individual and societal level.

Frames of (Un)recognition: Disability Denied and Dismissed

Once oppression has been internalized, little force is needed to keep us submissive.[12]

Disability scholar Lennard Davis stressed that we should not "ignore [deny or dismiss][13] the unstable nature of disability . . . [or] try to fix [disability]."[14] Throughout history, societal responses to disability's disruption and its unsettled condition have focused on control and containment through measures like institutionalization and medication. Judith Butler suggests

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[12] Deborah Marks, *Disability: Controversial Debates and Psychosocial Perspectives* (Routledge, 1999), 25.

[13] The bracketed words are the author's insertion.

[14] Lennard Davis, *Bending Over Backwards: Disability, Dismodernism, and Other Difficult Positions* (New York University Press, 2002), 26.

that anxiety is a catalyst for new possibilities, thus, this anxiety around disability warrants interrogation of assumptions that shape the ideal of normality.[15] Framed by fear, disability is often denied and dismissed. Drawing from Butler, we are challenged to ask, "Who fears disability and why?" She argues that our perceptions of whose life matters are influenced by dominant narratives and images of able-bodiedness and normality, urging us to critically examine these assumptions across various platforms and spaces.[16]

The narratives of the Indonesian women with disabilities cited above are merely a fraction of the multitude of stories that need to be heard. The profound impact of a negative framing of disability has a consequential effect on their self-image and self-worth, which is disturbing. It is worth listening to how dis/ableism cuts through their understanding of the self and its impact on them.

Anne recounts her childhood:

> *Orang tuaku memprioritaskan Pendidikan bagi saudaraku. Saya menolak sikap pembedaan itu, namuntidak berdaya. Sebagai Perempuan cacat, biaya pendidikan sangat mahal. Akibatnya, saya kurang berpendidikan.* (My parents prioritized education for my brother due to financial constraints. As a woman with a disability, the high cost of special education was unaffordable for me, resulting in inadequate education.)

This is how Elly looks at her disability:

> *Saya tidak maumenikah dengan seseorang yang secara fisik "normal." Saya takut dihina, dicemooh, atau bahkan diceraikan. Saya percaya jika pasanganku cacat akan memahami dan menghormatiku. Ajaibnya, doaku terkabul; suamiku cacat, meski tidak parah. Keluarganya sangat menentang pernikahan kami. Mereka takut saya menjadi beban atau*

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[15] Gary A. Olson and Lynn Worsham, "Changing the Subject: Judith Butler's Politics of Radical Resignification," *Journal of Advanced Composition* 20, no. 4 (Fall 2000): 728.

[16] Judith Butler, *Frames of War: When Is Life Grievable?* (Verso, 2010).

> *bergantung padanya.* (I hesitated to marry someone without a disability, fearing future insults, ridicule, or divorce. I believed a partner with a similar disability would understand and respect me better. Miraculously, my prayers were answered; my husband has a less severe disability. However, his family strongly opposed our marriage, fearing I might burden or rely on him.)

Megawati recalled:

> *Setelah kecelakaan dan cacat, ku menjadi pesimis sebagai suster. Kuingin meninggalkan biara, tetapi Pemimpin tidak mengizinkanku. Melalui refleksi dan bimbingan, akhirnya, ku pasrah pada penyelenggaraan Tuhan dan menerima keadaan cacat sebagai salib yang harus dipikul dengan setia. Ku menjalankan aktivitas dan berusaha bertanggung jawab.* (Becoming disabled after an accident made me doubt my religious calling. I wished to leave the Congregation, but the Superior General refused. After reflection and guidance, I entrusted my life to God's providence, embracing my disability as a cross to bear faithfully. I'm active in various activities and committed to responsibility.)

These narratives are forms of internalized ableism of which they are not aware. Internalized ableism means a disabled person has taken on society's negative views of disability. This leads to self-shame and a fear of seeking help, because they live in a world that often devalues them. For John McDermott, such experiences push persons with disabilities to self-denigration and exclusion, which for him are forms of "psychic oppression." This internalized oppression operates as a form of "starvation" where disability is considered an inherently negative and a problem, thereby severing persons with disabilities from "possibilities of future experiences."[17] For McDermott, such missed possibilities include the opportunity for emotional growth.[18]

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[17] John J. McDermott, *Streams of Experience: Reflections in the History and Philosophy of American Culture* (University of Massachusetts Press, 1986), 215.

[18] Marks, *Disability,* 25.

