

DePaul University Digital Commons@DePaul

College of Education Theses and Dissertations

College of Education

Fall 11-23-2021

Applying the Social Model of Disability: A Phenomenology of Initiating Change in Higher Education

Olena M. Marshall DePaul University

Follow this and additional works at: https://via.library.depaul.edu/soe_etd

Part of the Higher Education Administration Commons

Recommended Citation

Marshall, Olena M., "Applying the Social Model of Disability: A Phenomenology of Initiating Change in Higher Education" (2021). *College of Education Theses and Dissertations*. 225. https://via.library.depaul.edu/soe_etd/225

This Dissertation is brought to you for free and open access by the College of Education at Digital Commons@DePaul. It has been accepted for inclusion in College of Education Theses and Dissertations by an authorized administrator of Digital Commons@DePaul. For more information, please contact digitalservices@depaul.edu.

DePaul University

College of Education

Applying the Social Model of Disability:

A Phenomenology of Initiating Change in Higher Education

A Dissertation in Education with a Concentration in Educational Leadership

by

Olena M. Marshall

© 2021 Olena M. Marshall

Submitted in Partial Fulfillment of the Requirements for the Degree of

Doctor of Philosophy

November 2021

Signatory Page

We approve the dissertation of Olena M. Marshall.

Andrea Kapre

October 27, 2021

Associate Professor and Director, Educational Leadership Department of Leadership, Language, and Curriculum College of Education DePaul University Chair of Committee

Sally Julian

November 3, 2021

Associate Dean for Development College of Education DePaul University

Donne Lil

November 2, 2021

Instructional Assistant Professor Department of Leadership, Language, and Curriculum College of Education DePaul University

Certification of Authorship

I certify that I am the sole author of this dissertation. Any assistance received in the preparation of this dissertation has been acknowledged and disclosed within it. Any sources utilized, including the use of data, ideas and words, those quoted directly or paraphrased, have been cited. I certify that I have prepared this dissertation according program guidelines, as directed.

Author Signature: Muy le Marshuk Date: November 5, 2021

Abstract

In the past decades, disability service professionals in higher education began adopting the social model of disability as a theoretical and practical framework for creating more inclusive campus environments for students with disabilities who attend colleges and universities in growing numbers. Specifically, in the early 2000s, an international organization of disability service professionals, the Association on Higher Education and Disability, took on a strategic effort to shift the paradigm of disability services toward systematically removing barriers to full participation and transforming disabling environments—away from the prevalent modes of service focusing on the medical model, legal and regulatory compliance, and ad hoc accommodations, which many disability service professionals, scholars, and advocates have come to see as insufficient from the social justice perspective. Using the methodology of qualitative research in the interpretative tradition, this dissertation adds to the literature on the transition to the social model of disability by examining the social phenomenon of leading change as a lived experience of disability service professionals. A phenomenology based on the in-depth interviews with seven participants selected through purposeful sampling, this dissertation, first, offers rich descriptions of the factors that compelled participants to align themselves with the social model of disability and to initiate the efforts to put these ideas into practice, as they found this model to (a) be consistent with their personal and professional values; and (b) offer better solutions for serving students, resulting in greater professional satisfaction and meaning for participants themselves. This analysis also brings to the surface two especially salient themes in the narratives of change: (a) the gradual, iterative, reflective process of changing the followers' frames of disability services; and (b) the

iv

importance, for the leaders, to master the social model of disability and become skillful at articulating the social model of disability ideas when influencing the followers. Implications for transformational leadership in facilitating the paradigm shift are discussed.

Table	of	Contents

List of Tables	ix
List of Figures	x
Acknowledgements	xi
Epigraph	xiii
Introduction	1
Review of Existing Literature	5
Introduction	5
The Context of the Social Model of Disability	6
Relevant Critiques of the Social Model of Disability	
Association between the Social Model and Universal Design	
Literature on Transitioning to the Social Model in Higher Education	19
The Concept of Paradigm Shift	22
Conclusion	26
Conceptual Framework and Methodology	27
Introduction and Research Questions	27
Qualitative Research Methods	
Sampling Approach and Participant Recruitment	
Data Analyses	
Limitations	
Presentation and Analysis of Data	

Introduction	
The Vanguard Participants	
The Second Wave Participants	
Dispositions and Professional Journeys	43
Encountering the Social Model of Disability: The Vanguard Participants	52
The Role of Project ShIFT in Vanguard Participants' Histories	
The Vanguard Participants' Individual Trajectories	60
Encountering the Social Model: The Second Wave Participants	67
Aligning with the Social Model: A Summary	75
Liberation from the Habitual Perspectives on Disability Work	77
Leading Change: Diffusing the Social Model of Disability	81
Addressing Pro-Innovation Bias	
A Transformational Leadership Perspective on Diffusion of Innovation	
Prominent Transformational Leadership Themes	
Theme 1. Changing the Followers' Frames	
Theme 2. Striving for High Degree of Competence to Advance Reframing	
Conclusion	116
Bibliography	121
Appendix A. Approved Institutional Review Board Application	129
Appendix B. Information Sheet for Participants	131
Appendix C. In-depth Qualitative Interview Guide	133
Appendix D. Script For Contacting Potential Participants	135

Appendix E. Script for Contacting Participants Indicating Interest	136
Appendix F. Reminder for Participants who Agreed to Participate	137
Appendix G. AHEAD Announcement	138

List of Tables

Table 1. Examples of Disability Frameworks/Models/Theories Cited in Literature and	
Referenced in Participant Narratives	.10
Table 2. Main Elements of the Accommodation Approach and the Universal Design	
Approach	.16
Table 3. Demographic Characteristics of Study Participants	.36
Table 4. Vanguard Participants' Involvement in AHEAD Universal Design Strategy and	
Project ShIFT	59
Table 5. Examples of Transformational Leadership Dimensions in Participant	
Narratives	.92

List of Figures

Figure 1.	History of AHEAD's	Venture into Univer	sal Design	54
inguie ii	motory of minimize 5		bui Designinini	

Acknowledgements

I am grateful for the invaluable encouragement, guidance, and assistance I received in writing this dissertation.

First, I would like to thank the members of my dissertation committee Andrea Kayne, JD; Sally Julian, PhD; and Donna Kiel, EdD, of DePaul University's College of Education. They brought to the dissertation development process a rare talent for intellectual critique that was formative and enriching in my approach to the research topic *and* respected my ideas, independence, and creativity as an emerging scholar.

DePaul University, too, deserves credit for introducing me to the issues facing students with disabilities in higher education (the focus of this dissertation), because that is where I met Lynn Fuentes, JD, PhD, a disability scholar and advocate, who, in launching the Chronic Illness Initiative at DePaul University in 2003, led the charge to make students' lives better.

This project is indebted to the research participants who had the generosity and grace to share their professional journeys through in-depth interviews. Their gift of time and insights was made all the more precious by the onset of the global COVID-19 pandemic that overlapped with the interviews and unsettled all of our lives.

To Sally S. Scott, PhD, Director of Research at the Association on Higher Education and Disability (AHEAD), and to Nancy Chinn, EdD, Chair of the AHEAD Research Review Panel, I am thankful for their involvement with my research and the opportunity I was given to reach the AHEAD audience.

xi

My children Max and Laura, themselves high school and college students throughout my research and writing process, listened, read bits and pieces, and asked questions, making space for the dissertation in our family life and adding to the sense that my work mattered.

Finally, to all my friends and editors who showed no doubt in the imminent success of this endeavor even when I doubted myself—my heartfelt thank you.

Epigraph

...we must learn to love difference, to see it as a treasure and not as a threat. Community means the respect and love of difference. Then we discover that this body which is community is the place of communion.

—Jean Vanier, From Brokenness to Community

Applying the Social Model of Disability: A Phenomenology of Initiating Change in Higher Education

Introduction

The higher education system in the United States remains dominated by legal and medical frameworks in serving students with disabilities, despite the existence of alternative theoretical and applied models, some well-established and some emerging. Together, the alternative models call attention to the drawbacks of the medical and legal frameworks of disability and argue for more inclusive, comprehensive, and sustainable approaches to how colleges and universities may serve students with disabilities—in ways that have the potential to create system-wide benefits for all students. In this latter context, disability becomes another aspect of human diversity, rather than a deficiency that is to be remedied, rehabilitated, and overcome with targeted, often legally mandated accommodations traditionally facilitated by the university offices of disability services.

In the past decades some United States colleges and universities have taken visible, practical steps, in the absence of government mandates, to implement the social model of disability and the universal design practices, considered an essential tool for transitioning the institutions to the social model (see, for example, Hamraie (2017)). The Association on Higher Education and Disability (AHEAD), an international organization for disability service professionals, has been especially active since the early 2000s in leading this change in higher education on a national level. A few scholarly articles have inquired into how individuals introduce changes that are grounded in the social model of disability and principles of universal design within higher education institutions; overall, this transition

remains under-theorized and under-examined empirically in scholarship, offering little guidance with respect to the prevalence and characteristics of this phenomenon in the field. Overall, the social phenomenon of this change is not well understood, yet is critical to examine in order to help reform-minded faculty, staff, and senior administrators to initiate a wider adoption of models and methods that they consider essential to greater inclusion of students with disabilities.

In this context, a qualitative study was carried out with an intent to develop a phenomenology of how staff and faculty at four-year colleges and universities initiate the transition to the social model of disability services and universal design. Aiming to produce a phenomenology of this social phenomenon and situated in the symbolic interactionism and constructivist frames, the study set out to describe the process and meaning of this transition to the social model of disability from the point of view of those who lead, initiate, and undertake the change in higher education settings.

The author's participant recruitment efforts resulted in conducting and analyzing seven in-depth interviews with disability staff members. Three of the participants (collectively labeled in this study as "the vanguard participants") were among the first adopters of the social model reforms with a focus on higher education and were directly influenced by the leaders of the national movement within the AHEAD organization and by the concerted efforts of AHEAD to change how students with disabilities were served. Central to these AHEAD-linked efforts was the idea that the offices of disabilities themselves had to transition to the social model-informed ways of thinking and acting in order to convincingly model broader campus reforms, including changing the academic faculty domain. The vanguard participants brought the mindset of the "movement" and

"journey" to this long-term work, as well as the ongoing expectation of honing their own leadership and mastery of the social model and active reflection on lessons learned both from successes and mistakes. The other four participants (collectively labeled in this study as "second wave participants"), represented a later entry in the reform efforts. All participants grappled with overcoming entrenched attitudes and adopting new ways to create inclusive educational environments for students, both through broad systemic efforts and more granular efforts of changing one mindset, one process, one obstacle in the way of student success at a time. The process of gathering and analyzing the rich qualitative data in the context of existing literature brought the author to apply the diffusion of innovation theory and the transformational leadership theory to participant accounts, recognizing the explanatory power of these theories, when combined, to produce insights into the leadership traits/behaviors that may advance the social model-informed reforms in colleges and universities. It is anticipated that this initial phenomenological work can inform further research to create a grounded theory of adopting the social model of disability and generate actionable insights for creating inclusive campuses.

Following the review of existing literature and conceptual framework and methodology, this dissertation is organized to present experience of introducing the social model from the point of view of the participants. The study follows the participants' narratives as they discovered how the precepts of the social model aligned with their personal dispositions toward social justice and with their sense of right and wrong; and took an active stance (as leaders, managers, professionals, and private thinkers) toward correcting the compliance, legal, and medical model mindsets that they found to disadvantage the people they served.

The key limitations of the study consist in the small number of participants who self-selected to be in the study and only represented the disability services staff points of view, although faculty participation was initially expected. Nonetheless, the information generated by the study provides rich grounds for identifying several themes that can help inform further research and spur ideas for leadership formation for facilitating such reforms.

Review of Existing Literature

Introduction

Given the focus of this phenomenology on understanding how staff and faculty at four-year colleges and universities initiate the transition to the social model of disability services in order to create inclusive, barrier-free environments for students with disabilities, it is helpful to first understand:

- 1. What the existing literature tells us on the topic of the social model itself, including its history, and perceived strengths and weaknesses;
- 2. How colleges and universities and the AHEAD organization attempted to facilitate the transition to the social model, as captured in existing literature and what (limited) perspectives this literature offers on the experience of those professionals who set out to facilitate the change in the philosophy, organization, and practice of disability services in higher education; and
- 3. How the scale and importance of this transition to the social model—that this study's participants framed as a "movement," "paradigm shift," or, to Mole (2013), "a quiet revolution"—connect to the broader literature on paradigm shift, including in the organizational change contexts).

Given the early application of the social model in practice, especially when the vanguard participants in this study were working actively to gain a foothold within disability offices and the broader college and university context, a brief excursion into literature on innovation and early adopters is also warranted. This literature is briefly reviewed in the Presentation and Analysis of Data, to offer context for related findings.

The Context of the Social Model of Disability

The provision of services and individual accommodations to students with disabilities in colleges and universities has been governed in large part by the passage of federal legislation. "Under the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973 (Section 504), institutions of higher education are prohibited from discriminating against individuals with disabilities. This prohibition imposes on colleges, universities, and professional schools an obligation to provide disabled students with reasonable accommodations to ensure that the institution's requirements do not discriminate on the basis of such student's disabilities, as long as the student meets his or her burden of proving the requisite requirements of an ADA or Section 504 claim" (Denbo, 2003, pp. 145–146). The laws have expanded protections and access to education for individuals defined as "'disabled' under the ADA if he or she has '(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such impairment; or (C) [is] regarded as having such an impairment" (Denbo, 2003, pp. 149–150). As synthesized by Ju, Zeng, and Landmark (2017), "Legislative mandates require accessibility to postsecondary education for students with disabilities. Specifically, the reauthorized Individuals With Disabilities Education Improvement Act (IDEIA) of 2004 requires that schools prepare students with disabilities for 'further education.' Provisions in the Higher Education Opportunities Act of 2008 (PL 110-3145) further expanded postsecondary education opportunities for students with disabilities by developing and improving postsecondary programs and extending federal financial aid opportunities for students with disabilities to attend postsecondary institutions (Council for Exceptional Children, 2008)." Moreover, case law clarified the

scope of applications of this legislation in practice. Critically, students in the U.S. colleges and universities have to proactively seek accommodations as "courts have generally ruled that, unless an institution has knowledge of a student's disability, there is not duty to accommodate" (Kaplin & Lee, 2014, p. 522).

Despite the growth of postsecondary enrollment of students with disabilities and despite a range of accommodations now offered on college and university campuses in compliance with the law, the higher education environments fall short of ensuring equity and inclusion for students with disabilities. Nineteen percent of students enrolled in college report having a disability, per 2015–16 enrollment counts (National Center for Education Statistics, n.d.-a). Yet, students with disabilities remain "at higher risk of poor academic performance, and early departure from college" and the "methods for increasing retention and success [of students with disabilities] have been focused on physical accessibility and providing academic accommodations (Wolanin Steele, 2004), but have lacked attention to more universal approaches afforded to other students such as social or belonging interventions (Fleming, Oertle, Plotner, & Hakun, 2017)" (Fleming et al. 2017, p. 210). Overall, students with disabilities exhibited lower rates of post-secondary enrollment than their non-disabled peers and attained degrees or completed programs at lower rates than the general population: "Postsecondary school completion rates for young adults with disabilities ranged from 29 percent at 4-year universities, to 30 percent at 2-year or community college, to 55 percent at postsecondary vocational, business, or technical school" (Sanford et al., 2011). Students with chronic illness, both childhood and adult onset, have been found to complete college at lower rates than students without such conditions (Maslow et al, 2011); the health conditions and related educational needs of students with

chronic illnesses are traditionally not well understood, or served, by colleges and universities (Chu et al., 2020; Royster & Marshall, 2008). Lower completion "even with disability legislation and accommodations [have] led researcher to question the effectiveness of [disabled student services] and the accommodations they provide" (Lyman et al., 2016, p. 124). Scholarship about students with disabilities in higher education has been found lacking, historically and contemporaneously (Dukes et al., 2017).

To improve the experience and outcomes of students with disabilities on campus, scholars and practitioners of disability services have argued for transforming campus environments by moving beyond meeting the minimal requirements established under the law and by moving beyond the dominant medical model (e.g., Block, Loewen, & Kroeger, 2006; Gabel, 2010; Hartsoe & Barclay, 2017; and Mole, 2013). Compliance, while necessary for ensuring the minimum of service, is, in itself, insufficient for creating full and meaningful access advocated by the disability studies in education, both in terms of the postsecondary education environment and the postsecondary education policy (Gabel, 2010). The medical model (one of the many frameworks, models, or theories of disability found in literature and in practice (see Table 1), has come to dominate disability services: "By the early 20th century, social service agencies, educational institutions, health care personnel, and policymakers formalized the medical model of disability and placed disability under the authority of medical and quasi-medical professionals (Nielsen, 2012). From these beginnings, the medical model evolved and remains a major paradigm for understanding, treating, and working with people with disabilities" (Evans et al., 2017, p. 57). Aquino (2016), citing various sources, identifies key features of the medical model as:

- "the assumption that disability is located in biological impairments[;] ...implicit in the 'damaged body' trope of the medical model are uninterrogated assumptions about the normal body"
- "addressing an individual's disability as a mode for eventual change and improvement (Watermeyer, 2013), viewing disability not as a component of one's overall identity but a problem to be remediated through supportive services"
- "[providing] a foundation for policies and overarching legalities"
- "[establishing] a distinct separation between disability and all other demographic factors (e.g., ethnicity, social class, gender, etc.), thus increasing the potential for disintegration between disability and other identity memberships" (Aquino, 2016, p. 319).

Table 1

Examples of Disability Frameworks/Models/Theories Cited in Literature and Referenced in

Participant Narratives

Frameworks/models/theories of disability		
Cited in literature	Directly or indirectly referenced in participant narratives	
Active model ^c		
Critical disability theory ^b	Х	
Critical realism (philosophy) ^b		
Disability justice ^b	Х	
Disability-diversity (dis)connect model/intersectionality ^a		
Functional limitations (rehabilitation) model $^{ m b}$		
Interactionist model of disability $^{ m b}$		
Medical model ^{a, b}	Х	
Minority-group (socio-political) model ^{a, b}	Х	
Moral model ^b		
Social justice (ableist or disability oppression) model $^{ m b}$	Х	
Social model ^{a, b}	Х	

Note. Examples of the framework/models/theories are cited by:

^{a.} Aquino (2016)

^{b.} Evans et al. (2017)

^{c.} Levitt (2017)

The social model of disability is a frequently mentioned alternative to the variously termed legal, compliance, medical, and accommodation models of disability. The social model critically examines the environment for barriers that preclude full and equal participation of people with disability in society and advocates for eliminating such barriers in a systematic fashion. The social model understands disability "not as a limitation but as a socially produced mindset [and] increases the accountability of the environment around the individual with a disability and attempts to decrease the stigmatization of disability" (Aquino (2016), citing various sources). Evans et al. (2017) offer an extensive review of the social model, tracing its origins as "a big idea" to the United Kingdom "based on the Fundamental Principles of Disability (1976)," which has since evolved to address critical materialist, feminist, and cultural perspectives. Evans et al. (2017) identify "the main goal of adherents of social model" as "to make sense of and change disabling socio-political and cultural practices" (p. 63). Furthermore, per Shakespeare (2013), "[k]ey to social model thinking is a series of dichotomies" where "impairment is distinguished from disability," "the social model is distinguished from the medical or individual model," and "disabled people are distinguished from non-disabled people" (p. 216). Samaha (2007), recognizing that definitions of the social model vary in how much disadvantage of disability the observers attribute to the environment, which can be "revised once it is recognized as contingent," proposes his own definition "while remaining faithful to influential restatements of contemporary scholarship... The social model is a proposed definition of disability that is connected to human disadvantage. Stripped down to its basics, the model moves causal responsibility for disadvantage from

physically and mentally impaired individuals to their architectural, social, and economic environment" (p. 1255).

Elucidating the association between the social model of disability and social justice, Lowen and Pollard (2010) survey the emergence of the social model in the context of the Civil Rights and Disability Rights movements in the article titled "The Social Justice Perspective." They argue that viewed from the social model standpoint, "Disability stems from the failure of society to adjust to meet the needs of disabled people. [The social model] does not deny illness or the need for medical intervention; rather, it offers a lens that brings a clearer understanding of barriers created by society's attitude toward disabled people and how these barriers affect them" (p. 9). The authors direct some of their critique toward the disability service profession for continuing policies and practices that hinder social justice:

When one considers the Disability Rights movement and the struggle to achieve social justice, it seems that [disability service] professionals have not embraced the goals of this movement, nor understand that they might play a role in maintaining a system that discriminates against disabled people and hinders their goal to achieve social justice.

(Lowen & Pollard, 2010, p. 12)

As detailed in the Presentation and Analysis of Data, participants of this study expressed critical views of disability services preoccupied mainly with legal compliance and with the medical model of disabilities, which remain prevalent in the delivery of disability services. Participants expressed a strong preference for reform, favoring the social model of disability, which they associated with disability rights, human rights, social justice, and full

inclusion of students with disabilities in higher education: in other words, doing what is right and what is socially just.

Relevant Critiques of the Social Model of Disability

Evans et al. (2017) summarize the critiques of the social model with respect to: limiting the focus on the body; ignoring the effects of social interactions; insufficiently considering the experience of the under-privileged; and even having unrealistic expectations with respect to eliminating all barriers for persons with disability (pp. 63–64). Shakespeare, who is among the social model's prominent critics, argues that although the social model has produced some important benefits, it is no longer sufficient for framing disability. It is therefore necessary to re-imagine how disability should be conceptualized (Shakespeare, 2013; Shakespeare & Watson, 2001). Shakespeare (2013) writes:

While acknowledging the benefits of the social model in launching the disability movement, promoting a positive disability identity, and mandating civil rights legislation and barrier removal, it is my belief that the social model has now become a barrier to further progress. As a researcher, I find the social model unhelpful in understanding the complex interplay of individual and environmental factors in the lives of disabled people. In policy terms, it seems to me that the social model is a blunt instrument for explaining and combating the social exclusion that disabled people face, and the complexity of our needs. Politically, the social model has generated a form of identity politics which has become inward looking and separatist. (p. 220)

Echoing the criticisms of the social model noted by Evans et al. (2017), Shakespeare (2013) is concerned that "the social model so strongly disowns individual and medical approaches, that it risks implying that impairment is not a problem" and quotes Liz Crow (1992), remarking:

As individuals, most of us simply cannot pretend with any conviction that our impairments are irrelevant because they influence every aspect of our lives. We must find a way to integrate them into our whole experience and identity for the sake of our physical and emotional well-being, and, subsequently, for our capacity to work against Disability. (Shakespeare, 2013, pp. 217–218)

Specific to the British context is the issue, observed by Shakespeare and Watson (2001), that "the social model has now become the ideological litmus test of disability politics in Britain, used by the disabled people's movement to distinguish between organizations, policies, laws and ideas which are progressive, and those which are inadequate" (p. 10), although, in contrast to the British approaches, the American "perspective has not gone as far in redefining 'disability' as social oppression as the British social model. Instead, the North American approach has mainly developed the notion of people with disabilities as a minority group, within the tradition of U.S. political thought" (p. 10). Owens (2015) also links the diverging views on the social model to its development in the different historic and societal contexts of the United States and Great Britain.

