The Review of Disability Studies: An International Journal
Volume 4, Issue 3
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If you weren't at the Pacific Rim Conference on Disability in Honolulu this past Spring, you should have been! We had our first ever strand on Disability Studies, a new strand on Independent Living, plus a pre-conference session on International Disability Rights, all of which featured speakers from all over the globe. Attendees from colder regions appreciated our excellent weather, but most importantly there was great participation by people with disabilities and many topics that were of interest to us. We had a nice reception for RDS, with much wine, up on the 20th floor (great view) to celebrate ALMOST FIVE YEARS since David Pfeiffer, myself, Steve Brown and Bob Stodden founded RDS. Information about next year's conference will be posted soon, so keep an eye out at www.pacrim.hawaii.edu. Another web site to check out is our new RDS blog at www.rdsinternationaljournal.blogspot.com. We're still feeling our way around how to make this site active, so if you have any ideas, email me at mconway@hawaii.edu, or better yet, post a comment on the site!

You should know that we've updated our forum guidelines and submission guidelines. Go to our website www.rds.hawaii.edu to check out the latest guidelines. Also, you can now subscribe to RDS online using Pay Pal!

This issue of RDS has a wonderful diversity of articles, from an excellent review of Psychology research on women with disabilities, to a report on new medical policy in the Netherlands. We have some exciting forums coming up in future issues of RDS – look for forums on the Unruly Salon, the Pac Rim Disability Studies Strand, Human Security, Inclusive Economic Development, Interdisciplinary Dialogues, and more!

Aloha,

Megan A. Conway, RDS Managing Editor

Virtually Invisible Women: Women with Disabilities in Mainstream Psychological Theory and Research

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Abstract: A classical content analysis of PsycINFO journal abstracts from 1999 to 2003 revealed that women with disabilities are virtually invisible in mainstream psychology. We explore the implications of this invisibility.

Key Words: women with disabilities, content analysis, psychology

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

Introduction

Ask most people to name the largest minority population in the U.S., and many will respond readily "people of color" or some variation on the racial/ethnic minority theme. The true answer to the question is far more surprising. People with disabilities are the largest minority population in the U.S. , accounting for 19.3% or some 49.7 million of the civilian noninstitutionalized population five years of age and older. Additionally, disability is a fluid status, and after the age of 80, 73.6% of the U.S. population will be considered to have a disability. Though finding a "clear, concise, and consistent definition of disability remains elusive" , the Americans with Disabilities Act of 1990 identifies a person with a disability as any person having a "physical or mental impairment which substantially limits one or more of such person's major life activities," or as having "a record of" or being " regarded as having such an impairment" (S.933, section 3).

The American Psychological Association (APA), the largest professional organization for psychologists in the US and Canada, has defined multiculturalism as a perspective that "recognizes the broad scope of dimensions of race, ethnicity, language, sexual orientation, gender, age, disability, class status, education, religious/spiritual orientation, and other cultural dimensions" (APA, 2002, p. 11). For the past several decades, the APA has voiced a strong commitment to multiculturalism, supporting multicultural research and establishing several societies and divisions with a multicultural focus. Psychology's stated commitment to multicultural issues, coupled with the fact that people with disabilities comprise the largest minority population in the United States, illustrate the importance of focusing on disability issues within psychology. Further, because more than 25 million girls and women in the United States live with some form of disability, and because women are overrepresented in the population of individuals with disabilities (McNeil, 2001), women with disabilities should be a particular focus of psychological research.

Disability Issues in Psychological Theory and Research

Two paradigms have historically dominated perceptions of disability internationally: the medical model and the social/minority model. In the medical model, disability is reduced to a medical condition or deficit intrinsic to the individual (Tate & Pledger, 2003), and the focus

Table 1: Prevalence of Disability and Severe Disability by Age, Sex, Race, and Hispanic Origin (McNeil, 2001, p 9-10).[4]

Characteristics		Total Population	Any Disability		Severe Disability	
			Number	Percent	Number	Percent
Male, All Races	All ages	130,985	24,331	18.6%	14,754	11.3%
	Under 24 years old	49,157	5,181	10.5%	2,509	5.1%
	25 to 64 years old	68,331	12,348	18.1%	7,825	11.5%
	65 years and over	13,498	6,801	50.4%	4,421	32.8%
Female, All Races	All ages	136,680	28,265	20.7%	18,216	13.3%
	Under 24 years old	47,347	3,441	7.3%	1,689	3.6%
	25 to 64 years old	70,768	14,145	20.0%	8,542	12.1%
	65 years and over	18,565	10,679	57.5%	7,652	41.2%
Male, White, Non Hispanic	All ages	94,664	18,266	19.3%	10,460	11.0%
	Under 24 years old	31,878	5,900	18.5%	1,591	5.0%
	25 to 64 years old	51,372	9,160	17.8%	5,430	10.6%
	65 years and over	11,414	5,550	48.6%	3,439	30.1%
Female, White, Non Hispanic	All ages	98,570	21,212	21.5%	13,167	13.4%
	Under 24 years old	30,934	2,344	7.6%	1,107	3.6%
	25 to 64 years old	51,982	10,079	19.4%	5,956	11.5%
	65 years and over	15,655	8,787	56.1%	6,105	39.0%
Male, Black	All ages	16,048	3,380	21.1%	2,511	15.6%
	Under 24 years old	7,543	859	11.4%	509	6.7%
	25 to 64 years old	7,457	1,879	25.2%	1,493	20.0%
	65 years and over	1,048	643	61.4%	509	48.6%
Female, Black	All ages	18,322	3,957	21.6%	2,871	15.7%
	Under 24 years old	7,630	614	8.0%	309	4.0%
	25 to 64 years old	9,081	2,257	24.9%	1,695	18.7%
	65 years and over	1,611	1,086	67.4%	867	53.8%
Male, Hispanic	All ages	15,372	1,937	12.6%	1,311	8.5%
	Under 24 years old	7,593	559	7.4%	312	4.1%
	25 to 64 years old	7,094	1,002	14.1%	712	10.0%
	65 years and over	686	376	54.9%	288	42.0%
Female, Hispanic	All ages	14,714	2,215	15.1%	1,594	10.8%
	Under 24 years old	6,938	388	5.6%	214	3.1%
	25 to 64 years old	6,872	1,295	18.9%	920	13.4%
	65 years and over	904	531	58.8%	460	50.9%

Table 2. Summary of mainstream psychological journal abstracts found using the words "women" and "disability", "disabled", "handicap" or "handicapped" in a PSYCHINFO database search (N = 69).

Description of Abstract	Number	Percentage
People with disabilities are mentioned, but are not the focus of the research.	22	32%
Both women and men with disabilities are the focus of the research.	24	35%
Research is focused only on women with disabilities.	23	33%

for this paradigm is on achieving a cure. The newer minority/social model considers disability to be an intersection of characteristics of individuals and their social and physical environments. This new paradigm treats the individual as a whole person and incorporates environmental and situational contexts (Tate & Pledger, 2003), transforming disability into a social issue (Pledger, 2003). Thus disability, rather than being rooted in some medical condition, is a consequence of inaccessible environments. Because of its deficit-centered focus, disability activists consider the medical model of disability an outdated paradigm for understanding disability and advocate for the new paradigm that considers disability to be an example of cultural diversity. Noteworthy is the fact that this "new" paradigm has almost a 30-year history in the United States. Introduced in the U.S. by the late 1970s , one could reasonably expect contemporary psychology to reflect the social disability model.

Intersections: Disability and Other Identities

Psychological research often conceptualizes identities as unidimensional. While it is relatively easy to find research focused on issues relevant to single identities such as ethnicity, socioeconomic status, or sexual orientation, the multidimensionality of marginalized statuses remains, for the most part, invisible. A glimpse of statistics of people living with disabilities in the U.S. quickly reveals the folly of adopting a unidimensional perspective on identity. Because Caucasian people have a higher mean age than people of other racial/ethnic groups, one might expect this population to have higher rates of disability. Recent U.S. Census Bureau statistics note, however, that Caucasian people over the age of 65 have a lower overall disability rate than people from other racial and ethnic groups. The prevalence rate of severe[1] disabilities is also disproportionately higher for African Americans in the U.S. Intersections of sex, ethnicity and disability statuses reveal that across all ethnicities, women have higher levels of disability than their male counterparts (McNeil, 2001). The prevalence of disability status by age, sex, race, and Hispanic ethnicity is included in Table1.

Disability status also intersects with educational level and socioeconomic status. Regardless of the level of disability (i.e., severe or not severe), people with disabilities generally have lower education levels than people without disabilities. Additionally, ethnic minorities with disabilities typically have lower rates of education than Caucasians with disabilities. For example, of the 7.2% of college graduates in the U.S. with physical disabilities, 90% are Caucasian and just 4% are African-Americans, illustrating an intersection of ethnicity and educational status. Lower educational levels place those with disabilities at risk for discrimination as well as higher rates of poverty, low income, and unemployment.

Similarly Shut Up and Shut Out: Women with Disabilities in Feminist Psychology

As we have argued previously, the presence of disability among women in the U.S. makes a compelling case for including disability within the multicultural spectrum of psychology in general. Given feminist psychology's specific interest in understanding "the lives of girls and women in all their diversities," and in encouraging "scholarship on the social construction of gender relations across multicultural contexts" (APA, 2004, p. 1), we would expect feminist psychology particularly to recognize disability within the multicultural spectrum. Yet, a glance at the APA Division 35's (Society for the Psychology of Women) website suggests that even feminist psychologists who are committed to recognizing other multicultural identities for women sometimes neglect women with disabilities. Thus, the aforementioned website affirms the Division's commitment to recognizing "… a diversity of women's experiences which result from a variety of factors, including ethnicity, culture, language, socioeconomic status, age, and sexual orientation" (APA, 2004, p. 1), but curiously, omits disability from this list of experiences.

