

**Belonging and Understanding:
Disability Identity Grounded in Community**

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Introduction

Identity has been defined as an attempt to describe and understand the unconscious process of experiencing one's inner self and that self in relation to the world around one (Josselson, 1987). Erikson (1950, p. 235) describes it as "the accrued confidence in the inner sameness and continuity of one's meaning for others," the inner experience of oneself, thus, being mediated and reinforced by those around one. While Erikson (1959) never articulated a model of minority identity development, he did state that such "meaning" and "sameness" must come from a sense of community with others like oneself, which is particularly important for members of minority groups in countering the effects of prejudice on the identity development process. He later acknowledged that minority in-group identification "may signify an inner emancipation from a dominant group identity" (Erikson, 1968, p. 22), an allusion to the political aspects of the minority identity development process that minority identity theorists went on to further elaborate.

Cross (1971) acknowledged these political elements in his seminal work on racial identity development in which he directly linked the development of "Black consciousness" to the political action of the African American civil rights movement. Furthermore, he predicated racial identity development for individuals on a positive in-group identification with other African Americans. Cross, Parham, and Helms (1991) reviewed many "nigrescence" models and found that all models associated a positive racial identity with fortifying African Americans against racism, providing a reference group for responding to community needs and offering a means of transcending human differences while still embracing one's own blackness.

Disabled people, like African Americans and other minority groups, have engaged in a struggle for political equality, as well as positive personal and collective identities. Anspach (1979) calls this struggle "identity politics," politics that endeavors not only to change society's conception and response to disabled people, but also to change the self-concepts of disabled people themselves. It is the personal piece of "identity politics" that is the focus of this study as I sought to explore how disabled individuals come to develop disability identities and how they come to identify positively with other disabled people. The very idea of a disability identity flies in the face of long-standing societal "wisdom" about disability.

Historically, disabled people were once viewed as social and moral deviants, violations of the natural and cosmic order of the universe (Longmore, 1993). One of the responses to such perceived "deviance" was to protect society by segregating disabled people in asylums, jails, basements, and attics (Bryan, 1996; Crewe & Zola, 1983; Shapiro, 1993; Treanor, 1996). In many ways, disabled people were considered not fully human, allowed no role to play in society and given no basis for a positive social identity (Goffman, 1963; Parsons, 1951; Zola, 1993; Herman & Miall, 1990).

The contemporary perception of disability is generally a "medicalized" view. Disability is seen as a physical or psychological "defect", a violation of the standardized "norm" (Longmore, 1993; Robertson, 1994; Phillips, 1985; Davis, 1995; Gallagher, 1995). This view places disability in the category of pathology and disabled people in the category of "sick". As invalids, disabled people are seen to be in need of a cure or, at the very least, corrected as much as possible (Longmore, 1987; Zola, 1993; Goffman, 1963; Kirschbaum, 1991). In this "sick" role, disabled people are seen as not capable of fulfilling adult roles (Goffman, 1963; Kirschbaum, 1991) and as childlike, pitiful, dependent, helpless, emotionally unstable, weak, unattractive, asexual, and unintelligent (Fine & Asch, 1988; Rousso, 1988; Hillier, 1992). Rehabilitation medicine offers a means of ameliorating the stigma of this "sick" role through medical interventions and arduous therapy required to achieve some semblance of "normalcy", a life long struggle to overcome the functional limitations of disability (Longmore,

1993; Phillips, 1985; Herman & Miall, 1990; Parsons, 1951). This "overcomer" role perpetuates the belief that nothing positive can be associated with disability itself; it is only in moving away from disability that redemption is found.

