

Moving Beyond the Limits of Disability Inclusion: Using the Concept of Belonging Through Friendship to Improve the Outcome of the Social Model of Disability

Luke S. Carlos A. Thompson

Abstract—The medical model of disability, though beneficial for the medical professional, is often exclusionary, restrictive and dehumanizing when applied to the lived experience of disability. As a result, a critique of this model was constructed called the social model of disability. Much of the language used to articulate the purpose behind the social model of disability can be summed up within the word *inclusion*. However, this essay asserts that *inclusiveness* is an incomplete aspiration. The social model, as it currently stands, does not aid in creating a society where those with impairments actually *belong*. Rather, the social model aids in lessening the visibility, or negative consequence of, difference. Therefore, the social model does not invite society to welcome those with physical and intellectual impairments. It simply aids society in ignoring the existence of impairment by removing explicit forms of exclusion. Rather than simple *inclusion*, then, this essay uses John Swinton's concept of *friendship* and Jean Vanier's understanding of *belonging* to better articulate the intended outcome of the social model—a society where everyone can *belong*.

Keywords—Belong, community, disability, exclusion, friendship, inclusion.

I. INTRODUCTION

THE Disability Rights movement and the academic field of Disability Studies have been dominated by the social model of disability since the mid 1970s. The general aim of the social model of disability can be summarized by the word: *inclusion*.

A closer examination of *inclusion* as the focal point of the social model raises the following question: *what does social inclusion actually entail?* Answering this question honestly reveals a gap between what the social model of disability *aims* to achieve and what it *actually* achieves. The focus of this paper, then, will be to adjust the language of the social model to bridge the gap between the intended and achieved outcome. This will be done by utilizing John Swinton's concept of *friendship* and Jean Vanier's concept of *belonging*. It is worth noting that there are a variety of models that resist the individualistic, strictly medical definitions of disability. However, because the social model has become the dominant, authoritative, and formative ideology within the Disability

Rights movement and Disability Studies in (Britain and the United States), the focus of this paper will be to critique the social model as it is understood within a British context. This is because the American social model does not articulate disability as *solely* social oppression. However, as Disability Studies scholar Tom Shakespeare points out:

all [social-contextual approaches to disability] ...reject an individualist understanding of disability, and to different extents locate the disabled person in a broader context. To varying degrees, each of these approaches... [aim to improve] the lives of disabled people, by promoting social inclusion and removing the barriers which oppress disabled people [5].

Therefore, problems with the *inclusion* agenda are still present within the American social model, and—to one degree or another—within other social-contextual models as well.

Before one can constructively adjust the social model one must be aware of why the social model was introduced in the first place and the nature of its current articulation.

II. MODELS AND IDENTITY FORMATION

Sociologist and Disability Studies scholar, Colin Cameron, articulates a *model* as "...a framework of ideas used to make sense of a phenomena and experience in the social worlds we inhabit" [2]. Cameron goes on to assert that models represent "...a particular way of ordering and structuring knowledge..." [2]. In other words, models seek to *name* human experiences and aid in shaping the way that certain phenomena are perceived. For this reason, Disability Studies scholars and theologians alike assert that one's ability to *name* their own experiences is central to identity formation. Therefore, having the ability to articulate one's own experiences or self-identify can be profoundly humanizing [4], [3], [6], [15], [16]. In the same way, then, if one's experiences and identity are ascribed to them from without—though the intentions may be positive—this can be profoundly *dehumanizing*.

Though the language of self-articulation is helpful. Further qualification is required in order to avoid excluding those with intellectual impairments. As will become apparent, the problem is not that those with intellectual impairments are not able to communicate their own experiences. Rather, the problem at hand is that *inclusion*—over and against *belonging* in *friendship*—does not require the able-bodied to *learn* to be

Luke S. Carlos A. Thompson is a Ph.D. Candidate in Divinity at the University of Aberdeen, King's College, United Kingdom. (UK Phone: +4407716299402; United States Phone 813-444-8154; e-mail: r011st15@abdn.ac.uk).

with, belong to, understand, and befriend individuals with differing modes of communication. Therefore, it is not the case that those with intellectual impairments *cannot* articulate and name their experiences; rather, it *is* the case that *inclusion* does not necessitate that society *learn* to understand the various modes of articulation embodied by the intellectually impaired. This is not all that different from the way in which a friend gages (though perhaps subconsciously) the mood of another friend through *learning* to read personal mannerisms and body language.