Historically marginalized groups such as poor women and African Americans have been "shut up" and "shut out" of psychological inquiry (Saris & Johnston-Robledo, 2000). By crossing indicators of ethnic minority status with the keywords "adolescent/teenager," Cauce, Ryan, & Grove (1998) also found that this invisibility in the psychological literature extended to adolescents of color. Further, by conducting a content analysis of Child Development and the Journal of Research on Adolescence, they found that when adolescent ethnic minorities were represented in the psychological literature, they were more often poor or of lower socioeconomic status.

Motivated by this dearth of research on previously silenced groups, we sought to examine whether women with disabilities were similarly silenced in mainstream psychological literature. Specifically, we sought to examine the prevalence of women with disabilities in journals identified by the American Psychological Association (APA) as mainstream psychology journals. Because the APA is an institution with international influence, its identification of what constitutes "mainstream" may have some additional applicability even outside of the United States. In fact, a number of the journals identified by the APA as "mainstream," are published outside of the United States (e.g., British Journal of Health Psychology, Australian and New Zealand Journal of Family Therapy).

We performed a content analysis of psychological abstracts to investigate three research questions:

1. To what extent are women with disabilities (WWD) visible in APA-identified mainstream psychological research?
2. Do mainstream abstracts reflect the medical model or social model of disability?
3. Are the multicultural identities of WWD reflected in mainstream psychological research?

Method

Classical Content Analysis

Classical content analysis consists of three steps: (1) selection of data; (2) determination of categories, and (3) coding.

Selection

Following the methods used by Saris and Johnston-Robledo (2000), we conducted a classical content analysis using journal article abstracts listed on PsycINFO during the past five years (January 1999 to December 2003). We conducted a combined search of the words "women" and "disability" or "disabled," and because the APA has advocated for the use of the

Table 3. Summary of disabilities identified in mainstream psychology abstracts focused on women and disabilities (N= 69).

Type of Disability [a]	Number of abstracts	Percentage
Abuse-related disability	3	4.3%
Alzheimer's disease	1	1.4%
Arthritis	2	2.9%
Cancer	1	1.4%
Chronic pain, fibromyalgia	2	2.9%
Deafness	1	1.4%
Depression or depression with PTSD	3	4.3%
Developmental/intellectual disabilities	6	8.7%
Disability (specific disability not specified)	30	43.5%
Drug abuse	1	1.4%
Eating disorders	2	2.9%
HIV	1	1.4%
Limb reconstruction	1	1.4%
Multiple sclerosis	1	1.4%
Musculoskeletal disorder/musculoskeletal pain	2	2.9%
Obsessive compulsive disorder	1	1.4%
Physical disabilities (specific disabilities not specified)	5	7.2%
Postural tachycardia syndrome	1	1.4%
Psychiatric disabilities (specific disabilities not specified)	2	2.9%
Reproductive cycle conditions	1	1.4%
Schizophrenia	1	1.4%
Scleroderma	1	1.4%
Total	69	100%

[a] Rather than relying on the U.S. Census Bureau's six-category classification of disability to aggregate the disabilities that we found in our analyses of the mainstream abstracts, we have, consistent with our social model epistemology, reflected the terms that the abstracts used.

term "handicap" to refer to the environmental and attitudinal barriers that a person with a disability may encounter, we also conducted a combined search of the words "women" and "handicap" or "handicapped." We then used Saris and Johnston-Robledo's (2000) method of determining which abstracts were "mainstream." Specifically, we examined whether the abstract was published in a journal identified in the APA's 1997 publication, Journals in Psychology: A Resource Listing for Authors.[2]

Categories

Classical content analysis uses predetermined categories to reduce text so that it might be analyzed quantitatively (Ryan & Bernard, 2001). After identifying mainstream abstracts, we coded them for content using pre-selected

Table 4. Summary of additional aspects of identity present in mainstream psychological journal abstracts about gender and disability (N = 69).

Description of Abstract	Number	Percentage
Gender, disability and no additional aspects of identity	51	73.9%
Gender, disability, and one other aspect of identity	16	23.2%
Gender, disability, and two other aspects of identity	2	2.9%

categories. The first two categories were mutually, exclusive: (1) Only Women (this category was coded if WWD were the focus of the research) and (2) Both Women and Men (this category was coded if both WWD and men with disabilities were highlighted). We used these selection procedures to address our first research question regarding the extent to which women with disabilities are visible in mainstream psychological research in the U.S. In order to address our second research question, those abstracts coded as, "only women" were then coded using the following additional mutually exclusive categories: (1) Medical Model[3], and (2) Social Model.

All selected abstracts were then coded using four additional categories that addressed our third research question: Are other identities of WWD included in mainstream psychological research? These additional categories were: (1) Poor/Low-Income (the abstract recognized the demographic of gender, disability, and poor/low-income status); (2) Race/Ethnicity (the abstract recognized the intersection of gender, disability, and race/ethnicity); (3) Age (the abstract recognized the intersection of gender, disability, and age), and (4) Lesbian, gay or bisexual (LGB) (the abstract recognized the intersection of gender, disability, and being lesbian, gay, or bisexual). These final four categories were not mutually exclusive; an abstract could be coded as addressing both age and race/ethnicity.

Coding

Two coders (the first and third authors) agreed upon the pre-selected categories and then coded the abstracts independently. The coders then entered their findings into an SPSS data set by indicating "yes" or "no" when a category was present or not within an abstract. Cross tabulations of both coders' data were performed for each category to determine how often both coders identified each category as present across all abstracts. Inter-rater reliabilities, indicated by Kappa, were very good (Kappa across categories =.72-1.0): (1) Only Women (Kappa = 1.0), (2) Both Women and Men (Kappa =.97), (3) Medical Model (Kappa =.72), (4) Social Model (Kappa =.94), (5) Poor/Low-Income (Kappa =.79), (6) Race/Ethnicity (Kappa = 1.0), (7) Age (Kappa = 1.0), and (8) LGB (Kappa = 1.0). We resolved all discrepancies through discussion.

Results

Presence of Women with Disabilities in Mainstream Psychological Research in the U.S.

The PsycINFO search revealed 19,976 published journal abstracts using the word "women," 5,469 journal abstracts using the word "disability" or "disabled" and 449 journal abstracts using the word "handicap" or "handicapped." A search for a combination of these terms produced 397 records. This means that only 2% of all journal abstracts identified using the word "women" also included disability-related terms. Of these 397 records, 81% were found in special topic journals like Disability and Society, or Sexuality and Disability. Only 76 of the 397 records were found in journals that the APA had identified as "mainstream." Closer examination of these 76 records, revealed that 7 of these abstracts referred to "self-handicapping behavior."

Because these abstracts were related to the study of actively hindering one's own task performance and were unrelated to disability, we eliminated them from our analysis. Thus, only 69 (17%) of those 397 records mentioning women with disabilities were found in APA-identified mainstream journals.

We found that these 69 abstracts spanned a minority of journals. Only 39 (10%) of the 385 APA mainstream journals published these women-with-disability-related abstracts. Further, a 2003 special issue of the feminist psychology journal Women and Therapy was the source of 10 (14.5%) of these abstracts. In 14.5% of the abstracts, the research discussed took place outside of the U.S., demonstrating a low emphasis on disability-related issues within psychology in the U.S.

As seen in Table 2, in 32% of the cases, people with disabilities were mentioned in the abstract solely, and were not the focus of the research at all. Women and men shared the focus of the research on disability in 35% of the abstracts. Women with disabilities were a specific focus of the research in only 33% of the cases. The types of disabilities identified in each of the 69 journal abstracts are illustrated in Table 3. As this table illustrates, 43.5% of the abstracts used disability as a generic term with no reference to specific types of disabilities.

Medical Models and Social Models of Disability in Mainstream Psychological Research

We found that 9 of the 23 abstracts that focused on women with disabilities specifically reflected the medical model. For example, a 2001 study compared coping strategies in women diagnosed with 3 different types of chronic pain conditions: fibromyalgia, neck/shoulder pain, and back pain. The researchers found passive coping to be related to general dysfunction stemming from pain, and not to a specific diagnosis of fibromyalgia (Mellegard, Grossi, & Soares, 2001). Because this abstract focused on coping, which is a behavioral response intrinsic to an individual, we coded it as a medical model. The social model of disability was reflected in 11 of the 23 mainstream abstracts specifically focused on women with disabilities. Among them was a 2003 study of stereotypes about disability (e.g., that people with disabilities are helpless, challenged intellectually, and asexual) that found that societal representations of disability had a negative influence on the intimate relationships of women with disabilities. In 3 abstracts, we did not have enough information to determine the model (i.e., medical, social) the author had used to construct disability.

Intersections of Disability with Other Identities

The intersections of disability with other aspects of identity are illustrated in Table 4. Only 18 of the 69 abstracts (26%) addressed the intersection of gender, disability, and other aspects of identity such as age, race/ethnicity, poor/low-income status, or lesbian, gay, or bisexual (LGB) status. Specifically, 16 abstracts mentioned the intersection of gender and disability with one of these aspects; two did so with two aspects.