Finally, legal scholar Adam Samaha (2007) adds to the critique by questioning the utility of the social model from policy and legal perspectives in terms of defining disability policy, while also grouping other critiques around three problems—"the model's scope, the ambiguity of disadvantage, and the connections between impairment and social settings.

Some of these challenges are potent, but none eliminate the model's value" (p. 1262). Among such values are the model's capacities to question the status quo (i.e., "uncritical assumptions that disadvantage is natural and necessary," (p. 1253), to inspire action and social change, and to inform institutional design to align with new normative frameworks.

Association between the Social Model and Universal Design

Broadly defined, universal design is "a late twentieth-century design philosophy aimed at creating built environments that are accessible to both disabled and nondisabled users... What designers, users, and advocates mean by this term can be as varied as their conceptions of and relations to the idea of disability" (Hamraie, 2017, pp. xiii–xiv). Universal design, as a tool, is often associated with implementing the social model of disability and many iterations of this tool in the educational setting exist, e.g., universal design for learning, universal design for assessment, and universal design for instruction (Hartsoe & Barclay, 2017). Table 2 contrasts the accommodation and universal design as near opposites in how they approach the issues of disability, access, and human environment (source: Mole, 2013, p. 64).

Table 2

Main Elements of the Accommodation Approach and the Universal Design Approach

Accommodation approach	Universal design approach
Access is a problem for the individual.	Access issues stem from an inaccessible, poorly designed environment and should be addressed by the designer.
Access is achieved through accommodations.	The system/environment is designed, to the greatest extent possible, to be usable by all.
Access is retroactive.	Access is proactive.
Access is exclusive/specialized.	Access is inclusive.
Access is consumable.	Access, as part of the environmental design, is sustainable.

Source: Mole, 2013, p. 64, as adapted from AHEAD Universal Design Initiative Team (2004)

Like the social model of disability, universal design is subject to critique and has a long and complex history, as demonstrated in Aimi Hamraie's book, *Building Access:* Universal Design and Politics of Disability (2017), in which the author traces the origins of universal design to reducing variation in the interest of greater efficiency in first military and later civil manufacturing, and then to the intensive research efforts related to rehabilitating and integrating impaired veterans into the workforce. The author critically examines the *universality* of universal design, noting that at various points the design research focused on the subject of white male veterans attending the University of Illinois on the GI Bill, to the exclusion of women and minorities. Nieminen and Pesonen (2020), in the context of evaluating (from the perspective of students with disabilities) an undergraduate course designed with universal design principles noted a shift in focus from inclusion to test scores. The authors "argue that in order to widen access in higher education, Universal Design needs to be taken back to its roots and reconnected with the social model of disability," explaining: "Reframing [universal design] as a set of practices the purpose of which is to include rather than to boost learning results—means that there is a need to develop ways of measuring inclusion other than test scores" (p. 19). Evans et al. (2017) discussed how the ideas of barrier-free design formulated by Ron Mace in the 1970s for physical environments were later adapted for other fields, including higher education to remove environmental barriers to inclusion. Still, the extent to which the barrier removal can be feasibly accomplished has been questioned. Shakespeare (2013), critical of "the concept of barrier free utopia," wrote: "The idea of the enabling environment, in which all socially imposed barriers are removed, is usually implicit rather than explicit in social model thinking... Yet despite the value of approaches such as

universal design, the concept of a world in which people with impairments were free of environmental barriers is hard to operationalize" (p. 219). Still, the social model of disability has efficacy as a practical tool, where, "by identifying social barriers to be removed, the social model has been effective *instrumentally* in the liberation of disabled people. Michael Oliver argues that the social model is a 'practical tool, not a theory, an idea or a concept' (2004, 30)" (p. 217, italics Shakespeare's).

As described in the Discussion and Analyses of Data, this study found that participants, as disability practitioners, are aware of the juxtaposition between the practical/achievable aspects of the social model and its wholesale fulfillment, whereby no accommodation is needed; participants saw the idea of barrier-free environment as aspirational, long-term, and worth striving for in practice. Of note to this study is that participants mainly concerned themselves with the transition to the social model and often used the term universal design as near synonymous with the social model where it helped to communicate their preference for comprehensive environmental change over needbased, ad hoc, sporadic barrier removal for individual students. As referenced by study participants, universal design was understood in largely utilitarian, tool-like terms as, say, website accessibility enhanced by trained information technology staff. As such, universal design took on lesser significance in the interviews than the transformative power of the social model. This participant statement (Gwen) illustrates the connection between the concepts: "I finally realized that universal design is an application. It's a way you apply something. But you need something to guide that application, like universal design in and of itself isn't be-all and end-all. So what I saw is that [in] the social model thinking disability

[is] a difference and that you want to design for differences and include the most people number of possible. Universal design was a way to implement that philosophy."

Literature on Transitioning to the Social Model in Higher Education

Although the change from the prevalent medical model or legal/compliance-based thinking to the social model of disability appears desirable and may offer more seamless, inclusive, and accessible ways for students to pursue higher education, empirical research on transitioning to the social model in higher education is limited. Several studies reviewed below represent a sample of the available literature and methodological approaches that have been used for research on transition to the social model. Mole (2013) surveyed and interviewed disability service staffs at five universities on how they understood and applied the social model and universal design. She reported several emerging themes raised by disability staffs regarding the adoption of the social model and universal design: changing language and concepts of disability on campus; positioning disability staffs to take on a broader role within higher education institutions as experts and collaborators; expanding ownership for creating a welcoming environment beyond the disability staff, which the author described as a "radical shift in thinking"; engaging faculty to endorse/adopt universal design; and resolving the tension between how disability is documented and defined and the intent to build a campus-wide inclusive environment. Some respondents also voiced the need for funding to support change (pp. 72–74). Gabel (2010) described an application of the disability studies framework, with a focus on several iterations of the social model of disability, in creating change within one higher education institution, National Louis University, through focusing on changing the educational content, context, and culture. Thornton and Downs (2010) shared the experience of the

University of Arkansas at Little Rock in "embracing" the social model of disability and undertaking a strategic planning process with regard to "language, policy, process, and practice." From adopting the new title "Disability Resource Center," to changing focus from providing individual accommodations to changing disabling environments, to changing the mission of the Disability Resource Center, the University of Arkansas at Little Rock began a process of institutional transformation. This involved presentations for university leaders and work with individual faculty. In discussing the implications of this experience for other colleges and universities, the authors concluded: "As disability resource professionals frame their role as the designers of the service environment, the focus shifts toward creating a usable, equitable environment in the disability office and beyond. In doing so, the disability office becomes a model of universal design and the social response to disability. The role offers great potential for facilitating and sustaining change on the campus at large" (Thornton & Downs, 2010, p. 77). Park, Roberts, and Delise (2017) described the experience of offering the university faculty and staff a three-day professional development institute that covered universal design for instruction, accessible distance education and assistive technology, student and faculty rights and responsibilities, disability culture, hidden disabilities, and multiculturalism and disability. In a follow-up qualitative case study of how four faculty integrated universal design for instruction in their courses, the authors identified three potential factors influencing the degree to which faculty implemented universal design for learning: "the extent to which faculty (a) conceptualize universal design as an ongoing endeavor (versus a finite, achievable state); (b) engage in self-reflection; and (c) internalize a social model of disability" (p. 123). One of the implications of this study for further adoption of universal design is the need to recognize

and address how much the medical model of disability features in the higher education discourse and the extent to which is has been internalized by individual faculty members, by, for example, shifting attention to barriers from student needs.

This dissertation aimed to enhance the understanding of the factors related to initiating a transition to the social model on university and college campuses by creating rich descriptions of the process from the point of view of the disability service professionals initiating the change. More broadly, this dissertation aimed to add to the literature on disability in higher education, where other authors reviewed existing research on disability in higher education and pointed to research gaps. For example, Evans et al.'s 2017 book, Disability in Higher Education: A Social Justice Approach, called for "more, better, and broader research," pointing out that "Much of disability research still is based on medical or rehabilitation models, giving little attention to environmental considerations or the perspectives of disabled participants" (p. 441). Mole (2013) reported that "Despite the emerging popularity of universal design with disability service providers, there is a notable lack of research with regards to outcomes for stakeholders. This was expressed as a concern by one respondent in this study and is echoed in the literature (Finn et al., 2008; Burgstahler, 2008b; Embry et al., 2005)" (p. 76). Thornton and Downs (2010) also spoke about the need for more information on the experience of transition to the social model, writing, "Other universities around the country have been exposed to the social model and universal design, and are making necessary changes in their own policies and procedures to reflect this paradigm shift. [The University of Arkansas at Little Rock Disability Resource Center's] efforts to document specific changes made to date should prove to be helpful to other universities as they embark on a similar journey. The literature review clearly

revealed that there is the need for scholarly writing—both anecdotal and research-based in this area" (p. 77). This dissertation's phenomenological, in-depth qualitative approach to examining the lived experiences of staff enacting the social model in higher education expands the research-methodological approaches to the subject of transition to the social model of disability.

The Concept of Paradigm Shift

The transition to the social model in higher education has been likened both to a "paradigm shift" (Block et al., 2006; Thornton & Downs, 2010) and to a "radical shift in thinking" (Mole, 2013) in a sense that it represents a radical departure from the commonly practiced norms of thinking about disability and enacting disability services on campus. Other aspects of the scale of this reform are the size of the American higher education system and the organizational complexity of higher education institutions. In 2019–20, the field of degree-granting postsecondary institutions in the United States consisted of nearly 4,000 two- and four-year colleges (National Center for Education Statistics, n.d.-b). The concept of paradigm shift itself dates to Thomas Samuel Kuhn's *The Structure of Scientific Revolutions* that reimagined the process of scientific change as alternating periods of normal science and revolutions with a focus on science's problem-solving capabilities.¹ In the 1970 edition of *The Structure of Scientific Revolutions*, Kuhn wrote:

¹ For critiques of Kuhn's theories and concepts, see, for example, Firinci Orman (2016); Galison (2016); and Stanford Encyclopedia of Philosophy (n.d.).

The transition from a paradigm in crisis to a new one from which a new tradition of normal science can emerge is far from a cumulative process, one achieved by an articulation or extension of the old paradigm. Rather it is a reconstruction of the field from new fundamentals, a reconstruction that changes some of the field's most elementary theoretical generalizations as well as many of its paradigm methods and applications. During the transition period where will be a large but never complete overlap between the problems that can be solved by the old and by the new paradigm. But there will also be a decisive difference in the modes of solution. When the transition is complete, the profession will have changed its view of the field, its methods and its goals. (pp. 84–85)

In its broader use, the term "paradigm shift" referring to "a fundamental change in approach or underlying assumptions" (Oxford Dictionary, n.d.) has found application in fields ranging from medical research, to business management, to information technology and engineering, to education and many other fields. In the context of organizational change (akin to what the participants in this study undertake in shifting to the social model of disability), Bolman and Deal's 2008 book *Reframing Organizations: Artistry, Choice, and Leadership* places paradigm and paradigm shift alongside the concepts of frames (as well as the acts of framing and re-framing), which are central to their exploration of organizational change, management, and leadership:

A frame is a mental model²—a set of ideas and assumptions—that you carry in your head to help you understand and negotiate a particular "territory." A good frame makes it easier to know what you are up against and, ultimately, what you can do about it. Frames are vital because organizations don't come with computerized navigation systems to guide you turn-by-turn to your destination. Instead, managers need to develop accurate maps in their heads. Such maps make it possible to register and assemble key bits of perceptual data into a coherent pattern—a picture of what is happening. When it works fluidly, the process takes the form of "rapid cognition." (p. 11)

Bolman and Deal (2008) emphasize that managers need an ability to see and frame the organization from multiple perspectives—they identify structural, human resource, political, and symbolic frames—and point to studies indicating that "the ability to use multiple frames is associated with grater effectiveness for managers and leaders" (p. 19), including: the organizational structure, i.e., "the design of units and subunits, rules and roles, goals and policies"; the management of human resources, with a focus on the individual qualities and experiences; "the political view [of] organizations as competitive arenas for scarce resources, competing interests, and struggles for power and advantage"; and the symbolic frame that "focuses on issues of meaning and faith [and] puts ritual, ceremony, story, play, and culture at the heart of organizational life." Here,

² Per Bolman and Deal (2008), "Such mental models have many labels—maps, mind-sets, schema, and cognitive lenses, to name a few" (p. 10). Furthermore, "Among the possible ways of talking about frames are schemata of schema theory (Fielder, 1982; Fiske and Dyer, 1985, Lord and Foti, 1986), representations (Frensch and Sternberg, 1991), cognitive maps (Weick and Bougon, 1986), paradigms (Gregory, 1983; Kuhn, 1970), social categorizations (Cronshaw, 1987), implicit theories (Brief and Downey, 1983), mental models (Senge, 1990), definitions of the situation, and root metaphors" (p. 22).

Each of the frames is both powerful and coherent. Collectively, they make it possible to reframe, looking at the same things from multiple lenses or points of view. When the world seems hopelessly confusing and nothing is working, reframing is a powerful tool for gaining clarity, regaining balance, generating new options, and finding strategies that make a difference. (pp. 22–23)

Bolman and Deal (2008) distinguish framing from *reframing*, where the latter refers to the skill of taking action for change when the perspectives and tools relied on for organizational problem solving are no longer adequate to the situation in hand. Similarly, Gareth Morgan (1997) draws attention to the challenge of changing ways of thinking, while recognizing the influence of Kuhn's concept of paradigm change (1970) on management practice:

In organizational theory, the idea of challenging taken-for-granted ways of thinking is becoming well established, especially in the work of theorists recognizing the role of paradigms and metaphors in shaping how we think [citations omitted]. At a practical level it has become vitally important to challenge traditional paradigms and mind-sets as a means of coping with the demands of our postcapitalist society [citations omitted]. Thomas Kuhn's concept of "paradigm change" has become an important managerial concept and ideology for reshaping management practice. Almost any book on creative management develops the implication of this approach, showing how all problems and problems solution are products of how they are framed and that we can challenge and escape from cognitive traps by learning the art of framing and reframing, and finetuning skills of dialectical and other processes of critical thinking [citations omitted]. (p. 407)

The process of becoming aware of dominant paradigms in the delivery of disability services (within their own mindsets and their own organizations) and then taking action to reframe disability service provides a map for analyzing the mindsets and actions of the participants in this study who (a) became critically aware of how the social model offered a compelling alternative for organizing their work in disability; and (b) initiated and persisted at making an organizational shift to the social model. As experienced by participants, this transformation process was iterative, gradual, and time- and labor-intensive. As such it was more akin to gradual reshaping of organizational approaches, rather than punctuated by sudden, massive shifts in college cultures and practices.

Conclusion

In totality, the review of existing literature tells us that the social model of disability—decades old and justifiably criticized for its shortcomings, particularly as a theoretical model of disability—offers a valid frame for recognizing the deficiencies of disability services based on medical and compliance models and for making changes to achieve a more equitable environment for students with disabilities by removing environmental barriers to education to a feasible degree. However, the existing literature tells us little about the lived experiences of disability professionals enacting the change to the social model. As discussed in Presentation and Analysis of Data, this dissertation maps out the pragmatic approaches to reframing disability services around the social model through the lives of participants who perceive and use the social model as a tool for organizational change as part of the broader paradigm shift in disability services.

Conceptual Framework and Methodology

Introduction and Research Questions

Scholars, activists, and practitioners recognize the limitations of the legal and medical models, and the calls for greater inclusion of people with disabilities intensify. But literature remains sparse with respect to the motivations, paths, and experiences of people on college and university campuses who set out to move beyond the medical and legally mandated accommodation by advancing alternative ideas and practices, including those individuals advancing the social model of disability and using the tools of universal design. The social phenomenon of this change is not well understood, yet is critical to examine in order to help reform-minded faculty, staff, and senior administrators to initiate a wider adoption of models and methods that they consider essential to greater inclusion. As Mole (2013) observed,

Services for disabled students in US universities are evolving. Fueled by antidiscrimination legislation, these services began by accommodating the "deficiencies" of disabled students; but now, *they are identifying the campus environment as deficient and exclusive for disabled people* [italics added]. In a small number of services, a quiet revolution is taking shape; they are becoming proactive, campaigning for access, anticipating inaccessibility, educating their campuses about inclusion and their faculty about inclusive course and curriculum design. The social model of disability is the catalyst for this revolution. (p. 77)

Research Questions: Seeking to fill the gaps in understanding the phenomenon of change, this dissertation posed three research questions: (1) What factors, personal and organizational, compel faculty and staff to initiate efforts, broadly conceived, to put the ideas of the social model into practice on campus? (2) What is the process for this engagement and what meaning does it have for the actors? (3) What lessons can be learned from their experiences toward greater inclusion of students with disabilities, beyond individual, ad hoc accommodation? To answer these questions via a qualitative research design, Marshall sought to interview individual faculty and staff members (within and outside offices of disability services) at four-year colleges and universities who, within the prevalent medical model of disability and focus on compliance, initiated changes informed by the social model of disability so as to remove barriers to inclusion and transform campus environments. On a more granular level, Marshall's study inquired into: How participants first engaged with the issue of disability; How participants became aware of the social model of disability and how they responded to these ideas in the context of their personal and professional experiences; How participants decided to act on the ideas of the social model and went about implementing them; and What this change meant to participants as individuals and professionals and what lessons these experiences offered.

Given that this area of scholarship and practice is under-researched and undertheorized, this study was conceived as a phenomenology, using in-depth qualitative interviewing to invite participant-constructed narratives of change. Summarized by Ravitch and Carl (2016), phenomenological research is concerned with "individual's lived experiences of a phenomenon (such as homeless parenting or crisis leadership)," as "perceived by the actors in a situation"; and aims to "obtain comprehensive descriptions

that provide the basis for a reflective structural analysis that portrays the essence of the experience" (p. 24). In generating rich descriptions of participants' experiences and identifying the emerging themes by staying close to participant narratives, this dissertation may inform further study of the phenomenon from the grounded theory perspective³ to generate the beginning of a theory of facilitating transition to the social model of disability from the perspective of individuals leading and joining the change. Per Oktay (2012), phenomenology retains focus on the participant experience, whereas grounded theory aims "to generate theories from the data [and] employs inductive reasoning processes that stay close to the data through a constant comparison method" (p. 221). Further clarifying a theory-generating capacity of qualitative research, Oktay (2012) remarks that "the focus on the development of middle-range theory is the primary way that grounded theory differs from other qualitative methods [citations omitted]. Although qualitative studies done in other traditions may have theoretical implications, their aim is more likely to be a detailed ('thick') description of a culture or a setting (ethnography) or of the 'meanings' individuals ascribe to aspects of their cultures or their lives (phenomenology)" (p. 15).⁴ In pursuing

³ Per Charmaz and Belgrave (2015), "Grounded theory is a general methodology with systematic guidelines for gathering and analyzing data to generate middle-range theory. The name 'grounded theory' mirrors its fundamental premise that researchers can and should develop theory from rigorous analyses of empirical data. The analytic process consists of coding data; developing, checking, and integrating theoretical categories; and writing analytic narratives throughout inquiry. Barney G. Glaser and Anselm L. Strauss (1967), the originators of grounded theory, first proposed that researchers should engage in simultaneous data collection and analysis, which has become a routine practice in qualitative research. From the beginning of the research process, the researcher codes the data, compares data and codes, and identifies analytic leads and tentative categories to develop through further data collection. A grounded theory of a studied topic starts with concrete data and ends with rendering them in an explanatory theory" (para. 1).

⁴ For example, Aytas and Emil (2020) deploy a phenomenological approach to examine lived experiences of faculty with disabilities; Vaccaro et al. (2018) offer an example of using grounded theory approach to examine how college students with disabilities develop a sense of purpose through a process of using "imagination, exploration, and integration" (p. 42).

participant meaning, this type of research applies the symbolic interactionism theory (Oktay, 2012). In Blumer's (1969) formulation, the symbolic interactionism theory employs these premises: first, "human beings act toward things on the basis of the meanings that the things have for them. Such things include everything that the human being may note in his world—physical objects, such as trees or chairs; other human beings, such as a mother or a store clerk; categories of human beings, such as friends or enemies; institutions, as a school or a government; guiding ideas, such as individual independence or honesty; activities of others, such as their commands or requests; and such situations as an individual encounters in his daily life." Second, "the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows." And third, "these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters" (p. 2). The symbolic interactionism theory informed the conduct of this study. More broadly, this study is situated within the interpretative tradition of social science, which subsumes symbolic interactionism and seeks "to develop an understanding of social life and discover how people construct meaning in natural settings" (Neuman, 2011, p. 101). Interpretative social science⁵ takes on the constructivist orientation of social reality assuming that "the beliefs and meaning that people create and use fundamentally shape what reality is for them" (p. 102). Explanations of social world are context-dependent and rely on inductive reasoning applied to "in-depth description or picture with specific details but limited abstraction about a social situation or setting" (p.

⁵ Interpretive social science, along with positivist social science and critical social science, represent distinct approaches to social science research, organized around how they address fundamental questions about the nature of social reality, and the associated methods of collecting and interpreting data about social reality. For detailed discussion, see Newman (2011).

105) where researcher sets aside preconceived notions about the social phenomenon; explanations go beyond "the surface or observable level [so as] to examine people's complex inner lives" and potentially "transform existing conditions" (p. 107). Equipped with these understandings, this study concerned itself with developing a nuanced description of the transition to the social model of disability as enacted, experienced, interpreted, and understood by participants themselves. It sought to generate an understanding of the transition process as it is socially constructed and to create a fuller picture of the social phenomenon of change than what is available in scholarly literature today.

Qualitative Research Methods

Marshall set out to conduct in-depth qualitative interviews with higher education professionals who initiated the efforts toward creating a more inclusive environment for students with disabilities, which were grounded in their understanding of the social model of disability. The interview guide was developed to invite participants to describe the phenomenon as their personal, lived experience and to describe the meaning they derived from that experience. The interviews were anchored by open-ended qualitative questions, tailored to the participant roles and informed by the interviewing structure advocated by Irving Seidman (2013). He recommends conducting a series of three interviews with each participant, where "The first interview establishes the context of the participant's experience [i.e., "focused life history"]. The second allows participants to reconstruct the details of their experience within the context in which it occurs, i.e., the specific phenomenon or period of interest to the study. The third interview encourages the participants to reflect on the meaning their experience holds for them" (pp. 20–21).

