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Disability, Citizenship & Identity

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Disability has been recognized as a denial (Oliver, 1992) and as the antithesis of citizenship (Linton, 1998), and a disabled identity devalued for its “otherness” (Barton, 1993). Understandings of both citizenship and identity serve to reflect and to contribute to widespread perceptions of social roles, rights and inclusion. This paper reviews these two concepts as powerful social components within the context of disability, in terms of society’s provision and regulation of membership. These seemingly implicit structures are transgressed by the evolving disability movement. As inherently social concepts, both citizenship and identity provide a broad framework within which to explore the material and cultural exclusion of people with disabilities in the Western world. As Miles (2006) has observed, accurate and credible information about disability outside of a Western context is vital but rare. The notions of citizenship and identity, which I discuss here, need to be recognized for their inability to easily translate beyond this milieu and into the contexts of non-Western cultures (see for example Ghai, 2002). The established division between citizen and outsider has acted as a formative dimension of the disability rights movement and their quest for empowerment and autonomy, inclusion, valued citizenship and a positive disability identity. Using an interdisciplinary approach I will explore these areas in the development, support and progression of disability theory and activism and as counter forces to traditional exclusions. The advancement of a second phase of the disability movement will conclude this discussion, outlining the expansion of disability identity and culture and the pursuit of alternative citizenship outside of normative, ableist structures.

A major focus of the study of disability has been its re-definition by people with disabilities (Barnes & Mercer, 2001). Presently, various understandings continue to define this term: as a deficit (Thomas, 2002), a personal tragedy (Swain & French, 2000), a condition which requires *fixing* (Hughes, 2002), a socially imposed barrier (Barnes & Mercer, 2005, Oliver, 1990) based on degree of function (WHO, 2001), or as part of the experience of embodiment and day-to-day life (Corker &

French, 1999, Corker & Shakespeare, 2002, Shakespeare & Watson, 2001, Shildrick & Price, 1998). These definitions each have significant implications for language and meaning. Noting some of these major understandings, for the purposes of this paper disability is discussed as both a product of society and as an individual embodied experience existing in social space. It is important to note that disability writers, especially in the UK (i.e. Barnes, 2008, Morris, 1998) identify the use of the term *people with disabilities* as problematic, based on the lack of distinction between disability and impairment and the resulting blurring of the biological and the social. While noting this concern, the commonly used North American phrase *people with disabilities* will be employed here, as a critical analysis of terminology is the subject of an additional paper.

Citizenship

Citizenship theory, based on the work of T.H. Marshall (1950), provides a structure upon which to build and to explore disability in relation to societal entitlements. Contemporary, disability focused approaches, challenge and expand this traditional view of citizenship addressing the general failure to acknowledge people with disabilities as part of citizenry, and the associated denial of rights, membership and participation. Reviewing conventional citizenship formats, the recognition and role of disability is observed as problematic, based on the expectations which generally accompany the provision of citizenship. Disability often confronts traditional, un-accommodated notions of equality, productivity, dependency, and the fulfillment of social responsibility. Societal tendencies to connect inclusion with outcome and opportunity, demonstrate the exclusive nature of this type of defined grouping and are identified as a driving force in the perpetuation of insider/outsider binaries.

Defining Citizenship

Citizenship is alleged to be a set of practices, rights and duties which in turn define membership and status (Isin & Wood, 1999). It is generally agreed that this is a multi-dimensional concept equated with community participation, group identity, public practice and responsibility (Isin & Wood, 1999, Marshall, 1950, Roche, 2002). As a formal category, citizenship also includes legal rights and social allocations (Barbalet, as cited in Rummery, 2002) and is “one of the central organizing features of Western political discourse” (Hindess, as cited in Abberly, 2002, 121).

T.H. Marshall (1950) is credited with identifying citizenship as an area of sociological interest with the publication of *Citizenship and Social Class*. In this work Marshall determines three components of citizenship, Civil, Political, and Social. Civil citizenship is associated with individual freedoms regulated through law, representing civil rights, including the ownership of property and the ability to exchange goods, services and labour (Bellamy, 2008, Morris, 2005). Political Rights, which include the right to vote and to hold office allow individuals to exercise political power (Bellamy, 2008, Morris, 2005). Social rights maintain the greatest level of debate, however, in terms of who they have been enacted by and for. Social rights represent a way to ensure an appropriate standard of living which includes social welfare, cultural heritage (Bellamy, 2008) and to live a *civilized* life (Morris, 2005). These types of rights are considered by some to be the basis of human and civil rights (Oliver, 1993). The degree to which these rights have been endorsed for people is contestable, however, considering the denial of them to many.