Gender, Disability, and One Other Identity

Most of the abstracts examined the intersections of gender and disability and one other aspect of identity such as age, race/ethnicity, or low socioeconomic status. Age was the focus of 8 of the 18 abstracts. Among them was a 2003 study of the trajectories of disability from onset until death among a sample of Norwegians with disabilities aged 80 and older. The study found that older women were significantly more likely than men to experience serious physical and psychological effects due to disability. Race/ethnicity in combination with gender and disability was the focus in 6 other abstracts. For instance, a 2003 article discussed the culture of deafness and issues of cross-cultural therapy for minority deaf women, and noted that mental health professionals have traditionally neglected the needs of this population. Finally, poor or low-income status was the focus of 2 abstracts. One was a longitudinal study of women who received welfare benefits in an urban Michigan county that found that women with a co-occurrence of "human capital" problems with mental health and physical health problems were less likely to find and keep employment compared with women who did not have these problems.

Gender, Disability and Two Other Identities

Only two of the 18 abstracts focused on the intersection of gender and disability also examined other aspects of identity. A 2003 qualitative study examining conceptions of illness and disability of middle-aged African-American women with arthritis participating in a peer group health promotion program found that participants focused more on the communal aspects of having arthritis than the personal aspects of the condition. The other abstract encouraged counseling psychologists to recognize and incorporate into their practice the notion that although people may identify by race/ethnicity, disability or LGB status, more than one of these aspects of identity may be salient within individuals at any time (Bowman, 2003).

Discussion

We used this classical content analysis to investigate the coverage of women with disabilities in APA-identified mainstream psychological research. Our analyses revealed that research on women with disabilities accounted for a rather small proportion of psychological abstracts. Specifically, just 2% of all abstracts using the word "women" also incorporated disability-related terms. Further, only 17% of articles on women with disabilities were published in APA-identified mainstream psychology journals. It is important to note that 14% of these mainstream articles stemmed from a 2003 special issue of the feminist psychology journal, Women and Therapy, dedicated to women's visible and invisible disabilities. The paucity of research on women with disabilities in mainstream psychological research is disturbing for at least two reasons. First, people with disabilities constitute the largest "minority" population in the U.S.. Second, the dearth suggests that disability, in contrast to other identities (e.g., ethnicity, sexual orientation), receives token status in mainstream psychology in the U.S. Disability has yet to be integrated fully within mainstream psychological research. Alas, psychology's historic neglect of disability issues continues.

Despite the social model of disability's 30-year history in the U.S., we also found that only a handful of abstracts focused on the social model of disability. Not surprisingly, most of these stemmed from the aforementioned special issue of Women and Therapy. Almost half (n = 9) of the 23 abstracts that focused on women with disabilities reflected the old medical model paradigm. In light of rehabilitation psychology's historic focus on factors internal to the person with the disability, this finding is hardly surprising. Though a shift from the medical model to the social model in psychological research is long overdue, the latter model is not foolproof, either. Indeed, critics charge that the social model remains biased in favor of Caucasian men and obscures the needs of women with disabilities who share other minority identities.

Our study also found only a handful of abstracts that discussed disability within the context of other identities. The unidimensional focus of abstracts attending to research on women with disabilities is part of a larger problem within psychological research: the seeming inability to conceptualize people in all of their rich complexity and multiplicity.

Our study has implications for future research on women with disabilities. The most obvious, of course, is that more research on women with disabilities, particularly research that reflects the social model of disability, is desperately needed. Additionally, the absence of research makes it difficult for the field to establish theories around disability-related issues. This in turn hinders the development of theories that describe disability and other intersecting identities. Collins (1998) advocates for the use of a intersectionality framework where social phenomena such as race, socioeconomic status, and gender "mutually construct one another" (p. 63). In combination with additional research on WWD, such a framework could enhance the conceptual and methodological development of future theory and research on disability.

Our findings also raise provocative questions about why research with and on behalf of women with disabilities remains so scant in mainstream psychology. Scholars who have written about the exclusion of populations such as poor women , women of color , and people who are poor sound similar themes. In her examination of the exclusion of poor women in psychological research, Reid identified three obstacles that appear equally relevant to the exclusion of women with disabilities: personal affiliation, investigator training, and effort maximization.

Regarding personal affiliation, Reid has criticized psychologists for studying populations with whom they work, have easy access, or whom they most closely resemble. Herewith, we state the obvious: not only is more psychological research needed on disability issues, but more researchers with disabilities are critically needed to bolster the theoretical and empirical literature on women (and men) with disabilities. Moreover, greater collaboration between the disability community and researchers is necessary. And as Olkin and Pledger rightly caution, it is insufficient to simply include people with disabilities as researchers; they must have decision-making power and funding authority.

Reid has further argued that investigator training might be influential in excluding some populations from psychological research. She notes that researchers may be inadequately trained for work with diverse populations. Disability activists are unequivocal about the limited training that psychologists receive about theory and research relevant to people with disabilities. Accordingly, we join the chorus of disability activists advocating for psychologists to become multiculturally competent with regard to disability-related theory, research and practice.

The third obstacle, effort maximization, notes that researchers are more likely to exclude a population from research when they perceive that the population is not readily available, or may require special accommodations to allow participation. Indeed, people with disabilities may need a variety of accommodations, such as physical access to a research site or extra assistance to complete an interview or survey. With regard to accommodations for people with disabilities in psychological research, we join Olkin in identifying accommodation and access as civil rights issues.

The prevailing myth of objectivity in psychology notwithstanding, the reality of research is that it is rarely neutral. Rather, it may be used for emancipatory or oppressive ends (Fine, Weis, Weseen, & Wong, 2000). As such, the research endeavor is implicitly relevant to issues of civil rights. The fact that people with disabilities share many of the same social realities as other historically disenfranchised populations (e.g., poverty, lack of access to education and employment, etc.), attests that advancing knowledge about disability through research is an important social justice and civil rights issue. Thus, we embrace the injunction that "social researchers dare to speak hard truths with theoretical rigor and political savvy" (Fine, Weis, Weseen & Wong, 2000, p. 125). Indeed, we hope that our content analysis of the invisibility of women with disabilities in mainstream psychology will "inform and encourage social movements for 'what could be'" (Fine, Weis, Weseen, & Wong, 2000, p. 126). In the case of mainstream psychology, "what could be" is more visibility about the experiences of women with disabilities in psychological research. In turn, increased visibility within psychological research could foster greater advocacy for the rights of people with disability in and beyond the discipline of psychology.

Our study also has theoretical implications for the psychological study of intersecting multicultural identities for women with disabilities. On the one hand, understanding the complex phenomena associated with disability is in and of itself important. On the other, focusing on disability solely may obscure other important identities such as ethnicity, socioeconomic status, and sexual orientation. Moreover, it is important that disability not be the sole focus of the study. Thus, we were heartened to find abstracts in our content analysis describing studies conducted with women with disabilities that also investigated experiences such as wanting to leave an intimate partner or beliefs and experiences about sexuality.

In this study, we made a methodological decision to narrow our analyses to abstracts identified as "mainstream" by the APA. We do not wish to imply that literature published in APA-identified mainstream journals is more important or noteworthy than that published in non-mainstream journals. Indeed, primarily because they are beyond the mainstream and often are linked to the disability community, non-mainstream journals are the sites of cutting edge theory and research that reflect the social model paradigm and, as such, serve as exemplars for future directions in theory and research. We chose to focus our analysis on APA-identified mainstream journals largely because these journals can easily be found in the standard collections of most U.S. university libraries and therefore constitute what the majority of the field in the U.S. is reading. Segregating issues of disability into special topic journals contributes to a lack of knowledge about disability-related issues for professionals in the field, who may not have had the occasion to seek out the sometimes harder-to-find journals.

Although our study contributes to the knowledge about the presence of women with disabilities in mainstream psychological research, it is not without limitations. One of the most important is our study's sole reliance on abstracts. It is possible that although some abstracts may not have included words such as "disability" or "handicap," perusal of journal articles might have found disability issues to be a main focus. For example, researchers writing about issues of mental heath infrequently refer to this issue as "disability." Thus, our results may underestimate the actual number of articles focused on women with disability in mainstream psychology. Finally, our conclusions may reflect a manuscript submission bias. It is possible that there are more psychologists developing theory and conducting research on women with disabilities who choose to submit their work to non-mainstream journals because they perceive those journals to be more receptive to the focus of their work (J. Cohen, personal communication, November 15, 2004).

Several recent developments attest to a growing attention to disability within mainstream psychology. For example, a 2003 special section of the APA's flagship journal, American Psychologist, was dedicated to new perspectives on disability. Additionally, the APA Committee on Disability Issues in Psychology recently published a Resource Guide for Psychology Graduate Students With Disabilities, and disability is included in the title of APA's 2005 National Multicultural Conference and Summit theme, The Psychology of Race/Ethnicity, Gender, Sexual Orientation, and Disability: What Works, With Whom and Under What Circumstances. These important developments notwithstanding, our study shows that mainstream psychological theory and research lags far behind the APA's stated commitment to including disability status within the scope of multicultural perspectives in psychology. As we see it, the challenge that lies ahead for psychology is to make the now virtually invisible women with disabilities -- with all of their rich and complex multicultural diversity -- thoroughly visible in mainstream psychological research.

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Susan Faye Ritz, M.S., served as a project manager of the Prejudice Research Lab at the University of Tennessee at Chattanooga and has coauthored and made conference presentations relevant to prejudice towards people with disabilities.

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End Notes

[1] Individuals at least 15 years old are considered to have a severe disability if they used a wheelchair, cane, crutches or a walker; had a mental or emotional condition that seriously interfered with everyday activities; received federal benefits because they were unable to work; had Alzheimer's disease or mental retardation or another development disability; or were unable to perform functional activities (e.g., walking, using stairs), activities of daily living (e.g., getting around inside of the home), instrumental activities of daily living (e.g., preparing meals, using the telephone), work around the house, or if between the ages of 16 and 67, were unemployed because of a condition related to their disability.

