

From Charity to Equality: Striving for Social Inclusion of People With Severe Disabilities as a Pathway Toward Human Flourishing

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Abstract

It is our human nature to reject those who are different. Individuals with severe disabilities clearly remind us of the fragility and vulnerability of all human beings. In order to preserve our self-esteem, we tend to treat these individuals as utterly different from us. The rejection is an evolutionary-based reaction for protection coded deeply in our nervous system. In contrast, inclusion is exclusively a human act which requires effort and work. These individuals challenge our self-esteem as well as our physical and social environment. A positive response to these challenges leads to more human communities which are beneficial for all of their members. In contrast with the commonly held belief that fulfilling the special needs of people living with severe disabilities is a unilateral act of charity, inclusive communities are in fact more productive and provide dignity and worth to every human being throughout their life.

Keywords: Disability, Standpoint Theory, Terror Management Theory, Inclusion

Introduction

Disability is a multifaceted issue, and a battleground for many different disciplines and viewpoints. There is a wide range of approaches to defining and describing disability based on

biologically- or socially-constructed classifications. This paper reflects on the issue of social inclusion from individual and professional experiences of direct work with people with severe disabilities. This group consists of extremely vulnerable people suffering from different forms of social exclusion whose perspective and insight is chronically forgotten by policy makers, social experts, and academics. Nevertheless, the analyses of different biological, psychological, and social mechanisms of inclusion from the perspective of those with severe disabilities would enrich our knowledge about the relationship between society and disability. Furthermore, close examination of paradigms of disability sheds light on contradictive dynamics of human society which exclude “whilst simultaneously seeking to include” (Scanlon & Adlam, 2011, p. 241).

Although the basis of most scholarly writing and legislation is the social model of disability, the everyday personal and interpersonal experiences of people with disabilities suggest that society at large still considers disability from the viewpoint of the medical or, rather, the tragedy/charity model. The social justice view of disability proclaims the need for social equalization at systemic, social, and political levels, while the interference of subconscious mechanisms of rejection remains dominant when we encounter someone with disability.

The issue of social inclusion provides a broader perspective to study disability in its complexity. In other words, the analysis of the ecological context, or the interacting intrapersonal, interpersonal, organizational, community, and policy levels, leads to a deeper understanding of disability and its effect on the psychosocial environment.

The Perspective of Individuals With Severe Disabilities

Individuals with severe disabilities (or in other classifications, individuals with severe and multiple learning disabilities or individuals with severe and multiple disabilities) form a heterogeneous group. These people live with “concomitant impairments (such as intellectual disability-blindness, intellectual disability-orthopedic impairment, etc.)” which causes significant differences in speech or communication, basic physical mobility, sensory awareness, and/or significant differences in behavior far from the cultural norms. (National Dissemination Center, 2012, p. 6). They also “require extensive ongoing support in more than one major life activity in order to participate in integrated community settings and to enjoy a quality of life that is available to citizens with fewer or no disabilities” (The Association, 1991, p. 19).

Imagine a 32-year-old man in a custom seat wheelchair. He is blind, he cannot speak and he has difficulties with eating. He is able to communicate only through facial gestures and vocalization. He smiles when hearing the voice of people he knows well or when hearing jokes, but it is not clear whether he understands the verbal meaning or reacts to the emotional state of the joke teller. No one would say that his disability is exclusively a social construction or blame him for his disability (though this often happens when the disability is a consequence of a destructive life-style or accident caused by the person). He probably won't be envied as a privileged person who belongs to a protected minority using the benefits of positive discrimination. He is not a target of any advertisement as a potential customer.

Furthermore, as Forster (2011, p. 68) highlighted Reinders' thoughts, “disability rights movements (striving for empowerment, agency or political participation) have little to say” about him. He lives a quiet life with his family or in an institution but, in contrast with the common belief that his life is unhappy, he is able to enjoy many life events. He is a popular member of his local community. He has friends who visit him and take pleasure in spending time with him because his peaceful personality and visible joy upon small everyday events cheer up many people.