It is within the context of disability as a minority experience that we find the basis for a positive disability identity. Within the framework of minority identity development we find a useful approach for exploring disability identity development. Because the "identity politics" of the disability rights movement so resembles other minority movements, it would be easy to assume that the models and theories of identity development for those groups would suffice to explain disability identity development. These models do provide basic insights as to how members of minority groups move from being "other defined" and devalued, to self-defined and honoring of one's difference. Because the lived experience of disability is so multi-dimensional, however, any theory or model of disability identity development must transcend the differences of seemingly unrelated medical diagnoses. It must encompass the variety of dynamics that disability presents in people's lives over time. It must answer the question of whether there is a universal process disabled people go through in clarifying their personal positions in society. Are there psychosocial needs unique to our community in the process of developing a positive collective identity? What environmental challenges influence this process? What role does the body and its needs play in constructing a positive disability identity? Many of the answers to these questions are found in the stories of disabled people who are working to define themselves as members of the disability community and forging their own unique roles in the larger society.

Method

To begin to sketch out the broad strokes of how this process unfolds, I interviewed seven disabled adults between the ages of 40 and 53, five with childhood disabilities and two who had acquired spinal cord injuries later in life. These seven interviews were, initially, part of a larger study that included a broader scope of ages, disabilities, educational and socio-economic status and thus more reflective of the true nature of the disability community. All of the people discussed in this subset of the study had college degrees and were in professional roles. Six participants were White and one was African American; five participants were male, two female and all were heterosexual. Two participants had progressive disabilities; the other five were experiencing the effects of aging on their "static" disabilities. All participants had varying degrees of mobility impairment, with five using wheelchairs or scooter for mobility. One participant had a mobility disability and a psychiatric disability, as well as other chronic health conditions. Participants were chosen by purposive, or criterion-based sampling, selecting those people who had had their disabilities of long enough duration to have adjusted to changes due to later-in-life onset.

Theoretically, this sampling criterion reflects Erikson's (1950) timetable for mastering the pre-adolescent tasks that are the foundation for adolescent identity development. The interview questions were generated from the research literature on minority identity development, the personal experiences of disabled people, as well as the researcher's experience of living with a disability since childhood. The structure of the interview was intended to explore early disability experiences, family/friend relationships and relationships with other disabled people, whom the interviewees talked with about their disability experience and whom they identified with over time. As a disabled researcher, I viewed the interview process as a form of participatory action research, in that such interviews can provide an opportunity for psychosocial development through reflecting on one's life (Glesne & Peskin, 1992). Two weeks after the interview, I asked participants to reflect on the interview process to explore that possibility. The rationale for such reflection is also found in developmental psychology research that has demonstrated how reflection can deepen new insights stimulated by such an interview (Sprinthall, Sprinthall, & Oja, 1994). Later, several participants were asked to review the findings to verify the accuracy of my representation of their stories.

Results and Interpretation

The findings from these interviews revealed common themes that correspond with themes found in the archetypal tale of difference and belonging, *The Ugly Duckling* (Gill, 1993). They include themes of being different and alone, of experiencing cruelty and pain because of difference, of being defined negatively by others, of having no one who understands, and the inability to feel positively about oneself until encountering others who show that it is possible.

The first major themes in the lives of those I interviewed revolved around their "medicalized" disability experience. Participants perceived their families as very involved and willing to talk about the medical, "mechanical" aspects of disability. They believed their families, in fact, functioned as if the medical aspect were the only important aspect of the disability experience. All but one person spoke of a collective family effort in working towards the goal of being "normal" at all costs. The only person whose family was not actively involved in her rehabilitation had been hospitalized because of polio for a year, at the age of six, without ever seeing her family. She realized during the interview, for the first time in her life, that this separation may very well have been why her family never talked about her disability.

In fact, none of the people interviewed spoke of ever talking with family members about the inner experience of disability, the psychological and emotional struggles of being different from everyone else in their families and communities. They reported a general pattern of hiding the full extent of their physical and emotional struggles from their families and society in general. They did not want to be viewed as "different" and did not want to draw attention to their difference by talking about it. Yet, all spoke of the enormous amount of energy they spent pushing themselves to be as "normal" as possible, accommodating the expectations and intolerance of the non-disabled world around them.

