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Disability Identity and Racial-Cultural Identity Development: Points of Convergence, Divergence, and Interplay

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INTRODUCTION

Disability and Blackness are signifiers for two groups historically linked to social oppression, discrimination, marginalization, and stigmatization—conditions encumbering other socially defined groups, such as gay and lesbian people, Native Americans, Chicanos, etc. In the 1960s and 1970s, each group took turns finding ways to intrude, disrupt, and irritate the status quo. The ultimate aim was to reshape mainstream sensibilities and make the inclusion of individuals often regarded as strangers, deviants, or damaged people possible. Consciousness-raising, a key characteristic of these movements, stimulated in-group affiliation, attachment, and advocacy, thereby laying a foundation for group identity development. In its early evolution, the discourse on disability identity borrowed heavily from the discourse on racial-cultural identity in general and Black identity development in particular. Over time, notions of identity multiplicity and intersectionality surfaced in both the disability identity literature and the work of racial-cultural theorists, extending the complexity and relevance of both frameworks.

The organization of this chapter reflects the theoretical interplay between the discourses on racial-cultural identity development and disability identity development. The chapter starts with a rationale that links the dynamics, or the "work," of racial-cultural identity and disability identity. *Part One* moves to a summary of current trends in the racial-cultural identity literature. *Part Two* shifts the focus to disability identity. *Part Three* examines the usefulness as well as the problems of bridging

blackness and disability in the context of identity. Finally, the chapter ends in a discussion of potential directions for research and practice.

PART ONE: SUMMARY OF RACIAL-CULTURAL **IDENTITY DEVELOPMENT**

Race, Culture, and Existentialism

Concern for racial-cultural identity development can be found among persons whose humanity has been racialized by the larger society at five levels: (a) individualbiological, (b) individual-psychological, (c) group, (d) community, and (e) culture. There is the general misperception that race is a biological construct fundamentally wedded to a genetic classification system; however, the originators of the discourse always spoke of a hybrid concept linking race and culture. Henri Count Boulainvilliers, of 17th century France, is credited with being the first to coin the phrase discourse on race, and his definition was, to say the least, flexible. He thought the aristocracy was a superior race ordained to rule commoners whom he viewed to be another, albeit inferior, race (Guthrie, 2003). Two centuries later, Joseph Count Gobineau (1816-1882), another French thinker, gave birth to the so-called modern scientific racial classification system that divides humankind into various racial categories (White, Yellow, and Black). Gobineau's categorization of humankind made use of physical markers such as body-type, hair texture, lip size, facial features, etc. (Guthrie). However, the inventors of race always understood it to be a signifier of culture. It was not simply that Europeans were White and others were of a different color and physiognomy; the concept of race stretched to mean anything cultural or otherwise associated with each race (i.e., individual, family, kin, group, community, religion, society). In fact, Gobineau believed race created culture (Guthrie, 2003).

As a heuristic, the concept of race has constantly vacillated between notions of physicality and culture, resulting over the course of history in conceptual ambiguity. Here in the United States, the strong association of race with human physical features has caused many observers to overlook the racial plasticity played out in other settings. Race has been, and can be, interpreted to mean just about anything physical or cultural. In the genocidal encounters resulting in the Holocaust, the Slaughter of Armenians at the turn of the 20th century, the recent mass killing madness that was Rwanda, and the calamity of "ethnic cleansing" called Bosnia, the differences between exterminators and victims were not physical but imagined or actual cultural, religious, political and ideological differences, all falling under the rubric "race." In using race to explain everything—from the biological to the psychological and cultural—in the end nothing is explained. What can be said is that race is perhaps the

most diabolic yet efficacious concept of stigma invented by humankind. Its efficacy is derived not from scientific validity and "proofs" but in the power of one group to impose race-based stigma upon another.

Stigma imposition engenders an existential dilemma—if not crisis—within targetgroup members, compelling them to devote psychological energy that engages, dismisses, enacts, transacts, and, where possible, transcends the constraints of stigma. Combined with cultural elements derived from the target group's history and collective experience, stigma management can drive group identity and meaningmaking. In developing, sustaining, and refining stigma management competencies as well as in using culture as a shield, source of motivation, and anchor for meaningmaking, the discourses on racial-cultural identity and disability identity find common ground. Although the content or social representation for each discourse is descriptively distinctive, latent dynamics are similar. The purpose of the range of identities (i.e., there is no one disability identity or one racial-cultural identity) associated with each target group is similar: To live a meaningful life in the face of macro and micro aggressions linked to stigma and to absorb, protect, and perhaps contribute to the social group's culture and general welfare.

Epiphany, Conversion, and Resocialization

The Black Social Movement of the 1960s and 1970s had two phases: (a) a civil rights phase that took flight in reaction to the 1954 Supreme Court School Desegregation Decision and was all but grounded in the aftermath of riots following the murder of Martin Luther King, Jr. in 1968; and (b) a Black power phase that first emerged during the Watts Riots in 1965 and peaked in influence between King's murder and the mid-to-late 1970s. The modern discourse on Black identity (circa 1960s to the present) has its origins in the psychological experiences of young and middle-aged Black adults who were participants in the Black power phase. However, many of the Black power participants had their psychological roots in phase one activities in the 1950s and early 60s (civil rights). Consequently, their participation in phase two activities (Black power) necessitated an identity change captured in the phrase: Negro-to-Black-conversion (Cross, 1971).

Not surprisingly, a major psychological dynamic of the Black power phase was identity conversion, and theorizing conversion led to the psychology of nigrescence or simply Nigrescence Theory (Cross, 1971). The psychology of nigrescence explored a five-stage phenomenological model of identity conversion that took as its starting point a person holding an otherwise functional and healthy identity that discounted the significance of race (Pre-encounter). Subsequently, the Pre-encounter identity is challenged in thunderbolt-like fashion by an epiphany compelling the person to seek personal change (Encounter). The person submits to oceanic, true believer, and totalcommitment attitudes fueled by a war between the old and new self, taking place

just beneath the surface (Immersion-Emersion). The process culminates in identity habituation, psychological homeostasis, and worldview reformulation (Internalization). In the end, a pre-existing and fully formulated adult identity is transformed or reformulated through conversion. In its earliest iteration (Cross, 1971), Nigrescence Theory was linear and subject to prototypical depictions, as one identity type was associated with each stage.

In 1991 (Cross), Nigrescence Theory was expanded to account for the fact that persons entering the process (at the Pre-encounter identity stage) hold a wide range of identity constellations. However, the multiple expressions of Pre-encounter shared the tendency to accord limited importance to race and Black culture. Pre-encounter is the identity belief system held by Black people, who, beyond the fact that they are nominally Black, make meaning of themselves and the world around them through attitudes, philosophies, values, and worldviews that accord limited significance to race and Black culture. The stance is not necessarily negative but dismissive (low salience).

Several negative identity attitudes are also included in the revision of Preencounter, such as miseducation and racial-self-hatred. Miseducation attitudes reflect the tendency information about Black people and Black culture as factual, when in reality such information is stereotypical. Such negative stereotypes are "compartmentalized" by the person making it possible to embrace them as "truths" about the group but not the self, even though the person is a member of the disparaged group. Racial-self-hatred is the tendency to experience self-loathing, unworthiness, and selfhatred as a consequence of the person having internalized powerful negative ideas, feelings, and beliefs about being Black at both the collective and personal levels.

