Review of Disability Studies: An International Journal
Volume 5, Issue 2

Table of Contents

Research Articles

Essays and Creative Works

Book and Media Reviews

Gender and Disability: A First Look at Rehabilitation Syllabi and a Call to Action

Allen N. Lewis, Ph.D., Sarah Jane Brubaker,Ph.D., & Amy J. Armstrong, Ph.D.
Virginia Commonwealth University

Research Articles

Abstract: This study provides an overview of recent scholarship in the area of gender and disability, as well as findings from an evaluation of syllabi from five core courses in graduate rehabilitation education programs. Findings from this exploratory study revealed a need for more attention toward integration of the topic of gender and disability into rehabilitation education courses. Study results showed that in only one out of three courses where there would be a reasonable expectation to see such topics was the content actually addressed. Specific recommendations for enhancing attention to gender issues within rehabilitation education courses are offered.

Key Words: gender, disability, rehabilitation

*Editor's Note: This article was anonymously peer reviewed.

Introduction

The intent of this study is to investigate the pre-service education received by graduate-level rehabilitation counseling students related to gender and disability. The primary research question is, "To what extent are gender and its relationship to disability being addressed in selected rehabilitation counseling courses?" This question fits into a broader context of understanding what rehabilitation education programs are doing to address the topic of gender and disability, and ultimately of more importance, the potential impact of such efforts on vocational rehabilitation services.

The rehabilitation profession is charged with maximizing the strengths and employment potential of individuals with disabilities in order to increase community inclusion. Toward this end, researchers and practitioners investigate and implement best practices. Rehabilitation strives to achieve three primary measures of success for clients served: optimal health, maximum independence, and ultimately, a high quality of life. Actualization of each of these outcomes depends on individual preferences, functioning, and skills, as well as the demographic profile of the service recipient. Increasingly, gender is being viewed as an important demographic factor that influences the disability experience (Nosek & Hughes, 2003).

Theoretical advances in the areas of gender and sexuality have the potential to enhance our understanding of the experience of disability, and ultimately, empower advocates, practitioners, and people with disabilities to work for positive change. As researchers have begun to address the connections between gender and disability, they have realized that rehabilitation counselors must address unique psychosocial issues, as gender and disability combine to shape the interpersonal experiences of both women and men with disabilities.

Research-based knowledge on the impact of gender on the rehabilitation process is needed not only at the client and practitioner levels, but also at the pre-service education phase to target prospective professionals who intend to enter the field. Of paramount importance is counselor awareness of gender-based disparities among those who experience a disability, as well as increasing knowledge on how best to address those differences in order to optimize services for clients. The goal of developing assessments and interventions designed to consider relevant gender and disability issues is essential to full inclusion of all individuals who receive rehabilitation services and enhancing their life outcomes.

Literature

Developments in theory and research across various disciplines have expanded our understanding of how gender and disability combine in particular ways to shape the experiences of individuals with disabilities. In this section, we briefly review some of the major issues within this area of scholarship that are relevant to and should be incorporated into rehabilitation counseling education.

Prevalence

Women with disabilities are one of the largest and most marginalized groups within our society (Nosek & Hughes, 2003; Jans & Stoddard, 1999) based on their status as females as well as being identified as persons with a disability (Menz, Hansen, Smith, Brown, Ford, & McCrowey, 1989; Traustadottir, 1990). They outnumber men with disabilities and constitute 21% of the population of women in the United States (Jans & Stoddard, 1999). The authors recognize that gender affects the experiences of both women and men with disabilities in distinctive ways. However, because women most often face gender-based obstacles and biases, in this review of the literature, there is a focus on their experiences to ground the argument on the need for more attention to gender. Nevertheless, one must be ever mindful that rehabilitation courses should focus on the unique experiences of both women and men with disabilities.

Gender and Disability Theories

Some of the most promising recent advances in gender and disability theories have resulted from criticisms of and improvements to singular theories that have failed to fully address the combined foci of gender, sexuality, and disability. Scholars now recognize the importance of integrating foci from within feminist and disability theories in order to more fully address these interconnections.

Schriempf (2001) argues that both feminist theory and disability theory have failed to address the experiences and needs of women with disabilities, particularly around sexuality. Specifically, feminist theory's focus on the negative impact of the sexual objectification of women is ill equipped to address the negative experiences of women with disabilities that result from their social and cultural desexualization. Schriempf suggests that the social model of disability similarly fails to take into account the importance of the body in subjective and sexual experiences of women with disabilities. Others have similarly argued for the integration of the body and disability into feminism, and the importance of attention to the body and gender to theories and policies regarding disability (Gerschick 2000, Garland-Thompson 2002, Hughes & Paterson 1997; Edwards & Imrie 2003; Quinn, 1994; Watson, McKie, Hughes, Hopkins, & Gregory, 2004), The combined effects of gender and disability pose unique challenges to women and men with disabilities. For example, Thomas (2002) argues that women with disabilities, because of "disableism" and patriarchy, are at more of a risk of experiencing oppressive medical practices than able-bodied women, or men with disabilities.

Although more recently, scholars and activists have criticized some aspects of the social model of disability (Corker & French, 1999; Shakespeare 2006), we suggest that this model identifies some of the major ways in which women with disabilities are discriminated against in various aspects of social life. This model assumes that disability is not inherent in the person, but is constructed by society in its failure to provide people with access and treat them with the same respect afforded persons without disabilities. Rehabilitation research in the last 20 years has begun to explore the impact of the combined social locations and identities of gender and disability on quality of life, as well as health and well-being, yet prior to 1990, the topic had been sparsely investigated (Nosek & Hughes, 2003; Traustadottir, 1990). According to Nosek and Hughes (2003):

"We have little empirically based evidence suggesting that clinical practice is different in the psychosocial rehabilitation and community reintegration of women and men with disabilities…It is time to think and respond differently to femaleness and maleness in rehabilitation and research" p. (225).

Substantive Research

Gender affects the experiences of women with disabilities in terms of their access to resources such as health care, education, and employment (Froschl, Rubin, & Sprung, 1999; Gerschick, 2000; Nosek, Grabois, & Howland, 2002), all of which are social institutions that discriminate against them. In terms of employment, women with disabilities are less likely than men to be employed, and more likely to earn less money than men when they are employed (O'Harrah, 2004; Traustadottir, 1990). Women are underrepresented in rehabilitation programs and women with disabilities experience inequality in education and health care, more poverty, and less social inclusion compared to their male and able-bodied counterparts, as well as being subjected to policies and practices that were not originally designed to meet their needs (Fine & Asch, 1985, 1988; Kutza, 1985; Mudrick, 1988). Rehabilitation counselors need to be familiar with these issues, as they assist and advocate for clients seeking services within employment, education, health care, and other arenas.

Due to negative attitudes and stereotypes ascribed by the general public and rehabilitation counselors to women with disabilities, they are less likely to be referred to vocational training, have a harder time gaining access to rehabilitation programs, are less likely to receive quality training, and are more likely to be successfully rehabilitated into non-employment. Women with disabilities receive fewer and lower levels of benefits than men from programs designed for people with disabilities because such programs are designed and based on men's relationship to the labor market (Traustadottir, 1990). Rehabilitation counselors should critically examine their approach to assisting persons with disabilities and rehabilitation counseling's historical focus on vocation as paid employment. This conceptualization is also likely to be based on a male model of work and might need to be reevaluated and adjusted to fit the experiences, needs, and goals of women with disabilities.

Not only does the relationship between gender and disability produce unique barriers to social resources and institutions, but also gender and disability combine to shape the interpersonal experiences of women and men with disabilities. This area encompasses a number of issues, but for the purposes of this paper, we focus primarily on the ways in which gender shapes the experiences of women with disabilities in terms of their interpersonal relationships, including partnerships and parenting, and care giving experiences. Again, although these issues may not fit neatly into the traditional focus of rehabilitation counseling on vocation, they are related to independent living and essential to optimizing quality of life, also important domains of influence for rehabilitation counselors.

Because our current culture defines ideal femininity in terms of physical attractiveness, the ability to nurture, the desire to love and be loved, and the ability to mother in terms of femininity, women with disabilities experience negative consequences in those instances where there is a failure to meet these cultural expectations. Specifically, women are four times more likely than men to divorce after developing a disability, and their likelihood to marry is 25% to 33% of the probability of their male counterparts (Asch & Fine, 1985; Gerschick, 2000). Men with disabilities are more likely to find a partner who is willing to care for them than are women (Lorber, 2000). On the other hand, those disabled women who do have partners, but who wish to leave them, experience various barriers. According to Olkin (2003), such obstacles include "(a) physical needs; (b) financial needs; (c) custody concerns; and (d) relationship

issues" (p. 237). These same barriers are faced by women with disabilities in several additional aspects of their lives and illuminate multiple areas in which rehabilitation counseling clients might need assistance and advocacy.

As discussed previously in the Gender and Disabilities Theories section (two sections above), women with disabilities are often seen as asexual, and hence, are denied sex education, access to reproductive information, and services including birth control and fertility (Schriempf, 2001; Burns, 2002; Lorber, 2000; Saxton, 2003). Women continue to need sexual information provided during rehabilitation through education, therapy, and guidance by peers (Nosek & Hughes, 2003). Relatedly, women with disabilities often are not seen as fit parents, and this view shapes policies denying them custody and adoption (Saxton, 2003). Accessing services related to education, health care, and other needs clearly poses challenges to women with disabilities and needs to be addressed through rehabilitation counseling.

Because of the widespread discrimination they face in many social domains, women with disabilities experience multiple psychosocial challenges that impact their quality of life. Social connectedness has been found to be related to the development of self-worth, whereas isolation is related to health problems and mortality. Women with disabilities experience social isolation that may negatively impact their self-esteem, levels of depression, and stress (Berkman & Syme, 1979). For example, stress levels for women with physical disabilities have been reported at higher levels than those of the general population (Hart, Rintala, & Fuhrer, 1996). Women with disabilities appear to be at higher risk for depression in comparison to men with disabilities, women without disabilities, and the general population (McGrath, Keita, Strickland, & Russo, 1990). Contributing to women's depression are a variety of factors that include low levels of perceived control, lack of social support, low income or poverty, and abuse (McGrath, Keita, Strickland, & Russo, 1990; Warren & McEachren, 1983).

Women with disabilities also face serious health risks due to their vulnerability and stigmatization from the larger society where patriarchal and discriminatory views still pervade. They are likely to be victimized and may be more susceptible to violence and abuse due to their dual minority status as women, and as people with disabilities (Brownridge, 2006; Nosek, Foley, Hughes, & Howland, 2001). Abuse is five to eight times more likely among women with disabilities than men with disabilities, and more likely among women with than without disabilities (Nosek & Hughes, 2003). Women with disabilities are more likely than nondisabled women to experience abuse at the hands of attendants and physicians, as well as to experience abuse for longer periods of time (Hassouneh-Phillips & Curry, 2002). As primary advocates for many persons with disabilities, rehabilitation counselors need to be trained in how to assess and respond to the specific nuances of abuse in women with disabilities.

Each of the previously mentioned unique experiences of women with disabilities must be included in rehabilitation counseling education. Students must be trained in acknowledging and responding to these issues together with their clients.

Methodology

This investigation was both exploratory and descriptive. It was exploratory in that it represents a first attempt to look at rehabilitation courses amid a long-range research plan to do a much more rigorous examination over time. This study does not involve variable manipulation, and therefore, its descriptive attribute is grounded in the evaluation of selected rehabilitation course syllabi employing a content analysis approach.

The study cohort was extracted in late 2004 and early 2005 from rehabilitation counseling

graduate degree programs from across the United States that were member institutions of the National Council on Rehabilitation Education (NCRE). The NCRE Research Committee approved the use of the NCRE listserv by the investigators in the conduct of this study. NCRE members are either institutionally based, that is an entire faculty body at an educational institution is a member, or individually based (one faculty person is a member). NCRE consists of approximately 480 individual and institutional members.

All members were sent an email via the listserv in which they were asked to participate in an exploratory study on gender and disability by reviewing syllabi from five specific courses in graduate rehabilitation counseling programs. They were requested to provide all of their syllabi from the targeted courses. Five specific courses were targeted for the review: Introduction to/ Foundations of Rehabilitation, Case Management in Rehabilitation, Psychosocial Aspects of Rehabilitation, Medical Aspects in Rehabilitation, and Multicultural Counseling in Rehabilitation. The rationale for selecting these five courses was to review a subset of all course offerings that the study investigators agreed would be likely to include the topic of gender and disability as part of the core course content.

The response rate to the study, based on listserv data, was 30% at the university program level. That is, 30% of the institutions offering graduate programs in rehabilitation counseling responded, or 27 out of approximately 90 Council on Rehabilitation Education (CORE) accredited programs. The study sample included 40 syllabi across the 27 responding university programs. This represents from one to five syllabi for each responding institution with some variation across the 27 respondent programs. Course syllabi were used in this study since a syllabus is the most accessible single source of information on course content.

A content analysis was performed on each of the 40 received course syllabi. To avoid single reviewer bias, two raters independently reviewed each syllabus. The independent reviews were followed by a discussion between the two raters to reach agreement on the overall rating of each syllabus. Each syllabus was given one of four ratings: level 1 – gender is not an explicit focus in the course (i.e., the word "gender" is not mentioned on the syllabus); level 2 – gender is a minimally explicit focus of the course (i.e., the word "gender" is mentioned on the course syllabus among a list of many subtopics covered, but is not a key area the course covers.); level 3 – gender is a moderately explicit focus in the course (i.e., the word "gender" is mentioned as a main subtopic of a major focal area on the course syllabus); and level 4 – gender is a substantially explicit focus in the course (i.e., the word "gender" is a major content focal area in the course).

Results

Of the 40 course syllabi, 9 were from Case Management in Rehabilitation courses, 10 from Introduction to/Foundations of Rehabilitation courses, 4 from Psychosocial Aspects in Rehabilitation courses, 11 from Medical Aspects in Rehabilitation courses, and 6 from Multicultural Counseling in Rehabilitation courses. Of the Case Management in Rehabilitation course syllabi, 8 did not mention gender at all (level 1 "gender not mentioned"), and 1 syllabus mentioned gender as a main subtopic of a major focal area in the course (level 3 "moderately explicit focus"). For the course Introduction to/ Foundations of Rehabilitation, 8 syllabi did not mention gender at all (level 1 "gender not mentioned"), with 2 syllabi mentioning gender as one of the many subtopics addressed, but not a main subtopic of a major area (level 2 "minimally explicit focus"). For the course Psychosocial Aspects in Rehabilitation, 3 syllabi did not mention gender at all (level 1 "gender not mentioned"), and 1 syllabus mentioned gender as a major content focal area in the course

Table 1. Distribution of gender as a specific content area.

Course	Syllabi Received	Level 1 not mentioned	Level 2 minimal focus	Level 3 moderate focus	Level 4 substantial focus
Case Management	9	8		1	
Intro to Rehab Counseling	10	8	2		
Psychosocial Aspects	4	3			1
Medical Aspects	11	6	3	2	
Multicultural Counseling	6	1	1	4	

(level 4 "substantially explicit focus"). Of the syllabi for the course Medical Aspects in Rehabilitation, 6 syllabi did not mention gender at all (level 1 "gender not mentioned"), and 3 syllabi mentioned gender as one of many subtopics covered, but not a main subtopic of a major area (level 2 "minimally explicit focus"), and 2 syllabi mentioned gender as a main subtopic of a major focal area in the course (level 3 "moderately explicit focus"). When mentioned as a level 3 focus, gender was more about how disease affects the sexes differently, rather than the broader issues related to discrimination and differential service delivery based on gender. Finally, the course, Multicultural Counseling in Rehabilitation, had 1 syllabus that did not mention gender at all (level 1 "gender not mentioned"), 1 syllabus mentioned gender as one of many subtopics addressed (level 2 "minimally explicit focus"), and 4 syllabi mentioned gender as a main subtopic of a major focal area in the course (level 3 "moderately explicit focus"). See Table 1, which provides the same results regarding the syllabi by course just summarized above in tabular form.

Discussion

Though at first glance it may seem that this study evaluates a small number of course titles, the five courses reviewed actually represent a significant portion of the coursework in graduate rehabilitation counseling programs accredited by CORE. Most CORE-accredited programs are 48 to 60 credit degree programs with up to 12 credits devoted to the internship component and skills-based coursework. This means that most CORE-accredited programs offer 12 to 16 didactic courses. Therefore, a five-course subset of a degree that consists of 12 courses is 42% of course content offered, and for a degree that consists of 16 required courses, it is 31%. Both percentages represent significant proportions of the didactic coursework in graduate rehabilitation education programs i.e., almost a third, 31% to approaching one-half of courses, 42%. Therefore, this study, though exploratory, does examine syllabi for a substantial segment of the didactic coursework in CORE-accredited graduate rehabilitation counseling programs.

Among the five courses reviewed, those that dealt the least with gender were Case Manage-

ment in Rehabilitation, Introduction to/Foundations of Rehabilitation, and Psychosocial Aspects in Rehabilitation, with only 4 of 23 courses, or 17%, of this group mentioning gender. The topic of gender was most prominently represented in the two courses of Multicultural Counseling in Rehabilitation and Medical Aspects in Rehabilitation, and when these courses are combined, this reflects 10 of 17 courses, or 59% of courses in these two categories that mentioned gender. By course, the proportions of syllabi that mentioned gender were: Case Management in Rehabilitation (1 of 9 courses, 11%), Introduction to/Foundations of Rehabilitation (2 of 10, 20%), Psychosocial Aspects in Rehabilitation (1 of 4, 25%), Medical Aspects in Rehabilitation (5 of 11, 45%), and Multicultural Counseling in Rehabilitation (5 of 6, 83%). Overall, 14 of 40 course syllabi mentioned gender (35%). Caution is advised in interpreting these percentages since they are all proportions calculated within very small samples. It is also important to note that the findings are descriptive of the quantity of explicit references to gender in the syllabi, and not of the quality or intensity of activities within a course. Based on this first exploratory study, it appears that more work needs to be done towards integration of the topic of gender and disability into these five courses since 65% of the course syllabi reviewed did not mention gender.

This study has several limitations. First, the content review is an analysis approach that is qualitative and fundamentally interpretive. Therefore, the findings have limited generalizability beyond the sample of courses in this study though they do illuminate patterns worthy of further investigation. A second limitation is that some course syllabi mentioned the phrase "multicultural topics and issues," so in the absence of more specificity, the reviewers assumed this meant a focus on racial and ethnic differences. However, it could have been the intent of some faculty members to include gender issues broadly under "multicultural topics and issues" on some course syllabi. Wherever this may have been the case, the course was not given credit as having a focus on gender and disability due to lack of explicitness.

A final limitation in this study is that the sample of syllabi received and reviewed for each course (40 total syllabi reviewed: 9 from Case Management, 10 from Introduction to/Foundations of Rehabilitation, 4 from Psychosocial Aspects in Rehabilitation, 11 from Medical Aspects in Rehabilitation, and 6 from Multicultural Counseling in Rehabilitation courses) is a small fraction of the potential total number of syllabi representing course titles this study could have reviewed from among the approximately 90 CORE member institution graduate programs. Since each of the courses reviewed is a required course, the authors assumed that each of the approximately 90 CORE accredited programs would have these five courses. Keep in mind that the syllabi reviewed in this study were from 27 programs, or just under 1/3 of CORE programs.

Implications and Recommendations for Further Research and Strategies for Educators

Implications

Despite the small sample size and other study limitations already mentioned, the findings in this study provide preliminary insight into the extent to which rehabilitation education is addressing the topic of gender and disability. We conducted the study to gain a sense of the current state of rehabilitation education as a starting point for understanding the extent to which the five particular courses reviewed here address gender and disability. We suggest that not only should these five courses include more attention to gender and disability, but that the syllabus for every course needs to explicitly reflect this emphasis.

The positive findings in this study relative to the courses of Multicultural Counseling in Rehabilitation and Medical As-

Table 2. Recommendations for incorporating gender topics into the five core rehabilitation education courses.

Course	Course Topics Related to Gender	How to Address Gender	Recommended Reading/Activity
Intro/Foundations	Effects of disability on personal and social development	Discuss the importance of gender to identity and relationships with others	Fine & Asch (1985 & 1988)
	Services and resources available	Discuss findings about gender disparities in accessing services	Jans & Stoddard; Menz (1999)
	Social/sociological issues and impact on rehab	Review research on gender inequality in society in general	Lorber (2000)
	Client populations	Review research on gender differences in experiences of disability and adjustment	Provide training on assessing abuse/victimization
Case Management	Developing independent living plans	Assess gender differences in family and employment goals and research on and gender-specific obstacles	Traustadottir (1990 & 1991)
	Connecting clients to resources	Review research findings on gender disparities in accessing services	Nosek (2001, 2002, & 2003)
Medical Aspects	Social implications of medical issues	Discuss gender differences in how using and displaying the body impact identity	Edwards & Imrie, 2003; Gerschick & Miller, 1995; & Hart, Rintala, & Fuhrer, 1996.
Psychosocial Aspects	Coping with and adjustment to disability	Review literature on women and disability and major issues women face	Fine & Asch (1985 & 1988); Nosek (2001, 2002, & 2003)
	Social and sexual relationships	Review literature on women and disability and major issues women face	Provide training on assessing abuse/victimization
Multicultural Counseling	Impact of cultural differences among clients	Discuss cultural issues related to gender such as gender norms, beliefs, ideology e.g. values regarding marriage, children, sexuality that impact gender identity and how disability impacts all of this	Fine & Asch (1985 & 1988)

pects in Rehabilitation represent a solid foundation for rehabilitation education in its quest to do more pre-service professional preparation in the area of gender and disability. However, the apparent paucity of representation of gender and disability in other courses, for example, Case Management in Rehabilitation, warrants further consideration. Women have distinct service needs based on the earlier discussion of literature that elucidated the obstacles faced by this population.