Seidman called this method "an in-depth, phenomenologically-based interviewing" (p. 14) and summarized several related themes, including the focus "on the experience of participants and the meaning they make of that experience" in the context of the fleeting, time-bound human experience; the emphasis on the subjective understanding of the participant's experience; and the aim to "transform lived experience into a textual expression of its essence," where lived experience "is made up of the many constitutive elements that are part of our experiences that flow together, undifferentiated while we are in the stream of action. It is only when we step out of the stream of flowing action and through reflection reconstruct the constitutive elements of lived experiences that those constitutive elements become, in Schultz's words 'phenomena'." (pp. 16–17). In Marshall's study, the in-depth qualitative interviews were to be guided by flexible open-ended question prompts, allowing participant meaning to emerge and for the researcher to follow-up on and clarify emerging concepts, narratives, and ideas. The interview guide is provided in Appendix C.

Marshall initially aimed to interview all participants in person, unless prevented by the geographic location of participants; preference of participants; or availability of travel funds, but also anticipated conducting interviews via Zoom or similar technological aids with recording capabilities, where Marshall was to request participant consent to be recorded at the onset of the interviews. The onset of interviewing coincided with the onset of the COVID-19 pandemic, which dramatically restricted travel and in-person interactions and also disrupted professional and personal lives. The COVID-19-related disruptions may have also influenced the ability of potential participants to respond to Marshall's recruitment outreach, thereby limiting the total number of participants. Of the seven

participants who consented, all resided outside of Marshall's home state, including two residing outside the United States. As a result of these external constraints, six of the participants were interviewed via Zoom and one participant, due to the lack of unreliable internet access, was interviewed via email. Of the six interviews conducted via Zoom, one was conducted in two sessions due to an anticipated interruption; the remaining interviews were all conducted on one sitting as both the flow of the interviews and the participant's availability/willingness to continue enabled Marshall to cover the questions from the interview guide and to ask follow-up questions. The resulting six Zoom interviews ranged in duration, approximately, from 1 to 2 hours (the interviews with more experienced professionals tended to be longer) for a total of approximately 8.5 hours of recorded material, and one additional interview conducted in writing, via email, with subsequent email follow-up.

Sampling Approach and Participant Recruitment

While planning her study, Marshall aimed to identify faculty and staff at four-year colleges and universities who are known to experts, participants, or via scholarly or trade publications to have initiated efforts towards adoption of social model of disability on their respective campuses. The focus was on individuals, rather than institutions as it was in Mole's (2013) research project where she asked informants "to identify institutions the stated aim of which is to work towards a social model of disability" (p. 66). It was outside of the consideration of Marshall's research whether the initiatives undertaken were successful because the criteria for success in such efforts are still being developed; see for example critical questions raised by Block, et al. (2006). Using purposeful sampling, Marshall identified potential participants by (1) reviewing publications such as the *Journal*

of Postsecondary Education and Disability published by AHEAD (including Block et al. (2006)); the AHEAD 2019 Equity and Excellence: Access in Higher Education national conference agenda and session summaries (AHEAD, n.d.-a); and Tobin and Behling's 2018 *Reach Everyone, Teach Everyone: Universal Design for Learning in Higher Education*; and (2) asking experts in the field to identify individuals with relevant expertise and experience. Marshall's purposeful sampling approach was informed by Mole's 2013 study. She used "non-probability criterion-based selection utilized network sampling," asking key informants (i.e., someone who is "experienced in the field and has visibility among professionals who work in the service provision sector. The informant is a proponent of the approach and is published in AHEAD's *Journal of Postsecondary Education and Disability*") to identify "institutions the stated aim of which is to work towards a social model of disability in their delivery framework." Mole identified several additional institutions through literature research, ultimately recruiting five participants who worked as directors of disability services (p. 68).

Marshall chose AHEAD as the main site for participant recruitment because the association has taken on leadership in engaging postsecondary institutions in moving beyond the medical and the accommodation models of disability and creating systemic change toward reducing reliance on individual accommodation, and, instead, creating a campus environment "that the majority of participants will find … usable, equitable, and accessible without an accommodation" (Block et al., 2006, p. 118). Further signaling AHEAD's continuing focus on the social model and universal design—and affirming Marshall's focus on AHEAD as a participant recruitment site aligned with the purposes of the study—was the AHEAD 2019 Equity and Excellence: Access in Higher Education

national conference. For example, the conference agenda highlighted universal design for learning access among "important and emerging issues" and addressed how disability professionals can remove barriers to applying the social model and universal design principles in policies, courses, and campus experiences, beyond physical environments (AHEAD, n.d.-a). In conducting her study, Marshall followed AHEAD's protocol requiring researchers to submit a formal request to conduct research to AHEAD's Research Review Panel (AHEAD, n.d.-c). In early 2020, AHEAD's Research Review Panel approved Marshall's application to conduct research and announced the study to its members in an email dated February 27, 2020 (see AHEAD's announcement of Marshall's study in Appendix G); at that time the association had about 3,700 members in the United States and overseas (AHEAD, n.d.-b). The email announcing Marshall's study to AHEAD members resulted in a total of 12 AHEAD members expressing interest in the study. Of these 12, four committed to the study and were interviewed; three were excluded due to having no work experience in higher education beyond community college settings; and the remaining five either did not respond to Marshall's follow-up or opted out due to the COVID-19 pandemic, which complicated the participant recruitment process. The remaining three participants were recruited through publications and expert advice. Altogether, this process resulted in seven disability professionals participating in Marshall's study. Participants completed a basic demographic questionnaire and some volunteered information about their own disability in the course of answering interview questions. Table 3 below summarizes demographic characteristics, providing a cumulative participant profile to avoid easy identification of individual participants.

Table 3

Demographic Characteristics of Study Participants

Characteristic	Participant description
Geography	5 participants resided in the U.S., 2 resided overseas.
Gender	4 participants were female, 3 were male.
Age	Ages ranged from 32 to 72, with an average of 53.
Highest academic degree	1 participant had a PhD in special education. 6 participants had MA/MEd degrees in the fields of: counseling, counseling psychology, guidance and counseling, education and rehabilitation counseling, student affairs in higher education, and rehabilitation. Of these master's degree holders, one reported having an all-but-dissertation status in the field of curriculum and instruction.
Employment	One participant was retired and consulted on disability in higher education. Others held positions in higher education including coordinator, manager, associate director, or associate dean. All held positions as staff as opposed to faculty.
Race	6 participants were white. One participant's race is omitted.
Disability	3 participants reported having a disability.

None of the participants worked as college or university faculty at the time of the interviews; six worked in four-year college and university settings at the time of the interviews and one was retired after previously consulting with higher education on disability services.

Data Analyses

Marshall used the services of the https://transcribe.wreally.com/ website to "convert audio to text with automatic transcription." Once the automatic transcription was generated for the interview recordings, Marshall used the website's capability to listen to the audios at the lowered speed and to edit the automatically generated transcriptions for accuracy. In the process, Marshall began noting the emerging themes, which were at times signaled participants using specific terms like "social justice" or "expert." In rereading the text of the interviews on multiple occasions, Marshall analyzed the emerging themes both inductively (through grounding in the participants' own meaning-making) and deductively (against the backdrop of relevant scholarly literature). Where feasible, Marshall also used data sources in addition to the participant-generated data to increase the trustworthiness of the study via the practice of "triangulation" (Ravitch & Carl, 2016, p. 160), to confirm and clarify themes and essential facts by, for example, seeking additional information from public/published sources. As Marshall noted the emerging concepts and themes in participant descriptions, she also continued comparing, contrasting, and cross-referencing participants' responses to in-depth qualitative interviewing, adding her methodological memos and notations of the data. Marshall thereby engaged in data analyses as an ongoing and iterative process, allowing for clarifying and deepening of her understanding of the emerging themes. Altogether, to borrow Stan Lester's language, "the purpose of the

phenomenological approach is to *illuminate the specific*" (1999, p. 1, italics added), and Marshall's analyses paid close attention to the particulars of the situations, experiences, and meanings evoked by the participants. In addition to grounding the analyses in the data and being careful to allow for participants' own experiences and meanings to emerge, Marshall remained attuned to the instances where her emerging findings and the existing frameworks in the literature overlapped, thereby paying attention to a larger scholarly context. While conceived as a phenomenology with a focus on generating rich descriptions of the change phenomenon (rather than generating a theory of change), Marshall's dissertation noted themes related to the diffusion of innovation theory and the transformational leadership theory.

Limitations

In planning this study, Marshall anticipated recruiting 5 to 7 faculty and staff participants. This target number was ultimately met despite the disruptions caused by the COVID-19 pandemic that uprooted personal and professional lives in the early 2020, as the little-understood illness threatened lives and livelihoods. The composition of the participant group (all were staff members) limited the perspectives represented in the findings to those of disability staff members. The small group of participants and nonrepresentative, non-randomized sampling limited the generalizability of the findings. The strength of the study was in generating deep descriptions of individual motivations and experiences in challenging existing frameworks in pursuit of equity and access for students with disabilities.

Presentation and Analysis of Data

Introduction

This qualitative study tells a story of disability professionals in higher education who undertook the work of rethinking how students with disabilities could be served better and found that social model of disability offered a useful map for their personal and professional journeys as they sought to do what is just and what is right. The participants, whose ages ranged from 32 to 72 (a 40-year span) at the time of the interviews, were all higher education disability professionals who opted into the study. They differed in how and at what points in their careers they first encountered the social model; and differed in the degrees to which they enacted the change in their professional spheres of influence. Yet, all found that the social model provided what they considered a better alternative to how the system of disability services was organized, conceptually and practically; they also came to see the meaning of their work (as professionals and, some, as private human beings outside of the sphere of work) influenced and enhanced by the social model. To put it succinctly, the themes emerging from the data show how participants' private and professional worldviews and aspirations aligned and cohered, bringing greater meaning and satisfaction—in clear contrast to the frustrations produced by participating in disability work driven by compliance, welfare, and medical models of disability. The sense of meaning and purpose that arose helped participants face the not-inconsiderable challenges of undertaking the work of reframing and changing disability services within their organizations around the social model, and we will see that the scale of these undertakings and transformations was specific to participants. Such distinctions between participants were pronounced enough to justify categorizing participants (for the purposes

of highlighting commonalities and differences) as two distinct groups: the vanguard and the second-wave participants.

The Vanguard Participants

These participants (Gwen, female, age 72; Martha, female, age 56; and Warren, male, age 64) first encountered the social model through AHEAD's early strategic efforts to disseminate the social model and universal design principles of creating barrier-free environments for students with disabilities in higher education. (Participant names used in this text are fictitious, protecting participant identities.) As detailed in this chapter, the early strategic AHEAD efforts dated to the early 2000s. Once the work of re-framing began for the vanguard group, it continued for decades (from the early 2000s through the time of the interviews in early 2020), taking the form of continuous personal reflection, analysis, learning, and recalibrating their practices as informed by experience and professional development, as well as by disability studies and social justice literature. These participants undertook change on multiple planes: within themselves; within their own organizations where they brought change from within the offices of disability to a wider organization; through association with AHEAD and other national/international projects that brought persistent professional development and leadership formation to the audiences of disability professionals, diffusing the social model by writing, speaking, and consulting on the social model. The author came to regard this group of participants collectively as *the vanguard* due to their direct association with AHEAD's early strategic initiatives to diffuse the social model throughout higher education.

The Second Wave Participants

Labeled for the purposes of analyses "the second-wave participants," the remaining participants' first encounters with the social model as a concept—and the way they went about putting it into practice—are more apt to be thought of representative of as *a second wave* for the purposes of the analyses presented in this chapter. This group included people of wide-ranging ages and cultural experiences (Dara, female, age 65; Emmett, male, age 46; Caitlyn, female, age 38; and Jaden, male, age 32) who aligned themselves in their perspectives with the social model and sought to bring these ideas into practice in their own workplaces. This group, also essential to the diffusion of the social model and the progression of the paradigm shift in higher education disability services, differed from the vanguard group as: (1) chronologically speaking, the timing of their encounter with the social model and practical implementation followed that of the vanguard group; and (2) the scope of the social model implementation aligned closely with the scope of their professional responsibilities within their respective higher education institutions, and less with leading the large-scale strategy spearheaded by AHEAD.

Later in this chapter, while discussing social model dissemination from the perspective of the Diffusion of Innovation Theory as it applies to social change, we also discuss briefly how the vanguard and the second-wave labels may translate into the labels of individual innovativeness (e.g., *innovators, early adopters*), as summarized by Scott and McGuire (2017).

What the vanguard and second-wave participants had in common was this starting point: the recognition and value of diversity and the sense of right-and-wrong that likely influenced their entry into the field of disability. These dispositions, grounded in life

experiences, appear to have alerted participants to the deficiencies of existing disability services and informed their desire to find solutions, with the social model coming to serve as a frame, a map, and a guide for future work. And that is where this analysis begins—with looking at the formative life experiences and dispositions, in participants' own telling. We then see how these dispositions, essentially serving as the lens for discerning the right from wrong, set off early alarms for participants which took the forms of questioning practices, job dissatisfaction, and feelings that participants' personal life lessons, values, and dispositions were out of synch with their professional lives, which together dented their perceptions of the dominant frames of disability services. As social model ideas entered this "questioning" space through professional development, influence by leaders and literature, debate, academic learning, or job change, the work of the (re)framing of disability services began. Participants came to learn how the social model provided a practical and achievable way to reimagine identities, roles, processes, and services—and, for some participants, their lives' work.

The rest of the chapter brings into focus the organizational aspects of reframing disability services around the social model from participants' own perspectives. This tells us how participants' own ongoing work of symbolic reframing evolved from basic exposure to the concept of the social model to the desire to gain and hone a high degree of competence and confidence in the work of reframing (Warren termed this capacity "fluency"). This analytical work undergirded participants' organizational work to align disability services with the social model within their spheres of influence and differed substantially between the vanguard and second-wave groups. Here, the findings illustrate how participants went about the work of reframing (with the narratives concentrating

largely on the symbolic axis, but also touching upon the structural, human resources, and political dimensions), to bring along subordinates, colleagues, managers, and others to reimagine habitual (i.e., legal, compliance, medical disability-informed) disability work, organizational roles, and relationships.

Finally, the chapter reviews what participants' experiences can teach the advocates and practitioners of disability reforms, pointing to the power and intricacy of symbolic reframing in gaining allies; and highlighting the value of making incremental change in initiating and scaling up voluntary social-model-based transformation of higher education institutions to serve students with disabilities. The findings suggest that advocates of the social model may want to pay consistent attention to (a) recognize instances where the social model approaches may come into perceived conflict with the identities, roles, and values of faculty and staff; (b) consider offering a space where these conflicts are acknowledged and explicitly addressed, and potentially reframed in the spirit of collaboration and alliance-building around common purposes; and (c) develop personal and organizational strategies to address the limits of reframing around the social model so long as the social model remains a voluntary practice, in contrast to government-mandated compliance with disability laws and regulations.

Dispositions and Professional Journeys

In telling their life stories participants highlighted the family, educational, and professional experiences they chose as relevant to their professional journeys and encounters with disability. The interview prompts were "First, I would like to get to know you. Can you tell me briefly about growing up and about your education? Can you describe your professional journey? And How did you first engage with the issue of disability in your

personal and/or professional life?" These experiences tell us about the development of participants' worldviews that may be helpful in understanding how participants came to the junctures in their professional lives where the social model ideas resonated and took hold.

Two participants (Dara and Emmett) described how, growing up as people with disabilities, they experienced the disadvantages of educational systems that were illprepared to serve them. Dara grew up "very, very poor," raised by a widowed mother and changing schools nearly every year. Like several other participants, she expressed this experience in terms of *difference*, as having "a very clear understanding of what it's like to be treated differently through our low socioeconomic status, through socially not having what other people have or being able to do what other people do, and also through illness because I have had my chronic illness diagnosed when I was seven [and eventually became blind]. So I've been living with that ... [and] have a very good understanding of walking in other people's shoes." Dara credits her mother's influence for instilling in her the sense of self-worth and a capacity for self-advocacy:

Dara: "[My mother] did a wonderful job of teaching me that I am different. And that was with all good intentions so that I would understand—not so much discrimination—but I would understand being treated differently. I would understand people trying to help, I would understand people leaving me out—that kind of thing. I had a firm understanding socially of how that worked... I was really encouraged by her to ask questions all the time. Now, this wasn't so much the social model, but I think it really was the beginning of my understanding that I can control my environment through an understanding of what's going on and through saying what I think, and valuing the idea

that I'm the person with the disability and it is the doctors and the medical people who need to listen to what I say so that I would have an equal partnership with my doctor not 'they know everything and I have to do [what] they say because they know what's best idea.' I've always done that."⁶

Dara persisted in higher education despite setbacks and the lack of support for the blind, earning a bachelor's degree in speech and hearing science, a teaching certificate, and master's degree in reading, a second master's degree in rehabilitation counseling, and an all-but-dissertation, having run out of time to complete a doctorate due to her deteriorating eyesight and lack of assistive software to conduct research. She held positions as a counselor, a teacher, and a principal, but eventually lost her job: "I was fired because I was blind." This discriminatory dismissal led to difficulties in gaining/keeping jobs in K–12 education and elsewhere, depression, and reliance on welfare. Among the short-term positions that punctuated this period was a position in state rehabilitation counseling services. Dara's colleague left for a university job and later alerted Dara to a disability resource coordinator position in university disability services (the position Dara has held since 2015), where her career regained its footing and she came to experience the social model in practice.

Emmett's childhood injury caused impaired eyesight and he describes the negative "othering" attitudes he experienced in his secondary and post-secondary education that informed how he perceived the treatment of people with disabilities in his country:

⁶ Zola (1972) offers relevant critique of medicine "becoming a major institution of social control, nudging aside, if not incorporating, the more traditional institutions of religion and law. It is becoming the new repository of truth, the place where absolute and often final judgements are made by supposedly morally neutral and objective experts" (p. 487).

Emmett: "[I grew up] in a regular school where attitudinal barriers made me the 'other' and where my intellectual talents remained invisible. Even when I went for my postsecondary education, the interview had the conversation skewed towards what I cannot do even though my results reflected my intellectual ability. Because of this experience, my philosophy, which is based on social justice, took shape from an early age... [that] creating a barrier-free environment enables people with diverse needs to succeed in life. Attitudes and cultural practices that 'other' people on the basis of a disability limit appreciating how the society 'produces' disability and creates systems that maintain the culture of ableism. The ability of individuals with disabilities is hidden, not unearthed and nurtured. Equal opportunity is a distant. This cultural practice does not imagine any good that a person with disability could offer. While growing up I became conscious of the class society in which certain classes project themselves as powerful and subjugate others."

Emmett earned college, master's, and doctorate degrees focusing on special education, deaf education, and curriculum and instruction, as well as access to higher education for students with disabilities. In terms of career progression, after working in public school services for students with special needs, he took a job of assistant manager (2009) and became manager (2013) in a university disability resource center, overseeing the department and applying the social model approaches—which he came to understand through formal education, professional development, and practice—to eliminate barriers to educating students with disabilities.

The theme of growing up feeling different was also explicit in Gwen's account. As a child of missionaries, she spent a considerable part of her childhood in South America, "in a jungle where I didn't hear English other than with my parents and any other missionaries that came to visit our family. I grew up with indigenous kids... [and spoke the indigenous language.] So in my childhood I've always felt different. I never fit in because my childhood was so different from everybody else's." Gwen credited her family with instilling in her and her siblings humanitarian values ("peace not war; accepting people; giving when you have something and someone doesn't") and comfort with difference, explaining: "we learned early on that there were differences in people: languages spoken; different environments. I learned culturally to accept a broad range of people and I've always felt comfortable with differences." After completing a college degree, Gwen settled in Canada, where she earned master's degrees in English and Spanish, and in counseling psychology. She entered her career in higher education at a community college in the late 1970s, ran a state-funded organization focused on assistive technology for post-secondary organizations and employment services, and launched influential programs. Now retired, she is known as a pioneer and a leader in transforming disability services, contributing to professional development, writing, and advocacy.

Jaden emphasized his background as a first-generation college student attuned to equal opportunity ("college was a big transition in my life"). He studied psychology and "somewhere around junior/senior year where I think I would just notice people with disabilities around campus, at least visible disabilities, someone in a wheelchair, someone who's blind using the cane whatever, and I just naturally started thinking about what it would be like to be in their situation." With this emerging interest in disability and seeking

a career that "can provide me a lot of meaning and purpose in terms of positively impacting people with disabilities," he went to earn, in 2012, a master's in rehabilitation counseling and entered the university disability profession. At the time of the interview, Jaden's job history consisted of two positions, both in disability services in two different universities, which enabled him to contrast his work in a compliance-based disability service environment with the environment that he associated with the social model. He described how the latter environment aligned with his desire to remove barriers facing students with disabilities in higher education and with his passion for "equal opportunity and access. I feel like the little things that we all take for granted—anyone should have access to that, anyone should be able to perform daily tasks, to be able to have dignity, to be able to enjoy the things that we all enjoy."

Also a first-generation college student, Warren initially set sights on becoming a park ranger. On a summer internship while in college he met a camp director who, with government funding, launched an innovative summer camp integrating youths with and without special needs (learning, emotional, and physical) and invited Warren to run the program (in the late 1970s). He also began dating and married a woman who "had a hearing loss [and] had no accommodations, because that wasn't being done at that time; just relied on [family] and friends." He summed up these experiences as "kind of my introduction to all this disability stuff." What followed were various employment and vocational rehabilitation jobs and, eventually, from 2007 through the time of the interview, a career in post-secondary education disability services with four different colleges, ending with a position directing a disability resource center at a large university. He also earned a master's in guidance counseling. His work in the social model began in 2008 when, for

professional development purposes, he entered Project ShIFT ("Shaping Inclusion through Foundational Transformation"), which, as detailed further on in the chapter, aimed to socialize higher education staff and faculty to inclusive models of disability. For Warren, this encounter proved "life-changing," building on his commitments to diversity, where disability is just one aspect of human difference, and inclusion through changing disabling environments.

Caitlyn's first "exposure to disability support services" happened through her campus job in her master's studies in student affairs in higher education, with a focus on the higher education field, including management and student development. After graduation, she worked in settings where student support services encompassed the function of serving students with disabilities. In her last job in a small college disability services, "especially in the last five years or so I've taken over the role overseeing all of our accommodations and support for students with disabilities." Through practice, Caitlyn's understanding of disability evolved over time:

Caitlyn: "my concept of disability really shifted and I realized that folks needed accommodations for things that we couldn't see. In the different colleges that I've worked at, that has been the primary—the invisible disability: learning disabilities, attention disorders, psychiatric conditions, medical conditions—things that we can't see. And the academic accommodations that students need have been the primary focus as opposed to accommodations for any kind of physical disability. I think that my understanding of disability was pretty incomplete for a very long time and it wasn't until I started doing that work in the college setting where students needed the

academic accommodations that I started to think outside of that the physical disability realm."