III. HISTORICAL CONTEXT AND THE MEDICAL MODEL

Prior to the existence of the social model, secular explanation of disability and its lived experience were only legitimated within the context of medicine through the medical model. Within this model, *disability* is an individualized problem that is empirically *diagnosed* and should be *solved* or *fixed* through the appropriate application of medicine [2].

When discussing the medical model vis-à-vis mental health care, theologian and former psychiatric nurse, John Swinton, articulates the medical model in the following way:

Within this model the focus falls on overcoming disease [and bodily difference] through the development and utilization of universally applicable diagnostic criteria and specialized technical interventions. It draws on empirical research that is designed to develop *universal* methods and treatments that will deal with symptoms of the *typical* illness within the average patient [9].

People are reduced to a series of bodily functions. Or, as Swinton states, caring for people becomes similar to how a mechanic or engineer “fixes” a technical problem. Difference is a “...malfunction... the problem needs to be located and the particular malfunctioning part repaired in order that the machine can function effectively again” [9].

As a result, the secular responses to crucial, identity-based questions such as: what *is* a *disability*? Or, what does it mean to be *disabled*? are only allowed to be defined by, and treated within the parameters of skills garnered by, medical professionals. This is because within the medical model *disability* is an individual *problem* and the *disabled* are abnormal. It is understood to be the job of medicine and medical professionals, then, to reduce the abnormality as much as possible.

IV. HISTORICAL CONTEXT AND THE SOCIAL MODEL

In the 1970s, however, groups such as the Union of Physically Impaired Against Segregation (UPIAS) challenged the medical model of disability. UPIAS boldly redefines ‘*disability*’ in the following way:

In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society [10].

Within this context, *disability* is the result of external factors imposed upon individuals with differing levels of limitation.

According to the UPIAS, then, the social model is a concise articulation of *disability* that aids in furthering the central task of the UPIAS. This task is stated in the following way:

We [the UPIAS] see the essential task, at this point in time, as that of helping disabled people to organize together to take a more active part in struggling for the changes in society which will ensure that we are brought into the mainstream of life, rather than being excluded [10].

This understanding of what it means to be *disabled*, according to sociologist and Disability Studies scholar, Tom Shakespeare, “...shifts attention from individuals and their physical or mental deficits to the ways in which society includes or excludes them” [5]. Within this model *disability* is no longer the result of bodily ‘malfunction’; rather, *disability* is perceived as a social phenomenon constructed by society’s inability to adapt to and *include* a variety of different individuals. Now that the groundwork for the social model and its central emphasis has been laid, a critical look at inclusion is an order.

V. THE INADEQUACY OF INCLUSION

Simple *inclusion* offers minimal to no *lasting* social change or ideological equality. To put it another way, social inclusion requires that public buildings are accessible (ramps, automatic or push-button doors, parking spaces, etc.); that individuals with bodily impairments be considered for employment if task-descript qualifications are met; and, that equal pay be offered for employee competency irrespective of bodily difference. All of these changes in law and policy have greatly improved the living conditions of those with a variety of bodily impairments. However, at its best, this call for social change fails to account for the nuance in life experiences from one form of impairment to the next. At its worst, there is an emphasis upon physical impairments, thus overlooking individuals with intellectual impairments completely [1].

Taking intellectual impairments seriously offers a pointed and noteworthy critique of inclusion. *Inclusion* does not necessarily require society to alter its *perceptions* of—or *attitudes* toward—human difference. Instead, changes to infrastructure and social policies allow the negative impact of exclusionary misperceptions toward human differences to be less pronounced, not unlike a Band-Aid over a longstanding wound. Removing the Band-Aid so that the wound can breathe may be uncomfortable, but it is crucial to the healing process. Emphasizing inclusion may get individuals into the building, but inclusion offers little change in the way human difference is *perceived* and *received* by those *already* inside the building.

VI. BELONGING

Receiving and responding positively to human difference requires society to see and welcome individuals as *people*

first. Recognizing, then, that in order to do this well the *second* thing that must be done is to take into account the individuals unique limitations. *Receiving* within this framework, however, makes note of personal differences in order to see how and where these differences can *belong* within—and therefore enrich the tapestry of—the societal fabric. Philosopher and founder of the L’Arche communities, Jean Vanier describes this kind of receptiveness as *belonging*.