[2] Examples of journals cited in this reference include *Psychology of Women Quarterly*, *American Journal of Psychology*, *Journal of Consulting and Clinical Psycho*logy, and *Psychological Bulletin*.

[3] We coded abstracts as using the medical model if: (1) personality, coping or other variables intrinsic to the individual influenced the experience of disability, or (2) the abstract discussed how psychological and/or physical disability was created as a result of abuse, without discussing how structural or societal barriers limited options for women who have been abused.

[4] Numbers in thousands.

College Preparation and Participation: Reports from Individuals Who Have Speech and Mobility Disabilities

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Abstract: In this qualitative research study, nine individuals with mobility and speech disabilities reported on their experiences preparing for and participating in postsecondary education. Topics discussed include choosing a college, support from mentors and family members, self-determination, accessibility and accommodations, academic and social aspects of college, current activities and outcomes.

Key Words: postsecondary education, speech and mobility disabilities, transition

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

Introduction

Individuals who have physical and speech disabilities face substantial challenges in achieving academic success in school and adult life. As children, their talents and abilities may go unrecognized because their disabilities make it difficult to communicate what they know (Willard-Holt, 1998). Low expectations of adults may restrict their access to appropriate instruction and physical disabilities often limit their range of experiences (Koppenhaver & Yoder, 1993; Light & McNaughton, 1993; Marvin & Mirenda, 1993). Many students with speech and mobility disabilities have considerable difficulty with literacy learning (Koppenhaver & Yoder, 1992; Smith, 2005). Reading difficulties impact all aspects of academic study and may be a factor in limiting postsecondary academic pursuits for some students with speech and mobility disabilities. As a result of these issues, individuals with both physical and speech disabilities may face considerable difficulty completing postsecondary education and pursuing a career (Odom & Upthegrove, 1997).

Employment success for people with disabilities is highly correlated with educational attainment (Blackorby & Wagner, 1996). In fact, a stronger correlation has been reported between level of education and rate of employment for individuals with disabilities than for the broader population (Stodden & Dowrick, 2001). A growing body of literature explores employment issues for people with significant speech and mobility disabilities (Bryen, Cohen, & Carey, 2004; Isakson, Burgstahler, & Arnold, 2006; Light, Stoltz, & McNaughton, 1996; McNaughton, Light, & Arnold, 2002), yet little information is available on the postsecondary academic experiences of these individuals. Although we do not have data on the college experiences of individuals with physical and speech disabilities, there is a body of research on the postsecondary academic experiences of the broader population of students with disabilities (e.g. Blackorby & Wagner, 1996; Wagner, Newman, Cameto, Levine, & Garza, 2006). A comprehensive analysis published by the National Center for Educational Statistics (NCES) reported that students with disabilities were less likely to be academically prepared for college than their non-disabled peers (Horn & Bobbitt, 1999). Students with disabilities were less likely to apply for college admission than peers without disabilities. Students with disabilities who pursued postsecondary education were less likely than their non-disabled peers to attend a four-year school and were less likely to earn a degree. Nonetheless, 80% of individuals with disabilities who did earn a bachelor's degree reported finding employment after graduation; in addition, no significant differences were found in starting salaries for college graduates with and without disabilities (Horn & Berktold, 1999).

Although large statistical studies have clear value in documenting the broad picture of college preparedness and participation, there is also much to be learned from smaller qualitative studies that explore the experiences and perceptions of individual students. In a survey that examined the high-school-to-college transition experiences of 59 students with various disabilities, the participants reported that the three major barriers they faced in succeeding at college were (1) societal attitudes, (2) lack of preparation, and (3) financial constraints (Garrison-Wade & Lehmann, 2007). Participants reported that low expectations of high school teachers and lack of access to rigorous college-track classes left them ill-prepared for college-level work. The students reported that the factors that promoted their success included their own self-determination and the support and encouragement of family. Self-determination, including self-advocacy skill, plays an increasingly important role as students transition from high school where accommodations are the responsibility of the school district to college where more responsibility shifts to the student (U.S. Department of Education, 2007).

Purpose of the Research

A study was undertaken to explore the perceptions of individuals with speech and mobility disabilities about their preparedness for college and their postsecondary academic experiences. The researchers sought a greater understanding of the factors that contributed to the success of these students, as well as those factors that presented obstacles. It was expected that the results could help educators, parents, and others better support students with mobility and speech disabilities as they transition to college and careers.

Method

This exploratory study used an internet-based focus group to examine the postsecondary academic perceptions and experiences of individuals who have mobility and speech disabilities. The focus group is an effective research tool for uncovering the perspectives of individuals who have common characteristics and experiences with regard to the topic of study (Krueger & Casey, 2000; Vaughn, Schumm, & Sinagub, 1996). In recent years, computer-mediated communication (CMC) has played an increasing role in facilitating communication between individuals whose face-to-face interactions were constrained by distance, overloaded schedules, and/or disabilities that impact communication (Burgstahler, 2006). The development of assistive technology—e.g., expanded keyboards, on-screen keyboards, and Morse code input devices controlled with switches—makes electronic communication possible and practical for individuals with a wide range of disabilities. Asynchronous communication eliminates scheduling problems and allows individuals to take the time they need to formulate responses. It removes the stigma of speech impairments. Other recent studies have used CMC to support focused discussion among individuals with disabilities (McNaughton, Light, & Arnold, 2002; McNaughton, Symons, Light, & Parsons, 2006; Rackensperger, Krezman, McNaughton, Williams, & D'Silva, 2005). For individuals with speech and mobility disabilities, an asynchronous online focus group minimizes physical demands on participants and allows each participant to contribute at a pace and time that is appropriate and convenient (McNaughton, Light, & Groszyk, 2001).

Participant Recruitment

To participate in this study, an individual had to (a) be over 18 years of age, (b) be a high school graduate, (c) have a desire to attend college, (d) have both a mobility impairment and a speech impairment, and (e) have access to electronic mail. Potential participants were identified from a database of hundreds of individuals who had, since 1992, participated in at least one of many nationwide activities sponsored by the Disabilities, Opportunities, Internetworking, and Technology (DO-IT) Center at the University of Washington. DO-IT helps middle school, high school, and college students with a broad range of disabilities transition to and succeed in postsecondary education and employment (Kim-Rupnow & Burgstahler, 2004; DO-IT, 2006).

An email recruitment message was sent to fifteen individuals who had self-identified as having both mobility and speech disabilities and who had attended college or expressed a desire to attend college. Nine individuals agreed to participate.

Procedures

Participants were asked to complete a demographic questionnaire that included questions about their school and work history as well as their use of assistive technology for mobility and communication. After all participants had responded to the questionnaire, the researchers created a closed email list that was administered through the University of Washington list management system. The investigators facilitated the focus group by presenting topics for discussion and posting follow-up questions when appropriate. The discussion topics, queries, and responses were sent by electronic mail to all discussion group members. The focus group discussion took place over a period of 12 weeks, with a new topic presented every 5 to 10 days. The topics and queries posted can be found in Appendix A.

Analysis

The qualitative analysis software package Atlas.ti (Muhr, 2000) was used for coding and data management. The content of each electronic mail message posted by the participants during the discussion was entered into Atlas.ti. Each standalone unit of information was assigned a code that identified the main theme of the unit (Lincoln & Guba, 1985; Strauss & Corbin, 1998). The codes were refined through an iterative process and finally combined into code families or categories of codes. The findings in the following section are presented under three broad categories of content that correspond to the code families: preparation for college, the college experience, and outcomes and attitudes.

Findings

Six of the nine focus group participants were students at the time of the study; two were attending community colleges, three were pursuing four-year degrees, and one was in graduate school. The three oldest participants were not in school at the time; one had earned an associate's degree, one had earned two bachelor's degrees, and the third had left school without earning a degree. There were 6 male and 3 female participants ranging in age from 21 to 38. Seven of the participants had cerebral palsy and two had brain injuries. Participants used wheelchairs, scooters, a three-wheel bike, and walkers for mobility. They used both high-tech and low-tech augmentative and alternative communication (AAC) devices to supplement or replace speech. Each name included in this article is a pseudonym.

The focus group discussion generated 141 email messages over a 12-week period; 29 messages were from the two researchers and 112 were from the nine participants. Not all participants contributed to every topic. During the 4th week of the discussion, Crystal reported that she would not be able to continue in the focus group because of the workload of her classes. Her responses to the first three topics are included in the analysis. Note that, in the excerpts from email messages presented below, typographic and spelling errors have been corrected, symbols and abbreviations have been expanded, and standard capitalization has been used.

Preparation for College

Researchers asked focus group participants how well their pre-college school experiences prepared them for life after high school. The participants reported a range of experiences. Dana and Will reported that their schools provided training in independent living skills:

> "They designed an independent living class for me to take during high school to aide me through my transition, and we did activities like going out to eat, going shopping, going to the grocery store, going to the bank, visiting the independent living center etc. At least they attempted to prepare me but I feel they could have been more effective." (Dana)

> "The last semester of my senior year, my case manager let me get out of the building and do some other experiences, which was fun. I think the key is let the student be in charge of their destiny." (Will)

Michael reported that he developed study skills that served him well in college:

> "Elementary and high school prepared me for college by giving me a solid foundation of good study habits and knowing I always had to get my homework done early."

Other students felt inadequately prepared by their early school experiences. Brad and Benjamin both expressed disappointment with the academic opportunities available to them in high school:

> "Throughout middle school and high school, I took honors and Advanced Placement [AP] classes which were meant to be challenging and prepare me for college. Unfortunately, the AP classes at my high school were like standard classes at other high schools and didn't prepare me for college or the AP tests very well." (Benjamin)

Brad reported that he was not allowed to take the advanced placement (AP) classes that he desired and was dissatisfied with the advice he received:

> "My high school did not prepare me at all really, and this included my [Individualized Education Program] IEP team. For example, most people knew I wanted to go to college. I wasn't allowed to take AP classes. They almost messed up my entire college career by telling me that a foreign language class wasn't needed at all."