She also came to recognize that her current college's dated student support infrastructure and culture had fallen out of step with the needs of the changing student population that required more support services. Through her role, in trying to meet student needs for accommodation, she came to seek systemic solutions and found that her developing understanding of the social model and universal design provided some answers for her professional role within her campus—which was focusing on creating an inclusive environment on campus.

Finally, Martha's journey clearly echoed the above themes: of being exposed to disability (a high school project in the deaf community and American Sign Language), learning more about disability and marginalization in college, and then attending a graduate school for a master's degree in counseling that was committed to deaf culture and offered a framework of disability that appealed to what Martha called her "social justice frame." Later, while employed in disability services, Martha found these values, fortified by her graduate education—of respecting the agency, expertize, and authority of people with disability—to be at odds with the prevalent culture. In this organization, staff held patronizing views people with disabilities: that clients "should be grateful for what they get." In fact, it became a strain for Martha to maintain the values she acquired in graduate school, as "those [patronizing, diminishing] messages were stronger and more dominant than the kinds of messages I got while [in graduate school]; so it continued to be a kind of work, I guess, to make sure that I wasn't pulled into that kind of thinking." When she attended the AHEAD professional development institute that introduced her to the social

model and set her on a lasting path of learning about and applying the model, she found ways to reconcile her values with her work within higher education disability services.

In total, this brief review of participants' rich and varied life histories indicates an association between participant values of diversity, equality, justice, and empathy⁷ and the resonance of the social model in their professional lives, which was mediated by dissatisfaction with practices and attitudes toward people with disabilities that participants encountered in their places of work, education, and service (more on that sense of dissatisfaction below). When taking a nuanced look at the process of discovering and adopting the social model in the sections that follow, we see that the connection between the values, concepts, and practices was not immediate. Rather, it was a process of gradual discovery as participants came to:

- a. learn the tenets of the social model within the higher education environments of disability services which were dominated by legal, compliance, and medical models;
- b. connect these tenets to their own personal and professional frames; and
- c. change the practices and attitudes in their spheres.

⁷ This study does not attempt to compare participants on the measures of commitment to diversity, equality, justice, and empathy with their disability colleagues who work within other models of disability. The association between these qualities and affinity for the social model may be a direction for further research. For example, Kanov et al. (2004) review literature for associations between empathy, compassion, and sympathy, and relationship between compassion and caregiving (p. 815), and set out "to articulate the mechanisms through which organizational contexts enable the patterns of collective noticing, feeling, and responding that differentiate organizations as sites of human healing. For organizations in which dealing with human pain is a persistent and central part of the organization's mission (e.g., hospitals and health care organizations, fire-fighting units, social service, and support organizations) this form of collective compassion capability may be particularly important for sustained organizational survival and effectiveness" (p. 810).

An aspect of this process that is important to understanding the adoption of the social model is its non-linear character, with participants describing their repeat encounters with the model and iterative reflection. In totality, from the first minutes of the interviews to their concluding passages, the issues of values and meaning consistently rose to a high level of importance in how participants constructed their stories and realities, compelling an application of a symbolic lens to the broader narrative of the social model that emerged from this study.

Encountering the Social Model of Disability: The Vanguard Participants

In terms of its organization, this section first examines the experiences of the vanguard group and highlights where participant introductions to the social model were aligned with AHEAD's strategic initiatives to diffuse the social model throughout higher education. These strategies were summarized in the 2006 article, "Acknowledging and Transforming Disabling Environments in Higher Education: AHEAD's Role," by Lydia S. Block, Gladys Loewen, and Sue Kroeger—all recognized leaders of this movement. The history of AHEAD's vision and programs that addressed universal design and its social context in higher education began with the "2000 AHEAD conference in Kansas City. Sue Kroeger, AHEAD's president at the time, wanted participants to be exposed to the concepts of universal design and to begin thinking about its potential impact on the field" (p. 119). A series of AHEAD forums and publications followed, building out approaches to informing professionals and developing leaders, e.g., the 2002 universal design think tank and the 2005 and 2006 universal design leadership institutes. These milestones, during the period of 2000 through 2006, were captured by Block et al. (2006) as the History of AHEAD's Venture into Universal Design (reproduced as Figure 1). We see below that as vanguard

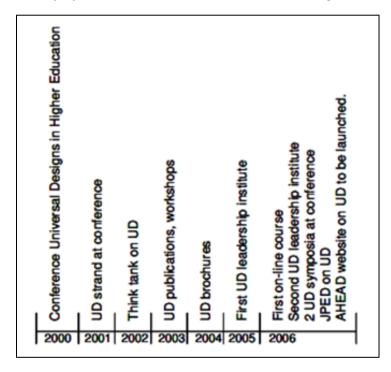
participants accounted for their emersion in the social model, many events that they described could be traced to that early AHEAD history (Table 4 and the Individual Trajectories section below). Overall, Block et al. (2006) acknowledged the alignment of the social model and universal design ideas with AHEAD's strategic agenda and noted the growing currency of the concepts among AHEAD members, but also stated the challenge of orienting the disability profession to a new paradigm of inclusion:

We are grappling with the task of changing the focus toward removal of the barriers that people with disabilities face in everyday life. In the social model of disability, the emphasis shifts from the need for service providers (as experts or helping persons who provide services) to a focus on the importance of allies. As an ally, our primary efforts are directed to serving or changing the environment, not the "client" or individual student. While we know that some students will always need individual support, the belief is that with some environmental changes, many students who typically get supports from Disability Services might be independent in many campus activities. (p.

119)

Figure 1

History of AHEAD's Venture into Universal Design



Source: Block et al, 2006, p. 118.

Note. The term "JPED" appearing in Figure 1 refers to the Journal of Postsecondary

Education and Disability, published by AHEAD. "Universal design" is abbreviated as "UD."

The Role of Project ShIFT in Vanguard Participants' Histories

In addition to participating in the AHEAD events captured in Figure 1, vanguard participants described Project ShIFT ("Shaping Inclusion through Foundational Transformation") as formative with respect to their involvement in the social model. Project ShIFT (2008–2011) was a national, U.S. Department of Education-funded project awarded to Lane Community College in Oregon. The project was aligned with AHEAD's philosophy of changing campus practices and aimed "to demonstrate a model that offers sustainability in institutional change by addressing underlying systems and campus-wide conceptualizations of disability" (Refocus, n.d.-b).

Vanguard participants played different roles in Project ShIFT: Gwen and Martha were curriculum developers/trainers and were further along in their association with social model reforms, whereas Warren, as project participant, received his first in-depth exposure to the social model through this program. Warren was one of the 25 Project ShIFT participants, selected through a competitive process, who participated in the annual summer institutes where they critically examined their own views on disability, learned new approaches, and devised applications for these ideas on their respective campuses to create inclusive, barrier-free requirements, e.g. "revised processes for meeting with students to discuss barriers and implement accommodations, including changes in the third-party documentation required to verify disability" and "discontinued awareness events that focused on disability simulations and use of discussions, events and activities that promote disability culture" (Refocus, n.d.-b).

One source was especially helpful in both communicating the purposes and impact of Project ShIFT and describing how the reform work continues to date: the Refocus web site, itself a *product* of Project ShIFT. Refocus was "created as a tool for examining the role the [disability] resource office can play in challenging stereotypes and creating truly equitable environment" and remains a public platform for disability professionals; it is authored by Carol Funckes, Sue Kroeger, Gladys Loewen, and Melanie Thornton, recognized for leading disability service reforms (Refocus, n.d.-a). Of interest to this dissertation is how Refocus elucidates the idea of shifting, rethinking, and reframing campus disability practices and the role of disability professionals is reform leaders on campus:

Historically the Disability Service (DS) office on a college campus is the entity entrusted by administration with responsibility for anticipating and responding to all issues related to disability. DS personnel usually operationalize this role by focusing on legislative requirements to ensure that the institution stays in legal compliance. Thus, DS staff spends the majority of its time requesting and reviewing disability documentation, determining and implementing individual accommodations and consulting on physical facilities. With an almost singular focus on legal compliance, DS offices typically lead their institutions to consider "what must be done" rather than "what can be done." This emphasis impacts their interactions with students and faculty, affects the development of policies and procedures and may keep the DS office, and by turn the campus, stuck in a compliance narrative that promotes a response based on an obligation rather than one based on the values of equity and inclusion. Project ShIFT was founded on the belief that if DS offices reframe their notion of disability and redesign their service delivery practices, they would send different, more positive

messages about disability to students, faculty and administrators. They would serve as leaders for faculty in the redesign of curriculum, the use of inclusive instructional strategies, and the infusion of disability into course content. Their leadership would include initiating and sustaining change on campus. (Refocus, n.d.-b)

Warren provided an additional perspective on the impetus for Project ShIFT, which, in the quote below, was conceived as a way to overcome an inert pace of reforms:

Warren: "Gladys Loewen and Sue Kroeger—they have been in the work for a much longer period of time and wrote with three others the Project ShIFT grant and were key trainers in that three-year project." "The underlying reason they wrote the grant was they realized they could talk about universal design (and had been for years as you see) but the fulcrum was to change the role of the disability services staff: from repetitively doing accommodations over and over—to one of being empowered to ask faculty to think about inclusive design on the front end, while also challenging the social construct of disability from one of the person as defective/deficient, to one of the 'problem is the design.'"

Scott and McGuire (2017) examined Project ShIFT as an effort advancing social-modelinformed paradigm shift, where "a consequential paradigm shift now reframes the analysis of disability away from the medical model where disability is inherent in the individual. In the current social model, disability 'stems from the failure of society to adjust to meet the needs of disabled people' (Loewen & Pollard, 2010, p. 9). Society is responsible to adapt and create environments that are inclusive and flexible. Equal access, preferably achieved by design, not by accommodations, is the goal)" (p. 119).

This overview maps the encounter of the vanguard participants with the social model in the context of AHEAD's early strategic efforts to advance the adoption of social model and UD concepts and practices in the field. Table 4 traces the initial involvement of vanguard participants with the social model along the timeline introduced in Figure 1, combined with Project ShIFT.

Table 4

Vanguard Participants' Involvement in AHEAD Universal Design (UD) strategy

and Project ShIFT

AHEAD programs and Project ShIFT	Vanguard participant role		
	Gwen	Martha	Warren
2000 Conference on UD	Program chair ^a		
2001 UD strand at conference	Program committee member ^b		
2002 UD think tank	Organizer, facilitator		
2003 UD workshops, publications	Presenter, editor ^c		
2004 UD brochures	Co-author		
2005 1 st UD leadership institute	Co-organizer, trainer		
2006 1 st online UD course 2 nd UD leadership institute Two UD symposia JPED issue on UD Website on UD	Co-organizer, trainer Co-organizer, trainer Co-organizer Author Co-designer	Attendee Attendee Presenter Author Contributor	
2008–11 Project ShIFT	Curriculum developer, trainer	Curriculum developer, trainer	Trainee

Note. AHEAD's UD strategy timeline is based on Figure 1, listing the initial UD strategies.

The efforts continued post-2006, but are not captured in Table 4.

^a Responsible for conference content, speakers, presenters, topics

^b Mentored program chair, coordinated a UD strand

^c Charged with publishing the Reframing Disability column

Moving from this macro perspective to individual stories of vanguard participants, we can explore the process whereby the social model resonated with participants' values; and with their professional dissatisfactions and desires to change specific practices and attitudes that they found in the field of disability services. We also see specific instances of reframing the habitual ways of thinking and acting around the social model that illustrate how vanguard participants acquired and refined their social-model-informed frames through continuous practice, critical reflection, and the work of advancing the social model in the field as organizational and thought leaders.

The Vanguard Participants' Individual Trajectories

Gwen's introduction to the social model and universal design occurred through AHEAD. Already an experienced disability professional and an active AHEAD member, she was critical of AHEAD's excessive focus on the legal model and compliance rather than the human rights perspectives—and was recognized for "thinking differently" by Sue Kroeger. Kroger, who at the time was developing a vision and a strategy for AHEAD's role in "transforming disabling environments" (see Block et al, 2006), asked Gwen to chair the 2000 AHEAD conference on universal design in higher education, although Gwen was new to the concepts of universal design and the social model at the time. Gwen recalled objecting to Sue:

Gwen: "you're asking [me] to be in charge of the intellectual content of the United States, which has a legal frame... in [my country] we don't have a law like that. We have the Human Rights Code, which says you cannot discriminate against age, disability, race, you know, like all the 'isms.' We use that as a guideline and we get to the same place you

do without a law. We do what's right and we end up at the same place, but the journey is different and the questions we ask are different."

Sue's invitation set in motion Gwen's decades-long learning, leadership, and reflection around these ideas as applied to the work of transforming disabling environments. The work involved learning from, being mentored by, and working alongside leaders and experts like Kroger, Elaine Ostroff (co-founder of Adaptive Environments and a leader in inclusive design), and Simi Linton (influential disability scholar and author).

At the same time, Gwen took on leadership roles in organizing, training, speaking, and writing on the social model and universal design (including through AHEAD, as reflected in Table 4) to transform thinking and action around disability services. Later in the chapter we see how Gwen applied these ideas toward organizational change. First, however, she underwent the immersion and transformation herself:

Gwen: "It's almost like, you know, people who are religious, you have this born-again feeling.⁸ You need to be immersed in [the social model] and fully believe it. It's not something you just decide to do and you do it, because you have to look at your language, you have to look at your attitudes, what you think disability is." "[My transformation] was a slow, long process, but I'm grateful that Sue [Kroeger] got me into this because it changed the way I did my job and it changed, it allowed me to claim

⁸ Of interest to Gwen's pointing out parallels between embracing the social model and having a religious transformation is Drønen's (2006) analyses of applying Kuhn's theory of paradigm shift to the study of religious conversion, where per Kuhn (1996), "The man who embraces a new paradigm at an early stage must often do so in defiance of the evidence provided by problem-solving. He must, that is, have faith that the new paradigm will succeed with the many large problems that confront it, knowing that the old paradigm has failed with a few. A decision of that kind can be made on faith" (Drønen, 2006, p.232). In particular, Drønen points to the role of crisis as precipitating adoption of a new paradigm (2006).

my disability." "I don't see myself as disabled like someone, you know, visibly disabled, and it took, that helped me embrace my journey in accepting my differences and being comfortable asking."

Gwen credited meeting Linton and reading her *Claiming Disability* (1998) as particularly affecting as this brought Gwen to recognize the value and power of acknowledging disability as a political tool, as opposed to the practice of hiding disability and using euphemisms to describe it.⁹ For example, this quote from *Claiming Disability* contrasts the notions of disability within medical and socio-political perspectives, and informs the demand that disabling conditions be changed:

When medical definitions of *disability* are dominant, it is logical to separate people according to biomedical condition through the use of diagnostic categories and to forefront medical perspectives on human condition. When disability is redefined as a social/political category, people with a variety of conditions are identified as *people with disabilities* or *disabled people*, a group bound by common social and political experience. These designations, as reclaimed by the community, are used to identify us as a constituency, to serve our needs for unity and identity, and to function as a basis for political activism. (Linton, 1998, p.12)

⁹ Gwen's reflection on claiming disability: "claiming disability allows you to use the word *disabled* or *disability* as a political tool like *women* in *the women's movement*. Vietnam Vets claim disability and Agent Orange as theirs, you know, something that affected them emotionally, intellectually, and physically . . . a movement needs to hang onto something and claiming disability allows you to use that word as a powerful tool: that it's not a negative thing, it's a positive thing, and that it's people's views on disability that impair you, their approach to disability that really makes you handicapped, or makes you impaired, or makes you not be able to participate in an environment... you view it as a difference and it's part of whom we need to include when we're looking at inclusion, then it becomes a powerful term."

This sorting of disabled students into medical categories was what Martha encountered when, after burnout in social services, she found herself (around 2000) working in a university-based federally-funded project to teach faculty specific methods of working with students with specific types of disabilities: "[Our approach was asking] how do you teach people who are deaf? How do you teach people who are blind? How do you teach people with learning disabilities? And initially I didn't question that; that was kind of what everyone was doing at the time." She began hearing about other universities exploring universal design and mainly thought of it in terms of universal design for instruction until she signed up for the AHEAD online course (see Table 4), which introduced Martha to the social model. For Martha, this experience was transformative, demonstrating how her values and her work as a disability staff member could align:

Martha: "The instructors were Sue Kroeger, Gladys Lowen, Carol Funckes, Bill Pollard, and Elizabeth Harrison, all of whom are good friends of mine now. . . They took this concept of universal design and kind of filled the gap for me. . . that was really about the social model. But because universal design was kind of a keyword at that point, they grabbed hold of that and started challenging: If we really do value universal design, then why is the [disability] service office so focused on the individual student? Why are we... providing separate services that are separate but not really equal? Those instructors really made me rethink or basically say, okay this concept of universal design isn't just about instruction, it's not just about environments. It's about how we view everything, where we put the problem of disability."

Martha: "[The experience] really was life-changing for me because... it all kind of came around: like the social justice perspective that was instilled in me by my friends, my deaf friends at [graduate school]. Suddenly I realized I can approach my work in a way where those two things work together... I didn't say that but I realized afterwards, in retrospect, that it felt like I kind of had these two different things happening. I had these beliefs in social justice and equity, and viewing disability, and being deaf as an identity and a culture. I had all that, but then my professional work was not fully aligned with that. And through that [AHEAD] course, I felt like I could at least move toward having those two things be more in alignment. So it was very powerful."

From this point, Martha's role evolved from a professional development participant to an active contributor, instructor, presenter, and author at AHEAD (Table 4), and she also sought to bring organizational change to her university work. Martha described Kroeger as influential significant influence: "her thinking about, her immersion in disability studies goes back further than us, and just her thinking about the problems of the typical approaches in our profession is much more well-articulated than most of us. Having the opportunity to sometimes argue with her [was] important I think for our own development—to just say, 'Wait a minute, how can that happen?'"

The professional paths of all three vanguard participants converged in Project ShIFT: Gwen and Martha as curriculum developers/trainers; and Warren as participant. For Warren, working as director for special populations at a community college, with years of disability work outside of higher education prior to that, the introduction to the social model through Project ShIFT proved as decidedly transformative, life-changing—just as Gwen and Martha felt when they "found" the social model. Warren described how Project

ShIFT "challenged us as disability services professionals in higher ed to rethink how we do our work because at that time it was very medical model-based...[diagnosis, documentation, decision-making, authority]" and "introduced us to the concept of the social model. None of us going in knew what we were getting into. So this is the best professional development thing I've ever done." Project ShIFT participants found the conversations difficult and even upsetting, but the trainers took the time to engage in discussions, and the ideas generate positive responses.

The discussions resonated with Warren's views of disability as "an aspect of diversity, civil rights, and social justice" and with his experiences with social service systems meant to limit access to disability benefits, "cut people off." Through Project ShIFT, Warren formed a new, satisfying approach to work—"I was so invested in the medical model for so long... I'm so happy that I met the trainers and got [the medical model] because I'd be a pretty miserable person without that lens." He also formed lasting relationships with the leaders in the field (Sue Kroeger, Carol Funckes, Gladys Loewen, and Melanie Thornton) and described the group as "still really active with the movement." As with the other vanguard participants, Warren went on to apply the social model in leading organizational change as a manager of disability services and a frequent national presenter and member of AHEAD.

Being a trainer on Project ShIFT, Martha witnessed a transformation in those she trained on the social model, similar to her own shift in thinking; but she also saw the limits of training where the social model ideas left some training participants unconvinced:

Martha: "[Project ShIFT] gave me the opportunity to see other professionals go through the transformation that I went through in working through the course. They were

immersed even further because they had these three week-long sessions together and did work throughout the year between those sessions... To be honest, there were some people that it just didn't resonate with them... It feels like there's a certain part of these shifts at this point in our profession that require people who already have those values in place (of social justice, equity, inclusion), for whom those ideas really resonate to say, 'Aha, this makes my work more fun. I feel better about doing things this way and I'm going to do the hard work'—because it is hard work of shifting the way we approach the work in the office. We had kind of a core group of people who had that experience, like 'Oh, how could I've ever done things any differently?' I think that was my experience, too. It's like once I made that shift, mentally, then I saw problems with the way I had done everything, I couldn't change it quickly enough. And there were people that had that same experience, and those people have become leaders in AHEAD, leading the same kinds of conversations with their peers."

To summarize, the commonalities within the vanguard group included the longer arc of participant engagement with the social model; being directly influenced and inspired by the leaders in the AHEAD organization and the social model reform movement; the networks of relationships formed to bring change informed by the social model; and their work to influence their own organizations and the disability profession at large, including via AHEAD. These characteristics set the vanguard participants apart from the secondwave participants for analytical purposes in this dissertation. Nonetheless, the vanguard and second-wave participants raised similar themes, including the value frameworks and dispositions they brought to their work in the disability field and desire to create welcoming campus environments for students with disabilities. As we see below,

dissatisfactions with the treatment of people with disabilities and with the existing disability service practices played a role in how second-wave participants came to align themselves with the social model.

Encountering the Social Model: The Second Wave Participants

The theme of alignment between personal values and the social model-based work environment is clearly present in Jaden's and Dara's accounts. They both encountered social model-based environment when they moved into new jobs, in about 2017 and 2015 respectively. Jaden, who had held only two jobs after graduate school at the time of the interview, described his first job in a compliance-driven disability service environment in decidedly negative, professionally unsatisfying terms and perceived this environment as a cause of his questioning his career choice of disability field:

- Service was "bare minimum"; "very, very fast turnaround meetings [with students]."
- "I thought I was in the wrong field because I was just so frustrated. It didn't provide me much meaning [and purpose in that role]. I was just going in and reading paperwork and making decisions for students and I really didn't have any interaction with them, I didn't really know how they were doing after they left my office."
- "I felt like something wasn't quite right, it just felt just kind of counterintuitive to be quickly meeting with the students and making these significant decisions on their behalf without much of their input. I felt like it was a disservice to the student to have them come in and say, 'Hey, we made all these decisions for you. This is how you use your accommodations. See you later.'"

 "It took finding out that it was not the work itself that was problematic for me, it was the work environment."

That "finding out" happened when Jaden took a job in a social model-oriented disability service office, which he described in terms of "student-focused," "collaboration with faculty and staff," a university priority; "making decisions for the student while incorporating their input"; removing barriers. In this job, Jaden learned that it "makes a big difference in the environment that you are working in, and the people that you're working with. You need to surround yourself somehow with people who... want to be progressive, who are champions of big ideas... we just, we want to do things the way that we feel are the right way to do things." It was here that Jaden had his first in-depth introduction to the social model, both in practice and in theory, and found that his own values and the tenets of social model and progressed from having a vague familiarity with models of disability and instinctive understanding of barriers to the affinity with the social model that was grounded in disability literature and practice:

Jaden: "[My supervisor] had a lot of experience in the field and was very passionate about [the social model]. He asked me if I wanted to help write this paper, and it was kind of my first exposure to this social model in detail. I think maybe in the past I vaguely heard about other concepts, you know the medical model and so forth, but never really dove into them. About three years ago was when I was first exposed to it in depth... I was learning a lot as we went through the process. But again, I think it was kind of fitting to how I believed we should be doing things in the first place instead of looking at the person as a problem. Let's look at the environment. Let's create a more

accessible world so we have less need for individual accommodations." "I found [that this college is] much more student-focused, and [students] are the centerpiece of the process... We also focus on, 'How can we remove the barriers in the environment so that they can have that equal access and opportunity?' rather than like we need to correct you—more of the medical model, like you [the student] have a problem that needs to be corrected."