Recommendations for Further Research and Strategies for Educators

A natural next step in terms of future research recommendations on this topic would be to survey rehabilitation educators to hear directly from them how the topic of gender and disability is being addressed in all courses, as well as to request all course syllabi for a comprehensive content review. Subsequently, the administration of a survey of all certified rehabilitation practitioners to measure self-perceptions of their preparation to deal with gender and disability topics, as well as perceived overall effectiveness, would be useful.

In addition to recommendations for future research on this topic, we provide "strategies for educators," which are suggestions for ways to incorporate more extensive and explicit attention to gender as a critical aspect of an individual's experience with disability. We suggest that this topic should be incorporated into rehabilitation education curricula, particularly in the five core course syllabi that we evaluated for this paper. In addition to providing a preliminary look at the current status of rehabilitation education's inclusion of gender and disability in the curriculum as this discussion has done, Table 2 includes some recommendations for how instructors might incorporate relevant gender topics into these courses.

Based on the common course objectives listed in the submitted syllabi, we have identified the primary topics of each course that the literature suggests are most relevant to gender and disability. We then list the specific gender topics that are related to the course topics, and provide suggestions for readings or course activities that instructors could utilize in order to include the topic in the course.

We want to stress that instructors of these courses need not be experts in the area of gender in order to include gender and disability topics. Numerous resources are available to instructors that can assist them in including gender and disability without a great deal of effort. First, most universities have Women's Studies or Sociology departments with faculty who are experts in the area of gender, and rehabilitation education instructors can utilize these resources, guest lecturers, and recommendations for reading materials, films, etc. Second, we also provide recommendations for readings within Table 2 that are available in the reference section of this paper.

There are also resources available online and through community organizations that provide information, referrals, and trainings on detecting and responding to abuse of women with disabilities. One program that is accessible online in many states (e.g. through Departments of Health) is the RADAR program. This program is designed to provide training to medical professionals. The acronym stands for **R**outinely inquire about current and past violence, **A**sk direct questions, **D**ocument findings, **A**ssess safety, and **R**eview options and referrals. Finally, inviting women with disabilities to speak in classes, or to be interviewed by students as part of a class assignment, and asking them to talk about their family and relationship experiences would provide valuable insights to the topic. This final recommendation of speaking to women with disabilities would be the most obvious recommendation and arguably one of the most important.

Conclusion

The findings in this study make clear a needed call to action. The call to action is twofold. On the one hand, we know that five courses could use more attention to gender generally and that three of them need a lot more specific attention to gender. To this end, we have provided a few specific strategies.

On the other hand, more study is required to further document the scope of the need to bolster the attention given to the topic of gender and disability within graduate rehabilitation counseling programs across the United States. Additional studies are needed that are comprehensive, rigorous, and multifaceted in approach in order to gain the best empirical understanding possible of the true nature and extent of the challenge of integrating gender and disability topics into graduate rehabilitation education coursework.

Allen Lewis, Ph.D., Sarah Brubaker, Ph.D., & Amy Armstrong, Ph.D., are professors in the departments of Rehabilitation Counseling and Sociology at Virginia Commonwealth University in Richmond, Virginia. This paper is a cross-disciplinary endeavor representing the disciplines of rehabilitation counseling and sociology. All inquiries should be addressed to the lead author, Dr. Allen N. Lewis, at P.O. Box 980330, Richmond, VA, 23298-0330, USA; anlewis@vcu.edu.

References

Berkman, L .F., & Syme, S. L. (1979). Social networks, host resistance, and mortality: A nine-year follow-up study of Alameda County residents. *American Journal of Epidemiology, 109*(2), 186-204.

Brownridge, D. A. (2006). Partner violence against women with disabilities: Prevalence, risk, and explanations. *Violence Against Women 12*(9), 805-822.

Burns, J. (2002). Women who have learning disabilities. "The third sex." Paper presented at NNDR's 6th Annual Research Conference, Iceland.

Corker, M., & French, S. (Eds.) (1999) *Disability discourse*. Buckingham and Philadelphia: Open University Press. Edwards, C., & Imrie, R. (2003). Disability and bodies as bearers of value. *Sociology, 37*(2), 239-257.

Fine, M., & Asch, A. (1985). Disabled women: Sexism without the pedestal. In M.J. Deegan, & N.A. Brooks (Eds.), *Women and disability: The double handicap*. New Brunswick, NJ: Transaction Books.

Fine, M., & Asch, A. (1988). Epilogue: Research and politics to come. In M. Fine, & A. Asch (Eds.), *Women with disabilities: Essays in psychology, culture, and politics* (pp.333-336). Philadelphia, PA: Temple University Press.

Froschl, M., Rubin, E., & Sprung, B. (November 1-4, 1999). Connecting gender and disability. *Gender and Disability Digest of the Women's Educational Equity Act Resource Center.*

Garland-Thompson, R. (2002). Integrating disability, transforming Feminist theory. *National Women's Studies Association Journal, 14*(H), 1-32.

Gerschick, T. (2000). Toward a theory of disability and gender. *Signs, 25*(4), 1263-1273.

Gerschick, T., & Miller, A. S. (1995). Coming to terms: Masculinity and physical disability. In D. Sabo & D. Gordon, (Eds.), *Men's health and illness: Gender, power, and the body* (pp.183-204). Thousand Oaks, CA: Sage Publications.

Hart, K. A., Rintala, D. H., & Fuhrer, M. J. (1996). Educational interests of individuals with spinal cord injury living in the community: Medical, sexuality, and wellness topics. *Rehabilitation Nursing, 21*(2), 82-90.

Hassouneh-Phillips, D., & Curry, M. A. (2002). Abuse of women with disabilities: State of the science. *Rehabilitation Counseling Bulletin, 45*(2), 96-105.

Hughes, B., & Paterson, K. (1997). The social model of disability and the disappearing body: Towards a sociology of impairment. *Disability and Society 12*(3), 325-340.

Jans, L., & Stoddard, S. (1999). *Chartbook on women and disability in the United States. An InfoUse Report.* Washington, DC: National Institute on Disability and Rehabilitation Research.

Kriegel, L. (2003). Taking it. In E. Disch, (Ed.), *Reconstructing gender: A multicultural anthology* (pp.196-197). Boston, MA: McGraw-Hill Higher Education.

Kutza, E.A. (1985). A look at national policy and the baby boom generation. *Generations (American Society of Aging), 22*(1), 16-21.

Lorber, J. (2000). Gender contradictions and status dilemmas in disability. In B.M. Altman & S.N. Barnartt, (Eds.), *Expanding the scope of social science research on disability* (pp.85-104). Stamford, CT: JAI Press, Inc.

McGrath, E., Keita, G. P., Strickland, B. R., & Russo, N. F. (1990). *Women and depression: Risk factors and treatment issues*. Washington, DC: American Psychological Association.

Menz, F. E., Hansen, G., Smith, H., Brown, C., Ford, M., & McCrowey, G. (1989). Gender equity in access, services, and benefits from vocational rehabilitation. *The Journal of Rehabilitation, 55*(1), 31-41.

Mudrick, N. R. (1988). Predictors of disability among midlife men and women: Differences by severity of impairment. *Journal of Community Health, 13*(2), 70-84.

O'Hara, B. 2004. Twice penalized: employment discrimination against women with disabilities. *Journal of Disability Policy Studies, 15*(1), 27-43.

Nosek, M. A., Foley, C. C., Hughes, R. B., & Howland, C. A. (2001). Vulnerabilities for abuse among women with disabilities. *Sexuality and Disability, 19*(3), 177-189.

Nosek, M. A., Grabois, E., & Howland, C. A. (1992). *Top 10 Barriers to Quality Health Care for Women with Disabilities. Research information on independent living, independent living research utilization*. The Institute for Rehabilitation and Research. Available at http://www.ilru.org/online/handouts/2002/Nosek/top10.html as of July 2003.

Nosek, M. A., & Hughes, R. B. (2003). Psychosocial issues of women with physical disabilities: The continuing gender debate. *Rehabilitation Counseling Bulletin, 46*(4), 224-234.

Olkin, R. (March-April, 2003). Women with physical disabilities who want to leave their partners: A feminist and disability-affirmative perspective. *Women & Therapy*, 237-247.

Quinn, P. (1994). America's disability policy: Another double standard? *Affilia,* 9, 45-59.

Saxton, M. (2003). Reproductive rights: A disability rights issue. In E. Disch, (Ed.), *Reconstructing gender: A multicultural anthology* (pp.289-295). Boston, MA: McGraw-Hill Higher Education.

Schriempf, A. (2001). (Re)fusing the amputated body: An interactionist bridge for feminism and disability. *Hypatia, 16*(4), 53-81.

Shakespeare, T. (2006). *Disability rights and wrongs*. London: Routledge.

Thomas, C. (2002). Medicine, gender, and disability: Disabled women's health care encounters. Paper presented at NNDR's 6th Annual Research Conference, Iceland.

Traustadottir, R. (1990). Employment, equality, and gender. Center on Human Policy: Paper funded by the Division of Special Education and Rehabilitation, School of Education, Syracuse University under a NIDRR/ OSERS/US DOE Grant.

Traustadottir, R. (1991). Mothers who care: Gender, disability, and family life. *Journal of Family Issues, 12*(2), 211-228.

Ville, I., Crost, M., & Ravaud, J. (2003). Disability and a sense of community belonging: A study among tetraplegic spinal-cord-injured persons in France. *Social Science & Medicine, 56*(2), 321-333.

Warren, L. W., & McEachren, L. (1983). Psychosocial correlates of depressive symptomatology in adult women. *Journal of Abnormal Psychology, 92*(2), 151-160.

Watson, N., McKie, L., Hughes, B., Hopkins, D., & Gregory, S. (2004). (Inter) dependence, needs and care: The potential for disability and feminist theorists to develop an emancipatory model. *Sociology 38*(2), 331-350.

A Race Apart: Genocide and the Protection of Disabled Persons Under International Law

A. Rahman Ford, J.D.
University of Pennsylvania

Abstract: The Convention on the Prevention and Punishment of the Crime of Genocide neglects to include persons with disabilities as a protected group. Such an omission denies the common etymologicali[1] "racial" ancestry shared by those groups included in the Genocide Convention and disabled persons. Further, it denies the historical fact that the Holocaust victimized persons with disabilities, along with other categories of groups already protected. Thus, the Genocide Convention should be amended to include disabled persons.

Key Words: race, disability, genocide

*Editor's Note: This article was anonymously peer reviewed.

"With the exception of Dr. Jekelius, I spoke to no other physicians about this matter. In any case, Dr. Jekelius was fully aware of what was happening and it was unambiguously clear from his remarks that he totally endorsed the entire operation against 'life unworthy of life' and that he was prepared to act as the Nazi state demanded. I finally realized that I could not save my child after this conversation. Therefore, I wanted at least to stop my child from being carried off somewhere. I also wanted to spare the child any further pain, if it had to die. For these reasons, I begged Dr. Jekelius, that if the death of my child could not be stopped, that it be quick and painless. He promised me this. I never learned whether he himself carried out the deed, or whether he let someone else do it and in what manner. I saw my child's corpse. I was struck by the look of pain on his face." Anny Wöld, testimony before the Vienna District Court in proceedings against Drs. Ernst Illing, Marianne Turk and Erwin Jekelius, March 1, 1946 (Gallagher, 2004, p. 222).

Introduction

On November 24, 1934, Anny Wöld gave birth to a son who could neither speak nor walk. The cause of his condition was unknown, as was the degree of suffering he might be experiencing. At the age of four, he was admitted by his mother to Gugging, a mental hospital and nursing home in Lower Austria. Ms. Wöld was fully aware of the Nazi enterprise of eliminating "life unworthy of life," the *Euthanasie* program that would provide the bureaucratic skeleton for the mass killing of more than 70,000 mentally and physically disabled persons (Gallagher, 2004). She made several vain appeals in her attempt to halt the execution of her son, an execution made possible by the complicity of the German medical community in the Nazi national program of racial hygiene. Indeed, when she confronted Dr. Jekelius, the Director of the Vienna City Psychiatric-Neurological Clinic for Children Am Spiegelgrund from 1940-1942 and member of the Nazi Party, about sparing the life of her son, she could only capitulate in futility as he swore allegiance to the demands of the Nazi State in the commission of his civic duty. From Dr. Jekelius, she could secure nothing more than a promise that the killing of "it" would be quick and painless.[2]

Many narratives of the Holocaust, both academic and popular, place principal emphasis on the severity of the atrocities committed against Jewish populations, and perhaps justifiably so given that Jewish deaths are estimated to be in the realm of 5.3 million. However, less researched is the fact that disabled persons were the first to die (Friedlander, 1995). The Nazi euthanasia maelstrom left, directly and indirectly, over 200,000 dead in its wake (Gallagher, 2004).

First, clandestine preparation for euthanizing disabled children was conceptualized, formalized, and executed. In October 1939, Hitler "enlarge[ed] the competence of certain physicians, designated by name, so that patients who, on the basis of human judgment, are considered incurable, can be granted mercy death after a discerning diagnosis" (Friedlander, 1995, p. 67). After the children, the adult disabled were killed. Those killed included persons with mental disabilities as well as physical impairments, all lumped together as degenerates and liabilities to the state. The official Nazi euthanasia program lasted from 1939 to the summer of 1941, after which it could no longer be kept secret. Hitler ordered the program halted, however the killings continued. Ironically, the killings grew more heinous after formal cessation of the program. They assumed a more ad hoc and haphazard manner, and decisions as to who would be killed became the jurisdiction of the individual physician rather than an official review committee. Sadly, the "Children's Campaign," the program for the killing of malformed and developmentally disabled children, and the killing of disabled adults, continued even after World War II ended.

The euthanasia and related programs were the illegitimate progeny of Darwinian evolutionary theory and the related principles of eugenics In 1920, psychiatrist Alfred Hoche and lawyer Karl Binding published *The Destruction of Life Devoid of Value*, imploring the German medical establishment to consider not only its role as health-giver, but also as life-taker. For them, the dogma of racial hygiene required the ethical physician to impart the gift of death on any patient who was deemed terminally ill, mentally incapacitated, or otherwise diseased. The "logic" of such opinions was further buttressed, entrenched, and reproduced by cinematic portrayals of "benign" euthanasia,[3] and even more surreptitiously through negative characterizations of the mentally disabled in common mathematics textbooks (Gallagher, 2004). An ideology of racial purity and Aryan supremacy permeated the German national conscience, and rendered such ethereal notions as race, nation, religion, and disability coextensive insofar as they provided a blueprint for the realization of the Nazi purification project. The echoes of the Nazi racial hygiene mantra would reverberate not only through concentration camps in Auschwitz and Birkenau, but also in the hallowed halls of the T4 euthanasia center where the medical ethics of physicians like Dr. Jekelius were compromised and perverted by a misbegotten love of country, and a concomitant piteous human agnosticism toward their patients.[4]

With the adoption of the Convention on the Prevention and Punishment of the Crime of Genocide (Genocide Convention) in 1948, the United Nations memorialized its commitment to preventing and punishing "acts committed with the intent to destroy, in whole or in part" against certain social groups (United Nations, 1948, Article 2). During the Genocide Convention's negotiations, the selection of these groups was contentious. Ultimately, four groups were chosen for protection: national, "ethnical,"[5] racial, and religious populations. These group monikers have been notoriously resistant to precise definition. Far from being mutually exclusive, they suffer from significant conceptual overlap, and have historically context-specific and geospatially contingent meanings. Race, for example, is sufficiently amorphous to reasonably encompass Germans (a nationality), Jews (a religious group) and Gypsies (a darker-skinned ethnic group) (Schabas, 2000), as the story of the Nazi ideology of racial purity demonstrates. Other groups, such as linguistic, political, and, most importantly for our purposes, persons with disabilities were denied legal refuge in the Genocide Convention.

Schabas (2000) argues that the inclusion of only four groups in the Convention is appropriate for at least two reasons. First, these are the groups that Rafael Lemkin, the man widely regarded as the progenitor of genocide as a legal and political concept, intended to be pro-

tected from genocidal acts. Schabas supports this claim with Lemkin's reference to "national" groups in Lemkin's work *Axis Rule in Occupied Europe*. Schabas argues that "national" was understood to incorporate Jews, given "[t]he historical circumstances and the context of Nazi persecution" (p. 113). Second, Schabas refers to the etymology of the term "genocide" itself; it derives from the Greek word *genos* meaning "race" or "tribe." This construction comports with the desire to protect groups recognized as "national minorities" (p. 113) prior to WWI. Schabas concludes that "[d]iluting the definition, either by formal amendment of its terms or by extravagant interpretation of the existing text, risks trivializing the horror of the real crime when it is committed" (p. 114).

Schabas' defense of the limited scope of protection offered by the Genocide Convention, particularly with regard to the inclusion of disabled persons, is inadequate. He argues that Lemkin entertained the protection of narrowly circumscribed "national" groups, and Jews were clearly meant to be included in "national" given the circumstances of the Nazi extermination program. However, the same Nazi ideology that targeted Jews for extermination targeted disabled persons for extermination first, subjecting both disabled children and adults to the same rituals of mass killing endured by Jews. Thus, while it is true that disabled persons were not considered a national minority prior to World War II, they should be protected under the Genocide Convention because they were killed along with the Jewish and Gypsy "races" under the same Darwinian-derived *Rassenhygiene* program. Furthermore, the practical manifestation of the construction of the genos in the case of Nazi Germany evidences quite clearly the fraternal nature of not only race, ethnicity, nationality and religion, but also disability. All five concepts share a common point of intellectual origin and racial animus, and international law regarding genocide should be amended to conform accordingly.

To be sure, much progress has been made in the domain of international disability law, particularly with the recent adoption of the United Nations Convention on the Rights of Persons with Disabilities (Disability Convention). The landmark convention, adopted December 13, 2006, formalized the aspirations of persons with disabilities and disability advocates who for decades pressured the United Nations to bestow the needed recognition upon the world's largest, and arguably most vulnerable, minority group. Perhaps most importantly, the Disability Convention identifies disabled persons as a legally cognizable group, although heterogeneous in its constitution, and places it among race, religion, gender, children, and national minorities in the pantheon of fundamentally persecuted world constituencies that require concerted and collective effort to achieve equality of opportunity and recognition of human rights. However, while the Disability Convention is a landmark document, it falls short of criminalizing systematic discriminatory actions taken against persons with disabilities, actions which when taken in the aggregate, may result in mass loss of life (United Nations, 2006).

Schabas' use of the term "dilute" to describe the inclusion of additional groups under the aegis of the Genocide Convention is sadly reminiscent of the rhetoric deployed in the Nazi regime to "cleanse" Germany of the virus of "useless eaters." Indeed, the eyes of the Nazis, disabled persons had to be excluded from the polity because their very presence diluted the German gene pool. This paper argues that the inclusion of disabled persons as a group protected by the Genocide Convention would not dilute, but purify its stature as a document forged in the aftermath of World War II atrocities to prevent and punish the killing of innocents. The intellectual nexus between those groups currently protected and persons with disabilities, bound in Darwinian-derived and eugenics-based theories of race supremacy, warrants such an amendment. In addition, contemporary academic literature now recognizes disabled persons as a

socially stigmatized group entitled to human rights as such, not as atomistic individuals who suffer from isolated physical and psychological afflictions.

I will first examine the text of the Genocide Convention itself, with an inspection of key terms and phrases, and with significant attention paid to positions for or against the expansion of protected groups. Second, the event that prompted the adoption of the Genocide Convention, the Holocaust, will be explored. Here, the conceptual and practical marriage between race, ethnicity, nation, religion, and disability will be discussed, as viewed through the lens of the Nazi Socialist ideology and the regime's euthanasia program. The influence of ideas of essentialized, immutable, and inevitable racial hierarchy, derived from eugenics, will be emphasized to demonstrate the common etymological ancestry of the five groups – race, ethnicity, nation, religion, and disability – and to substantiate the claim that disabled persons should also be protected by the Genocide Convention. Next, the trajectory of international disability law subsequent to the Holocaust will be traced to further bolster the argument that disabled persons have gained standing as a "group" in international law worthy of genocide protection, but that current law does not offer adequate protections. This examination will touch on the legal paradigm shift from individual "medical" understandings of disability to a more equality-based human rights posture toward disability discrimination law. Finally, I will summarize my findings and provide recommendations in my conclusion.

Before I proceed, it may be appropriate to include a note about the relationship between race and disability. Race is conceived of broadly as a social construct in this paper. I adopt Winant's (1994) minimalist definition; race is a concept that signifies and symbolizes sociopolitical conflicts and interests in reference to different types of human bodies. For me, and as I interpret the racism promulgated by the Nazi regime during the Holocaust, racism operated as the "fetishism" of not only bodies, but also beliefs. Certain bodies (i.e., Roma, disabled persons) were assigned a lower value than others. Similarly, certain beliefs were assigned a lower value (i.e., Judaism). The assignment of these group values created a clear social hierarchy; those of the "pure Aryan race" were citizens while those of the "lower races" had to be eliminated.