Recognizing the on-going contribution of Marshall’s theory of citizenship, Isin & Wood (1999) point out the necessity of continuing to explore the evolving nature of citizenship at a deeper level. Roche (1992) argues that citizenship can hold different meaning depending on personal

circumstance, while Oliver (1993) describes it as a way to talk about the relationship between individuals, groups and society. Held (1991) sees citizenship as reflective of a fight for membership based on the assertion of control in hierarchical and stratified systems (as cited in Barton, 1993). Morris (2005) argues that the commonly accepted categories of citizenship, liberal citizenship, communitarianism and civic republicanism, are inadequate in the consideration of full inclusion for people with disabilities. To attain citizenship, she argues, people with disabilities must obtain access, self-determination, participation, and the opportunity to contribute and the recognition that contribution is not about specific responsibilities but social capital. Social capital (see Bourdieu, 1986, Coleman, 1993, Putnam, 1995, 1996, 2000) refers to the enrichment provided to communities through the active engagement of individual members (Homan, 2004). This, like citizenship, is a relatively homogeneous concept. This type of communal participation is noted to result in networks, social trust (Putnam, 1995), social bonds and civic engagement (Homan, 2004) but has also been recognized to contribute to negative attributes including rigid group norms and intolerance (Coleman, 1993, Putnam, 1996).

The widely used term *citizenship*, is identified as a condition for full membership in society (Christie & Mensah-Corker, 1999, Rioux, 2002) fulfilled by participation in political process, social life and community (Morris, 1998). To be disabled, Oliver (1993) has observed, is to be refused the elemental rights of citizenship. Membership is negated through lack of physical accessibility, poverty, segregation and an overall denial of civil and human rights (Morris, 1998). Exclusion, Byrne (2005) notes, is done to people by people, creating an oppression which, Young (1990) argues is a part of everyday life and is experienced through exploitation, marginalization, powerlessness, cultural imperialism and violence. These oppressive forces stand in contrast to the core values linked to civil

society which include: social justice, participation, equality, learning, cooperation, and environmental justice (Home Office Civil Renewal Unit, as cited in Morris, 2005).

Equality

Equality is said to make sense as a concept most readily when it is applied to understandings of citizenship (Armstrong, 2006). This encompasses the way in which citizenship defines forms of equality and the resulting interaction of people as equals (Turner, 1986). Disability literature addresses the issue of equality in relation to citizenship, at length. Rawls' (1971) *Theory of Justice* is frequently recognized as a major contribution to the consideration of equality and explores justice through the provision of equal liberties, equal benefit and equal opportunity.

Where Marshall posits an equality of status, Rawls puts forth an unbiased distributive justice. These influential theories are challenged, however, in their ability to provide equality on the basis that the provision of equality is linked with uniformity. These theories are argued to inadequately address issues of political conflict, external pressures and economic trends (Bellamy, 2008, Nussbaum, 2006), as well as ignoring questions of race, sexuality, globalization (Armstrong, 2006), and disability. They are also thought to lack a focus on rights and responsibilities (Morris, 2005). Dahrendorf (1996) challenges the possibility of egalitarianism through this type of framework, determining that "whatever citizenship does to social class, it does not eliminate either inequality or conflict." (42). Minnow (1990) observes that mandating equality ignores the factors which initially created the disparity.

Distributive justice and equality theories are challenged as means to equitable participation and value based on the role of opportunity as indicative of equal citizenship. Emphasis on the affording of opportunity, associated with obligation over rights, is recognized as detrimental to the

inclusion of people with disabilities. Productivity, a social obligation through such means as employment then, becomes determinative of rights and thus serves as a precursor to citizenship (Barton, 1993). It is argued that this type of opportunity, rather than providing balance gives the freedom to become unequal (Whitty, 1992, as cited in Barton, 1993). Recognizing this type of concern, Rioux (1994) distinguishes between *formal equality*, based on equal treatment, *liberal equality*, through equal opportunity and special treatment, and *equality of outcome* based on an end result. The author challenges the historic disenfranchisement of people with disabilities provided with like opportunity, when such achievement may be unattainable. She cites the need for alternatives supporting the “equal value, benefit and rights of all irrespective of their relation to the norm” (69), and citizenship as an entitlement on the basis of personhood. Barton (1993) argues that the end result of distributive justice is a system based on meritocracy and productivity. For those who are unable to compete within this system, a commitment to equal citizenship becomes moot. If “active” citizenship is the sought-after model, defined by the right to participate in the market economy, Fraser (2003) argues that the current liberal stance fails to address inequality outside of this provision of opportunity to earn. She posits that *re-distribution*, contributes to increasing wealth and suggests instead, *recognition*, where assimilation to cultural norms is not necessary for the granting of equal respect. In response to this type of criticism of Rawlsian concepts of equality, Malhotra (2006) recognizes adaptations needed to make Rawls’ theories applicable to people with disabilities including: the elimination of barriers to structural environments, an acknowledgment of the social basis of good, the inclusion of disability as part of identified characteristics and the use of critical theory to address marginalization and discrimination in relation to this population. These adaptations recognize a social citizenship which identifies disability and speaks to an equality which advocates: “the individuals’ rights to be included in the institutions of society, to have basic needs

met, to be cared for when needed, to develop capacities and to make contributions to society”

(Roehrer Institute, as cited in Rioux, 2002, 217).