Dara arrived in a university disability service department that is committed to the social model after years of working as an educator and a disability service provider. Her career encompassed advancement to the position of a school principal and significant education attainment all the way to the all-but-dissertation status, but was also punctuated by setbacks like losing jobs and being on public assistance, which Dara described as "a terrible spiral downward with depression and shame." As a person with disability, she experienced first-hand how disabling environments can be, as when lack of access limited her ability to do research and reading in her doctoral program, or when as an educator she had to find strategies to access students' paper files because "nothing was computerized." Like Emmett, she had her competency questioned, as when a work meeting was called where colleagues raised discomfort about her work and she was not invited to attend. Dara also recognized the imbalance of authority between the medical profession and the disabled person and thought "it is the doctors and the medical people who need to listen to what I say so that I would have an equal partnership with my doctor," which Dara associated with her early, intuitive sense of the social model. Her formal, theoretical introduction to the social model happened in her graduate studies, as she "began to see a whole different paradigm that... took my breath away, when I began to discover that this is

really a thing, that this is out there, that there is something that has always felt right to me, but I've never been able to fully experience." Through her graduate studies she connected to the ideas and histories of people on the margins who "had been silenced" and to the social model, which she phrased as "the social dynamic where... the environment creates the disability. And that was incredibly empowering. Just personally it was incredibly empowering." She finally came to experience the social model in practice in her current job, which happened years after reading the social model literature. Dara offered an account of what becoming part of an inclusive environment felt like, from the perspectives of a person with disability and a disability professional:

Dara: "I spent most of my childhood and... young adult life hiding [my disability] and denying it to myself, and working every day to be as able as everybody else. When I began to lose my vision, I began to feel disabled, so much more disabled, and I began to *behave* like I was disabled because I [was] familiar with the medical model and knew that there were things I wasn't ever going to be able to do, and knew that people pitied me, or excluded me, or overly tried hard to help me and make me feel good, you know, and it felt awkward and embarrassing."

Dara: "And then, through learning about the social model, I felt like a Pioneer because I had credibility as a person with a disability and I was able to speak more openly and be listened to."

Dara: "When I came to work at the university—that was my first real experience with the social model as a person with a disability. There were no limits in terms of support, and education for me, and accommodations for me—whatever I needed to do the job because I was hired and valued for my education, my intellect, and my communication

with other people. The rest of it wasn't even a consideration. That would just be taken care of so that I could do the job. And it still holds true today to the nth degree with every person I work with in my department. I'm learning how to be, what it feels like to be valued as an equal."

Dara: "[My current job is a completely inclusive environment.] It allowed me a sense of self-worth personally and professionally that I didn't know existed. I knew I could talk about [the social model] and I knew it was a great idea and everybody should be doing it, but experiencing it has given me so much more self-worth and I'm so much more able to be vulnerable professionally and socially without feeling ashamed or embarrassed of mistakes I might make, or things I don't know. So it really helped me know, really believe and feel that I am OK."

In Dara's view, her department is deeply committed to inclusion and she is moved to be part of this community, rather than facing obstacles and challenges alone, as was her past. It is "an environment that is extremely current and proactive and hyper-aware of the social model and of individualization and of universal design"; where leaders and staff "are fiercely committed to all of those things"; "where the whole department has this same and beautiful understanding, and many other people throughout the university do also. It feels like I may have caught a small wave and I'm able to… be part of something bigger than just my own understanding, and my knowing… how good it can be. So I'm now able to work with other people, with and without disabilities, students and faculty and staff who do have this powerful understanding and a powerful drive to make these changes in our community and in our university. I'm quite lucky to have caught the wave because… now, where I work, it's more than one person at a time."

Emmett, who, like Dara, is disabled, also came to understand the social model and universal design over time. His first introduction to the social model was as a theory and occurred in an undergraduate course. At that time, the social model "did not really make sense to me, having been trapped in and socialized into the medical model for a very long time... throughout my training in special education." The concepts began to make sense later, when his PhD advisor asked Emmett, working as an assistant manager in a university disability office at the time (about 2009), to look at models of disability as a context for understanding access to higher education. Through his research, Emmett "discover[ed] perspectives on disability beyond impairment. I began to question the model of service [where] disability was missing in learning and teaching policies, strategic plan, exam procedures did not outline provisions for students with disabilities. It was as if there were no students with disabilities on campus" (Emmett lives and works outside of the US, where different disability policies exist). He also researched universal design and learned more about it when he attended a professional conference on the subject. Emmett explains that "the need to create a barrier-free higher education learning environment prompted me to act [on the] ideas of social model and universal design; [to question] the medical model;... [and] to examine the social arrangements of higher education environment." Now a manager of university disability services, Emmett is working within the department, with university leadership, and across university functions to transform his campus environment by practicing the social model and universal design. On reflection, Emmett agreed that his personal experience with disability, his advanced education and professional development, and knowledge of different models of disability all contributed to his desire to put these ideas into practice. And, he added, his "extensive reading in the

area of higher education and disability [and] Neo-Marxist ideas have helped [me] to understanding the plight of persons with disabilities in its distinctiveness." Finally, as a disability scholar Emmett has published journal articles, a book chapter, and book reviews on the issues of disability rights and inclusion.

As with Emmett, Caitlyn's account pointed to the distance between first encountering the social model ideas and later coming to practice the social model on campus. Working as a student services professional on college campus (roughly starting around 2010) she became concerned that more and more students with learning disabilities and developmental disorders were entering college, but her college had dated ideas about disability and had inadequate structures for student support. Several years prior to being interviewed for this study, she began researching the social model, universal design, and universal design for learning on her own. Caitlyn "came to wrap my head around the social model of disability," "started to put the pieces together," and the ideas that one could design environments to be broadly inclusive "really resonated." She later completed a post-graduate certificate program in Universal Design and Technology Integration at Landmark College Institute for Research and Training. Along with independent learning and professional development, she was learning from her campus colleagues that things needed to change, and she began applying the social model and universal design concepts, now in her role as Associate Dean of Academic Advising. Asked to recall what prompted her to put these ideas into action after completing the certificate, she pointed to her experience with the campus behavioral intervention team:

Caitlyn: "One of the things that we've started to see with our behavioral intervention team is a little bit of scope creep where folks are now reporting any kind of behavior that is bizarre to them. It really started to take up a lot of our time rather than worrying about the students who are a danger to themselves or someone else; people were reporting behaviors that I know from my experience are consistent with someone who may be on the autism spectrum, for example; not behaviors that are harmful or dangerous or disruptive—just kind of different."

Although a lot remains to be done to create an inclusive campus environment, Caitlyn expressed optimism about change:

Caitlyn: "I have been cheered to see the movement in this area among young people... As problematic as the term 'neurodiversity' is (it's used in a lot of problematic ways), I've been really cheered by that movement because I think... [it] is rooted in the social model. While it may not completely encompass physical disability at this point, maybe I'm just really tuned into different movements and organizations and groups that are doing that work. So I'm skewed, I'm sure my perception is skewed, but I've been cheered about that because I think even without using the language of the social model of disability that's starting to get some traction. And it's in the grand scheme of the world, globally, and what happens I know is minimal, but that's been really cool to see. Even on my campus where we are pretty behind the times in a lot of ways, people are starting to use that language. They're not necessarily implementing everything that we need to reduce all the barriers in the environment, but they're starting to use that

language. So I agree ... it's going to take a while, but I think it's starting, and I'm enthused to see some of the movement."

Aligning with the Social Model: A Summary

This study explored factors that compelled participants to put the social model and universal design ideas into practice, what the process looked like, and what meaning engagement with social model had for participants. In tracing participants' first encounters with the social model, several common factors emerged indicating how the social model took hold as a mindset and a practice frame once participants became familiar with it. The common gateways to learning about the social model were doing independent reading, working on postsecondary degrees, participating in professional development, and encountering mentors and leaders who nurtured both understanding and practice. Among the vanguard participants, for example, AHEAD leaders were particularly influential, and all of them named Sue Kroeger's work to pioneer frameworks, strategies, and practices to disseminate social model ideas and practices into the disability profession on a national and international scale. Through first-hand accounts, we witnessed how participants formed an affinity to the social model and set out to put it into practice. The common themes that emerged from these accounts were that participants:

 expressed the values of diversity, social justice, human rights, disability rights, and empathy; and found that their dispositions and identities aligned with the social model;

- even prior to encountering the social model, developed critical and negative perspectives (some as disabled people themselves) on disability services framed by other models (compliance, legal, medical) and were dissatisfied with how people with disabilities were served in participants' respective work settings;
- were exposed to the social model in theory and practice, on multiple occasions, and over time, as their understanding of, and the affinity to the social model, strengthened; and (some) were particularly influenced by thought leaders in the field;
- came to the conclusion that the social model offered a better alternative and better solutions for advancing inclusion of people with disabilities and were prompted to act—creating inclusive environments and changing mindsets and practices around the social model;
- In working with the social model, found a greater sense of self-worth, professional purpose, and job satisfaction.

Drawn from participants' lived experiences, these findings regarding the process of change may be instructive to the advocates and practitioners of the social model, and the implications are synthesized in the Conclusions chapter of this dissertation. Briefly, when setting out to shift mindsets and practices on their campuses or within the disability profession (especially given the scale of the paradigm shift being pursued in higher education), if could be helpful for reformers to draw on the lessons from the complexities and nuances of their own adoption of new models of thinking and behavior.

Liberation from the Habitual Perspectives on Disability Work

In the narratives of leading change around the social model, an important space is occupied by how participants themselves underwent the process of transformation that liberated them from long-held, deep-seated assumptions and patterns of behavior. Participants of different ages and lengths of disability careers reported the experience of being deeply socialized into the medical model over time (i.e., time as subjectively experienced by participants, rather than objectively measured). For example:

- "so invested in the medical model, for so long" (Warren)
- "trapped in, and socialized into, the medical model for a very long time" (Emmett)
- "initially I didn't question that; that was kind of what everyone was doing at the time" (Martha)

The phenomenon of entrapment in ways of seeing and doing things is recognized in the management and organizational literature as a source of difficulty in initiating or accepting change. The influential organizational theorist Gareth Morgan captured this phenomenon in a significant chapter of his 1986 *Images of Organizations:* "Exploring Plato's Cave: Organizations as Psychic Prisons." Drawing on the cave allegory from Plato's *The Republic*, which famously illustrated how a person's knowledge of reality is influenced by particular perspectives, Gareth argued that organizations themselves can influence reality and act as psychic prisons, explaining:

The metaphor joins the idea that organizations are ultimately created and sustained by conscious and unconscious processes, with the notion that people can actually become imprisoned in or confined by the images, ideas, thoughts, and actions to which these processes give rise. The metaphor encourages us to understand that while

organizations may be socially constructed realities, these constructions are often attributed an existence and power of their own that allow them to exercise a measure of control over their creators. (p. 215)

In practical terms, this means that organizations exhibit visions and cultures that "lead to blind spots. Ways of seeing become ways of not seeing. All the forces that help people and their organizations create the shared systems of meaning that allow them to negotiate their world in an orderly way, can prevent them from acting in other ways." This idea is equivalent to McLuhan's "fish swimming in the water and unable to perceive it" metaphor (p. 217) and is also recognized as "*groupthink*, a term coined by Irving Janis to characterize situations where people are carried along by group illusions and perceptions that have a self-sealing property" (p. 219). Morgan illustrated how these entrapments can result in decisions and practices undermining the success of organizations and sometimes of entire industries.

The particular challenge that this phenomenon of psychic prison/blind spots/groupthink represents for managers is raised by the question: How does one change and create organizational change in a conformist environment? Or, to paraphrase using the term employed by Bolman and Deal (2008), How does one "break" the frame, where "Framing involves matching mental maps to circumstances. Reframing requires another skill—the ability to break frames" (p. 12)? Morgan (1997) argued that "By recognizing paradoxes tying one into status quo, we can take a first step toward escaping them" (p. 407). Morgan's application of psychoanalytical theories to organizational settings produced insights on what makes change possible, i.e., actively questioning the fundamental premises of organizational reality; recognizing the hold of enduring meanings of individual

participation in an organizational culture ("shared norms, believes, ideas, and social practices," p. 228); and addressing the desire to preserve this meaning and values when facing organizational change where attachments to ideas, values, and roles can become rigid and where change may appear threatening (pp. 236–238). We saw participants engage in similar processes when they began questioning the organizational realities of serving students with disabilities, rethinking the roles of disability professionals, and reframing disability services—and ultimately came to pursue the social model in practice, breaking away from settled models and leading organizational change. In Bolman and Deal's (2008) telling, "Narrow, oversimplified perspectives become fallacies that cloud rather than illuminate managerial action... For those with better theories and intuitive capacity to use them with skill and grace, it is a world of excitement and possibility" (p. 41). Morgan, similarly, pointed to the freedom of transforming unsatisfactory conditions, arguing that

a vision of confinement is invariably accompanied by a vision of freedom. For Plato, this freedom rests in the pursuit of knowledge about the world. For the psychoanalysts, it has rested in knowledge of the unconscious and in the capacity of humans to create a better world through an improved understanding of how we construct and interpret our realities... [By asking questions], We are encouraged to look for messages coming from outside our particular "cave" and to use them for gaining new leverage on our world. This can bring enormous benefits to individuals and organizations, offering a way out of the "groupthink" and "cognitive traps" that may lock us into ineffective and undesirable patterns of behavior. (p. 244)

Another example of how habitual thinking and closed imagination can be a barrier to change came from Martha, as she recalled sharing ideas about fully inclusive campus environments with the director of the campus disability resource center:

Martha: "And when I said 'full participation,' she said 'Is that really possible?' I think that that's the kind of thinking, you know, [that] we can't promise something that we can't deliver on. The reality is sadly that often full participation doesn't happen. In little conversations like that [you recognize] that we, as professionals, often serve as the gatekeepers to access and inclusion. And sometimes disabled students end up being limited by our lack of imagination or lack of vision for what could and should be possible."

This idea of the importance of managerial imagination was also recognized by Boleman and Deal (2008) as a factor that can limit organizational aspirations and results, and can serve as an excuse for management failures: "It can be comforting to think that failure was unavoidable and we did all we could. But it can be liberating to realize there is always more than one way to respond to any problem or dilemma. Those who master reframing report a sense of choice and power. Managers are imprisoned only to the extent that their palette of ideas is impoverished" (p. 19). For participants, the social model came to represent an alternative to other frames of disability services that they found professionally and personally unsatisfying and conflicting with their personal and professional values.

Leading Change: Diffusing the Social Model of Disability

Once the ideas of the social model took hold among participants, they worked to apply and disseminate these ideas in practice, promoting change within their organizational and professional spheres of influence in what could be described as a collective work of paradigm shift. In the interviews, participants were prompted to reflect on leading change with open-ended questions like "How did you go about sharing and acting on these (i.e., the social model and universal design) ideas?" As reviewed earlier, the ideas of the social model and universal design have been around for decades, yet the field of disability services remains dominated by the medical model as both the literature and participant stories attest, and the paradigm shift to the social model is an ongoing project rather than a fait accompli. As recently as 2017, Scott and McGuire applied the diffusion of innovation theory to how campuses adopt universal design for instruction (and analyzed Project ShIFT in that context), arguing that the theory is relevant to the paradigm shift toward the social model of disability and adoption of universal design on campus to advance inclusion, despite the long arch of both disability laws and universal design ideas. The authors argued that the diffusion of innovation theory offers a useful lens for analyzing the process of the adoption of universal design for instruction, for raising critical questions about the process and documenting outcomes (e.g., generating "proof" of the benefits of change that may convince faculty and managers of the benefits of change), and for "[alerting] proponents of the movement to limitations that may impede progress" (Scott and McGuire, 2017). Originated by E.M. Rogers in the 1960s, the diffusion of innovation theory continues to find current applications in fields as varied as education, medical research, and public health policy. Rogers (1995) defined innovation as "an idea, practice,

or object that is perceived as new" (p. xvii) and diffusion as "the process by which an innovation is communicated through certain channels over time among the members of a social system. Diffusion is a special type of communication concerned with the spread of messages that are perceived as new ideas. Communication is a process in which participants create and share information with one another in order to reach a mutual understanding" (p. 35) and may encompass a variety of formal and informal networks, as well as in-person and mediated channels. As noted by Scott and McGuire (2017), interpersonal communication within professional development venues and communication with near peers "who are most similar to the potential adopters along such lines as education levels" have been found effective for diffusing innovations (p. 121). Among the key attributes that determine the spread of adoption are the characteristics of the innovation itself (e.g., its relative complexity, evidenced or perceived advantage over existing solutions, and compatibility with existing values), the time it takes to adopt the innovation, and the influence of change agents. Paralleling Scott and McGuire's (2017) analyses, it would be reasonable to argue that the work of participants, which extended beyond the universal design-informed instructional design, contained the elements of diffusion of innovation and that the theory, although not explicitly applied to this study at its onset, offered relevant concepts to analyze participant reflections on adopting and disseminating the social model, including through Project ShIFT among vanguard participants.¹⁰ As discussed earlier, participants in this study found that the social model

¹⁰ Further application of the diffusion of innovation theory to analyze the spread and adoption of the social model in higher education practice is believed to represent a productive direction for future research. For example, future research may ask: Given that the evidence of efficacy of the social model (positive outcomes) may help the advocates of the social model convince skeptical

offered advantages over the practices they witnessed in the field and aligned with their values and dispositions. Using the concepts from the diffusion of innovation theory, participant narratives indicated:

- using a variety of <u>communication channels</u> to share the social model and encourage its use: the Internet, journal publications, professional publications like brochures and newsletters, presentations to campus members, conferences, professional development events, and staff trainings, to mention a few examples;
- working through a variety of <u>social systems</u>, including professional organizations, campus groups (upper administration, staff of various campus departments, faculty, and disability professionals), networks of agencies, and individuals;
- using <u>formal and informal channels</u> like management positions within organizations, professional interactions between disability professionals and faculty, mentoring others, long-term associations, and positions in the field as opinion leaders or experts to exert influence and persuade others to adopt social model;
- recognizing <u>time</u> as a dimension of diffusing the social model on campus, often remarking on the slow pace of adoption; and
- and exhibiting <u>individual innovativeness</u>, i.e., willingness to adopt the social model early relative to many peers in disability service, to take risk, and to influence others.

disability professionals or faculty, what are the types of evidence that are particularly effective with specific audiences? How do advocates learn about and master the use of these resources?

The vanguard participants, recognizing the relevance and value of the social model, were involved with AHEAD's strategic efforts (see Table 4) to diffuse the social model in the field, remained involved in the movement for many years, and came to be recognized as leaders. They initiated early efforts to transform their own disability offices around the social model, changing the mindsets, language, practices, and professional roles and found that removing environmental barriers (like over-reliance on medical documentation by disability services and strict timelines limiting students' ability to seek accommodations) served students better. The terms *(lead) innovators, change agents,* and *opinion leaders* help capture the leadership qualities of vanguard participants who challenged commonly accepted campus solutions, risked mistakes and resistance to change, and made their values known.¹¹ The ongoing effort to introduce and refine new practices was a recurring theme in vanguard participants' interviews. This theme was illustrated by Gwen's remarks on being an early, long-term leader in the field designing and promoting new practices:

Gwen: "[As consultant in retirement,] I thought I should pursue my passion, which is, really what I wanted to do was undo the wrongs I had done since 1981 when I started the sole focus on disability services ... I wanted to tell people what I would do

¹¹ As summarized by Scott and McGuire (2017), "Some individuals adopt a new idea much more readily than others. Rogers (2003) described this quality as innovativeness, or earliness in relation to others in adopting an innovation. Adopter categories range from innovators (the small number of risk-takers who are first to adopt) to laggards (the small number who are the last to adopt or never adopt an innovation). In between these two extremes are the early adopters who follow the lead of innovators and play an important role by adopting the innovation and furthering dissemination to peers in their local network. They are often viewed as opinion leaders in the system to whom others look for advice and information. Soon to follow are the early majority who adopt new ideas but are not typically viewed as opinion leaders in the group. Finally, the late majority approach innovation with skepticism and caution waiting until most of their peers have adopted the innovation and there is substantial proof of its merits" (p. 121).

differently if I were in the field now. That's how I always framed when I would come in as a consultant."

Gwen, on correcting dated ideas and practices, when teaching a workshop to disability service professionals: "I said, 'A lot of you know me. I've been a colleague of yours, we worked together on projects. And I'm here today to tell you what I've done wrong in my job and what I would do differently, and I want you to learn from my mistakes.' And so that's how I started... And people were quoting me, 'But you started it and I still like your stuff that you did with brain injury.' And I said, 'God, I wrote that in 1989. Why are you still using that? You know, that's so old-school.' And they said, 'But no one else has done anything like that before.' I said, 'Okay, okay, don't use that anymore.' It's trying to get people to—when you've been a leader in the field—to try and get people to realize that you changed and not to just quote your old stuff. And that's important to me." Gwen: "I own my mistakes just because I was… one of the first people . . . Everybody . . . would come to me, the people modeled their offices after what I did."

The second wave participants, too, exhibited efforts at furthering the dissemination of the social model within their social networks. Jaden and Dara, both through job changes, entered university cultures that had already adopted the social model prior to their respective arrivals. Through their persistent advocacy for inclusion and eliminating barriers in working with individual faculty, Jaden and Dara can be seen as continuing the work of diffusion of innovation into campus subcultures, leading the work for change on a smaller scale, in their relatively modest positions as coordinators. Emmett and Caitlyn appear to represent a generation of student-services managers who, by virtue of exposure granted by their graduate education and professional development, built on the cumulative

experience, knowledge, and influence of the innovators who had come before them (or, to put it differently, appeared to "capitalize on the influence of opinion leaders" (Scott & McGuire, 2017, p. 121). They advanced awareness and adoption of the social model on campus in their formal management roles (Emmet as manager of the university disability resource center, and Caitlin as associate dean of academic advising). From their respective narratives, Emmet and Caitlin seemed to be among the first administrators to actively promote the social model in student disability practices on their respective campuses.