Examining the issue of disability from this perspective, we have some sort of *absolute* point of view. The life experience of these individuals reframes the question of inclusion and sheds light on the different anomalies of systemic and individual thinking about disability. It is important to add that living with severe disabilities is an exclusively human phenomenon. Thus, treating, valuing, and caring for an individual with a major support need is also an exclusively human behavior.

Severe Disability and Social Context: Being “Too Far Out in the Cold”

Scalon and Adlam (2011) described the dynamics of the welfare state and its systems for social care with the concept of a *colonial vision of inclusion*. They exemplified this concept with the dominant sociopolitical structure of the ancient Athenian democracy which “allowed some to be citizens of the city-state or metropolis whilst denying this privilege to others” (p. 242). They described the colonial model whereby *we*, invite *they*, to join *us* and receive the benefits of our application and industry on different conditions. Some people with disabilities are able to gain this symbolic citizenship but, to use Adlam, Pelletieri, and Scanlon's words, only “those who are already not too far out in the cold” (Adlam et al., 2010, p. 13). Individuals with severe disabilities are too far from the strict social norms.

The social versus the medical model

The medical and rehabilitation models of disability put emphasis on medical solutions to subnormal abilities or dysfunctional thinking. In this paradigm, disability is seen as a personal impairment and professionals are supposed to provide individualized treatments (Johnstone, 2004, Swain et al., 2003; Thomas, 2004).

There are different approaches closely related to the medical paradigm, namely the *expert or professional* model and the *tragedy or charity* model (Darcy et al. 2016, Humpage, 2007, Oliver, 1996). The former enrolls in the traditional authoritarian model of medical treatment where professionals play a crucial role in the management of disability. In this model, professionals classify and identify the impairment and its limitations, and prescribe and provide the medical treatment for their remediation. Under the authority of the medical community, a wide range of paramedical professionals provide treatment, training, therapy, counseling, or other services to reduce personal and social consequences resulting from the impairments. The tragedy/charity model considers people with disability as victims of circumstance, emphasizing their need for help. The medical paradigm is still dominant in the everyday life of people with severe disabilities, and usually deprives them of the ability to make the simplest everyday decisions affecting their life. The *social model of disability* emerged as a reaction to the medical model, emphasizing that physical or mental impairment does not cause disability in itself; the main disabling factors are the physical, social, and attitudinal barriers (Barnes & Mercer, 2010; Becker, 1982; Oliver, 1996; Reindal, 2010; Shakespeare & Watson. 2001; Shapiro, 1993; Stocker, 2001).

While the social or human variation model seems to be the officially accepted paradigm at present, the life experience of people with severe disabilities proves that the main attitude of society towards an individual with disabilities continues to be based on the stereotype that disability is a tragedy which should be pitied. Actions emerging from this conception tend to establish a culture

of caring for: Benevolent acts of charity lead to unequal situations, reinforcing the subordinate role that a person with severe disabilities usually plays in all areas of their lives. They are excluded not only from the distribution of social goods, they are deprived of free choice, excused from the normal obligations of society, and often viewed as not even desiring to share these social goods and obligations. This benevolent depiction of disability serves to strengthen the self-esteem of the *non-disabled* person, especially if the situation offers an expert role or a power position (Bagenstos, 2000; Kama, 2004; Oliver, 1996; Tompson, 2001). For example, the attitude that imposes and maintains control over someone with severe disability may be a way for parents or family members to feel compensated for caring for a person with severe disability.

Human society has not found an adequate response to the needs of these individuals. Their presence is challenging for our physical environment, social and healthcare systems, and preconceptions about humanity or human dignity. In order to overcome the first subconscious negative reaction, we should reflect on our value systems and identify the contradictions at both personal and social levels. This process holds a lot of potential because, instead of providing support to enable people with severe disabilities to function as a part of the current structure, these encounters urge individuals or communities to re-organize their systems and re-define their values.