Resonant with a similar perspective, trauma expert Gabor Maté asserts that trauma arises internally as a response to a distressing experience—when we struggle to process or adequately cope with situations that could potentially cause harm. Thus, internalized ableism can be seen as a manifestation of trauma. Disability studies often overlook the emotional dimensions of stigma and trauma. Deborah Marks eloquently explains the acts of self-exclusion and voluntary erasure, identified as internalized ableism or, as she terms it, "internalized oppression": "Internalized oppression is not the cause of our mistreatment, it is the result of our mistreatment. It would not exist without the real external oppression that forms the social climate in which we exist. Once oppression has been internalized, little force is needed to keep us submissive. We harbour inside ourselves the pain and the memories, the fears and the confusions, the negative self-images and the low expectations, turning them into weapons with which to re-injure ourselves, every day of our lives."[19]

Marks aligns with Mason's perspective, emphasizing the importance of exploring not only the interactions of persons with disabilities with others but also their relationship with themselves. Among the respondents, their responses varied—one opted for societal withdrawal, another exhibited concealed anger and resistance, and yet another responded compliantly with her congregation.

Recognizing the diverse responses of these Indonesian women with disabilities to internalized oppression is crucial, particularly when these responses are ingrained in a person's system of beliefs, often without their awareness. Marks asserts this perspective: "Some experiences are so painful that we repress them from conscious awareness. Yet they continue to affect self-esteem and shape thoughts and actions."[20]

Many persons with disabilities emulate and "embrace" what is required by an ableist society, assuming identities that deviate from their authentic selves, contributing to their marginalization.[21] Thereby, to "fit" in,

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[19] Marks, *Disability*, 25.

[20] Marks, *Disability*, 26.

[21] Campbell, *Contours of Ableism*, 26.

"disabled people become complicit in their demise, reinforcing impairment as an undesirable and [negative] state,"[22] perpetuating a constant state of ambivalence as they navigate a society that habitually erases their presence and context.[23] This habitually occurs in the experiences of Toba Batak women.[24]

Instead of embracing disability as ontological, it is imperative to expose the processes and production of dis/ableism that devalue disablement and the disabled. Further, dis/ableism as an epistemological framework and an ontological modality of perceiving one's being[25] has framed the person's understanding of identity, making them unknowingly complicit in their own being's demise and cultural erasure. The inconvenient reality of disability prompts many to avert their gaze, seeking remedies or cures, mirroring the often uncritical and unimaginative hermeneutic of healing narratives in the Bible.

Within this context, dis/ableism embodies the dominant power, supported by the consensus of the mainstream, perpetuating the notion that able-bodiedness is the "gold standard" of being fully human. The convergence of "networks of association that produce exclusionary categories and ontologies" effectively leads to an internalized ableism that legitimizes compulsory normality.[26]

Acquainted with people's lives, contexts, narratives, and responses to internalized ableism, we are compelled to reconsider the precariousness of their existence, prompting us to respond with indignation, opposition,

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[22] Campbell, *Contours of Ableism,* 28.

[23] Campbell, *Contours of Ableism,* 27.

[24] Toba Batak women are part of an indigenous community in North Sumatra, Indonesia, where a deeply patriarchal and patrilineal system privileges male lineage and authority and where cultural beliefs and clan-based social systems normalize and perpetuate gender hierarchy. Within this structure, women are often valued primarily for obedience, domestic labor, and bearing sons, resulting in social, economic, and political marginalization. Disability further intensifies their experience of exclusion. Megawati Naibaho, "The Investigating the Oppression of Toba Batak Women: Call for Empowerment and Woman Leadership," *Studia Philosophica et Theologica* 23, no. 1 (2023): 159.

[25] Campbell, *Contours of Ableism*, 28.

[26] Campbell, *Contours of Ableism,* 19–20.

and critique against the hegemony of compulsory dis/ableism. In this context, the imperative to reframe disability becomes paramount, echoing the sentiments of Judith Butler, "There are ways of framing that will bring the human into view in its frailty and precariousness, that will allow us to stand for the value and dignity of human life, to react with outrage when lives are degraded or eviscerated without regard for their value as lives."[27]

Butler's idea of "frames of recognition" reveals how our views of groups, contexts, and situations are socially shaped. These frameworks frequently influence our sense of responsibility, sometimes without critical examination, toward specific groups, like persons with disabilities. This critique is crucial for highlighting systems that overlook or fail to embrace diverse perceptions and manifestations of humanity, particularly concerning disability.

Butler compels society and the Catholic Church to pause and re-evaluate the negative assumptions and frames surrounding disability that contributed to the production and maintenance of dis/ableism and associated phobias—creating exclusion, disenfranchisement, and violation for women with disabilities. Privileging able-bodied lives has effectively rendered the lives of Indonesian women with disabilities, in the words of Butler, ungrievable and unmournable.[28] Internalizing ableism leads them to believe their lives scarcely matter and compels them to hide from public scrutiny, effectively erasing their narratives from wider acknowledgment. Therefore, dis/ableism has undermined and excluded women with disabilities from the equation of full and meaningful human experiences.