Supportive Teachers and Mentors

Some participants mentioned specific teachers who played a supportive role in their early education. Rebecca reported that a teacher she met when she was very young helped her family navigate the public school experience:

> "My preschool teacher had a daughter with cerebral palsy that was five years older and I kept in touch with that teacher all through my schooling …. So, my teacher kept telling my mom and me what to watch out for and what kind of problems we might come across."

One of Jennifer's teachers played a significant role in her decision to go to college:

> "My high school drama teacher put the college bug in my head. I thought she was cool because she was a free spirit [and an] environmentally conscious person, so I listened to all of her cool college stories."

Benjamin was influenced by a teacher who encouraged him to expand his assessment of his own capabilities:

> "One teacher whom I had for two years of journalism … knew all along that I possessed more abilities than I even knew were in me… [He believed] in my abilities enough to encourage me to push my limits. While he was my teacher for journalism … he wanted me to find a way to

> take pictures…. I brushed it off by telling him I would look into it, having no real intention of doing so…. A few weeks later when my parents returned from the school's open house, my dad said that [my teacher] had suggested he help me adapt a camera so I could take photographs.

A week or so later, I was taking pictures of our wrestling team in action... [My journalism teacher] … believed in my abilities and in me as a person. I left his class knowing that I had many more abilities within myself waiting to be discovered."

Family Support

Many participants reported that they received their strongest support and encouragement from family:

> "My high school team always knew I wanted [to attend] and would attend college, yet they didn't really help me that much…. My mom always was behind me and pushed me." (Brad)

> "Mom and my assistants and friends always encouraged me because they all know that with the right help that I could do most anything… Some of the teachers and other helpers thought that … I shouldn't be mainstreamed because with my physical and language disabilities I couldn't always show them what I knew." (Rebecca)

> "Well, nobody really pushed me for college except my parents and my IEP team. It was very interesting because [going to college] was my choice." (Will)

> "My mom, dad and brother along with my teachers encouraged me to set high goals for myself, not to mention I set high goals for myself anyway." (Michael)

Initial Areas of Interest

Focus group members reported a variety of academic and career interests while they were in high school. Michael had the goal of becoming an elementary school teacher. He wrote, "I planned my entire life to be a teacher." Crystal stated that, while she was in high school, her career interests included "archeology, civil rights activist, librarian, forensic anthropologist." Dana, Benjamin, and Brad reported that they were interested in technology and computer science Dana wrote, "My main interests have always been computers, software and augmentative and alternative communication." Jennifer said that she enjoyed working with people and wanted a job where she could "inspire people to empower themselves." Will also sought to inspire people and reported, "I always had a desire for public speaking. People need to be inspired somehow… Speaking is my calling for sure!!!"

Rebecca reported that she had three specific career interests while she was in high school:

> "At first I was interested in becoming a person that goes around to different businesses and makes sure that they are accessible to all people. My second interest was working in a preschool because when I was in high school I took child psychology and volunteered in a preschool and really enjoined it. Also when I was in high school my friend … and I started our own business as our junior and senior high school projects making and selling soap… Besides earning money, our goal [was] to help the community interact with disabled people in business… I would like to own my own business."

Choosing a College

Five of the participants began their college careers at four-year colleges, while four started out at community colleges. Several participants mentioned proximity to home and family as an important factor in their college choice. Dana reported:

> "I chose [a state university] primarily because it's in my hometown, and at that time it was questionable how independent I might have been, so my parents preferred me to stay nearby home."

Like Dana, Brad attended a four-year college after high school graduation:

> "I selected the two schools I applied to by knowing about … the programs I was interested in by national recognition or word of mouth. The largest factor was accommodations given."

Financial considerations were a factor in the choice of a college. Jennifer reported: "I went to [a state college] my freshman year because of in-state tuition and free rent."

The participants in this study were also concerned with issues of accessibility and levels of support available from campus organizations charged with providing services to students with disabilities. Hugh chose a community college in his area because "they have the most comprehensive service for cerebral palsy students." Jennifer reported that she was influenced by "a wheel-chair friendly campus" and Brad reported that accessibility issues and campus terrain played into his decision as well.

Two students reported that it was through campus visits and informational events that they learned about the schools they eventually attended:

> "I picked [a community technical college] because I toured it once and I really loved it. I was on a tour with some students from my high school, and I liked it the best out of all the colleges we visited…. You felt a sense of community from [students of] all different backgrounds." (Will)

> "I had originally intended on going to [a state university], but I changed my mind my junior year in high school when I went to a college fair and learned more about [a small private college]. I chose [that school] for its Christian environment and smaller classes." (Benjamin)

Will reported that he could have used more help with the college application process:

> "College was a challenge for me because I was on my own as far as applying. I had to know when everything was due (I didn't), get everything in on time (I didn't)... At my high school, the special education program there never really stressed the issue of getting forms in. I felt that they didn't prepare me for what I had to do. Maybe it was my laziness too, I'm not ruling that out."

Similarly, Dana reported that "high school graduation was almost like getting dumped out on the street by the school system to fend for yourself… I feel they could have done more to prepare me."

The College Experience

Participants who lived on campus found the experience both challenging and rewarding. According to Benjamin:

> "For me, the biggest challenge (yet most rewarding) was living on campus. I lived at home my freshman year because I didn't think I could live on campus due to the amount of help I need. Late in my first year, though, my dad and I decided to make it work by finding a roommate who was willing to help me out.

We didn't tell my mom until a couple weeks before I moved because we knew she would not be happy. When she found out, she thought it wouldn't work. My dad humored her by saying, 'Maybe you're right, but we have to let him try.' She changed her mind after she saw how happy I was living in the dorms. The next summer when I moved back home for a few months, she couldn't wait until I went back, and I felt the same way!:) Funny thing is that I found myself only using my roommate for help part of the time. The rest of the time, I'd ask the guys on my floor for help, and girls often offered to feed me (which I didn't mind AT ALL!)."

Brad reported challenges finding personal care assistants. Jennifer reported that living in a dormitory presented her with challenges during her first year, yet she did not believe that her disability created those challenges:

> "It took my first semester of college of trial and error and more error to 'figure life out'... cleaning, cooking, laundry, timeliness, sleep, bills, and so on…My roommates were just as lost. I have not met a college freshman … [who was] prepared…Working freshman orientation for three years, [I observed that] everyone had the 'deer in headlights' look."

Accommodations

Rebecca reported that it was difficult for her to make the transition to college:

> "I had a challenge when I moved from having a one-on-one assistant to a program at a college … [without] the same support. …When I first got [to college], the program had someone who went to class and helped me with my assignments and that was great. But after a couple of quarters … [they] just stopped going to class and sitting down with me to help me with my assignments. I started to get very frustrated and couldn't figure out why I wasn't getting the help anymore. After a while I had mom set up a meeting … to see what was going on…They said that they only have to help me for the first year and then they don't have to help me any more. They also told me that maybe college wasn't the right thing for me…After the meeting, for the two next quarters I had gotten a tutor and had the same one and did great."

After changing his major, Brad had difficulty getting the accommodations he needed:

> "One thing I faced that I didn't [foresee] was getting denied some accommodations from Disabled Student Services [DSS]… Mid-way through my second year I had switched from engineering/computer science to liberal arts. This required a lot more reading — and I need e-text, something that my paperwork said I may need. [The] DSS view was you've gone this far without it, you shouldn't need it. My reply was yes, but I was taking courses that were heavy in math, so running a calculus formula through [text-to-speech software] would be basically useless for me. Also when I read a lot my eyes get more tired than an average student…[DSS] claimed my eye tiredness wasn't anything real; I just had to deal with it, and also they only give the accommodation of text to e-text to students who are labeled LD…To make a long story short, it took a threat of going to court for them to find me needing the accommodation without having a [diagnosis of] LD."

Access to appropriate technology can play a powerful role in supporting the academic success of students with disabilities. As Will reported, "Ah technology, the thing that can either be very beneficial or drive you up the wall." Dana, one of the older participants in the focus group, had attended college a decade earlier and had dropped out after one semester. Dana reported:

> "Another thing I didn't have access to when I attempted college is my [AAC device] which allows…me [to] compose written work by use of my programmed vocabulary to speed up things. Another thing is I didn't have a screen reader at the time, which now I do and really benefit by, it has really opened up a whole new world for me…I feel that I would have

> probably succeeded in college if I had all these ducks in order before starting."

Social Interactions and Communications

Meeting new people and interacting in social situations can present challenges. Benjamin reported:

> "I have found it can be difficult to make friends simply because of my unclear speech. People tend to be afraid to talk to me because they can't understand me at first. Funny thing is that my wife and I went to the same college but hardly ever talked because she was afraid to talk to me. It wasn't until we started going to the same church that we became friends. Once people get past the uncomfortable stage, though, they usually treat me like anyone else."

Brad and Hal reported difficulties connecting with others:

> "My experience has been generally poor for making friends. Occasionally I will talk to a few people before class, but … usually they just forget to tell [me] about study groups…Occasionally I'll see somebody from a class, and we say hey, but that's it." (Brad)

> "It's usually way easier for me to make friends with guys. When women find out that I care for them, they usually freak out bad. It becomes just disastrous." (Hal)

Will, on the other hand, reported that he makes friends easily and maintains a positive attitude even when relationships are challenging:

> "I socialize a lot, so making friends isn't that hard...I have a tendency to walk up to random strangers and just start talking…You make more friends that way… There were some challenging relationships in my school, but it wasn't because of my disability. It was more typical college awkwardness…In all, I can connect with just about anyone, anywhere, and that's a blessing."

