

DISABILITY JUSTICE: REFRAMING HOSPITALITY AND REVISIONING INCLUSION

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One of the sectors in our society that has a long experience of injustice is persons with disabilities. It is their disability that is often seen, while their person/being is all together pathologized or medicalized. As a result, they not only experience discrimination, they are also stigmatized. They experience marginalization in all aspects of life, socio-economics, and politics. They are misrepresented in literature, media, and everyday conversations, when often their conditions are identified with negative associations, especially in metaphors, such as: “are you deaf,” “love is blind,” “he is lame,” and “this is insane.” This paper is an attempt to bring to the fore how persons with disabilities continuously experience injustice, even in the Church. Using the post-Synodal Apostolic Exhortation Amoris Leticia it will expose how the Church still carries a negative view about persons with disabilities as well and adopts the models of disability that it has internalized for centuries. Is the inclusion of PWDs in the Ecclesia considered authentic disability justice? To answer this, I attempted to enhance Rabbi Julia Watts Belser’s inclusion paradigm by using Jacques Derrida’s ethic of hospitality, which can be seen as virtue as well as a form of disability justice.

INTRODUCTION

Seventy years after the United Nations Declaration on Human Rights, we still witness massive injustices against humanity, including Persons with Disabilities. In 2008, 177 countries ratified a treaty on the rights of Persons with Disabilities (PwDs). The question is, where are we today in disability justice in our local communities, society and in our state?

Similarly, on the final report of the Synod of Bishops on the Vocation and Mission of the Family, and *Amoris Laetitia*,¹ Pope Francis reiterates the role of families living with people with special needs. Though his intention is benevolent, nonetheless, this perspective of seeing PwDs to be dependent on others and treating disability as something tragic does not only facilitate the charity model of disability but it also deprives the disabled of their agency. Could it be that the charity model that the Ecclesia has been accustomed effects injustice? What models (and the mainstream's internalized perspectives) of disability that covertly facilitates injustice towards the disabled? What models of disability seem to promise an equitable society for both the able and disabled people? In this case, how can states and the Ecclesia afford authentic disability justice for persons with disabilities that they deserve?

To answer my questions, this article is divided into three parts. The first part begins with the often ignored narratives of PwDs, which in fact will give readers a better understanding of their context. In the second part, I will attempt to bring us into awareness the two dominant models of disability that society and even the Ecclesia have internalized, enabled, maintained and practiced, that effect disability injustice. This I will begin by presenting some general principles of the Convention on the Rights of Persons with Disabilities (CRPD) as well as present the relevant portion of the post-Synodal report *Amoris Laetitia* (AL) that addresses the families living with disabled members. In the third part, I will offer possible ways to practice disability justice by presenting alternate models of disability. In addition, this part highlights the stance of Rabbi Julia Watts Belser's argument on the insufficiency of the inclusion paradigm. As a response, I would employ an enhanced notion of Jacques Derrida's ethic of hospitality from the lens of a Filipino deaf community, where I belong. Lastly, is a theological reflection cum invitation to trample our ableist and sanist biases, through the practice of hospitality—a virtue and a form of disability justice.

¹ Catholic Church and Pope Francis, *Post-Synodal Apostolic Exhortation: Amoris Laetitia, On Love in the Family* (Vatican, Rome: Holy See, 2016).

BEING DIFFERENT: OBJECTIFYING THE DISABLED FROM ALL SIDES

One morning, while attending a Sunday Holy Eucharist at one of the churches in Chicago, I noticed a sole deaf young man a few pews in front of me. My immediate instinct was to look in front to see if there was a Sign Language (SL) interpreter. With the intent for him to sense that he was not alone, I began to sign, which he noticed and informed his mother in SL, 'girl deaf at the back.'² After the celebration, I approached the family. The mother was surprised as she thought I was deaf; she told me that her son was shy and does not want to be looked at or be a source of distraction. I saw that he refrained his mother from signing during the entire Eucharist, which she obliged. The father informed me that he was trying to learn the SL, but was honest enough that he lacks patience in learning the language. The family also informed me that their son attends signed mass only occasionally.

Another event was a conference I attended in Yangon, Myanmar (2018), where one of the participants was an Anglican priest who is sightless. He told me that his condition was acquired, due to a wrong dosage of medicine administered when he was an infant. Interested in knowing how he will manage his days during the conference, I observed that in the first two days, he navigates the venue with some assistance, but on the third day, he can navigate the place on his own, walks straight without a cane! Out of curiosity, I courageously inquired how he was able to manage in navigating the venue without assistance. He then told me that he simply senses the air in between the walls/barriers, which indicates a pathway.³ To us this is amazing, but to him this is his normal 'waze.' Out of respect, I further inquired about how he wants to be identified, that is, is it appropriate to identify him as 'blind person' as 'visually-impaired,' or as 'sightless.' He preferred to be identified as sightless. He told me that it really depends on the person, for

² Good thing with signing is you get to know what is being talked about even in a distance.