The African American participant spoke of his family being "culturally fortified" to deal with disability as just another impediment to involvement in the broader culture. Yet, even he was unprepared for the shock of rejection by his peers when he was finally able to attend a racially segregated public school in tenth grade. He "just wanted anonymity [but] instead, I stuck out like a damn whore in church on Sunday!" For other participants, realizing the futility of thinking they could "pass" as normal may not have been quite that dramatic, but the impact on their lives was no less significant.

Over time, the attempt to "pass" as normal, to not be seen as different, took its toll on the participants' lives. What followed, for five of the seven participants, was an internal revolution to reject the "walk-at-all-costs" standard of "normalcy". All participants spoke of being urged by medical professionals and families not to use any assistive technology that would further mark them as different. For two participants, refusing to walk and choosing to use a manual wheelchair became an individual act of resistance, after enduring 10 years of pointless surgeries and arduous therapies. For others, using a wheelchair required wheelchair-using role models to make it okay to "take to a chair".

In making this choice, each person encountered negative reactions from family and friends, as it was perceived that "they had given up" or were somehow "less than" they could be. One man stated that he thought that as long as he was walking his family felt better, had hope that he would eventually be normal again. For each of them, though, the choice to use a chair actually "liberated" them and gave them the energy to "get on with life." For some, another round of liberation occurred later in life, when they chose to use power chairs, though this choice, too, required the support of power chair users to make it acceptable.

The two participants who do not use chairs expressed a need to continue to push against "weakness" or to work to stave off the loss of ability due to aging. The isolation these two were experiencing, due to their increasing fatigue and slowness, was a common theme found in everyone's story throughout their disability experience. For all participants, though, it had been the unavoidable isolation of being the only disabled person in their world that had the most powerful impact on their sense of self. The psychosocial implications of being the only disabled person in a family and community were intense for those interviewed. They spoke of being an oddity, "a sight to be seen" in their

town, the target of self-proclaimed healers, subjected to stares from "gawkers", embarrassed by money offered by strangers, and never feeling as if they belonged anywhere.

Several spoke of how their disability affected their sexual development, of feeling asexual as an adolescent or not feeling entitled to have a partner. Others spoke of great uncertainty about how their disability would be perceived by potential sexual partners. One man spoke of being socially "knocked out of life" by polio and "feeling that he had the socializing skills of a 9 year old when he was 25, 26 years old!" Another spoke of abandonment by friends after becoming paralyzed at 18, and being hurt by their lack of curiosity at what his changed reality might mean to him.

For some, the isolating aspects of inaccessibility increased their feelings of not belonging, because they were unable to participate in everyday activities with their age peers. One participant actually observed that the "psychosocial issues of disability" causes one to either "withdraw or become very strong and very assertive - guerilla gimps." All participants in this study had adopted some variation of this "strong" path, though the degree to which they grounded their strength in the disability community itself varied at the time of the interviews.

The civil rights movement was in progress when all of the participants were reaching early adulthood and each spoke of how that struggle for equality had positively affected their lives as disabled people. Several spoke of an early affinity with the concerns of other minority groups, though they did not yet see themselves as belonging to a minority group at the time. Conversely, one White man commented that, even now, he finds African Americans to be far more open towards him as a disabled person, more willing to even acknowledge his existence as a stranger rolling down the street.

Some participants were directly involved in the civil rights movement and, through that involvement, began to understand their own disability experience as one of discrimination and lack of equal access. The desire to fully participate in an inaccessible society drove these participants to get involved in the disability rights movement. This burgeoning understanding of disability rights created the first basis for positively identifying with other disabled people, the first step towards experiencing a sense of disability community. Disability rights, then, became the catalyst for unlearning their aversion to the company of other disabled people, an aversion participants felt was taught by a society that only honored "normalcy".