Rethinking identities: Terror Management Theory

Terror Management Theory (TMT) (Greenberg, Pyszczynski, & Solomon, 1986; Greenberg, Schimel, & Martens, 2002; Mikulincer & Florian, 2002; Solomon, Greenberg, & Pyszczynski, 1991) explains the psychological background of these challenging encounters. According to this theory, individuals with visible signs of human fragility are potentially dangerous for the self-esteem of others, because “human beings manage deeply-rooted fears about their vulnerability” (Martens, Goldenberg, & Greenberg,

2005, p. 223). From this perspective, the role of social exclusion is to avoid facing our own vulnerability and, thus, mortality. The defensive reaction occurs when a disturbing factor “motivates people to engage defensive attitudes and behaviors that provide symbolic protection (i.e., faith in a meaningful worldview and a sense of self-esteem)” (p. 225). The basic assumption of this theory is that we use two seemingly contradictory psychological mechanisms to cope with mortality concerns and the vulnerability of human beings, both rooted in the need for “meaning and belonging to a greater and more enduring structure than the self” (Mikuliner & Florian, p. 261).

Reminders of mortality challenge one’s personal worldview. Consequently, individuals react with defensive responses that exclude the triggering factors or with positive responses accepting the inevitability of death. This means reframing personal value-systems and life expectations, striving for meaningful life and gaining symbolic immortality by generative actions (McAdams & de St. Aubin, 1992; McAdams, Hart, & Maruna, 1998). While rejection is driven by fear and defense, acceptance has a deep and positive impact on the whole personality: people and even communities are motivated to shift their value-systems and find intrinsic sources of self-esteem.

The Anatomy of Exclusion and Rejection

Social exclusion is a common phenomenon around the world. Kurzban and Leary (2001, p. 187) state that “despite people’s best efforts to be accepted ... social rejection is a pervasive feature of social life.” The first natural human reaction upon encountering someone with multiple signs of severe disability is an emotional disturbance in the observer. In order to relieve anxiety, people tend to reject those who deviate from social norms or cultural standards (Oaten, Stevenson, & Case, 2011, Rimmerman, 2013). While in other cases of social exclusion the difference is perceived as potential danger for cultural practices, a certain worldview, or social structures, seeing an

individual with severe disabilities triggers death anxiety. Thus, behind the frequently occurring general and benevolent pity, there are contradictory, negative, and even subconsciously hostile feelings. People often feel guilty because of these negative emotions. Understanding and accepting the roots of our negative reactions towards individuals with severe disabilities helps to us overcome and learn a new attitude.

From an *anthropological view*, Frölich (1996) argues that the existence of people with severe disabilities challenges our conceptions about human beings. He argues that we define human beings according to the anthropological development of hominoid species. We consider ourselves as *homo erectus* [upright human], but many people with severe disabilities cannot keep a vertical body position without support. Another milestone of human development is the use of tools, we are *homo ergaster* (working human), *homo habilis* (handy or able human), and *homo faber* (maker or working human). In sharp contrast many of these individuals are unable to use their hands. Finally, we define ourselves as *homo sapiens* (wise human) having the unique ability to communicate through oral language, while many of these people cannot speak or prove their ability to use and understand complex abstract concepts. Thus, the encounter with someone not possessing these distinctive features of our identity causes us to question our notions about being human.

From a *psychological perspective*, Oaten et al. (2011) state that perception of difference is sufficient to evoke existential anxiety, especially in the case of physical disability and disfigurement, because in these encounters we face our own vulnerability, dependence and mortality. As a result, someone with severe disabilities does not challenge norms, social structures, or value systems. Instead, they challenge our overall conception about human beings and, thus, about our existence. Isaksen (2002) interprets this as the idea that, “viewing a person whose symbolic self is overshadowed by the physical self” confronts us with the frightening life perspective of our “inability to impose mind over body” (p. 802).

From a *socio-psychological perspective*, Oaten et al. (2011) argue that social identity theory has established that strict categories of in-groups (including the self) and out-groups (different from the self) strengthen self-esteem and a sense of belonging. There are also non-human examples for social exclusion of outgroup members. For example, different primate populations tend to reject those who have interacted with out-group members. This behavior is associated with disease avoidance function in primate populations (Freeland, 1981; Oaten et al., 2011; Taylor, 1984). In addition to this ancient inheritance, downward comparison enhances self-esteem. Thus, categorizing people as *disabled* reinforces the sense of normality of the others (Kama; 2004; Thomson, 2001). These categories reproduce and reinforce each other, influencing attitudes about disabilities directly or more often in a subconscious way.