³ While for Daniel Kish, who is also sightless he use sonar or "echolocation" to navigate spaces. View his talk in Ted Talks, https://www.ted.com/talks/daniel_kish_how_i_use_sonar_to_navigate_the_world.

some, it is all right to be identified as visually-impaired. However, for most of them, to be identified as blind is often hurtful and insulting. In fact, his past is not without discrimination and stigma. He told me that the parents of his wife were against in marrying him, because they see him to be useless and would only be a burden to their daughter. He heard hurtful comments such as, 'what kind of future will you have with this blind man?!' For him this is disheartening to hear and made him feel worthless. They saw his limitation, his sensory condition and dismisses his potentials. His story is just one among the many, were we still retain an unfavorable perspective that disabled people are incapacitated. His wife stood firm to her decision to marry him. In their years of marriage, they now have a daughter.

One of the TED Talk speakers, Stella Young,⁴ brought to her audience a lens that critiques media on its representation of persons with disabilities. Often their condition is made in contrast to able-bodied people, just to present a point that there are disabled people whose capabilities are limited and yet they are able to conquer their own limitations. This perspective hurts many of them because the able-bodied would feel good at the cost of the PwDs condition. Young said strongly, 'we are not an inspiration.' Young insists that images of PwDs with quotes such as: 'The only disability in life is a bad attitude,' 'your excuse is invalid' and 'before you quit try.'" For Young, these are big lies, which she labels as 'inspiration porn.' Young deliberately used the term 'porn' to emphasize that society has fallen into a trap where it objectifies PwDs for the benefit of non-PwDs. For Young, when disability is removed from the equation, we will see that they are just ordinary people trying to live each day, thus, there is nothing special about them at all.

⁴ Stella Young, "I am not an inspiration, thank you very much," TED talks.com, June 2014. Her video on Ted Talk is available at https://www.ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much.

Similarly, Rabbi Julia Watts Belser,⁵ during the disability forum at the Kennedy Institute of Ethics at Georgetown University was proud of her signature walk when she was young. Being a wheeler, Belser sees her condition as an indelible mark of her identity. In addition, she views her spins on a downhill road as sensual joy that is ‘exquisitely beautiful.’⁶

In another frame of disability spectrum, Lydia Brown,⁷ talks about her sense of being a perpetual outsider, for being queer, an Asian and a neurodivergent. Her context bespeaks well of the intersectionality of disability. In the same forum, Brown shares that her context makes her feel on the edge—a sort of ‘inside yet out,’ a sort of liminality, which is best articulated by Lennard Davis:

The idea of intersectionality—that identity groups intersect, overlap, and need to forge alliances rather than think of themselves as separate and apart—has become an important way to regard disability in relation to other groups and categories. When we think of women, transgender people, LGBTQ, people of color, different cultures and peoples throughout the world—we also want to think about how disability intersects and overlaps with those groups. The aim is to avoid having a white, patriarchal, hetero-normative, ableist viewpoint that disguises itself as a universal point of view.⁸

Another form of disability is one that is invisible such as the circumstances of Eleanor Longden⁹ and Elyn Saks, who were

⁵ Rabbi Dr. Julia Watts Belser, is an Associate Professor at the Department of Theology at Georgetown University, with expertise on rabbinic literature and Jewish feminist ethics. She was born with cerebral palsy.

⁶ This is how she described her experience.

⁷ Lydia X.Z. Brown started a blog “Autistic Hoya,” with well reception because of its upfront thoughts on disability justice, neurodiversity, intersectional activism.

⁸ Lennard Davis, ed. *Beginning with Disability: A Primer* (New York: Routledge, 2018), 11.

⁹ Dr. Eleanor Longden is currently a post-doctoral service user research manager at the Psychosis Research Unit. Her circumstance brought her to assert that the voices in her head were “a sane reaction to insane circumstances.” She is an advisory member of the forthcoming World Health Organization Quality

diagnosed with schizophrenia, as well as two of my students diagnosed with dissociative identity disorder (DID)¹⁰ and borderline personality disorder (BPD) are susceptible to sanist bias.¹¹ One thing in common among them is hearing voices [and emerging personalities], which in the field of psychiatry it is justifiable to tame or even eliminate those voices by taking pills. Based on their experiences, the medication only make their condition much worse, because they felt an eerie void where they begin to question their existence. This sense of void often leads them to hurting themselves, just to feel if they exist. For some, they resort to suicide. Further, it is difficult for people with mental illness [disorder] to disclose their circumstance, even to their families because they are afraid of being misunderstood.

Being objectified, stigmatized, marginalized, perceived to be different and not to have a sense of belonging are some of the painful realities of disability injustice that PwDs experience each day. How are we to effect authentic disability justice?

DISABILITY IS A JUSTICE ISSUE AS WELL

The discussion and treaty on the rights of persons with disabilities (PwDs) started in 1991. A General Assembly of the United Nations adopted the treaty in 2006 and ratified in May 3, 2008. The United Nations on the Convention of the Rights of Persons with Disabilities (CRPD) is a treaty ratified by State Parties acknowledging PwDs as stakeholders and therefore are rights holders. The general principles of the CRPD are as follows:

Rights Initiative, which aims to improve quality of services and promote human rights, empowerment, and inclusion for individuals with mental health difficulties. Drawing from her experience, she has written books and articles about recovery-oriented approaches to psychosis, dissociation and complex trauma.