Participants began to perceive other disabled people as colleagues in a political struggle for equal access and rights, rather than reminders of the horrors of their early "medicalized" experiences. For all of those interviewed, a growing awareness of disability rights led to an acknowledgement of anger previously undetected or unsafe to express. And yet, the company of other disabled people was still required to validate those feelings and make it safe to fully feel them. It is a refrain that echoes across the spectrum of minority experiences - the need for a sense of belonging with ones' own kind to know the wholeness of oneself (Erikson, 1958).

The very notion of disability community was alluded to in every interview, though some participants had a more overt collective identity than others. None of the participants explicitly set out to find the disability community, but "knew" it when they encountered it - even if it was a single relationship with another disabled person. All spoke of the "comfort" of being in the company of people who "understood", of the acceptance they felt from others who shared their common experiences. This comfort took the form of not having to prove abilities, even in the face of obvious limitations. They spoke of having feelings validated by those who understood what their struggles and issues actually were, even though the other person did not have the same disability.

One told of how much fun it was to share stories, both of success and pain, and how the telling and hearing built the bonds of community. Another spoke of the comfort of the unspoken communication from shared experiences, an "awareness" that is only possible with other disabled people. Two participants spoke of this bond between disabled people as having spiritual dimensions, a "soul connection" that arises from such a bodily experience. Several described how collective political action led to an increasing personal openness about their own limitations, while at the same time admitting it took time to become comfortable with disabled people who had more limiting disabilities

than themselves. Another spoke of needing the disability community to believe in himself and in the future. He credited his professional development to the disability community who nurtured him through their support and advice, to say nothing of their prodding and challenging!

The person who least identified with disabled people grounded her identity primarily in her professional work, a field that held no disabled role models for her. Similarly, she struggled with isolation in managing other aspects of her life, such as motherhood and the late affects of polio, finding it difficult to connect with other women and "old polios" for the support she needed. One man spoke of being conscious of the need to deliberately reach out to disabled people who are isolated within their disability experience, so they can begin to experience the comfort of shared feelings. He saw his willingness to share his experiences as the way to nurture others' self-understanding and the ability to see more options in life. Such a sense of "generational" obligation to other disabled people is further evidence of the deepening of a collective identity that is developing within our community.

Conclusions

Even in this very limited pilot study of disability identity development, we find that each person's positive sense of self is grounded, initially, in a positive collective disability experience. Although the limited sample of this study did not include people with a broad range of disabilities or backgrounds, the participants gave very useful information for further study that can explore other commonalities of the identity development process. While not everyone interviewed claimed disability as a primary social identity, the positive disability experiences they did have came solely from other disabled people. Each participant spoke of the psychological and emotional comfort experienced in being with or talking to other disabled people. Furthermore, the concept of disability rights proved to be the initial positive link for many in coming together with other disabled people at all.

Reframing disability as a minority experience made it possible for these people to see how one can incorporate one's disability into a whole sense of self and how that self is grounded in the disability community. The "felt" connection with other disabled people was said to have spiritual dimensions that were, in some way, linked to the unique aspects of the disability body/mind/spirit connection.

Sexuality was also a facet of disability identity development that was alluded to by participants, though it was usually in reference to sexuality with non-disabled people. Only two people spoke of sexual relationships with another disabled person and the meaningfulness of those relationships seemed to be connected to their positive disability awareness. It was striking that the other participants were concerned with how their disability would be perceived by potential partners, rather than viewing it as an integral part of who they are in any relationship. Comfort with one another's own disability seems to be the key to a greater sense of individual wholeness and integration within society at large.

While it is true that the initial battles to legislate access and civil rights protections have been won, the individual's challenge of insisting that those rights be enacted is inextricably linked to a positive disability identity (Hahn, 1985). From this study, it appears that a positive disability identity is primarily grounded in having a positive collective experience with other disabled people and that an awareness of disability rights can play an important part in connecting with others.

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