The contexts and narratives of Indonesian women with disabilities can either haunt, disturb, or bother us, or we stubbornly refuse to be affected by them. If we opt not to be haunted, there is no loss, because life is not acknowledged to begin with.[29]

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[27] Butler, *Frames of War*, 77.

[28] Butler, *Frames of War*, 98.

[29] Butler, *Frames of War*, 97.

Interlude: Visitations, A Nanoscopic Synodality and Micro-Synodal Spaces in Homes

Initiating transformative change does not require grand gestures or extravagant endeavors. Often, the catalyst lies in seemingly insignificant or even imperceptible actions. The cumulative effect of these small, incremental steps can yield profound results. In this context, we have employed the terms ‘nano’ and ‘micro’ to emphasize the potential impact of minute activities.

The term “nano” is frequently employed in scientific contexts, such as nanotechnology, nanoparticles, and nanomaterials. Derived from the Latin word “nanus” or the Greek “nanos,” meaning “dwarf,” the term precisely denotes one billionth of a unit. However, given its polysemic nature, “nano” extends beyond the technical or scientific lexicon. In this instance, we have adopted a linguistic and rhetorical approach to the term. Consequently, the terms “nanoscopic” and “micro-synodal” are employed as descriptors, communicating not only an observation but also an extremely minute pastoral activity with potential impact when regularly practiced.[30] Such social-pastoral activities are exemplified through home visitation, which is analogous to a table fellowship that is akin to the historical Jesus’s actions as depicted in the Gospels.

Moreover, synodality can be understood as a mode of church governance characterized by a deep commitment to listening to its people. This listening extends beyond mere auditory perception, involving a genuine intent to understand that fosters meaningful conversation, exchange, reciprocal engagement, and inclusion. Through this process, the church can cultivate transformation and well-being, both individually and communally.

The Gospels portray Jesus as a man deeply invested in human connection, often engaging in table fellowship. In first-century Palestine, the patron-client system and honor/shame-based culture were prevalent.

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[30] Max Boholm, “The Use and Meaning of Nano in American English: Towards a Systematic Description,” *Ampersand* 3 (2016): 165.

Jesus's table fellowship challenged these hierarchical and binary structures, fostering a sense of community and equality. The communal nature of meals in first-century households, involving shared meals, often served on a single platter and eaten with broken flatbread, facilitated storytelling and a sense of familiarity, thus fostering egalitarianism and undermining discrimination. By breaking down social barriers and embracing those marginalized by society, Jesus's open commensality demonstrated a radical commitment to inclusivity and challenged the prevailing power system that valued status and hierarchical structures.

My (Megawati) attempts to realize the mission of Jesus through my engagements in the community could illustrate the pastoral impact of nanoscopic interventions. My personal inclination towards human connection has led me to prioritize engagement with marginalized individuals, particularly women with disabilities. Given my own experience with disability, I feel a deep empathy for their unique challenges. To ensure their comfort and convenience, I offer them the autonomy to determine the time and place of our meetings, respecting their existing commitments. While scheduling can be demanding, open dialogue and mutual understanding have consistently facilitated productive arrangements. It is important to emphasize that my visits are always conducted with their explicit permission, reflecting my unwavering respect for their agency.

During my visits, I strive to create a warm and welcoming atmosphere, actively listening to their needs and concerns. These interactions are not isolated events but rather ongoing engagements designed to foster a sense of connection and belonging, consciously avoiding the perception that they are objects of charity. Hence, I aim to cultivate genuine friendships with those marginalized by society in general and the church in particular. Consistent visitation has facilitated the development of deep rapport, characterized by mutual trust, respect, and compassion, rather than a transactional relationship.

The nanoscopic synodality of listening, conversation, and relationship-building, coupled with the micro-synodal spaces provided by home visits, extends beyond mere pastoral activity. These interactions create a fertile ground for transformation, impacting both the lives of the visitor and the one being visited.

A notable example of nanoscopic synodality occurred during my initial visit to Anne, an Indonesian woman with disabilities. Initially expressing distrust and skepticism towards my presence, Anne's reservations were rooted in a traumatic past experience with a nun from our congregation. This deeply rooted prejudice, stemming from the negative encounter, made her initially hesitant to engage with me. However, through sustained interaction and genuine empathy, Anne eventually recognized my individuality and was willing to accept my visit, sharing her personal narrative as a woman with disabilities.