¹⁰ It is also referred to as Multiple Personality Disorder (MPD).

¹¹ Sanism is another form of discrimination against people with mental illness. Some words that carry a sanist bias when giving a remark to a person as insane, crazy or possessed.

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
2. Non-discrimination;
3. Full and effective participation and inclusion in society;
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
5. Equality of opportunity;
6. Accessibility;
7. Equality between men and women;
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.¹²

For Belser, these principles implicitly sets the tone of inclusion paradigm, which bares the minimum requirement that the civil society and State parties must commit to deliver and implement.¹³ However, evident to this date are varied forms of discriminations against PwDs tangled in “isms,” such as ableism, lookism, and sanism. Ableism is discrimination and prejudice against PwDs, whereby the ‘able-bodied’ person sees themselves to be superior over PwDs or those perceived by society as disabled. Similarly, sanism or mentalism is oppression against people with mental illness/disorder or those considered by society as ‘mad’ or ‘insane.’ In both cases, the disabled are subject to ‘lookism,’ whereby they are under scrutiny and intent gaze by the public, yet this is not without unbiased treatment. With the society’s perspective pegged on the medical and charity paradigms, this proves to be a challenge to effect and enforce societal transformation. The negative experiences of PwDs raise questions about the enforceability of the CRPD treaty by State parties, as well as of the citizenry in living-out the above-mentioned principles. Part of the difficulty in implementing the said principles are the internalized and dominant perspectives of disability by most able-

¹² Convention on the Rights of Persons with Disabilities

¹³ There has been eleven sessions that CRPD committee has conducted as of this writing. The sessions are held every second week of June, the latest was June 12-14, 2018.

bodied, which in effect devalues and disqualifies the disabled. What are those imperceptible views that many of us carry, which is oppressive towards disabled people and therefore enables disability injustice to exist?

DISABILITY (IN) JUSTICE: DOMINANT MODELS OF DISABILITY

Our ablelist attitude towards disability and persons with disabilities (PwDs) is grounded on the various dominant models of disability, namely: medical, functional, moral and charity. All these models have disenfranchised, displaced, and disqualified many PwDs from active participation in our society and ecclesial communities.

The most dominant model of disability that society has internalized is the medical model. This model focuses on the body that is under scrutiny and diagnosis. This model searches and evaluates the defect and deformity that must be cured either through medicine, therapy or corrective surgery. Justice for this model is finding a solution or treatment, which ironically at times deprives the disabled of their agency. Recently, in South Korea, parents of deaf children are the ones who make the decision if and when their deaf child will to go through cochlear implantation (CI). There is a growing population of children who go through CI as early as six months old, obviously a decision made by parents. The problem with cochlear implants is that it is actually a form of brain surgery that removes all residual hearing of the person and is replaced by the CI device, making the child a partial-borg. The problem with cochlear implantation is that it does not promise clarity of hearing, and it also fails to address speech that remains unclear, which is a cause of bullying and ridiculed by others. With this circumstance, many of the deaf with CI ended up with resorting to sign language. It is unfortunate that society enforces normalcy upon them without giving the freedom to decide for themselves. By forcing the society's definition of normal upon them is in effect disenfranchises their agency, which is a form of disability injustice.

Closely related to the medical model that sees the disabled body as defective is the functional model that concerns with the proper functioning of the body. Justice in this model is for the body to undergo therapy or rehabilitation in order to perform activities. This is usually applied to neurodivergent people,¹⁴ and those who are diagnosed with mental illness/disorder who are thought to be ‘mad’ or ‘insane’ by psychological definition and classification.¹⁵ To regulate their condition, they are medically advised to take medications that could lessen or control their mental and emotional episodes or attacks. They are medicalized and rehabilitated to tame their ‘madness.’ In this case, justice is a treatment which is pharmacological for those with mental illness or disorder, while for those who are intellectually disabled ‘treatment’ is often custodial.¹⁶ One might say that there is nothing wrong with this. On the onset perhaps it is seemingly harmless, but when we closely listen to the narratives of those under treatment, one will discover that medicine does more for the able-bodied than to them. In taming them, the life and day-to-day activities of the able-bodied caretakers is uninterrupted. They are subject to medicalization because most able-bodied does not know how to deal with their erratic and ‘disturbing’ actions/behaviors. The easiest solution to control is to silence them with anti-depressant or tranquilizers. Their episodic attack presents discomfort and therefore seen as a disruption to ‘normal’ life. At some worse case, such as in some European countries, specifically in Hungary and Czech Republic, the neurodivergent are placed in group homes (segregated institution) funded by the European Union (EU).¹⁷ Here they are

¹⁴ The neurodivergent in this paper pertains to those within the intellectual and mental spectrum, such as autism and mental disorder.

¹⁵ Psychologist and psychiatrists uses the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) that defines and classifies mental disorders.

¹⁶ Giampiero Griffo, “Models of Disability, Ideas of Justice, and the challenge of Full Participation,” *Modern Italy* 19, no. 2 (2014): 147-159.