Without question, this brief description is an oversimplification. To trace the complete intellectual history of race and its relationship to disability would be quite an undertaking. My goal here is simply to show that in the specific case of Nazi Germany, the concept of race was broad enough to encompass distinctions based on skin color (the more conventional physical trait associated with race) as well as ability. However, I do not assert that race and disability are in fact identical or coextensive, even in this particular case. Such an assertion would not only be beyond the purview of this paper, but also arguably intellectually irresponsible. This paper seeks to highlight the similarities between the two concepts and leaves the parsing of the differences for another project sufficient in depth and breadth to give such a subject the attention it deserves.

Genocide, Eugenics, and Euthanasia

The Genocide Convention and Group Inclusion

As defined by the Genocide Convention, genocide "means any of the following acts committed with intent to destroy, in whole or in part, a national, ethnical, racial or religious group, as such:

a. Killing members of the group.
b. Causing serious bodily or mental harm to members of the group.
c. Deliberately inflicting on the group conditions of life calculated to bring about its physical destruction in whole or in part.

d. Imposing measures intended to prevent births.

e. Forcible transferring children of the group to another group" (United Nations, 1948, Article 2).

The Genocide Convention punishes not only genocide, but also conspiracy to commit genocide, direct and public incitement to commit genocide, attempts to commit genocide, and complicity in genocide (United Nations, 1948, Article 3). Rulers, public officials, and private citizens may be punished under the convention (United Nations, 1948, Article 4). Whether states can be held culpable under the Convention for the act of genocide is debatable.[4] The Convention does not require that the members of the group actually be killed, which has led to much confusion. However, the action taken must be taken against the group "as such" with intent to destroy, not merely against the individual members of the group, or the group for some other reason (e.g., political). To date, 133 states have ratified the convention.

The origin of the concept of genocide is found in the writings of Lemkin. For him, genocide is intended to:

> "Signify a coordinated plan of different actions aimed at the destruction of essential foundations of the life of national groups, with the aim of annihilating the groups themselves. The objectives of such a plan would be the disintegration of social institutions, of culture, language, national feelings, religion, and the economic existence of national groups, and the destruction of the personal security, liberty, health, dignity, and even the lives of the individuals belonging to such groups. Genocide is directed at the national group as an entity, and the actions involved are directed against the individual, not in their individual capacity, but as members of the national group" (as cited in Rummel, 2006, p. 32).

Rummel makes it clear that the historical backdrop for Lemkin's conception was the Jewish Holocaust and the prevention of similar mass killings that may occur in the future. Indeed, early applications of "genocide" were reserved exclusively for the Jewish Holocaust. However, subsequent interpretations have expanded the ambit of the term, making its precise nature nebulous. Genocide's meaning has been generalized to include *any* mass murder by government, such as the mass killing of political groups and the unintentional spread of diseases to indigenous populations. The "non-killing" element of the convention has also led to "genocide" expansion, including: government policies that let one race adopt children of another race, South African apartheid, and deaths in the Soviet Gulag. To ameliorate the confusion, Rummel proposes the term *democide*, which is more restrictive than genocide because it requires that members of the group in question actually be killed and that the killing be done by a government. However, it is also broader in that it includes more groups than those articulated in the Convention (Rummel, 2006).

Like Rummel, Chalk and Jonassohn (1990) find the Genocide Convention's definition of genocide unwieldy and bereft of academic rigor. They argue that it is of limited scholarly utility because: (1) it fails to distinguish between killing and non-killing, (2) it excludes political groups and social classes, (3) the United Nations itself is composed of sovereign states with an inherent antagonism toward international judicial institutions, and (4) "the wording of the convention is so restrictive that not one of the genocidal killings committed since its adoption is covered by it…" (p. 11). However, most problematic for Chalk and Jonassohn is the convention's "narrow definition of what constitutes a victim group, and potential perpetrators have taken care to victimize only those groups that are not covered by the convention's definition" (p. 11). They define genocide as a "form of one-sided mass killing in which a state or other authority intends to destroy a group, as that group

and membership in it are defined by the perpetrator" (p. 23). This definition envisions no reciprocity from the victim group, the intent to kill all members of the victim group, an exclusion of civilian casualties of war, a strict intent requirement, and state action.

With regard to the selection of groups that may be the victims of genocide, Chalk and Jonassohn's definition leaves the matter open; the guiding principle is the subjective view of the perpetrator. By placing no ceiling on the number of potential victim groups, their definition "allows the inclusion of groups that had not previously been considered under the United Nations convention as potential victim groups (e.g., the retarded, the mentally ill, and homosexuals…)" (p. 26). In her 37 case comparative study, Barbara Harff (2003) proposes a definition that pairs genocide with *politicide*: "the promotion, execution, and/or implied consent of sustained policies by governing elites or their agents – or, in the case of civil war, either of the contending authorities – that are intended to destroy, in whole or in part, a communal, political, or politicized ethnic group" (p. 58). This definition seems to permit fewer groups, largely restricted to ethnic/racial, religious or political groups, but does include groups that are either self or authoritatively defined.

This brief review of the Genocide Convention and related literature reveals several problematic aspects of how a "group," which qualifies for protection under the Genocide Convention, has been and should be determined. With regard to the expansion of protected groups, any expansion of protected groups, to both strengthen the convention's legitimacy as a deterrent against potential perpetrators of mass killing and provide a foundation for rigorous scientific analysis of the prevalence of genocidal episodes, should be undertaken with caution. Schabas' position on expansion is too confining because he opposes *any* expansion, thus denying the dynamic temporally-contingent dimension of group naming, with a result that inhibits growth in both ideas of institutional protection for vulnerable populations and efforts at progressive scholarship production.

Conversely, Chalk and Jonassohn advocate too broad an expansion, embracing almost any group, so long as it is identified as such by the alleged perpetrator. This definition may be viscerally appealing to human rights advocates, but from a legal standpoint its lack of an objective measure by which to gauge group membership may leave it impotent in carrying out the Genocide Convention's implicit purpose – to create an agreement under which mass killing could be condemned and those populations most susceptible to the scourge could be protected.

Likewise, Harff's definition is too broad because a political group can be interpreted to mean almost any group, and identification of the groups is subjective. With regard to Chalk and Jonassohn, and Harff's definitions of genocide, Rummel's admonition that genocide has been overly generalized should be seriously considered. Thus, rather than overexpand the aegis of the Genocide Convention and reduce it to a document that becomes resistant to meaningful judicial application, the best approach may be to merely add to those groups already protected by the convention. For reasons alluded to above and further elucidated below, disabled persons should be included. Their inclusion would comport with Chalk and Jonassohn's subjective conception of group identification because the Nazis identified disabled persons as a group and proceeded with a program for their extermination "as such." The authors even expressly mention disabled persons as a group to be included. Finally, this position also comports with Harff's more expansive conception of genocide.

Eugenics and the Evolution of German *Rassenhygiene*

While the addition of groups to the Genocide Convention is controversial, inclusion of disabled persons can be justified because of the common etymological ancestry of the ideas of

race, nationality, religion, and disability that pervaded intellectual thought and informed state policies during the early 20th century. In his discussion of the underpinnings of the Nazi targeting of persons with disabilities, Mostart (2002) identifies six genocidal markers: (a) Darwinism and the biology of determinism, (b) eugenics, (c) forced prevention of disability, (d) disability propagandized as life unworthy of living, (e) disability as justification for individual state-sanctioned murder, and (f) disability as state-sanctioned homicidal health policy. The rudiments of the eugenics movement were an extension of social Darwinist principles of biological superiority; biology determined which groups were dominant and environment could do little to nothing to alter these outcomes.

In the late nineteenth and early twentieth centuries, prominent eugenicists and other intellectual descendants of Francis Galton were preoccupied with control of those who were deemed "unfit." For the American eugenics movement, this meant control of biological threats such as new Eastern European immigrants, Blacks, and other "degenerate" peoples (Tucker, 1994). Eugenicists and politicians alike believed that undisciplined reproduction by "undesirable" groups would adulterate American stock because they were inferior to the Caucasian race. Thus, eugenicists supported anti-miscegenation and segregation laws to avoid the mongrelization of America. Like Blacks and Eastern Europeans, "degenerates" were also a focus of concern for eugenicists. A degenerate was defined as one who "fail[ed] chronically in comparison with normal persons, to maintain himself or herself as a useful member of the social life of the state" (p. 61). This category included, among others, the feebleminded, insane, epileptics, diseased, those with impaired hearing or vision, and cripples. Invoking quasi-theological, ethical, and legal justifications, Herbert S. Jennings vilified the defective gene as a biological monstrosity:

> "The embodiment, the material realization of a demon of evil. Such a thing must be stopped whenever it is recognized. The prevention of propagation of even one congenitally defective individual puts a period to at least one line of operation of this devil. To fail to do at least so much would be a crime" (as cited in Tucker, 1994 p. 69).

Eugenics was also practiced in many of the Nordic states: Denmark, Sweden, Finland, and Norway all had compulsory sterilization programs by 1926, before they were implemented in Nazi Germany (Barnett, 2004).

Academic discussions of race in Germany were not new; race and the study of the science of human variation had been occurring since the 1800s (Schafft, 2007). Schafft argues that Germans had utilitarian motives and deployed race to describe human difference because "the social categories of Jew, Pole, Serb, Mongol, or Gypsy were of significance to them and could be used to justify policies that furthered their economic and political goals" (p. 205). Although there was significant intermarriage de jure equality between Jews and other groups in pre-Nazi Germany, there did exist a latent anti-Semitism upon which Hitler and his compatriots were able to seize. The trope of "German blood" came to embody the essence of Germanness, the cultural conscience of the volk. In the context of disability, this sentiment was first memorialized in the Law for the Prevention of Offspring with Hereditary Diseases, promulgated in 1933 (Poore, 2003). As the Nazi Party took control in 1939, with Hitler appointed Chancellor, public vilification of genetic degenerates conflagrated.[7] Two weeks after an address by Wilhelm Frick, Ministry of the Interior, to the Expert Advisory Council for Population and Race Politics, the Law for the Prevention of Genetically Defective Progeny was enacted (Tucker, 1994). The law allowed for the involuntary sterilization of those afflicted with "weakmindedness," schizophrenia, insanity, epilepsy, blindness, deafness, bodily de-

formities and other ailments. Genetic Health Courts were to decide who should be sterilized.

The institutionalization of the Nazi program of *Rassenhygiene* continued with the creation of medical academies tasked with inculcating dedication to state and race in its graduates. The creation of these academies is emblematic of the Third Reich's infusion of National Socialism with a scientific rationality, the combination of which supplanted professional ethical allegiances to human life. The Nuremberg Laws were the crescendo of the Third Reich's formalized racial hygiene project, aimed specifically at the parasitic Jewish "counterrace." Adopted unanimously by the Reichstag in 1935, the laws forbad marriage and extramarital relations between Germans and Jews and disenfranchised German "subjects" who were not of German blood. A quote from Hitler's *Mein Kampf* can best help us understand the prohibition on interracial marriage:

> "A folkish state must therefore begin by raising marriage from the level of continuous defilement of the race, and give it the consecration of an institution which is called upon to produce images of the Lord and not monstrosities" (as cited in Dawidowicz, 1975, p. 65).

The Genocide of Disabled Persons Begins

Disabled children were murdered first. Shortly after the start of World War II, Hitler authorized young Nazi officers Brandt and Bouhler to implement the children's euthanasia program under the auspices of the Office of the Chancellery of the Fuhrer (KdF). The program was classified and clandestine, and operated under the deceptive moniker "Reich Committee for the Scientific Registration of Severe Hereditary Ailments" (Friedlander, 1995). KdF officials, Herbert Brack, Hans Hefelmann, and Richard von Hegener, convened a panel of academics to review registration forms to determine which children should be sterilized. Guidelines were issued by the German Ministry of the Interior (RMdI), the ministry headed by Wilhelm Frick. Under the guidelines, midwives and physicians were required to submit the following information on all newborns with medical conditions: name, age, sex, description of the illness, details on hospital stay, an explanation of how the child's function is disrupted by the illness, projected life expectancy, and chances for improvement. A subsequent decree issued by the RMdI required the reporting of religion, as well as his relatives' medical histories (Friedlander, 1995).

Three self-professed euthanasia adherents, Werner Catel, Hans Heinze, and Ernst Wentzler, were medical experts who evaluated registration forms. Those selected for the program – so-called "Reich Committee children" – would then be diverted to children's killing wards, of which Brandenburg-Gordon was the first established in July 1940. To maintain secrecy, parents were advised that their children would be receiving "therapeutic" care. Instead, the children were subjected to medical experiments by the doctors, nurses, and staff at the killing hospitals both before and after being killed. Another child killing ward was established in Bavaria later in the year and was headed by Hermann Pfanmueller. Pfanmueller had previously helped to enforce racial and eugenics legislation and conducted tours of his facility to display the degeneracy of its inmates. Such wards were eventually established throughout Germany (Friedlander, 1995).

Many of the Reich Committee children were starved to death, with rations withheld. However, the preferred method of killing was with medication, specifically luminal, an anticonvulsant with sedative and hypnotic properties. The medication was put in food in high doses or delivered via injection. The actual order to kill was issued by the Reich Committee; children with neurological disorders or physical deformities were deemed incurable and were euthanized. The criteria used to select children were subjective. Many physicians labored under the assumption that certain disabilities prevent-

ed a child form leading a productive life when in fact, there was scientific evidence to the contrary (Friedlander, 1995).

The killing of disabled adults began in the summer of 1939. Brant and Bouler, the managers of the children's euthanasia program, again took the lead. Local governments sent reports to the RMdI listing all institutions in which mental patients, epileptics, and the feebleminded were held. As with the children's program, registration forms were used for all potential "patients." The following patients who were unable to work and who had these conditions were registered: schizophrenia, epilepsy, senile diseases, therapy resistant paralysis and syphilis, encephalitis, terminal neurological disorders, all types of feeblemindedness, criminal insanity, lack of German citizenship, and lack of German or related blood, including Jews, Negroes, Gypsies, hybrids, etc., (Friedlander, 1995). The collection of these data served multiple purposes, not the least of which was to determine the logistics of transporting patients from their local medical facilities to the euthanasia wards.

Just as with the child killings, the criteria for selection were subject to widely varying interpretations. Many of those diagnosed with mental disorders were instead physically impaired and had their full faculties about them. This distinction became moot, however, because the overarching motive was not to treat, but to sterilize or kill those unable to serve as productive members of society as determined by their lack of labor value. After selection by medical experts, the transport office, known as the Gekrat, arranged for the movement to the killing facility. Those of sound mind knew their fate, but had no say in the matter because: "The insane person himself is in no position to judge his situation" (Friedlander, 1995, p. 84). Relatives and guardians, and even some local facility administrators, were deceived into believing that the patients were being transported as a precaution for the war. In reality, these "cripples," "psychotics," and "psychopaths" were being relocated to T4, the killing center.

The above narrative demonstrates that the Nazi euthanasia program, as well as the genocide generally, was no singular bureaucratic proclamation or act. Rather, it was a process; the culmination of series of calculated and reinforcing acts, engineered for the particular purpose of racial hygiene and the preservation of those deemed fit. As Fitzgerald (1999) explains, "[I]n relation to people with disability, this may mean that the very narrow psychological sentiment of control of people with disability which manifested first in institutionalization (and its associated deprivations and abuses) may gain expression in decidedly more permanent infringement of human liberties; the taking of life" (pp. 274-275). In Nazi Germany, the result was indeed the taking of life, on a massive scale and with fabricated justifications. The narrative also shows how ideas of race, ethnicity, nationality, and religion cannot be extricated from ideas of disability, either in theory or practice. These phenomena have traveled similar etymological trajectories, from scientific rationales to social constructionism, and all concern the disciplining of bodies by states. Thus, the inclusion of disabled persons as a protected group under the Genocide Convention is both reasonable and necessary.

A Convention for Disabled Persons

Group Recognition and Human Rights

Jones and Marks (1999) remark that "[w]hat it is very important to appreciate is that even if there existed a perfect regime of human rights … this is only going to be a small part of what is necessary to bring about true equality for people with disabilities" (p. 4). Their observation is a reflection of the sobering truth that de jure protections are simply words on paper and incapable by themselves of equalizing humanity. This impotence is made particularly palpable in the case of the United Nations, an institution with no enforcement mechanisms of which to

speak. To be sure, advances in international disability theory and law have produced a seismic paradigm shift from a narrow "medical" rubric, which regarded disability as an individual affliction, to one in which disability is conceived of as a sociopolitical construct requiring a human rights response for the protection of a group. However, "[d]espite being one of the largest minority groups in the world, encompassing 600 million persons (of which two out of three live in developing countries), disabled people had been rather ignored during the first three decades of the United Nations' existence" (Degener, 2000, p. 187).

Although progress is apparent, the identification of persons with disabilities as a group requiring protection has been glacial. The Universal Declaration of Human Rights (UDHR), negotiated and ratified amidst the backdrop of Nazi World War II atrocities, neglected to identify persons with disabilities as a protected group. Under Article II of the UDHR (1948), "[E]veryone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status." Similarly, Article 16 of the UDHR fails to include persons with disabilities with race, religion and nationality as inappropriate limitations on the right to marriage. Article 25, which pertains to an internationally accepted standard of living, does assert that every person has the "right to security in the event of unemployment, sickness, disability, widowhood, old age, or other lack of livelihood in circumstances beyond his control." This reference, however, conceptualizes disability as an individual condition – conforming to the medical model of disability – rather than as a sociopolitical construct, like race, ethnicity, nationality, and religion.

In 1971, the United Nations General Assembly took a step forward, proclaiming the Declaration on the Rights of Mentally Retarded Persons (Declaration on Mentally Retarded). The resolution called on member states to accord mentally retarded persons, "to the maximum degree of feasibility, the same rights as other human beings" (United Nations, 1971, paragraph [1]). The right to medical care, economic security, community integration, and the right against exploitation and degrading treatment were some of the core principles of the resolution. Four years later, the United Nations passed the Declaration on the Rights of Disabled Persons (Declaration on Rights of Disabled), effectively extending the protections of the Declaration on Retarded Persons to "any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and/or social life, as a result of deficiency, either congenital or not, in his or her physical or mental capabilities" (United Nations, 1975, paragraph [XXX]). In contrast to the Declaration on Retarded Persons, the Declaration on Disabled Persons placed more overt emphasis on the protection of civil and political rights (United Nations, 1975, paragraph [4]). In addition, the declaration seemed to proceed further in creating a distinct class of disabled persons, by according protection regardless of race, colour, sex, language, religion, political or other opinions, national or social origin, state of wealth, birth or any other situation…" (United Nations, 1975, paragraph [2]).

In 1982, The United Nations began implementation of its World Programme of Action Concerning Disability (World Programme on Disability). The plan, described as a "an international long-term plan based on extensive consultations with Governments, organs and bodies within the United Nations system and intergovernmental and non-governmental organizations" (World Programme of Action Concerning Disability, paragraph [9]), placed squarely on state governments the obligation of "awakening the consciousness of populations regarding the gains to be derived by individuals and society from the inclusion of disabled persons in every area of social, economic and political life" (United Nations, 1982, paragraph [1]). The

programme's three core objectives – prevention, rehabilitation,[8] and equalization of opportunities were to be applied to the rising global disabled population, with particular attention paid to the plight of disabled persons in developing countries (United Nations, 1982, paragraph [4]).[9] The vulnerability of women, children, the elderly, victims of torture, and refugees was also highlighted.

With regard to planned international action to ensure the protection of disabled persons, the United Nations proposed a series of measures under the World Programme. Of principal focus was the mobilization of economic resources; a trust fund was established to aid developing countries in realizing the objectives of the programme. However, the programme's clearest statement on human rights left the matter of accountability nebulous: "[I]ncidents of gross violation of basic human rights, including torture, can be a cause of mental and physical disability. The Commission on Human Rights should give consideration, inter alia, to such violations for the purpose of taking appropriate ameliorative action" (United Nations, 1982, paragraph [9]). This statement articulates no specific punitive action that may be taken against the gross violators of the human rights of disabled persons. The vagueness of "appropriate ameliorative action" may be politically sustainable, given that it extends the necessary legal latitude to assess each instance on a case-by-case basis. However, the programme recognizes that states susceptible to violations against disabled persons should bear the substantial share of the burden of amelioration, but makes only a cursory mention of what might occur in the event those states either neglect their obligation or intentionally target disabled persons. This omission is problematic and should not be immune to both legal and moral scrutiny.

Toward a Convention for Disabled Persons

At the close of the United Nation's Decade on Disabled Persons (1983-1992) a Draft Convention on the Elimination of All Forms of Discrimination against Disabled Persons was presented to, and subsequently rejected by, the General Assembly on the grounds that it would not be ratified by a majority of member states. In lieu of a convention, which would have the force of international law, the United Nations Commission for Social Development convened an expert working group that developed the Standard Rules. The Standard Rules, adopted by the General Assembly in 1993, attempted to reconcile disability as an individual's functional impairment, and disability as social construction with implications of inferiority and consequent discrimination (Michailakis, 1999). As an instrument that is not legally binding, its influence was only moral.

The Standard Rules were followed in 1994 by the United Nations Committee on Economic, Social and Cultural Rights' adoption of General Comment Number 5, which finally turned to a human rights approach to the interpretation of the International Covenant on Economic, Social and Cultural Rights (ICESCR) (1966) as applied to persons with disabilities. The General Comment made plain that "[i]n order to remedy past and present discrimination, and to deter future discrimination, comprehensive anti-discrimination legislation in relation to disability would seem to be indispensable in virtually all States parties." However, these emendations were a far cry from a binding treaty that could formally solidify the rights of disabled persons.