Vanier describes belonging as, “the basic human need” [11]. In other words, this is a key component of what makes people *human*. According to Vanier, persons learn what it means to be *human* when persons become comfortable with the reality of limitation and embrace it as part and parcel of being human. In fact, it is the *limited* nature of all humans—able and *disabled* alike—that creates the framework for community [12]-[14]. Vanier calls this “mutual interdependency” [11]. Vanier elaborates upon this basic human need in the following way:

[this] need is for at least one person who believes and trusts in us. But that is never enough, it doesn’t stop there. Each of us needs to belong, not just to one person but to a family, friends, a group, and culture...Belonging is important for growth to independence; even further, it is important for our growth to inner freedom and maturity [11].

For Vanier this is crucial because, “we do not discover who we are, we do not reach true humanness, in a solitary state; we discover it through mutual dependency, and weakness, in learning through belonging” [11]. It is this embrace of mutual dependence, rather than simply unidirectional ‘tolerance’ present within simple *inclusion*, that creates space for true *belonging*. In other words, belonging, correctly articulated, is a relational bridge between the intended and achieved outcome of *inclusion* highlighted within the social model. Making *belonging* the conceptual center invites both the temporarily able-bodied *and* the disabled into community *with*—rather than toleration of—one another. Swinton draws upon Vanier’s concept of belonging and highlights its contrast to *inclusion* within the context of dementia by stating that:

“belonging” is not the same as “being included.” To be included, one simply needs to be present “somewhere,” wherever “somewhere” might be. Belonging is different. In order to belong, one needs to be missed if one isn’t there. In order to belong to the community of strangers, people with dementia and their families need to be missed when they’re absent. If they’re not missed, they don’t belong; and if they don’t belong, there is no true community—for anyone [6].

It is *belonging*, then, that serves as the bridge between where the current social model concludes (*inclusion*), and what the ideologies that birthed the social model are actually inviting society into.

With *belonging* firmly situated at the center of the social model, the next step is to provide a framework within which *belonging* can be applied in praxis.

VII. FRIENDSHIP

The daily outworking of *belonging* is best expressed within the context of *friendship*. A closer look at Swinton’s aforementioned articulation of *belonging* illustrates this well. Swinton asserts that in order for people to belong—in their current state—individuals must be *missed* when they are absent [6]. In other words, the *disability* is noticed, welcomed, and accounted for between friends; rather than, being seen as a disadvantage between unequal individuals. *Friendship* allows *both* individuals to contribute to the life and community that *both* individuals inhabit. In fact, this mutual benefit is such that if a person isolates themselves the change within, or total absence of, the partnership is keenly felt.

Friendship does not demand that policies change so that those at the margins of society can be *included*. Rather, as Swinton states, friendship liberates and enables *all* people to live humanly [8]. For Swinton, the goal of friendship is “rehumanization” [8]. Which, as Vanier points out, is discovered through interdependence, the acknowledgement of limitation as *human*, and a *mutual* sense of belonging. It follows, then, that to highlight one voice to the exclusion of another renders true *community* impossible, and therefore, society itself *incomplete*. It is important to note here that this is not an argument against the necessity or benefit of changes in social policy. Rather this paper asserts that changes in social policies and greater accessibility are best understood as *steps toward* a greater destination: *belonging* expressed through *friendship*. This kind of *friendship* acknowledges that the able-bodied *need* the *disabled* just as much as the *disabled* need the able-bodied. There is a mutual recognition of what bioethicist and philosopher, Daniel Sulmasy calls “intrinsic dignity” [7]. According to Sulmasy, intrinsic dignity,

...is a value that commands respect. To respect something requires both that one recognize its value and that one make choices consistent with the proper appreciation of that value. Respect starts with recognition and acknowledgement...If the value at stake is truly intrinsic...then it is an objective value and must be recognized for its proper worth by everyone [7].

Understanding this ‘intrinsic dignity’ as an objective reality that informs friendship, then, affirms and necessitates the need for social change vis-à-vis *disability*. However, unlike within the current social model, change is not *only* for the benefit of the *disabled*; rather, change is warranted so that able-bodied people can learn from being in relationship with the *disabled* and vice versa. This enriches the social model by requiring society to shift its definition of *who* it is that occupies the ‘margins’ of society. In other words, the goal is not simply for the able-bodied (already humanized) members of mainstream society to make *their* world more accessible. Rather, the goal becomes for *both* to recognize that by excluding the other *both* have an incomplete understanding of what it is to be human. Furthermore, being in community with one another (being *friends*) brings out the *humanness* within everyone involved. This requires, then, that able-bodied individuals recognize the need for those previously deemed to be ‘at the margins’ to contribute to social norms, culture, and identity formation.