¹⁷ *People and Power*, “Europe’s Recurring Shame: From Bulgaria to Brussels,” Al Jazeera.com, December 12, 2019, <https://www.aljazeera.com/programmes/peopleandpower/2019/12/europe-recurring-shame-bulgaria-brussels-191211004311122.html>. A similar situation in Kazakhstan, where it is legal to give-up on children with disability and bring them to homes. Javaid, Osama Bin, Al Jazeera, “Disabled children in Kazakhstan: Parents work to change practice,” Al Jazeera.com,

susceptible to violence. In the documentary where the institutions or group homes were revisited, it was discovered that they face harsh and hostile conditions. It was exposed in a documentary how they endure physical and verbal abuse from caretakers. If were unable to contain them, some are sedated, while others are locked, caged or chained. Their condition was brought to the attention of the European Union (EU) that financially sponsors the group homes. However, EU's response was in inaction and they even refused to accept partial responsibility for the ongoing harsh conditions of the neurodivergent.

In a particular shank in Mogadishu, Somalia a traditional therapy is believed that it can drive-out depression using a hyena.¹⁸ For some Somalians, mental illness is a form of possession by the evil one. It is believed that a hyena can devour the 'jinns' or the evil spirits that causes the mental illness. In the past, people with mental illness are locked inside a room with an unrestrained hyena. This case shows that disability is associated to the morality of the person, and this demonstrate the moral model of disability.¹⁹ It is thought of that disability is a result of personal sin or of a generation sin, a curse or punishment from a divine entity. Whatever the case, disability is taken negatively, where a deity has the power to cause and heal bodily conditions. In addition, though the term 'disability' is not categorically spelled out in the Judeo-Christian scripture, nonetheless, disability are often equated to 'blemish' and sensory or mobility dysfunctionality such as being blind, deaf, mute, lame as well as demonic possession.²⁰ Further, the moral model perceives disability as a test of faith where a person's perseverance or patience is tested. When a person with disability is not healed this is a proof of the individual's lack of faith. It is unfortunate that there are still

February 3, 2020, <https://www.aljazeera.com/news/2020/02/disabled-children-kazakhstan-parents-work-change-practice-200203102427644.html>.

¹⁸ Reuters, "Somalis Turn to Dr Hyena to Fight Depression, Mental Illness," *nytimes.com*, March 2, 2020, <https://www.nytimes.com/reuters/2020/03/02/world/africa/02reuters-somalia-hyena.html?searchResultPosition=7>

¹⁹ Marno Retief, and Rantoa Letšosa, "Models of disability: A brief overview," *HTS Teologiese Studies/ Theological Studies* 74 no. 1, March 6, 2018, <https://doi.org/10.4102/hts.v74i1.4738>

²⁰ As in the case of the boy in seizure (Mk 9.14-19; Mt 17.14-20; Lk 9. 37-43) is believed to be possessed by the evil enemy.

some packets of this belief existing even in this postmodern era, which in fact contributed to the stigmatization of persons with disabilities.

Intertwined with the medical model, the charity model of disability that is likewise deeply ingrained into our consciousness. Disability in the charity model is seen as a tragedy and the disabled is a helpless victim that needs care. This model is widely practiced by many religious congregations whose charism and mission/apostolate is charity and the care for persons with disabilities, specifically to neurodivergent (often referred to as intellectually disabled). Practicing justice for this model is to provide needed care for persons with disabilities, which is not totally wrong. However, at some point, however good the intention may present before us, it matters that we be cautious on how these ‘innocent’ charitable action do engender and facilitate an ableist bias in society and in the ecclesia. Further, institutionalizing persons with disabilities, though well-meaning also raises the question of segregation, which is a form of rejection (or forsaken by their own families) and exclusion. As such, it produces a silhouette of exclusionary community where it hones stigmatization that views the persons with disabilities and even disability itself to be socially undesirable.²¹ Furthermore, persons with disabilities who resides in institutions have become objects of charity, where groups or individuals will visit especially during the Christmas season, or for reasons of academic exposure [or study/research/project]. This perception is not only internalized by able-bodied people or normate²² but also by some disabled persons themselves. It is therefore quite unsettling that the charity model has facilitated negative stereotypes on persons with disability, which caused harm. Are there other measures that the Church has done to afford justice to PwDs not in the guise of charity?

The Apostolic Exhortation, *Amoris Laetitia* (AL) of Pope Francis, reiterates what is penned on the Post-Synodal final report

²¹ Griffo, “*Ideas of Justice*,” 148.

²² The term, ‘normate’ is coined by Rosemary Garland-Thompson whose research focuses on disability studies and feminist theory.