In 2006, the United Nations completed the human rights shift by adopting the Convention on the Rights of Persons with Disabilities (Disability Convention). It purports to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (United Nations, 2006, Article 1). Several obligations are imposed on states: passage of appropriate legislation, the abolition of discriminatory legislation, promotion of research and development,

and training for disabled persons. Certainly, the convention addresses many of the needs of disabled populations worldwide; however, it makes no mention of the historical connection between disability and genocide. Although the convention represents a formidable step in the protection of persons with disabilities and received generous support from United Nations member states,x it remains to be seen whether it can reduce the likelihood of the most vulnerable population being victimized by mass killing, or whether the convention is a substitute for inclusion among the groups protected by the Genocide Convention.

Conclusion

This paper has attempted to demonstrate the intimate connection between disability and genocide, and the need for disability to be included as a protected group under the Genocide Convention. Some may argue that since the Holocaust, disabled persons have not been targeted as such, and thus, their inclusion is unnecessary. Unfortunately, whether this is true is unclear because disabled genocide victims rarely have their stories told, as the Nazi case evidences. Still others may argue that other international crimes, such as crimes against humanity, are sufficient to protect persons with disabilities. While this may be true, genocide is the highest of all crimes, and inclusion, even if largely symbolic, would only accelerate the human rights movement for disabled persons. It could also reinforce the international norm of equal opportunity for marginalized groups, enhance reputation effects for defectors from the Disability Convention and related instruments, as well as bring international political pressure to bear on states such as the United States, which has refused to sign the Disability Convention.

In sum, international human rights law, as well as domestic laws and regional treaties, should embrace the human rights agenda of disabled persons. This position fully acknowledges the bureaucratic fetters that inhibit international legal progress, in the form of bargaining among self-interested sovereign states, while at the same time imploring the United Nations and its member states to fulfill their roles as the vanguard of the socially marginalized and politically dispossessed. Disabled persons should no longer be a race apart from their brethren when it comes to protection from genocide.

A. Rahman Ford, J.D., is currently a Ph.D. candidate at the University of Pennsylvania. His research interests include race, disability, identity, law, and democratization. He also holds a Juris Doctor degree from Howard University.

References

Ascribe Newswire (2005). University of Florida study: Nazis punished more leniently for crimes against handicapped. Retrieved May 9, 2007, from http://newswire.ascribe.org/cgi-bin/behold.pl?ascribeid=20050913.111122&time=12%2023%20PDT&year=2005&public=0.

Barnett, R. (2004). Keywords in the history of medicine: Eugenics. *Lancet*, 363, 1742.

Chalk, F., & Jonassohn, K. (1990). *The history and sociology of genocide: Analyses and case studies*. New Haven, CT: Yale University Press.

Dawidowicz, L. (1975). *The war against the Jews: 1933-1945*. Holt, Rinehart, & Winston.

Degener, T. (2000). International disability law – A new legal subject on the rise: The interregional experts meeting in Hong Kong, December 13-17, 1999. *Berkeley Journal of International Law, 18*(1), 180-195.

Diehl, J, (1987). Victors or victims? Disabled veterans in the Third Reich. *Journal of Modern History, 59*(1), 705-736.

Fitzgerald, J. (1999). Bioethics, disability and death: Uncovering cultural bias in the euthanasia debate. In M. Jones & L. Basser Marks (Eds.), *Disability, diverse-ability and legal change*. Kluwer Law International.

Friedlander, H. (1995). *The origins of Nazi genocide: From euthanasia to the final solution*. University of North Carolina Press.

Gallagher, H. G. (2004). Holocaust: The genocide of disabled peoples. In W. Parsons & S. Totten (Eds.), *A century of genocide: Critical essays and eyewitness accounts*. Routledge.

Harff, B. (2003). No lessons learned from the Holocaust?: Assessing risks of genocide and political mass murder since 1955. *American Political Science Review, 97*(1), 57-73.

International Court of Justice (2007). *Bosnia & Herzegovina v. Serbia & Montenegro*. General List, No. 91.

International Labor Organization (1983). Convention concerning vocational rehabilitation and employment (disabled persons), ILO recommendation No. 159.

International Labor Organization. (1955). Recommendation concerning vocational rehabilitation of the disabled, ILO recommendation No. 99.

International Labor Organization. (1988). Recommendation concerning vocational rehabilitation and employment (Disabled Persons), ILO recommendation No. 168.

Jones, M., & Basser Marks, L. (1999). Law and the social construction of disability. In M. Jones & L. Basser Marks (Eds.). *Disability, diverse-ability and legal change*. Kluwer Law International.

Michailakis, D. (1999). The standard rules: A weak instrument and a strong commitment. In M. Jones & L. Basser Marks (Eds.), *Disability, diverse-ability and legal change*. Kluwer Law International.

Mostart, M. (2002). Useless eaters: Disability as a genocidal marker in Nazi Germany. *Journal of Special Education. 36*(3), 155-168.

Poore, C. (2003). Who belongs? Disability and the German nation in postwar literature and film. *German Studies Review, 26*(1), 21-42.

Rummel, R. J. (2006). *Death by government.* Transaction Publishers.

Schabas, William A. (2000). *Genocide in international law.* Cambridge University Press.

Schafft, G. (2007). *From racism to genocide: anthropology in the Third Reich*. University of Illinois Press.

Sofair, A., & Kaldjian, L. (2000). Eugenic sterilization and a qualified Nazi analogy: The United States and Germany, 1930-1945. *Annals of Internal Medicine, 132*(4), 312-319.

Tucker, W. (1994). *The science and politics of racial research*. University of Illinois Press.

United Nations. (1948). *Convention on the prevention and punishment of the crime of genocide.*

United Nations. (1948). *Universal declaration of human rights.*

United Nations. (1966). *International covenant on economic, social and cultural rights.*

United Nations. (1971) *Declaration on the rights of mentally retarded persons.* Gen. Ass. Res. 2856 (XXVI).

United Nations. (1975). *Declaration on the rights of disabled persons.* Gen. Ass. Res. 3447 (XXX).

United Nations. (1982). *World programme of action concerning disabled persons.* Res. 35/52, 9.

United Nations. (2006). *Convention on the rights of persons with disabilities.*

Winant, H. (1994). *Racial conditions: politics, theory, comparisons.* Minneapolis, MN: University of Minnesota Press.

Endnotes

[1] By "etymological," I refer quite simply to the history of words and concepts, the sources of those histories, the relationships between histories and the evolutionary trajectories those histories might travel.

[2] Ms. Wöld's reference to her son as an "it" is indicative of the dehumanization of the disabled during the Nazi era. The disabled's lack of standing as sociopolitical beings even translated into the post-Holocaust legal realm, preventing many victims of the Nazi euthanasia program from securing a judicial remedy. In his dissertation research, Shane Stufflet found that the killers of the disabled were treated much more leniently by courts than were the killers of Jews. "More than half of the Nazis tried for crimes against the mentally handicapped – 57 percent – were acquitted … and only 1.6 percent received life sentences, none of which were served." Conversely, "only 24 percent of the Nazis tried for crimes against the Jews were acquitted, with about 11 percent receiving life sentences" (Ascribe Newswire, 2005). Unlike Jews who were able to testify and potentially win judges sympathy, the mentally handicapped were unable to as a result of their limitations.

[3] Gallagher describes the German film I Accuse, in which a physician husband kills his wife because she has multiple sclerosis.

[4] The eugenics-inspired Nazi regime in Germany found a sibling in the United States, which also implemented policies aimed at "degenerates." These policies included forced sterilization, marriage restrictions, and segregation and were supported by an alliance between the mainstream medical establishment and the eugenics movement. In the opinion of Sofair & Kaldjian (2000), "[t]he goals of eugenic sterilization in the United States and Germany were similar in that they aimed for improved genetic composition of their citizenry and hoped to create a society in which every individual was economically useful and the fiscal burden of institutionalization, crime, and charity were decreased" (p. 318).

[5] "Ethnical" is a term used in the Genocide Convention.

[6] See for example, Bosnia & Herzegovina v. Serbia & Montenegro (International Court of Justice, 2007), which held that Serbia violated its obligations under the Genocide Convention by failing to prevent genocide, but evidence was insufficient to show that Serbia committed genocide.

[7] Nazi Socialist propaganda envisioned three categories of disabled: (1) disabled veterans who here valorized as war heroes; (2) physically handicapped German Civilians, portrayed as being potentially rehabilitated; and (3) those who were deemed unfit, incapable of rehabilitation and a drain on the nation's resources (Mostart, 2002). Although the Nazis demonized the previous regime for its maltreatment of the war veterans, its record is no better. Under the Nazis, the veterans were "[s]howered with rhetoric" and "psychologically manipulated and organized to support the regimes militaristic policies – policies that created millions of new veterans, who were then left to face the ruins of a second lost war" (Diehl, 1987, pp. 705-706).

[8] The issue of rehabilitation has also been addressed by conventions and recommendations by the International Labor Organization (ILO), including but to limited to pronouncements in 1983, 1955 and 1988.

[9] The report estimated that more than 500 million persons were afflicted with physical, mental or sensory impairments, "and at least 25 percent of any population is adversely affected by the presence of disability" (United Nations, 1982, (4)). Factors identified as contributing the disabled person's marginalization included wars, violence, poverty, geography, natural disasters, stress and urbanization.

[10] Remarking upon the Disability Convention's precursors, Argentinean Ambassador Roberto Garcia Moritán acknowledged the quest for integration by the 7.1% of the Argentine population that self-identifies as disabled. See Statement by the Vice Minister of Foreign Affairs, Trade, and Worship Ambassador Robert Garcia Moritán (March 30, 2007). Representing the European Union, Parliamentary State Secretary in the German Ministry of Labour and Social Affairs Franz Thonnes remarked that the long-term goal of the Disability Convention was to "change the way the public perceives persons with disabilities, thus ultimately changing society as a whole." See European Union Statement on the Occasion of the Signing of the Convention on the Rights of Persons with Disabilities (March 30, 2007). Thirty-eight other parties made statements at the signing ceremony.

Promising Interventions for Promoting STEM Fields to Students Who Have Disabilities

Sheryl Burgstahler, University of Washington, USA
& Chuan Chang, University of Hawaii at Manoa, USA

Abstract: This study compared two groups of transition program participants—those with reported strengths and career goals in science, technology, engineering, or mathematics (STEM) and those without—regarding their characteristics and perceptions of the social, academic, and career benefits of program interventions. Consistent with previous research on gender and STEM, more males than females reported strengths and goals in STEM. Results suggest that type of disability may play a role in the perception of STEM fields as career options, perhaps resulting in less interest in these fields on the part of students with mobility/orthopedic impairments. While the STEM group expressed more interest in technology-related activities, non-STEM participants consistently rated themselves higher in self-advocacy skills and perceived that program participation improved their social skills more than did STEM participants. Regarding motivation to attend college, academic interest and love of learning/challenges was cited more often by members of the STEM group, while job/career preparation was identified by more of the non-STEM students. As far as motivation for employment, financial security was selected by significantly more of the STEM-oriented participants and pursuit of independent living was chosen by more of the non-STEM participants. Results suggest that program interventions may help change college study and career plans of those who do not initially have STEM interests. Based on the responses of the two groups in this study, the authors make program recommendations for increasing the representation of people with disabilities in STEM fields.

Key Words: technology, transition, self-determination

*Editor's Note: This article was anonymously peer reviewed.

A bachelor's degree or higher is a prerequisite for many challenging careers, particularly those in science, technology, engineering, and mathematics (STEM). However, people with disabilities are significantly underrepresented in postsecondary programs despite a moderate increase in college enrollment rates over the past 10 years (Blackorby & Wagner, 1996; National Council on Disability and Social Security Administration, 2000; Wagner, Newman, Cameto, & Levine, 2005), and few students with disabilities successfully pursue studies in STEM (National Science Foundation, 2004; Office of Disability Employment Policy, 2001). Females face additional challenges to pursuing STEM careers (Burgstahler & Doyle, 2005; Chinn, 1999; National Science Foundation, 2002, 2004). These factors contribute to the low number of adults with disabilities qualified for today's high-tech jobs (Benz, Yavonoff, & Doren, 1997; Blackorby & Wagner, 1996; Butterworth & Pitt-Catsouphes, 1997; National Organization on Disability, 2004). The situation raises serious concerns as the job market for more routine work is increasingly shifting overseas (Cavanagh, 2006; U.S. Department of Labor, Bureau of Statistics, 2004). The demand for qualified professionals has been widely recognized, and many observers agree on the need to raise the quality of mathematics and science education in U.S. schools. Two goals have been proposed—to raise the overall math and science achievement for all students and to stimulate and support high performing students capable of pursuing college studies and careers in STEM subjects (Cavanagh, 2006). For students with disabilities, STEM training may be promoted with the same dual purposes.

Enhanced support for people with disabilities during transition periods from high school to college and employment has been recommended by researchers and practitioners (Kohler & Chapman, 1999; National Council on Disability and Social Security Administration, 2000). Programs for racial/ethnic minorities, women, and people with disabilities have identified promising practices for bringing students from underrepresented groups into STEM fields. These include (a) hands-on science experiences in precollege environments, (b) work-based learning and research experiences, (c) bridge programs between academic levels, and (d) mentoring (Burgstahler & Cronheim, 2001; Cohen & Light, 2000; Doren & Benz, 1998; Kaye, 2000; National Science Foundation, 2005; Stainback, Stainback, & Wilkinson, 1992). Comprehensive projects that integrate a variety of interventions have been found to be more successful in recruiting and retaining students with disabilities in STEM fields than isolated efforts (American Association for the Advancement of Science, 2001; Malcom & Matyas, 1991; National Science Foundation, 2005). It has also been found that programs that offer multiple components and continued involvement of participants are more effective than single-strategy activities in encouraging low income and minority students to attend college (Cunningham, Redmond, & Merisotis, 2003).

Little empirical research data related to transition programs is reported in the literature (Fisher, 2000; Kohler & Chapman, 1999; Kohler & Hood, 2000; Kohler & Troesken, 1999). The current study builds on previous work (Kim-Rupnow & Burgstahler, 2004) by further comparing two groups of transition program participants, those with reported strengths and career goals in STEM and those without, regarding their characteristics and perceptions of the social, academic, and career benefits of program interventions. The current researchers hoped to gain insights that could be shared with programs designed to increase the participation of people with disabilities in STEM. Researchers in both studies analyzed data provided by participants of an exemplary transition program hosted by the Disabilities, Opportunities, Internetworking, and Technology (DO-IT) Center at the University of Washington in Seattle. The DO-IT Scholars program (DO-IT, 2006) was selected to be explored in the current study because (a) it serves students with a wide range of disabilities, (b) it has well-defined components that lend themselves to comparative analysis, (c) it has characteristics of successful programs that include longevity, prestigious awards, sustained operations, attention in the press, and ongoing support from funding agencies, and (d) as a result of support from the National Science Foundation, it has a large group of participants interested in STEM fields (National Science Foundation, 2005; Kim-Rupnow & Burgstahler, 2004).

Development of interests and competencies for STEM begins in the early years (Jacobs & Eccles 1992; Simpkins, Davis-Kean, & Eccles, 2006). However, high school is a time when many students are formulating career plans. Most DO-IT Scholars are accepted into this competitive program at the end of their sophomore year. These college-bound students face significant challenges in pursuing postsecondary studies and careers as a result of disabilities that impact their vision, hearing, mobility, learning, attention skills, social interactions, and health. When DO-IT Scholars move from high school to college, most continue to participate in the program as mentors to younger Scholars. DO-IT activities are designed to help participants develop self-determination, social, academic, technology, and career skills. The program employs three primary interventions. Each offers activities in all fields of study and careers, but funding from the NSF has assured that opportunities to increase interests and skills in STEM are available throughout.

Summer Study – Scholars participate in multiple residential programs at the

University of Washington, where they are introduced to other young people with disabilities, are trained in computer and Internet use, socialize, and prepare for college, careers, and independent living.

Year-round computer and Internet activities – Computer and Internet skills continue to develop year-round in support of academic and career development and facilitate communication with mentors and peers in a mentoring community.

Work experiences – Internships and other work-based learning activities give students opportunities to explore their own interests, develop skills, practice disclosing their disabilities and seek accommodations, use technology at worksites, and learn to work with supervisors and coworkers.

Findings of previous research regarding DO-IT interventions are reported in earlier articles; results from focus groups and surveys are summarized below:

Parents of DO-IT Scholars reported that DO-IT increased their children's interest in college, awareness of career options, self-esteem, and self-advocacy, social, academic, and career/employment skills (Burgstahler, 2002).

DO-IT Scholars reported that DO-IT participation helped them prepare for college and employment, develop Internet, self-advocacy, computer, social, and independent living skills, increase awareness of career options, and increase self-esteem and perseverance (Burgstahler, 2003; Kim-Rupnow & Burgstahler, 2004).

They reported the greatest effects of the Summer Study to be the development of social skills, followed by academic and career skills; and the greatest effects of the year-round computer and Internet activities to be the development of career skills, also followed by academic and social skills (Burgstahler, 2003; Kim-Rupnow & Burgstahler, 2004).

Scholars reported positive aspects of email, which included being able to stay close to friends and family; to get answers to specific questions; to meet people from around the world; to communicate quickly, easily, and inexpensively with many people at one time; and to communicate independently without disclosing their disabilities (Burgstahler & Cronheim, 2001; Burgstahler & Doyle, 2005). They predicted that access to the Internet would contribute to their success in college and careers, and reported that peer and mentor relationships provided psychosocial, academic, and career support, and furthered their academic and career interests (Burgstahler, 2003; Burgstahler & Cronheim, 2001; Burgstahler & Doyle, 2005; Kim-Rupnow & Burgstahler, 2004). In particular, most reported that DO-IT mentors stimulated interests in STEM (Burgstahler & Cronheim, 2001; Burgstahler & Doyle, 2005).

Those who participated in work-based learning opportunities reported increased motivation to work toward a career, knowledge about careers and the workplace, job-related skills, ability to work with supervisors and coworkers, and skills in self-advocating for accommodations (Burgstahler,

2001; Burgstahler, Bellman, & Lopez, 2004).

DO-IT Mentors – Mentors reported a variety of topics they discussed with Scholars, including STEM, college issues, disability-related issues, careers, and computers, adaptive technology, and the Internet (Burgstahler & Cronheim, 2001).

Research Questions for Current Study

With funding from the NSF, further analysis of the data collected in the retrospective survey of DO-IT Scholars (Kim-Rupnow & Burgstahler, 2004) was undertaken to compare two groups of DO-IT participants, those with reported strengths and career goals in STEM and those without, regarding their characteristics and perceptions of the social, academic, and career benefits of DO-IT interventions. The following research questions were addressed in the new study:

1. How do participants who have STEM strengths and career goals (the STEM group) compare with those who do not (non-STEM group) with respect to gender, disability type, primary/major areas of postsecondary study, and motivations for going to college and gaining employment?

2. How do participants who have STEM strengths and career goals compare with those who do not regarding perceived changes in themselves in the areas of academic skills, social skills, levels of preparation for college and employment, levels of awareness of career options, and personal characteristics such as perseverance and self-esteem during their participation in the DO-IT program?

3. How do participants who have STEM strengths and career goals compare with those who do not regarding perceived value of program components and what they consider to be the greatest overall impact of DO-IT on their lives?

Method

Participants

A total of 173 Scholars participated in the DO-IT program from 1993 to 2000. This number does not include one Scholar who passed away after the first Summer Study and another who dropped out of the program. Of the 173 participants, DO-IT was able to locate and contact 155. These individuals were sent an email message asking them to complete a web-based survey or, alternatively, to request an email version of the survey, and to give permission to include their responses in the study. Nonrespondents were mailed a follow-up printed survey and a postage-paid return envelope. Seventy-five Scholars responded to the questionnaire (44 via web-based questionnaire, 3 via email, and 28 via postal mail), resulting in a 48% response rate. This final sample of 75 consisted of almost even numbers of male (52%) and female (48%) participants who were up to 26 years old (with 81% of age 18-23). For 42% of the participants, their primary disability was a mobility/orthopedic impairment; the rest of the sample was fairly evenly divided with respect to sight, hearing, learning, and other disabilities. Ninety-one percent of the participants had graduated from high school at the time the survey was conducted.

