

# Développement Humain, Handicap et Changement Social Human Development, Disability, and Social Change



## Personal and Collective Disability Identity Development

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Volume 24, numéro 1, avril 2018

Représentations sociales et handicap : regards croisés sur le sens commun du handicap  
Social Representations and Disability: Perspectives on the Common Sense Notions of Disability

URI : <https://id.erudit.org/iderudit/1086201ar>

DOI : <https://doi.org/10.7202/1086201ar>

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Éditeur(s)

Réseau International sur le Processus de Production du Handicap

ISSN

1499-5549 (imprimé)

2562-6574 (numérique)

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Citer cet article

Curtis, R., Hall, A., Weaver, S. & Meyer, J. (2018). Personal and Collective Disability Identity Development. *Développement Humain, Handicap et Changement Social / Human Development, Disability, and Social Change*, 24(1), 7–20. <https://doi.org/10.7202/1086201ar>

Résumé de l'article

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## Personal and Collective Disability Identity Development

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Article original • Original Article



### Abstract

The purpose of this paper is to explore how individuals with disabilities establish and maintain a social identity that incorporates meaning and context into a personal and collective perspective defined as disability identity. Beginning with a broad lens, the concepts of identity and social identity are explored. Theories and concepts that have shaped and refined the concept of social identity, specifically within a context of disability, are introduced. Disability Identity development is explored as to the key components and constructs that bring forth a comprehensive view of identity development for individuals with disabilities. Finally, these components are brought together within the context of Independent Living in order to show how this movement supports a positive, life-enhancing worldview of disability.

**Keywords:** disability, disability identity, collective identity, personal identity, independent living

### Résumé

Le but de cet article est d'explorer comment les individus avec un handicap établissent et maintiennent une identité sociale qui incluent un sens et un contexte dans une perspective personnelle et collective définis comme une identité handicap. En commençant avec un sens plus large, les concepts d'identité et d'identité sociale sont explorés. Des théories et des concepts qui ont créé et précisé le concept de l'identité sociale dans un contexte de handicap sont présentés. Le développement de l'identité handicap est exploré par rapport aux construits et composantes clés qui amènent une perspective compréhensive du développement de l'identité pour les gens avec handicaps. Finalement, ces composantes sont mises ensemble dans un contexte de Vie Indépendante afin de voir comment ce mouvement promut une vision globale plus positive du handicap.

**Mots-clés :** handicap, identité handicap, identité collective, identité personnelle, vie indépendante

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In recent years, scholars working in an array of social science and humanities disciplines have taken an intense interest in questions concerning *identity*. Much research has been devoted to the *identity politics* of race, gender, and sexuality (Abes, Jones, & McEwen, 2007; Mpofu & Harley, 2006; Putnam, 2005). In social theory, questions of identity are included in numerous arguments on gender, sexuality, nationality, ethnicity, and culture (Kymlicka, 1995; Taylor, 1989; Young, 1990). For example, Hogg and Abrams (1990, p. 2): Identity is “people’s concepts of who they are and how they relate to others”; Deng (1995, p. 1): “Identity is used... to describe the way individuals and groups define themselves and are defined by others on the basis of race, ethnicity, religion, language, and culture,”; Jenkins (2000, p. 4): Identity “refers to the ways in which individuals and collectivities are distinguished in their social relations with other individuals and collectivities,”; Katzenstein (1996, p. 59): “The term [identity] (by convention) references mutually constructed and evolving images of self and other”; and finally, Taylor (1989, p. 344): “My identity is defined by the commitments and identifications which provide the frame or horizon within which I can try to determine from case to case what is good, or valuable, or what ought to be done, or what I endorse or oppose.”

The purpose of this paper is to explore how individuals with disabilities establish and maintain a social identity that incorporates meaning and context into a personal and collective perspective defined as *disability identity*. As an individual with a disability, how does one define oneself, in what manner, in what terms, with what accompanying attitudes and expectations? As a collective group, how do individuals with disabilities want to be defined and named by others in society; what is normative and life-enhancing compared to what is derogatory and shaming? Individually and collectively, we are in a place in time and history to shape Disability Identity formation by movements composed of people with disabilities who have a vested interest in the disability rights movement seeking independent living rights and responsibilities. These efforts have the ability to establish

Disability Identity as a normalized aspect of society by defining the lived experience of those with disabilities and by normalizing that lived experience.