Boundaries of Citizenship

In the consideration of disability rights, citizenship has been a popular topic for government, policy makers, academics and advocates alike (Barton, 1993, Rummery, 2002). Bauman (2004) argues that “It is exclusion, rather than the exploitation suggested a century and a half ago by Marx, that today underlies the most conspicuous cases of social polarization, of deepening inequality, and rising volumes of human poverty, misery and humiliation” (41). Where citizenship is able to provide a platform for equality and emancipation, it is also identifiable as a site of exclusion, hierarchy and social control defining insiders and outsiders (Mann, as cited in Armstrong, 2006). By its very ability to include and create belonging for some, it is argued, the process of giving citizenship is mandatorily exclusionary of others (Armstrong, 2006, Walmsely, 1993). As Bellamy (2008) has pointed out, membership is at the core of citizenship, but this association is applicable only to a restricted group who must be able to *fit in* and *contribute in appropriate ways*. Armstrong differentiates *genuine outsiders* who are beyond geographical boundaries, from those who are excluded internally, who are present but unaccounted for. Linklater’s (2002) observation that favoritism exists and reinforces a duty to citizens over outsiders, speaks to this systematic denial of inclusive citizenship for people such as those with disabilities. This divisive concept of belonging reveals itself as problematic and demands consideration of Galvin’s (2003) query to people with disabilities asking “how can we claim unity without falling into the same exclusionary practices that have served to create our divisive identifications in the first place?” (675).

Denials: Citizenship & Positive Identity

Using Nussbaum's (1997) notions of the three capacities necessary to develop humanity (the ability to examine one's self and traditions critically, to see beyond one's own locality, and to consider what it might be like to be in someone else's situation and to be an intelligent reader of that person's story) a prolific denial of humanity is established through the common rejection of citizenship for people with disabilities. Contributing to this denial and movement away from Nussbaum's capacities are the role of deficit and charity models, modernity and industrialization. Disability is addressed as demonstrative of this rejection on both systemic and individual levels motivated by power, progress and productivity and reflected in social policy, issues of daily living (Bérubé, 2003, Prince 2004) cultural representation, education, transportation and autonomy (Shakespeare, 1993).

Medical and Charity Models

A contributing factor to the exclusion of people with disabilities has been cited by Oliver (1990) as the result of medicalization and the focus of the medical profession exclusively on the body. The control of disease, Oliver argues, is linked with the control of the person, leading to the growth of medical authority and the devaluation of lived experience (Barnes & Mercer, 2010). Diagnosis, treatment and rehabilitation of functional limitations are suggestive of biological weakness (Hahn, 1985). Such ideology is viewed as perpetuating values of physical normality and placing functional impairment within the realm of personal tragedy (Barnes & Mercer, 2010). Stemming from this type of approach to physical difference, conceptions of charity, pity and helplessness have come to surround understandings of disability (Russell, 1998). Compassion, Longmore (2008) notes, becomes inseparable from self-aggrandizement and belittlement. Charitable

portrayals present “stereotypical images of cripples as patient, saintly Tiny Tims waiting for God to take them home, or as totally distraught inferiors waiting for someone – or some charitable organization – to cure us[sic]...” (Russell, 1998, 185). The dependence, put forth by such imagery, is argued by Russell to be a major force in oppression, and is equated with the low social status and vulnerability identified by Barton (1993) which accompanies disability and poverty. This is reflective of stigma, which Bauman (2004) notes that, self-respecting people would shun, based on their own internalized fear of exclusion. Linton (1998) adds another dimension to the conception of dependence pointing out the necessity of appearing helpless in order to receive social benefits. Socially valued conceptions of independence re-enforce needs-based dichotomies. A more realistic conception of interdependence is called for, which includes choice and self-determination (Morris, 1998, Oliver, 1993).

Modernity

The seeking of progress has been a major focus of modernity with able-bodiedness and normality equated with advancement (Baynton, 2001). Radford (1994) cites five themes of modernity which have contributed to marginalization resulting from modern ideals including: market forces penetrating all aspects of life, creative destruction, surrender of control, use of language and an obsession with instrumental rationality. The physical differences and functional limitations often associated with disability serve to exclude based on this type of thematic understanding. Thomson (1997) indicates that cultural standards of normalcy, such as beauty, independence and competence have come to validate people’s existence. Glassner (1992, as cited in Hughes, 2002) identifies this standardization and quest for perfection as a form of *tyranny*. Modern beliefs have presented people with disabilities as unsuited to exist or to procreate, and as mistakes of nature to be fixed (Hughes, 2002). Disabled bodies are viewed as antithetical to progress and as

altogether representative of difference (Thomson, 1997). In opposition to a physically impaired body, the standard is argued by Davis (2006) to signify an interchangeable form of worker, and normality, a format for *measurement, categorization and management* (Baynton, 2001).

