Emerging Perspectives on Disability Studies
EMERGING PERSPECTIVES ON DISABILITY STUDIES

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First and foremost we would like to thank all of the contributors who have patiently worked with us over the past few years. The success of a project like this is then contingent upon the willingness of busy, well-published, in-demand senior scholars to contribute, and for busy emerging scholars, many of whom are still finishing degrees and searching for jobs.

We know that it has been a long road, and we are extremely grateful for your willingness to participate in this project.

We are also thankful to our friends and family for their support and understanding as we have moved through this process. We particularly thank Lianne and Lauren, our supportive and wonderful wives. A special thank you also goes to Marlena Warner for her help with editing the chapters, checking references, and just generally putting up with us.
In the summer of 2010, we met to discuss the possibility of developing a book with chapters from senior scholars in disability studies paired with chapters from emerging scholars. We envisioned a diverse book, a book that looked at the various interdisciplinary intersections with disability studies, one that would remind readers of the roots and beginnings of disability studies as a field in inquiry and introduce emerging scholars who build on those strong roots. The original structure of this project was to be one book with chapters from senior scholars and emerging scholars paired together to form discrete, thematic sections, but the number of contributions necessitated breaking this project up into two separate books.

The first book *Foundations of Disability Studies* includes the contributions of senior scholars in disability studies. This second companion volume, *Emerging Perspectives on Disability Studies*, contains the work of emerging scholars who, although relatively new to the field, are producing work that extends our understanding of disability studies and its applications in interdisciplinary contexts. The emerging scholars were gracious, supportive, and vested in the long process of writing and revising the chapters that comprise this volume. We are privileged to have had the opportunity to work with every author, and we know we are introducing a group of scholars whose names will soon be familiar, if they are not already so.

This second book, *Emerging Perspectives on Disability Studies*, was the most fun to work on because we had the opportunity to read over one hundred different submissions from many disparate fields of study that intersect with disability studies. After spending two months spamming various listservs with calls for abstracts, we had a pile of new work to review and consider. Some of the work came in the form of abstract concept papers, other work came in the form of dissertation chapters, and some of the work just defied description; but throughout the process, we felt that we had a front row seat to the latest disability studies scholarship.

Although it was exciting to read all of the submissions there came a point where we had to make some hard decisions about which
chapters would be included, and which chapters we would have to reject. As with our *Foundations of Disability Studies* book, we were guided by the virtue of diversity throughout this process and opted for work that was new, different, and built upon the senior scholars’ work that we had selected. We also strove for diversity in regional, racial, ability, and gender representation…although in the end, the pressures of finishing degrees and starting new careers meant that we lost some of our original contributors. Nevertheless, we feel that the voices we have chosen to include represent an interesting window to the future of disability studies. The emerging scholars in disability studies that contributed to this book include Anjali Forber-Pratt, Steven Aragon, Christopher Riddle, Thomas Jordan, William Southwell-Wright, Lien Claes, Elisabeth De Schauwer, Geert Van Hove, Rodney Hume-Dawson, Sarah Parker Harris, Randall Owen, Robert Gould, Carrie Snow, Rebekah Moras, and Margaret Rose Torrell.

Again, we realize that the scholars who contributed to this project do not represent the entire field of disability studies; we realize that there are other voices, other perspectives, and other issues of equal importance. Our intent was, to the best of our ability, to highlight some of the interdisciplinary scholars who are using disability studies as a framework to understand the world we live in and to build new meanings that include disability as a central component of what it means to be human. We have done our best to honor each scholar’s voice and perspective.

As you read these chapters, you may notice that some of them reference work by the senior scholars who contributed to the first volume of this set, *Foundations of Disability Studies*. As noted earlier, our original intent was to pair senior scholars with emerging scholars in a single text. While still in the development process, we informed the emerging scholars about which senior scholar we were going to pair their work with and several chose to explicitly highlight the connection between their work and the work of the senior scholars. The original pairings were thematic in nature and included new perspectives on disability identity; historical constructions of (dis)ability; the geography and archaeology of disability; the musical and spiritual nature of disability; minority politics, governmentality, and disability rights; neurodiversity and challenges to medicalized constructions of autism; and questions of identity and citizenship and participation in political and sexual economies. Reading both texts side by side may make these pairings evident.
Chapter Overviews

In chapter 1, Forber-Pratt and Aragon theorize that college students with physical disabilities experience stages of managing physical disability: becoming disabled and accepting disability, as well as family and friends accepting the disability; meeting others like them and learning about peers with physical disabilities; adopting the values of the group, including independence, social justice/equality; and becoming a role model for others, becoming one who “gets it.” What it means to “get it” from an insider’s perspective is a thoughtful consideration of what it means to have a physical disability in America today. Today’s college students with disabilities, the first generation to have lived the majority of their lives with the Americans with Disabilities Act (ADA) in effect, have important stories to tell. Forber-Pratt and Aragon propose a model of the trajectory into disability culture for college students with a disability.

Chris Riddle challenges the social model of disability from the perspective of an interactional model in chapter 2. He proposes that without impairment, there can be no experience of disabling barriers. An ontological critique of the social model is that the reality of impairment, such as Down’s syndrome being caused by an extra chromosome, is a brute fact. A social function, such as how society constructs what it means to have Down’s syndrome, must have a brute fact on which to base its conception. Riddle suggests that the problem with the social model of disability is that it ignores the brute facts of impairment, focusing too much attention on social construction. What it means to be “disabled” is the heart of the disability studies; Riddle presents an interactionist perspective that includes both brute facts and social constructions to find a sort of balance in our theoretical understanding of what it means to be disabled.