“The Vocation and Mission of the Family in the Church and in the Contemporary World, (VMF)” specifically the care for persons with special needs. It states, “[T]he sudden entrance of a person with a disability in a family creates profound and unexpected challenges and upsets a family’s equilibrium, desires and expectations,²³ giving an impression that disability is a tragic occurrence. In addition, the apostolic exhortation views disability as a disruption, because ‘the reality of the family and every aspect of its life are profoundly disturbed.’²⁴ In this case, even the Church retains a negative notion of disability, seen as a disequilibrium and an unwelcomed interruption. The exhortation articulates that the family who faces a “difficult trial of a child with special needs” bare the challenges of new responsibilities and therefore are “greatly admired”²⁵ is overtly leaning to a charity model of disability. Further, in the Post-Synodal report and AL, Pope Francis believes that the able-bodied must render service to the disabled, which is a “test of our commitment to show mercy in welcoming others and to help the vulnerable to be fully a part of our communities.”²⁶ However, this exhortation runs contrary to empowerment; indeed there is the intention to make them part of our communities but active participation is not in the equation. The Church up to this day have not fully grappled and understood what disability means. This is perhaps due to a lack of conversations with persons with disability themselves. The deeply ingrained perception that disabled people are helpless, powerless, dependent and who needs care. Similarly, when disability is seen as disruption to families is a means to perpetuates disability injustice. Though the charity model is benevolent, nonetheless, a reframing of perspective that give credence to the socio-cultural lens of disability is wanting. The ecclesia has been critiqued by Nancy Eiesland, when she asserts that “the Church has been a city on the hill— physically inaccessible and socially

²³ Synod of Bishops, “Family, Inclusion and Society,” in *The Vocation and Mission of the Family in the Church and in the Contemporary World* (Final Report) (Vatican City: Holy See, 2015), 21.

²⁴ Ibid.

²⁵ Ibid.

²⁶ Pope Francis, *Amoris Laetitia* 47, 37.

inhospitable.”²⁷ Is the ecclesia truly that far from the praxis of disability justice?

STEPS TOWARD DISABILITY JUSTICE HOSPITALITY AND INCLUSION: LEVELING THE PLAYING FIELD

Article I of the CRPD defines disability as those who “have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”²⁸ Further, Article II of the same treaty assures PwDs with “reasonable accommodation,” which pertains to the

[Necessary] and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to PwDs the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

Though defined, nonetheless, disability is a fluid category in disability studies. With this, how will we draw the line of accessibility and accommodation that fits the fluidity of disability?

HOSPITALITY: VIRTUE RE-FRAMED TOWARDS DISABILITY JUSTICE FROM DEAF PRAXIS

As presented in the first section of this paper, disability in the life context of Lydia Brown is not merely fluid, but I suggest,

²⁷ Nancy Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability* (Nashville, TN: Abingdon Press, 1994), 20.

²⁸ “The Magna Carta for Disabled Persons in the Philippines defines disability as those “suffering from restriction of different abilities, as a result of a mental, physical or sensory impairment, to perform an activity in the manner or within the range considered normal for a human being.”

borrowing from Gilles Deleuze, disability is rhizomatous.²⁹ Disability is not a static category, rather is multifaceted and at times is compounded. In his latest book, *Beginning with Disability: A Primer*, Lennard Davis acknowledges the fluidity and difficulty of defining disability because at times it overlaps, and tangles with disease and disorder.³⁰ A person could have rheumatic heart disease but he/she is not disabled, or one's disability is a result of the person's heart ailment. Similarly, there are those who have cerebral palsy and at the same time are deaf or deaf-blind. The closer we look at disability, the more we see its complexities. Considering the rhizomatous and fluid aspect of disability, how can we actualize disability justice? It would be worth to retrieve Jacques Derrida's ethic of hospitality, and re-frame it as a virtue from the lens of (Filipino) deaf.

For Derrida, hospitality is an aporia, that is, a situation where possibility-impossibility is present, because the one who affords hospitality also has the power to be hostile, and it is possible to be a hostage as well. A guest can abuse one's power, thereby controlling the host. Here, both the host and the guest could be hostile or remain cosmopolitan or welcoming to each other. Hence, affording hospitality can turn both parties to be either wicked or welcoming, hostile or hospitable, turning the situation either violent or a virtuous act. It all depends on one's disposition on power. In this regard, what can we learn from the deaf praxis of hospitality?

A safe and hospitable space where deaf learned to know and accept their identity are in schools and deaf communities. For deaf people who accepted and embraced their identity, they consider deafness not as defect, damage, deficit or loss but rather they see it as a gain. Deafness is their identity signature whereby removing it is in effect discarding their identity. Analogous to deaf identity is Nancy Eiesland's question if she will be able to walk in the afterlife, which she articulated in her book, *The Disabled God*.

²⁹ Gilles Deleuze and Félix Guattari, *A Thousand Plateaus: Capitalism and Schizophrenia*, trans. Brian Massumi (Minnesota: University of Minnesota Press, 1987).

³⁰ Davis ed., *Disability: A Primer*, 6.

She however dreaded such idea, because if she were not disabled in the afterlife, she felt that she would totally be unrecognizable even to herself, and perhaps even before God. The same is true with Rabbi Besler, who considers her disability as part of her very being as human person. For most of the disabled, an indicator that they have completely embraced their identity as disabled is seen through humor of their physiological (anatomical) condition, which often occurs within their community, where they are not and do not feel disabled.

This attitude is reflective of the identity model of disability exhibits hospitality beginning with the self.³¹ Disabled people comprises a minority in our society who sensed that social, economic, political systems in place seems to have consciously left them out of the equation. Society defines the able-bodied through opposite reference to PwDs, that is, a normal body is measured by looking at what is lacking in a disabled person. The result is that society has devalued disability as well as the disabled. Similarly, the society has failed to listen to the narratives of the disabled, in effect, disenfranchising them from active participation. Ironically, society seems to forget that disability is an existential reality of human experience.