Industrialization & Productivity

Noting the earlier discussion of the role of responsibility in the granting of citizenship, Oliver's (1999) observation of people with disabilities as three times more likely to be unemployed than the rest of the population of working age, is reflective of the widespread negation of citizen status for this group. A general lack of opportunity for people with disabilities is cited by Rioux (1984), as a type of equality shared by people with disabilities, "they have been equally mistrusted, equally misunderstood, equally mistreated and equally impoverished" (272). It is widely argued that as industrial capitalism developed from a feudal system, people with disabilities who had previously been able to participate in the labour force, became unable to contribute and therefore became systematically excluded (Oliver, 1990, 1993). Gleeson (1999) upholds this belief, identifying the movement from feudalism to capitalism as responsible for *spatial, temporal, and economic* restrictions placed upon people with disabilities. The focus on productivity that has come to dominate is said to have devalued the work of those unable to meet standards of increased efficiency. The oppression that people with disabilities are currently subject to is argued to be rooted in the structures that make up capitalism and cannot be understood outside of the mode of production (Oliver, 1990, 1999). The capitalist market requires profit and people with disabilities are seen as a barrier to the maximization of earning (Russell, 2002) and thus denied the positive social attributions which accompany productive labour (Shakespeare, 1997). To change this role, Barnes (1999) argues, will require a major cultural shift, where ideals of positive identity can no longer be

connected solely with the ability to participate in the labour force through able-bodied and able-minded standards.

The Disability Rights Movement

Since the 1960's the disability movement has progressed in the fight for disability rights. Out of this activism, disability studies developed, fighting for societal inclusion and value. In an analysis of the development of this movement, Shakespeare (1993) cites Ethel Klein's (1984) identification of the stages of political consciousness in the women's movement, which have also been shown to be reflective of the disability movement. Klein identifies: affiliation through group membership, rejection of traditional definitions and the recognition of personal problems as political and systemic issues as the basis for a movement. The disability rights movement is argued to have followed a similar trajectory in its pursuits. Providing various understandings and approaches to disability, this movement has challenged negative conceptions and denials attempting to replace constructions of passivity and objectification with autonomy and inclusion (Shakespeare, 1993). Describing some of these paradigms, approaches to the re-conception of disability will be looked at through the achievements, strengths and barriers of various models including: the Social Model, Independent Living, Civil and Human Rights Models, Political Identity and Post-modern/Post-structuralist approaches.

Though it is noted that the fight for disability rights has a long history which pre-dates recent developments (Oliver, 1993) the disability rights movement as it is now conceived, was shaped in the second half of the 20th century (Pfeiffer, 2001). Activists brought forth a challenge to devaluation based on their personal experience, while highlighting barriers and confronting conventional thinking (Barnes, Oliver & Barton, 2002). The study of disability which has grown out

of this activism, has sought empowerment and emancipation, in research, the distribution of knowledge and experience and the ability to influence policy decisions (Ward & Flynn, 1994). Encompassing this large disenfranchised group, the disability movement has progressed and developed through many incarnations. Major contributions are discussed below.

The Social Model

Developed in opposition to the widespread, negative perception of disability, a radical stance was adopted in the 1970's which relied on a socio-political explanation, known as the social model (Oliver, 1981) or the social barriers model (Finkelstien, 1991). The social model has directed focus away from an individual approach to disability towards a societal understanding of it and, using a materialist approach, emphasized economic, political and social barriers. Antithetical to the conventional concentration on individual physical limitations, this approach looks at “the ways in which physical and social environments exclude individuals with impairments from participating in mainstream society” (Barnes & Mercer, 2005, 1). The social model distinguishes between impairment, the biological, and disability representing the social barriers created by a society which does not accommodate those with physical, sensory and intellectual impairments. This distinction is observed to highlight the role of limitations which obstruct empowerment and inclusion for people with disabilities. It refocuses attention from functional limitations to environmental and cultural barriers which disable people, and identifies experiences of disability within the context of larger structural and institutional disabling environments (Barnes, 2006). Based on The Union of the Physically Impaired Against Segregation UPIAS (1975) Fundamental Principles. Disability is understood as

a situation, caused by social conditions, which requires for its elimination, (a) that no one aspect such as incomes, mobility or institutions is treated in isolation, (b) that disabled

people should, with the advice and help of others, assume control over their own lives, and (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people.

Linked especially with the work of Finkelstein (1980) Oliver (1990) Barnes and Mercer (2005) the social model continues to be a powerful force in the disability rights movement today. Based on this level of influence this model has also, however, been criticized as a “sacred cow” (Shakespeare & Watson, 2001) and as exclusive and inadequate (Thomas, 2002). The social model has been cited for its failure to address personal experience (Crow, 1996), the division of impairment and disability and the lack of inclusion of impairment in analysis (Bickenbach, Chatterji, Badley, & Üstün, 1999, Davis, 2006, Shakespeare & Watson, 2001). It has also been considered reductionist in terms of the application of social barriers to all aspects of oppression (Crow, 1996), for its link to identity politics (Shakespeare & Watson, 2001) and the lack of recognition of cultural process (Corker & Shakespeare, 2002, Shakespeare, 1997). In spite of intense criticism social modelists remain a powerful and active force in the field of disability today.

Independent Living

Based on the goal of inclusive community living leading to increased citizenship and participation, the Independent Living Movement (ILM), is linked with self-help, consumerism, empowerment and autonomy. The ILM affirms the right to be part of the community, to have choice, to receive high-quality service and to refuse service (Longmore, 2003). Started at Berkley in 1974, the aim of ILM was to enable people with disabilities to live freely outside of institutions (Zames Fliescher & Zames, 2001). The movement, cited as a source of pride (Hasler, 1993), has also been condemned for its link with US individualist culture and its concentration of young, educated people with physical disabilities (Barnes & Mercer, 2010).