Thomas Jordan’s chapter in chapter 3 presents an interrogation of exceptionalism in American culture through an analysis of cinema and mass media during the Vietnam era where our very identity as the dominant world power is threatened by minority and extremist groups; America, as a country, isn’t just obsessed with ensuring that our citizenry is standardized, it is also concerned with ensuring that its unique brand of commercial/consumer culture and representative democracy are also recognized as the standard against which all other cultures and systems of governance are measured. America’s colonial obsession with “exporting democracy” and free-market capitalism over the past 60 years was also another attempt at standardizing
world perceptions of normal, healthy, and productive governance
and culture. Whether the export of US culture is through military
means or via cinema, mass media, or our celebrity culture, it is all
the same. America’s superheroes and villains, beauties and beasts
have been exported to the most remote corners of the world, and
are used as benchmarks for setting expectations about appearance
and behaviors and help define good and evil. The problem that arises
with this inordinate focus on proselytizing about our exceptionalism
is that it further reinforces opinions about our political and personal
exceptionalism, which can be a double-edged sword. Tom Jordan’s
chapter looks at how these two forces influence the perception and
treatment of war veterans in the United States. What happens when
a “normal,” healthy representative of the United States goes abroad
to preach the good word of democracy and capitalism at the point
of a gun, is injured, and has to return to a country that continues to
view its citizens with disabilities as second class at best and monsters
at worst? Where did the stereotype of the disabled, homeless, insane
Vietnam veteran come from if not from ourselves? Jordan interro-
gates these intersecting discourses of exceptionality, but the answers
are not easy.

From the very beginning of society, we have used space to com-
municate status and belonging. Whether it is the exclusion of the
physically disabled from the ancient Jewish temple/tabernacle, the
mountain top infanticide practiced in ancient Greece, or the segre-
gation of students with intellectual impairments from the regular
education classroom, the use of space serves as a clear mode to com-
municate one’s place in society. The study of the social geography of
disability continues to silently investigate the nonverbal behaviors
and material spaces that hold the ability hierarchy firmly in place.
In chapter 4, Southwell-Wright extends this tradition of sociospatial
inquiry into the past through his argument that disability studies
is an important theoretical lens for understanding history and spe-
cifically for interpreting archaeological evidence of past societies.
Whereas in chapter 5, Claes, De Schauwer, and Van Hove provide an
application of spatial theory to the contemporary treatment of indi-
viduals with mental illness in Belgium, with a specific focus on how
we use space to reinforce otherness and to regulate identity.

Chapter 6 by Rodney Hume-Dawson considers his own experi-
ence of growing up in Africa with polio and attending crusades in
the hope of healing his physical disability. Using a transformative
learning model, he explores how his perspective on spirituality has
shifted through engagement with disability studies. He presents his analysis of how people with disabilities are sacred and reflect God; he proposes that people with disability are divine and reflect a deeply spiritual nature; meaning that people with disabilities are nuanced, complex, and fundamentally complete human beings—not in spite of disability, but because of it. Rodney Hume-Dawson challenges limited constructions of disability through interrogations into what is means to be spiritual and in so doing challenges dominant discourses about participation and personhood.

Harris, Owen, and Gould provide an astute analysis of liberal welfare states’ (including the United States, United Kingdom, and Australia) paradoxical efforts at shrinking social support while, supposedly, enhancing the independence and employment of individuals with disabilities in chapter 7. The authors caution that the simultaneous push for “welfare to work” schemes, while dismantling systems of social support cannot possibly lead to better employment outcomes. To a certain extent, the dominant voice of free-market capitalism that is driving the dismantling of systems of support for people with disabilities is directly at odds with the desire to see more people with disabilities in the workforce. The free-market drive for efficiency and productivity automatically places people with significant disabilities at a disadvantage in the employment arena. Although the liberal and conservative divide in the United States, United Kingdom, and Australia has grown and led to a kind of political stalemate, Harris, Owen, and Gould sound a rarely heard note of reason and compromise by pointing out that competitive employment policy cannot possibly be successful without attendant “redistributive supports.” Their conclusion is good and right and hearkens back to the spirit of struggle and compromise that made civil rights policy possible in the first place.

In chapter 8, Carrie Snow challenges majoritarian narratives of autism from the Diagnostic and Statistical Manual IV-TR. She presents eight common narratives/discourses about autism and neatly unpacks how each is a medicalized and deficit construction. She then provides two rich case studies of how two young adults in high school with the label “Asperger Syndrome” have capacities/strengths in each of the eight “deficit” areas. Her explication of each narrative, then resounding challenge to each one, is a powerful discourse for educators, families, and young adults working toward a strength-based conceptualization of autism. Snow’s analysis moves our understanding of Asperger Syndrome and related conditions from the
two-dimensional deficit model that seems to prevail in school and diagnostic settings, toward a more holistic three-dimensional conception of what it means to be “neurodiverse.”