Just as the revised theory (Cross, 1991, 1995) reconfigures Pre-encounter to account for identity variability at the front end of the process, identity diversity is also incorporated into the dynamics of identity resolution. To the extent that the original model linked a single identity type with Internalization, the revised theory associates advanced identity development with not one, but a broad range, or "cluster," of identity configurations. To make explication of the theory manageable, the following identity exemplars are highlighted throughout the revised theory: (a) Afrocentric (race and Black culture salience expressed as a monocultural orientation); (b) Bicultural (synthesis of being Black and American, identity duality, fusion, and shared salience); (c) Multicultural (a sense of Blackness fused with two or more additional cultural reference points); and (d) Intersectional (an extension of the multicultural exemplar where the additional reference points are social class, sexual orientation, disability identity, and/or religious perspective, etc., as in a person who is Black, female, lesbian, disabled, and poor). Moderate-to-high salience for race and Black culture is common to all exemplars (none of the exemplars reflect low salience or negative salience) but the configuration of salience can be expressed monoculturally, biculturally, multiculturally, or intersectionally. Any and all of these identity exemplars are the result of socialization processes (Cross & Fhagen-Smith, 2001; Cross & Cross, 2007), and three patterns of socialization have been highlighted.

Pattern A: Traditional Socialization and Identity Acquisition

The inculcation of some variant of Blackness through traditional socialization (infancy across early adulthood) is called Pattern A. The emphasis on variant makes clear that cutting edge discussions of traditional socialization of Black youth result not in one, but in a range, of identities with the common attribute of according moderate-to-high salience to race and Black culture. From this perspective Afrocentric (high-singular salience), Bicultural (dual-cultural salience), Multicultural (a sense of Blackness fused with multiple points of cultural salience), and Intersectional (a sense of Blackness fused with a range of additional identity concerns such as being Black, disabled, lesbian, and female) are all possible outcomes of traditional socialization.

On the other hand, Tatum (2003) points out that not all Black parents subscribe to the centrality of race. Some raise their children in the opposite direction; striving, instead, to inculcate a positive identity that accords limited salience to race and Black culture, as in an Assimilated identity or Color-Blind-Humanist frame of reference. One could also add the so-called Cosmopolitan identity (Appiah, 2006) that fuses elements of assimilation, passing, and a yearning to be invisible. From the vantage point of the Cosmopolitan, discourses on racial-cultural and disability identity are trivialized and treated as passé, and to engage in such discourses is said to perpetuate one's own oppression (Davis, 2007). Consequently, a comprehensive life span perspective on racial-cultural socialization (Cross & Fhagen-Smith, 2001; Cross & Cross, 2007) maps the unfolding of both race and culturally salient expressions of Blackness (i.e., Afrocentric, Bicultural, Multicultural and Intersectional) as well as low-salient stances (Assimilationist, Colorblind, Cosmopolitan, and Humanist oriented). As to the latter, Cross and Cross label positive but low-salient identity patterns as Alternate identities.

Every variant of Black identity is understood to emerge as a consequence of generic psychological processes. However, due to space limitations, we will only highlight a process germane to the period covering pre-adolescence and early adulthood. For example, the general literature on human development shows that youth enter pre-adolescence with ideas and feelings about themselves and the world shaped, in large measure, by their parents and significant others. In a general sense keeping the focus within Western societies—identity proclivities expressed by preadolescents have been constructed and inculcated but not critically self-examined. However, when they enter the more autonomous spaces of middle school and especially high school, identity exploration, contestation, and experimentation become commonplace. By late adolescence and early adulthood, scrutiny gives way to identity habituation and internalization, revealing a young adult who has taken ownership of the self. Marcia (1966) refers to these three developmental points—drawn

from the writings of Erik Erikson—as identity statuses wherein pre-adolescent identity is equated with a formulated but relatively unexamined identity status known as Foreclosed, the exploration-testing dynamics of adolescence as Moratorium, and the point of self-acceptance, habituation, and self-ownership as *Achievement*.

Grafting Marcia's perspective to a discussion of Black identity development, Cross and Fhagen-Smith (2001) state that regardless of the type of Black identity being tracked across the life span—Afrocentric, Assimilated, Bicultural, etc.—each will be the object of the same psychological processes. Thus, the development of an Afrocentric variant of Black identity will be no more or less subject to Foreclosed, Moratorium, or Achieved experiences than the unfolding of any other type of Black identity. The same is true for the development of positive (Alternate) identity options that accord limited salience to race and Black culture (i.e., Assimilated or Humanist). As an aside, the trajectory need not be linear because a teen may enter Moratorium with an Assimilationist stance and exit with a frame dominated by Bicultural attitudes and/or some other frame; in another instance, a young girl may enter Moratorium with an intense Afrocentric gaze only to emerge at early adulthood with an openly lesbian focus.

Pattern B: Conversion as Resocialization

The successful acquisition of a variant of Black identity through Pattern A may preclude having to go through a conversion experience (Pattern B) later in life, with several important exceptions. First, a parent may raise a child such that race and culture issues are downplayed or treated as trivial. Thereby, a self-concept is fashioned deriving little, if any, meaning from race and Black culture (e.g., Assimilationist and Humanist stances). Such a child may emerge as an adult with the type of identity that places her/him at risk for a racial-cultural epiphany. Here we use "risk" to connote frame vulnerability, not pathology. A person operating with a frame of reference that accords limited salience to race and Black culture is at risk of encountering a race and culture-loaded experience for which the person's ongoing frame of reference has no answer. If the encounter takes on the force of an epiphany, it may trigger a fullblown conversion. Additionally, should too much internalized racism leak through socialization resulting in miseducation—or worse—elements of racial self-loathing, the stage is set for Pattern B as a corrective for self-negativity. A conversion takes place after the results of traditional socialization have taken hold; consequently, a conversion experience involves psychological re-socialization.

Pattern C: Recycling

For the sake of argument, let us presume that in a random sampling of 10,000 Black people between the ages of 15 and 30, 85% arrived at their sense of racial-cultural

identity through Pattern A and the remainder through identity conversion, or Pattern B. In a manner of speaking, this foundational identity can be achieved through either pathway. Independent of whether a foundational identity is the result of Pattern A or Pattern B, how is continued growth and possible expansion of the foundational identity explained? The possibility of growth beyond either Patterns A or B has been considered by Parham (1989), the distinguished Black psychologist, Afrocentric philosopher, and past president of the Association of Black Psychologists. He refers to this added growth as identity recycling, and Cross and Fhagen-Smith (2001) label it Pattern C. According to Parham, a person with a well-developed core identity encounters a racial-cultural-related question/challenge tied to personal, family, and employment contexts. The immediate solution may not be obvious—literally throwing the person for a loop. In working through and processing the "challenge," the person's foundational or core identity is enhanced in the sense that the person is now able to incorporate into her/his narrative what it is like to be confronted with, and live through, the challenge in question. As life involves a constant series of such challenges, a person is afforded various opportunities to develop a view of life that is thick, deep, rich, and complicated. In this example we are stressing how a sense of wisdom can develop. Of course, life's microaggressions can have a reverse effect leading to pain, bitterness, depression, alienation, and hatred, but in the limited space we have available here, we err toward the positive progression across the life span.

... Nigrescence Recycling begins with an adult Foundational Black Identity, and in response to a Life Span Encounter, a person discovers a minor or major gap in his or her thinking about Blackness. Should the person take the encounter seriously, a state of Immersion-Emersion is entered as a way to resolve the challenges posed by the life span encounter. Following the transition phase, Internalization of the Enhancement becomes evident. Finally, the overall developmental outcome is an Enhanced Foundational Identity. . . . Consequently, whether a person has achieved a Black identity through Nigrescence Pattern A (identity development through the formative socialization process during infancy, childhood, preadolescence, and adolescence) or Nigrescence Pattern B (Black identity development achieved through identity conversion), he or she will likely be subject to continued growth through Nigrescence Pattern C. (Parham's concept of Nigrescence Recycling; Cross & Fhagen-Smith, 2001, pp. 266)

The Black Identity as a Lived Experience

The last element of Nigrescence Theory that shows promise in dialogue with the discourse on disability identity is an analysis of how race and Black culture are transacted in everyday life. Boykin's (1986) Triple Quandary Theory suggests that Black

people must learn to negotiate three "worlds" or types of experiences: (a) the world of marginalization, insult, discrimination, and racism; (b) the world of the mainstream; and (c) the world that constitutes the Black community itself. Building on Boykin's perspective, Strauss and Cross (2005) identified five transactional modalities that operationalize identity as a lived experience in everyday life: (a) Buffering (transacting racism and discrimination), (b) Code-switching (moving in and out of the mainstream), (c) Bridging (transacting friendships across social categories), (d) Bonding and Attachment (transacting relationships within the Black community), and (e) Individuality (transacting one's sense of individuality). In this model, the five forms of expressiveness connote not five different identities within the same person, but a coherent identity that reticulates a repertoire of expressions. The person is said to be the same person from one situation to the next (identity coherence); however, the demand characteristics of the situation determine what form of identity expression (or mix of expressions) the person will apply.