Design and Procedure

The survey questionnaire was designed to collect perceptions of the impact of specific DO-IT Scholar interventions on respondent lives. The questionnaire was divided into four sections: (a) demographic information, (b) technology-enhanced Summer Study programs, (c) year-round computer and Internet activities, and (d) changes in Scholars as a result of participation. In the Summer Study section, respondents were asked to rate the value of program

Table 1

Percentages (Numbers) of Responses Regarding Gender, Disability, Area of Postsecondary Study, and Primary Motivations for Postsecondary Education and Employment, by STEM & Non-STEM Groups

Category	STEM	Non-STEM
Gender		
Male	64.9% (24)	41.7% (15)
Female	35.1% (13)	58.3% (21)
Primary disability		
Mobility	27.0% (10)	58.3% (21)
Sight	19.0% (7)	8.3% (3)
Hearing/Speech	16.2% (6)	5.6% (2)
Learning	16.2% (6)	8.3% (3)
Other	21.6% (8)	19.4% (7)
Primary disability (dichotomized)		
Mobility	27.0% (10)	58.3% (21)
Non-mobility	73.0% (27)	41.7% (15)
Area of postsecondary study (unclassified omitted)		
STEM-related	86.7% (26)	25.9% (7)
Liberal/General	13.3% (4)	74.1% (20)
Primary motivation for postsecondary education		
Academic interest/Love of learning/Challenges	39.4% (13)	15.6% (5)
Commitment to family and friends	21.2% (7)	12.5% (4)
Getting a good job/Career preparation	30.3% (10)	53.1% (17)
Success in life	3.0% (1)	9.4% (3)
Other	6.1% (2)	9.4% (3)
Primary motivation for employment		
Pursuit of independent living	26.7% (8)	48.4% (15)
Financial security/Incentive plan	60.0% (18)	35.5% (11)
Contribution to social change	.0% (0)	3.2% (1)
Helping others	6.7% (2)	3.2% (1)
Other	6.7% (2)	9.7% (3)

components such as career and college preparation on a scale ranging from 1 (not valuable at all) to 5 (extremely valuable). In the year-round computer and Internet activities section, respondents were asked to rate the importance of activities such as online communication with peers and mentors on a scale from 1 (not valuable at all) to 5 (extremely valuable). They also

rated the value of both the Summer Study and year-round computer and Internet activities in developing their social, career, and academic skills on a scale from 1 (not valuable at all) to 5 (extremely valuable). In the final section, respondents retrospectively assessed their level of specific skills (e.g., self-advocacy) at three different points in their lives–before participating in DO-IT, after the first Summer Study, and at the time of the survey. Statistical analyses consisted of descriptive statistics, including frequency, cross-tabulation, and means, as well as inferential statistics, including Pearson Chi square test, independent-samples T-test, and mixed two-way repeated measures ANOVA. Open-ended responses were analyzed to identify themes in the narratives.

Results

Two groups of respondents were identified by their responses to questions about their academic strengths, personal strengths/talents, and career goals. About half of the respondents (37) reported having strengths and future career goals in areas related to science, technology, engineering, or mathematics (STEM group). The other half (36) did not report strengths and career goals in STEM (non-STEM group). Two subjects were coded as missing because they did not provide information on any of the three variables. Following is a summary of the results by research question.

Research Question 1: How do participants who have STEM strengths and career goals (the STEM group) compare with those who do not (non-STEM group) with respect to gender, age, disability type, primary/major areas of postsecondary study, and motivations for going to college and gaining employment?

Differences By Demographics

Gender

As indicated in Table 1, the STEM group contains nearly twice as many males as females (65% vs. 35%), while the non-STEM contains more females. Pearson's Chi square test confirms that this disproportionality is unlikely due to a chance distribution of males and females into the two groups (χ^2 (1, N = 73) = 3.95, p < .05).

Primary Disability

Participants provided information on their primary disabilities in the demographic section of the survey, which were then coded into five categories: mobility/orthopedic (coded "mobility" in the current study), sight, hearing/speech, learning, and other. The "other" category included health impairments (kidney disease, Lyme disease), seizure disorders, Tourette's, traumatic brain injury, and other conditions whose functional impact was not clear and did not fit into the disability-related categories. Table 1 shows the distribution patterns for the STEM and non-STEM groups. Because of the low prevalence of types of disabilities other than mobility, these data were dichotomized (mobility disability vs. other disability) for analysis with Pearson's Chi square test. Significantly fewer participants in the STEM group have a mobility disability when compared to the non-STEM group (27% vs. 58%; χ^2 (1, N = 73) = 7.32, p < .01). Put another way, students with mobility impairments were much less likely to report STEM strengths and career goals. Of the 31 respondents with mobility impairments, only one-third reported (10) STEM strengths and career goals. In contrast, of the 42 individuals with other types of disabilities, almost two-thirds (27) reported STEM strengths and career goals.

Primary/Major Areas of Postsecondary Study

Sixty-seven respondents had graduated from high school. Of these, 60 transitioned to postsecondary training and provided information on their areas of postsecondary study. Responses were coded into three categories: STEM-related, liberal/general, and undecided/unclassified. Table 1 shows that a majority of the respondents chose to study in an area aligned

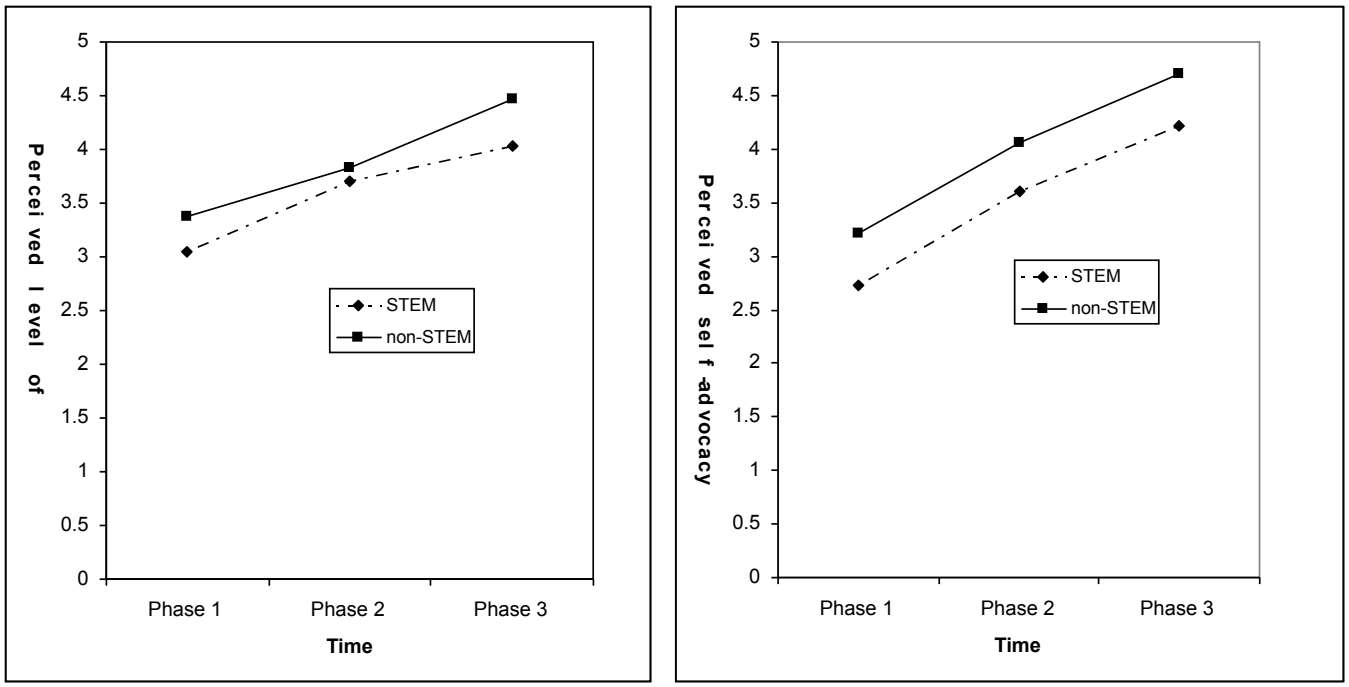

Figure Caption

Figure 1. Perceived Changes in Social Skills and Self-advocacy Skills Over Time by STEM and Non-STEM Groups

with their strengths and career goals. Because of the low prevalence of unclassified students (3 in total), this category was omitted from analysis with Pearson's Chi square test. This analysis confirms that the two groups differed significantly in their choices of majors, with the participants in the STEM group being more likely to study in STEM-related areas than those in the non-STEM group (χ^2 (1, N = 57) = 21.51, p < .001). Interestingly, there was a higher percentage of students in the non-STEM group who majored in STEM fields (26%) as compared to the percentage of those in the STEM group who majored in non-STEM fields (13%). However, a binomial test shows that the differences in the rates of interest-major crossover were not statistically significant (p = .079, ns).

Motivation for College and Employment

Sixty-five respondents, including those who had not yet graduated from high school, responded to open-ended questions about primary motivations for attending postsecondary school, as well as motivations for selection of careers. Responses on motivations for going to college were coded into 5 categories: academic interest/love of learning and challenges, commitment to family and friends, getting a good job or career preparation, pursuit of success in life, and other motivations. Table 1 shows the response patterns for the STEM and non-STEM groups. Because of the low prevalence in the pursuit of success and other motivation categories, they were omitted from analysis with Pearson's Chi square test. This analysis shows that the differences in response patterns between the remaining groups were significant at the .05 level (χ^2 (2, N = 56) = 5.93, p = .051). Examination of Table 1 reveals that academic interest and desire to learn were important to more members of the STEM group than of the non-STEM group, while getting a good job was identified as a primary motivator for more of the non-STEM respondents.

Pursuit of independent living and financial security were the most frequently selected motivators for seeking employment in both groups (see Table 1). The low response categories – contribution to social changes, helping others,

and other motivations – were omitted from the analysis because the expected frequency in those cells fell below 5. Pearson's Chi square analysis shows that the group differences in the response patterns were significant at the .05 level (χ^2 (1, N = 52) = 3.82, p = .051). Examination of Table 1 reveals that financial security was selected by significantly more of the STEM group and pursuit of independent living was selected by significantly more of the non-STEM group.

Differences in Skills

Research Question 2: How do participants who have STEM strengths and career goals compare with those who do not regarding perceived changes in themselves in the areas of academic skills, social skills, levels of preparation for college and employment, levels of awareness of career options, and personal characteristics such as perseverance and self-esteem during their participation in the DO-IT program?

DO-IT Scholars were asked to assess their academic skills, social skills, levels of preparation for college and employment, levels of awareness of career options, and personal characteristics such as perseverance and self-esteem at three points: prior to their involvement in DO-IT (Phase 1), immediately following their first DO-IT Summer Study (Phase 2), and at the time of the current survey (Phase 3). An earlier analysis of the survey data (Kim-Rupnow & Burgstahler, 2004) revealed that, overall, DO-IT Scholars considered themselves significantly improved in these areas.

This upward trend was further analyzed in the current study by comparing the STEM and non-STEM groups over time. A 2 x 3 analysis of variance (ANOVA) with repeated measures was conducted with the STEM group membership as the between-group factor and the three time points (phases) as the within-group factor. With this design, a significant group by time interaction would indicate a different pattern of change in the dependent variables over time for the two groups.

Social Skills

A significant group by phase interaction was observed in the area of social skills (F (2, 65) = 3.26, p < .05), indicating that the pattern of change in perceived social skills was different for the STEM and non-STEM groups over the three phases of DO-IT participation. Further analyses of the interaction effect revealed that the non-STEM group increased more dramatically than did the STEM group despite significant improvements perceived by participants in both groups during the course of the DO-IT program (see Figure 1). Specifically, the two groups did not differ in social skills at Phase 1 (before DO-IT) (F (1, 66) = 1.20, p = .28) and Phase 2 (after the first DO-IT Summer Study) (F (1, 66) = .31, p = .58). However, significant group differences were observed at Phase 3 (F (1, 66) = 4.41, p < .05), with the non-STEM group reporting a higher level of social skills than the STEM group. When examining the simple main effect of phase within the group variable, participants in each group perceived significant social skill improvements over time (F (2, 65) = 13.14, p < .001) for the STEM group and (F (2, 65) = 19.12, p < .001) for the non-STEM group. Pairwise comparison further identified significant changes between Phases 1 and 2, and Phases 2 and 3 for each group; the mean difference in both pairs of comparisons was statistically significant at the .05 level based on a Bonferroni adjustment.

Self-Advocacy Skills

A significant main effect of Phase was observed (F (2, 126) = 73.26, p < .001), indicating that participants of both the STEM and non-STEM groups considered their self-advocacy skills improved significantly over time. In addition, the main effect of STEM/non-STEM group membership was significant (F (1, 63) = 7.71, p < .01). This result indicates that the STEM and non-STEM groups differed in perceptions of their self-advocacy skills, with participants in the non-STEM group rating them-

selves significantly higher in self-advocacy skills than those in the STEM group throughout the phases (see Figure 1). No significant interaction between the group and the levels of phase was observed.

Internet Skills, Computer Skills, Preparation for College and Employment, Perceived Career Options, Perseverance, Self-Esteem, and Independence

According to self-ratings, Internet skills of the participants improved significantly over time for both the STEM and non-STEM groups, as indicated by the significant main effect of phase ($F(2, 64) = 63.36$, $p < .001$). Pairwise comparisons further indicated that participants in both groups perceived significant increases in Internet skills from Phase 1 to Phase 2 and from Phase 2 to Phase 3. However, neither the main effect of the group, nor the interaction between group and phase was statistically significant at the .05 level, indicating that the participants in both groups improved similarly over time in the area of Internet skills. Similar statistical analyses were conducted regarding computer skills, level of preparation for college, perceived career options, level of preparation for employment,

Table 2

Rating Differences between STEM and Non-STEM Groups Regarding DO-IT Summer Study and Year-Round Computer and Internet Activities

DO-IT program activities	STEM		non-STEM		*df*	*t*
	M	*SD*	*M*	*SD*		
Summer Study activities						
Computer and Internet use	4.50	0.61	4.20	0.99	69	1.54
Face to face interaction and developing relationships	4.29	0.72	4.03	1.07	67	1.21
College preparation	4.14	0.87	3.94	1.08	69	0.84
Career preparation	3.85	0.86	3.71	1.03	66	0.64
Internship at Summer Study	4.06	1.00	4.11	0.99	35	-0.15
Summer Study activities in developing						
Social skills	4.00	0.70	3.71	0.91	66	1.50
Academic skills	3.66	0.91	3.32	1.04	67	1.43
Career skills	3.97	0.78	3.67	1.05	63	1.31
Year-round computer and Internet activities						
Access to home computer	4.55	0.91	4.56	0.71	56	-0.07
Access to adaptive technology	4.32	1.12	3.50	1.53	50	2.22*
Online communication with peers	3.94	1.04	3.58	1.20	67	1.37
Online communication with adult mentor	3.89	1.14	3.63	1.19	66	0.94
Access to information and resources on the Internet	4.57	.69	4.18	0.85	68	2.10*
Year-round computer and Internet activities in developing						
Social skills	3.79	0.91	3.21	1.14	65	2.31*
Academic skills	4.18	0.83	3.91	0.91	69	1.25
Career skills	4.25	0.72	3.65	1.05	67	2.68**

Note. * $p < .05$. ** $p < .01$

perseverance, self-esteem, and independence. The main effect of phase was consistently significant, indicating that the participants in both groups perceived improvements throughout the course of DO-IT with respect to these areas. In all cases, neither the main effect of the group, nor the interaction between group and phase was statistically significant, indicating that the participants in both groups improved similarly over time in the tested areas.

Differences in Impact

Research Question 3: How do participants who have STEM strengths and career goals compare with those who do not regarding perceived value of program components and what they consider to be the greatest overall impact of DO-IT on their lives?

Summer Study

Participants were asked to rate the value of each of the following Summer Study activities using a 5-point Likert scale with "1" representing "not valuable at all" and "5" representing "extremely valuable": (a) computer and Internet use, (b) face-to-face interaction and developing relationships, (c) college preparation, (d) career preparation, and (e) internship at Summer Study. All of the activities were rated highly, with scores ranging from 3.85 to 4.50 for the STEM and 3.71 to 4.20 for the non-STEM groups (See Table 2). Participant ratings of each of the program components were analyzed using independent-samples t test to determine whether the perceived values were different for the STEM and non-STEM groups. No group differences were found in the ratings of any of the activities, indicating that participants in the two groups rated similarly the value of the activities offered at the Summer Study. In addition to program components, participants rated, using the same rating scheme, the overall value of Summer Study in developing specific social, academic, and career/employment skills (See Table 2). Even though the STEM group gave slightly higher ratings than did the non-STEM group regarding the value of Summer Study in developing such skills, these differences did not reach statistical significance.

Year-Round Computer and Internet Activities

In addition to the Summer Study program, DO-IT participants were provided year-round computer and Internet activities that included (a) access to a home computer, (b) access to adaptive technology, (c) online communication with peers, (d) online communication with adult mentors, and (e) access to information and resources on the Internet. All of the activities were rated as valuable by both the STEM and non-STEM groups, with access to a home computer and access to information, and resources on the Internet receiving the highest ratings (See Table 2). Group differences emerged on two of five year-round computer and Internet activities. Specifically, participants in the STEM group valued access to adaptive technology and access to information and resources on the Internet more highly than did those in the non-STEM group ($t(50) = 2.22$, $p < .05$, and $t(68) = 2.10$, $p < .05$) respectively. Furthermore, STEM group members also reported the overall year-round computer and Internet activities to be more valuable than did their non-STEM counterparts in developing their social skills ($t(65) = 2.31$, $p < .05$) and career/employment skills ($t(67) = 2.68$, $p < .05$). However, the two groups did not differ on the perceived value of such activities in developing academic skills.

Results of the qualitative data analysis were consistent with the quantitative findings. When participants were given an opportunity in an open-ended format to identify the aspects of the DO-IT programs perceived to be most valuable for promoting their positive social, academic, and employment outcomes, they mentioned social interaction, access to computer and Internet, mentors, and preparation for college and careers, including resume writing, mock interview, and field trips. For example, one participant commented that, "Just interacting with ev-

erybody and learning about everybody's life and lifestyles" is valuable. Another said, "The simple idea of staying in the dorms and show[ing] that it could be done was the most integral part." Other comments included: "DO-IT has shown me that information is empowerment and that through the computer and social networking there is virtually free access to information for everyone." "I looked at my disability and my life in a different light. I noticed that others had it worse than me, but that doesn't stop them. I felt that help shaped [sic] my life more." "I still am in close contact with my beloved mentor after 8 years. I pursued sign language because of the program and was a part of many disability awareness programs in college due to DO-IT." No qualitatively different response patterns were associated with the STEM and non-STEM groups.

Greatest Overall Impact of DO-IT

Members of STEM and non-STEM groups expressed similar views regarding the impact of DO-IT activities. Individual psychosocial development and readiness for college and career pursuits were the two main areas that emerged from participant responses to the open-ended question, "What has been the greatest impact of DO-IT on your life?" with almost equal number of people in each group, 53% vs. 47% in the STEM and 48% vs. 52% in non-STEM groups, valuing DO-IT each way.

Discussion and Implications for Other Programs

The current study was undertaken to compare characteristics and perceptions of the social, academic, and career benefits of DO-IT interventions of two groups of DO-IT Scholars – those with reported strengths and career goals in STEM and those without. Although the characteristics of participants in the two groups were similar and they responded similarly to many program components, differences between the two groups have implications for other programs that serve to increase the participation of students with disabilities in STEM fields.

Characteristics of Non-STEM and STEM-Oriented Participants

The researchers found significant differences in demographic variables between the two groups of students, including those related to gender, disability type, primary areas of postsecondary studies, and primary motivations for going to college and seeking employment.

Gender

More male than female participants reported strengths and career goals in STEM fields. This finding is consistent with the literature on STEM interest in the overall population, suggesting that students with disabilities face issues of gender equity in STEM education and occupations similar to those faced by members of the general population (National Science Foundation, 2002, 2004). Programs designed to increase the representation of students with disabilities in STEM fields should consider applying strategies proved successful in increasing the representation of girls and women in STEM fields, such as working to increase math, science, and computers ability self-concepts; providing career counseling that includes science, math, and computer course requirements for a variety of STEM-related careers; mentoring; and offering motivating, out-of-school, hands-on, math and science activities (Zarrett & Malanchuk, 2005; Skolnick, Langbort, & Day,1982; Simpkins, Davis-Kean, & Eccles, 2006).

Disability Type

Differential post-school outcomes across disability categories have been found in earlier studies. For example, the National Longitudinal Transition Study Two (NLTS2) reported that youth with emotional disturbances, multiple disabilities including deaf-blindness, and other health impairments remained among the least likely to have finished high school. However, youth with orthopedic impairments in 2003

reported the second highest school completion rate 86% (following a rate of 94% for youth with visual impairments) and the fourth highest participation rate (40%) in postsecondary education (Wagner, Newman, Cameto, & Levine, 2005).

Researchers in the current study found an interesting phenomenon—the non-STEM group had a higher percentage of members with mobility impairments than the STEM group. The authors went further to separate strengths and career goals, and found that the aforementioned disproportionality was more salient with respect to the career goals variable than the strength variable. In other words, students with mobility impairments in the current study were less likely to report STEM career aspirations than STEM strengths when compared to their peers without mobility impairments. Students develop academic and career interests as they grow up and a multitude of factors influence the process, including self-perceptions, parent and teacher expectations and beliefs, home environment, school experiences, participation in structured out-of-school activities, peer influences, and community experiences (Simpkins, Davis-Kean, and Eccles, 2006; Simpkins & Davis-Kean, 2005; Eccles, Midgley, & Adler, 1984; Jacob & Eccles, 1992). Disability type may play a role by directly and/or indirectly (through the mediating effects of the expectations of parents, teachers, and others) influencing a student's perception of STEM fields as viable career options. The authors suspect that parents, teachers, and students themselves, who are often unaware of the great variety of career options in STEM fields and of assistive technology that provides access to computers and scientific equipment, may perceive STEM fields as posing too many physical barriers to those with disabilities that affect mobility. Students with mobility impairments who have STEM interests might be discouraged from considering STEM fields as career options. Programs designed to increase participation in STEM should be aware of stereotypes and other negative attitudes concerning the appropriateness of STEM fields for people with certain types of disabilities. In school and transition programs, efforts should be made to increase the awareness of assistive technology and the wide variety of types of career positions in STEM fields among students with mobility impairments, their parents, educators, and service providers, so that these students will not steer away from STEM career paths simply because of their disabilities. Participants should be encouraged to look beyond the physical abilities typically used in a science lab (e.g., holding beakers) to careers that apply STEM knowledge in ways that do not require performance of these tasks (e.g., statistical analysis of lab results). As one Scholar articulated, what he gained from DO-IT participation was, "Realizing that I had more career choices than I previously thought I had."