At its very core, disability studies is a field that revolves around questions of identity, citizenship, and the basic conception of personhood. In the final two chapters, Moras and Torrell interrogate these categories by asking us to question the fundamentally ableist assumptions about the most basic human rights including participation in the sexual economy. Social markers of privilege (i.e., citizenship, sexuality, and gender) can open doors of opportunity, but on converse, the lack of these markers can sentence a person to a life on the margins of society and even cause those in power to question their very categorization as a “person.” Moras considers sexual self-advocacy for women with intellectual disabilities, bringing together feminist theory and disability studies to consider the sexuality of women with intellectual disabilities in chapter 9. She first considers how intellectual disability and developmental disabilities are defined, and notes that categories of disability can be both useful and limiting, especially within the realm of sexuality. Her analysis indicates that culture has given individuals with disabilities a limited set of rights; meaning that the dominant culture is fine with people with disabilities participating in schools, workplaces, and communities, but continues to have grossly paternalistic, patriarchal, and backward attitudes about the sexuality of women with disabilities.

The book concludes with a companion chapter to Moras’s chapter by Margaret Rose Torrell on disabled masculinities. Whereas Moras’s focus is on attitudes toward the sexuality of women with disabilities, Torrell provides an eminently readable analysis of how society has (mis)constructed the disabled male. Her chapter provides a perspective on how traditional discourses of masculinity have served to marginalize and devalue males with disabilities, casting them as impotent and feminized. She lays the groundwork for further work that interrogates the intersection of gender and disability studies.

As is evident from these chapter summaries, this book represents a diverse, if not disparate, overview of emerging scholarship in the field of disability studies. Nevertheless, like identity, disability studies is a field that is constantly evolving and reinventing itself with the demands of culture, time, and discourse. We feel that these chapters provide some insight into the struggle to understand this constantly shifting identity, and into what it means to be fully human.
Social and psychosocial development for all students is a central goal of higher education. Courses in college student development and student affairs have become core classes across universities for students majoring in higher education leadership, higher education policy studies, and related areas. Such courses are designed to expose program majors to the profile of students attending institutions of higher education including four-year universities and community colleges. Additionally, such courses introduce participants to the theories that help explain how postsecondary students from various backgrounds develop social and psychosocial identities and the potential barriers and challenges they face on college campuses while moving through this process. As Evans, Forney, Guido, Patton, and Renn state, “becoming knowledgeable about student development requires serious study, including critical analysis and evaluation of theory and research” (2010, 2). Armed with this knowledge, daily interactions with students are improved and “program planning and policy development are both enhanced” (Evans et al. 2010, 2).

Over the past decade, courses in student development have emerged to address social and psychosocial identity development in areas including race, ethnicity, acculturation, multiracial, sexual orientation, and gender. Despite being over 30 years post Bogdan and
Biklen’s (1977) “Handicapism” and a recent NCES report (2011) that found students with disabilities comprise approximately 10 percent of all postsecondary enrollments, such courses and related textbooks on student development have, for the most part, excluded disability identity development. To address this gap in the literature, we describe a developmental trajectory model of how individuals gain entry into disability culture and subsequently develop an identity. This model emerged through the views of four college students, with varying physical disabilities, on their perceptions of disability culture and how they came to identify as part of this group. As part of a larger research study, in-depth interviews were conducted to capture interpretations of the core features of disability culture and the trajectory of how one enters into disability culture.

This chapter is both timely and critical as current college students with disabilities represent the first generation to have lived the majority, if not all, of their lifetime with the Americans with Disabilities Act (ADA 1990) law in effect. Therefore, their story is important to capture and tell, as their perceptions may be quite different from those who came before them. Additionally, there is a history of the voice of people with disabilities being silenced in discussions about disability and those without disabilities speaking on behalf of the population.

The stories provide important historical perspectives that inform views on contemporary disability theory. The social model of disability posits that disability exists due to society’s failure to remove social, economic, and environmental barriers, which then alienates people with disabilities and denies them basic civil rights (Barnes and Mercer 2001; Finkelstein 1980; Oliver 1983; Shakespeare and Watson 2002). During the late eighties into the early nineties, people with disabilities formed a collective identity (Masala and Petretto 2008). This collective identity provided a voice for a group, though in recent years, there has been considerable debate about the modern day, post-ADA application of the social model of disability (Albert 2004; Bickenbach 2009).

It is only natural that 20 years after the passing of the ADA that the utility of the social model is called into question and reassessed for its applicability. It is our contention that we must explore and reassess perceptions of disability and how a person with a disability enters into a disability culture, specifically for college students born near or after the ADA. This means it is our duty to capture views of members of physical disability groups (i.e., spinal cord injury, cerebral
palsy, amputees, etc.) to begin to piece together the puzzle of what disability looks like today.

Current Research among Populations with Physical Disabilities

Research on identity and self-authorship focused on the adult population can inform our understanding of the development of a developmental trajectory model of disability identity within the demographic of people with physical disabilities. Across adult populations, several researchers have focused their work on identity and its development in relation to multiple identities and stigmas. Information across these areas helps to further the discussion on identity development within the population of individuals with physical disabilities. The literature specifically on individuals with physical disabilities is somewhat sparse.

Among the first to research disability identity are Arthur Frank and Carol Gill. Frank (1993) describes how the acquisition of a disability leads to a period of critical reflection and eventual change of one’s previous identity to accommodate for the physical and emotional changes that come with acquiring a disability. Gill described disability culture as “certainly, our longstanding social oppression, but also our emerging art and humor, our piecing together of our history, our evolving language and symbols, our remarkably unified worldview, beliefs and values, and our strategies for surviving and thriving... the most compelling evidence of a disability culture is the vitality and universality of these elements” (1995, 17). Charmaz (1995) also notes the identity struggle that chronically ill individuals face because of the threat to one’s core self.