Rights Models

Rights have been highlighted as an important avenue to inclusive culture for people with disabilities. Oliver (1993) has argued that citizenship can be attained through the enactment of rights rather than based on needs and this sentiment is upheld by Barton (1993) who notes movement away from concern “...over questions of needs to those of *rights* (emphasis original)” and that “nowhere is this more evident than in relation to the issue of citizenship” (239).

Bickenbach (2001) distinguishes between human and civil rights as they apply to disability connecting civil rights with citizenship and the state and human rights with elemental entitlements for all humans. Ellis (2005) contests this division as artificial and calls for the combination of these processes in the pursuit of overall rights. Human Rights outline the principle that all people have fundamental entitlements, based on the 1948 UN Universal Declaration of Human Rights, with goals of equal opportunity, full participation and respect for difference (Bickenbach, 2001). Human rights have been associated with disability rights in the areas of self-determination, equality, democratization, de-institutionalization, independent living, poverty, housing, education, employment, family support, violence, health and well-being (Roeher Institute, 1996). Unique to Canada, section 15 of the Charter of Rights and Freedoms, recognizes the constitutional rights of people with disabilities and is premised as an example for the rest of the world (D’Aubin, 2003). The recent ratification by many countries of the United Nations (2006) *Convention of the Rights of People with Disabilities*, has also marked progress towards the international recognition of disability as a human rights issues. This convention has identified premises of dignity, autonomy, non-discrimination, participation and inclusion, respect for difference, equality of opportunity, accessibility, diverse capacity and identity. Rioux & Valentine (2006) point out a continuing relationship between

disability and human rights but the failure of governmental entitlements to grant citizenship. Noting this type of relationship Quinn & Degener (2002) advocate the necessary recognition of inherent human worth in the pursuit of human rights.

Civil rights are based on the legislation of equality and anti-discrimination (Russell, 1998) which was inspired by the women's rights movement, the large number of Vietnam veterans with disabilities (Shakespeare, 1993), and to the greatest extent, the fight for rights by African American people. Civil rights centre on political efforts shaping movement towards full participation and equality (Bickenbach et al., 1999). Hahn (2002) has stated that "the fundamental goals of the disability movement are nearly identical to the aim of other minorities. They are striving to improve their status in society" (171). Finkelstien (1993) observes, however, that unlike other groups, people with disabilities who are in pursuit of rights still often seek to change themselves.

Noting issues of inequality, poverty, unemployment and welfare dependence, Hahn depicts the major issues for civil rights as prejudice and discrimination, and the apex of civil rights for people with disabilities as the enactment of the ADA (Davis, 2006). Shakespeare (1993) distinguishes the American civil rights focus, directed towards objectives of individual rights, consumer involvement, the pursuit of entry into wider society, and the ultimate goal of self-reliance, from the British goals of political autonomy and democratic participation. This focus is instead on the removal of structural barriers and the rejection of the conception of social normality. Both approaches, the author notes, serve as a pathway to reform, a challenge to traditional understandings of disability and as a source of empowerment and inspiration for participants.

Though civil rights served as a basis for increased participation and citizenship, this movement has been criticized for its lack of enforceability (Barnes et al., 1999, Lee, 2002) and shortage of attention to structural forces (Bickenbach et al., 1999, Russell, 1998).

Post-Modern/ Post-Structural Approaches

Highly critical of the dominance of the social model, post-modern and post-structural approaches to disability rights have asserted power in the contemporary realm of disability rights. To a great extent, in the tradition of post-modernism, these theories are defined against other models. The pursuit of disability rights in this area is reflective of a rejection of macro level theories of society. Challenging grand theories (Davis, 2006), lived disability experience is given the preeminent focus, using the feminist correlation of the personal and political (Pfieffer, 2001, Thomas, 2002). Issues of embodiment, culture, language and discourse (Barnes & Mercer, 2010, Davis, 2006) are addressed as moving beyond the disability/impairment separation. Acknowledging the contributions of the social model from the past, post-modern and post-structural thinkers deem it as having fulfilled its usefulness (Shakespeare, 2006, Shakespeare & Watson, 2001, Tremain, 2005). In response to these criticisms, social model representatives maintain this approach as an avenue towards collective action, but also as a model never intended to be comprehensive. Post-modern disability action and theory is questioned based on its lack of ability to address material factors, and a social model of impairment has been suggested as a method of acknowledging both social structures and individual experience (Oliver, 1996).

The disability rights movement has been identified as contentious due to a lack of common discourse, discrepancies in disability representation, beliefs about who is able to make effective contributions to the field, and concern that the movement is made up of a privileged class of white, educated, visibly disabled people (Albrecht, 2002). Though the disability rights movement is thought by some to be diminishing, a victim of its own success (Zames Fliesher & Zames, 2001),

disability literature continues to develop and the field to grow, calling for the second phase of the disability movement.