Examining the *biological roots* of rejection, abnormal physical features have a profound stigmatizing impact on social encounters. Oaten et al. (2011) describe the Disease Avoidance Model, proposing that signs that can be predictive of contagious diseases (such as facial lesions, dermatological disorders, abnormal movement or behavior, and changes to the physical structure of the body) activate a so-called disease-avoidance system. Even in the case of a false alarm, signs of primary disease evoke strong emotional responses such as disgust and avoidance. These reactions are driven by neurobiological systems and cannot always be influenced by conscious decision-making. The authors argue that social isolation of diseased individuals is an evolutionary based form of protection against infection. This reaction can be observed among primates and other animals as well (Behringer, Butler, & Shields, 2006; Dugatkin, Fitzgerald, & Lavoie, 1994; Freeland, 1981; Kiesecker, Skelly, Beard, & Preisser, 1999). The fact that social ostracism of diseased individuals can also be seen at many different taxonomic levels supports the evolutionary origins of social exclusion (Dugatkin et al.; Lancaster 1986).

Facial disfigurement, which has an even

stronger negative impact on social relationships, is highly prevalent among individuals with severe disabilities. Facial expression is among the most important nonverbal channels of human communication and, thus, a distorted face is challenging, especially when verbal communication is severely limited. People with severe disabilities may have bizarre hand movements, involuntary changes in facial expression, or semi-conscious vocalizations. As a result of social isolation and the lack of a supportive environment for social learning, the behavioral patterns of these individuals do not follow societal norms. Because of the lack of structured social conventions, people with severe disabilities are often associated with unpredictable and, thus, dangerous behavior (Stier & Hinshaw, 2007). A negative first impression induces fear and leads to negative prejudgments. Socially unacceptable behavior and social exclusion form a vicious circle.

Inclusion: Shift of Norms and Value Systems

Research conducted in the field of supported employment exemplifies the positive interpersonal and organizational changes resulting from social inclusion. Ironically, adding a less productive member to the team makes the whole organization more productive (Csányi, 2009). The reason for this transformation is the change in organizational culture. In addition to increased creativity and problem solving, the results have shown improvement in cooperation, morality, loyalty, personal connection and communication. Inclusive organizational culture, where workers feel respected and valued, is considered to be key for productivity. Research about organizational change describes the process of transformation of individual and organizational value systems. The shift of value-systems means that values associated with self-transcendence, for example the interests of others, outweigh those connected with self-enhancement, such as the pursuit of power. In other words, inclusive cooperative organizational culture seems to be more profitable than power and

achievement oriented competitive systems. From this point of view, the inclusion of people living with impairments, even if they do not always meet the high individual standards of an organization, is not merely a benevolent act, but one that brings about positive changes in the atmosphere that ultimately lead to better and more profitable organizations.

The *Universal Design* (UD) paradigm also serves as an example of progress. UD was originally a slogan for designing products and spaces. When the Social Model of disability emerged, it emphasized social and physical barriers as a cause of disability and mainstreamed the barrier-free approach. As a practical consequence, barrier-free designs often concentrated on one particular life condition, usually the needs of wheelchair users. Mainstreaming these standards was expensive and not helpful for almost all without that particular condition. The UD approach emerged as a practical response to the human diversity model, which understands disability as a structural or functional variation. The aim of UD was to accommodate the full range of human variation proclaiming that “people of all abilities are included in the intended population of users of a product or environment” (Joines, 2009, p.159). UD intends to make physical and social spaces more convenient for everyone. Instead of mainstreaming a particular condition, the design should be flexible, simple and equitable in use. Designers proclaimed that, “when mainstream products are universally designed it means a larger market for manufacturers, less cost for adaptations, and reduced risks of misuse or accidents” (Björk, 2009, p. 118). For this approach, an individual with complex and extended support needs is not an exception with unique and special needs but a client inspiring new and better solutions. As UD became more popular in designing social and learning environments, it became a new paradigm of inclusion. From this perspective, the successful inclusion of people with severe disabilities leads to more flexible and equitable socio-political systems and communities.

Inclusion means that we should change our perspective from the colonial practice that saw individuals with severe disabilities as exceptions.