One of the ways that shapes the identity model of disability is their collective narrative of exclusion that mobilized them in creating organizations and movements that strongly invoke their diverse identities and engender their unique culture. It is in their communities that they have a great sense of belonging. They take pride of their identity, yet with a full knowledge that their condition will be a standing struggle and often not without frustrations because the society is still behind in recognizing and accepting the reality of disability. In addition, the identity model of disability is a step towards a vision of change, whereby collectively they were able assert their rights in society. In lobbying their positive collective identity, they formed an assemblage that celebrates their identity—disability pride march. They have informed the able-bodied society that in affording hospitality by accepting them as a human variety, society is paving the way for an accessible and accommodating

³¹ This model is also referred to affirmation model

society, thus embracing difference that invites us to re-vision inclusion.

RE-VISIONING INCLUSION PARADIGM: ACCESS AND ACCOMMODATION TOWARDS PARTICIPATION

For decades, persons with disabilities have been asserting their rights to agency and recognition by society. As mentioned earlier, it is quite a paradox that deaf people found meaning in their identity and deaf culture through their collective experiences of segregation, stigma and exclusion. Just as culture is a construct, so does disability culture,³² where the able-bodied mainstream society accords to them with often a negative and patronizing image or representation.

Society has placed disability in a cultural 'location' that even the mainstream able-bodied would not desire to be. Their representation remains at a level of victim, tragedy, pity, or inspiration porn. Considering them to be different, who does not fit in to the definition of 'normal' in society are segregated in group homes, are institutionalized, at times sterilized or were objects of experimentation. For persons with disabilities, all this are disabling cultures that able-bodied have constructed. The disabling assumptions and notion of disability is disability injustice, because society has fabricated what it means to be disabled, excluding in the equation their experiences and narratives. Representations of disability in arts, films and other platform media have placed them on unfavorably and even in a negative light,—a disgrace and devalued members of society. Contributory to the disability injustice is the failure of the able-bodied society to acknowledge the construed misrepresentation of PwDs as well as its refusal to be held accountable in continuing their disablement, stigmatization and marginalization in almost all spheres of life. With the reality of PwDs exposed above, it is about time to listen and learn from the disability culture and recognize how this can lead to disability justice.

³² At times this can be referred to as the cultural model of disability, yet in a re-imaged way.

Most of the persons with disabilities are born in an able-bodied family, to which they are seen to be different. However, outside the family, that is, in communities with their friends who are similarly disabled is a hospitable space where they exchange insights, develop a dignified self-identity and grow meaningful relationships. Their respective communities are safe spaces of culture of difference, where differences is well respected and accepted. Their unique culture invites the mainstream able-bodied people to re-vision an inclusive society that respects their agency and to recalibrate the current consciousness that enforces normality, which is truly disabling. Closely linked to 'difference,' which is a characteristic of their culture is 'resilience.' Society is consciously structured for able-bodied people. Because of this, the disabled have struggled in a society that is often hostile and discriminatory, yet they also have learned to adapt and be resilient to the everyday challenge they encounter. Part of their resilience is patience, which is subsumed in hospitality. A concrete example of this is the Filipino Deaf community where I belong, where hospitality is a welcome interruption, just as they accommodate a hearing person. On the onset, one might see this as a reversal of power, but when you are with them, you will sense unbiased treatment. The ethics of hospitality from the (Filipino) deaf is a virtue; it is a good that welcomes a non-deaf as an equal. The deaf welcomes the interruption who sees each encounter as a step for the hearing mainstream to be more aware of who deaf people are. As mentioned in the previous section, if for some able-bodied the disabled is a disruption and interruption to their daily activities, the same is for the disabled, because they know the need to adjust and accommodate them into their world, into their space. They welcome an interruption and disruption in their 'normal' way of life by accommodating the able-bodied. Welcoming the mainstream able-bodied epitomizes the disability culture that shows resilience in a society that is not ready to adjust according to their terms. Furthermore, in an unwelcoming environment, the disabled have learned to 'troubleshoot' when matters seem difficult for them, not wanting to ask for assistance, because doing it on their own is part and parcel of their self-determination and an exercise of their agency, a demonstration of their resilience.

Another salient mark of the disability culture is the value of community. To be in their community is a moment where disability disappears; it is a space where they are no longer disabled, but are able-bodied it is therefore a space of reversal. The community is a hospitable space where they can be themselves, share experiences and stories, humor, new ideas and so on. It is a space that prepares them for an engagement, a dialogue among diverse individuals and cultures. In fact, it can be said that disability culture is not only multifaceted, but it is also multicultural because it is enveloped with complexities, layers of identities and contexts, and it can be said that their culture hones authentic inclusion. Disability culture is offering the able-bodied mainstream a new way of looking at disability and persons with disabilities, as one who accepts difference, has an attitude of resilience and who values community. These are some of the ways they offer that could enable the mainstream to practice disability justice in a concrete way such as accommodation, which is a step towards inclusion. However, is accommodation enough to bring about disability justice?