Area of Postsecondary Study

A majority of the Scholars in each group chose postsecondary study in an area aligned with their reported strengths and career goals. It was reasonable to expect that students with STEM strengths/career goals would be more likely to major in STEM fields, and the statistical analysis supports this hypothesis. Interestingly, there was a higher percentage of Scholars in the non-STEM group who ended up majoring in STEM fields (26%) than of Scholars in the STEM group who majored in non-STEM fields (12%). Even though it is inconclusive as to whether DO-IT interventions encouraged participants to major in STEM, findings in this study suggest that career decisions are subject to influences and change as young adults engage in exploring various career options in search for the best fit. DO-IT provided these participants opportunities for exploration through hands-on science experiences, work-based learning, exposure to assistive technology, access to mentors and peers, and skill training. Findings suggest that programs designed to increase STEM participation for students with disabilities should not ignore students who are not initially inter-

ested in STEM. Instead, interventions should be tailored to the interests of these students and provide opportunities that may increase their awareness of the wide variety of STEM careers, interest in STEM, and confidence in pursuing STEM fields.

Motivation to Attend College

The two groups of participants differed in their primary motivations for attending college. Academic interest and love of learning/challenges was cited as important to more of the STEM-oriented students, while job/career preparation was identified as a primary motivator for more of the non-STEM students. These results are consistent with the findings from research on young adults' decisions to pursue math, science, and information technology careers. Zarrett & Malanchuk (2005) found that individuals with both high interest in computers and positive self-concepts in math and computers were most likely to aspire to information technology (IT) professions. The findings suggest that programs designed to increase participation in STEM should capitalize on the academic interests and strengths in STEM-oriented students, and at the same time, make sure that non-STEM-oriented participants learn about the many career opportunities available in STEM fields through work-based learning, Internet searches, and other activities.

Motivation to Seek Employment

Pursuit of independent living and financial security were reported as the top two motivations for seeking employment, but what is more interesting and worth noting is the group differences. While financial security was selected by significantly more of the STEM-oriented participants, pursuit of independent living was chosen by more of the non-STEM participants. The pattern of differences poses interesting questions as the link between the STEM and non-STEM groups and these motivators is likely to be mediated through other variables. Further examination of the characteristics associated with STEM and non-STEM participants, such as mobility impairments and gender, will be helpful to better understand the association between the STEM and non-STEM orientations and motivations for pursuing employment. These results also suggest that it is important that DO-IT and similar programs help students develop practical skills in independent living and employment that can bring financial security.

Perceived Value of Program Components

Technology

There were some differences regarding the perceived value of information technology between the STEM and non-STEM groups. The STEM group rated year-round computer and Internet activities, especially the access to adaptive technology and to information and resources on the Internet, higher than did their counterparts in the non-STEM group. Research findings suggest that program organizers be aware that technology use might be considered more valuable by participants with STEM strengths and goals than by those who do not report STEM strengths or goals. Efforts to tailor technology interventions to the specific interests of students with little interest in STEM should be undertaken. With mentors from STEM fields, the Internet can be used to support a community that promotes STEM interest within a social setting. In this case, participants with little interest in STEM studies and careers might be drawn more to working with people than to working with the technology alone. Technology could become more appealing to this group when it is used to address the needs of these students to be socially connected with others, perhaps through group work and interaction with peers and mentors.

Skill Building

Overall, DO-IT Scholars reported themselves improved in academic skills, social skills, levels of preparation for college and employment, levels of awareness of career options, and personal characteristics such as perseverance

and self-esteem during the course of their participation in the DO-IT program. They learned from program activities and from each other. As reported by one participant with a hearing impairment, "I started using sign language after I saw that I understood it when watching the interpreters. Now I use interpreters for education, large meetings, conferences, classes, etc." The impact of the program in developing participant skills and opening their eyes to new possibilities was a common theme among respondents, regardless of their STEM or non-STEM orientations: "I realized that I had more career choices than I thought I had." "I am becoming more independent." "I learned how to advocate for myself." Group-related differences were not large with non-STEM-oriented participants consistently reporting higher levels of self-advocacy skills and social skills than STEM participants. The higher levels of social and self-advocacy skills perceived by the non-STEM group may be related to the reported strengths of these participants, which often included communication, people, and/or negotiation skills.

Participants, STEM-oriented or not, valued the skills, experiences, and encouragement they gained from Scholar involvement. The experiences and insights of survey participants can help other transition programs enhance the college and vocational success of students with disabilities. As previously reported by Kim-Rupnow and Burgstahler (2004), aspects of the program considered essential to helping participants achieve positive social, academic, and employment outcomes include access to computers and the Internet, development of social skills, self-advocacy skills, and self-esteem; and preparation for college and careers. The comprehensive combination of technology-enhanced learning activities, on-site, hands-on activities, and work-based learning experiences that DO-IT provides may have more impact on academic and career outcomes than either approach separately, as has been previously reported in the literature (American Association for the Advancement of Science, 2001; Cunningham, Redmond, & Merisotis, 2003; Malcom & Matyas, 1991; National Science Foundation, 2005). Other programs should also consider providing a comprehensive set of interventions that assure technology access to support the development of academic and career skills, peer and mentor interaction, and smooth transitions between academic and employment levels of involvement.

Limitations of the Study and Recommendations for Further Research

The findings of the current study apply to the population that DO-IT participants are drawn from—college-bound teens with disabilities who are motivated to participate in an extracurricular technology, academic, and career program with a reputation and program that encourages consideration of STEM fields and who have supportive adults to assist with the application process. Caution should be exercised in generalizing the results of this study to other populations. They should be interpreted in light of limitations reported in the earlier study (Kim-Rupnow & Burgstahler, 2004). Specifically, the response rate of the present study was 48%; a larger sample could have yielded more power to the analyses involving multiple subgroups. Also, the impact of program components was based on the retrospective self-reporting of survey respondents. Their perceptions may not accurately reflect the actual impact of specific interventions due to potentially skewed recalls and subjectivity of self-assessment. Self-rating, as well as quantitative measures at actual points in time, might have given more objective evaluations.

The results of this study suggest a number of important issues to address in further research. First, more longitudinal follow-up research on programs like DO-IT is needed, since little of such data is currently available in published literature. Collection of evaluation data should occur at critical steps – such as before the Summer Study, immediately after the Summer Study, six

months later, one year later, and several years later – in order to detect the long-term effect of program activities. Second, empirical studies that include both program participants and non-participant peers should be conducted since comparisons made to a control group provide more convincing data regarding program effectiveness. Third, multiple methods and multiple perspectives should be incorporated; data from parents, high school teachers, counselors, and program staff provide additional perspectives regarding program effectiveness. Fourth, further examinations on relationships between program perceptions and impact, and gender and disability type, should be conducted to provide insight on how to tailor program activities to specific participants. For example, further studies are needed to understand the complex relationships between mobility impairments and the development of STEM-related academic interests and career choices, including the social and environmental factors that moderate such relations. Fifth, a follow-up study could be designed to help us understand what interventions made some participants in the current study turn away from other interests and goals to pursue STEM careers. Lastly, more empirical research is needed to determine the long-term impact of technology-oriented summer programs, online and on-site peer and mentor supports, and other college and career transition supports on increasing potential interest in and pursuit of STEM fields among students with disabilities.

Conclusion

This study was undertaken to explore differences in the characteristics of two groups of participants in a transition program—those with reported strengths and career goals in STEM and those without – and their perceived social, academic, and career outcomes as a result of participation. Consistent with previous research, more males than females reported initial strengths and goals in STEM. The smaller percentage of participants with mobility impairments reporting STEM orientation suggests that disability type may play a role in student perceptions of STEM fields as career options. Research results suggest that it may be possible for programs to increase the interests in STEM careers of individuals not initially oriented in these areas. This result is encouraging for DO-IT and similar programs that serve to increase participation in STEM careers by people with disabilities. Those without reported interests, aptitudes, or career goals in STEM tended to value social opportunities and development more highly than those with STEM interests and reported less interest in technology-related activities. Non-STEM participants consistently rated themselves higher in self-advocacy skills and perceived that program participation improved their social skills more than STEM participants.

Programs should keep in mind differences between participants with initial STEM strengths and goals, and those without, as they tailor activities to the needs of their participants. Such programs should take special steps to recruit: (a) females (because, as a group, they are less likely to have an interest in STEM already) and (b) students with mobility disabilities who show interest in STEM, yet have low expectations for pursuing STEM fields due to various reasons. For example, in the DO-IT Scholars program, students with all interests are recruited and a large number of program activities, but not all, are STEM-related. Programs that serve to increase the representation of people with disabilities in STEM fields should also undertake efforts to document their practices, institute pre and post-tests, and follow up with participants to assess both overall program outcomes and the relative value of specific interventions for specific groups of students. Dissemination of results can help others improve postsecondary academic and career outcomes for people with disabilities. One vehicle for dissemination is the series of promising practices published in the AccessSTEM Knowledge Base (DO-IT, n.d.).

Sheryl Burgstahler, Ph.D., is an Affiliate Associate Professor in the College of Education

and the founder and director of DO-IT, the Alliance for Students with Disabilities in Science, Technology, Engineering, and Mathematics (AccessSTEM), and Accessible Technology Services at the University of Washington in Seattle.

Chuan Chang, Ph.D., is at the Center on Disability Studies, University of Hawaii at Manoa.

The DO-IT Scholars program has been funded by the National Science Foundation (grant numbers 9725110, 9800324, and 9550003) and the State of Washington. Preparation of this article was partially supported by grants from the U.S. Department of Education, the National Institute on Disability Rehabilitation Research, and the Office of Special Education Programs (grant #H133B980043), as well as the Rehabilitation Services Administration (grant #H235N010014) and the National Science Foundation (award #HRD0227995 and #HRD0833504 for AccessSTEM projects). The opinions expressed in this paper are those of the authors and do not necessarily reflect those of the funding agencies.

Correspondence concerning this article should be addressed to Sheryl Burgstahler, Box 354842, DO-IT, University of Washington, Seattle, WA 98195. Telephone: 206-543-0622. Fax: 206-221-4171. Email: sherylb@u.washington.edu

References

American Association for the Advancement of Science. (2001). *In pursuit of a diverse science, technology, engineering, and mathematics workforce*. Washington, DC: Author.

Benz, R. B., Yavonoff, P., & Doren, B. (1997). School-to-work components that predict post school success for students with and without disabilities. *Exceptional Children, 63*, 151–165.

Blackorby, J., & Wagner, M. (1996). Longitudinal post school outcomes of youth with disabilities: Findings from the National Longitudinal Transition Study. *Exceptional Children, 62*, 399–413.

Burgstahler, S. (2001). A collaborative model promotes career success for students with disabilities: How DO-IT does it. *Journal of Vocational Rehabilitation, 16* (129), 1–7.

Burgstahler, S. (2002). The value of DO-IT to kids who did it! *Exceptional Parent, 32*(11), 79–86.

Burgstahler, S. (2003). DO-IT: Helping students with disabilities transition to college and careers. *National Center on Secondary Education and Transition Research to Practice Brief, 2*(3).

Burgstahler, S., Bellman, S., & Lopez, S. (2004). Research to practice: DO-IT prepares students with disabilities for employment. *NACE Journal, 65*(1). Retrieved February 20, 2007, from http://www.naceweb.org/FormsLogin.asp?/pubs/journal/fa04/bellman.htm

Burgstahler, S., & Cronheim, D. (2001). Supporting peer-peer and mentor-protégé relationships on the Internet. *Journal of Research on Technology in Education, 34*(1), 59–74.

Burgstahler, S., & Doyle, A. (2005). Gender differences in computer-mediated communication among adolescents with disabilities: Science, technology, engineering, and mathematics case study. *Disability Studies Quarterly, 25*(2). Retrieved February 20, 2007, from http://www.dsq-sds.org/2005_spring_toc.html

Butterworth, J., & Pitt-Catsouphes, M. (1997). Employees with disabilities: What managers, supervisors, and co-workers have to say. *Employment in the Mainstream, 22*, 5–15.

Cavanagh, S. (2006, June 7). NAEP scores show fewer budding scientists. *Education Week 25*(39), 5, 16.

Chinn, P. (1999). Multiple worlds and mismatched meanings: Barriers to minority women engineers. *Journal of Research in Science Teaching, 36*(6), 621–636.

Cohen, K. J., & Light, J. C. (2000). Use of electronic communication to develop mentor-protégé relationships between adolescent and adult AAC users: Pilot study. *AAC Augmentative and Alternative Communication, 16*, 227–238.

Cunningham, A., Redmond, C., & Merisotis, J. (2003). *Investing early: Intervention programs in selected U.S. states.* Washington, DC: The Institute for Higher Education Policy. Retrieved February 20, 2007, from http://www.millenniumscholarships.ca/images/Publications/investingeng_web2.pdf

DO-IT. (n.d.), *Search the AccessSTEM Knowledge Base*. Seattle, WA: University of Washington. Retrieved February 20, 2007, from http://www.washington.edu/doit/Stem/kb.html

DO-IT. (2006). *DO-IT Scholars*. Seattle, WA: University of Washington. Retrieved February 20, 2007, from http://www.washington.edu/doit/Brochures/Programs/scholars.html

Doren, B., & Benz, M. R. (1998). Employment inequity revisited: Predictors of better employment outcomes of young women with disabilities in transition. *Journal of Special Education, 31*(4), 425–442.

Eccles, J. S., Midgley, C., & Adler, T. (1984). Grade-related changes in the school environment: Effects on achievement motivation." In J. F. Nicholls (Ed.), *Advances in Motivation and Achievement: The Development of Achievement Motivation*. Greenwich, CT: JAI Press.

Fisher, S. (2000). *Towson University Outreach*. Towson, MD: Towson University. Retrieved February 20, 2007, from http://www.ed.uiuc.edu/sped/tri/towsonuniversity.htm

Jacobs, J. E., & Eccles, J. S. (1992). The impact of mothers' gender-role stereotypic beliefs on mothers' and children's ability perceptions. *Journal of Personality and Social Psychology, 63*, 932-944.

Kaye, H. S. (2000). Computer and Internet use among people with disabilities. *Disability Statistic Report 13*. San Francisco, CA: University of California, Disability Statistics Center.

Kim-Rupnow, W. S., & Burgstahler, S. (2004). Perceptions of students with disabilities regarding the value of technology-based support activities on postsecondary education and employment. *Journal of Special Education Technology, 19*(2), 43–56. Retrieved February 20, 2007, from http://jset.unlv.edu/19.2/rupnow/first.html

Kohler, P. D., & Chapman, S. (1999). *Literature review on school-to-work transition*. Champaign, IL: University of Illinois at Urbana-Champaign, Transition Research Institute. Retrieved February 20, 2007, from http://www.ed.uiuc.edu/sped/tri/2stwresearch.htm

Kohler, P. D., & Hood, L. K. (2000). *Improving student outcomes: Promising practices and programs for 1999–2000*. Champaign, IL: University of Illinois at Urbana-Champaign, Transition Research Institute.

Kohler, P. D., & Troesken, B. J. (1999). *Improving student outcomes: Promising practices and programs for 1998–1999*. Champaign, IL: University of Illinois at Urbana-Champaign, Transition Research Institute.

Malcom, S. M., & Matyas, M. L. (Eds.). (1991). *Investing in human potential: Science and engineering at the crossroads.* Washington, DC: American Association for the Advancement of Science.

National Council on Disability and Social Security Administration. (2000). *Transition and post-school outcomes for youth with disabilities: Closing the gaps to post-secondary education and employment*. Washington, DC: Author.

National Organization on Disability. (2004). *Harris 2004 Survey of Americans with Disabilities*. Washington, DC: Author. Retrieved February 20, 2007, from http://www.nod.org/Resources/harris2004/harris2004_pres.pdf

National Science Foundation. (2002). *NSF's program for gender equity in Science, Technology, Engineering, and Mathematics: A brief retrospective 1993 -2001* (NSF Publication No. 02-107). Arlington, VA: Author. Retrieved February 20, 2007, from http://www.nsf.gov/pubs/2002/nsf02107/nsf02107.pdf

National Science Foundation. (2004). *Women, minorities, and persons with disabilities in science and engineering* (NSF Publication No. 04-317). Arlington, VA: Author. Retrieved February 20, 2007, from http://www.nsf.gov/statistics/wmpd/pdf/nsf04317.pdf

National Science Foundation. (2005). *Research in disabilities education* (NSF Publication No. 05-23). Arlington, VA: Author. Retrieved February 20, 2007, from http://www.nsf.gov/pubs/2005/nsf05623/nsf05623.htm Office of Disability Employment Policy. (2001, November). *Improving the availability of community-based services for people with disabilities.* Washington, DC: Author.

Simpkins, S. D. & Davis-Kean, P. E. (2005). The intersection between self-concepts and values: Links between beliefs and choices in high school. *New Directions for Child and Adolescent Development, 110*, 31-47.

Simpkins, S. D., Davis-Kean, P. E., & Eccles, J. S. (2006). Math and science motivation: A longitudinal examination of the links between choices and beliefs. *Developmental Psychology, 42*(1), 70-83.

Skolnick, J., Langbort, C., & Day, L. (1982). *How to encourage girls in math and science*. Englewood Cliffs, NJ: Prentice Hall.

Stainback, W., Stainback, S., & Wilkinson, A. (1992). Encouraging peer supports and friendships. *Teaching Exceptional Children, 24*(2), 6–11.

U.S. Department of Labor, Bureau of Labor Statistics. (2004). *Occupational Outlook Handbook, 2003-04 Edition, Computer System Analysts, Database Administrators, and Computer Scientists.* Washington, D.C.: U.S. Government Printing Office, 2004. Retrieved February 20, 2007, from http://www.bls.gov/oco/ocos258.htm.

Wagner, M., Newman, L., Cameto, R., & Levine, P. (2005). *Changes over time in the early postschool outcomes of youth with disabilities. A report of findings from the National Longitudinal Transition Study (NLTS) and the National Longitudinal Transition Study-2 (NLTS2)*. Menlo Park, CA: SRI International.

Zarrett, N. R., & Malanchuk, O. (2005). Who's computing? Gender and race differences in young adults' decisions to pursue an information technology career. *New Directions for Child and Adolescent Development, 110*, 65-84.

Little Displays: The Photographs of Ricardo Gil

Ann Millett, Ph.D.
University of North Carolina at Greensboro

Abstract: Ricardo Gil is a little person who photographs his family and lifestyle. I compare Gil's images to images of little people drawn from fine art, the freak show, and popular culture. Gil's photographs express dwarfism as an embodied perspective and subject position.

Key Words: photography, dwarfs, representation

> "His photographs are deeply intimate, filled with the banal details of life and tempered by an engrossing self-examination as Gil, sometimes quite literally, measures himself against a larger world" (Miller, 1999).
>
> "The photographs in the folios are part of a larger collection entitled, "A View of My Own." I am a dwarf, as is my wife, and we are raising our average-sized daughter. Since 1991, I have documented my family and my perspective of the world. Thank you for visiting" (Gil, 1999-2003).

Gil's quote is the introduction to his website, which features photographs of himself, his wife, and his daughter in their daily family routine and on outings. He literally documents his perspective of the world, as the images show the embodied view of an individual who does not fit the "normal" world designed for the average-sized. Gil's photographs, however, revel in the average, as they celebrate the mundane qualities of his everyday life. The actions and environments the images depict make his series resemble a typical family album of a not so typical family, of dwarf parents and an average-sized daughter, Lily.

*Johann's Kiss (*1999; 2000)

In *Johann's Kiss* (1999; 2000), Gil spotlights his wife, Meg, sharing a moment of affection and praise in a kiss on the cheek with an average-sized man, who kneels down to her height. Figures in the background are headless, but this is not the work of an amateur, rather it presents the embodied viewpoint of the photographer. *Lily and Bars* (1999-2003) shows a playful moment in the life of Gil's daughter in a close-up of her hanging from a jungle gym. At this proximity to his daughter, Gil's viewpoint is "normal," or average-sized. The closeness of the image replicates the bond between father and daughter, despite or perhaps, even because of, their differences. Father and daughter see eye-to-eye.

Gil's photographs show viewers how the little person sees, which proves not so unusual. He hangs the photographs in shows at his height, not to disarm his average-sized viewers or necessarily force them to kneel, but rather because this is the height at which he prefers to view artwork (Bird, 1999). *Mannequins* (1999-2003), is self-conscious of this viewpoint. It de-

Lily and Bars (1999-2003)

Mannequins (1999-2003)

picts the legs of mannequins that likely advertise pants, for the forms purposefully have no upper halves. While this is Gil's characteristic viewpoint of all bodies from his dwarf height, these "half" figures are indeed "normal." The mannequins fool the eye, which is Gil's point. Exemplified by this subject matter, Gil's images make the viewer look twice. In *Dance* (1999-2000), the heads of the figures are outside the frame of the photograph, but the female dancers from this viewpoint are not lacking. Their dance is captured by the dramatic twisting of their bodies, adorned in party dresses; their identities are irrelevant and their facial expressions are predictable, based on the main subject of the image, the dance.