Because disability can occur at any point throughout the lifespan, it is difficult for researchers to agree upon a model of disability identity development. As Charmaz (1994, 1995) pointed out in her longitudinal study of 55 adults with a chronic illness, there is a difference between acquiring a disability if one has already achieved identity synthesis, or at least a well-formed identity, versus acquiring a disability when already grappling with one’s identity development. Though, as is true in the general population, a healthy identity, or in this case disability identity, has benefits. A healthy, intact identity provides a strong sense of self and ability to face ableism by reaffirming desired goals and personal worth (Albrecht and Devlieger 1999; Campbell 2008; Mpofu and Harley 2006; Noonan et al. 2004).
Just as in the nondisabled population, individuals with disabilities often have multiple competing or complementing identities. Research has shown how individuals with disabilities must integrate what it means to be a woman or a man, and develop or redevelop, that identity in congruence with their disabled identity (Asch 2001; Barron 1997; Charmaz 1994, 1995; Najarian 2008; Yoshida 1993). In her autobiography, Jenny Morris (1991) discusses this struggle of developing her identity as a woman with a disability as a member of a society that has predefined roles that women with disabilities ought to adopt. Similarly, in Barron’s (1997) qualitative study, one of the emergent themes from the interviews was described as the dream of womanhood. The interviewees described the struggles to overcoming the stereotyped belief that women with physical disabilities are asexual and cannot become homemakers or mothers.

Notably, Ostrander (2008) examined the intersection of multiple identities—masculinity, disability, and race. Results from this study, interviews with 11 men with spinal cord injury who identified themselves as an ethnic minority as well, revealed that the interaction of disability and ethnic identity was not deemed important, whereas other theoretical studies have presented the argument that the interaction between disability and one’s ethnic identity is important (Alston et al. 1996; Asch 2001; Mpofu and Harley 2006).

Stereotypes and stigmas also impact the identity development of people with disabilities. One such stigma is ableism, or discrimination against people based on physical ability in favor of those without disabilities. Ableism greatly influences identity development. As part of a program evaluation report, Ferreyra (2001) explained the heightened risk that adolescent females with physical disabilities have for developing and maintaining their sense of self because of stigmas and oppression. Several empirical studies related to women with disabilities have concluded that stigma and experiences of oppression jeopardize one’s development of identity (Anderson 2009; Barron 1997; Najarian 2008; Noonan et al. 2004; O’Toole 1979; Wendell 1989). Other empirical studies have reached the same conclusions with a broader definition of disability (Emery 1986; Hayden, Davenport, and Campbell 1979; Onken and Slaten 2000; Ostrander 2008).

To combat the degradation of disability identity development due to stigmas or oppressive experiences, some have included stories of individuals who report the best way to overcome such negative experiences was having a positive role model: someone established in disability culture (Barron 1997; Anderson 2009; Noonan et al. 2004; Weeber 2004).
The Model

In developing this model, we documented experiences from four college students with physical disabilities at the University of Illinois to understand their perceptions on disability culture and how they came to enter and identify with disability culture. The students interviewed for this study were between the ages of 19–24, and have lived the majority of their lives with the ADA in effect. As noted earlier, the disability literature up to this point addressing identity was, for the most part, conducted close to the passing of the ADA or sampled populations of adults who did not reap the benefits of the ADA for the majority of their lives. The University of Illinois was selected based on its rich disability history and culture. While it has a diverse population of students with disabilities, Illinois also promotes interaction between disabled and nondisabled counterparts. The University of Illinois has a deeply rooted disability culture, which made it a rich starting point to capture these experiences and stories. Illinois is home to the Division of Rehabilitation and Educational Services (DRES) known as the first postsecondary disability support service program in the world. This program has led to many disability-related “firsts,” many that have attracted numerous students with disabilities across the world to the University (University of Illinois at Urbana–Champaign Disability Firsts 2008).

To gather information, we interviewed 4 students and conducted 30 hours of observation in settings where persons with disabilities naturally congregate on the campus. The two settings used for observation were a residence hall designed specifically for students with severe physical disabilities and the resource building for students with disabilities. Both locations offer support for students including academic support, recreation opportunities, sport-specific coaching, social experiences, and daily life settings as well as psychological support. The participants interviewed were Adam, Alice, Betty, and Cindy.

After collecting and analyzing these accounts, the information was used to define the core values of disability culture. The three central values were social justice, independence, and giving back to others. Using these as the foundation, further discussion with the students led to the development of how these values came to be and how these individuals learned the ways of the group and assimilated into disability culture. The stories from the students were used to describe a developmental trajectory model of how individuals gain entry into disability culture.
Developmental Trajectory into Disability Culture

The developmental progression that all interviewees described was telling about disability culture. Shown in Figure 1.1 is the trajectory of an individual with a physical disability into disability culture based on conversations with participants. While the following stages are described, it is understood these are fluid. In the center of the circle representing disability culture, there are smaller circles of the subgroups identified by the interviewees as athletes with disabilities, students living at the residence hall for students with severe physical disabilities, those with other disabilities, and one group that straddles the bounds of the circle including personal-care attendants, family, and close friends.