Addressing Pro-Innovation Bias

Although participants embraced the social model and advanced its adoption in the field, they did not do so uncritically, assuming that it was desirable simply because it was new and different from existing practices. Rather, participants analyzed the advantages and disadvantages of different models, and acknowledged the practical difficulty of removing all barriers to create universally accessible campus enrolments, echoing some of the criticisms of the social model reflected in Review of Existing Literature. For example, in the quote below Gwen expresses the notion that the social model does not mean that it is feasible to eliminate *all* barriers, removing *all* need for individual accommodation:

Gwen, recalling an impassioned argument at the 2002 AHEAD Think Tank on Universal Design about the limits of inclusive environments: "The president of AHEAD at the time, who was blind, said, 'Are you saying that in universal design I don't have the right to an accommodation anymore? It's my right, it's in the law, and I'm going to demand my rights for accommodation.' So we had a discussion around: When environments are designed inclusively, do people still have a right to an accommodation? And why would you still need an accommodation? And it's true: there will always be some people who

need an accommodation:... someone who needs a classroom person to do things in a biology lab or... someone to be hands or eyes or whatever... Universal design doesn't remove accommodation. You'll always have some people who need something different. But you could still aim to get 90% or 85% included in your class."

Dara contrasted her ideas about the social model with her own actions requesting an accommodation, when she recalled requiring her students to submit written assignments in a format that she could read as a blind person, when universal tools were not available. "It was like a fiasco—making [students] do it the way I needed it done. So that's quite an experience: to say that I'm teaching this [social model, universal] way, but I'm behaving totally in the medical model." Dara also described coaching college students with disabilities—who, she believes, have been "trained to live with the medical model"—on how to balance access to inclusive environments with requesting accommodations that are specific to them.

In recording these critical analyses of the social model, this study answered a potential concern in the literature about pro-innovation bias—a phenomenon defined by Roger (2003) as "the implication in diffusion research that an innovation should be diffused and adopted by all members of a social system, that is should be diffused more rapidly, and that the innovation should be neither re-invented nor rejected" (p. 106), or, simply, "the assumption that an innovation should be adopted" as phrased by Scott and McGuire (2017) who also cautioned about "the intuitive appeal of universal design" (p. 126).¹² Overall, participants saw the social model as a practical tool that could help college

¹² See Godin and Vinck's (Eds.) 2017 *Critical Studies of Innovation: Alternative Approaches to the Pro-innovation Bias* (2017) for a detailed critique of the under-examined aspects of pro-innovation bias.

campuses come closer to full, universal inclusion, while leaving room for individual accommodation. In this way, the participant conception of the social model was not absolutist or idealistic, but practical and instrumentalist, reflecting a view of the social model as a practice for building inclusion, as argued by Oliver (Shakespeare, 2013).

A Transformational Leadership Perspective on Diffusion of Innovation

Gwen's quote above explicitly connected the concepts of innovation and leadership in her work of advancing the social model by influencing followers. Likewise, the literature has explicitly linked the diffusion of innovation theory to the transformational leadership theory, where transformational leadership is defined "as the process through which leaders 'broaden and elevate the interests of their employees,... generate awareness and acceptance of the purposes and mission of the group, and... stir their employees to look beyond their own self-interests for the good of the group" (Siangchokyoo et al., 2020, p. 3). In addition, Crawford et al. (2003), writing on the connection between the diffusion of innovation theory and the transformational leadership theory in the *Journal of Leadership Education*, synthesized a definition of transformational leadership as a process of change (a) encompassing individual, interpersonal, micro-level influence; and (b) affecting the social system, i.e., an organization at large, where "transformational leaders begin with a social fabric, disrupt that environment, and then recreate the social fabric to better reflect the overall business climate" (Crawford et al, 2003, p. 59). In their own study that tested a statistical relationship between innovation and major types of leadership (transformational, transactional, and laissez-faire), Crawford et al. (2003) found that innovation was "significantly related to all subscales of transformational leadership," elaborating:

There is good reason for the relationship between transformational leadership and innovation. Innovation shares one major characteristic with transformational leadership—change. The basic concept that underlies transformational leadership is the ability to change the current—transcend the present—to achieve a higher plane of leadership. The concept of transformation is very similar to innovation, although change is largely assumed in the innovation and technology literature... Thus, the relationship between these elements is not accidental or contrived. Innovators at all levels are interested in change. (pp. 66–67)

While this dissertation is conceived as a phenomenology (in that its primary focus is on generating narratives rather than theories), the apparent relevance of the theoretical linkage between the diffusion of innovation theory and the transformational leadership theory to participant narratives invites a brief review of the transformational leadership theory as "a cornerstone in leadership research" (Siangchokyoo et al., 2020, p. 2). Originating with Burns's *Leadership* (1978), the concept emphasizes that "leaders address themselves to followers' wants, needs, and other motivations, as well as their own, and thus they *serve as an independent force in changing the makeup of the followers' motive base*" (p. 20, emphasis in the original). While several formulations of transformational leadership exist, according to the model formulated by Bass and Avolio (1995),

the extent to which leaders are considered transformational is a function of four leader dimensions: (1) Idealized influence (role modeling attributes and behaviors); (2) Inspirational motivation (articulations of compelling and inspiring visions of the future); (3) Intellectual stimulation (challenging existing assumptions and stimulating

new ways of thinking); and (4) Individualized consideration (attending to followers' needs and concerns)" (Siangchokyoo et al., 2020, p. 3)

Earlier in this chapter, we discussed how the adoption of the social model on campuses warrants a characterization as (diffusion of) innovation when viewed as a major change from the prevalent models of disability. Applying the connection between innovation and transformational leadership to participant narratives, we can see evidence, and thus argue, that participants exhibited dimensions of transformational leadership in their work of advancing the innovation of the social model. This application helped bring to the surface participants' leadership attitudes and behaviors associated with transformational leadership and to connect the subjective individual narratives to the broader themes in organizational literature. We also saw how some participants learned from the leaders in the movement to transform campus inclusion and took on roles as formal leaders in their own right, while others acted as informal leaders in advancing the social model despite their modest position titles. In this sense, this application constitutes a contribution of this dissertation to the literature on the social model and can be expanded in future research by further examining the process of transformational leadership from the perspectives of the leaders and those of the followers.

An extensive body of leadership literature offers detailed interpretations of the characteristics and behaviors aligned with each of the above dimensions of transformational leadership. Table 5 extrapolates these categories and labels from Cetin and Fayda-Kinik's (2015) analysis and is followed by excerpts of the narratives that offer examples of participant behaviors and attitudes aligned with the dimensions of transformational leadership. Of note, this study did not attempt to catalogue the frequency

or prevalence of such dimensions in participant narratives; further research along these lines of inquiry can clarify these issues.

Table 5

Dimensions Associated Concepts (Qualities and Behaviors)	
Charismatic Leadership	Role models
or Idealized Influence	Respected, admired, emulated by followers
	Clear vision and sense of purpose
	Risk-takers
	Charisma
	High morality, trust, integrity, honesty
	Unusual competence
	Address crises
	Recognize followers' achievements
	Improve organizational performance
	Dependable
	Consistent
Inspirational Motivation	Motivate others
•	Generate enthusiasm
	Challenge people
	Committed to goals and shared vision
	Exciting
	Compelling
	Vision for the future
	Elevate expectations of followers
	Present optimistic, attainable view of the future
	Shape expectations, meaning
	Articulate complex issues clearly
	Create a sense of priorities and purpose
Intellectual Stimulation	Solicit new ideas, new ways of doing things
	Stimulate others to be creative
	Re-examine assumptions
	Recognize patterns that are difficult to imagine
	Propose and entertain "foolish" ideas
	Encourage followers to revisit problems
	Create "readiness" for changes in thinking
	Help followers develop new ideas
	Stimulate followers to take alternative routes to
	problem solving
	Take a closer look at all possible solutions
Individualized	Pay attention to the needs and potential for developing
Consideration	others
	Establish supportive climate
	Respect/recognize difference: strengths/weaknesses,
	likes/dislikes

Examples of Transformational Leadership Dimensions in Participant Narratives

Dimensions	Associated Concepts (Qualities and Behaviors)
	Aware of individual concerns
	Assign projects based on ability and need
	Encourage dialogue, active exchange of views
	Active listeners
	Promote self-development in followers

Note. Adopted from Cetin and Fayda-Kinik, 2015, pp. 520–521

- Example 1. Warren: "I always go to the faculty office because I want to show respect. I want to show authenticity. I want to see what their workspace looks like... It's just being authentic and consistent [in] messaging, and good [at] listening. That's why I'm so thankful about the counseling background I had because I'm okay with dead space, you know, like I'll ask a question. I'll just, okay, they get to fill it. I think we have to be really careful not to go in and be the expert, right, because they're the experts of their classroom."
 - <u>Evident Charismatic Leadership or Idealized Influence qualities:</u> high morality, trust, integrity, honesty; consistent
 - <u>Evident Individualized Consideration behaviors</u>: establish supportive climate; respect/recognize difference: strengths and weaknesses, likes and dislikes; active listening
- Example 2. Gwen, on motivating disability professionals to change: "you are in charge, you have designed these procedures, you're telling faculty to change their design, but you haven't looked at your own design. So I could get them to look at, 'What are you doing? That's a hoop for a disabled person. That's a barrier that's slowing them down. That's making them be different than anybody else.' It's a very humbling process to look

at what you are doing to stop a disabled person. And some people get very uncomfortable. Some people get it right away and some people cling to 'but it works, this fits my frame.' I said then you need to know that you are the cause of these barriers and you need to carry that weight on yourself. You are making these rules—not the institution. So can you tell a faculty member that they need to change when you're not changing? You have to look at 'Are you going to walk the talk, or are you going to not walk the talk?' So it's confronting that in a sort of a gentle way, really having them look at what they do and what could they do different."

- <u>Evident Inspirational Motivation behaviors</u>: motivate others; challenge people; shape expectations, meaning; elevate expectations of followers
- <u>Evident Intellectual Motivation behaviors</u>: re-examine assumptions; encourage followers to revisit problems
- Example 3. Jaden: "[Disability accommodation] is oftentimes done by the faculty, but a lot of them have never had training in this kind of stuff. They could tell you how to send a rocket to the moon but they can't tell you how to create universal design... A lot of them are very interested in learning that kind of stuff. Very few give that pushback and oftentimes when that stuff does come up, it's usually related to: They are already overworked, they are doing research, they are teaching, they are tired. [And then disability staff tells them what to do.] We always try to approach that in a very inclusive way, like we don't try to go to faculty and sort of beat them over the head or point a finger at them or something, make them feel bad... We try to let them know that we are partnering in this process. We understand that there are certain things that you

don't know how to do yet, but we want to teach you, want to coach you through that process."

- <u>Evident Individualized Consideration behaviors</u>: establish supportive climate; respect/recognize difference: strengths and weaknesses, likes and dislikes
- Example 4. Gwen: "It's ongoing, it's an evolution, and it keeps changing. I had to work with people on my team who liked 'helping,' wanted to cling to the word 'help' and [with] those who were getting [the social model]. And we're moving along... everybody. We are all part of a team, and we are on this journey together, but... we are at different places and we have to help each other and support each other and accept where all of us are, and we were all going to make mistakes."
 - <u>Evident Individualized Consideration behaviors</u>: respect/recognize
 difference: strengths and weaknesses, likes and dislikes
 - <u>Evident Inspirational Motivation behaviors</u>: motivate others; challenge people; shape expectations and meaning
- **Example 5.** Warren: "We do a lot of interaction with faculty. So I've posed to my staff: every one of those [interactions] is an opportunity to win a faculty member over and we [don't] always have a chance to get it right, so we don't always have to commit right then. We have every opportunity to come back and be strategic with leadership here to talk about how we might re-approach and give the right answer, the right solution."
 - <u>Evident Intellectual Stimulation behaviors</u>: encourage followers to revisit problems
 - Evident Inspirational Motivation behaviors: motivate others

Example 6. Emmett: "The need to create a barrier-free higher education learning environment prompted me to act on ideas of [the social model and universal design]. The medical model mold had... deep roots and the struggle of students with disabilities was never problematic beyond the impairment to examine the social arrangements of higher education environment... I embarked on training faculty, colleagues at Disability Resources, and campus outreach to colleagues in the physical space and IT; ... students with and without disabilities; ... and management... The concept of disability was demystified, and colleagues developed an in-depth understanding of how access could be promoted and sustained; saw each other as strategic partners that could create a barrier-free learning environment on campus; started imagining how these ideas could be mainstreamed to attain a whole-campus response to disability issues; developed interest in disability issues. Colleagues created platforms to start dialogues on these matters. Faculty engaged students in projects guided by these principles... I felt extremely happy to see positive responses that altered ways that created and maintained disability."

- <u>Evident Inspirational Motivation behaviors</u>: motivate others; generate enthusiasm; create shared vision; compelling; shape expectations, meaning; articulate complex issues; create a sense of purpose
- <u>Evident Intellectual Stimulation behaviors</u>: re-examine assumptions, recognize patterns that are difficult to imagine, encourage followers to revisit problems, create "readiness" for changes in thinking, help followers develop new ideas, stimulate followers to take alternative routes to problem solving, take a closer look at all possible solutions

- **Example 7.** Gwen, on addressing the fear among disability staff that the social model would make their roles and authority obsolete: "What I really tell people is: 'Don't do this by yourself. It has to be collaborative. You have to let go of the reins. You cannot be the disability expert on campus. You need everybody to be a disability expert.' And of course they were raising, 'Well, then what's my job? You know, if disabled students are all accommodated I won't have a job.' And I said, 'Just think how many years it's going to take until *every* campus is universally designed and students are *all* included. That's in your dreams and in my dreams—it's not in my lifetime. You'll never be without a job. Just change your job, change your job to consult [on inclusive] environments, ... focus on the environment and change that environment."
 - <u>Evident Individualized Consideration behaviors</u>: pay attention to the needs for developing others; respect/recognize difference: strengths and weaknesses, likes and dislikes; aware of individual concerns; encourage dialogue, active exchange of views
 - <u>Evident Inspirational Motivation behaviors</u>: motivate others; generate enthusiasm; challenge people; committed to goals and shared vision; vision for the future; elevate expectations of followers; shape expectations, meaning; articulate complex issues clearly; create a sense of priorities and purpose
- **Example 8.** Dara, a former teacher and principal, on appealing to faculty for universal inclusion of students with disabilities: "The easiest way that I have always approached [this] is to ask, 'What is the goal? Is your goal to force students? To teach with fear? Is your goal to make the instruction so difficult that people drop out of your class? Or is

your goal to teach them the beauty and the wonders of chemistry? Is it your goal to help every student leave your classroom with some more understanding of... the miracle of chemistry? You have to figure out what your goal is and from that work backwards... It has to be like a reflective process for each one of us, each time."

 <u>Evident Inspirational Motivation behaviors</u>: motivate others; generate enthusiasm; challenge people; shared vision; exciting; compelling; elevate expectations of followers; present optimistic, attainable view of the future; shape expectations, meaning

Example 9. Caitlyn, on introducing the ideas of the social model and universal design on campus: "We started to see with our behavioral intervention team a little bit of scope creep, where folks are now reporting any kind of student behavior that is bizarre to them [as inappropriate or disruptive]... I actually did a presentation just a few weeks ago for our faculty about... managing classroom behaviors, and I presented this kind of spectrum where certainly there are behaviors that you'll see in the classroom that are dangerous; there are certainly behaviors that you'll see that are disruptive; there are some that are disrespectful. But I encouraged them to think about their own, where they're coming from, and what they were doing in the classroom, what instructional experience they were creating, what environment they had created, and whether the behaviors that they were seeing were a response to [those environments]... I wanted to cover this topic and encourage people to think about their own framework, and their own classes and design, and what demands it was putting on students that yielded these behaviors that they were then interpreting and how they were interpreting those behaviors."

<u>Evidence of Intellectual Stimulation behaviors</u>: solicit new ideas, new ways of doing things; re-examine assumptions; recognize patterns that are difficult to imagine; encourage followers to revisit problems; help followers develop new ideas; stimulate followers to take alternative routes to problem solving; take a closer look at all possible solutions

Prominent Transformational Leadership Themes

This analysis of participant narratives brought to the surface two especially salient themes in the accounts of change: (a) the gradual, iterative, reflective process of changing the followers' frames of disability services in the university context, especially with respect to how the followers perceived their roles and imagined full inclusion on campus; and (b) the importance, for the leaders, of mastering the social model of disability and becoming skillful at articulating its ideas so as to influence change on the individual and organizational levels.

Theme 1. Changing the Followers' Frames

The concepts of transformational leadership were closely associated with participant narratives about reframing mindsets and practices around the social model: first their own, and then those of professional peers, subordinates and university managers, and faculty (these are collectively referred to as followers, i.e., individuals whom participants aimed to influence). The Review of Existing Literature situated the concept of frames, framing, and reframing in the literature, as these concepts relate to the capacity of managers to acknowledge and problematize their own perspectives and use imagination and leadership to transform organizations. This chapter continued the exploration of these concepts as occurring in participant interviews, from the perspectives of organizational

change and transformational leadership. By highlighting the salience of (re)framing, this qualitative study adds nuances to the understanding of how the social model of disability is being advanced in the field with an intent to achieve a groundswell toward realizing a paradigm shift in higher education. Participant analyses of models of disability clearly signaled that disability model language and frameworks served as tools to organize, understand, evaluate, critique, and reimagine their work places and professional roles (see earlier discussion). As Gwen remarked, "I really think you have to have a framework, some philosophy, or some guiding principles. It doesn't have to be the social model, but the principles of the social model work." The interviews evidenced that participants, as leaders, worked to impart an active understanding of the social model principles and practices by engaging in transformational leadership practices; they also recognized that the process of transformation took time and was replete with tensions and resistance to change that often had to do with followers' professional identities and organizational roles. In this context, participant concerns with the *time* and *pace of change* frequently surfaced in the interviews, as articulated in these statements from Gwen: "People tell me, 'You say too much, but you have good ideas, but you don't know how to pace yourself.' So for me, I had to learn to pace myself, to frame it, to use my passion in a way, to present it in a way that was workable for people so that it could be heard and there could be change made." The narrative echoes Morgan's observations on the complex, laborious, time-related processes that managers need to anticipate when undertaking organizational change, particularly when the process entails changing the workers' sense of identity tied to their roles:

[When identities are challenged,] The fear of loss this entails thus often generates a reaction that may be out of all proportion to the importance of the issue when viewed

from a more detached point of view. This unconscious dynamic may help explain why some organizations have been unable to cope with the changing demands of their environment and why there is often so much unconscious resistance to change in organizations. (p. 237)

Morgan phrased this phenomenon as "a reluctance to relinquish an old identity and move on" (p. 238) and encouraged change agents to create conditions for the transition where people can "explore their situations and the options they face" because "people frequently need time to reflect, think over, feel out, and mull through action if a change is to be effective and long-lasting. If the change agent tries to bypass or suppress what is valued, it is almost sure to resurface at a later date" (p. 238). This association of organizational change with transforming professional identities came across in participants describing how some disability professionals identified strongly with the role of "helper," "expert," "case manager," or "gate keeper" in relation to people with disability—the mindsets that participants thought was important to overcome in a social model environment, changing the balance in power and influence between disability service professionals and people with disabilities. This shift in the roles and identities of disability service professionals from helpers/experts to allies with disabled people was also advocated by AHEAD. As quoted earlier, and it is worth repeating, "In the social model of disability, the emphasis shifts from the need for service providers (as experts or helping persons who provide services) to a focus on the importance of allies. As an ally, our primary efforts are directed to serving or changing the environment, not the 'client' or individual student" (Block et al., 2006, p. 119). As leaders, participants used persuasion, dialogue, education, and individualized approaches, as well as hiring practices to facilitate a shift in professional

roles and identities and organizational cultures. Participants stayed persistent and consistent in their messaging:

Martha: "We had one person, for example, who is kind of fresh out of a program like [rehabilitation counseling] and really loved the case management [model]... We didn't want to [engage disabled students] in a way that looks clinical. We were trying to move away from that kind of clinical approach and that was a little difficult for people who'd been really trained in that approach... Knowing that we really couldn't affect change campus-wide with the culture that we had, we just kept working on those kinds of things and I think it did make a difference."

Warren: "I've hired eleven new people over four years. People that weren't going to get on board with the social model, they realized that I was going to stick around so they left, and that was a good thing. And I've attracted people because of the social model. I've got two current positions open [that call for applicants who are fluent in the social model]. I am very out there about this stuff. I want people that are interested in not only doing the interactive process with students, but contributing to our disability awareness programming that we're doing, which is all based on the social model in disability studies."

Gwen, on disability service staff reactions to shifting away from the "helping" roles: "[Some staff] were upset because they said, 'You know, in my country people ignore disabled people, they're hidden. And I'm so proud to tell my relatives in China that I help disabled people.' And then we have to talk about: What does help mean? What's the frame around help? What's wrong with helping? And so that took a long time. [The case managers] got it fast, most of them, not all of them. Maybe they got it easier

because they've had the university degrees, you know, there's a different mindset there just from a life history. But the support staff and the technicians that you know [felt], 'I like knowing that I'm helping a blind person when I'm configuring this computer. I like that I'm helping them.' ... it took a while to get everybody onto that page." Martha: "We had new [disability service] staff coming in and we worked to ... immerse them in the social model thinking around disability. But that too is a challenge: people come in with their frames and we couldn't totally replicate the experience that I had in the AHEAD course. So for some people it was a little hard to give up their frames of disability in that office."

In interacting with faculty, staff, and senior administrators, participants approached change from the perspective of achieving social justice for people with disabilities. For example, Warren referred to "disability [as] an aspect of diversity, civil rights, and social justice, and that's what it is. Civil rights. And that's what moves me. So we are framing everything here and everywhere I've been, we frame this as a form of diversity. It's just a difference. It's neutral. It's the environment that's disabling and it's about social justice and it's about civil rights." Martha mentioned becoming "more fluent in, I guess, social justice speak," but also cautioned that leading change requires a nuanced, political use of language that recognizes how different parties in a dialogue may vary in how they interpret terms and values:

Martha: "I know myself and a lot of my colleagues, we use language that would cause someone to quickly label us as social justice warriors or liberals who have a pie-in-thesky attitude..." [She brought up George Lakoff's *Don't Think of an Elephant! Know Your Values and Frame the Debate. The Essential Guide for Progressives*, explaining] "He talks

about the power of language in politics and how [we are] being so polarized in the way we talk, the way we think. So one of the things that he advocates is that if we want to have influence, we have to learn how people who think differently than we do use language. So if I say the word 'freedom,' that means one thing to me, it means something else to someone who's more conservative. And if I use it and they think about it differently, then we're not really communicating."