A similar experience unfolded with Elly, another Indonesian woman with disabilities. Creating a third space for the "missing people," another visitation with a woman with disability is called for. Before my home visit, Elly admitted that she was hesitant to meet me. She discussed the matter of my visit with her husband. The husband encouraged her, and she later agreed to welcome me into her home. Upon our first meeting, Elly expressed heartfelt gratitude for my visit, acknowledging the joy and connection it brought. Our shared time fostered a deeper bond and strengthened our unity.

Our conversations encompassed a wide range of topics, from the daily challenges of survival to the pursuit of financial stability. Laughter often punctuated our interactions, sharing light-hearted moments. However, the depth of our connection was evident in the more serious and emotionally charged conversations that frequently moved us to tears, leading to moments of shared vulnerability. Our home visits typically concluded with a prayer, reaffirming the presence of God in our lives and providing strength and encouragement for our continued journeys.

The stories recounted by disabled women during my visitations, as well as my own life journey with disability, reveal the pervasive and persistent nature of prejudice against disability.[31] Home visitation, a form of nanoscopic synodality, has proven to be an enriching experience. These intimate spaces, micro-synodal in nature, facilitate as well as embody the spirit of open-commensality (table fellowship). Beyond personal enrichment, home visitation offers a valuable opportunity to deepen our connection with marginalized individuals. Through these personal encounters, we can tangibly touch the lives of others, fostering an atmosphere of genuine love, respect, and mutual affirmation of our shared dignity as women with disabilities created in the image of God. Home, as a micro-synodal space, fosters encounters and engagements that embody nanoscopic synodality. In these intimate settings, listening becomes a reflexive process, allowing me to not only hear their stories but also to reflect on my own experiences.

Through our shared experiences, several transformative changes have occurred. Notably, these individuals have come to embrace their unique identity and recognize their inherent dignity. Despite societal marginalization and neglect, they have discovered that they are not alone and that some care for and support them. This newfound optimism has strengthened their faith in God, fostering a belief in divine care and guidance. Home visitation, as a praxis of ethical care, is characterized by mutual respect and agency, devoid of power differentials. This approach aligns with feminist ethics of care, which prioritizes interdependence and caring relationships free from power asymmetry. A particularly inspiring development is the willingness of these individuals to forgive those who have caused them harm. Through the process of nanoscopic synodality within their micro-synodal homes, transformative change has taken place.

As a nun, I have undergone a profound transformation through these home visitations. These encounters have significantly impacted my life, prompting me to step beyond the confines of the convent and engage with marginalized individuals. I am now more motivated to fulfill my calling as

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[31] See Eva Feder Kittay, "The Ethics of Care, Dependence, and Disability," *Ratio Juris: An International Journal of Jurisprudence and Philosophy of Law* 24, no. 1 (2011): 49–58.

a religious, dedicating myself to the service of others. I encourage my fellow sisters to recognize the importance of this vocation, emphasizing that it is not about personal gain but rather about serving the needs of others.

My own journey has been marked by self-acceptance and a shift in perspective regarding disability. Initially viewing disability as a limitation, I have come to recognize its potential as a source of strength and growth. The loss of my right arm has shaped my worldview, enabling me to see the world through the lens of an Indonesian woman with disabilities. This experience has taught me the value of interdependence and the courage to seek assistance, fostering humility. I was previously aware of societal vulnerabilities, but living with a disability has deepened my awareness and sensitivity toward marginalized groups—especially women with disabilities. This personal experience has fostered a deeper sense of solidarity and empathy, allowing me to connect more meaningfully with those facing similar challenges.

We cannot ignore the pervasive nature of prejudice against disability. Home visitation, as a contemporary reimagining of Jesus's table fellowship, offers a transformative experience for both the visitor and the visited. Through this process, individuals can undergo a *metanoia*, a gradual realization of self-acceptance that fosters respectful, caring relationships grounded in trust and agency. In home visitation, the absence of power dynamics fosters coexistence, interdependence, and solidarity that reflect God's commitment, as the practice—marked by inclusivity—transcends distinctions and categorizations. From an ecclesiological perspective, Jesus's outreach to the marginalized can be seen as a manifestation of the divine spirit.[32]

Jesus's "open commensality confounds the insider/outsider binary, fractures the normative order and breaks open God's kingdom of love, justice, and equity."[33] Through its engagement with Indonesian women with disabilities, this praxis can be understood as a disability theology that

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[32] Joseph N. Goh, *Doing Church at the Amplify Open and Affirming Conferences: Queer Ecclesiologies in Asia* (Palgrave McMillan, 2021), 6.

[33] Goh, *Queer Ecclesiologies in Asia*, 152.

resists ableism, exclusion, and the erasure of persons with disabilities. As Megawati elucidates, home visitation debunks power asymmetry.