Additionally, this paper serves as a call to activism. A basic component of Feminist Theory espouses – *the personal is the political* – and where better to examine this concept brought to life than in the disability rights movement? The four basic assumptions that form the philosophy of the independent living movement state that all life is of value; *anyone*, whatever their impairment, is capable of exerting choice; people who are disabled by society’s reaction to physical, intellectual, or sensory impairment have the right to assert control over their lives; and disabled people have the right to fully participate in society (Morris, 1993a). We need an enhanced understanding of Disability Identity in order to bring these concepts into an everyday reality; one that occurs as an individually lived-experience and one that provides a meaningful context within society for *all* people.

## Disability Identity Development

Models that help to undergird the concept of Disability Identity include those that are non-linear and view identity from multiple perspectives. Conceptually, this includes the integration of disability both physically and from a psychosocial perspective into an individual perspective in a positive, life-affirming, enhancing manner. If individuals with disabilities are regarded in a normalized and positive perspective on an individual basis then a collective societal perspective will follow. In this way discrimination and oppression can be named for what they are and directly addressed because individuals with disabilities realize they are not alone in their lived experiences that all too often hold discrimination and oppression. Additionally, the focus on disability would be perceived as one aspect of a person’s life; not the wholly defining and labeling persona. Finally, by incorporating the uniquely *positive* aspects of being a person with a disability, individuals could experience life on their own terms. In this way insight and problem-solving which typically are associated with the disability experience



are emphasized and named as positive attributes of such individuals and potentially viewed as positive character traits associated with people in our society.

### Personal Identity Development

Initial ventures into understanding the development of personal identity were focused on the development of individuals singularly. Identity theory generally focused on role identities of the *individual* from a uniquely *internalized* perspective. *Identity* was conceptualized as internal, consisting of internalized meanings and expectations associated with an individual's role (Burke & Tully, 1977), and, *roles* were considered external and linked to social positions within the social structure. Each role or set of roles was embedded in one or more groups that provide context for meanings and expectations associated with the role. Stryker and Serpe (1982) give examples of groups that provide contextual meanings to roles such as networks, organizations, classes, unions, and other social units that have a set of established and accepted ideals and standards for group membership. Social Role Valorization (SRV) theory (Wolfensberger's, 1982) indicates that social roles dominate people's lives and that individuals perceive themselves and each other in terms of these respective roles. The value attributed to various social roles tends to instrumentally affect the behaviors directed toward individuals, depending upon the value or devalue of that particular role as it exists within the social hierarchy. Those individuals in valued roles tend to be treated well and those in devalued roles tend to be treated poorly (Wolfensberger, 2011).

Wolfensberger's (2011) discusses those roles that are stereotypically devalued in most Western societies and the possible results of this societal role devaluation. It is theorized that SRV can be utilized to "upgrade" some of the more devalued roles, thereby elevating the value of those individuals who typically occupy those roles. Not surprisingly, at the top of Wolfensberger's (2011) list of devalued roles are those individuals who are impaired in some way, including those with sensory impairments,

physical, psychological and/or cognitive disabilities. The next most devalued individuals on his list are those whose behavior is considered socially deviant, including individuals who are excessively hyperactive, are unorthodox in their sexual orientation, and those who use alcohol and/or drugs. Next are those who possess extreme physical characteristics such as excessive tallness or shortness; individuals who rebel against the social order; the poor; the illiterate or those with seemingly nothing to contribute to the intellectual growth of society; and, finally; those individuals who are unassimilated into the culture such as religious minorities and racial and ethnic minorities (Wolfensberger, 2011).

### Collective Identity Development

#### - *Moving from individual identity to social identity*

Tajfel (1982) first introduced the concept of social identity as an individual's knowledge that she belongs to certain social groups together with some emotional and value attachments that fit in with this group membership. Motivated by an underlying need for self-esteem, social identity rests on intergroup social comparisons that seek to confirm or establish in-group membership and create distinctiveness between the ingroup and the outgroup (Turner, 1985).

To explain the nature of the relationships between groups including concepts such as status, stability, permeability, and legitimacy, and the way these concepts influence a positive social identity, Tajfel and Turner (1979) utilized the concept of social categories in describing one's social identity. For example, social categories are defined by implicit and/or explicit rules of membership. These membership rules are driven by the individuals who are assigned or not assigned to the category. Additionally, social categories are understood in terms of sets of characteristics. Beliefs, desires, moral commitments, or physical attributes thought typical of members of a category, or behaviors expected of said members in certain situations define the parameters of the group characteris-

tics. This is true in the case of social roles such as mother, professor or student (Tajfel, 1982).