This reinforces and strengthens our existing value system and worldview while it helps to solve problems for those with a severe disability. Reacting from the charity or tragedy model, playing the superior role of the professional, or simply pitying these individuals does nothing to help our communities discover and confess inconsistencies in our practices or to experience any of the transforming benefits of inclusion.

The first step: Take a new perspective

Continuing their metaphor from ancient Greek policy, Adlam et al. (2010) offer a new concept as a response to the colonial model of inclusion. The Greek philosopher Diogenes, the Cynic, called excluded groups *cosmopolitan*, that is, citizens of the world. Diogenes did not accept the offered metropolitan position, proclaiming that “the world belongs equally to all its inhabitants, who concomitantly belong to the whole world” (p. 4.). Thus, instead of striving for the privilege of citizenship, he established a new concept about equality, defining his position as cosmopolitan. Instead of talking about an excluded minority, the term cosmopolitan allows us to consider the outsider position from a positive perspective. Cosmopolitan citizens, like philosophers or artists, seem to have a level of independence from social norms. Like the symbolic characters of artists, clowns, or the court jester, individuals with severe disabilities have freedom from societal norms which gives them the ability to cross the boundaries of social acceptance (Aarts & Dijksterhuis, 2003).

Changing the value system of the community

Csíksszentmihályi (1996, p. 25) describes creative individuals as “people who experience the world in novel and original ways” and “individuals whose perceptions are fresh, whose judgments are insightful, who may make important discoveries that only they know about.” According to his interpretation, the main characteristics associated with an artistic talent are creativity, originality, novelty, and independence. Living in a marginalized position or with serious impairment

is a condition which changes the everyday task of life into challenging situations where there is no prior correct solution or answer. Having a disability forces individuals to find their own unique ways of problem solving. Furthermore, because of different medical conditions, their perception of the physical world is usually different from the average person. Thus, I would argue that creativity in a basic form is highly prevalent among individuals living with severe disabilities. This creative approach appears in simple situations and could become a source of inspiration for other members of the community. For example, Nick Vujicic, the young man with Tetra-Amelia syndrome, (the absence of all four limbs) became an inspirational speaker, using his own life-experience to talk about overcoming difficulties and disadvantages.

The social role those with severe disabilities often play is similar to the archetype of the Clown or the Court Jester. The critique portrayed by these symbolic characters can be deeply serious and comical at the same time. Similarly, individuals with limited metacognitive abilities cannot cope with social absurdities or inconsistent behavior. They often react in unexpected and, thus, humorous ways to point out inconsistencies in our cultural norms and habits. Another consequence of this inability to understand less clearly communicated messages is recognition of the need for clear and direct communication. The simple and obvious description of tasks and responsibilities leads to transparent and more effective structures in the workplace, and can facilitate the possibility of open communication in other types of communities.

Changing individual worldviews

Personal experience often leads to the re-creation of one's worldview. An exchange from my own life serves as an example. I was having a lengthy discussion with a lawyer, when she asked me about my job. After listening to my answer, she asked me, "What is the meaning of their life?" I was astonished. I had heard this question many times hidden behind other words and questions, but never in this open way. I answered shortly, "The

same as yours". After a long meaningful pause, she shared her conclusion with me: "As a lawyer, I keep proclaiming that human beings have rights not because they are able to do something, but because they are humans. But as it seems, I have never understood what this really means."

When someone has an encounter with a person with severe disabilities, it can challenge our previous beliefs and concepts about human fragility, vulnerability, and dignity. This can be a difficult moment, because of the major contradictions and inconsistencies between our value-systems and actual behaviors.

Quality of their life is a scale of our humanity

Considering the social inconsistencies from the perspective of individuals with severe disabilities, the most blatant contradictions are what Schlitz (2012, p. 49) refers to as the "inherent contradictions of the disability rights movement in the beginning and end of life context." The coexistence of justified prenatal testing and embryo selection with the promotion of social inclusion and equality for people with disabilities sheds light on "the inadequacies of modern humanism's presumptions that rationality, autonomy, and self-determination are the paramount values to be protected in our laws and our practices" (Schlitz, p. 51). The UN's Universal Declaration of Human Rights (1948, Preamble) proclaims the "recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family." Different international documents (for example, the International Covenant on Economic, Social and Cultural Rights, 1966, and the International Covenant on Civil and Political Rights, 1966), universally agree that all human rights derive from the inherent dignity of the human person.