Home visitation can be understood as a praxis of feminist ethics of care. While the concept of care has often been associated with dependency, this perspective overlooks the possibility of care-based ethics that challenge power inequalities.[34] In this context, care is conceived as a personal and communal relationship that respects and affirms the agency of the individual being visited, whereby they actively "participate in decisions which affect their lives," and "share fully in the social life of their community."[35] By respecting the agency of Indonesian women with disabilities and acknowledging our diversity, we affirm their dignity and strengthen our commitment to understanding our shared humanity.[36] By exercising nanoscopic synodal practices through home visitation, we search for the "missing people" of the church.

Where are the "Missing People"? . . . in the "Desert Area": *Fratelli Tutti*, An Overture to Micro-Synodal Spaces

Pope Francis's encyclical *Fratelli Tutti*, offers a pertinent appeal for individuals to reassess their relationships with one another. The document also addresses various forms of hostility and imposed doctrines that create division and subjugation among different groups—hostility that can be understood as referring to notions of compulsory normality and the broader regime of ableism. Their existence compels us to confront a reality we typically turn away from acknowledging. It is essential that we educate ourselves and challenge our understanding of what it means to live a meaningful and joyful life with disability—recognizing that, despite disability, there is something to gain and potential to be realized.

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[34] Kittay, "The Ethics of Care," 54.

[35] Jenny Morris, "Impairment and Disability: Constructing an Ethics of Care That Promotes Human Rights," *Hypatia* 16, no. 4 (2001): 16.

[36] Jenny Morris, "Impairment and Disability," 16.

In a globalized society that, as *Fratelli Tutti* notes, makes us "neighbors but does not make us brothers" (no. 12), the acknowledgment of lives whose dignity is denied or violated resonates with the experiences of persons with disabilities. This stark reality emphasizes the unequal treatment of human rights, echoing Butler's argument on the varying grievability of lives. Some are unjustly seen as subhuman, rendering their lives as being considered ungrievable.

While the church staunchly upholds the inherent dignity of individuals, contradictions abound, sparking questions about navigating indignity and inequality in human lives. This predicament prompts reflection on the consequences of denying the reality of disability. Societal hostility and derogatory attitudes toward persons with disabilities fostered barriers opposing the church's call for a culture of encounter. *Fratelli Tutti* emphasizes that true wisdom involves engaging with reality, advocating for attentive listening, and genuine engagement with persons with disabilities. The encyclical underscores the essential aspect of encounter, which is the "ability to sit down and listen to others, typical of interpersonal encounter . . . [where] the modern world prevents us from listening attentively to what another person is saying. . . . We must not lose our ability to listen" (no. 48).

Our capacity for genuine listening has diminished, accompanied by a decrease in patience and an increase in intolerance towards anything that deviates from our established standards. *Fratelli Tutti* underscores how "Persons or situations we find unpleasant . . . or disagreeable are simply deleted" (no. 47). Although the encyclical mentions disability twice only, it commendably acknowledges the significance of listening to their stories because "each of them is able to offer a unique contribution to the common good through their remarkable life stories. . . . We need to have the courage to give a voice to those who are discriminated against due to their disability, because sadly, in some countries even today, people find it hard to acknowledge them as persons of equal dignity" (no. 98).

The long overdue action that society and the Catholic Church can take is to give adequate representation and equal participation of persons with disabilities in their forums that will elevate and amplify their voices, which have been unheard and silenced for a long time.

As Anne expressed:

> *Secara fisik kami memang sudah terbatas dan mengalami diskriminasi di masyarakat. Ku berharap para pastor dan suster menghargai dan menerima, bukan sebaliknya, malahan menjadikan kami terpuruk dan dikucilkan.* (Physically, we are already limited and experience discrimination in social interactions in society. I hope that the priests and nuns will increasingly respect and accept us with all our limitations, rather than making us worse off and excluded.)

Her articulation is a hard truth: they have been in the "desert area," which is a space of exclusion. As the encyclical pointed out, "vulnerable members of society are the victims of unfair generalizations" (no. 234); therefore, to mitigate prevailing "hostility," it is imperative to include their stories to challenge our "unfair generalizations" of disability.

The encyclical states that "each day offers us a new opportunity, a new possibility. . . . We have the space we need for co-responsibility in creating and putting into place new processes and changes" (no. 77). Part of this process is to "seek out others and embrace the world as it is" (no. 78), despite the fear of the unknown, the one we cannot control, and a sense of "inadequacy" that might leave us overwhelmed.