Martha pointed out that having a social justice orientation did not, by default, translate into a person's affinity to the social model of disability, as when she described "a speech pathologist who [is] very social justice minded, but somehow she… was kind of entrenched in… that old thinking about disability and access; she wasn't really ready for that kind of [inclusive] language around disability. She liked 'we're going to do what's in compliance with the ADA' kind of approach." Gwen, on another hand, carefully weighed another approach to reframing: convincing managers of the merits of the social model and universal design by pointing to the cost-savings and other efficiencies that can result from creating universally inclusive environments. The transactional nature of this argument, where serving students with disability should be deserving of the cost, seemed to conflict with the equal rights, social justice perspective on disability:

Gwen: "I found [that institutions] got it... when I told them that accommodations were Band-Aids [where] you accommodate a student in every exam, in every assignment, in every class, in every semester, for every year that they're on campus. And it's done over and over and over again and it's thrown away: the exams, the quizzes—everything." "When you start talking 'sustainable' rather than 'throw-away,' institutions listen to this money. And everybody's into doing more for less. I hate that term [where you see

people as bags of money]. And it's our fault, because we've said to our dean or supervisor, 'God, I've got three deaf students that I wasn't counting on this year. I thought we'd have four, but now we have three more and it costs way more than I thought. Whatever we gonna do?' That's how we would present it to our administrators, and we got to say stop saying that."

Also contested were the meanings of *fairness*, *accommodation*, and *level playing field* as these related to students with disabilities. Participants recalled how faculty expressed concern about removing obstacles as giving disabled students an unfair advantage or failing to prepare them for the "real world." Participants also recalled disability professionals using similar lens on people with disability: in Martha's words, "with a lot of professionals it's [about] making sure that students don't get more than they deserve, ... making sure that they don't get an unfair advantage." It also mattered which campus groups (faculty or the social model advocates) had the power to define those meanings and which group (faculty or social model advocates); and some participants described the power balance in terms of gaining and losing ground in achieving change. Dara explained, "There are a lot of examples where instructors insist on the way they are doing it and that it cannot change under any circumstances, and sometimes it's a tough sell, but we get there." Participants placed the quality of relationships with faculty (ranging, in the interviews, from collaborative to adversarial) in the context of organizational cultures and also recognized the stressors and constraints, like lack of time or training, that worked against faculty's willingness to adopt more inclusive practices:

Jaden: "[At this college], I feel like the culture is a lot better. It's very welcoming. It's very inclusive. And faculty are often times more curious and interested in helping

students. I mean, I don't have specific data to go off but in just my experience... while working at [the previous college] I felt like there was a little bit more faculty who were more riled up and didn't agree with what we did."

In their organizations, participants appreciated tangible and visible support from upper administrators for building inclusive environments, which came in the form of, for example, communicating inclusive values to the campus communities and investing in hiring and training disability staff so that students can be served beyond the basic case management. When participants encountering strong opposition to their efforts from faculty and administrators, this experience imposed emotional costs of participants and required strategies for dealing with obstacles, including persisting, seeking alternative solutions, or even retreating from a reform issue. The emotional aspects of the work came across clearly in Dara's detailed narrative on one contentious issue that resulted in a better outcome for the student involved and a comprehensive change to the course requirements, making it more universally accessible:

Dara: "I had a student who could not, under any circumstances, stand up in front of the class and give a presentation. It was actually damaging to her to have to be forced to do that. But the instructors, in fact the whole team of instructors, which was pretty much the department, were forcing her to do this, that there was no other way around it. I went to a meeting with all of them and with the student, and we talked through the process, and for about an hour they were insisting that it was part of the curriculum, that everybody had to do it, and there was no other way around it. And the more we talked, [we] discovered: it really wasn't in the syllabus as a learning outcome that you stand up in front of a class and give a presentation. It wasn't something that you would

even do very often professionally unless you loved to teach about your profession, but as a practitioner you wouldn't have really any opportunities to stand in front of a group; and the online version of this same class did not require standing up in front of a class and giving a presentation. As those points began to emerge, ... there was less and less pushback from each instructor, and they agreed on an alternative for this student at that meeting. Since then, there now is no requirement for a student to stand up in front of the class and give a presentation. It's an option now. If you do it, you can do this, or you can do this, or you can do this—three different ways to demonstrate your knowledge. So that's one example." [Describing how she felt at that meeting] "I was furious at the meeting. I was absolutely furious that they were so righteous, that they knew they were so right to do this, and that they believed that by forcing her to do this, she would get over [her] disability. That's exactly wrong. So I was very, I was angry but, you know, not angry outwardly. Just trying to help them see and understand; and it is very hard to move them off the mark because they have a program... and they know what's best for the students, and this is how they do the teaching, and it was really more about them than about the student. So I was very angry at first, and then as the meeting went on, I began to see them listening to me and understanding that they may just be stubborn and they didn't know why they were being so stubborn as we kept talking. We didn't come out with a solution at that meeting but... a few days later and by the next semester. There's now no requirement for presenting, it's an option. So I did feel good [about this outcome] but I still didn't feel like [faculty] understood why ... Or maybe they understood it, but... didn't own it yet, that they were doing it because they were kind of pushed into it, talked into it, or moved in that direction kind of against their will.

And I just hope that over time they will. I believe that the universal approach does allow everybody to access their academics."

Martha related the episode below (edited for brevity) as an example of something that "did not go well" and, in hindsight, she should have approached differently with the advantage of experience and learning leadership theory. Here, she described how she and her colleagues tried to convince the faculty senate to formally endorse "the philosophy of universal design."

Martha: "myself and our director and associate director crafted a statement like that and we went to our vice chancellor in student affairs... Our vice chancellor, I think, gave us the worst possible advice at that point that he could have: ... 'You could take this to faculty senate and present to them.' Now, knowing what I know about faculty senate and about the culture of that particular campus, which was very faculty-driven, I would never have done that... it didn't go well. Instead what we got was a whole lot of resistance from faculty who thought, there was one particular person who kind of led the bandwagon and said that if we adopt this, then that means that the disability office can tell us how to teach our classes... I mean it's kind of like politics and our culture today, you know, someone takes something and they twist it and they scare everyone with it. And so that didn't go very well ... The result of that [was] we got resistance in other places because they sowed the seed that the disability resource was trying to infringe on their academic freedom in some way. I learned a whole lot from that experience about what not to do... I think that change like that needs to start and stay in our areas of influence first, or our spheres of influence, and give it some time. Outside of that, we need to move very slowly and build relationships and have conversations

before anybody tries to take on change of that size or magnitude... It was way too quick. We should have stayed in our world for a little bit longer... I have to say the people who were resistant to change, I don't think their intentions were bad at all [but] they were afraid that our approach was going to mean that anybody could get accommodations and therefore students, with, in their words and I quote, 'real disabilities' would not have the level of services that they needed and deserved... [Remarking on the emotional impact of that experience], Now it's easy to look back kind of intellectually at what happened and learn from the mistakes, but it was very frustrating and it definitely had an impact on our level of enthusiasm toward the work that we were doing... I mean it was hard. The person who was kind of the, the one who led the bandwagon against universal design on the campus, which sounds so, when you say it like that, it kind of sounds silly, doesn't it? But he and I, I mean I would see him on campus, but I don't think I ever really resolved my difficulties with him, which, I left the campus in 2012, but during that time it was still pretty raw, I guess you'd say, emotionally... I think when anyone has a setback like that it can cause people to be fearful of making any kind of changes and be more stifled. But I do think that what worked for us is we just realized, okay, we just need to, we still had a lot of work to do in the office, and we just needed to focus there. That's kind of where we went."

Participants thereby raised the issue of relevance to advancing the social model on campus: acknowledging, understanding, and addressing the role of value systems and the issues of power and influence within an organization. As described by Morgan (1997), "in any organizations there may be different and competing value systems that create a mosaic of organizational realities rather than a uniform corporate culture [where] gender, race,

language, and ethnicity, religious, socioeconomic, friendship, and professional groups can have a decisive impact on the cultural mosaic" (p. 137) and this "may give rise to different norms and patterns of behavior with a crucial impact on day-to-day functioning" (p. 137). Further, "different norms, beliefs, and attitudes to time, efficiency, and service can combine all kinds of contradictions and dysfunctions. These can be extremely difficult to tackle in a rational manner because they are intertwined with all kinds of deep-seated personal issues that in effect *define* the human beings involved" (p. 137). Per Morgan, leaders in formal and informal positions of power can influence organizational cultures as managers who have access to organizational tools to encourage and discourage behaviors, or as informal opinion leaders, where culture encompasses "shared values, shared beliefs, shared understanding, and shared sense making" (p. 138), which are recognized as related to symbolic organizational frames and symbolic leadership role (Bolman & Deal, 2008). For participants, navigating and changing the value systems accounted for a considerable part of the work to advance the social model: a laborious, often slow process, with mixed success where this work did not take hold on campus or did so only temporarily and then retreated, when individuals left the organization and new people were hired, necessitating a new round of the social model reframing. This made organizational change an ongoing, iterative process even on campuses where the organizational commitment to the social model and inclusion of students with disabilities was clearly signaled by the upper administration. One strategy to address the impact of turnover was described by Warren, who integrated criteria and questions about the social model and social justice into advertising open position postings ("seeking candidates that embrace a social justice model of disability") and into candidate interviews, asking "How might the social model of

disability impact higher education disability services?" Despite the challenges and concern about the pace of change, participants expressed optimism about progress, as when Dara described "seeing many more professors making their curriculum and their format of delivery much more universal." Martha spoke of the need to reach a "tipping point" in the process of change:

Martha: "There really has to be an effort to sustain that, I think, until you reach... a tipping point where you have enough people where one or two people leaving doesn't make a huge difference, you can sustain it. But that takes a lot of time and energy and a lot of commitment I think from the top, from the leadership... We had administrators who said that they loved what we were doing and they were on board, but they were not to the point where without us being the voice for that, they would have initiated that messaging about the commitment of the campus. So I recognize that those pieces would have been necessary to sustain it."

Theme 2. Striving for High Degree of Competence to Advance Reframing

In connection to the task of reframing and the challenges that this task entailed, participants expressed a desire to have a high level of mastery of the social model—facts, arguments, and disability literature—in order to articulate their positions and advance change. Warren and Martha used the words "fluent" and "fluid" to capture this quality. Participants' conception of being "fluent" paralleled what Bolman and Deal (2008) described as the ability of good managers to use mental frames in navigating complex organizational situations:

...the quality of your judgement depends on the information you have at hand, your mental maps, and how well you have learned to use them. Good maps align with the terrain and provide enough detail to keep you on course... Different circumstances require different approaches... The ultimate goal is fluid experience, the sort of knowhow that lets you to think on the fly and navigate organizations as easily as you drive home on a familiar route. You can make decisions quickly and automatically because you know at a glance where you are and what you need to do next. There is no shortcut to getting this kind of experience. It takes effort, time, and feedback. Some of the effort has to go into learning frames and ideas behind them. Equally important is putting those ideas to use. Experience, one often hears, is the best teacher, but that is only true if you reflect on it and extract its lessons. (p. 12)

Examples below illustrate what being fluent in the social model meant to participants and how one became fluent: through reading disability literature, observing and modeling AHEAD leaders in the social model and universal design movement, developing effective arguments, and practicing debate.

Gwen: "in working with faculty, the first thing [faculty] say is, 'Prove to me that [the social model] theory works.' In the early days, in the 2000s, there was nothing in the literature, there was no research that proved that it works. And so all I could say—it was effective for some faculty—'Prove to me that the social welfare model works, prove to me that disabled students are successfully integrated and treated equally in the system…' You really think it works when we put a Band-Aid on [the student's situation] after the fact?… So when you frame it that way, they sort of get it."

Martha, on emulating a leader in the field and acquiring fluency: "Sue [Kroeger] has this way of arguing with someone: she doesn't feel, she doesn't get all worked up about it or invested in it, because she's had these conversations so many times that she can just kind of question what they're thinking: 'Well, OK, if that's what you believe in.' And it's so effective, it's so much more effective than when I get agitated with people, and so it's just fun to watch. I guess the thing that is important to me, ... one of the things that we came to talk about, is the importance of not just kind of barely grasping the social model or reading about it, but really being able to be fluent in this conversation about what that means on a day-to-day basis. Those conversations with Sue helped me to feel more competent and confident. If I could go back now [to some difficult situations I had], ... I would feel much more able to have a dialogue, express my concerns or my wonders about their fears or their criticisms. And I feel like it... would have gotten me further than where I was at that time, because at that time I knew what I wanted to happen, I felt like I was right, but it became all about 'I'm right and you're wrong' rather than 'Let's just kind of think about this together.' And that, too, has been something that feels like a valuable lesson from this whole journey."

Warren, after first encountering the social model through Project ShIFT, continued learning and sought to make his professional peers, subordinates, and the campus community well versed in the social model. In describing the depth of his reading on disability, while scanning the authors on his bookshelf, he remarked on being "a good student of the social model," explaining: "we have to be really fluent [in order] to move to the social model. We have to really understand what the disability studies authors and the academic field authors offer us." Emmett described how advanced education and professional learning

informed his understanding of different models of disability and his desire to apply this knowledge. To him, this process was "coupled with extensive reading in the area of higher education and disability. Neo-Marxist ideas have helped [me] to understand the plight of people with disabilities in its distinctiveness." To disability professionals who are starting out in the field, Emmett advised "reading extensively: first of all understanding the concept of marginality"; reading "about progressive realization of the rights of persons with disabilities"; and reading disability scholarship.

In sum, developing fluency in the social model encompassed, in the context of this study, both the knowledge of the model and the mastery of rhetorical skill that participants developed through the practice of direct engagement with skeptics and opponents, as well as those who were new to the social model ideas. Participants mentioned how they worked to immerse and educate the followers: (a) supporting and encouraging staff in attending professional development events like conferences, workshops, or a master class on disability studies and disability practice; (b) integrating disability literature and social justice perspectives on disability into campus presentations; and (c) bringing prominent disability authors to campus.

In seeking change, participants exhibited many of the qualities and behaviors associated with transformational leadership as they sought to create professional environments that led others to imagine alternatives to their organizational roles and longheld belief systems, which to some followers were intrinsic to their professional and personal identities. In placing a high emphasis on fluency, participants may have been addressing the need to convince others in the positive impact of the innovation of the social model. As described by Rogers (1995), "An innovation presents an individual or an

organization with a new alternative or alternatives, with new means of solving problems. But the probabilities of the new alternatives being superior to previous practice are not exactly known by the individual problem solvers" (p. xvii). Per Scott and McGuire (2017), in applying the diffusion of innovation theory to universal design for instruction, the lack of documented outcomes, or "proof" that "resonates with faculty and administrative audiences," represents an obstacle in advancing universal design for instruction on campus (p. 126). We see the challenge presented by the lack of evidence earlier in this chapter, in Gwen's description of a rhetorical strategy that she found effective with faculty in the early 2000s when the evidence was lacking: "Prove to me that the social welfare model works, prove to me that disabled students are successfully integrated and treated equally in the system." As quoted earlier from Kuhn (1996), early adherents of new paradigms act while confronting a lack of evidence that the new paradigm will succeed where the previous one failed at problem-solving (Drønen, 2006, p.232); but "concrete examples providing clear applications and outcomes are important tools for persuading the next group of potential adopters" (Scott & McGuire, 2017, p. 125). Participants in this study persisted in the often difficult task of persuasion, deploying the tools, arguments, information, and skills that were available to them at different points of their professional journeys to lead others in adopting the social model.

Conclusion

The journeys of participants who were interviewed for this dissertation tell a story of the disability service profession in transition. With the aid of a phenomenological approach that focused on participants' own meaning-making from the experiences they lived through within a specific span of time, the individual narratives of seven disability service professionals, taken together, bring to life the image we have gleaned from the journals and books in the realm of disability studies: the disability profession in higher education moving away from the long-established attitudes, roles, and practices which can be summed up, using Simi Linton's (1998) term, as "paternalistic impulses" toward disabled people:

Work in disability studies has critiqued the tendencies of individual practitioners to assume that they know what is best for disabled people. Practices exist that limit freedom, infantilize people with disabilities, force dependency, create and perpetuate stereotypes through the use of tools such as testing and diagnosis, constrict pleasure, and limit communication and political activity among disabled people. When interventions are based on the projections and needs of professionals or are driven by maintenance of the status quo in government, medicine, and education, then disabled people have a vested interest, for our own sanity and well-being, in questioning whose interests are being served. (p. 82)

Such tendencies are what participants in this study recognized in their own profession and organizations. They saw that the reality of serving—or "helping"—people with disabilities largely as a matter of the legal and administrative regimen or medical sorting fell out of step with the spirit of social justice and equal rights. Like many disability service

professionals in higher education, participants began adopting the social model of disability as a theoretical and practical framework for creating more inclusive campus environments for students with disabilities who attend colleges and universities in growing numbers. Some of participant experiences aligned with AHEAD's early strategic efforts to shift the paradigm of disability services toward systematically removing barriers to full participation and transforming disabling environments—departing from the prevalent modes of service focusing on the medical model, legal and regulatory compliance, and ad hoc accommodations, which many disability service professionals, scholars, and advocates have come to see as insufficient from the social justice perspective. As was argued by Loewen and Pollard (2010), "Disability Service professionals must make a paradigm shift in attitude and action that moves disability into a social movement resulting in full inclusion in all aspects of community life," where "disability is not an isolated issue of social welfare but must and should be acknowledged as a struggle for human dignity, non-discrimination, equal opportunity, and personal empowerment through independence" (p. 14). Participants in this study, each in his or her own way, walked the walk of the paradigm shift, to borrow a Thornton and Downs (2010) phrase, and this dissertation adds important nuances to the literature on the transition to the social model by examining the social phenomenon of leading change as a lived experience of disability service professionals.

In sum, this qualitative study offers rich descriptions of the factors that compelled participants to align themselves with the social model of disability and to initiate the efforts to put these ideas into practice, as they found this model to: (a) be consistent with their personal and professional values that brought them into the disability field and were honed in their work; and (b) offer better solutions for serving students, resulting in greater

professional satisfaction and meaning for participants themselves. This analysis also reveals two especially salient themes in the narratives of change: (a) the gradual, iterative, reflective process of changing the followers' frames on disability services; and (b) the importance, for the leaders, of mastering the social model of disability and becoming skillful at articulating its ideas when influencing the followers. In the process of change, participants exhibited many of the qualities and behaviors of transformational leaders, questioning and reframing followers' concepts of what it means to fully include students with disabilities in higher education. Hence the distinction in Dara's account (above) of a difficult negotiation with faculty where the course requirements changed but not the faculty mindsets, at least not definitively: "I still didn't feel like [faculty] understood why ... Or maybe they understood it, but ... didn't own it yet, that they were doing it because they were kind of pushed into it, talked into it, or moved in that direction kind of against their will." The significant extent to which the narratives of change demonstrated the focus on the symbolic frames in organizational development should serve as a reminder for current and future advocates of the social model to pay attention to the coexisting cultures and values that inform the ways of doing things in the complex and contested spaces of higher education institutions.

Participants sought to achieve change within the organizational settings where the ideas and practices of the social model departed significantly from the accepted ideas and practices; where acceptance of the social model varied among campus constituencies with different degrees of power and different value systems (even among members of the same disability service office); and where different conceptions of disability and disability services co-existed and competed for dominance—a significant challenge in leading

organizational change and influencing others, which participants recognized. Participants reflected on their experiences, learning from role models, experts, and scholars, and from their own practice (e.g., Martha remarking, "leadership concepts helped me to understand what went wrong"). They persisted in addressing one misconception, one barrier at a time, where change was not a swift revolution, but a gradual, laborious process of changing mindsets, repeating itself as new people joined the disability service profession and disability service offices, potentially bringing along new misalignments and thereby raising the question among the advocates of the social model: What needs to happen to achieve a "tipping point" (a participant's term) in the disability service profession so that the gains are sustained over time? In fact, the time it took participants themselves to transition to the social model from the models into which they were initially socialized through postsecondary education and professional experiences featured in the overall concern about the pace of progress. Further exploration of the transformational leadership theory and methods in this space, drawing on participants' own experience with developing affinity to the social model, can help guide change agents and is suggested as direction for future research. Another direction for future research is to explore the process of the transition to the social model and the questions it raises for different constituencies (faculty, senior, administrators, and disability service professionals), in an integrated fashion: simultaneously, from all points of view. This research may lead to insights about accelerating the paradigm shift by proposing frameworks for social change that: (a) are attuned to, synthesize, and address the values, professional identities, organizational processes and constraints, and the language and fears of different stakeholders; and (b) identify and

present the arguments, project outcomes, and disability literature that satisfy the wellintentioned skeptics, while recognizing, as participants did, the limits of reframing.

Leaders who have dealt with the challenges and emotional impact of resistance to the social model change might like to see a literature review synthesizing relevant leadership lessons and strategies and indicating a path forward that acknowledges the limits of voluntary adoption of the social model, perhaps where the social model is codified into university-wide or departmental policies for staff and faculty.

Finally, having had the privilege of meeting participants and being moved and instructed by their journeys, this author hopes that their individual stories, told in full, will reach a broader audience of readers who will be similarly inspired to work for change.

Bibliography

Aquino, K. C. (2016). A new theoretical approach to postsecondary student disability: Disability-diversity (dis)connect model. *Journal of Postsecondary Education and Disability*, 29(4), 317–330.

Association on Higher Education and Disability (AHEAD). (n.d.). 2019 AHEAD annual conference, Equity and Excellence: Access in Higher Education. Retrieved from https://www.ahead.org/events-programming/conferences/2018-annual-conference/past-conferences/2019-conference

- Association on Higher Education and Disability (AHEAD). (n.d.). About AHEAD. Retrieved from https://www.ahead.org/about-ahead
- Association on Higher Education and Disability (AHEAD). (n.d.). AHEAD supported research. Retrieved from https://www.ahead.org/research/ahead-supported-research
- Aytas, H., & Emil, S. (2020). The lived experiences of faculty members with disabilities in Turkish universities: Implications for higher education leadership and management. *Research in Educational Administration & Leadership*, *5*(4), 1123–1155.
- Bass, B. M., & Avolio, B. J. (1995). *Manual for the multifactor leadership questionnaire*. Palo Alto, CA: Mind Garden.
- Block, L. S., Loewen, G., & Kroeger, S. (2006). Acknowledging and transforming disabling environments in higher education: AHEAD's role. *Journal of Postsecondary Education and Disability, 19*(2), 117–123.
- Blumer, H. (1969). *Symbolic interactionism perspective and method*. Englewood Cliffs, N.J.: Prentice-Hal.

- Bolman, L. G., & Deal, T. E. (2008). *Reframing organizations: Artistry, choice, and leadership* San Francisco, CA: Jossey-Bass. A Wiley Imprint.
- Cetin, M., & Fayda-Kinik, F. S. (2015). An Analysis of Academic Leadership Behavior from the Perspective of Transformational Leadership. *Procedia - Social and Behavioral Sciences, 207*, 519–527.
- Charmaz, K., & Belgrave, L. B. (2015). Grounded theory. In G. Ritzer (Ed.), *The Blackwell Encyclopedia of Sociology*. Retrieved from https://onlinelibrary.wiley.com/doi/abs/10.1002/9781405165518.wbeosg070.pu b2
- Chu, L., Fuentes, L. R., Marshall, O. M., & Mirin, A. A. (2020). Environmental accommodations for university students affected by Myalgic
 Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). *Work, 66*(2), 315–326.
- Crawford, C., Gould, L., & Scott, R. (2003). Transformational Leader as Champion and Techie. *Journal of Leadership Education, 2*, 57–73.