The 2nd Phase Disability Movement, Disability Identity and Culture

Citizenship and identity are recognized by Isin and Wood (1999) as two parts of the same question; citizenship as universal and identity are particular. The pursuit of citizenship by and for people with disabilities has been demonstrative of the fight for inclusion, for the provision of both opportunity and outcome and the right to be a part of society. Having outlined major contributions of the disability movement to date, Longmore (1995) has noted that the time for the second phase of the disability movement has come. Whereas in the past, equality of access, opportunity and inclusion, have been the major objectives, the pursuit of collective disability culture and identity is recognized as the successive focus. Though the first struggle has not yet concluded, Longmore acknowledges that this second goal can be realized concurrently. Classic theories of identity will be outlined as basis for social understandings of individuals and groups. Challenging traditional exclusions and negative expectations, the development of positive disability identity and culture are discussed as formative aspects of the evolving disability movement asserting people with disabilities as a valued and distinct faction of society (Shakespeare, 1996).

Sociological Theories

Some disability theorists have denounced sociological analysis of disability based on the focus on illness and reaction to illness as a force in the maintenance of *voicelessness* for this population (Barton, 1993). Others, however, have identified this type of study as providing useful building blocks upon which social oppression can be understood, and as a relevant and constructive approach to understanding disability and identity in social space (Barnes & Mercer, 2010).

In *The Social System* (1951), prominent sociologist Talcott Parsons' explores the fulfillment of roles in the maintenance of order. His depiction of the "sick role" is of particular importance to the study of disability because of his identification of illness as a kind of deviance. Outside of usual roles, the sick, Parsons observes, are relieved of social responsibilities and blame for their illness. Reinforcing the position of patient and doctor, the sick are expected to regard their condition as negative and to try to get well by following medical advice. Criticized by disability advocates for its disregard of social forces and the continued support of medical intervention as a means to normalization, the sick role points towards socially embedded notions of devaluation, and the dependence of the *sick* resulting in diminished identities of those who remain within this role (Barnes & Mercer, 2010).

Challenging this type of abstract theory, symbolic interactionism provides a base from which to conceptualize how people come to understand themselves. This theory maintains that human's act towards things based on the meanings that are ascribed to them which are developed out of social interaction. Cooley's (1964) concept of the "Looking Glass Self" describes the way which individuals view themselves based on how they think others perceive them. Mead (1934) expands this idea with a theory of self, which he notes, is developed through communication, symbols and the intersection of community values and attitudes with personal beliefs. Criticized in the 1970's for failing to address structures, power and history, more contemporary writing has revitalized this line of inquiry focusing on role-making (Stryker, 1980) linked with post-modern, feminist, and cultural theory (Plummer, 1991). Through this type of analysis, culture and social setting are revealed as determinative forces in conceptions of who we are. Analyzing modernity, Giddens (1991) argues that self-identity is not found "in the reaction of others, but in the capacity *to keep a particular narrative going*" (54, emphasis original). He cites identity as bound within our stories, quoting Taylor's (1981)

observation that “In order to have a sense of who we are, we have to have a notion of how we have become, and of where we are going” (cited 54). This observation initially appears to challenge the role of interaction, but in fact upholds the social basis of identity formation and re-enforces Shakespeare’s (1996) conclusion that “identity ... connects the social and the personal and involves the individual putting themselves in a collective context” (100).

Goffman’s work also looks at the development of identity through personal presentation. He writes about *impression management* and *dramaturgy*, in which life and personal presentation are considered as theatrical metaphors. Goffman (1963) discusses identities which are outside of the norm, as a reflection of negative attributes. A *stigma* is ascribed to those who are considered “not quite human” (as cited in Davis, 2006, 132) resulting in shame, self-hate, self-derogation, lack of respect and self-consciousness. Managed by passing, covering or withdrawal stigma serves to maintain the status quo. Goffman’s theory of stigma has been criticized for its focus on the passive acceptance of labeling and a lack of recognition of human agency in accepting or rejecting roles (Bury, 1997). This basis however, reflects understandings and social implications of designated roles.

Fluid and Changing Identities

While Parsons’ and Goffman have identified fixed and assigned identities, post-modern interpretations such as Foucault’s analysis (1977), seek to uncover multiple or hybrid identities which exist within a series of social practices and structures. Bauman (2004) describes the essence of identity as changing. What was once fixed has now become both revocable and negotiable. While noting the availability of new and changing identities, he also draws attention to the continued relation of identity to security and the mobility of identity as bounded by hierarchical relations. Bauman states that

...identification is also a powerful factor in stratification; one of its most divisive and sharply differentiating dimensions. At one pole of the emergent global hierarchy are those who can compose and decompose their identities more or less at will, drawing from the uncommonly large, planet-wide pool of offers. At the other pole are crowded those whose access to identity choice has been barred, people who are given no say in deciding their preferences and who in the end are burdened with identities enforced and imposed *by others*; identities which they themselves resent but are not allowed to shed and cannot manage to get rid of. Stereotyping, humiliating, dehumanizing, stigmatizing identities..." (38)

Where Goffman questioned the existence of an authentic identity, the pursuit of empowerment (Malhorta, 2001) and positive, rather than authentic identity, has been a goal of the disability movement (Barnes & Mercer, 2010). Oliver (1990) identifies history, structural forces and cultural images as involved in the process of identity formation, but also acknowledges the prospect of change through the confrontation of these images. Borsay (2002) disparages previous disability identities linked to medicine and charity, recognizing the necessity of fluidity in identity, and the seeking of alternate sources of positive identity. Morris (1993) highlights the need to understand prejudice in order to challenge it as well as the negative impact of abnormality through the assumption that people with disabilities seek standard identities. The development of positive disability identity, she argues, stems from a challenge to traditional values and judgments and by the creation of disability culture.