Additionally, the encyclical underscores the significance of exploring fuller existence through another. Healthy relationships facilitate an expansion of self-awareness and a deeper appreciation for diversity (no. 89). By rejecting dis/ableism, meaningful connections with persons with disabilities become attainable, as experienced by the authors of this chapter.

The Indonesian women with disabilities, despite residing in a "desert area," demonstrated, as indicated in the encyclical, a "remarkable system of welcoming pilgrims as an exercise of the sacred duty of hospitality" (no. 90). But the truth is the opposite—they transform hostility into hospitality, not out of a "sacred duty," but because they do not want the (temporary) able-bodied other to experience hostility.

The capacity of persons with disabilities to welcome others is a witness to how "love made possible by God's grace as a movement outwards towards another," where the other is no longer a stranger, but someone "united to ourselves" (no. 93). The encyclical rightly expresses that our engagement can cultivate an affinity that will "make us freely desire to seek their good"—not only a matter of charity but also justice.

The encyclical also states, "Social love is a force capable of inspiring new ways of approaching the problems of today's world, of profoundly renewing structures, social organizations, and legal systems from within" (no. 183). This transformation becomes feasible if society is willing to attentively listen to the perspectives of persons with disabilities. By transgressing barriers, listening to them can facilitate a shift towards a society that is inclusive and has universal accessibility.

The presence of persons with disabilities, with their unique lives, perspectives, and cultures, presents a valuable contribution to the broader (temporary) able-bodied society (no. 133). Viewing disability as a distinct way of life, characterized by interdependence, bestows significance upon their humanity—an ontology and epistemology derived from their marginalized position. Consequently, granting them a platform for active participation in decision-making processes, whether in civic or ecclesiastical spheres, makes possible a praxis of social justice—disability justice.

Disability Justice: Re-framing Disability, Transgressing Dis/ableism

An ideal may be "lost" by being rendered unspeakable, that is, lost through prohibition or foreclosure.[37]

A queer disability theologian, Rabbi Julia Watts Belser, shared in a forum about her disability (born with cerebral palsy): "It feels like people . . . are

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[37] Judith Butler, *The Psychic Life of Power: Theories in Subjection* (Stanford University Press, 1997), 196.

not interested in it (disability), just want to shield that away and get this very thin core of some kind of standard normal. I guess I'm not that interested in being 'normal' . . . . I love it (disability). I was not going to let it be erased."[38] The invisibility and erasure of their experiences and lived realities stems from societal frames of disability as a loss, tragic, and sad. It is crucial to critically analyze these frames that have led to the dismissal of our ethical responsibility toward them. As Butler has put it, "The prohibition of images and representations more generally circumscribes the sphere of appearance, what we can see and what we can know. But it would be a mistake to think that . . . a certain reality will then be conveyed. The reality is not conveyed by what is represented within the image."[39]

When there is no image, no name, or representation of toxic positivity, it projects an inauthentic life that denies the existence of vulnerability, precarity, or marginality.[40] Butler suggested that the obvious presence of discrimination should make us evaluate our ways of framing. Filtering, censoring, and controlling what aspects of life are brought to attention or emphasized perpetuates erasure and marginalization of their reality. This distortion takes place neither inside nor outside the image, but through the very framing by which the image is contained.

The experience of Indonesian women with disabilities has been marked by derealization, prompting a call for ethical action. Butler emphasizes the crucial role of framing and language in shaping our perceptions,[41] which do not convey the full reality.[42] For ableist thinking to be maintained, certain ways of imagining need to remain unspeakable and unspoken. We then ask, what must remain unspeakable for the regime of ableism to continue to exercise power? The absence from representation and

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[38] Julia Watts Belser, "Conversations in Bioethics 2017: Disability," The Kennedy Institute of Ethics, Georgetown University, February 2, 2017, sitearchives.georgetown.edu/kie-cib/our-conversations/2017-disability/index.html.

[39] Butler, *Precarious Life*, 146.

[40] Butler, *Precarious Life*, 146.

[41] Butler, *Frames of War*, 79.

[42] Butler, *Precarious Life*, 146.

participation of women with disabilities should prompt inquiry into why their narratives are obscured, leading to a numbing effect on our emotional response to their concerns.[43]

Acknowledging the universality of disability does not imply essentialism. It is crucial to recognize that at some point in our lives, or in the lives of those close to us, we may have encountered impairment or disability due to illness, surgery, or prolonged health issues. For many, these circumstances are framed as disruptions or obstacles to their plans, sometimes leading to feelings of being burdensome to our families, inadvertently fostering internalized ableist perspectives.