Jennifer recommended giving new acquaintances time to become comfortable, "Just gotta give time and space. Show them respect. Remain confident, not overbearing. And if it takes a few interactions, so be it." Dana agreed, "I have always learned to not force people to be comfortable around me, they have to do it themselves, and if they don't, they just don't."

Rebecca reported that having a friend along can facilitate interactions with new acquaintances:

> "Some people are afraid to talk with me. When I have someone with me, that person starts a conversation and then we have me join…to show everyone that if you just are patient that you can have a regular conversation with me. I just started to feel comfortable to start a conversation with a person that I am just meeting for the first time. I didn't feel comfortable going up to people that didn't know me because I was so worried about if they would be able to understand me…DO-IT helped me become more social when I am in groups and around people that I don't know very well."

Jennifer reported that shared connections and repeated encounters help her connect with others:

> "My personal relationships usually stem from a disability connection, my sister, and/or the 'rate of repeat'…i.e. dorm, class, small town, Starbucks at 6 a.m., city bus...wherever. And my sis and I are really close, so her friends are my friends, and my friends are her friends. But wherever I meet friends, we share commonalities... soulful, compassionate, love for outdoors and environment, etc."

In one social relationship, Benjamin found that he was able to help another student by accepting help from her:

> "There was one girl during the later part of my sophomore year of college who asked if she could feed me almost every meal. We became good friends, and she confided in me that she was anorexic, so helping me eat forced her to eat as well. She was helping me, but it turned out I was helping her as well!"

Change in Plans

Brad and Michael were both seniors at four-year colleges at the time of the focus group discussion and both had experienced changes in their paths while in college:

> "I had my heart set on [specific state university] for a long time, so I didn't even check into other schools. After being [there] for two and a half years, I still didn't feel accepted there, or that it was the right place. I…transferred to [another state college], which has the perfect environment for me. I feel right at home here. The classes are set up how I want them to be, and everyone is more enlightened here overall." (Michael)

While in college, Michael's career plans also changed:

> "I decided elementary education was not the field for me because of all the hands-on type stuff required of teachers…Now I am planning on being a school counselor."

Brad's plans changed when he was not admitted to the very competitive computer science department at the university he attended:

> "I began college looking to major in computer science. After getting told … that I should look elsewhere, I began to explore other disciplines. Currently I am studying political science. My interests are still basically unchanged."

Jennifer and Benjamin both graduated from four-year colleges and worked in their chosen fields for a number of years before their circumstances led to career path changes:

> "I've always enjoyed working with people...I started in recreation therapy. With all the budget cuts and no driver's license, I couldn't really advance further in the field. Then, I got into social services… [Now] I'm in my second week of my master's degree for social work." (Jennifer)

> "I was a programmer for 2.5 years before being laid-off in the dot-com bust. After trying to find a job for over a year, I tried motivational speaking full-time for a few years but only landed a few bookings. Now I speak part-time, but much of my time is spent working on a non-profit foundation my wife and I started … to help people with mobility impairments get the equipment they need and want." (Benjamin)

Outcomes and Attitudes

In the following paragraphs the authors report participant academic and career progress and share some of the participants' insights and advice.

Hugh, 38, was the oldest participant in the focus group. He graduated from a community college when he was 29 years old and was a featured speaker at his community college graduation. He transferred to a large state university but left without earning a bachelor's degree. Hugh had worked part-time doing website design, but at the time of the study he was unemployed. About his previous job he wrote, "I worked there for a few months as a volunteer, then they hired me as a part-time employee. I MISS THAT JOB." His advice for others is, "Just believe in yourself! Plain and simple."

Benjamin, 32, earned a Bachelor of Science (B.S.) degree in Computer Science and a Bachelor of Arts (B.A.) degree in Communications. He is married and has a daughter. Benjamin is enthusiastic about his work with the foundation that he and his wife have started:

> "Although still in its infancy, the foundation is showing VERY promising signs of being very successful. I'm thrilled because I'll be helping people with a problem that is too often overlooked."

Benjamin's advice is, "Never let 'good enough' be 'good enough.' Go beyond others' expectations and your own!"

Dana, 29, attended a four-year college right out of high school, but dropped out during freshman year. Dana has now been employed with the same company for more than six years:

> "I have grown up with the impression that neither my parents, nor support staff are always going to make decisions for me, so I have to take responsibility of determining what things suit me best…I worked with OVR [Office of Vocational Rehabilitation] for a few years on finding employment opportunities for me, and we were getting nowhere until I started communicating with…various people myself. If I didn't take charge, I would probably be still traveling to the OVR office discussing it, and no real progress would have been made."

Jennifer is 28. She attended a four-year college and received a B.A. in Recreational Therapy. She worked in that field for a few years before returning to school to pursue a graduate degree in Social Work. Jennifer reported that her job searches were sometimes grueling, but paid off in the end. She wrote that she once applied for over 80 jobs before landing one. She reported, "I DO wind up with fantastic jobs always. And I am a dedicated employee. [It] just takes time and keeping a positive mindset." Her advice for others includes:

> "Find something you are good at and like to do…. Be kind, be nice, be respectable, be responsible for your actions, laugh at yourself, work hard and it will pay off. Keep trying even if you have applied for every job out there. Put yourself out there and have fun. Enjoy life."

Crystal, 26, received her Associate in Arts (A.A.) degree from a local community college and then transferred to a large research university where she is pursuing a degree in anthropology. She left the focus group in the fourth week because of the heavy workload of her classes.

Rebecca, 24, is currently attending a community college. She hopes to someday open her own business. She wrote, "One very important thing to remember is that in college you are your biggest self-advocate."

Brad is 22. He is a senior at a large research university, majoring in political science. He has worked in the technology field full-time during the summers and part-time during the school year. He advises, "Just stand up for yourself… Don't let people tell you no just because you have a disability."

Michael is 21. He is a senior at a four-year college. He plans to go to graduate school and pursue a career in school counseling. His advice is, "Be assertive. Don't settle for less than you deserve. Don't believe what doctors say. Put yourself out there. Enjoy being alive."

Will is 21 and is in his first year of community college. He reminds students to keep in mind the social aspects of college when researching schools by visiting a campus to see "how people interact with each other outside of class…see what the social setting is as well as the academic."

Discussion

The individuals recruited for this study had participated in a variety of DO-IT activities focused on supporting the academic and career success of middle school, high school, and college students with disabilities. Given their involvement in these activities, as expected, the focus group members had greater participation and persistence in postsecondary education than averages reported in the literature for students with significant disabilities. Five participants entered four-year colleges immediately after completing high school; four attended two-year community colleges. Of the four who initially attended community colleges, two later transferred to four-year schools; the other two are still community college students. One of the two who transferred to a four-year college dropped out without completing a bachelor's degree; the other is a college junior. Of the five who went directly to four-year colleges, two earned bachelor's degrees, two are college seniors, and one dropped out. One participant who left college without a degree has been successfully employed for several years.

Choosing a College

Primary reasons for choosing a school reported by participants in this study were very much like those of other college students — location, cost, and availability of programs. Campus access and academic accommodations were also important considerations. In addition, issues of independence and family support carried great weight for these individuals; young people who relied on family members to provide personal care assistance had to make new arrangements when moving away from home. High school graduation and the move toward post-secondary education is an important step in the maturation of all adolescents. For individuals with significant disabilities, asserting independence from one's family can have multiple layers of complexity.

Academics and Accommodations

The students reported that their academic experiences were not without challenges. Some felt that their high school classes had not prepared them well for college. In some schools, academics took a back seat to independent living skills. Once in college, some participants reported difficulties getting the accommodations they felt they needed in order to be successful. Their experiences highlight the critical importance of the development of self-determination, including self-advocacy skills, by students with disabilities who plan to pursue college.

Support and Self-Determination

Participants in the focus group cited family members as consistent and critical supports in their pursuit of postsecondary education. Participants also reported that individual teachers who took on a mentoring role were important in helping them develop the confidence they needed to pursue postsecondary education. They cited participation in DO-IT activities as a factor in their success. These results are consistent with earlier work suggesting that mentors, family support, and participation in a high quality transition program can help high school students who have disabilities develop the vision of a future that includes college and a career.

It is interesting to note that even when the researchers' questions concerned supports from others, participants often reported that it was by taking things into their own hands that they were able to overcome obstacles and move forward. Participants reported that they developed strategies to advocate for accommodations and to communicate effectively in both academic and social situations. The support they received from adults was often support for their own developing self-determination.

Outcomes

Participants demonstrated considerably higher levels of participation and persistence in postsecondary education than is typically reported for students with disabilities. However, participants who had pursued employment reported some of the same difficulties finding work that have been reported in the literature for this population. Those participants who were successful in finding paid employment did so primarily through networking, personal contacts, and volunteering.

Limitations

Caution should be exercised in generalizing the findings of this exploratory study. The individuals who were recruited for this study may not be typical of the population of individuals with mobility and speech disabilities; they all had plans to attend college, had participated in programs designed to support their academic and career success, and had ready access to mentors, computers, and the internet. In addition, those individuals who agreed to participate in the focus group may have chosen to do so in part because they had been successful; those who chose not to participate may have had less positive postsecondary experiences. Furthermore, for many participants this was a retrospective study, and memory can be fallible.