Positive Disability Identity

The growing recognition of disability and difference as the basis of positive identity is accompanied by the power of self-definition, disability pride, self-confidence, solidarity and community (Barton, 1993, Gill, 1995, Hahn 2002, Morris, 1998, Shakespeare, 1996). Finkelstein (1993) describes the disability movement as a force in the encouragement of common identity and as a united front against oppressive and exclusive practices. He identifies the importance of the

redefinition of disability in positive terms, noting that “as long as we are different no amount of denial can help us assimilate into a world designed for people with able-bodies” (1987). Real integration, he argues, can be achieved through “the free choice to identify ourselves as a social group” (3). The development of culture promotes citizenship, reframes the way in which disability has traditionally been presented and celebrates disability history, identification, pride and community (Zames Fliescher & Zames, 2001). It represents strength and unity (Swain & French, 2000) which encourage a political identity as part of a cultural minority and oppressed group (Shakespeare, 1993). The transgression of conventional attitudes towards disability through the deliberate seeking of an alternate identity reflects Hall’s (1990) observation about the changing nature of identities, that “far from being fixed in some essentialized past, they are subject to the continuous ‘play’ of history, culture and power... (225, as cited in Vernon & Swain, 2002:85). Identities are now described by Modood (1997) as being more “consciously chosen, publicly celebrated, debated and contested” (cited Vernon & Swain, 2002:86). The formation of positive identity through the development of disability culture is maintained by Morrison and Finkelstien who state that “...to encourage the growth of disability culture is no less than to begin the radical task of transforming ourselves from passive and dependent beings into active and creative agents for social change” (11-12, as cited in Barnes, 2008, 11-12).

Identity Politics

Minority group or identity politics, often linked with both civil rights and the social model, are argued to be a productive paradigm for people with disabilities whose rights are denied by an ableist society (Davis, 2006). “Rather than pursuing the common interests of humanity - equality of rights, the satisfaction of material needs, universal respect for the dignity of the individual, their efforts are directed mainly at asserting the rights of their own group” (Littleton, as cited in Isin &

Wood, 1999, 3). The basis of identity politics is "...the relationship between marginalization and politics of resistance and affirmative empowering choices of identity and a politics of difference" (Hetherington, as cited in Vernon & Swain, 2002, 84). This type of group identification encourages radical policy (Barnes & Mercer, 2010), the raising of consciousness and the recognition of oppression through special rights, and visible group agendas (Siebers, 2002). Minority or identity politics, however, have also been widely contested. Lee (2002) describes obstacles to this political premise outlining the changing nature of identity, the development of sub-groups and differential priorities. The formation of special interest groups is argued to fail to address the role of a disabling society and the stigmatization and devaluation of disability (Hahn, 2002). By concentrating on a single political force it is accused of separating interest groups from wider rights issues and marginalizing people with disabilities to isolated causes (Crowther, 2007, Russell, 1998). Shakespeare (1996) also questions the essentialist premises of identity politics based on the oppositional approach taken and the negation of multiple identities and simultaneous oppressions. Asch (2001) calls for a human variation model, recognizing the universality of difference and removing the *us versus them* boundaries suggested by identity politics. Siebers (2007), in the face of such arguments, upholds the necessity of this premise and counters claims of narcissism and division by highlighting dissenter's attempts to attack efforts towards equality with the imposition of further oppression.

Multiple Oppressions

Where a common disability identity and united community have been major goals of the disability movement, the presence and recognition of additional and differential identities has given rise to the acknowledgment of individual and groups multiple identities. The pursuit of a united disability identity, Vernon (1998) suggests, underlines the failure of both society and those involved in the fight for disability recognition to address the experience of multiple oppressions. Multiple

oppressions are described as the simultaneous ascription of more than one stigmatized identity, experienced concurrently or independently (Vernon, 1998). Disability writers are noted to have failed in the past to address these additional sites of oppression which can include categories such as gender, race, sexuality, and age. Vernon observes the social model's failure to speak to these issues based on the pursuit of unity, however shows this to be a common tendency of oppressed groups in general who tend to focus on single oppressive issues.

Gender

The role of gender and disability is discussed at length as an influential factor in the discussion of disability and identity. Fine & Ash's (1988) edited collection addresses the diminished role of power for women and girls in Western society and the general exclusion of disabled women in feminist discourse. Morris (1991, 199) describes the inability of women with disabilities to fulfill traditional female roles. Thomson (2006) cites identity as "at the centre of feminist theory" (268) and the politicization of feminist disability analysis as a counter narrative for both feminist and disability activists. Shuttleworth (2002, 2004) addresses masculinity and disability, and the role of physical functioning in the fulfillment of traditional male roles.