Stage 1: Acceptance Phase

Regardless of whether a person was born with a disability or it was acquired, individuals go through an acceptance phase. Depending on how aware the person is of his or her surroundings and what age he or she was when the disability was acquired, the individual may go through the stages of grief outlined by Kübler-Ross (1969) as well as Kübler-Ross and Kessler (2005), including denial, anger, bargaining, depression, and ultimately acceptance. This happens within the individual first, accepting disability as an individual. For example, one interviewee, Adam, stated, “I never think because of my disability that I can’t do blah blah blah [sic].” This individual has accepted his disability and has made the decision to not let it limit him. Even on the documentation form to utilize disability services at this university, after asking about demographic information, a question reads, “To the best of your knowledge, please describe your disability. Include diagnosis as well as cause and date of onset.” In order to utilize services coming into the university setting, it is assumed that the individual is comfortable describing their diagnosis, their story, and their needs. It is expected they have passed through this developmental milestone.

The developmental progression that all interviewees described was telling about disability culture. Also wrapped up in this stage is the acceptance from family, close friends, and supporters of the person with the disability. Their acceptance is pivotal for individuals with disabilities to be able to succeed and move forward to become a member of disability culture. One interviewee reflected on the
Stage 1: Acceptance Phase
- Become disabled/born with disability
- Person accepts own disability
- Friends & family are accepting of the disability

Stage 2: Relationship Phase
- Person meets others like herself/himself and engages in conversation. Learns about the ways of the group

Stage 3: Adoption Phase
- Adopts the values of the group: independence, social justice/equality

Stage 4: Giving Back to the Community Phase
- Become a role model for others, help those who “don’t get it yet,” give back to community

Figure 1.1 A model of social and psychosocial identity development for postsecondary students with physical disabilities.
acceptance that came from his siblings saying, “It was honestly my sisters and my brother…like I knew I was different but I never viewed myself as being different and so, no one ever really brought it up like ‘oh you’re different’ we just we made it work. It just came natural.” An interesting extension to explore would be to examine how individuals on the periphery, like siblings, also go through a process of becoming a part of disability culture as a subgroup of family members of people with disabilities as shown in figure 1.1.

Stage 2: Relationship Phase

The second stage is meeting other people with disabilities, forming relationships, and learning the ways of the group. This is where and when several themes of what defines disability culture emerge. It starts with the initial meeting of other people with disabilities. Adam said, “There were a lot of people in wheelchairs! I never really hung out with people in wheelchairs [before] so suddenly there were just people in wheelchairs everywhere and it was also like I was expected to hang out with them as well, but at the same time it was kinda like we had this common ground like we were in a wheelchair so that kinda connected us.”

Another interviewee, Betty, stated, “I felt like wow, I remember feeling like wow, we’re like all the same, we’re connected.” All the interviewees described this power of instant connection. In addition, one interviewee expanded on the depth of this connection saying,

I really really felt like it was a family. It was a home away from home…I came here and there was a ready-made community for me. It really was. Partly disability, partly because it’s small…and those two things together. Beckwith was just like here [are] these 21 people you’re going to live with all the time. The people at Beckwith were like my brothers and sisters. They may not know my deepest darkest secrets but I felt very comfortable with them. We could tease each other and be familiar with each other.

There was a power of attraction here that largely came simply by coming to this university where there was an established population of people with disabilities.

The fact that all interviewees and observation participants described this phenomenon is evidence that it was significant.
Stage 3: Adoption Phase

The third stage entails individuals adopting the core values of disability culture: independence and social justice.

Independence

Part of independence meant being able to manage personal hygiene. It is one piece that unites people with disabilities and sets them apart from the nondisabled world, because it allows for conversations to be had that would otherwise be embarrassing with people who are not considered insiders. For example, Betty explained,

> We say stuff in front of each other like, it sucks when you have to pee and your PA [personal-care attendant] isn’t there. We talk about peeing and pooping at the dinner table, we do. I think it’s a hallmark of disability culture in general.

People with disabilities feel there is a mutual level of understanding with these issues, and it is assumed that the other person with a disability will not judge you because you need assistance to use the bathroom, or that you may have an accident, whereas a nondisabled person may. It is a safe community to discuss these issues. This mutual understanding and level of comfort contributes to independence too. Betty noted, “I used to say growing up: ‘When I live by myself blah blah blah [sic],’ but we had no clue what that was going to look like or how to execute that until coming here.” Betty further explains how she learned to become a self-advocate and to learn how to manage what she could of her independence.

Also related to independence was the ability to navigate the world. Alice talked about her dependency on other people with disabilities to learn how to navigate a restaurant with four stairs outside of it. She explained that prior to coming to the university, where she was relatively isolated from other people with disabilities, she had no idea how to tackle that kind of problem, and that she would tend to not go to a place like that because it was inaccessible. She said,

> It’s something that an able-bodied person can never relate to you about because they’re like oh four stairs no big deal, but, that might as well be a mountain if you can’t walk up them. Since being here, though, I learned those little daily frustrations, more so than big major issues, kinda bring people together, and we learn from each other, well I did.
She went on later to describe the process of learning that these places are not off-limits, but by learning to advocate for herself and to request assistance to get inside or watching others climb up the stairs in their wheelchairs that perhaps she could do the same thing. Adam also commented,

I wasn’t a very good person in a wheelchair when I first got here. I got teased because of my lack of life skills but I’m better now! Disability related, I can jump a curb now, I learned how to get gas in my car, you know things like that.