According to Anita Ghai, an Indian academician and disability rights activist, "The (disabled) other, in its very strangeness, simply mirrors and represents what is deeply familiar to the centre (able-bodied) . . . . It is this process of marginality that produces the resentment, enmity and repugnance for the one who is sensed as the (disabled) other . . . [because] disability provokes fears and anxieties about 'able body' mortality, and very easily renders itself [now] as the 'other.'"[44]

Disability is framed as an uncomfortable reality. Perhaps the resistance to embrace and resist re-imaging disability as a gain, stems from its instability and threat to abled-body. Indeed, for many of us, disability provokes fears and anxieties about "able body" mortality. Nonetheless, this compels us to challenge the all-too-long belief, which even some feminists fall into, that disability is conjoined with dependence and weakness, which contradicts and threatens the image of (fiction of) independence and strength, making feminist disability studies relatively missing in many feminist discourses. It therefore necessitates reframing the negative perceptions and assumptions of disability—dis/ableism—because this is vital to achieving disability justice.

A step towards disability justice is to render disabilities visible, and acknowledgment of disability can prevent the violence stemming from our

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[43] Butler, *Frames of War*, 100.

[44] Anita Ghai, *Rethinking Disability in India* (Routledge, 2015), 300.

past denials and erasures.[45] As Lennard Davis asserts, it is necessary to emphasize that disability is central to human existence for as long as humans have bodies.[46] Our conversations with Indonesian women with disabilities became a space for the praxis of micro-synodality, characterized by attentive listening to their narratives. Anne drew parallels between our conversation and the gospel story of Jesus in the house of Mary and Martha. Immersed in the dialogue, she forgot to bring out her prepared bread, likening herself to Mary's excitement in Jesus's presence. We firmly told her that it was the reverse, she was "Jesus, the storyteller here, and we are eager to listen," and we shared a moment of laughter.

In a similar vein, Elly was reluctant to travel due to numerous negative encounters that stripped away her humanity and reduced her to stares because of her disability. What struck us profoundly was her change of heart by the end of our conversation; she expressed to her husband (also disabled) and only child, "I am now willing and ready to travel." This shift exemplifies how fostering a culture of encounter with persons with disabilities who internalized oppression can transgress dis/ableism. Indeed, encounters hold the power that can transgress and put an end to dis/ableism—a form of disability injustice.

With a glimpse of the reality of Indonesian women with disabilities, it is about time to listen and learn from them, beginning with an encounter, entering their "desert area" that is an oasis in a world that is growingly indifferent and hostile. In addition, an encounter will pave the way to knowing their context, which can compel the call towards inclusion, access, and accommodation via active participation of persons with disabilities in society, which can result in disability justice.

In addition, in her article, "Violence, Disability and the Politics of Healing,"[47] Watts Belser advocates for accessibility, offering a reinterpreted

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[45] Anna Marie Riedl, *Judith Butler and Theology* (Brill Schöningh, 2021), 56.

[46] Davis, *Bending Over Backwards*, x.

[47] Julia Watts Belser, "Violence, Disability, and the Politics of Healing: The Inaugural Nancy Eiesland Endowment Lecture," *Journal of Disability and Religion* 19, no. 3 (2015): 179, doi.org/10.1080/23312521.2015.1061470.

perspective on Isaiah 45:2–3 as God's decisive commitment to remove obstacles, which for her is a divine gift of access.[48] In the framework of disability justice, Jennie Weiss Block highlights the need for the church to examine its hidden oppressive structures,[49] which the respondents in this study encountered. Likewise, feminist disability theologian Nancy Eiesland challenges the church's reinforcement of a "disabling theology." In her words: "The problem is a disabling theology that functionally denies inclusion and justice for many of God's children. Much of church theology and practice—including the Bible itself—has often been dangerous for persons with disabilities, who encounter prejudice, hostility, and suspicion that cannot be dismissed simply as relics of an unenlightened past. Christians today continue to interpret and spin theologies in ways that reinforce negative stereotypes, support social and environmental segregation, and mask the lived realities of people with disabilities."[50]

Furthermore, disability justice can happen by considering disability as a gain, something to offer that makes life worthwhile. Watts Belser challenges the Christian and Jewish traditions that worship a God that is hyper-capable—the ultimate able figure. This translates to us "worshipping" ability, perfection, power, capability, and no limits, which we project onto our lives. In her experience of disability, she posits a profoundly provocative query of imagining God who experiences disability, her experience of epiphany when she re-imagined the text in the book of the prophet Ezekiel about God's chariot—"God has wheels!"[51] In this text encounter, Watts Belser experienced a "powerful sense of kinship,"[52] which is a newfound realization of how God moves in the world. When navigating the rough terrain and steep slopes with a gentle

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[48] Belser, "Violence, Disability, and the Politics of Healing," 184.