Race and Ethnicity

Another defining factor of identity for people with disabilities which until recently has been largely unaddressed is race and ethnicity. Vernon & Swain (2002) discuss the isolation created for those who exist at the extremes of marginalization as members of both an ethnic minority and a disabled population. Stuart (1993) upholds this contention, identifying the limited availability of identity and the seclusion which is encountered by people with disabilities who are black. Based on this particular experience, Stuart calls for a distinct, black, disability identity. Issues of post-

colonialism and disability have also recently surfaced, drawing attention to the disability experience in locations of colonial oppression. Ghai (2002) for example discusses the negotiation of disability identity and the role of the disability experience within the context of the developing world.

Sexuality

Sexuality is discussed by Shakespeare, Gillespie-Sells, & Davies (1996) who call attention to the overall lack of discussion surrounding disability and sexuality. McRuer (2006) identifies both disability and homosexuality as challenges to dominant ideology, but also opportunities for progress. Corbett (1994) points to gay men and lesbian women as ignored based on both sexuality and disability, and Hearn (1988) argues that her lesbianism is discounted because of the association of disability and asexuality. As in Stuart's (1993) description, gay, lesbian and bi-sexual people with disabilities are depicted as marginalized by homosexual identity groups (Vernon & Swain, 2002).

Age

Age is also discussed as an issue surrounding disability oppression and identity, both in terms of differential treatments of acquired and congenital disabilities, and also based on the increased presence of disability in age. Values particularly prevalent in the United States (Albrecht, 2002), of youth, individualism, productivity, athleticism, and competitiveness, antithesize the process of aging and the possibility of disability which Morris (1991) argues is linked with fear of pain, illness, physical and diminished intellectual incapacity.

Disability Arts

In the movement towards positive disability identity, a united community of diversity has developed in the arts as a cultural tool of empowerment. Disability narratives serve as both a counter

force to customary misrepresentation and as a political entity controlled by and for people with disabilities (Abbas, Church, Frazee & Panitch, 2004, The Arts Council of England, 2003). Disability arts challenge negative stereotypes, build community, reject dominant ideologies of normality and have been observed to bring strength and pride (Vernon & Swain, 2002).

Disability art is the development of shared cultural meanings and the collective expression of the experience of disability and struggle. It entails using art to expose the discrimination and prejudice disabled people face and to generate group consciousness and solidarity (Barnes et al., 1999, 205-206)

Noting the intrinsic role of culture in determining how people with disabilities identify and are identified, the re-definition of disability through art by this population is described as having the potential to educate, change dominant attitudes, make people uncomfortable, and to result in a move beyond a rights based approach to the “creation, exploration and advancement of disability culture” (Abbas et al., 2004). Contrary to traditionally limited access to artistic activities by people with disabilities (Morrison & Finkelstein, 1993, Vasey, 1989) and the dominant use of this medium as therapy, “arts and disability” is reframed as “disability arts”. This re-signification shows this practice to be inherently political and is identified to signifying *post-tragedy disability culture* (Hevey, 1993). Disability arts demand that both the production and consumption of mainstream art be accessible to people with disabilities, emphasizes the lived experience of disability as a source for artists to draw from, and serve as a response to social exclusion (Barnes & Mercer, 2001). Beginning in the 1980’s, this movement has evolved from an initial recognition of people with disabilities as artists and the presentation of art within the disability community to the current growth of the movement and associated politics into the wider community (Walker, as cited in Abbas et al., 2004).

Disability arts has had tremendous success, though many remain who are reluctant to celebrate disability identity or who are enmeshed in able-bodied frameworks (Barnes, 2008). The

audience for these artistic endeavors is largely made up of those who are already involved in or connected to the disability movement. Morrison and Finkelstien (1993) describe a common assumption that artistic endeavors are elitist and that disability arts re-enforce negative images. In addition to these barriers, increased funding, training programs, performance opportunities and accessible venues have been cited as gaps in the Canadian context (Abbas et al., 2004). Given the recent comments by Canadian Prime Minister Stephen Harper that “ordinary people don't care about arts funding” (Toronto Star, September 24, 2008) it would seem fortunate that the pursuit of distinct and valued disability culture rests outside of the realm of “ordinary people”.

Conclusion

Citizenship through a Western world perspective determines the valued role of belonging within a community, a nation and a world. Identity and determinations of self-identity within this framework uphold a similar power. In an increasingly globalized world, these understandings are likely to change and to adapt to a diversity of perceptions and traditions. At present, the focus of the new disability movement, the seeking of positive disability identity, shifts the locus of control from wider society to individuals who themselves have disabilities. Previous determinations of citizenship and identity were based on rights, responsibilities, *equal* opportunity, and societal reactions to roles played and prescribed. These understandings have demonstrated themselves to be conceptually problematic for people with disabilities who are unable or unwilling to fit into these seemingly naturalized groupings. The recognition of oppressive forces through various incarnations of the disability movement has fought for inclusionary membership, autonomy, empowerment and positive identity. The current movement seeking disability culture and identity has upturned previous rejections and seeks not only the goals of the first wave, but strongly emphasizes the valuation of

disability as difference and the creation of disability culture as imperative to empowerment and positive disability identity.

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