Conclusions and Future Research

Participants in the reported study demonstrate that individuals with mobility and speech disabilities can successfully pursue postsecondary education when they have academic access, support, and the self-determination to pursue that goal. Yet, barriers remain. Elementary and high school educators need to recognize the role that expectations can play in limiting or expanding a student's academic achievement. Students with disabilities require and deserve equal access to challenging academic curricula. Teachers at all levels must learn how to make their classrooms and instructional practices accessible so that all students are challenged to take rigorous classes that prepare them for higher education and satisfying careers. Students with disabilities are the experts on their academic interests and must be consulted and supported as they make decisions about high-school classes and post-secondary plans.

Additional research is needed to identify factors that support the success of students with mobility and speech disabilities in post-secondary education as well as factors that contribute to the high college dropout rates among students with disabilities. What must be done to ensure that students with speech and mobility disabilities have full access to rigorous academic curricula in K-12 schools? What practices most effectively foster the development of self-determination? A longitudinal study tracking the experiences, opinions, and progress of students with disabilities as they pass through critical junctures toward a career would provide information of use to students, families, and educators. In addition, collecting information on students' college preparation and participation from parents and educators would expand on the findings. Reports on college participation and graduation rates of students with significant disabilities make it clear that there is much to learn and much to be done to support them in college and careers.

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Acknowledgments

The content of the article is based upon work supported by the National Science Foundation (Cooperative Agreement # HRD-0227995) and the U.S. Department of Education (Grant # P333A050064). Any opinions, findings, and conclusions or recommendations expressed in this material are those of the authors and do not necessarily reflect the views of the federal government.

Appendix A: Topics and Related Questions for Online Focus Group Participants

1. Career and academic interests

What academic or employment fields have you considered or pursued? Have these goals/interests changed over the years?

2. Early school experiences

In what areas did your elementary and high school classes prepare you for college? In what areas did they not prepare you?

3. Encouragement in setting goals

When you were in high school and beginning to think about your future, describe how specific people in your life did or did not encourage you to set high goals for yourself.

4. Internal characteristics

Think about a success that you had achieving a goal. What were your own internal characteristics that enabled you to achieve that goal?

5. Choosing a school

If you have attended college, how did you select the school(s) that you applied to and attended?

6. Difficulties and challenges succeeding at college

Did you experience challenges applying for, attending, or succeeding at college?

7. Personal relationships

What has been your experience in getting to know people and making friends at school or work? Has it been easy or difficult getting to know people?

8. Technology

What types of technology do you use at school or work? What difficulties, if any, have you had getting access to the technology you need or managing the technology that you use?

9. Finding work

If you are currently working, how did you go about finding your job? If you have tried, but not been successful in finding work, what experiences have you had in the search process?

10. Advice for others

What advice or strategies for success in college, work, and/or in adult life do you have for younger students who have disabilities similar to your own?

11. Final open question

What else would you like to tell us about your experiences that might help us better understand the factors that impact college and career success for students with disabilities?

Consuming Disability: A New Dutch System for Hearing Aid Distribution

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Abstract: In the context of a Dutch market-oriented health care reform, this article investigates the role of two powerful, yet little examined actors in the field of hearing disability: multinational corporations and technology. Based on a notion of "co-production," the article develops an explanation of the new Dutch system for hearing aid distribution resulting from the interplay between new hearing technologies and an emerging corporate discourse on disability. The results point to technology as a potentially important site for democratic intervention.

Key Words: hard of hearing, corporate discourse, co-production

Introduction: European Health Care and a Dutch Market-Oriented Health Care Reform

Affluent European countries organize, manage, and finance health care in different ways. But the systems share some common principles: universal access to care and insurance, solidarity in the distribution of costs, and a good standard of care. As outlined in a background paper for the Dutch EU Presidency (Ministry of Health, Welfare, & Sport, 2004), a series of changes related to service provision have emerged within European welfare states. Governments are concerned about the financial and social sustainability of their welfare systems, as well as the efficiency of their health care systems. The well-known rationalization is that public health systems are increasingly coming under strain due to the rising costs of health care. Behind the concern is the proportional increase of the aging population, the emergence of new and expensive medical innovations, and citizens' growing expectations regarding the quality and availability of demand-driven healthcare provisions. Consequently, European governments are seeking ways to make the system more efficient so as to reduce pressure on public budgets. As a result of globalization, nation states must make adjustments in order to match the global economy. For example, to make an adjustment in order to move in a marked-oriented or neo-liberal direction due to globalization. A common approach is to economize by introducing competition elements into the system for instance through privatization. Coupled with the commercialization process is the changing role of the recipients of government programs from *users* to *consumers:*

> "The customer has to become a critical care consumer, and should be encouraged to make responsible choices. Insurers should compete in price, service and quality, and health care providers should be stimulated to provide efficient and effective health care. Governments will have an important role in guaranteeing quality, accessibility and affordability of health care. However, the foundations of the current Dutch health care system have to be renewed, taking into account the current political insights, by putting responsibilities with the persons and institutions that are involved" (Ministry of Health, Welfare, & Sport, 2005a p. 9).

In January, 2006, the Dutch government introduced a new health care system.[1] The reform seeks to combine the introduction of competition elements with the realization of a right to health.[2] A review of policy statements, such as the above, reveals four underlying assumptions that largely cohere with a neoclassical model of the market (e.g., Christensen & Lægreid, 2001):

- Deregulation and competition will increase consumer choice and quality of service.
- The informed and critical consumer acts as an autonomous agent making the "right" or "rational" choice.
- Introducing the principle of cost sharing will work as an incentive for consumers to act as responsible and quality oriented agents in the market.
- Proximity in the market will stimulate a more user-driven development.

With the new health care policy, the government remains responsible for the accessibility, affordability, and quality of health care, but gives the parties in the market greater freedom and greater responsibility to compete for the business of the insured. Citizens get more financial responsibilities, but also have more influence and choices in terms of health care insurance. The insurers negotiate with care providers on the price, content, and organization of the care. Under pressure from their insured parties, insurers are then expected to push for higher standards in their contracts with care providers, in terms of both quality and cost. The assumption is that care providers will have to work in a more performance-oriented manner, while having more opportunities to distinguish themselves in relation to one another and customize the services they provide. The question arises, can governments, by partly privatizing their health care systems, succeed in guaranteeing the availability, accessibility, and quality of health care service, and if so how?

In the Netherlands, hearing disability is considered a health issue and regulated by the Ministry of Health Welfare and Sports. The shift in health care policy thus, has consequences for hard of hearing people. Following the reform, the Dutch system for hearing aid distribution has been deregulated. In the emerging system, hard of hearing people shift from patients to consumers, as the distribution of hearing aids is moved out of audiological clinics and into hearing aid shops. In addition to the policy reform, there has been another salient shift in the hearing aid field. Following the digitization of hearing aids, the number of technological innovations has increased considerably. New products and techniques bring novel possibilities for audiological rehabilitation practices. But the effect of these new technologies cannot be seen in isolation from their social context of use. Thus, taking a non-deterministic approach to technology, this article investigates how specific information technologies combined with national policy regimes are transforming the geography of expertise and responsibility in the Dutch audiological field. More than merely improving fitting procedures, or increasing service efficiency, new technologies are involved in shaping the very meaning of hearing disability in intricate ways. To untangle some of this complexity, I mobilize a theoretical framework that combines a sensibility for discursive ordering attempts with a concern for the material dimensions of disability.

Before proceeding, a qualification is needed. At this stage it is difficult to assess how effective the new system will be and what implications will be for hearing disabled people.[3] It is possible that the larger role of the insurance companies will result in a more cost efficient system. This system, in turn, may enhance the availability and affordability of products and services. However, from the perspective of people with disabilities, such a system also contains its risks, some which I will discuss in this paper. The purpose of this exercise is not to denigrate the new health care system, nor to suggest that all existing problems in the new system could be solved through this or another reorganization. The privatization of health care services is not prohibiting to the welfare of disabled people *per se*. The needs and demands of hard of hearing people may be satisfied through whatever mixes of public and private services are appropriate in the national context. As such, this is not an exhaustive description or analysis of the Dutch health care system. Rather it is an attempt to investigate the transition from policy to practice. In this case, the everyday practice of hearing aid distribution.

Theoretical Framework

Hearing Disability as a Sociotechnical Matter

Whether in the home, at work or leisure, technology plays an important role in the lives of people with disabilities, and also in the way disability is conceived, experienced, and framed in society (Goggin & Newell, 2005b). Today, hearing loss affect approximately 10% of a country's population. The majority of this group is hard of hearing.[4] A hearing loss can affect individuals of all ages and may occur at any time from infancy through old age. The ability to communicate successfully with other people is often considerably reduced when a person cannot hear everything that is being said. Many people with hearing loss experience emotional or social difficulties and isolation due to miscommunication and misunderstandings. Devices and systems based on information and communication technologies are widely implemented as assistive tools for hard of hearing people, among which the hearing aid is the most common. A hearing aid is an electronic device that amplifies and changes sound to allow for improved communication. To obtain a hearing aid, one consults an audiologist or a dispenser[5] to have the hearing loss measured and depicted as an audiogram before selecting a hearing aid.

With the digitization of hearing aids, there has been an expansive growth in the market for hearing technologies. Digitization indicates that the sounds coming into the hearing aid are converted into "bits" of data - numbers that can be manipulated by the microprocessor inside the hearing aid. This manipulation makes it possible to tailor and process sounds more precisely, compared to analog (non-digital) technology. Digital hearing aids thus, offer more flexibility for the fitting procedure. The dispenser can tailor the hearing aid allowing for several listening modes, automatic volume control, and automatic noise reduction. The hearing aids can also be programmed to make automatic adjustments according to soundscape.[6] But while digitization has increased flexibility, the complexity of the fitting procedures has increased. In response, hearing aid producers invest a great deal in developing user-friendly fitting instruments for dispensers. These interfaces are also designed to facilitate a holistic consultation between the dispenser and their clients and may increase the quality of service provision. However, I argue that technological innovations cannot be seen in isolation from the sociopolitical system in which they are used. We need a theoretical framework that can capture the interplay between technology and society.