In response to the negative effects and limitations of the medical and charity models, the social model of disability brings to the fore what the two cited models tend to ignore that is society's structure is made for able-bodies engendering another form of discrimination—ableism. The shortcoming of the medical and charity models is that disability remains the fault of the individual. For the person to be integrated in society, he/she must adjust or be rehabilitated. This perspective is opposed to the argument of the social model of disability where it sees that the society is responsible in creating barriers and the one that disables persons with disabilities. In his chapter, "A new model of the social work role in relation to disability,"³³ Mike Oliver suggests that we look at how our environment, physical and social, impose limitations to persons with disabilities be this in a covert or overt way.³⁴ The imposed limitations and barriers (attitude, participatory, structural) on

³³ Mike Oliver, 'A new model of the social work role in relation to disability', in *The handicapped person: A new perspective for social workers*, ed. Jo Campling. (London: Radar, 1981), 19-32.

³⁴ *Ibid.*, 28.

persons with disabilities is a form of exclusion and oppression,³⁵ therefore it can be a justice issue.

The social model of disability strongly suggests a radical change in society that exhibits inclusion by tangible accommodation and access for persons with disabilities. In the Philippines, there are laws that benefits persons with disabilities, but on the individual, academy, ecclesia and industrial level, its implementation is in a slow pace, and ableism and infrastructure barriers are still present and felt by them. One means to effect societal change on structure is for the government, educational institutions, places of worship, private corporations to adapt a universal structural design (USD) that will accommodate all citizens. Through USD one aspect of exclusion will be eliminated. On matters of communication, there are applications that removes language barrier, particularly with deaf people. The application, FSL Buddy,³⁶ was created by a deaf student for hearing people who wants to learn and easily communicate with deaf people. Another application, Live Transcribed,³⁷ was created by a student from Massachusetts Institute of Technology (MIT). For the sightless, there is the Braille EDGE 40 which is a powerful refreshable display that reads content on a computer screen and converts it to braille characters. These are some of the assistive technology that emerged from the needs that were brought to awareness because of disability. Applications and assistive technology are some ways that create access for persons with disabilities that afford them self-determination and agency, and to its effect will give them the opportunity to actively be involved in society. Nonetheless, any invention that will ease the life of persons with disabilities has to be coupled with a change of paradigm in seeing disability.

³⁵ Cathal O'Connell, Joe Finnerty, Joe. and Orla Egan, *Hidden Voices: An Exploratory Study of Young Carers in Cork* (Dublin, Ireland: Combat Poverty Agency, Poverty Research Initiative, 2008), 15.

³⁶ The FSL Buddy Apps is available at Google Play store.

³⁷ The Live Transcribed is available at both Apple Store and Google Play store.

In her article, “Violence, Disability and the Politics of Healing,”³⁸ Rabbi Besler suggests that inclusion, as a paradigm is insufficient if we want to actualize disability justice. No doubt that inclusion is promising for the community of PwDs, however, my interpretation of Besler’s argument on inclusion as an ‘obvious access’ having the potential to ‘overshadow the more complicated, more challenging work of transforming our politics, of expanding the scope of who and what we value,’³⁹ is quite critical and less hopeful. Indeed, ‘obvious access’ might overlook the essential—person; but for them and in particular for deaf people, they highlight the positive aspect that could pave the way in creating new space(s) towards inclusion. In reference to the scripture, the prophet Isaiah saw and heard the strong words from the Lord who told him, ‘I will go before you, and make the crooked places straight: I will break in pieces the gates of brass, and cut in sunder the bars of iron,’⁴⁰ is a commitment that God decisively removes all obstacles so people can enter, and Besler has taken this to mean as a Divine gift of access.⁴¹ Also in agreement with Besler’s thinking is Jennie Weiss Block who calls on the church to be critical to imperceptible oppressive and discriminating ecclesia structures. For it is the duty of the ecclesia (authorities and communities) to ensure that persons with disabilities can actively participate within Christian communities.⁴² In addition, Block reiterates that the ecclesia should be forthright on the reality that many of the persons with disabilities have systematically been excluded to communal access and participation.⁴³ Similarly, Eiesland sees that the Church has settled with the charity model that disenfranchise persons with disabilities. For Eiesland, the Church has to admit its shortcoming

³⁸ Julia Watts Besler, “Violence, Disability, and the Politics of Healing: The Inaugural Nancy Eiesland Endowment Lecture,” *Journal of Disability and Religion* 19, no. 3 (2015): 3, 177-197, DOI:10.1080/23312521.2015.1061470. Besler, “Politics of Healing.”

³⁹ *Ibid.*, 185

⁴⁰ New American Bible

⁴¹ Besler, *Violence, Disability...* 184.

⁴² Jennie Weiss Block, *Copious Hosting: A Theology of Access for People with Disabilities* (NY: Bloomsbury, 2002), 11.