Contrary to its depiction as a theoretical dead-end and political Neanderthal (Davis, 2007), Black identity theory has evolved into a cutting edge perspective. It supports a rich, complex, and relevant discussion of stigma management and culture engagement, and offers directives for counseling-clinical applications. It can even help comprehend Alternate identity options such as Color-blind, Assimilated, Humanist, and Cosmopolitan. Given this capacity for handling complex expressions of identity within a heterogeneous group, Black identity theory may offer useful insights for research and practice regarding disability identity.

PART TWO: OVERVIEW OF DISABILITY IDENTITY

Background and State of Scholarship on Disability Identity

As has been true for African Americans and other groups engaged in social justice movements, the civil rights activism of Americans with disabilities sets the stage for their heightened concern with questions of personal and group identity. This interest in self-definition was bolstered by the language and spirit of the 1990 Americans with Disabilities Act (ADA). The ADA recognized that people with a wide range of disability types and social backgrounds compose "a discrete and insular minority:" subject to social discrimination. However, little empirical research has addressed identity issues affecting people with disabilities, in contrast to the large body of research from the 1970s to the 1990s linking ethnic, gender, and sexual minority identity to such benefits as high self-esteem and resilience to prejudice (Anspach, 1979; Cross, 1971; Goffman, 1963; Marcia, 1966).

One possible reason for this lag in research is that, historically, the dominant paradigm in disability research has been medical or remedial, that is, pathology-focused. Instead of viewing disability as a social/political/cultural phenomenon and regarding people with disabilities as a distinct social group, researchers have traditionally perceived people with disabilities as a dysfunctional sector of the general population, defined by deviant biology. Consequently, researchers who investigated self-concept in persons with disabilities have tended to focus on individual adjustment clinically measured against norms. Disabled people's identity thus has not been considered worthy of study in its own right as a cultural or subcultural phenomenon.

Medical models that frame disability as a disruption of normal experience have several severe limitations for explaining aspects of disability identity formation, either as a conversion experience or as a developmental process:

- 1. They treat the process as a problem of individual adjustment, failing to address the social and cultural forces acting on the individual, such as discrimination.
- 2. They focus only on the potential negative impact of disability rather than viewing disability in terms of potential personal enrichment, community, and
- 3. They have little to say about the development of self in persons who have been disabled all their lives; therefore, they have few positive guidelines about "normal" disability identity development to offer counselors, teachers, etc.
- 4. They pay very little attention to within-group variation or intersections of identity based on gender, race, sexual orientation, etc.

Another possible barrier to research on disability identity is that, until recently, researchers in the disability fields have rarely been persons with disabilities. Much of the empirical work on identity models for other nondominant cultural communities (racial, ethnic, women, and gay/lesbian) has been led by scholars indigenous to those communities. The personal interest and direct experience derived from group membership may be significant in motivating, energizing, and guiding identity research efforts.

A third barrier may be ambivalent feelings of group members toward embracing a devalued identity. In written autobiographical accounts and research interviews, persons with disabilities commonly report having absorbed from society and its prime messengers—family, teachers, and health professionals—the sense that their disabled parts are inferior and should be transcended. Drawing from the discussion of negative racial identity in the previous section (Cross, 1991, 1995), this phenomenon can be viewed as a prime example of miseducation paving the way to disability self-hatred. Since most people with disabilities live in families with nondisabled members, they have few of the opportunities for direct intergenerational transmission of positive identity that women and ethnic/racial minority members experience

(Gill, 1994). Consequently, until the past two decades, researchers may have detected little interest among disabled people in issues of identity.

That is no longer true. After two generations of disability rights and independent living activism, many Americans with disabilities have expressed a significant shift in attitude about their group, their place, and who they are in society (Longmore, 2003). A disability historian, Longmore refers to this shift of interest to questions of identity as the "second phase" of the disability rights movement, contrasting it with the political struggle for antidiscrimination laws that marked the "first phase." In some ways this shift parallels the transition from "civil rights" to "Black power" discussed earlier in the section on racial-culture identity.

Growing interest in disability identity is now evident in many forums: autobiographical books and memoirs (e.g., Hockenberry, 1995); disability studies texts (Davis, 2003; Siebers, 2008); online disability discussion groups and advocacy websites; festivals, parades, art exhibits, and performances focusing on disability culture and pride; panels addressing identity at disability studies conferences; and journal articles analyzing the existence, trajectory, form, value, and even risks of disability identity. Furthermore, broader interdisciplinary efforts exploring politicized or minority identity have started to invite work from disability studies scholars, most notably the series of seminars and books generated by the Future of Minority Studies project at Cornell and partner universities across the country.

Most of the scholarship on disability identity, however, is conceptual, with scattered efforts to validate empirically some of this work. Goffman's (1963) classic work on stigma and spoiled identity has been particularly influential and widely cited. Goffman had much to say about the impact of social forces on the self-image of persons with disabilities, particularly the devastating impact of prejudice. Written before the contemporary disability rights movement, however, his analysis reflects little recognition of persons with disabilities as active agents in constructing positive personal identities bolstered by identification with a stigmatized but nonetheless vital and powerful minority group (Anspach, 1979). As an "outside" observer, his work reflects none of the affirmative tone or dynamism of the models offered by Cross (1971), or of Boykin (1986) and colleagues for other socially marginalized groups.

Current Debates Regarding Disability Identity

Along with increased political and intellectual interest in disability identity, challenging critiques have emerged as well. Some disability scholars agree with the general postmodern criticism of minority identity (discussed earlier in relation to Cosmopolitan identity expression) that identity politics is an outmoded and destructive project (Davis, 2003). They argue that collective cultural identity re-inscribes oppression by substantiating arbitrary categories imposed by the dominant culture (Galvin, 2003). This process, they say, imposes a restrictive mythology of common ex-

perience on individuals simply because they share a physical or mental characteristic. Why, they might ask, would a woman professor who has been blind from birth have much in common with a war veteran who has recently sustained a brain injury? They assert that it is essentialist to believe that any biological feature, including skin color or functional impairment, is a valid basis for identity. A related criticism of identity politics is that it holds members of a group hostage to the pain of social injury, a dynamic that seems antithetical to empowerment.

Alongside these general criticisms of group identity is a critique that focuses on disability in particular. Some disability scholars argue that the idea of disability identity establishes impairment as the foundation of one's identity. Thereby, it bolsters the medical model of disability and imposes an arbitrary binary distinction of disabled/nondisabled upon the continuum of human variation (Davis, 2003; Galvin, 2003). This criticism recalls the concern discussed earlier that Black identity validates biological markers such as skin color as a basis for distinguishing human difference. Critics also argue that disability is an unstable category with more permeable boundaries than other minority group parameters. Anyone can become disabled, and one's functional status is highly context dependent. Therefore, they maintain, it makes no sense to view persons with disabilities as sharply distinct from persons without disabilities. Following from the potentially encompassing nature of disability as a category, it is also argued that the disability population is extraordinarily diverse and, therefore, the idea of a common disability identity isolates disability artificially from intersecting identities related to race, gender, sexuality, class, age, and other axes of social significance (Galvin).