The social situation and quality of life of these individuals serve as a sensitive scale of humanity within a community. Their life situation provides an unambiguous indication of the extent to which a given society values all human life.

Human beings tend to exclude those who are different and, because of this, need clear decisions and regulations to provide a worth and meaningful life for those who cannot be valued for their mental capacity or physical ability. The principle of human dignity proclaims that human life is unconditionally valued, regardless of what the person owns or accomplishes. When a social-care system based on the overall value of a human being provides respect, opportunity, and participation for its most disabled members, this is a clear commitment and a guarantee for lifelong dignity for all of its members throughout their lifespan. In contrast, when the most vulnerable members of a society are not treated as equal, it endangers the social security of all because the value of a member of the society is based on less stable, achievement centered, and extrinsic sources. Additionally, research proves that an individual's self-esteem is also more stable when rooted in non-achievement-based sources (Arndt, Schimel, Greenberg, & Prszczyński, 2002; Pyszczyński, Greenberg, Solomon, Arndt, & Schimel, 2004; Schimel, Arndt, Banko, & Cook, 2004; Schimel, Arndt, Pyszczyński, & Greenberg, 2001). Martens et al. (2005) argue that, "people appear more secure when focusing on intrinsic sources of self-esteem, on inner and stable qualities" (p. 235).

Conclusion

Building an inclusive society requires a continual process of learning from human diversity. Individuals with severe disabilities challenge our social and political systems and our concept of humanity, well-being, and human fulfillment. Facing human vulnerability is a reminder of one's own mortality.

Terror Management Theory describes rejection and re-creation of identity as two initial reactions to these reminders of death. The former is supported by different evolutionary-based defense mechanisms. Human beings tend to reject those who are different. In sharp contrast with denial and rejection, inclusion needs effort and work. The practice of changing viewpoints, rethinking values and social systems, and reframing identity

is a uniquely human trait. This inner work leads to individual development, and this reflective analysis leads to better quality in one's physical and social environment. The social inclusion of the most vulnerable members of the community is a testimony *per se* and *in se* about the unconditional nature of human dignity. This commitment is beneficial for all members of the society providing real social security regardless of productivity, health condition, or other factors.

Based on the experience of inclusion in the labor market, inclusive communities are more productive due to positive changes in their organizational culture, such as creativity, humor, personal connectedness, and the overall ambience of the workplace. The benefits of inclusion manifest themselves in universally designed physical and social environments that aim to satisfy the needs of the full range of human variation.

This occurrence offers an extended explanation for agency, traditionally associated with self-dependence, that is, a sense of mastery, empowerment and social recognition. From the perspective of inclusion, the definition of agency would refer to the relation between the individual and the community, wherein a sense of mastery, empowerment and social recognition is pursued through positive changes in the community. As many of these individuals cannot participate in the labor market, the utilitarian approach of the human existence needs to be changed to one that considers the intangible benefits of the presence of these individuals in the community.

Expanding this effect to the whole society, we could expect that a successful inclusion of people with severe disabilities provides a radical critique of the so-called narcissistic value system of welfare societies. This value-system is based on power, derived in status, wealth, control, and dominance over others and resources, and is characterized by the priority of momentary pleasure, fame, bodily perfection, and the avoidance of attachment and empathy (Lasch, 1979; Vodopivec, 2008). Building up a society based on the human variation model of disability requires an ongoing reflection on

personal and social inconsistencies, and thus opens a pathway for maturing and growing humanity.

In addition to striving for meaningful life and gaining symbolic immortality by generative actions, taking-on the perspective of a friend with severe disabilities allows us to learn about our own value and dignity, too. Our social or financial status is meaningless for these individuals. They befriend us merely because of our personality. From this perspective it is not the society which respects its most vulnerable members, but these members show a new way of respect and dignity to a society that has been wounded by consumerist and utilitarian value systems.

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