#### *- Social identity composed of multiple dimensions*

Multiple dimensions of identity offer a conceptual depiction of relationships that are socially constructed and recognize that each dimension cannot be fully understood in isolation. The model is based on the work of Reynolds and Pope (1991) and Deaux (1993) and also founded on the results of grounded theory research with women college students by Jones, et al. (1984).

The model of multiple dimensions of identity describes the dynamic construction of identity and the influence of changing contexts on multiple identity dimensions, such as race, sexual orientation, culture, and social class. The model portrays identity dimensions as intersecting rings around a core, signifying how no one dimension can be understood without considering its relationship to other dimensions (Jones, et al., 1984). At the center of the model is a core sense of self, comprising “valued personal attributes and characteristics” (Jones, et al., 1984, p. 383). Surrounding the core and identity dimensions is the context in which a person experiences life, i.e., family, socio-cultural conditions, and current experiences. The salience of each identity dimension to the core is fluid and depends on contextual influences. For example, both Feminist and Queer Theory help to illustrate and enhance this model.

#### *- Social identity and Feminist Theory*

A greater understanding of social identity is seen by the incorporation of constructivist thought and the idea that individuals possess multiple identities. Feminist literature introduced a framework of intersectionality that recognized how socially constructed identities are experienced simultaneously, not hierarchically (McCann & Kim, 2002). Much of the study on multiple identities in the literature grew out of Black feminist scholarship that challenged feminism’s Eurocentric assumptions (Hooks, 1984). Collins (1990) termed this framework a

“matrix of domination” and explained that viewing relationships from an intersecting perspective expands the analysis from merely describing the similarities and differences to distinguishing these systems of oppression and how they interconnect (p. 222).

Autobiographical narratives from two feminist scholars, Lorde (1984) and Anzaldua (1987), illustrated a “new consciousness” (Anzaldua, pp. 101) associated with integrating multiple identity dimensions within a matrix of domination rather than a hierarchical structure. Lorde, an African American lesbian feminist socialist mother of two and a member of an interracial couple explained that her “fullest concentration of energy is available... only when I integrate all the parts of who I am... without the restrictions of externally imposed definition” (pp. 120-121). Anzaldua, a Mexican American lesbian and a mestiza discussed her ability to bring together multiple identities into a new, integrated identity where “the self has added a third element which is greater than the sum of its severed parts. That element is a new consciousness.” (pp. 101-102). To fully embrace individual experiences, it is necessary to explore differences within each aspect of identity as each is influenced by the simultaneous experience of the other dimensions (McCann & Kim, 2002).

#### *- Social identity and Queer Theory*

Relevant to the re-conceptualization of social identity as including multiple identities is the postmodern perspective of queer theory, which suspends the categories of lesbian, gay, bisexual, masculine, and feminine (Tierney & Dilley, 1998). Components of queer theory challenge traditional identity categories based on the assumption that identity is performed and therefore unstable (Butler, 1991) and comprised of fluid differences rather than a unified, singular identity (Fuss, 1989). Fuss suggests that the failure to study identity as difference implies a false unity that overlooks variations that exist within identity categories such as race and class (1989). She goes on to explain that categories are insufficient because differences within those categories cause them to have



“multiple and contradictory meanings” (Fuss, 1989, p. 98).

- *“Meaning making” - Constructivist-developmental theories and social identity*

Constructivist-developmental theorists began to enhance the concept of identity as being composed of multiple dimensions by incorporating intrapersonal, cognitive, and interpersonal domains of development into a single unit and describing the interrelated development of each domain from simple to complex (Kegan, 1994). Kegan’s integrated theory consists of five orders of consciousness representing increasingly complex meaning-making structures. These meaning-making structures are sets of assumptions that determine how an individual perceives and organizes life experiences (1994). The intrapersonal dimension of such a framework presents a relationship between theorized orders of consciousness and theories of social identity development (Kegan, 1994).

Abes, Jones, and McEwen (2007) considered Kegan’s (1994) constructivist-developmental theory and the model of multiple dimensions of identity in a study exploring how lesbian college students perceived their sexual orientation identity and its interaction with other dimensions of identity, such as race, religion, social class, and gender. Results of Abes, Jones, and McEwen’s study suggested that meaning-making capacity served as a filter through which contextual factors are interpreted prior to influencing self-perceptions of sexual orientation identity and its relationship with other identity dimensions. How context influenced these perceptions depended on the complexity of the meaning-making filter. Participants with complex meaning-making capacity were able, more so than those without less developed capacity, to filter contextual influences, such as family background, peer culture, social norms, and stereotypes, and determine how context influenced their identity. Complex meaning-making also facilitated the ease with which sexual orientation was integrated or peacefully co-existed with other dimensions of identity (Abes, Jones, & McEwen, 2007).