**Social Justice**
Social justice also took on a variety of meanings and interpretations, and was a central theme. For some, this was about understanding the complexities of equal access to education and how as a member of the culture one has a responsibility to continue to pave the way for others. For other individuals, this was more about fair and equal access to opportunities or structural accessibility of buildings.

The emotions surrounding the fight for social justice were telling. In some cases, the fight was a personal quest to seek individual justice and ensure the institution was in compliance with the laws. One interviewee reported, “You’re denying a student with a disability the right to have their own room which is wrong; it goes against university policy for sure, and probably against ADA! Really?? Ugh, it just makes me so mad!” The same individual went on to describe the emotions surrounding this fight and feeling “like I was a second class citizen.” It was a somber moment when the interviewee verbalized that feeling of being second rate. But he described the feeling that gave him the drive and passion to fight the issue even more.

Some respondents were less passionate about the fight. There was one conversation during an observation about a campus building that a student traveled to every day for courses in her major. Although recently remodeled, even the main door was not physically accessible. In this situation, the individual reported a sense of apathy toward the situation. She explained that yes, it was inaccessible, extremely frustrating because she was 100 percent dependent upon someone else being there or accompanying her to the building just to get in the main door, and she recognized it was wrong, but her response was that she tried, on her own, to fix the issue, nothing came of it, and she was graduating soon anyway.
When inquiring about how one fights these battles in the name of social justice, the interviewees described a very individualistic approach to the issue. Both of the individuals in the stories presented above, used an individualistic approach to try to solve the injustice. All respondents described internalizing the issue, coming up with a strategy or approach—sometimes seeking advice from other people with disabilities—but the implementation or execution of the fight was something they took on themselves. One interviewee explained,

I don’t think any of us [people with disabilities] today are looking to stage a revolution or a crusade, we’re not ever going to chain ourselves to the courtyard steps like you hear about back in the day. What those people did before us was very important; it was because of their work that we can be like this today. I can fight the battle if it comes up on my own, I don’t need the power in numbers because most of my environment is accessible now. So, it’s not that these issues aren’t big deals or that there aren’t things to improve on, it’s just different now. It may only be one restaurant that isn’t accessible, so I can just go to a different one.

This individualistic approach to social justice is perhaps characteristic of this particular generation.

The comments shared here reflect a distinction of the society in the past for people with disabilities versus the society today. The acknowledgment of the previous battles and the contributions made also speaks of Gill’s (1995) definition of disability culture, specifically the shared experiences of oppression mentioned earlier. Though not explicitly stated by this particular interviewee, the comment about just choosing a different restaurant introduces an element of adaptability and desensitization to inaccessible places because so much is taken for granted. During an observation, one individual explained that, “it’s the disability dream world here. And that is good and bad, it makes it a heck of a lot harder to leave, that’s for sure.”

Because this particular university setting is known as one of the world’s most disability friendly campuses, it is not surprising that there were not many social justice fights reported by students here. Individuals with various disabilities deal with inequalities differently, such as avoiding inaccessible restaurants. Though the theme of social justice continues to exist even at a university considered to be the highest quality in its accommodations for people with disabilities as was mentioned above from Adam’s story about feeling like a second-class citizen because of having to fight for an accessible dormitory room.
and additionally from Cindy who had to fight in order to participate in study abroad.

**Stage 4: Giving Back to the Community Phase**

The fourth stage moves beyond the individual concerns of independence and social justice, and entails becoming a role model for others which helps those who are still learning the ways of the group and, in turn, giving back to the community. This stage parallels Gill’s (1997) disability identity integration phase of coming out where the individual synthesizes how they feel with how they present themselves. One participant stated, “As students and young adults with disabilities, I think we kinda need to be a role model and to take a stand.” Embracing this as a civic duty to help other people who may not quite get it yet, and to reach out especially to young children with disabilities and be a positive role model for them gave individuals a sense of pride. During an observation when discussing speaking to younger kids with disabilities about college life, one person commented, “It’s important to do this outreach, to show other’s what is possible.” To us, this stage is truly about identity synthesis and embracing one’s disability.

**Getting It vs. Don’t Get It Yet**

What we found in this study is that within disability culture there is a subgroup of people who “get it” and people who “don’t get it yet.” This distinction is vitally important to one’s status within disability culture. The people who “don’t get it yet” are on the brink of being called outcasts. They are the people who everybody with disabilities reaches out to try to help and to teach them the ways of the group, but there comes a point when it is up to the person to make the decision to change and become accepting of their disability and disability culture or not. This concept is central to the developmental progression that emerged during this study of what it takes to become an accepted member in this disability culture.

“Doesn’t get it yet” is an emic concept that is synonymous with “still in the dark” that members of the disabled community at the University of Illinois use to describe individuals who have not yet come to terms with their disability. Within this context, “doesn’t get it yet” means that the individual is still in denial or angry about their disability and is having a pity party and believes their life is over. Characteristics of a person who “doesn’t get it yet” are that the individual struggles with independence including personal hygiene issues, and perhaps is lacking in the knowledge or appreciation of equipment.
that can be enabling for their independence. For individuals who grew up with their disability, this term was described as representing individuals who had been sheltered from other people with disabilities and perhaps their parents had babied them, therefore they are unable to do daily activities on their own, thus they “don’t get it yet.” Interestingly, an in-group member can easily point out a person who doesn’t get it yet based solely on the type of equipment they are using, if they have a poor fit in their wheelchair, power or manual based on their perceived function—meaning, if they have high back support and push handles when they are fully capable of sitting on their own and pushing themselves, they are labeled right off the bat as one who “doesn’t get it yet.” The concept of “doesn’t get it yet” emerged during the observations. It would come up when individuals were discussing a potential student, a newly injured individual or an incoming transfer student. Two examples are provided below.