Gil's photographs witness the "normal" world that does not fit his own. Disability Studies scholar Rosemarie Garland-Thompson (1997; 2001) has most thoroughly investigated the "stare," which she states occurs in the daily life of individuals who do not corporeally adhere to the norm of appearance and which marks them derogatorily as "other." Garland-Thompson (2001) states, "Photography mediates between the viewer and the viewed by authorizing staring." The gaze/stare that photography sanctions and depends on marks the subject/body as not just "abnormal," but sub-normal, according to Garland-Thompson, and allows for distance and difference to be constructed between nondisabled viewers and disabled subjects. She focuses on photographs of the disabled by nondisabled, or so-called "normal" photographers, but Gil's photographs instead stare back, as he stares at himself and his family with love, admiration, and self-identification.

Bird (1999) describes Gil's portraits and self-portraits as self-confident, humorous, and scientific, as they depict multiple aspects of his multidimensional subjectivity. Simultaneously, they embody the history of the representation of little people, by sharing similarities with historical images, as well as marked visual and discursive differences. Barthes (1981) writes that photography is tormented by the ghost of painting, and Gil's photographs confront histories of painted, photographed, and live displays of little people.

Dance (1999-2000)

In addition to becoming supernatural and medical monsters, little people during the 15th and 16th centuries were uniquely kept at royal courts as prodigies, jesters, comic fools, clowns, and the caretakers and entertainers of royal children. These little people performed their amusements before the family and guests, portrait artists (most famously, Spanish painter Diego Velásquez), and before society at large in private quarters and in public fairs, festivals, celebrations, and other spectacles. Dwarfs kept at royal courts were considered wonders and part of a collection of "exotic" decorative items, which were commonly found in curiosity cabinets. Renaissance travelers to "exotic" lands, such as Africa, India, and Central America, reported seeing races of little people called pygmies and heard native myths about little people descended from monkey gods (Daston & Park, 1998).

Yet, legends surrounding little people were not all degrading. Adelson (2005) reports that in ancient Egypt dwarfs were associated with the gods of creative powers, such as childbirth, which elevated their status. Adelson states, "The Egyptian courts were unique in that they offered roles to dwarfs as priests and courtiers, as well as jewelers and keepers of linen and toilet objects." She points out that some historical court dwarfs, such as painter Richard Gibson (1650-1690), who were kept in the court of Charles I of England, offered formal training in their crafts and provided food and clothing.

These histories and myths are dense with symbolism of little people as divine and/or animalesque. In the genre of art historical portraiture, dwarfs are included iconographically as miniature offsets to reinforce the authority, austerity, and power of an often elaborately costumed king or queen, as exemplified in Coello's sixteenth century paintings *Magdelena Ruíz with Doña Isabel, Clara Eugenía and Monkey* (here also with a monkey), or often paired with other symbolic subjugates like dogs and particularly, female children. A major example of this convention is Velásquez's canonical *Las Meniñas* (1656), a portrait of the Spanish royal family, which ironically foregrounds the traditionally disempowered: the princess or *infanta* Margarita, her attendant female servants, two court dwarfs, and the loyal pet dog, lying down to accentuate his submission. In these examples, across history and context, little people were expected to serve or amuse others. They played roles as fools, soothsayers, and sages, and they performed as tricksters for notoriety and sustenance.

Velásquez's painting of a dwarf kept at the Spanish court, *The Dwarf Sebastian de Morra* (c. 1645), frames and aggrandizes in an up-close perspective, the full body of its subject in historical costume, here seated with his hands curled under suggesting that he may have physical impairments. His ambivalent returned gaze seems reluctant, almost vacant, or stereotypically idiotic. Mannix (1999) states that historically, by being or *behaving* idiotic, court dwarfs were able to speak freely, criticize, and mock authority, such that performative gestures, which manipulated their subordinate and comic reputations, gained little people the statuses of royal sidekicks and prodigies. Velásquez's painting suggests the privileged status of de Morra at court, for it is a conventional, individual portrait, perhaps commissioned, rather than a composition that presents a dwarf as a domesticated offset to reinforce royal power. Yet, the portrait showcases and strongly lights the body, accentuating

its "abnormality." Hevey's portrait, *Nabil Sharon as Richard the Third* (c. 2000) of a little person dressed as a court dwarf for a contemporary drama production shows the legacy of these roles in the contemporary arts.

Bakhtin (1968) writes about the "miniature" as a metaphor for a subcultural society with its own rules, norms, values, and standards for bodies, as well as its own sanctioning of embodied pleasure. Bakhtin focuses on the folk humor, comic traditions, and parody of Middle Ages and Renaissance carnivals, in which dwarfs and giants were caricatures and exaggerations. Such "carnivalesque" societies, according to Bakhtin, are outside of traditional systems of dogma and therefore, operate by their own unique rules and structures. Bakhtin's metaphorical carnival engaged alternative languages to conventional narrative and representation, and the miniature body, for his is microcosmic of its utopian, anticonventional setting. Bakhtin writes that in the 16th and 17th centuries, the art historical Renaissance and Baroque times, that the corporeal spectacle featuring little people was vital.

Awaiting the Magic Kingdom (1999; 2000)

In the 18th century, this miniature figure was connected to Commedia del-arte, which featured the performances of miniature and gigantic bodies. The 19th century miniature body became burlesque, blasphemous, monstrous, or tragic, and stood in opposition to rationalism. In art, the miniature was featured in Romanticism, whereas in the increasingly scientific world, it became the subject of teratology, the science of monsters. In the 20th and 21st centuries, this miniature body is known to us from fairy tales, like "Snow White and the Seven Dwarfs," in which male dwarfs are asexually innocent and childlike, or in the case of "Rumpelstiltskin," childishly mischievous, and in some versions of the story, hypersexual and immature, like horny adolescents. Examples of such laughing and laughed at miniature characters also appear in literature.[1]

Minnie Mouse Costume (1999; 2000)

Gil's photograph, *Awaiting the Magic Kingdom* (1999; 2000), shows him and his family in this mythical entertainment setting. Here, they wait in line to experience all of the activity and adventure the "Magic Kingdom" has to offer any family. On this quite "normal" family vacation, however, Gil's family faces a twist on their own histories. One can imagine them meeting other little people performing as fictional characters at the park. In *Minnie Mouse Costume* (1999; 2000), Gil captures in a photograph, his

daughter sporting a typical children's costume, yet she bears an atypical relationship to it. Minnie Mouse is a fictional parody of little people and an example of dwarfs' fictionalization in real life and in contemporary society.

In the 20th century, the American freak show employed many little people to perform. In one example, Lucia Zarate (1880), "the smallest woman," is featured center stage and centrally framed in a photograph from the Burns' (1998) archive of clinical photography. This image crosses the genres of medicine and popular entertainment, as was characteristic of the medical/fantastical presentations of the freak show. Freak show little people were often staged alongside amiable giants to exaggerate their caricatured smallness. To enhance the miniature body, little people were alternatively assigned larger than life personas and names, in what Bogdan (1998) has termed an aggrandized mode of presentation, in a pairing of opposites. This method exploited historical and iconographic connections between little people and ironic parody.

1.The most famous "freak" displays were Barnum's "General Tom Thumb,"[2] and his wife, Lavinia Warren, who was referred to as "the most photographed woman in the world" (Jay, 2001, p. 1002). Other little people made celebrities by the freak show include Admiral Dot, who was a midget; Leopold Kahn, who, like other midgets, was 25 inches tall, but had the proportions of an average size person; the "Russian Midgets," who were dwarfs with shortened legs and arms; Mercy Lavinia Warren Bump (1841-1919); and George Washington Morrison Nutt (Commodore Nutt), who commonly wore a naval uniform. Midgets were most often made "majors" while dwarfs were "generals" in title, reflecting their statuses. Little people were also most often staged in colonies. The most famous was Liliputia, modeled on the fictional land in Swift's 1796 satirical novel *Gulliver's Travels*[3], at the Dreamland theme park at Coney Island, and others included "dinkyville," midget farms, and midget cities (Mannix, 1999). In these communities, performances consisted of impersonations, songs, dances, and skits. These little people as "freaks" embodied long traditions of mythological, literary, and historical little bodies on display for the entertainment of "normal" viewers (Bogdan, 1988; Mitchell, 2002).

In freak show venues, little people with impairments or misproportioned bodies often played the roles of clowns or non-Westerners. In one example, the "Black Dwarf," was featured outdoors as an exotic primitive (Mitchell, 2002). Exhibits such as this, influenced by anthropology and pseudosciences of the time such as, phrenology and physiognomy, staged many little people as animals. Audiences viewed dwarfs as a "lost race" or an animal, mythical, and exotic. Animalistic epithets included toads, apes, baboon, dogs, pygmies, and missing links. Exhibited little people in these settings were said to be "stunted" or arrested in evolutionary development, as physiognomically indicated by their "stunting" in corporeal size. Here, the individual body was a metaphor for social body or race and as a quintessential social outcast to "normal" (i.e., Western civilization) (Donley & Buckley, 1996).

Bathing Suit Portrait (1999; 2000)

Party (1999; 2000)

Bathing Suit Portrait (1999; 2000) is uncharacteristic for Gil's suite of images. This self-portrait features the photographer in a pseudo-objective, clinical format, wearing only a cloth that covers his private parts and standing stiffly. He is displayed like a freak subject or animal specimen. The expression on Gil's face is one of discomfort, as he returns the medical or scientific gaze at his body. The viewer can imagine him as the object of study or measurement by anthropologists or other scientists. This photograph reminds the viewer that the objectification of little people outlives the practices of 19th century "experts," or the freak show enterprise. The medical gaze at physical difference from the norm is operating in covert, deceptive venues.

Little people of the freak show starred in their portrait carte di visites, hand-sized souvenir images patented in Paris by photographer André Adolphe Eugène. Examples of commercial and art photography have played a major role in the exhibition of little people, a history which informs Gil's frames. German photographer, Sander, sought to catalog German people, and within a pseudo-objective suite of types he features a dwarf among circus people and a "Cretin" (Sontag, 1977). Photographed little people, as many in more contemporary times, were put on display. Venues for display have become more mainstream. According to Adelson (2005), examples of roles for little people to entertain an audience include "being tossed" in a bar, playing stereotypically negative roles in mainstream films, leaping about in bizarre costumes at half time in football games, acting as mascots, providing "atmosphere" in music videos, participating in reality TV, and appearing in pornographic films or at bachelor parties. She also cites circus clowns, midget wrestlers, strippers, and stars of reality TV, as roles which stage little people under the following appellations: hunchback, cretin, goblin, pygmy, jester, fool, clown, gnome, dwarf, midget, freak, monster, grotesque, cripple, buffoon, and idiot. Fine art photography likewise, features dwarf bodies, as in the example of Arbus' portrait of a sideshow performer "Cha Cha," (*Mexican Dwarf (a.k.a Cha Cha*) in His Hotel Room) (1970), on a hotel bed wearing only a towel. Adelson points out that such sexualizing of little people is common in the frames of performance venues as well as fine art. These representations, albeit absurd, nonetheless inform images of little people in everyday life, especially when viewers have never known a little person personally.

Hevey (1992) articulates that images such as these carry on traditions of the freak show. They are *of* the physically different from "normal" *by* the so-called "normal," *for* non-disabled or "normal" audiences. Hevey underscores photography's connections to theater and drama as a venue for performance. Barthes (1981) also calls photography theatrical and oversignified because it crosses categories and contexts. For Barthes, photography in essence is theatrical, such that all photographic subjects perform before the camera. In distinction to other forms of representation, Barthes writes that photographs can never be severed completely from their referent, such that the photographed body contains that body. Photographs provide the viewer unique access to the body displayed by them. Like Barthes, Sontag (1977) views photography similarly, as it transforms history into spectacle.

Public Restroom (1999; 2000)

For Sontag, photography neutralizes distress, miniaturizes experience in order to control it, and conveys simultaneous absence and presence, as photographs both reveal *and* conceal.

Tagg (1988) also writes about the theatricality and performative nature of photographs because they are inevitably deceptive, distorted images of reality, and therefore, illusionary. Bearing historical and symbolic links to the freak show, Tagg points to all the myriad contexts of photographs, including medicine, physiognomy, surveillance, spectacle, documentary, journalism, popular culture, advertising, and evidence, as photographs maintain links to identity and identification (e.g., mug shots, IDs), and are productions of truth and reality. Furthermore, Tagg states, photographs produce and mediate reality, while they change in meaning over time. Photographs, in these ways according to many photography scholars, bear intricate associations with freak shows.

While Gil's images display the miniature body, they do the opposite of these historical venues for display. Rather than constructing the dwarf body as scientific, curious, or freakish, Gil's photographs accentuate the mundane and nonetheless, sentimental aspects of everyday life. His images lobby for civil rights by stressing the qualities and experiences that his family shares with so many others. Such displays of group identity were symbolized, according to Adelson (2005), in the 1957 formation of the group the Midgets of America, later known as the Little People of America, organized by dwarf actor and rights advocate Billy Barty and the owner of a hotel in Reno, which was billed as the "smallest little city in the world." The Short Statured People of Australia was then organized in 1962 by another actor, George Whitaker. These organizations represent the demand for equal representation and rights.

Gil's photographs of his daily life are assertions of everyday reality to offset the mythologies surrounding the dwarf body and lifestyle. Mythical dwarfs may be found in garden statuaries as fairy tale gnomes and ornamental creatures, while Gil's dwarfs occupy the domestic gardens of middle class America. Mendacity, is here seen, as the ideal of comfort and the pleasant safety of routine. Gil presents the embodied perspective of a little person facing the enormity of the average. *Party* (1999; 2000) features Gil socializing. He looks awkward and uncomfortable with a plate of food in his hands and his back to a mirror, which reflects the average-sized guests who surround, but seemingly ignore him. One is not sure why the subject looks so out of place. it is not obvious from his size, but rather, his social anxiety may be due to unknown strangers or an awkward get-together. This kind of feeling could happen to anybody.

In *Public Restroom* (1999; 2000), we see the upper portion of Gil's face reflected in a bathroom mirror, the only part of himself that is visible at his height. These kinds of encounters with an oversized world are just as much a part of Gil's daily life as the celebrations and loving embraces featured in other works. The discomfort Gil faces in a public restroom is likely irritating, but not life-altering. It is the daily inconveniences that compose, but do not overwhelm Gil's frames, as the viewer of the photograph sees Gil's world as multidimensional and multifaceted.

Ann Millett, Ph.D., is an art historian who teaches courses on art and the humanities for the University of North Carolina at Greensboro. Her research bridges art history with disability studies, as she analyzes the work of disabled artists and the representation of disabled bodies in visual culture.

References

Adelson, B. M. (2005). Dwarfs: The changing lives of archetypal 'curiosities' - Echoes of the past. *Disability Studies Quarterly, 25*(3).

Bakhtin, M. M. (1968). *Rabelais and his world*. Cambridge, MA: M.I.T. Press.

Barthes, R. (1981). *Camera lucida: Reflections on photography*. New York, NY: Hill & Wang.

Bird, S. (1999). *A unique way to document family history*. Retrieved February 2007, from http://www.ricardogil.com/

Bogdan, R. (1988). *Freak show: Presenting human oddities for amusement and profit*. Chicago, IL: University of Chicago Press.

Burns, S. B. (1998). *A morning's work: Medical photographs from the Burns Archive & Collection, 1843-1939* (1st ed.). Santa Fe, NM: Twin Palms.

Daston, L., & Park, K. (1998). *Wonders and the order of nature, 1150-1750*. New York, NY: Zone Books & Cambridge, MA: MIT Press.

Donley, C., & Buckley, S. (Eds.) (1996). *The tyranny of normal: An anthology*. Kent, OH: Kent State University Press.

Garland-Thompson, R. (1997). *Extraordinary bodies: Figuring physical disability in American culture and literature.* New York, NY: Columbia University Press.

Garland-Thompson, R. (2001). Seeing the disabled: Visual rhetorics of disability in popular photography. In P. K. Longmore & L. Umansky (Eds.), *The new disability history: American perspectives* (pp. 335-374). New York, NY & London, England: New York University Press.

Gil, R. (1999-2003). *Ricardo Gil photography*. Retrieved February, 2007, from http://www.ricardogil.com

Hevey, D. (1992) *The creatures that time forgot*. London, England & New York, NY: Routledge.

Howells, R., & Chemers, M. M. (2005). Midget cities: Utopia, utopianism, and the vor-schein of the 'freak' show. *Disability Studies Quarterly, 25*(3).

Jay, R. (2001). *Jay's journal of anomalies: Conjurers, cheats, hustlers, hoaxsters, pranksters, jokesters, imposters, pretenders, sideshow showmen, armless calligraphers, mechanical marvels, popular entertainments* (1st ed.). New York, NY: Farrar, Straus, & Giroux.

Mannix, D. P. (1999, c.1969). *Freaks: We who are not as others*. New York, NY: RE/Search Publications.

Miller, A. (April, 1999). Ricardo L. Gil, Seiko Tachibana, David Wolf at the Berkeley Art Center. *Artweek*. Retrieved February, 2007, from http://www.artweek.com/

Mitchell, M. (2002). *Monsters: Human freaks in America's Gilded Age. The photographs of Chas. Eisenmann*. Toronto, Canada: ECW Press.

Sontag, S. (1977). *On photography*. New York, NY: Farrar, Straus, & Giroux.

Tagg, J. (1988). *The burden of representation: Essays on photographies and histories*. Basingstoke, England: Macmillan Education.

Endnotes

[1] Examples include Pär Lagerkvist's The Dwarf, Edgar Allen Poe's "Hop-Frog," and Ray Bradbury's "The Dwarf." Excerpts are included in (Donley & Buckley, 1996).

[2] As he was constructed through his public performances, marketing materials, and souvenir photographic portraits, but born Charles. S. Stratton.

[3] Howells & Chemers (2005) state, "Liliputia contained a circus, a firehouse with a half-sized fire engine pulled by miniature horses, a live band, a military garrison, areas for "surf bathing," and saddle pony riding and miniature automobile rides for children. But the central attractions were the residents of this performance community."

***Editor's Note: Permission to reprint the photographs given by Ricardo Gil, 2008. Gil's photographs can also be viewed at www.ricardogil.com.

Book Review

Title: *Quick Guides to Inclusion: Ideas for Educating Students with Disabilities*

Authors: Michael Giangreco & Mary Beth Doyle (Eds.)

Publisher: Baltimore: Paul H. Brookes, 2007

Paper, ISBN: 978-1-55766-897-4, 352 pages

Cost: $39.95 USD

Reviewer: Megan A. Conway

I opened Quick Guides to Inclusion fully expecting not to like it. I had just been in a conversation with a colleague about the lack of representation of disability history, culture, and perspectives in teacher education and was ready to be critical. However, as I thumbed through the pages of Quick Guides and saw sections devoted to stereotypes, authentic engagement, universal design, cultural diversity, and "what students want teachers to know," I realized there may still be hope. While the book does not take the huge step of discussing disability studies and culture (darn!), it does put forth very current concepts related to students with disabilities in the classroom. The book is an excellent resource for both practicing teachers and pre-service teachers.

Quick Guides has an easy-to-follow format. Sections such as "Foundational Ideas," "Curriculum and Instruction," and "Relationships and Self-Determination" are comprised of one-page "quick guides" that speak to specific strategies or topics. Other sections are devoted to communication, literacy and numeracy, transition, and personnel and administration. The language of the quick guides is easy to understand, but there are also additional references at the end of each section for the more academically-minded. The book has a nice, easy-to-read font, which I appreciate, being nearly blind, but which also lends itself to being user-friendly.

Some of the sections I liked best: One of the first topics in the book urges teachers to "be the teacher for all of your students" (p. 8), and discusses how teachers need to avoid being just "hosts" and start being teachers to students with disabilities (because teachers feel that paraprofessionals and special education teachers are the "real" teachers for these students). Another section talks about how disability-based stereotypes are (wrongly) considered to be acceptable, where race-based and gender-based stereotypes are not. Many of the quick guides talk about how stigmatizing it can be for students to have paraprofessionals trailing along behind them. An entire section is devoted to "Listen to Me, What Students Want Teachers to Know" (p. 75), which is an interesting and important section, although the authors (Mary Schuh, Frank Sgambati and Carol Tashie) seem to focus more on the "thoughts" of students with intellectual and emotional difficulties than on students with other types of disabilities.

Other sections give teachers practical suggestions for maximizing the participation of students with disabilities in their classrooms, such as through the use of Universal Design for Learning, assistive technology, and just plain, good teaching strategies. The emphasis is on treating a student's disability as a diverse learning need rather than as a "big problem," which is a step in the right direction as far as I am concerned.

I was still looking for something I did not find in Quick Guides to Inclusion, a discussion of disability studies, history, and culture. One section did talk about integrating famous people with disabilities into the curriculum, but that was the end of being radical. Perhaps the next edition will speak to recognizing the importance of the disability experience as an essential component of working successfully with students with disabilities in the classroom.

Megan A. Conway, Ph.D., is the managing editor of RDS. She may be reached at mconway@hawaii.edu

Book Review

Title: *My Body of Knowledge: Stories of Disability, Healing, and Life.*

Authors: Karen Myers and Felicia Ferlin (Eds.)

Publisher: Ostego, MI: PageFree, 2006.

Paper, ISBN – 1-58961-509-3, 220 pages

Cost: $14.95 USD

Reviewer: Steven E. Brown

My Body of Knowledge contains 34 entries from established authors and unknowns. Many disabilities are represented in five chapters or sections, divided into: "Affliction, Onset, and Crisis;" "Isolation, Preoccupation, and Recovery;" "Reflection, Interpretation, and Spirituality;" "Interaction, Negotiation, and Relationships;" and "Integration, Distraction, and Recreation."