The results of Abes, Jones, and McEwen’s (2007) study suggest that incorporating meaning-making capacity would more thoroughly depict the relationship between context and salience of identity dimensions, as well as the relationship between social identities and the core of identity. This re-conceptualized, the integrated model portrays the interactive nature of the relationships among components of the identity construction process: context, meaning-making, and identity perceptions. Meaning-making capacity is depicted as a filter in the model and how contextual influences move through this filter depends on the depth and permeability of the filter. The filter is in direct proportion to the person’s meaning-making capacity. Regardless of differences in meaning-making, context influences identity perceptions (Abes, Jones, & McEwen, 2007).

Incorporating meaning-making capacity into the concept of social identity within a context provides a richer portrayal of not only *what* relationships people perceive among their personal and social identities, but also *how* they come to perceive them as they do. By incorporating personal and multiple social identities, Abes, Jones and McEwen’s model provides a holistic representation of the intrapersonal domain; with the inclusion of meaning-making capacity, the re-conceptualized model provides a holistic representation of the integration of intrapersonal development with cognitive and interpersonal domains. It also provides a lens to understand more clearly how people view themselves and this knowledge allows professionals to more effectively engage in meaningful and individualized partnerships to help them develop a more complex understanding of their identity and the power associated with defining identity for themselves (Abes, Jones, & McEwen, 2007).

### **Definitions of Disability and their Impact on Identity Development**

The definition of disability, much like the definition of ethnicity (Aspinall, 2001) and more recently, gender (Barr, Budge, & Adelson, 2016), may be defined several different ways, often with contradictory meanings. Three major

themes of how disability is defined include a) functional limitations which stem from a medical understanding of disability, b) administrative definitions which determine an individuals' eligibility for benefits and services, and c) subjective definitions which include a person's identity and self-categorization as having a disability (Gronvik, 2009). There is a definite fragmentation of meaning between society's definition, which often views disability as distinct categories and academia, which attempts to operationally define disability into a single category that can be quantitatively studied (Altman, 2014). These conflicting and often confusing definitions of disability directly contribute to the complexity and diversity of disability identity formation.

### **Disability, Functional Limitations and the Medical Model**

Typically, the majority of society views the definition of disability from a medical model perspective in that the disability resides within the body and is something to be cured (Smart, 2009). This perspective often leads to defining disability as distinct categories of impairment related to medical diagnoses as "deaf," "blind," or "diabetic" (Shakespeare, 2013). This viewpoint completely disregards environmental impact and individual response to disability and therefore offers only a linear, one-dimensional definition of a complex process. This perspective presents many complicated issues for the person with the disability, one of the most difficult being the potential negative impact this view has on disability identity development. Not only is there the possibility of internalization of these largely negative views by the person with the disability, there is also the creation of a power differential between the person with a disability and "normal" (or nondisabled) members of society.

Based on a medical model of disability, those with disabilities often feel the need and social pressure to seek a "cure" (Marks, 1999). Attitudinally, society typically reflects that physical and mental impairments are a general devaluation of the person (Wright, 1983). Disability is associated with a body that is weak, inade-

quate, or abnormal and these attributes are often generalized into dispositional character traits (Taub, Blinde, & Greer, 1999; Wolfensberger, 1982) and consensually held stereotypical assigned identities (Nario-Redmond, 2010). To protect the self from such negatively assigned identities, one may seek to increase the permeability of the boundary between "disabled" and "nondisabled" groups. In this way social pressures are created for people with disabilities to distance their identity of "self" from one of disability as a social category (Schur, 1998). If medical intervention can eliminate or hide impairments one can escape being identified as having a disability. For example, individuals may choose to have plastic surgery to alter characteristic facial features of children with Down syndrome in an effort to alleviate some of the stigma associated with this label. One may strive to overcome the disability and the adaptation of a disability identity by compensating or trying harder in the face of obstacles, rejecting accommodations and striving to meet normative standards of achievement (McVittie, Goodall, & McKinlay, 2008; Phillips, 1985). The emphasis across these strategies is disability identity suppression, grounded in the assumption that a person with a disability can improve self-esteem and increase feelings of acceptance by minimizing or suppressing their impairments and trying to appear as much like the norm as possible (Charmaz, 1995).