1. **Researcher Field Note Excerpt:**

   “Doesn’t get it” means that the individual is perhaps hateful towards other people with disabilities. There is a sense of resentment there because they do not want to associate with them, by ignoring them it means they are not really like them and that they can still get out of this world of disability. Individuals who “get it” are the ones who are leading successful lives—they hold a job as opposed to living off of SSI income, they do something meaningful and constructive with their lives either by obtaining an education or through athletics or through community outreach or whatever. The individuals who “get it” are also the ones who carry the responsibility of reaching out to those who “don’t get it yet” to assist them—to show them the ropes, to reassure them that it’s okay to be frustrated about your disability at times, to laugh when certain mishaps happen and to make the most of it.

2. **Observation:** One individual was asked to reach out to a family of a young kid who was recently injured. The conversation followed like this:

   “XXX is currently still in rehab having only been injured about a month ago. XXX thought his future was set—to go to college to play football and wrestling on full scholarship. Then, disaster struck and his life as he once knew it was over. The family is still grieving this loss and struggling...
Anjali J. Forber-Pratt and Steven R. Aragon

with coming to terms with the disability. Would you [current wheelchair athletics coach] call this kid up?”

“Well you know, they just don’t get it yet, it’s all too new.”

“This is exactly what he needs right now though, is just to know that you’re out here and that there are people with disabilities who don’t piss on themselves and who are athletes and who have jobs.”

“Are they ready to hear from me?”

“The family seems ready, they are already laughing about stories. I think they are ready to ‘get it.’”

“So, they seem willing to learn. Okay.”

“Look, they need to meet people to move on to that next step.”

“What’s their number?”

The underlying assumption is that until one “gets it” they are not considered a true member of disability culture, they are in a pool of likely members, but until they fully assimilate they are more like a lurker from the outside looking in. It takes the community of the insiders to help that outsider to learn how to “get it” if they are newly injured or to pull them away from their parents and assimilate them into the culture.

However, there also are certain individuals who “don’t get it,” period. That is, the community has tried to help this person out and there is little hope for that individual; they may just continue to lead a life of learned helplessness and are viewed as an outcast by the disabled culture. These are the individuals who are also labeled as, “not doing anything for the cause.” This means that they are perpetuating negative stereotypes, such as needing help with all of their daily living skills even if they are physically able to do so, or relying on others to do everything for them—like calling to make appointments or ordering food. We suggest that a person who “doesn’t get it yet” is in need of being taught otherwise, they need to be educated by the group and taken under their wing and shown the ropes. The “yet” infers that there is hope for these individuals, but once an individual moves over to the label of that individual “doesn’t get it” period, then there is doubt that the person can ever learn because of their history of being closed off to the disabled community.

Implications and Applications

This developmental trajectory begins to describe the path that individuals with disabilities go through to become accepted members of
disability culture. Based on the stories told, individuals with disabili-
ties come in contact with others like them by coming to this univer-
sity. But for many, it was the first time they thought about actually
being a part of a larger culture and took the time to reflect on what
that means. Care was taken to gain perspectives from a variety of
students with physical disabilities. Even though boundaries were
described and depicted in the model, such as between athletes and
nonathletes, at the heart of the stories captured, similarities could
be seen. The diversity of the stories—both young men and women,
across different physical disability groups, who had acquired disabili-
ties at different points in time helped to frame the proposed trajec-
tory. Results clearly indicate commonalities of shared values and how
one gains entry and acceptance by others in the culture exist across
physical disability groups.

For Policymakers

Policymakers, particularly connected to institutions of higher edu-
cation, are facing difficult challenges in today’s economy. They are
faced with financial struggles and the need to attract, retain, and
graduate students. Policymakers are required to prove they are
meeting the needs of diverse students of color, gender, sexual orien-
tation, and disability. Even though, disability is often overlooked in
these conversations, it is of the utmost importance that policymak-
ers consider the needs of students with disabilities. In order for these
particular students to graduate, their needs must be met. In order to
meet these student needs, they need to be aware of what they are.
This is why policymakers ought to consider the trajectory and stages
presented here.

It is our recommendation that university and college policymakers
revisit existing policies and any new policies that are being developed
or implemented to ensure that they are inclusive. We encourage poli-
cymakers to ask whether their policies contain language, provisions,
and guidelines that support the full integration of all students includ-
ing those with disabilities into academics and campus life. Policies at
a university or college setting may be aimed specifically to facilitate
diversity, or may be related to academic procedures, resident hall life,
parking, communications, or student work. Ideally, if the policy is in
fact inclusive, when implemented as intended, it helps to promote
a campus culture where no students are excluded, marginalized,
treated unfairly, or prevented from accessing any resources, respon-
sibilities, or benefits of being a university or college student.
For Campus Culture

As mentioned earlier, inclusive policies help to create an inclusive culture and one that promotes college student development and identity exploration. Campus communities are constantly developing programming and awareness programs about different cultures and subgroups of students to help make students feel welcomed and to foster their development not just as scholars but as young adults. Adopting inclusive practices in the day-to-day operations of the campus community including how students interact with each other and with instructors and administrators. It is well accepted that students entering higher education have to learn to manage the complexities of their relationships among their peers and their social environments. Students with disabilities are no different from students with other differences, perhaps due to race, sexual orientation, gender, socio-economic status, and so on.