Each section begins with a short description of its contents by the editors followed by a poem. Sections address disabilities as diverse as Crohn's Disease and migraines, and activities as common to those with disabilities as anyone else (e.g., sex.). The final piece, written by editor Myers, narrates a daunting experience made palatable by an awaiting meal. This is fitting since editor Ferlin literally begins the book with the cover illustration of a disembodied skeleton.

Like all anthologies, a story that appeals to one reader may not be as appreciated by another. Unlike most collections about the disability experience, this one includes authors of color and diverse sexual orientations, which makes the book unusual.

One of my favorite essays describes a trip to Martinique in the Caribbean, after the author learns that he is HIV+. His encounter with a white sea snake, which he learns the next day is one of the world's most venomous, and contemplation of his condition, leads him to the conclusion "Wherever I go, I am my own home" (p. 121).

One of the funniest writers around, Sharon Wachsler, describes an encounter with a local health clinic. After an enervating day she concludes, "I'm ready to celebrate by going to bed for several days" (p. 72). Anyone whose disability includes pain and fatigue will identify with that comment.

The strength of this set of essays is that readers will find themselves both identifying with some writers and learning about experiences outside of their own from others. I highly recommend it.

References

Wachsler, S. *Pap goes the wheezer*. pp. 68-72.

Williams, A. *Pas de deux with Mr. D*. pp. 112-121.

Steven E. Brown, Ph.D., is the Media Reviews Editor for *RDS* and an Associate Professor at the Center on Disability Studies at the University of Hawai'i. He may be contacted at: sebrown@hawaii.edu

Book Review

Title: *The Facts of Life. . And More: Sexuality and Intimacy for People with Intellectual Disabilities*

Author: Leslie Walker-Hirsch

Publisher: Baltimore: Paul H. Brookes Publishing, 2007

Paper, ISBN: 978-155766714-4, 320 pages

Cost: $29.95 USD Available from http://www.brookespublishing.com or www.amazon.com

Reviewer: Rhonda S. Black

Leslie Walker-Hirsch is a pioneer in the field of sexuality for individuals with intellectual disabilities. She is the creator of the widely-used Circles® healthy sexuality curriculum for individuals with mild to moderate developmental

disabilities (1993, Circles I: Intimacy and Relationships [revised]; 1986, Circles II: Stop Abuse; 1988, Circles III: Safer Ways; James Stanfield Publishing, http://www.stanfield.com) that utilizes a Circle of Friends approach to describe appropriate and inappropriate contact with different people at different levels of friendship/intimacy. Walker-Hirsch has been actively involved in providing sexuality training classes for young adults and adults with disabilities, parents, administrators and direct service providers for more than 25 years. With 15 contributors, Walker-Hirsch has presented a wide range of topics from various perspectives, creating one of the most comprehensive works on sexuality and individuals with intellectual disabilities to date.

The first chapter discusses sexuality education and intellectual disability across the lifespan. It describes sexuality as part of social development and outlines changes in appropriate socialization that occur when transitioning from childhood to adolescence to adulthood. Especially important is the discussion about behaviors such as tickling, appropriate for children, but not young adults – dispelling the myth that those with intellectual disabilities are eternal children. This chapter also highlights the need for sexuality education to decrease social isolation and dependence. Again, the focus is on appropriate social relationships, including intimate adult relationships. Accompanying each topic are case study-like scenarios that bring the issue to life. For example, one case tells of how a young man with Down syndrome touched the breasts of a girl because he was dared to by some popular boys at school. Another case describes how a 12 year-old girl with mild intellectual disability gave her mother a passionate French kiss one evening after her friend had told her that a peck on the cheek was not "real" kissing. The scenario also described how her mother explained different kinds of kisses for different people and purposes. Nine of these scenarios are presented in the first chapter alone.

The second chapter presents key components of a comprehensive sexuality education program based largely on Walker-Hirsh's Circles® curriculum. In addition to basic anatomy and hygiene, this curriculum focuses on empowerment, social and relationships skills, and rights and opportunities. The third chapter covers stages of development and basic instructional techniques addressing attention, memory, incidental learning, and learning transfer. This chapter concludes with a section on positive behavioral supports.

The next four chapters are in my opinion, unique, and set this book apart from similar texts on the market today. These chapters discuss parent perspectives; skills needed by direct support workers; addressing cultural differences between staff/teachers and program participants; supporting gay, lesbian, and bisexual relationships; and includes a wonderful chapter titled "In Their Own Words: Couples Tell Their Stories." The Parent Perspectives chapter, coauthored by Emily Kingsley, a nationally-known pioneer in parent advocacy, discusses awkward situations for parents, such as providing transportation for dates and arranging social encounters, and issues surrounding whether their adult offspring will become parents themselves. The Cultural Diversity chapter discusses how various aspects of culture affect sexuality of persons with disabilities. Courtship and marriage practices, expectations of acceptable behavior for men and women, communication styles, and expectations concerning adults roles are topics included in this chapter. I especially liked the section about avoiding cultural stereotypes. While understanding individuals and their families may have different values from one's own, this chapter emphasizes the nonproductive and nonresponsive nature of making assumptions such as "the Chinese believe XYZ about sexuality." The final chapter in this section is titled "Supporting Diversity in Sexual Relationships: On Being Gay, Lesbian, Bisexual, or Transgender with an Intellectual Disability." This is the first text I have seen to explicitly and purposefully include information on this topic. Diversity in rela-

tionships is an especially sensitive topic for residential care providers and one that needs to be openly discussed. This chapter provides some valuable suggestions and resources for service providers to address sexual orientation and gender identity variations as "part of the human experience that deserve to be celebrated" (p. 169).

The next section contains two chapters related to risk management. This text fills a gap in the literature regarding this topic. Scholars such as Richard Sobsey (1991, *Disability, sexuality, and abuse: An annotated bibliography;* 1994, *Violence and abuse in the lives of people with disabilities: The end of silent acceptance?*) have warned us about the vulnerabilities of adults with disabilities with respect to sexual exploitation. In a more personal storytelling manner, Dave Hingsberger (1990, *I to I: Self concept and people with developmental disabilities*; 1995, *Just say know!: Understanding and reducing the risk of sexual victimization*) has taught about the social nature of sexuality and the risks of over-protection to people with intellectual disabilities. This text combines warnings with easy-to-read scenarios to inform the reader about the risks of both exploitation and over-protection. Topics, such as consent assessment and the components of a comprehensive sexual abuse prevention program, are extremely good resources for any service professional. Much of the information again comes from Walker-Hirsch's Circles Curriculum® related to building a community of support and teaching the differences between friends, acquaintances, and strangers. The final section focuses on treatment issues such as seeing an obstetrician/gynecologist for a pelvic exam, helping individuals recover from sexual abuse and sexuality, and mental health.

Overall, the text is well-written by noted authors in an accessible format complete with research findings, practical applications and case-study scenarios. The text covers a broad range of topics thus, filling gaps of previous books in this area. I would highly recommend this book for professionals working with young adults and adults with intellectual disabilities. On a more personal note, I have ordered a copy for myself as a must-have for my library.

Rhonda S. Black, Ph.D., is Professor of Special Education at the University of Hawaii at Manoa. She teaches courses in transition, social competence, research design, and methods for general education teachers. She can be reached at rblack@hawaii.edu.

Book Review

Title: *Instructional Materials for Teaching Sociology & Disability Studies*

Authors: Lynn Schlesinger & Diane E. Taub (Eds.)

Publisher: American Sociological Association (ASA), 2004, 340 pages

Cost: $18.00 USD (ASA member) or $22.00 USD (non-member). Orders by phone can be made by calling call (202) 383-9005 x389 or at: http://www.e-noah.net/asa/asashoponlineservice/ProductDetails.aspx?productID=ASAOE367D04

Reviewer: Heng-hao Chang

This second edition of *Instructional Materials for Teaching Sociology & Disability Studies* is a collection of syllabi and articles related to teaching disability studies and sociology. As an interdisciplinary field, disability studies can trace some of its theoretical roots to sociology, drawing on works such as Parsons' classic work on the "sick role," in *The Social System* (1951) and *Goffman's Asylums* (1961) and *Stigma* (1968). On the other hand, disability has been an issue of sociological inquiry in subfields such as medical sociology, deviance, social problems, social welfare and social policy, as well as recent studies of new social movements, identity politics, and the sociology of body. Nevertheless, a sociological course focusing solely on disability issues is fairly new. Sponsored by the American

Sociological Association (ASA) committee on the status of persons with disabilities, this edited volume intends to promote disability issues in existing courses as well as the development of new courses on disabilities.

Considering the interdisciplinary and diverse nature of the field, Schlesinger and Taub collected materials from several resources including Footnotes, the newsletter of ASA; the Society for Disability Studies email listserv, and personal contacts. Courses taught by sociologists, listed in sociology department catalogs and disability studies courses with a sociological focus were included.

The volume is divided into eight sections. Section I explains the rationale of editing this volume and its structure. Section II contains several articles which advocate the significance of disability studies. Section III covers syllabi from disability studies courses, other interdisciplinary courses, and courses taught outside the United States. Section IV reproduces syllabi for courses that focus on disability from a sociological perspective. Section V includes syllabi for courses that combine disability studies with other fields such as health, gender, and social policy. Section VI selects articles and syllabi for courses in sociology, such as social problems and politics and sociology of deviance that address disability issues. Section VII presents a variety of assignments such as library research, film, and video projects. Section VIII provides relevant references for teaching disability.

Schlesinger and Taub successfully organize course syllabi to present different ways of incorporating disability studies and sociology. Although *Instructional Materials for Teaching Sociology & Disability Studies* is mainly written for instructors who are interested in disability studies and sociology, anyone who is interested in teaching disability studies or related issues at the collegiate level and above will find this edited volume helpful. The section on exercises and assignments in particular will help instructors plan different class activities and make their collegiate level class more interesting. Students in disability studies will also find rich resources in this volume. In addition, readers can grasp a sense of the history of the development of disability studies and sociology.

To create a new topic in an established academic discipline is not easy. Since the American Sociological Association formally accepted the section application of Disability and Society in 2007, this volume will become a useful tool for every sociology department to develop courses on disabilities and to include disability issues into existing courses.

References

Goffman, E. (1961). *Asylums: Essays on the social situation of mental patients and other inmates*. Chicago: Aldine.

Goffman, E. (1968). *Stigma: Notes on the management of spoiled identity.* Englewood Cliff, NJ: Prentice-Hall.

Parsons, T. (1951). *The social system*. New York: Free Press.

Heng-hao Chang, Ph.D., is Assistant Professor at Department of Sociology, Nanhua University, specializing in Sociology of Disability, Social Movement, Political Sociology and Medical Sociology. He may be contacted at:

No.32, Chung Keng Li, Dalin Chia-Yi, 622, Taiwan
TEL: 886-2-5-2721001 EXT 5309
FAX: 886-2-5-2427150
EMAIL: henghao@mail.nhu.edu.tw, henghaoc@gmail.com

Disability Studies Dissertation Abstracts

*** Editor's Note: This is a new section of RDS courtesy of Jonathan Erlen of the University of Pittsburgh. Abstracts listed below are selected from a full list of disability-related dissertation abstracts updated quarterly. The full list is available at: http://www.hsls.pitt.edu/guides/histmed/researchresources/dissertations/index_html.

A case study of the involvement of undergraduates with physical disabilities in campus organizations at East Tennessee State University.
Alexis, Lance Travis. Proquest Dissertations And Theses 2008. Section 0069, Part 0514 87 pages; [Ed.D. dissertation].United States -- Tennessee: East Tennessee State University; 2008. Publication Number: AAT 3308016.

A critical discourse analysis of the early phase of the total communication movement in deaf education (1969--1971).
Adams, Megan Lynn. Proquest Dissertations And Theses 2008. Section 0088, Part 0282 105 pages; [Ph.D. dissertation].United States -- District of Columbia: Howard University; 2008. Publication Number: AAT 3304480.

A qualitative study of experiences of Aboriginal caregivers of children with developmental disabilities.
Clouston, Joyce Ellen. Proquest Dissertations And Theses 2008. Section 1101, Part 0452 351 pages; [Ph.D. dissertation].Canada: Wilfrid Laurier University (Canada); 2008. Publication Number: AAT NR38001.

A step beyond inclusion: A case study of what one principal did to improve achievement for students with disabilities.
Royce, Maryellen. Proquest Dissertations And Theses 2008. Section 0656, Part 0514 204 pages; [Ed.D. dissertation].United States -- New York: State University of New York at Buffalo; 2008. Publication Number: AAT 3307595.

Audience response & disability representation in four film and television dramas: A qualitative audience study.
Arenas Velez, Fernando. Proquest Dissertations And Theses 2008. Section 0099, Part 0708 258 pages; [Ph.D. dissertation].United States -- Kansas: University of Kansas; 2008. Publication Number: AAT 3307181.

Challenges & struggles: Lived experiences of individuals with mental illness, substance abuse, and general medical conditions.
Villena, Anna Liza D.. Proquest Dissertations And Theses 2007. Section 0034, Part 0569 213 pages; [Ph.D. dissertation].United States -- California: University of California, San Francisco; 2007. Publication Number: AAT 3297810.

Jean Vanier and the transformational model of rehabilitation: Principles of care for concerned professionals.
Forster, Donna Marie. Proquest Dissertations And Theses 2008. Section 0283, Part 0382 161 pages; [Ph.D. dissertation]. Canada: Queen's University (Canada); 2008. Publication Number: AAT NR37072.

Korean grandparental involvement and support and the influence of these factors on families of children with severe disabilities.
Lee, Misuk. Proquest Dissertations And Theses 2008. Section 0169, Part 0529 417 pages; [Ph.D. dissertation].United States -- Oklahoma: The University of Oklahoma; 2008. Publication Number: AAT 3304226.

Narrative interviews with family members of a traumatic brain injury survivor: A qualitative inquiry.
Andreatta, Nicole. Proquest Dissertations And Theses 2008. Section 1389, Part 0622 85 pages; [Psy.D. dissertation].United States -- California: Alliant International University, San Diego; 2008. Publication Number: AAT 3305355.

Reading autistic experience.
Trice, Natalie Collins. Proquest Dissertations And Theses 2008. Section 0079, Part 0298 197 pages; [Ph.D. dissertation].United States -- Georgia: Georgia State University; 2008. Publication Number: AAT 3308464.

Social competence and collaborative guided inquiry science activities: Experiences of students with learning disabilities.
Taylor, Jennifer Anne. Proquest Dissertations And Theses 2008. Section 0283, Part 0529 222 pages; [Ph.D. dissertation]. Canada: Queen's University (Canada); 2008. Publication Number: AAT NR37109.

Student teachers' explicit and implicit perceptions of attention deficit hyperactivity disorder.
Berglof, Hollie K.. Proquest Dissertations And Theses 2007. Section 0241, Part 0530 90 pages; [Ph.D. dissertation].United States -- Utah: Utah State University; 2007. Publication Number: AAT 3306422.

The 2002 No Child Left Behind Act (NCLB), the amended 2004 Individuals with Disabilities Educational Act (IDEA), and promoting the American democratic ideals of equity and access: A critical enquiry based on the work of Michel Foucault and Jean-Francois Lyotard.
Bethel, Bambi. Proquest Dissertations And Theses 2008. Section 0481, Part 0514 168 pages; [Ed.D. dissertation].United States -- Missouri: University of Missouri - Saint Louis; 2008. Publication Number: AAT 3308002.

Tracing the tensions, constructions, and social relations surrounding community integration practice for individuals with severe mental illness: A focus on assertive community treatment.
Horgan, Salinda Anne. Proquest Dissertations And Theses 2007. Section 0283, Part 0347 202 pages; [Ph.D. dissertation]. Canada: Queen's University (Canada); 2007. Publication Number: AAT NR37212.

Who was eligible? The public education of children and youth with disabilities in regular classrooms in China from 1986 to 2006.
Cui, Fengming. Proquest Dissertations And Theses 2008. Section 0017, Part 0524 148 pages; [Ed.D. dissertation].United States -- Massachusetts: Boston University; 2008. Publication Number: AAT 3308130.

RDS Information

Information for Advertisers

The Review of Disability Studies, published by the Center on Disability Studies at the University of Hawai'i at Manoa, invites advertisements from (a) publishers of books, films, videos, and music, (b) employers with position announcements, and (c) producers and distributors of products and services. For questions or to advertise with RDS, please email rdsj@hawaii.edu or call 808-956-5688.

Why Advertise With RDS?

The Review of Disability Studies is the ideal vehicle for reaching an international audience in the field of disability studies. We have and are pursuing affiliations with other major organizations in the field.

Subscribers are academics, advocates, and libraries. It is a highly receptive audience for appropriately targeted advertising. Research shows that specialty journals such as the Review of Disability Studies are cited by professionals as the most useful source of information for the purchase of products and services, more so than conferences, direct mail, and direct sales.

Copy Requirements and Cost

Advertisements must be submitted in an electronic format - preferably a PDF file with fonts embedded or as a Microsoft Word file - in an email attachment sent to rdsj@hawaii.edu.

Dimensions for a half page are 7 x 4 inches at a cost of $300. Dimensions for a full page are 7 x 8 inches at a cost of $500.

Discounts:

10% discount for 3, 4 or 5 insertions

20% discount for 6 or more insertions

10% publishers discount

10% discount for first time advertisers

Please note: Only one type of discount will be applied to each booking. Combinations of discounts are not accepted.

Frequency and Length

RDS is published four times a year and runs approximately 50 pages.

Terms and Conditions

1. All advertisements submitted are subject to editorial approval. We reserve the right to refuse or to remove advertisements at our discretion.
2. A confirmation of your order will be supplied upon acceptance.
3. We cannot make any guarantees as to publication dates. While we will make every effort to ensure that your advertisement will be published, the Review of Disability Studies may run ahead or behind schedule.
4. All advertisements are accepted on a space available basis. On rare occasions it may not be possible to accommodate a particular advertisement. Should this be the case, a refund or substitute issue will be offered.
5. No liability is accepted by the Center on Disability Studies or the University of Hawai'i for the content of any advertisements or quality of any products, materials, or services advertised.
6. The Center on Disability Studies and the University of Hawai'i do not accept any liability for loss or damage arising from the use of any products or materials purchased as a result of advertisement publication.

7. Invoices for all advertisements must be settled within 30 days of receipt from the date as postmarked.

8. All advertisement prices are subject to sales tax, general equity tax, value added tax, or any similar tax if chargeable and at the current rate.

9. Prices are correct at the time of publication. The Center on Disability Studies, at the University of Hawai'i at Manoa, reserves the right to increase advertisement rates at any time.

About the Center On Disability Studies

The mission of the Center on Disability Studies (CDS), at the University of Hawai'i at Manoa, is to support the quality of life, community integration, and self- determination of all persons accomplished through training, service, research, demonstration, evaluation, and dissemination activities in Hawai'i, the Pacific Region, and the mainland United States.

The Center on Disability Studies is the umbrella for some 25 funded projects. It originated as the Hawai'i University Affiliated Program (UAP) funded by the Administration on Developmental Disabilities of the U.S. Department of Health and Human Services. It was established in 1988 as part of a network of over 60 UAP's in the United States. It is now a University Center for Excellence in Disability Education, Research, and Service.

Although core funding for the Center is provided by the Administration on Developmental Disabilities, other federal and state funds are provided by the Maternal and Child Health Bureau of the U.S. Department of Education, various other programs in the U.S. Department of Education, the University of Hawai'i, and the State Planning Council on Developmental Disabilities.

The activities of the Center for Disability Studies extend throughout the state of Hawai'i, the mainland United States, and the Pacific region with funded projects in several initiative areas including intercultural relations and disability, mental health, special health needs, Pacific outreach, employment, and school and community inclusion.

The Center provides a structure and process to support and maintain internal professional development, collegiality, and cooperation, reflecting an organizational commitment to excellence. Center activities reflect a commitment to best practice and interdisciplinary cooperation within an academic, community, and family context. Activities are culturally sensitive and demonstrate honor and respect for individual differences in behavior, attitudes, beliefs, and interpersonal styles.

SUBSCRIPTION FORM

Subscription period is for one year (4 issues) and includes a print and electronic version.

Please enter a one-year subscription of the Review of Disability Studies for:

Name of Subscriber: _____

Address: _____

_____

_____

Email: _____

Phone: _____

Please Select:

__Personal $50.00 (personal check only)

__Libraries and Institutions $100.00 (check or purchase order)

__Student $25.00 (please provide a photocopy of a photo ID or other proof of status)

__Additional $15.00 for first class mail outside the U.S. and Canada

__This subscription is being sponsored by _____

Address of Sponsor: _____

Email of Sponsor: _____

**Sponsors will receive one free copy of RDS and their name will be listed on our sponsor list.

Amount enclosed by check or purchase order $_____

(Please make payable to RCUH 2144)

Credit Card #_____Exp Date_____

VO#_____

Please select if you would like an alternative format to the print version:

__Braille __Large Print __Audio Cassette

Subscribe online at www.rds.hawaii.edu/subscribe/

Email form and payment information to velina@hawaii.edu or mail to:

The Review of Disability Studies

Center on Disability Studies

1776 University Avenue, UA 4-6, Honolulu HI, 96822

For questions please email rdsj@hawaii.edu or phone 808-956-5688