In response to this medical model mindset, Nagi (1965) introduced a definition of disability that included functional limitations that were related to the *impact* of limitations on activities of daily living (Hahn & Pool-Hegamin, 2001). Surveys and censuses world-wide conceptualize disability's functional limitations in so far as they impact activities of daily living (United Nations, 1996).

In order to fully understand how disability definitions impact identity formation, Altman (2014) defines disability emphasizing how it is necessary to be examined completely. For example, she explains that the process may begin with an accident, birth defect, or disease and includes both personal and environmental char-



acteristics associated with each. Whatever physical or environmental functional limitation(s) that is produced becomes a characteristic of that person, one of many, that impacts individual and collective disability identity development (Altman, 2014). The impact of the specific functional limitation is then dependent on how receptive the environment is or is not to that limitation. This explanation of the disability process demonstrates that the disability resides both within the individual, as well as within specific societal environments. Therefore, environment may impact disability identity development in either a positive or negative way depending upon how it interacts with the individual's response to the functional limitation. To summarize, Altman presents disability identity development as a result of a combination of individual physical limitations as they relate to specific environments and in doing so, demonstrates the diverse and broad nature of the definition of disability (2014).

### **Administrative Definitions of Disability**

Administrative definitions of disability provide benefits and services to those deemed eligible (Gronvik, 2009). Federal and state legislation are what dictate eligibility criteria in relation to specific benefits (Hedlund, 2004). Therefore, if a person is granted a benefit or service intended for people with disabilities, he or she is considered disabled [sic] (Barron, Michailakis, & Soder, 2000). The eligibility criteria are different for different benefits and services which results in a large variety of definitions of disability (Altman, 2014; Mashow & Reno, 2001). Again, these confounding qualifications for eligibility to receive various benefits and services also serve to confuse the disability identity development process.

### **Psychosocial Factors of Disability and Identity Development**

Psychosocial factors associated with disability have the potential to add additional meaning-making to one's disability identity development. One such psychosocial factor is the meaning-making attached to disability based on the nature in which the disability occurs, i.e., a disa-

bility that is acquired in the course of one's life versus a disability that is congenital in nature. Theories of adaptation to disability abound, however, disability identity is not the same as acceptance of disability (Mpofu, 1999). Until recently, the stages' theories of adaptation to disability (STADs) proposed that there are predictable or "normal" stages of responding to a disability (Bishop, 2005; Chan, Cardosa, & Chronister, 2009; Linveh & Parker, 2005). Taken from the Stages of Loss theory (Kessler & Kubler-Ross, 2005), most existing STADs' models include six phases or stages that a person with a disability (PWD) is likely to experience; they are: shock, defensive retreat, depression or mourning, personal questioning, and finally, integration (Kessler & Kubler-Ross, 2005; Smart, 2009). Traditionally, STADs theories have been applied only to the individual who is experiencing the disability and ignores additional psychosocial factors (Linveh & Parker, 2005).

Although most PWDs have these same generalized experiences that are analogous to the phases of the grieving process *when dealing with an acquired disability*, there are other significant considerations that the STADs' models fail to address when the disability is congenital (Linveh & Wilson, 2003; Smart, 2009). Smart contends there is an important distinction concerning the individual responses to disability between those with acquired disabilities versus those with congenital disabilities. With congenital disabilities, the parents, siblings, and often grandparents, progress through these stages, not necessarily the PWD (Smart, 2009). The person with a congenital disability knows no other way of life other than the one her or she was born with (Smart, 2009). Therefore, it is a logical conclusion that the individual is more likely to progress through the "typical" stages of external environmental control development, very similar to a child born without a disability. It is also a logical conclusion to assert that a child born with a congenital disability does not adapt to his or her environment, rather he or she develops the coping mechanisms that most typically developing children possess in order to manage his or her environment (Chan, Cardosa, & Chronister, 2009).



A significant psychosocial factor that often is ignored, however, is that as an integral part of the PWDs immediate environment, the family and friends' dynamic affects the individual's positive or negative response to the disability. Smart makes the argument that in cases of congenital disabilities, it is often the mother who internalizes much of the guilt and pain associated with having given birth to an imperfect child. As a result of legitimate medical questions about the mother's health and/or decisions she may have made during the pregnancy, society passes judgment and the mother internalizes these judgments more than other family members because she is biologically responsible for the child's well-being during the pregnancy.