[49] Jennie Weiss Block, *Copious Hosting: A Theology of Access for People with Disabilities* (Bloomsbury, 2002), 11, 122.

[50] Nancy L. Eiesland, *The Disabled God*: *Toward a Liberatory Theology of Disability* (Abingdon Press, 1994), 10.

[51] Julia Watts Belser, "God on Wheels: Disability and Jewish Feminist Theology," *Tikkun* 29, no. 4 (2014): 29.

[52] Belser, "Disability."

grade, she flips the framing of disability as lack, loss, sadness, and a tragic condition into something positive; she frames her spins on a downhill road as sensual joy that is "exquisitely beautiful."[53]

By engaging with the narratives of Indonesian women with disabilities, we shed the layers of fear and hostility, thereby opening ourselves to social friendship marked by a celebration of diversity. Our interaction with them strengthens our commitment to disability justice by reframing the discourse, recognizing that both disabled and able-bodied individuals share similar aspirations, hopes, and diverse narratives that enrich and shape our collective existence.[54]

Conclusion

In the context of the recently concluded Synod of Synodality, this chapter delves into the lived experiences of a demographic of "missing people": Indonesian women with disabilities. Their narratives intertwine tales of marginalization, trauma, and internalized dis/ableism, yet are infused with a singular hope in God.

Engaging with these individuals must transcend transactional interactions to avoid shallowness in our listening. Superficial engagements risk rekindling experiences of dis/ableism, potentially reopening wounds, and perpetuating feelings of objectification. The pervasive existence of dis/ableism within both the church and society has significantly marred their self-perception. Continuously reframing disability into a positive existence is integral to a genuine culture of encounter, transforming solidarity into resistance against the dis/ableism regime. Through this, the attainment of disability justice signals the realization of God's reign in the present moment.

Synodality embodies an ongoing process. It demands the creation of secure micro-synodal spaces that foster trust and healthy relationships with

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[53] Belser, "Disability."

[54] Kristine Meneses, "Disability Justice: Reframing Hospitality and Revisioning Inclusion," *HAPÁG: A Journal of Interdisciplinary Theological Research* 16, nos. 1–2 (2019): 81.

these unrecognized and unthought individuals—Indonesian women with disabilities—within both societal and ecclesiastical realms. It prompts us to question our frames of disability that positioned them as being "outside" the church. Perhaps it is time to reconsider the lens through which we view their involvement. Rather than perceiving them as outsiders to be approached, they might rightfully belong within, even within the metaphorical "desert area," which paradoxically holds an oasis of hospitality. Reversing disability as inherently negative into a catalyst of new possibilities—gain, beauty, and fun—is an exquisite form of disability justice.

Kristine Meneses is a dedicated disability and queer theologian who is affiliated with the Department of Theology in Ateneo de Manila University, Philippines. She earned her PhD in theology from the St. Vincent School of Theology. As a committed advocate for Deaf and disability rights, Dr. Meneses has served as a volunteer sign language interpreter since 2008. Her academic research primarily centers on disability justice, drawing from both disability and queer theological frameworks. She also engages with continental philosophy, mad studies, and trauma theory. Her recent work explores the intersections of decoloniality and posthumanism. From 2018 to 2020, Dr. Meneses held the position of Coordinator for the Ecclesia of Women in Asia. Meneses also holds membership in various theological association, such as the Catholic Theological Ethics in the World Church, Catholic Theological Society of the Philippines, Catholic Biblical Association of the Philippines, and Asian Resource Women Centre. Her latest publication is "Deaf *Beki* Humor: A Pastoral-Theological Articulation of *Pagbabangong–Dangal–*Resurrection," *Critical Research on Religion* (Sept 2024).

Megawati Naibaho, also known as Sr. Caroline Naibaho, is a member of the Kongregasi Suster Kasih Yesus Dan Maria Bunda Petrolongan Baik (KYM) [The Congregation of Sisters of Charity of Jesus and Mary Mother of Good Succour]. She obtained her PhD in theology from Adamson

University—St. Vincent School of Theology in the Philippines. Her research interests focus on theological ethics and moral theology. Currently, Sr. Caroline serves as an educator at Dian Mandala Pastoral College in Gunungsitoli, within the Sibolga Diocese of Indonesia, and she is also a member of the General Council of the KYM Congregation. Among her recent publications are "Woman Leadership in Toba Batak Society: A Critical Study on Patriarchy," *Journal of Asian Orientation in Theology* 6, no. 2 (2024): 259–280, and "Perempuan Disabilitas dan Hubungannya dengan Teologi Belas Kasih Katolik," *Studia Philosophica et Theologica* 24, no. 1 (April 2024): 84–101.