Social ecological theory, described by Bronfenbrenner (1979), depicts the dynamic between individuals, their social environments, and the mutual influence one has on the other. It organizes and explains these relationships at various levels (i.e., microsystem, mesosystem, and macrosystem). This theory has helped scholars to better understand the big picture of the phenomena of identity development and engagement in school (Benner, Graham, and Mistry 2008).

For Service Providers

For some individuals, enrolling in college is the first time they have encountered other individuals like them, and they are processing this piece of their identity. To us, it is no different from providing support to students who are at risk of dropping out, such as first-generation college students. This is not to say that all students with disabilities are at risk. Rather, it is to provide service providers in higher education settings with an awareness that across the disability spectrum individuals will likely be at different points in their needs of support. To understand the trajectory from an identity and developmental perspective means that a disability service provider or an academic advisor may be able to provide better support and sympathy (or perhaps empathy) based on their stages. Depending on where an individual is at in this development process, these may be confounding variables to a student’s academic success, if, for example, they are enjoying learning the ways of the group and finally feeling like they are a part of a larger community, perhaps their schoolwork slips.
Additionally, when disability service providers do a routine intake form and ask about the level of support a student with a disability may need, it is important for them to be aware that the student may never have thought about that. It is possible due to the nature or occurrence of his/her injury or due to exceptional support from home or public school setting that the student him/herself is unaware of their true needs—accommodation or equipment related. Therefore, keeping this trajectory in mind will help service providers to meet the needs of students with disabilities. Worth noting, the setting used for this particular study is an anomaly in that there are large numbers of students with disabilities at this university. This particular campus setting, for example, has dedicated disability service providers—one specifically for students who are deaf or blind, one for students with physical disabilities, one for students with learning disabilities, and one for students with psychological needs. In this situation, these disability service providers have a heightened awareness of the complex identity issues and struggles students with disabilities face as they begin to identify with this larger culture, though, in other university or college settings without a large disabled community, the service provider may be a general student affairs person or somebody without this much intimate knowledge of disability.

For the Community of People with Disabilities

For many of the same reasons mentioned above, this trajectory has important implications for the greater community of people with disabilities. While students with disabilities are not necessarily as worried about the same issues that policymakers are, they are the ones facing the day-to-day issues including the stark statistics of low expectations by others, low retention rates, low employment rates, and low levels of education attained on the basis of his or her disability. With the emic concept of “getting it” versus “doesn't get it yet,” there is an underlying expectation that people who do identify with the disability culture will help those looking to become comfortable with their identity and feel like a welcomed part of the group. In order for people with disabilities to do that, however, some knowledge of the process may be beneficial. We also believe that much of this may be intuitive for people with disabilities who do “get it” as they were the ones that described this process as if it was common knowledge.

For college students with disabilities, it is important for them to know that they are not alone. It is helpful to see this trajectory as a
process. Particularly for those students with disabilities at institutions of higher education without a strong disabled community to realize that there is a broader disabled culture out there, should he/she choose to want to explore it more. It is no different from adoptees who often rediscover or explore their roots when they are ready to return to their place of heritage; when the time is right, individuals with disabilities may want to reach out to this community. Anecdotally, this also is an emerging trend with individuals who receive cochlear implants at early ages who are then “finding” the Deaf community later in life as they go through these developmental stages outlined in this trajectory. It is believed there are some parallels to what is presented here with the development of one’s Deaf identity, based on the interviews. However, due to the rich history and language of Deaf culture, this issue would warrant significant further study before such conclusions could be drawn. Davis (1995, 2002, 2007) challenges the notion of Deaf culture as a cultural/linguistic minority group, and suggests that the Deaf community could be a new model for how we think about ethnicity/cultural identity. Therefore, there could be some application from what is presented here, but again a more in-depth study focused on this population would be required.

One of the researchers who does self-identify with having a disability, also feels that this knowledge is exceptionally important for the people on the cusp of disability culture—the close friends, family members, or perhaps disability-specific service providers in the community or sport setting, outside of academia—who may interact with newly injured individuals specifically servicemen and women. Oftentimes, these individuals are quickly provided for in terms of equipment needs and opportunities to reintegrate into civilian society, but the psychological process of accepting one’s disability is forgotten.

Summary

In this chapter, we have presented a model of social identity development applicable to individuals with disabilities in postsecondary settings. We argue that the current field of postsecondary student development needs theories that help us to better understand the process of social identity development for persons with disabilities, just as there are theories to help us understand other groups of diverse students. Additionally, seminal works in the field of disability studies need updating to include the current voice of college students with
various physical disabilities who have lived the majority of their lives covered by the ADA.

While we do not believe that this model explains the social identity development of all students with disabilities on college campuses, we do believe the model creates awareness of potential stages of development and opens the door for policy conversations and more research around this phenomenon. There are numerous areas of further research and more conversations to bring into the discussion—such as students with learning disabilities, visual impairments, and/or psychological or emotional disabilities; this preliminary model presented in this chapter serves as a starting point.

Note

1. Within this article, we follow the convention of using the capitalized “Deaf” when aspects of the cultural and linguistic minority status of individuals are noteworthy. Whereas, we employ the lowercase “deaf” when there is no particular intent to highlight cultural or linguistic status.

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