The STADS theories are more accurately applied when the disability is acquired. Nonetheless, the loss theory (which includes distinct and identifiable stages of grief) is missing two important components when addressing individual response to acquired disability: the impact of stigma and prejudice and the lack of mental preparatory time to prepare for the loss. There is usually a period of time to prepare emotionally and behaviorally for the loss associated with impending death, aging and chronic/terminal illness (Smart, 2009). Conversely, this is not the case with an acquired disability. It is often sudden and traumatic with little to no time to prepare psychologically for the death of the person before the disability. Essentially, the feelings of loss and grieving that stem from mourning the loss of the pre-disability identity. Additionally, factors like education level, economic security, family support, the availability of treatment and the stigma and prejudice that exist within the individual's community, all influence the disability experience (Bishop, 2005; Chan, Cardoso, & Chronister, 2009; Livneh & Antonak, 2005; Smart, 2009). Environmental factors to consider include the degree of prejudice within the individual's community; discrimination toward type and severity of disability; and whether the individual is also subject to prejudice and discrimination because of other perceived identities such as belonging to cultural/ethnic/racial minority groups.

## Subjective Definitions of Disability

Subjective definitions of disability mean that a person defines him or herself as having a disability (Gronvik, 2009). This means that disability is incorporated into that person's sense of identity. Depending upon context and environment, it may be incorporated in positive ways at times and negative ways at others. However, the key to this definition of disability is one of subjectivity and voluntariness of self-labeling. In other words, conscious choice by the individual with the disability is at work. This can provide a source of individual and collective disability identity empowerment.

## The Influence of Disadvantaged Identities

As stated by Calderon-Almendros and Ruiz-Roman, identity gives sense of meaning to individuals and collective groups and forms the way they see themselves and others (2016). However, these sources of meaning are being constructed from places of inequality (Calderon-Almendros & Ruiz-Roman, 2016). This puts some individuals and groups at a disadvantage. The terms "advantaged" and "disadvantaged" are used to refer to individuals belonging to groups with relative high or low status or power within a specific social context (Curtin, Kende, & Kende, 2016). Groups such as ethnic minorities, people with disabilities, LGBTQ persons, and individuals who belong to a lower socioeconomic group exhibit commonalities in identity formation. They begin with a disadvantage: discrimination and social inequality (Fraser-Burgess, 2012). This unequal starting point that marginalized groups derive meaning from negatively impacts identity formation and again, creates a power differential. Collective culture, through power and perceived control over reality, impose certain interpretations on others (Calderon-Almendros & Ruiz-Roman, 2016). In other words, they proclaim a collective identity that is perceived as legitimate and can be referred to as one's legitimating identity. These groups in positions of power produce meaning from seemingly legitimate sources and have no interest in legitimating the identities of those groups considered to be



from devalued social statuses as in the case of people with disabilities. Also, the terms advantaged and disadvantaged identities tend to focus on singular aspects of identity, rather than intersections or multiple identities (Curtin, Kende, & Kende, 2016).

Another disadvantage that minority identities experience is a sense of belonging only within identity-specific communities as is the case with ethnic minorities and transgender individuals (Barr, Budge, & Adelson, 2016). Due to the ambiguity of the definition of disability, people with disabilities are perhaps at an even greater disadvantage for healthy collective identity development. In that the term disability is so indefinite and confounding, both among individuals with and without disabilities, group membership and a sense of belonging are challenging to establish. As Tajfel and Turner (1979) point out in their theory of social identity development, identity is formed through interactions with social groups. When one is continuously excluded from social groups, identity development is impeded and/or adversely affected.

### **Impacting Disability Identity: Independent Living**

Macro issues that continue to exist for PWDs are numerous and include a lack of inclusion into mainstream society that is fueled by stigma, prejudice and discrimination; a lack of empowerment, including personal choice as a person living in a democracy; real work for real pay; and finally, the inability to create a successful and effective collaboration between people with and without disabilities to help reduce some of the stigma and prejudice between the two communities (Martin, 2001). While we applaud some of the efforts and progress made as a society in these areas, at times, however, only minimal consideration is given to the promotion of independent living for individuals with disabilities.

The concept of independent living is not a new one and, typically, we all desire to take control and responsibility of our own life. Unfortunately, for people with disabilities, particularly signifi-

cant physical disabilities requiring assistance, many are excluded from this process. For many, the opportunity to be independent, self-determining, and exert choices may be rare. Due to a combination of social and economic factors, many people with disabilities are relegated to the margins of a society, provided only with obligatory consideration with regard to primary social issues. They are oftentimes hidden away in institutions, receive special education, participate in supported employment and provided with segregated housing. As a result of the numerous attitudinal, architectural, and institutional barriers, assisting people with a disability falls mainly on family members, local organizations and government agencies. The reality of many disabled people's lives is merely one of daily existence. It is a life of survival at minimal levels of subsistence and tolerance and thus contributes to the historically reinforced dependency status that many with disabilities hold (Faughnan, 1979).