Within this understanding of the social model, it is the contribution of the *disabled*—in conjunction with the voice of the able-bodied—that equals ‘mainstream’ society.

VIII. CONCLUSION

Critiques of the social model range from asserting that the model must be adjusted to stating that the model has outlived its usefulness and must be replaced altogether [1]. However—regardless of where an individual’s beliefs are on this spectrum—it is clear that change *is* needed. If *inclusion* is upheld as the end goal, neither the social model nor any model erected in its place, can act as a bridge into a society where human difference would be *missed* if it were not present. Replacing *inclusion* with Vanier’s concept of *belonging* as the focal point challenges both the *disabled* and the able-bodied to acknowledge a mutual *need for*—rather than toleration of—one another. It is the internalization of this reality, then, that results in Swinton’s articulation of *friendship* being seen as the avenue through which *belonging* is achieved. These adjustments to the social model clearly maintain the importance of, and ongoing need for, social change. However, filling in these gaps allows the push for social change to be motivated by an acknowledgement of ‘intrinsic dignity’ and personal differences between mutually dependent *friends*.

REFERENCES

- [1] Barnartt, Sharon N., and Barbara Mandell Altman, eds. *Exploring Theories and Expanding Methodologies: Where We Are and Where We Need to Go*. 1st ed. Research in Social Science and Disability, v. 2. Amsterdam; New York: JAI, 2001, Ch. 1, 9-28.
- [2] Cameron, Colin, ed. *Disability Studies: A Student’s Guide*. 1 edition. Los Angeles: SAGE Publications Ltd, 2013, 98-99.
- [3] Eiesland, Nancy L. *The Disabled God: Toward a Liberatory Theology of Disability*. Nashville: Abingdon Press, 1994, 25.
- [4] Hauerwas, Stanley. *Suffering Presence: Theological Reflections on Medicine, the Mentally Handicapped and the Church*. Notre Dame, Ind: University of Notre Dame Press, 1986, 166-167.
- [5] Shakespeare, Tom. *Disability Rights and Wrongs*. New York: Routledge, 2006, 9-29.
- [6] Swinton, John. *Dementia: Living in the Memories of God*. Grand Rapids, Mich: William B Eerdmans Publishing Co, 2012, 279.
- [7] Swinton, John, and Richard Payne, eds. *Living Well and Dying Faithfully: Christian Practices for End-of-Life Care*. Grand Rapids, Mich: William B. Eerdmans Pub. Co, 2009, 234.
- [8] Swinton, John. *Resurrecting the Person: Friendship and the Care of People with Mental Health Problems*. Nashville: Abingdon Press, 2000, 23.
- [9] Swinton, John. *Spirituality and Mental Health Care: Rediscovering a “Forgotten” Dimension*. London; Philadelphia: J. Kingsley Publishers, 2001, 49-52.
- [10] Union of the Physically Impaired Against Segregation, and the Disability Alliance. *The Union of the Physically Impaired against Segregation and the Disability Alliance Discuss Fundamental Principles of Disability: Being a Summary of the Discussion Held on 22nd November, 1975 and Containing Commentaries from Each Organisation*. London, November 22, 1976, 3-4. An unabridged copy of this discussion can be accessed at: <http://disability-studies.leeds.ac.uk/files/library/UPIAS-fundamental-principles.pdf>
- [11] Vanier, Jean. *Becoming Human*. London: Darton, Longman & Todd, 1999, 35-41.
- [12] Vanier, Jean. *The Broken Body*. London: Darton, Longman and Todd, 1988.
- [13] Vanier, Jean. *Community and Growth*. London: Darton, Longman and Todd, 2007.
- [14] Vanier, Jean. *From Brokenness to Community*. The Wit Lectures. New York: Paulist Press, 1992.
- [15] Yong, Amos. *The Bible, Disability, and the Church: A New Vision of the People of God*. Grand Rapids, Mich: Wm. B. Eerdmans Publishing Company, 2011.
- [16] Yong, Amos. *Theology and Down Syndrome: Reimagining Disability in Late Modernity*. Waco, Texas: Baylor University Press, 2007.