In addition to rejecting disability identity as a construct, some scholars criticize any effort to compare or analogize race and disability. They argue that it is inaccurate and disrespectful to impose parallels on phenomena that are different in so many ways, including their history, social dynamics, personal and group experience, forms of violence, and impacts. Additionally, there is a concern that such comparisons may reenact the conflation of race with biological deficiency, a notion that has historically fueled discrimination against African Americans (Baynton, 2001).

An interesting recent development in group identity discourse addresses some of these criticisms of disability identity. It comes from minority studies scholars working in a critical realist framework who engage with postmodern critics to defend the honor of minority identity (Alcoff, Hames-García, Mohanty, & Moya, 2006). They agree that simplistic notions of group identity can be divisive or can tether a person's sense of self to biological markers on one hand or social injury on the other hand. Nonetheless, they assert that unjust treatment predicated on embodied difference is a social reality for many people, whether the "difference" is skin color or atypical body functioning. Arguably, such treatment shapes disabled people's experience in ways that link them, regardless of the nature of their individual impairments, motivating collective forms of resistance.

This realist perspective can be helpful in evaluating and responding to criticisms of disability identity. Although people with disabilities are a heterogeneous collective (and what social minority group is not heterogeneous?), and although disability is an unstable arbitrary category (and what socially defined category is stable?), people categorized as disabled in our society do have resultant experiences in common that potentially connect them. Perhaps it is time to ponder some larger questions, such as: Why must linkages between persons who share stigma be constraining rather than empowering? Why can collective identity not expand to embrace and celebrate heterogeneity rather than downplay it? In other words, in the spirit of Cross's (1991, 1995) Multicultural and Intersectional identities, why can there not be a grown-up version of identity politics? A wise form of identity politics encompasses diversity and cultural intersections as givens and encourages affirmative communitybuilding as well as coalition-building without the constriction and separation that is associated with its earlier forms. For example, Der-Karabetian and Ruiz's (1997) research on Latino identity indicates it is possible to have a strong minority identity while concurrently celebrating one's place in the majority culture. Or as a disability rights teeshirt from the 1980s eloquently proclaimed, "I want it all!"

PART THREE: BLACK IDENTITY THEORY AS INSPIRATION TO **EXPLORE DISABILITY IDENTITY**

Black Identity Theory and Implications for Disability Identity

We seek to demonstrate that Black identity theory may inform ideas and theorybuilding around disability identity; however, it is not our intention to argue for or to present an exhaustive explication of the fit between the two discourses. In concluding this discussion of racial-cultural identity and disability identity, we list some elements of Black identity theory that seem particularly relevant to disability identity development:

1. Black identity as meaning-making: Central to the discourse on Black identity is not physicality per se but the existential encounter with society's categorization of oneself as a member of a stigmatized social group. Independent of stigma, the meaning one may derive from the culture of the group is also of core importance. In parallel, disability identity is first and foremost a discourse driven by meaning-making and interpretation in response not necessarily to one's physical/cognitive difference but to society's categorization of people perceived as different.

- 2. Black identity and patterns of socialization: Black identity theory and ideas about disability identity first crossed paths in the early and late 1970s. Adults and in some cases adolescents narrated the way epiphanies lead to identity conversions or identity resocialization. The stage-model approach sprang from these explorations. Today both communities are concerned with the socialization of youth. Black identity theory is instructive in showing that there are multiple socialization pathways across the life span and patterns of analysis potentially applicable to disability identity.
- 3. Multiple Black identities: Black identity theory embraces the perspective that there is no singular expression of Black Identity. Around the identity-nodes of low, moderate, high, and negative salience are clustered multiple exemplars that help explain the range of meaning-making systems to be found in the Black community. The need to codify identity variability within the disability identity discourse is critical, including the task of deconstructing notions of Assimilation, Passing, Humanism, and Cosmopolitan. A multifaceted identity model that accounts for variability in identity expression is consistent with the ontological and experiential complexity of disability.
- 4. Identity as enactments: The move toward an activity theory approach to Black identity—that is the doing of identity in everyday life—is a major breakthrough. In place of static personality states, traits, and categories, the discourses on Black and disability identity can now stress the enactment or expression of identity in everyday life, as transacted across a range of contexts. The transactional categories of Buffering, Code-switching, Bridging, Bonding, and Individuality may be particularly useful in understanding various strategies of social interaction adopted by disabled persons across varying contexts.

Ideas for Research on Disability Identity Suggested by **Black Identity**

As indicated earlier, systematic research on disability identity is meager and has not flourished in a climate that is skeptical of politicized cultural identity. There have been some studies that attempt to formulate or validate theories of disability identity but few have looked at the intersection of disability and other group identities, including Black identity. Gill, Taylor, Nepveux, Ritchie, & Weeber (2007) are engaged in qualitative research that has begun to explore these intersections. Recurrent themes in the data thus far include the following:

• Disabled persons commonly report experiences of isolation and silence in families regarding disability. Except for instances in which disability has been openly discussed as a negative element in family life, it is rarely addressed at all.

- There is a positive relationship between disability identity and positive contact with disability groups. Possibly, per Cross (1971, 1995), Immersion and Bonding/Attachment are important correlates of a positive disability identity, as they are for Black identity.
- A variety of negative and positive encounters can initiate the development of disability identity. For example, a disturbing encounter with disability discrimination can prod someone toward a disability identity but so can meeting a romantic partner who demonstrates appreciation for the disabled individual "just the way she/he is!"
- It is critically important to most people with disabilities to be recognized as full and complex human beings. They differ in how important they think disability is in shaping who they are. Some worry that any focus on their disability status will prevent others from recognizing their full humanity. Perhaps they are leaning toward a disability version of humanist or cosmopolitan identity expression or are invested in passing or assimilating to the nondisabled world. Others feel that they can never feel fully accepted if they downplay their disability, suggesting a more disability-salient identity analogous to the Afrocentric outcome in Black identity theory (Cross, 1971).
- There is no simple relationship between race and disability. Some people of color with disabilities have prioritized their identification and affiliation with persons who share their cultural/racial heritage and have had little contact with disability groups. They tend to see disability in terms of limitation rather than identity. Race has high salience but disability has low salience in their expressions of identity. Other people of color have had substantial contact with disability groups. They are more likely to identify as disabled and to reference parallels between race and disability. For example, some say that their experiences of race-based oppression have prepared them to understand disability as a social minority experience. Race and disability are both highly salient for them, suggesting intersectional expressions of identity.

Looking at such findings in the context of Cross' racial-cultural identity work is interesting yet challenging. Regarding the developmental issues crucial to Pattern A identity formation, for example, disability, unlike race, may not even factor into an individual's life experience until well into adulthood. A large proportion of individuals have developed stable identities as nondisabled persons before becoming disabled, and the fact of disablement itself, then, constitutes an abrupt encounter event. An interesting research question is, does this new encounter with disability trigger a new Pattern A identity quest befitting a new person with a disability, or does it resemble more a dramatic variant of the Pattern B conversion? Furthermore, after

reaching some form of psychological resolution subsequent to becoming disabled, individuals may experience additional events, both positive and negative, that shake their identity moorings. These events may stimulate them to develop a disability identity or to revise their inaugural effort at incorporating the disability experience into their core identity. Does this process have features in common with the Pattern C recycling process described by Cross and Fhagen-Smith (2001)?

For persons disabled early in life, there are particular barriers to Pattern A development of a disability identity. Family taboos about acknowledging disability may compound the isolation of a child raised in a family where few, if any, individuals have disabilities. Ironically, the isolation may continue through the school years if disabled children are the beneficiaries of progressive school inclusion policies that mainstream them into "regular" education classrooms where there may be no other disabled children. It is understandable, then, that many children with disabilities develop adult identities in which disability has low salience and low positive valence. Research on the disability identity issues of disabled children raised in the mainstream would help illuminate the hazards and opportunities of inclusion. For example, studies of parents' and teachers' communications about disability may uncover some interesting dynamics between identity formation and the messages about disability that surround children as they develop. Another important aspect of development is the nature of reference groups for identification. Do children with disabilities who have opportunities to "hang out" with other children with disabilities develop different identities, or more or less robust identities, than children who are embedded in a largely nondisabled world?