No one can stop an idea whose time has come (Disabled People's International, 1991). Independent living is an idea whose time has come as all over the world people with disabilities are themselves acting as catalysts for change. The independent living movement has evolved from a social movement to a catalyst of change by redirecting the course of disability policy and practice. In this way, the felt presence and impact of the independent living movement will become a major factor shaping disability identity development within the larger culture. According to Turner (1969), "there is a revision in the manner in which a substantial group of people looking at some misfortune see it no longer as a misfortune warranting charitable consideration but as an injustice which is intolerable in society" (p. 321).

The independent living movement emerged in the United States in the 1970's and was inspired by strong and proactive leadership from individuals with disabilities. The first practical manifestation of the movement resulted in the establishment of a Center for Independent Living (CIL) at Berkeley University in California. The CIL was incorporated as a self-help group in 1972 and managed by persons with disabili-

ties (Dejong, 1979). Critical to its organization at that time was the university's masses of young people who, free from familial or economic responsibilities, were better able to organize around the issue of independent living. Since Berkeley, numerous CIL's have emerged in the United States and Europe offering a wide range of related services such as peer consultancy, advocacy services, training in independent living skills, and personal assistance services. Regardless of the type of services offered or role played, the CIL's have one thing in common; it is people with disabilities who are at the center.

The philosophy of the independent living movement is based on four assumptions; that all human life is of value; that anyone, whatever their impairment, is capable of exerting choices; that people who are disabled by society's reaction to physical, intellectual, or sensory impairment have the right to assert control over their lives and that disabled people have the right to fully participate in society (Morris, 1993a). Essentially, the independent living philosophy espouses living like everyone else. Some examples are being able to have control of one's own life, having opportunities to make decisions that affect one's life and being able to pursue activities of one's own choosing, regardless of disability. The philosophy is not designed to avoid the possibility of risk or potential failure. Dejong (1979) points out that it is the dignity associated with personal decision to take a risk that defines precisely what the independent living movement is all about. Without the possibility of failure an individual with a disability lacks true independence. Furthermore independent living must be distinguished from living independently. The latter implies that a person with a disability is trained by so called "experts" and "professional" to do everything for themselves and live without help, whereas the former is concerned about quality of life, with help. The person with a disability is not a patient in need of care, but is someone who requires assistance with certain activities, a process over which he or she must control and manage.

The independent living movement and its underlying philosophy give rise to many unique

accounts of personal achievement. While some accounts may expose noteworthy triumphs resulting in widespread social change, others may be more subdued resulting in a positive change affecting only the life of a single individual. Regardless of the perceived magnitude, it is the change that is present in the day-to-day lives of individuals with disabilities that give life to the movement. Without the realization of these individual victories, the movement serves no real purpose. Individuals with disabilities need to share their unique perspective of what is wrong in society and how to make it right. All individuals committed to the movement need to be willing to get involved, speak out and take risks.

### **Implications for Disability Identity Development**

Disability identity is characterized as a cultural-developmental phenomenon by which an individual with a disability incorporates the disability-related difference into his or her self-definition and regards that difference as a resource for participation in normative activities of his or her society (Barnartt, 1996; Grant, 1997; Hahn, 1997; Hahn & Belt, 2004; Mpofu, 1999). The term disability holds different meanings for different people and has historical, social, legal and philosophical influences on its interpretation (Gronvik, 2009). Therefore, disability identity development is complex and involves both individual and collective group processes.

Currently, there are those with disabilities who seek to find ways for the lived experience of disability to be a positive, life-enriching experience; a positive cultural heritage, or a centrally defining aspect of identity (Grandin, 1996; Olney & Brockelman, 2003). This approach is consistent with the independent living movement and the disability rights movement, which have challenged the strategies of curing the person, passing as if there is no disability, and the social disengagement of those with disabilities. Instead, these social justice movements *by* people with disabilities *for* people with disabilities encourages people, with both visible and less apparent conditions, to own the disability and with this ownership, the right to mi-



minority group membership in an effort to begin to positively identify with one another (Barnartt, Schriener, & Scotch, 2001). More specifically, group members may use the same social construction theories that have assigned them to the socially devalued categories of “less than” and “sick” to establish new standards or dimensions of social comparison, transform normative values, and bolster pride (Hinkle, Taylor, Fox-Cardamone, & Ely, 1998). For example, *ableism* is the automatic assumption by those without disabilities that those with disabilities cannot perform certain tasks because of their disability (or *type* of disability) (Mpofu & Harley, 2006). A healthy disability identity would be a protective factor for ableism (Mpofu & Harley, 2006).