⁴³ *Ibid.*, 122.

or even failure to empower the PwDs because they are in some ways culpable in supporting ‘social structures and attitudes that have treated people with disabilities as objects of pity and paternalism.’⁴⁴ She even went further by challenging the Church on how it could have facilitated a ‘disabling theology’ that disqualify persons with disabilities to be involved actively in its affairs, planning and even decision-making. She states,

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.⁴⁵

In the attempt to remove barriers, it is imperative to meet eye-to-eye, to converse and listen to the narrative of the diverse other—fellow persons with disabilities. I envision that access and accommodation brings us to an awareness that there is no point to fear difference. In fact, the mainstream able-bodied can surely learn from the disability culture, such as resilience, value of a community, respect for diversity only when we welcome them. Hospitality through inclusion could dismiss discrimination, both structural and attitudinal. In the end, both the disabled and the able-bodied, the diverse humanity have similar desires, hopes, and a variety of stories that makes this our lives thrive.

The argument of Belser that, ‘if we treat disability primarily as an access problem to be solved, we overlook the vibrant, transgressive potential of disability as a radically different way of

⁴⁴ Eiesland, *The Disabled God...*, 10

⁴⁵ *Ibid.*

being in the world,⁴⁶ is a challenge and process where we hope that the majority will be able to see disability not as a loss but a gain. From having a physical sight to being sightless with a ‘vision,’ architect Chris Downey, firmly articulates, “I’m absolutely convinced I’m a better architect today than I was sighted.”⁴⁷ When asked if he wants to regain sight, his response,

If I were to get my sight back—it would be—(SIGH) I don’t know. I would be afraid that I’d—I’d sort of [sorta] lose what I’ve really been working on. I don’t really think about having my sight restored. There’s—be some logistical liberation to it. But—will it make my life better? I don’t—I don’t think so.⁴⁸

The able-bodied are invited to see the physical access and accommodation for the PwDs as pathways of encounter with them. Disability justice in the light of their embraced identity, disability culture and the social model bespeaks of hospitality as a virtue (good) that invites the able-bodied to welcome interruption and disruption. It is by welcoming them that we will no longer dread the existential reality of disability and disorder, but dance and celebrate diversity. Belser’s articulation of the ‘gift of access’ is Divine hospitality where God levels the playing field by “making crooked places straight,” eliminating fear, embracing diversity and establishing inclusion. Deaf praxis of hospitality as virtue (good) is not easy, yet truly possible as long as we continue to re-negotiate, re-think, re-engage,⁴⁹ until we reach and make authentic inclusion a reality in society. Only then we can claim that disability justice is here.

⁴⁶ Belser, *Violence, Disability...*185.

⁴⁷ Chris Downey, “Architect Goes Blind, says He’s Actually Gotten Better at His Job,” interview by Leslie Stahl, 60 Minutes. CBS News, January 13, 2019, <https://www.cbsnews.com/news/architect-chris-downey-goes-blind-says-hes-actually-gotten-better-at-his-job-60-minutes/>. Downey became sightless a decade ago after a brain surgery. He is now one of the trustees of the LightHouse for the Blind and Visually-Impaired.

⁴⁸ Chris Downey, *Gotten Better*.

⁴⁹ Geoffrey Bennington, *Politics and Friendship: A Discussion with Jacques Derrida*. Center for Modern French Thought, University of Sussex, December 1, 1997.

CONCLUSION

This article underscored how our society has facilitated disability injustice by presenting the medical and charity models of disability, which many have internalized. It is unfortunate that even to this date we continue to medicalize varied forms of disability and disorder, resulting to an ableist (and even sanist) attitude where PwDs are negatively perceived as different, deviant, a disruption and interruption. By focusing on the physical (as well as mental) conditions of PwDs, they were made objects of experimentation, and thereby enforcing normalcy. The charity model of disability has likewise disenfranchised PwDs by seeing them as objects of pity and of inspiration. We seldom ask ourselves of our ulterior motives for being benevolent, is it because we want to pacify our guilt, or to uplift our numbed disposition. Similarly, media representations have turned PwDs into inspiration porn for the benefit of the mainstream able-bodied people. All of these are forms of hostility and therefore disability injustice in the guise of charity and inspiration, yet we remain uncritical on whose agenda is on the platform.

The identity, cultural and social models of disability offers another perspective in seeing persons with disabilities and disability in general. In addition, these models showed us that disability is a justice issue that we often dismiss. Each of these models prepare us for a more inclusive society. The initial step towards inclusion is hospitality towards the PwDs that is exhibited in varied forms, be this structures and infrastructures of accessibility, reasonable accommodations and active participation. In response to Belser's fear of a limiting vision of inclusion, I invite you to encounter and engage with PwDs on a personal level, which is an inaugural step of hospitality and a decisive act to dispose fear. Further, listen to the narratives of PwDs is a means to level off the playing field, which eventually could pave the way to create access and accommodation. From the Deaf praxis of hospitality, they showed how to level the 'crooked places' (our paradigms/perceptions), and to unlearn and uproot our harmful biases and 'isms' (ableism, lookism and sanism). A society and ecclesia that seriously commit towards radical transformation could begin by affording hospitality to

persons with disabilities through access and accommodation (structural and attitudinal). This is an imperative to engender authentic inclusion of PwDs in our society and ecclesia and to actualize disability justice, and only then we can claim that the reign of God is truly at hand.

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