The relationship between salience and positiveness or negativeness of disability in identity certainly calls for further empirical investigation. Does a low-salient but negative disability configuration underlie the identity of the "overcomer" or of the exceptionally assimilated disabled person who pursues membership in the dominant nondisabled culture and avoids contact with disabled peers? Does a highsalient negative disability configuration characterize the disabled person with internalized low self-expectations? Additionally, it would be interesting to know if low-salient disability identities are more likely for some types of impairments. For example, is disability generally less salient for persons with learning disabilities than for wheelchair-users because the impairment of the former group is less immediately apparent during everyday social interactions? Are persons with less apparent impairments more likely to seek assimilation or to attempt "passing" (as nondisabled) than are individuals with obvious impairments? If so, to what effect? Another set of questions concerns the ways in which salience or identity patterns are influenced by historical context. There have been dramatic changes in public life between 1970 and the present. Not only are social systems and values different but the media that deliver cultural messages have changed. For example, how does online communication shape or possibly homogenize individual and group orientation to identity, pushing

toward Humanist and Assimilationist stances? How do such media encourage group identity building by enabling communication among those with similar statuses who previously had more difficulty getting and staying in contact?

Another interesting research question is how assimilation responses of disabled children raised in their primarily nondisabled families compare to assimilation responses in cultural minority children adopted by dominant culture families. In this regard, children with disabilities may be viewed as bicultural or as transcultural "adoptees," bridging the world of disability and the nondisabled world (Gill, 1994). Do disabled children, like transracial adoptees, benefit from exposure to adult peers to instill pride in their differences from their adoptive families and to teach them strategies for addressing their marginalization in the mainstream?

The disability rights and disability pride movements have helped inspire a new breed of parent who views disability in sociopolitical terms (Gill). Such parents are conscious of the social marginalization that their disabled children will confront. They take steps to ensure that their kids form bonds with strong role models with disabilities, engage in disability-positive cultural activities, and learn strategies from disability advocates. There are also persons with disabilities who are raising children with disabilities in a milieu of disability activism and culture (Gill). There is no longitudinal research tracking the development of such "enculturated" children to date. However, it would not be surprising to find that these children end up with a Pattern A identity in which disability is salient and positive. Similarly, persons who acquire disabilities as adults, have contact with strong disability groups, and have had exposure to disability pride and culture activities may be more likely to see disability as an important and valuable aspect of identity. Therefore, they may be more likely to achieve a positive, salient disability identity through Patterns B or C.

In terms of identity transactions in daily life, disability again presents complex scenarios to study. Regarding bridging, for example, many persons with disabilities form relationships with both disabled and nondisabled persons. However, depending on the salience and positiveness of disability in their identity configuration, one or the other type of relationship may be deeper or more desired. An interesting bridging phenomenon unique to many disabled people is their relationship to nondisabled personal assistants, interpreters, and readers. Often these relationships develop a depth and cross-cultural trust that cannot be characterized simply as a service provision. For example, such assistants may be given entree into disability or deaf community activities and may learn the language, culture, and codes of those communities. Regarding bonding, the rapidly expanding disability art and culture movement has been drawing disabled people into connection with other disabled people whom they might have formerly avoided for fear of reinforcing stigma. Through enjoying art and performance by disabled artists, by learning about disability history, and by celebrating disability pride, many persons with disabilities are acknowledging a new sense of belonging and community that they did not expect to

have in their lifetimes. These under-investigated phenomena provide important opportunities for research that can expand our understanding of variations in the identity formation process.

Ideas for Practice Suggested by Links between Disability **Identity and Black Identity**

The discussion of links between the discourses on Black identity and disability identity highlights several points to consider in providing counseling and other services to persons with disabilities:

- 1. Diversity within the group: Although most socially defined "minority" groups are heterogeneous, the complexity of the disability category is underacknowledged in service delivery. Disability status intersects with multiple axes of diversity and marginalization, including race, gender, sexuality, class/caste, and age. Moreover, varieties of impairment—physical, sensory, learning, psychiatric—contribute to disabled people's diversity of experience and perspectives. Disability does not trump all other human differences; neither should it be dismissed as inconsequential.
- 2. Disability affirmative approaches: Part of acknowledging that disability is a social category is realizing that despite its legacy of oppression, disability can be a stimulus of community-building, pride, and culture. Professionals who understand the sociopolitical nature of disability are less apt to convey messages that disability is inherently tragic and limiting. Informed professionals can support clients in seeking information and support from the disability community, in seeking action against injustice, and in discovering the emerging disability culture.
- 3. Developmental variations: It may be helpful for professionals to recognize the developmental aspects of disability identity. Clients will differ in the manner and timeframe by which they integrate disability into their sense of self. For example, an individual disabled since childhood may have little trouble accepting disability (Pattern A acquisition), but may not have had many opportunities to develop a positive identity foundation. In contrast, a person disabled later in life may have developed a strong, elaborated identity but may harbor lifelong stereotypes that suggest disability is antithetical to a positive self (which could foreclose the unfolding of a Pattern B conversion). Another individual might be revisiting identity concerns late in life after encountering a challenge to an achieved disability identity (Pattern C recycling). Exploring where the individual is in the trajectory toward disability identity (and her/his concurrent identities) and not expecting uniformity among clients may help determine the kind of supports that will be most helpful.

- 4. Expressive variations: Similarly, professionals cannot expect all people with disabilities to end up with one particular identity configuration. Variations in the salience and positiveness of one's disability experience may result in a multiplicity of disability identity and alternate expressions across individuals. Furthermore, the shape of disability identity for a particular client may fluctuate across time and contexts as she/he enacts different styles for different situational demands. Again, professionals who are prepared for these variations in identity may be better positioned to support individuals with disabilities who, for example, need to Code-switch and project Assimilationist or Cosmopolitan qualities during a job interview yet may seek Bonding/Attachment to a disability community for affirmation after a grueling week on the job market.
- 5. *In-group representation and power issues*: Acknowledging disability as a sociopolitical category as well as a potential site for identity development urges professionals to increase their awareness of issues of power and representation.

Understanding that people with disabilities report a long history of oppressive treatment in service systems may help professionals respect a client's wariness or pessimism regarding the service relationship. Professionals who convey awareness of this history and of the sociopolitical aspects of disability may seem particularly trustworthy. Such professionals are often better at relating in a way that reduces power inequities between service provider and receiver and signals a genuinely collaborative approach. They convey respect for who the client is as an individual and as a member of a stigmatized group. Whether or not the service provider has a disability may also affect rapport and trust in work with a disabled client. Such issues of group representation matter to many disabled persons just as they often matter to members of other marginalized groups.

CONCLUDING THOUGHTS

The future of disability identity is full of potential. As Black identity theory posits, stigma management can drive group identity and meaning-making. In the case of disability, the need to buffer the pain and material consequences of stigma can precipitate a quest for a strong disability identity. But the very permeability of the disability category and its potential applicability to any human being pushes the agenda beyond individual identity toward a social mission of redefining humanity and acceptable human differences. The idea of a strong, positive disability identity contradicts the judgment of functional limitation as tragic and as "other," leading logically and emotionally to a drive to make the world more universally open.

As universal design and inclusion practices take hold, there is a commonly expressed hope that the full range of human functional variation will be accepted and planned for and that disability will become an obsolete category. The same hope has been expressed with respect to race. However, it is not necessarily the people living under those categories who harbor that hope, nor is it clear that disability oblivion, any more than "color blindness" would be ideal. Some disability activists may prefer a world that respects the value of life with disability, that honors the contributions of the disability culture, and that supports a disability-centric identity. Others with disabilities might hope for a world that accepts them as people first and that encourages a Cosmopolitan identity. Others yet may want it all: a neutral acknowledgement from society that human differences exist, as well as social conditions that support an endless variety of identity outcomes based on individual proclivities rather than restrictive categories. We do not yet have data to confirm the relative benefits of these different identity pathways.