A self-actualized and healthy identity for people with disabilities would contain relevant content and goals linked to disability. Therefore, disability identity is characterized as a source of difference and at the same time regarded as a resource for participation in the activities that people without disabilities participate in, in mainstream society. Additionally, there is at present no widely recognized theory on disability identity development. The lag in the development of theories of disability identity relative to identity development in other minority statuses parallels the historical delay by civic society in recognizing people with disabilities as a minority or culturally distinct group (Mpofu & Harley, 2006).

Constructs do exist that have the capability to be the foundation for a theory of disability identity development (Mpofu & Harley, 2006). Interactional models appear to be the most logical and practical models to explain the identity formation process of intersecting marginalized identities (Whitney, 2006). Interactional models are those which dynamically incorporate aspects of biology, cognition, and social and historical surroundings without using a fixed linear scale (Cramer & Gilson, 1999). Furthermore, interactional models posit identity as fluid and dynamic. These models share the following assumptions: a) defining one’s self within the salience of disability status; b) understanding and accepting the psychosocial ramifications of the

disability as a component of self-actualization; c) creating a higher awareness of disability-related prejudice and discrimination by those without disabilities; and d) possessing a strong disability identity used to recognize and combat disability related stigma (Noonan et al., 2004).

Inspired by the civil rights struggle of other minority groups such as African Americans and women, people with disabilities have begun to define who they are and where their place is in society. Gill (1997) emphasizes the concept of integration and provides a foundation based on strength for a future model of disability identity development. Gill’s (1997) work focused on the importance of the integration of self in forming identity and presents a multi-stage, non-linear model for the identity formation of individuals with disabilities. Gill’s four aspects of disability identity formation explain the process of integrating the disability aspect, both physical and psychosocial, into the individual’s salience hierarchy in a positive way. *Coming to feel we belong* focuses on recognition of oppression; *Coming home* focuses on initial contact with others with disabilities thus the realization that one is not alone; *coming together*, defines the process of integrating one’s whole self and abandoning the references to certain body aspects or traits as “good” or “bad”; and finally *coming out* focuses on the external presentation of one’s self to the world, or in other words, taking pride in a disability identity. Therefore, separation-individuation is seen as a primary struggle for people with disabilities to improve their prospects of integration into a foundation for group identity development (Mahler, 1968) as well as individual growth and identity development.

Additionally, issues of social justice do relate to laws and legal protections that have been afforded to disadvantaged groups and serve to bolster identity for such groups. The Americans with Disabilities’ Act (ADA) (1990) is a prime example of how legislation and policy, although slow at times, can and does affect social change in the U.S. based on legal precedent. This anti-discriminatory legislation that protects those with disabilities from inequitable practices under the law has helped to give people

with disabilities a sense of equal value and an expectation of societal acceptance and accommodations for their differentness. It also places the blame for “not fitting in” more on the creators of the restrictive environments, roles and occupations, and less on the individuals with disabilities themselves (McCann & Kim, 2002).

It is the intersection of disadvantaged and advantaged identities that better predict politicized identification and activist commitment toward promoting social change to overcome discrimination and social injustices (Case, Iuzzini, & Hopkins, 2012). Indeed, the process of identity politics is shaped by the multiplicity of available identities and their intersections, as well as experiences of marginalization and privilege connected to one's identities. Therefore, disability rights activism, with the inclusion of the philosophical foundation of the independent living movement has the potential to serve as a foundation for a comprehensive understanding of disability identity development. By utilizing the four assumptions of independent living, i.e.: that *all human life is of value*; that anyone, whatever their impairment, is *capable of exerting choices*; that people who are disabled by society's reaction to physical, intellectual, or sensory impairment have *the right to assert control over their lives*; and, that *disabled people have the right to fully participate in society* (Morris, 1993a), a definition of disability identity would include a sense of pride one has in assured self-acceptance regarding one's right to a normalized existence, fully participating in society based upon individual choice, *despite and at the same time because of one's disability*. Essentially, the independent living philosophy espouses living like everyone else. Such a foundation coupled with an enhanced understanding of identity development from both an individual and collective perspective would help to provide a rare but valued source of pride. The resulting theories regarding disability identity development would serve as a source of empowerment in the development of the aspect of identity that includes disability making the previously disadvantaged aspect of identity (disability) now an advantage.

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