Denbo, S. M. (2006). Disability lessons in higher education: Accommodating learningdisabled students and student-athletes under the Rehabilitation Act and the Americans with Disabilities Act. *American Business Law Journal*, *41*(1), 141–203.

Drønen, T. S. (2006). Scientific revolution and religious conversion: A closer look at Thomas Kuhn's theory of paradigm shift. *Method & Theory in the Study of Religion, 18*(3), 232–253. Retrieved from

https://www.jstor.org/stable/23551769?seq=1#metadata_info_tab_contents

- Dukes, L. L., III, Madaus, J. W., Faggella-Luby, M., Lombardi, A., & Gelbar, N. (2017). PASSing college: A taxonomy for students with disabilities in postsecondary education.
 Journal of Postsecondary Education and Disability, 30(2), 111–122.
- Evans, N. J., Broido, E. M., Brown, K. R., & Wilke, A. K. (2017). *Disability in higher education: A social justice approach*: John Wiley & Sons.
- Firinci Orman, T. (2016). "Paradigm" as a central concept in Thomas Kuhn's thought. International Journal of Humanities and Social Sciences, 6(10).
- Fleming, A. R., Plotner, A. J., & Oertle, K. M. (2017). College students with disabilities: The relationship between student characteristics, the academic environment, and performance. *Journal of Postsecondary Education and Disability, 30*(3), 209–221.
- Gabel, S. L. (2010). A disability studies framework for policy activism in postsecondary education. *Journal of Postsecondary Education and Disability*, *23*(1), 63–71.
- Galison, P. (2016). Practice all the way down. In R. J. Richards & L. Daston (Eds.), *Kuhn's "Structure of Scientific Revolutions" at Fifty: Reflections on a Science Classic*. Chicago and London: University of Chicago Press.
- Godin, B., & Vinck, D. (Eds.). (2017). Critical studies of innovation: Alternative approaches
 to the pro-innovation bias (B. Godin & D. Vinck Eds.). Cheltenham, UK;
 Northhampton, MA. USA: Edward Elgar Publishing.
- Hamraie, A. (2017). *Building access: Universal design and politics of disability*. Minneapolis: University of Minnesota Press.
- Hartsoe, J. K., & Barclay, S. R. (2017). Universal design and disability: Assessing faculty beliefs, knowledge, and confidence in universal design for instruction. *Journal of Postsecondary Education and Disability*, *30*(3), 223–236.

- Ju, S., Zeng, W., & Landmark, L. J. (2017). Self-determination and academic success of students with disabilities in postsecondary education: A review. *Journal of Disability Policy Studies, 28*(3), 180–189.
- Kanov, J. M., Maitlis, S., Worline, M. C., Dutton, J. E., Frost, P. J., & Lilius, J. M. (2004). Compassion in organizational life. *American Behavioral Scientist*, 47(6), 808–827.
- Kaplin, W. A., & Lee, B. E. (2014). *The law of higher education*. San Francisco, CA: Jossey Bass. A Wiley Brand.
- Kuhn, T. S. (1970). *The structure of scientific revolutions* (2nd ed.). Chicago: University of Chicago Press.
- Lester, S. (1999). *An introduction to phenomenological research*: Stan Lester Developments, Taunton. Retrieved from

https://www.rgs.org/CMSPages/GetFile.aspx?nodeguid=7ad9b8d4-6a93-4269-

94d2-585983364b51&lang=en-GB

Levitt, J. M. (2017). Developing a model of disability that focuses on the actions of disabled people. *Disability & Society, 32*(5).

Linton, S. (1998). Claiming disability: Knowledge and identity (4th ed.): NYU Press.

Loewen, G., & Pollard, W. (2010). The social justice perspective. *Journal of Postsecondary Education and Disability, 23*(1), 5–18.

Lyman, M., Beecher, M. E., Griner, D., Brooks, M., Call, J., & Jackson, A. (2016). What keeps students with disabilities from using accommodations in postsecondary education?
A qualitative review. *Journal of Postsecondary Education and Disability*, 29(2), 123–140.

- Maslow, G. R., Haydon, A., McRee, A., Ford, C. A., & Halpern, C. T. (2011). Growing up with a chronic illness: Social success, educational/vocational distress. *Journal of Adolescent Health*, *49*, 206–212.
- Mole, H. (2013). A US model for inclusion of disabled students in higher education setting: The social model of disability and Universal Design. *Widening Participation in Lifelong Learning*, 14(3, Winter).
- Morgan, G. (1997). *Images of organization* (2nd ed.). Thousand Oaks, CA: SAGE Publications.
- National Center for Education Statistics. (n.d.). *Digest of education statistics. Table 311.10. Number and percentage distribution of students enrolled in postsecondary institutions, by level, disability status, and selected student characteristics: 2015–16.* Retrieved from https://nces.ed.gov/programs/digest/d19/tables/dt19_311.10.asp
- National Center for Education Statistics. (n.d.). *Digest of education statistics. Table 317.10. Degree-granting postsecondary institutions, by control and level of institution: Selected years, 1949–50 through 2019–20.* Retrieved from
- Neuman, L. W. (2011). *Social research methods: Qualitative and quantitative approaches* (7th ed.). Boston, MA: Allyn & Bacon.

https://nces.ed.gov/programs/digest/d20/tables/dt20_317.10.asp?current=yes

- Nieminen, J. H., & Pesonen, H. V. (2020). Taking Universal Design back to its roots: Perspectives on accessibility and identity in undergraduate mathematics. *Education Sciences, 10*, 1–22.
- Oktay, J. S. (2012). Grounded theory. Oxford, New York: Oxford University Press.

- Owens, J. (2015). Exploring the critiques of the social model of disability: The transformative possibility of Arendt's notion of power. *Sociology of Health & Illness 37*(3), 385–403.
- Oxford Dictionary. (n.d.). Definition of paradigm shift in English. https://www.lexico.com/en/definition/paradigm_shift
- Park, H. J., Roberts, K., & Delise, D. (2017). The effects of professional development on universal design for instruction on faculty perception and practice. *Journal of Postsecondary Education and Disability*, 30(2), 123–139.
- Ravitch, S. M., & Carl, N. M. (2016). *Qualitative research: Bridging the conceptual, theoretical, and methodological*. Los Angeles, London, New Delhi, Singapore, Washington DC: Sage.
- Refocus. (n.d.). Examining our practices. https://exploreaccess.org/projectshiftrefocus/about.htm
- Refocus. (n.d.). Project ShIFT. Retrieved from https://exploreaccess.org/projectshiftrefocus/project-shift.htm

Rogers, E. M. (1995). *Diffusion of innovations* (4th ed.). New York, NY: Free Press.

- Royster, L., & Marshall, O. (2008). The Chronic Illness Initiative: Supporting College students with chronic illness needs at DePaul University. *Journal of Postsecondary Education and Disability*, *20*(2), 120–125.
- Samaha, A. M. (2007). What good is the social model of disability? *University of Chicago Law Review, 74,* 1251–1308.
- Sanford, C., Newman, L., Wagner, M., Cameto, R., Knokey, A. M., & Shaver, D. (2011). *The Post-High School Outcomes of Young Adults With Disabilities up to 6 Years After High*

School. Key Findings From the National Longitudinal Transition Study-2 (NLTS2) (NCSER 2011-3004). Menlo Park, CA: SRI International.

- Scott, S., & McGuire, J. (2017). Using diffusion of innovation theory to promote universally designed college Instruction. *International Journal of Teaching and Learning in Higher Education*, 29(1), 119–128.
- Seidman, I. (2013). Interviewing as qualitative research: A guide for researchers in education & social sciences (4th ed.). New York and London: Teachers College Press. Columbia University.
- Shakespeare, T. (2013). Social model of disability. In L. J. Davis (Ed.), *The Disability Studies Reader* (pp. 214–221). Retrieved from ProQuest Ebook Central,

http://ebookcentral.proquest.com/lib/luc/detail.action?docID=1125176

- Shakespeare, T., & Watson, N. (2001). The social model of disability: An outdated ideology? *Research in Social Science and Disability*, *2*, 9–28.
- Siangchokyoo, N., Klinger, R. L., & Campion, E. D. (2020). Follower transformation as the linchpin of transformational leadership theory: A systematic review and future research agenda. *The Leadership Quarterly*, *31*(1), 2–18.
- Stanford Encyclopedia of Philosophy. (n.d.). Thomas Kuhn. Retrieved from https://plato.stanford.edu/entries/thomas-kuhn/#CritInfl
- Thornton, M., & Downs, S. (2010). Walking the walk: Modeling social model and universal design in the disabilities office. *Journal of Postsecondary Education and Disability, 23*(1), 72–78.
- Tobin, T. J., & Behling, K. T. (2018). *Reach everyone, teach everyone: Universal Design for learning in higher education*. Morgantown: West Virginia University Press.

- Vaccaro, A., Kimball, E. W., Moore, A., Newman, B. M., & Troiano, P. F. (2018). Narrating the self: A grounded theory model of emerging purpose for college students with disabilities. *Journal of College Student Development, 59*(1), 37–54.
- Vanier, J. (1992). From Brokennes to Community. New York and Mahwah, NJ: Paulist Press.
- Zola, I. K. (1972). Medicine as an institution of social control. *Sociological Review, 20*(4), 487–504.

	DEPAUL UNIVERSITY		
	CINIVERSITI I		
	Office of Research Services Institutional Review Board 1 East Jackson Boulevard Chicago, Illinois 60604-2287 312-362-7593		
	Fase 312-362-7574 Research Involving Human Subjects		
	NOTICE OF INSTITUTIONAL REVIEW BOARD ACTION		
T	Oler Markell MA Contrate Student Collins of Education		
To:	Olena Marshall, MA, Graduate Student, College of Education		
Date:	October 17, 2019		
Re:	 Research Protocol # OM090919EDU "Applying Social Model of Disability and Universal Design: Phenomenology of initiating change in higher education" 		
Please	review the following important information about the review of your proposed research activity.		
This s	<u>Details</u> ubmission is an initial submission.		
This s Your i	ubmission is an initial submission. research project meets the criteria for Exempt review under 45 CFR 46.104 under the following ry:		
This s	 abmission is an initial submission. research project meets the criteria for Exempt review under 45 CFR 46.104 under the following ry: (3) (i) Research involving benign behavioral interventions in conjunction with the collection of information from an adult subject through verbal or written responses (including data entry) or audiovisual recording if the subject prospectively agrees to the intervention and information collection and at least one of the following criteria is met: (A) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects; (B) Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; or (C) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects can readily be ascertained, directly or through identifiers linked to the subjects, and an IRB conducts a limited IRB review to make the determination required by 45 CFR 46.111(a)(7). 		
This s Your i	 abmission is an initial submission. esearch project meets the criteria for Exempt review under 45 CFR 46.104 under the following ry: (3) (i) Research involving benign behavioral interventions in conjunction with the collection of information from an adult subject through verbal or written responses (including data entry) or audiovisual recording if the subject prospectively agrees to the intervention and information collection and at least one of the following criteria is met: (A) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects; (B) Any disclosure of the human subjects ' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects ' financial standing, employability, educational advancement, or reputation; or (C) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects can readily be ascertained, directly or through identifiers linked to the subjects; and the human subjects can readily be ascertained, directly or through identifiers linked to the subjects, and an IRB conducts a limited IRB review to make the determination required by 45 CFR 46.111(a)(7). (REQUIRES LIMITED IRB REVIEW OF PRIVACY AND CONFIDENTIALITY) (ii) For the purposes of this provision, benign behavioral interventions are brief in duration, harmless, painless, nor physically invasive, not likely to have a significant adverse lasting impact on the subjects, and the investigator has no reason to think the subjects will find the interventions offensive or embarrassing. Provided all such criteria are met, examples of such benign interventions out include having the subjects play an online game, having them solve puzzles under various noise conditions or having them decide how to allocate a		

Appendix A. Approved Institutional Review Board Application

Approval Details

Your research was originally reviewed on September 24, 2019 and revisions were requested. The revisions you submitted on October 7, 2019 were reviewed and approved on October 17, 2019.

Number of approved participants: 7 Total

You should not exceed this total number of subjects without prospectively submitting an amendment to the IRB requesting an increase in subject number.

Funding Source: 1) None.

Approved Performance sites: 1) DePaul University.

Limited IRB review of the privacy and confidentiality protections in place, and where applicable the Broad Consent, have been completed.

Reminders

Under DePaul's current institutional policy governing human research, research projects that meet the criteria for an exemption determination may receive administrative review by the Office of Research Services Research Protections staff. Once projects are determined to be exempt, the researcher is free to begin the work and is not required to submit an annual update (continuing review). As your project has been determined to be exempt, your primary obligation moving forward is to resubmit your research materials for review and classification/approval when making changes to the research, but before the changes are implemented in the research. <u>All changes to the research must be reviewed and approved by the IRB or Office of Research Services staff.</u> Changes requiring approval include, but are not limited to, changes in the design or focus of the research project, revisions to the information sheet for participants, addition of new measures or instruments, increasing the subject number, and any change to the research no longer eligible for an exemption determination).

Once the project is complete, you should submit a final closure report to the IRB.

The Office of Research Services would like to thank you for your efforts and cooperation and wishes you the best of luck on your research. If you have any questions, please contact me by telephone at (312) 362-6168 or via email at <u>jbloom8@depaul.edu</u>.

For the Board,

Dessida Cloth

Jessica Bloom, MPH Assistant Director of Research Compliance Office of Research Services

Cc: Andrea Kayne, JD, Faculty, College of Education

Page 2 of 2

Appendix B. Information Sheet for Participants

INFORMATION SHEET FOR PARTICIPATION IN RESEARCH STUDY Applying the Social Model of Disability and Universal Design: Phenomenology of Initiating Change in Higher Education

Principal Investigator: Olena M. Marshall, graduate student in the College of Education

Institution: DePaul University, USA

Faculty Advisor: Andrea Kayne, JD, Associate Professor; Director, Educational Leadership Doctoral Program, College of Education, DePaul University

I am conducting a research study because I am trying to learn more about how faculty and staff members in higher education institutions initiate efforts to apply social models and universal design in serving students with disabilities and/or broader student population. In particular, I would like to understand: What factors, personal and organizational, compel faculty and staff to initiate the efforts, broadly conceived, to put social model/universal design ideas to practice on campus? What is the process for this engagement and what meaning does it have for the actors? What lessons can be learned from their experiences toward greater inclusion of students with disabilities, beyond individual, ad hoc accommodation? I am asking you to be in the research because I understand that in your work at a four-year college or university you initiated a project to implement a project/program or otherwise proposed ideas for serving students, informed by the social model of disability and universal design.

If you agree to be in this study, you will be asked to participate in up to three one-on-one interviews with the Principal Investigator, where we may discuss how you first engaged with the issue of disability; how and when your learned about the social model of disability and the tools of universal design; how you decided to act on these ideas, how you went about it; what meaning the experience had to you personally and professionally; and what lessons you might have learned from the experience. I will ask you to complete a basic demographic questionnaire.

The demographic questionnaire will ask you your geographical state, gender, age, educational level, employment status, and ethnicity/race. I will ask you to complete the demographic questionnaire at the end of the first interview and anticipate that it will take up to five minutes of your time to complete.

The interview may be conducted in-person or via phone or Zoom, or a similar aid, and I would like to audio-record the interviews, if you agree, to ensure that I capture, and will be able to transcribe, your ideas accurately. You will be able to decline to answer any question or stop the interview. I hope to conduct up to three interviews with you, each about 60 minutes long, to allow time to discuss your experience and thoughts in detail.

When you first give me your information it will be linked to you with a code number and I will have a key that tells me who that code number belongs to. For a period of time, it will be possible to link this information to you. However, I have put protections in place, such as storing the information in a secured computer under password protection. After the study is completed (in about 12 months), I will remove all identifiers and make the data deidentified. The data will be kept for an undetermined period of time in the de-identified way, and there should be no risk to you should someone gain access to the data.

Your participation is voluntary, which means you can choose not to participate. There will be no negative consequences if you decide not to participate or change your mind later after you begin the study. You can withdraw your participation at any time during the interview. You can withdraw your participation at any time, by contacting me at <u>olenamarshall@gmail.com</u>. Since the information you gave me is still identifiable and linked to your name (or other direct identifier), I can remove your data from the research at any time.

If you have questions, concerns, or complaints about this study or you want to get additional information or provide input about this research, please contact my faculty advisor Andrea Kayne, JD, Associate Professor; Director, Educational Leadership Doctoral Program, College of Education, at andrea.kayne@depaul.edu.

If you have questions about your rights as a research subject, you may contact Susan Loess-Perez, DePaul University's Director of Research Compliance, in the Office of Research Services at 312-362-7593 or by email at sloesspe@depaul.edu. You may also contact DePaul's Office of Research Services if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.

You may keep this information for your records.

I have explained the study to you, and by signing the document below, you are indicating your affirmative agreement to be in the research.

Appendix C. In-depth Qualitative Interview Guide

Applying the Social Model of Disability and Universal Design: Phenomenology of Initiating Change in Higher Education

Olena M. Marshall In-depth Qualitative Interview Guide

NOTE: If feasible, the researcher will conduct three interviews with each participant, roughly grouped around (i) life history, (ii) implementing social model and universal design ideas, and (iii) reflecting on the experience. In the event that is not feasible, the researcher will adjust the interview flow.

Thank you for agreeing to participate in this study.

This interview is being audio-recorded for research purposes. If you object to being recorded at any point, please let me know and the recording will stop. Do you agree to being recorded? Recording starts now.

i. Life history

First, I would like to get to know you. Can you tell me briefly about growing up and about your education?

Can you describe your professional journey?

How did you first engage with the issue of disability in your personal and/or professional life?

What is your engagement with the issue of disability in higher education?

ii. Implementing social model of disability and universal design ideas

How and when did you become aware of the social model of disability?

- What was your reaction?
- Where did you work and what was your job at the time?

How and when did you become aware of the tools of universal design?

- What was your reaction?
- Where did you work and what was your job at the time?

Please tell me what prompted you to act on the ideas of social model of disability and/or universal design?

- How did you go about sharing and acting on these ideas?
- Who were the colleagues involved? How did they react?
- Tell me in detail what happened?
- How did you feel about the experience?

iii. Reflecting on the experience

What lessons did you learn from the experience of implementing social model of disability and/or universal design ideas?

Please reflect on the meaning that the experience of implementing social model/universal design ideas had in your personal and professional life?

Do you have any advice or insights for others engaged with the issues of disability?

What ideas do you have for creating greater inclusion for students with disabilities in colleges and universities?

Other issues

Would you be willing to share your resume with me and materials that would enable me to understand your experience better? Please send these materials to [email address].

Would you be willing to complete a basic demographic questionnaire? (Attached)

Appendix D. Script For Contacting Potential Participants

Olena M. Marshall Script for Contacting Potential Participants

Hello, I am Olena M. Marshall, a graduate student in the College of Education at DePaul University. I am conducting a research study because I am trying to learn more about how faculty and staff members in higher education institutions initiate efforts to apply social models and universal design in serving students with disabilities and/or broader student population. In particular, I would like to understand:

What factors, personal and organizational, compel faculty and staff to initiate the efforts, broadly conceived, to put social model/universal design ideas to practice on campus?

What is the process for this engagement and what meaning does it have for the actors?

What lessons can be learned from their experiences toward greater inclusion of students with disabilities, beyond individual, ad hoc accommodation?

I am asking you to be in the research because I understand that in your work at a four-year college or university you initiated a project to implement a project/program or otherwise propose ideas for serving students, informed by the social model of disability and universal design. I am interested in speaking to you as someone involved in the issues of higher education and disability.

For more information about this study, please see the Information Sheet attached.

If you would like to learn more about this study or if you would like to participate in the study, please email me at [email address]. I hope to hear from you in the next seven days.

Sincerely,

Olena M. Marshall

Appendix E. Script for Contacting Participants Indicating Interest

Olena Marshall Script for Contacting Participants Who Have Indicated Interest in Participating in the Interview

Hello, I am Olena Marshall, a graduate student in the College of Education at DePaul University. Thank you for indicating your interest in participating in the research study, The Information Sheet about the study is once again attached for easy reference.

At this point, I would like to work with you to set up a time and date for the interview that is convenient to you. Please let me know if a phone, Zoom, and in-person interview (if feasible) would be preferred.

Sincerely,

Olena M. Marshall [Email and cell phone number omitted]

Appendix F. Reminder for Participants who Agreed to Participate

Olena Marshall Reminder for Contacting Participants Who Have Agreed to Participate in the Interview

Dear participant,

Thank you for agreeing to participate in the upcoming interview for the research, Applying Social Model of Disability and Universal Design: Phenomenology of Initiating Change in Higher Education.

I am writing to remind you that we have scheduled the interview for

- Date
- Time
- Place (physical address, phone number, zoom meeting details).

If you need to contact me, please do not hesitate to reach me via email [] or cell phone # [].

I sincerely appreciate your willingness to participate.

Olena M. Marshall

Appendix G. AHEAD Announcement

31/2020	Gmail - Research Opportunity!		
M Gm	ail	Olena Marshall <olenamarshall@gmail.com< th=""></olenamarshall@gmail.com<>	
Research O	pportunity!		
AHEAD <ahead@ Reply-To: ahead@ fo: olenamarshal</ahead@ 	gahead.org	Thu, Feb 27, 2020 at 10:00 AM	
	AHEA	D Association on Higher Education And Disability®	
s	udy, our Research Review Panel, chair	e AHEAD membership as participants in a red by Dr. Nancy Chinn, thoroughly reviews odology, and Institutional Review Board (IRB) afety of participants.	
P		d approved by AHEAD's Research Review witation below and assist Olena Marshall in	
D	ear AHEAD members,		
D **		e in the Educational Leadership program in n, is conducting a qualitative study titled, universal design: Phenomenology of	
si h a o si	ave initiated social model and/or univend learning or campus activities, she ir lenamarshall@gmail.com about parti	er at a four-year college or university and ersal design-informed changes in teaching	
п	· · · · · · · · · · · · · · · · · · ·	hour of participant's time, with up to 2 ipants to explore and communicate their	
n		n, this study will add to the literature on the ocial model and universal design from the he change in their institutions.	
	mail/u1021k=aa732a74508.dow=at8aaaab==118-aaa	thid=thread-f%3A1659706282684076370%7Cmsg-f%3A1659706282684	