Nonetheless, some young parents and professionals are encouraging children with disabilities to internalize a universal humanistic ideal, hoping, like Black parents who downplay the salience of race (Tatum, 2003), that these children will accept their differences but will view them as fundamentally unimportant. It will be fascinating to see the kinds of identities these children of the universe grow up to have. Will they end up with the strongest sense yet of their own value as disabled people, or will they find themselves ill-equipped to deal with the social and political vicissitudes awaiting them? Time will tell and, hopefully, researchers, service professionals, and activists alike will study and learn from what unfolds.

REFERENCES

- Alcoff, L. M., Hames-García, M., Mohanty, S. P., & Moya, P. M. L. (2006). *Identity politics reconsidered*. New York: Palgrave Macmillan.
- Anspach, R. R. (1979). From stigma to identity politics: Political activism among the physically disabled and former mental patients. *Social Science & Medicine*, 13A, 765–773.
- Appiah, K. A. (2006). Cosmopolitanism. New York: W. W. Norton.
- Baynton, D. (2001). Disability and the justification of inequality in American history. In P. K. Longmore & L. Umansky (Eds.), *The new disability history: American perspectives* (pp. 33–57). New York: New York University Press.
- Boykin, A. W. (1986). The triple quandary and the schooling of Afro-American children. In U. Neisser (Ed.), *The school achievement of minority children* (pp. 57–92). Hillsdale. NJ: Lawrence Erlbaum.
- Cross, W. E., Jr., (1971). The Negro-to-Black conversion experience. Black World, 21, 13-27.
- Cross, W. E., Jr., (1991). Shades of Black. Philadelphia: Temple University Press.
- Cross, W. E., Jr., (1995). The psychology of nigrescence: Revising the Cross model. In J. S. Ponterotto, J. M. Casa, L. A. Suzuki, & C. M. Alexander (Eds.), *Handbook of multicultural counseling* (93–122). Newbury Park, CA: Sage.

Cross, W. E., Jr., & Fhagen-Smith, P. (2001). Patterns of African American identity development: A life span perspective. In C. L. Wijeyesinghe & B. W. Jackson (Eds.), *New perspectives on racial identity development: A theoretical and practical anthology* (pp. 243–270). New York: New York University Press.

Davis, L. J. (2003). Bending over backwards: Disability, dismodernism, and other difficult positions. New York: New York University Press.

Davis, L. J. (2007). Deafness and the riddle of identity. *The Chronicle of Higher Education*, pp. B6–B8. Der-Karabetian, A., & Ruiz, Y. (1997). Affective bicultural and global-human identity scales for Mexican-American adolescents. *Psychological Reports*, *80*, 1027–1039.

Galvin, R. (2003). The paradox of disability culture: The need to combine versus the imperative to let go. *Disability & Society*, 18, 675–690.

Gill, C. J. (1994). A bicultural framework for understanding disability. *Family Psychologist*, 10, 13–16. Gill, C. J., Taylor, R., Nepveux, D., Ritchie, H., & Weeber, J. (2007). *Family life and relationships: Perspectives from adults with disabilities*. Poster session presented at the annual meeting of the Society for Disability Studies, Seattle, WA.

Goffman, E. (1963). Stigma: Notes on the management of spoiled identity. Englewood Cliffs, NJ: Prentice Hall.

Guthrie, R. V. (2003). Even the rat was white: A historical view of psychology (2nd ed.). Boston: Allyn and Bacon.

Hockenberry, J. (1995). Moving violations—War zones, wheelchairs, and declarations of independence—A memoir. New York: Hyperion.

Longmore, P. K. (2003). Why I burned my book and other essays on disability. Philadelphia: Temple University Press.

Marcia, J. E. (1966). Development and validation of ego identity status. *Journal of Personality and Social Psychology*, 3, 551–558.

Parham, T. A. (1989). Cycles of psychological nigrescence. *The Counseling Psychologist*, 17(2), 187–226.

Siebers, T. (2008). Disability theory. Ann Arbor: University of Michigan Press.

Strauss, L. C., & Cross, W. E., Jr. (2005). Transacting Black identity: A two-week daily-diary study. In G. Downey, J. S. Eccles, & C. M. Chatman (Eds.), *Navigating the future: Social identity, coping, and life tasks* (pp. 67–95). New York: Russell Sage.

Tatum, B. D. (2003). Why are all the Black kids sitting together in the cafeteria?: Conversations about race. New York: Basic Books.

Conclusion: How Race, Culture, and Disability Intersect: Pragmatic and Generative Perspectives

Christopher B. Keys, PhD

INTRODUCTION

The editors and contributors to this book consider that human diversity merits attention from scientists, instructors, students, and practitioners in rehabilitation. In this view, scientists develop theory about the nature of the intersections of race, culture, and disability. Researchers study the critical psychological, social, and rehabilitation dimensions in that intersection. Instructors create, implement, and evaluate methods for engaging students in thinking about human diversity. They consider how students' views of race, culture, and disability affect their interactions with members of groups different from themselves and their provision of rehabilitation services to these individuals. Students seek opportunities to study culture and diversity, to reflect on their own cultural roots and its impact on themselves and others, and to learn from and work with those from different backgrounds. Practitioners develop cultural competence (CC) and see serving a multiethnic populace with a variety of disabilities as an opportunity to learn and serve in a profound and humbling way. Our purpose in this book has been to provide a state-of-the-field report of the study and professional practice occurring in the intersection of race, culture, and disability. We have sought to present the theoretical, empirical, and pedagogical perspectives of intellectual leaders in rehabilitation, disability studies, psychology, and related fields concerning this intersection.

We can consider this intersection from at least two perspectives. First, what is the pragmatic value of studying this intersection? What are the practical problems to be identified and solved and the issues to be addressed? What are the actions to be taken? This pragmatic perspective places problem solving at the center, emphasizing problem identification, problem specification, and finding and developing solutions, when feasible, that keep problems solved over time.

Second, we consider a generative perspective that seeks to frame questions of value for exploring this domain of human complexity: What are the key dimensions of the intersection of race, culture, and disability? How are they developed and what influences do they have? What is their heuristic value? This generative stance promotes a breadth of perspectives and understanding and the growth of relevant theory and research. It seeks knowledge from research without explicit benefit in the near term. Taken together, these two approaches complement one another and lead to the development of a body of science at the intersection of race, culture and disability. This research has great potential for enhancing our present understanding, our future research directions and our awareness of actions necessary to address racial disparities among people with disabilities receiving human services.

PROBLEM SOLVING IN THE INTERSECTION: A PRAGMATIC PERSPECTIVE

One useful way to reflect upon the preceding chapters is to consider them from a problem definition, identification, and problem-solving perspective. This pragmatic perspective guided our structuring of this book and seeks to make manifest the utility of our present knowledge, thereby encouraging future action and intellectual exploration in the intersection of race, culture, and disability. The key problems defined, identified, and documented are disparities in services for people with disabilities related to race and/or ethnicity. This is the primary problem identified in this volume and in the race, culture, and disability literature more generally. These disparities primarily are taken to mean that there is less access to services, shorter duration of services, less variety of services available, and less successful service outcomes for members of diverse racial and ethnic groups with disabilities than for members of the dominant White culture with similar disabilities (Chapter 6, Chapters 9 and 10).

Disparities also exist in the development, testing, and use of assessment resources (Chapter 4). Some psychological tests have been normed with samples that include members of some diverse ethnic and racial groups (e.g., African American and Latino). Measures that have been normed on samples that include all multicultural groups are very few to nonexistent. Tests, that are normed on any particular racial or ethnic group so as to better capture the diversity within each cultural group, are also quite rare.

Other factors like socioeconomic class, gender, and cultural practices may enter into consideration of the meaning of these disparities. Often, these factors are related to and result from racism, sexism, and/or ableism that are part of the mainstream

culture. Some argue that these disparities are not solely the result of societal prejudice and discrimination but result from the behavior and qualities of the members of diverse ethnic and racial groups with disabilities. That theoretical possibility may merit further study, although the tendency to blame the victim inappropriately is ever-present in this formulation (Ryan, 1970). In fact, mainstream society has much more economic, social, and political power and cultural influence than do people with disabilities, especially those who are also members of diverse racial and ethnic groups. Therefore, it seems altogether appropriate to consider what the contributions of mainstream society are to the current disparities as a major point of departure.

The disparities members of diverse racial and ethnic groups with disabilities encounter need to be addressed so that they can have more equitable access to, assessment by, and treatment from rehabilitation services. In turn, reducing and eliminating these disparities is expected to lead to more equitable positive treatment outcomes for diverse racial and ethnic group members with disabilities. A key focus for increasing equity is enhancing the CC of service providers. Balcazar, Suarez-Balcazar, Willis, and Alvarado (Chapter 14) insightfully review most of the conceptual frameworks for exploring CC that have been developed in the last four decades. Lewis and Shamburger (Chapter 12) describe an innovative approach to enhance rehabilitation students' CC. Cook, Razzano, and Jonikas (Chapter 7) suggest some valuable content for cultural competency training with professionals and students concerning mental health issues in particular. Matteliano and Stone (Chapter 11), among others, have developed valuable resources on CC teaching concerning many immigrant groups for educators and practitioners. Garcia (Chapter 13) demonstrates that in areas often not considered in thinking about CC such as ethical decision making, culture and diversity are important considerations for those seeking to be fully competent. Kundu, Dutta, and Chan (Chapter 16) illustrate how to incorporate CC into rehabilitation activities such as job placement. Arango, White, Kielhofner, Odoms-Young, and Watkins-Turner (Chapter 17) highlight the development of CC as the main problem-solving message of this book. They emphasize the importance for all individuals, including members of diverse groups, to enhance one's own CC and to continue to do so over time. This enhancement may increase both understanding of other cultures and learning to provide services to members of those cultures. Balcazar et al.'s (Chapter 14) synthesis model of CC indicates the many dimensions of culture that are relevant. We have focused more on culture as defined by race and ethnicity in this book as has much of the scientific literature on culture. As our understanding of the culture increases, it also may lead to greater knowledge and appreciation of both disability culture and the intersection of culture, race, and disability and thus more effective service provision (Chapter 3). Thereby, generative knowledge of culture over time may have pragmatic value for rehabilitation services.

Although noted, less attention is paid in this volume to how to enhance the racial and disability diversity of those providing services, educating future professionals,

and conducting rehabilitation research. Distinct progress has been made during the last generation in recruiting and educating members of diverse racial and ethnic groups and individuals with disabilities to become rehabilitation counselors, educators, and researchers. Having more diverse cohorts of rehabilitation and disability studies professionals helps bring the diversity of our nation and the world into the rehabilitation profession. It makes diversity part of the air we breathe and an issue whose relevance is palpable every day. Without the diverse talent that has developed to date, this book would not have been possible. Having a more diverse professional population in rehabilitation provides models for those who are from diverse groups and have disabilities. It can educate and engage Whites that are experienced in mentoring more diverse talent and in providing other forms of support. Building on the progress to date, the field of rehabilitation has much to do to develop more multicultural talent, especially professionals who both have disabilities and are members of diverse racial and ethnic groups. Benefits realized to date are not permanent and need to be sustained and enhanced.

Another issue of note concerns levels of analyses and operation. Most of the work about solving the problem of disparities has focused on the CC of rehabilitation counselors, other practitioners, and researchers and how to train these individuals. However, problems at larger levels of analysis than the individual or the dyad also contribute to the persistence of disparities in service provision and need to be identified and addressed. Clay, Seekins, and Castillo (Chapter 8) identify larger systemic factors that limit the development of Native American service provision. Smith and Alston (Chapter 9) examine the multiple disadvantages affecting minority women with disabilities. Hasnain and Leung (Chapter 10) consider the limited supports and services available to Asian/Pacific Americans with disabilities in this country. Kundu et al. (Chapter 16) articulate how to build a cultural dimension into services for job placement using a systemic approach. Suarez-Balcazar et al. (Chapter 15) focus on building agencies' evaluation capacity to assess services for members of diverse racial and ethnic groups with disabilities in a culturally competent manner. These efforts broaden our thinking to include program, organizational, community, and larger scale factors as we consider the causes, mechanisms, and solutions of disparities and other issues of diversity that affect individuals, agencies, and tribes.

In brief, this volume, like most theory and research in the nascent area of race, culture, and disability, has emphasized the service disparities between members of different ethnic and racial groups with disabilities. Disability has been a defining feature of those involved and the disparities examined have been those among racial and ethnic groups. Disparities among those with different disabilities from diverse ethnic and racial groups have received little if any attention. In the future, issues to explore include: How are individuals with different disabilities treated within racial and ethnic groups? In the mainstream there is a hierarchy of disability that privileges those with sensory and mobility impairments and disadvantages those with cognitive and emotional disabilities. Does this hierarchy operate in other racial and ethnic groups? What is the impact of having dual statuses of a disability and a racial minority in the United States? What are the organizational and community dimensions of race, culture, and disability and how can we best understand them? How do mainstream societies' norms, policies, and systems affect those with disabilities from diverse racial and ethnic groups constructively and destructively? We know much less about these areas of the intersection and in the future we hope to know more.

KEY DIMENSIONS OF THE INTERSECTION: A GENERATIVE PERSPECTIVE

A second perspective seeks to explore the intersection of race, culture, and disability, which has two crucial dimensions— historical and intersectional. Fujiura and Drazen (Chapter 2) provide a cogent review of much of the work to date and the work to be done. The definitions of race and disability have been linked historically in the early 1900s during the eugenics era (Block-Lourie, Balcazar, & Keys, 2001). Those who were disabled and those who were African American were seen as biologically different and inferior in ways that, at least at that time, justified and allowed sterilization and medical experimentation on them without their knowledge or consent. In recent decades as knowledge of biology has increased, so has awareness of the social component of our views of race and disability. As we unravel the mysteries of the genome in biology, it is equally important to increase our understanding of the social and ecological dimensions of racism and ableism, both separately and together.

In the United States, race is now recognized by many as a social construction that is used to maintain the privileged position of the dominant racial group-Caucasians. Similarly, the social model of disabilities underscores the responses of others and of society to those with physical, sensory, cognitive, and/or psychological impairments as a central aspect of disability (Longmore, 2003). As the social dimensions of race and disability become more widely recognized, our ability to consider them in their societal context with many layers of present and historical meaning increases. The rich meanings of African American identity theory and its implications for the development of disability identity can be explored constructively (Chapter 3). The role of disparities in services as a function of the race and/or ethnicity of people with disabilities garners increased attention (Hill-Briggs et al., this volume; Wilson & Senices, this volume). The contextual factors that agencies and individuals with disabilities from diverse communities face as they seek to obtain and provide rehabilitation services to people of color are considered more fully (Chapter 15).

In short, future research might include social dimensions to the study of race and disability. This will lead to more complete, accurate, and constructive ways of examining the interaction of these terms than were available in past generation. Race and disability are much less likely to be treated as rigid, biological categories that have immutable impacts on intellectual endowment (cf. Herrnstein & Murphy, 1994). Instead, racial and disability differences are now seen as disparities that may reflect shortcomings of the service system rather than of the individuals seeking services. The victims are no longer reflexively blamed (cf. Ryan, 1970). Rather, social perspectives provide a more nuanced understanding of the flexible, contextual dimensions of race, culture, and disability and of the many biological and social similarities that human beings share (cf. Bond, 2007). Notwithstanding the progress we still need to make, because our definitions are less exclusively biological, our understanding of race and disability is more complex and complete. Our intellectual capacity for addressing societal prejudices is enhanced, and our ability to address issues of disparities has grown. This book is a result of and reflects the sea change in American society's perspective on race and disability since World War II.

INTERSECTIONALITY

The intersectional quality of race, culture, and disability speaks to the importance of examining these constructs as they overlap and interact (Chapter 2). Historically, while links did exist between race and disability as targets of discrimination, researchers have generally been more focused on individual categories of difference from the mainstream (Braddock & Parish, 2001). Examining the combination of differences and their meaning did not galvanize scientists' attention or that of many others. Lack of numbers, means of connection, and resources impeded progress. Persons of diverse racial backgrounds with disabilities have not been a primary focus of the disability movement, which has historically been populated largely by middle-class White people with disabilities. Similarly, members of diverse racial and ethnic groups with disabilities have not been a focus of groups coping with racism and promoting positive ethnic and racial identity. These groups have had primarily able-bodied members of a particular race or ethnicity.

During the last decade or so, funding agencies have begun to invest in these intersections of race, gender, sexual orientation, and social class. Researchers have begun to address the complexity of individuals with multiple statuses that differ from that of the dominant White, middle-class, able-bodied, straight male (Chapter 17). Some university scholars in the humanities and the social sciences have thoughtfully examined the intersections in which different racial and ethnic groups participate,

including, for example, not only race and gender but also race and social class (cf. Bond, 2007).

The contributions to this volume indicate that we are making important progress in developing relevant theory, research, pedagogy, and practice concerning the intersection of race, culture, and disability, yet we clearly have more ground to cover. For example, Gill and Cross (Chapter 3) introduce a rich vein of identity theory that has been invaluable in clarifying developmental pathways and the factors that influence them for African Americans and for people with disabilities considered separately. As they suggest, future work will beneficially consider the identity development of members of diverse racial and ethnic groups with disabilities. More generally, race and disability are combined empirically in a number of studies (McMahon, Parnes, Keys, & Viola, 2008; Taylor-Ritzler, Balcazar, Keys, Hayes, & Garate-Serafini, 2001). However, the development of theory to account for similarities and differences between various racial groups with disabilities that clearly explains the reality and impact of living in the intersection, remains to be done. For example, color plays a role in the disability community such that darker skin seems to be associated with poorer service access and rehabilitation outcomes in disparity research (Chapter 5). That is, racism leads to less support for persons of darker skin color with disabilities.

On the other hand, the disability aspects of the intersection have been less explored. How does ableism operate for members of diverse racial and ethnic groups? Once we acknowledge that matters of race and disability have important social dimensions that intersect, then generative research questions regarding both mainstream and diverse cultures quickly arise. How does mainstream society treat people with disabilities who have different accents, skin colors, and backgrounds? What are the manifestations of prejudicial attitudes and discriminatory actions toward those members of diverse racial and ethnic groups with disabilities? How are they in accord with the norms of dominant society?

There is also little theoretical or empirical work that captures the meaning of being exposed to both racism and ableism together and separately over time. How do the cultures of those who are targets of racism and ableism develop, support their members, and help them respond? How do different cultures respond to differences in disability, race, and ethnicity? At the supraindividual level what happens when two different cultures interact, such as African American culture and disability culture? These kinds of cultural issues are central to understanding race, culture, and disability. For example, different cultures, including those of Native Americans, Latinos, Caucasians, or African peoples, respond very differently to strong emotional displays (Chapter 7). These kinds of differences may emerge from generative research. They also underscore the pragmatic importance for American rehabilitation service providers to be familiar with the cultures of immigrants to the

United States (Chapter 10; Chapter 11) and the diverse cultures in this country (Chapter 14).

In the future, Watts (1993) has noted that multiple forms of research will be necessary to examine diversity in its full complexity. For example, to date, research concerning race, culture, and disability has been more comparative of groups and quantitative in method. This approach has been effective in identifying disparities between Whites and other racial and ethnic groups in rehabilitation services. Now, we also need qualitative research to conduct in-depth ethnographic studies of the lives of people who are members of diverse racial and ethnic groups with a variety of disabilities (Chapter 19). These studies can usefully explore race, culture, and disability, and racism, prejudice, and ableism separately and/or together. How do they influence daily lives, personal activities, psychological well-being, and opportunities to participate and be fully engaged in families and communities? We need participants of different cultures and races with a variety of disabilities to give voice to their experiences of living in the intersection of race, culture, and disability. We need to examine the impact of ableism and racism in depth and with the focus yielded by good qualitative interviewing and ethnographic research (cf. Jason et al., 2004). Thereby, we can ground future theory and research more fully in the lived experience of people with disabilities who are members of diverse racial and ethnic groups (cf. Keys, McMahon, Sanchez, London, & Abdul-Adil, 2004).

In closing, as described through the chapters of this book, the authors ask that we make more explicit the role and value of race, culture, and disability not only separately but also jointly at all levels of the rehabilitation process and more generally in society. A challenge for the future is to develop a more complete account of how race, culture, and disability are taken into consideration by rehabilitation service systems and other contexts of importance (Chapter 18). Also, how do intervention programs promote the CC of their staff and student trainees? For these efforts, generative and pragmatic research of many kinds will be needed. Generative research will cast a broad net of intellectual curiosity and will focus our understanding on the concerns affecting people in rehabilitation specifically. Taken together, these perspectives may yield synergies that enable us to both study and act on the findings concerning the intersection of race, culture, and disability. These findings may have both direct benefit and enhance our understanding. It is hoped that they help lead us to a place where, to paraphrase and build on the words of Maya Angelou, we can have the compassion to see through complexion and impairment to our common humanity, the respect to value our differences, and the courage to create a more just society.

REFERENCES

Block-Lourie, P., Balcazar, F., & Keys, C. (2001). From pathology to power: Rethinking race, poverty, and disability. *Journal of Disability Policy Studies*, 12, 18–27.

- Bond, M. (2007). *Workplace chemistry: Promoting diversity through organizational change.* Lebanon, NH: University Press of New England.
- Braddock, D. L., & Parish, S. (2001). An institutional history of disability. In G. L. Albrecht, K. D. Seelman, & M. Bury (Eds), *Handbook of disability studies*. (pp. 11–68) Thousand Oaks, CA: Sage.
- Herrnstein, R., & Murphy, C. (1994). The bell curve: Intelligence and class structure in American life. New York: Free Press.
- Jason, L., Keys, C., Suarez-Balcazar, Y., Taylor, R., Davis, M., Durlak, J., et al. (2004). Participatory community research: Theories and methods in action. Washington, DC: American Psychological Association.
- Keys, C., McMahon, S., Sánchez, B., London, L., & Abdul-Adil, J. (2004). Culturally anchored research: Quandaries, guidelines, and exemplars for community psychology. In L. Jason, C. Keys, Y. Suarez-Balcazar, R. Taylor, M. Davis, J. Durlak, et al. (Eds.), *Participatory community research: Theories and methods in action.* Washington DC: American Psychological Association.
- Longmore, P. K. (2003). Why I burned my book and other essays on disability. (pp. 174–198) Philadelphia: Temple University Press.
- McMahon, S., Parnes, A., Keys, C., & Viola, J. (2008). School belonging among low-income urban youth with disabilities: Testing a theoretical model. *Psychology in the Schools*, 45, 387–401.
- Ryan, W. (1970). Blaming the victim. New York: Vintage.
- Taylor-Ritzler, T., Balcazar, F., Keys, C., Hayes, E., & Garate-Serafini, T. (2001). Promoting attainment of transition related goals among low-income ethnic minority students with disabilities. *Career Development for Exceptional Individuals*, 24, 147–167.
- Watts, R. (1993). Paradigms of diversity. In R. Watts, E. Trickett, & D. Birman (Eds.), *Human Diversity*. (pp. 230–243) San Francisco: Jossey-Bass.

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