The field of Disability Studies has given us important new perspectives on disability, particularly by drawing attention to previously unwritten histories of disability, the social construction of disability (and normality), and the experiences of people with disabilities as a minority group. Despite the wide variety of approaches and topics, surprisingly few studies have developed a critical analysis of technology. This is unexpected given that technology is widely implemented in rehabilitation programs and often plays an integrative part in many disabled peoples' lives. When technology is actually addressed, often it is treated as a "black box," (i.e., as an independent variable that explains social developments in a unilinear fashion). The content of technology is not seen as problematic or in itself in need of any further analysis. The lack of critical engagement perpetuates a potent myth about technology: that technologies are liberating for their projected users, while paradoxically being held to be value-free (Goggin & Newell, 2003). Technological solutions are held out for this potential to abolish or ameliorate the disability that is seen to lie within the individual. In its reliance on technology as a fix to more complex social problems, the reductionist gaffe of the medical model on disability is reproduced. This approach is inadequate if we aim for a more complex understanding of disability, including its material dimension. Therefore, I suggest taking Disability Studies in a new direction by combining it with perspectives from the field of Science and Technology Studies (STS), a field that seeks to open the "black box" and illuminate the interplay between technology and society.

Through studies of emerging knowledge, research practices, and the study of political institutions, the STS field has demonstrated how the idiom of "co-production" importantly extends the vocabulary of traditional social sciences, offering fresh analytic perspectives on the nexus of technoscience, power, and culture (Jasanoff, 2004). The concept seeks to provide a theoretical perspective on how systems emerge as a result of the interaction between the level of social organization and the level of technological production. Technology is not an external determinant of social order, but neither is the opposite the case, that social structures alone can explain technological developments. Neither science and technology, nor society, are transparent entities with a monopoly on explanatory force. On the contrary, they are mutually constituted in the same historical process. The concept of co-production illuminates how technoscientific knowledge both embeds and is embedded in social identities, institutions, representations, and discourses (Harbers, 2005). Accordingly, it is argued that ways of knowing the world are inseparably linked to the ways in which people seek to organize and control it. Moser (2003, p. 27) has noted that we should "treat material environments and objects not only as resources or props, which can be mobilized by humans partaking in interaction, but as constitutive of and participating in the structuring of action, as part of the conditions of possibility of action as well as of actors." The notion of co-production thus allows us to intervene in the field of hearing disability as a sociotechnical domain. Alleged essences of science and technology, such as objectivity, neutrality, and efficiency are replaced by detailed empirical accounts of the relationship between technoscience and social order.

”Technology” is of course, in itself, a slippery term and difficult to define. For the intervention in the Dutch distributive system, I use Bijker's (2006) broad definition: At the most basic level technology refers to sets of physical objects or *artifacts* such as a hearing aid. At the next level, it also includes human *activities*, such as in the technology of doing a hearing test," where it also refers to the designing, making, and handling of such tests. Finally, and closest to its Greek origin, technology refers to *knowledge*: it is about what people know, their expertise, as well as about what they do with devices. Technology, therefore, is not only machines or procedures to perform a special task, but also the social and cultural context within which techniques and artifacts are being developed and applied. A context which, in the Dutch case, can be understood as an emergent corporate discourse on disability.

An Emerging Corporate Discourse on Disability

In a market, economic scarcities and externalities have to be managed. Traditionally, regulation refers to the direct intervention of the State, as a last resort authority, that defines how economic agents are allowed to use the resources in a common economic space. Typically, the regulation of public utilities sets the content of the services provided to a client and fixes the frame of the relationship among service providers. Under the current Neoliberal rule, interventionist government policies are attacked for their cost in personal freedoms and economic efficiency. Instead, a new model of a regulatory regime based on decentralized and State-free regulation is proposed. It is now a desideratum that corporations, professionals, and consumers will regulate themselves and manage a wide variety of policy matters formerly left to the state, including the "problem" of disability. The idea being that stakeholders dissatisfied by the parties they are interacting with can set-up new networks or relationships, wherein standards and control mechanisms can be negotiated. The vestigial role of the government bureaucracy or regulatory agency is only to set minimal rules of conduct that enable the market to perform. But the European governments' newfound trust in the market and its claim for individual freedom and power has not gone by undisputed, and an extensive counter debate has erupted. Authors are concerned about the lack of democratic control in markets dominated by multinational corporations.

Goggin & Newell (2003; 2005b) have identified what they see as an emerging corporate discourse on disability.[7] They are concerned with how multinational corporations increasingly are designated control over developments and regulation of the technological markets that affect the daily lives of disabled people. This shift in power occurs in conjunction with the transnational commerce often referred to as globalization. Following the success of the corporate model at a national level, many corporations have become transnational or multinational corporations, growing beyond national boundaries to attain sometimes remarkable positions of power and influence in the process of globalization. Such multinational corporations are the predominant form of business in the European market for hearing technology. Growth by expansion, acquisition, or merger has resulted in a plethora of groupings scattered around the globe.[8] While dispensers operate on national and local level, the hearing products they purvey, and the technologies that they work with are the result of centralized research and development. In the spread of corporations across multiple continents, the importance of corporate culture has grown as a unifying factor and a counterweight to local national sensibilities and cultural awareness. In addition, the complexity of ownership and distributional chains, which transcend national boarders and regulations, makes it challenging to regulate the behavior of these powerful actors within national legislative frameworks. The concern here is that by deregulating disability markets, politicians relinquish the opportunity for democratic control on issues that influence the lives of disabled people in critical ways.

Related to this concern, Rose (1999) has coupled the increasing control of corporations with a new form of political power. To understand this shift, he mobilizes Foucault's concept of "governmentality." The argument is twofold and relates to distribution of power in advanced liberal government and the constitution of citizenship in this context. First, governmentality designates a society in which power is not centred simply in a state or in transnational corporations. Rather, power is dispersed across a network of loosely connected sites. With the commercialization of disability markets, the "freedom" and "power" of disabled people are increasingly articulated through the market, as the freedom to choose and the power to purchase. In this situation, the "consumer-citizen" emerges and is required to play a role in constructing and policing these zones of limited autonomy and freedom. As consumers, disabled people are free to choose a service provider and negotiate an individual service package with insurers and dispensers. But, with the freedom to choose follows new responsibilities. Rose underlines the way in which advanced liberal forms of government rest upon the activation of the powers of the citizen. As governments retract their regulatory power in the market, the hard of hearing are supposed to act as self-activating citizens and do the work of making choice, competition, and new technologies possible. The critical question is how liberating the freedom and the power of the market really is for disabled people, since there is considerable work involved in being free to choose. It demands a highly sophisticated and active subject to stay informed about product developments and service standards. What is more, the power to purchase is unevenly distributed. The market tends to produce difference.

Through privatization of service provision, disability is turned into an individual matter that can be managed and dealt with in the market place. The challenge is how to ensure the consumers, as a collective, good quality products and high standards services. The Dutch government has renounced state intervention for self- or co-regulation. The government encourages the actors to establish standard committees, quality assessment boards, and consumer platforms to regulate the hearing aid market. Hearing aid users' participation in such regulatory initiatives may bring the market closer to the consumer and stimulate a more user-driven development of technology. However, participation requires substantial resources. Given that many user organizations struggle financially and have problems recruiting volunteers, the opportunity to act as a strong player in this deregulated market may, in reality, be scarce.

In order to further understand the contemporary shaping of disability in the corporate field, we need to recognize and chart the ways that new institutions are purveying power and look at how such self-regulation within specific markets actually occurs. With the commercialization of hearing aid market, follows a social construction of disability as a consumer issue, and the disabled subject as a consumer citizen. The pertinent question is what normativities underlie this construction and what interests it serves. With the notion of a corporate discourse on disability I want to open up the sites of active citizenship and consumerism for an exploration of the cultural practices accompanying new hearing technologies. There are, however, limitations to the discourse theory literature. Authors tend to focus their critique on the level of policy making and regulatory regime. This offers an interesting and important framework for the analysis of the way technology is used to manage disability. But my interest is not restricted to exploring this new corporate notion of disability as free-floating discourse. In line with the concept of co-production, I am interested in how the corporate discourse emerges through the interrelatedness of disability, technology, and government. Thus, I propose to extend the analytical framework and look at what happens to policy in practice as the Dutch system for hearing aid distribution is deregulated.

Methodology

To explore the new Dutch system for hearing aid distribution, I take a two-fold approach. First, I map the issue of hearing disability as I have encountered it in my studies of public policy. Then, I move from public policy to everyday practice, from formalized deliberation to actual implementation, as I study what happens when the development of policies on disability are to be transformed into dynamic relationships between policy makers, practitioners, technologies, and the hard of hearing. In the analysis, I juxtapose policy and practice to explore the interferences between different modes of ordering hearing disability as they occur in practice. The contribution of this kind of multivariate research methodology is to bring both discursive and material dimensions into the same frame of study, and to posit their relationships on the basis of first-hand empirical research.

The data for the study was collected during fieldwork in 2005 and 2006.[9] The material stems from three sources: written material, in-depth interviews, and participatory observations. To map the underlying principles, key objectives, and means of implementation for the health care reform, I have reviewed policy documents issued by the Dutch Government, in particular the Ministry for Health, Welfare and Sports.

The description of the new system for hearing aid distribution is based on reviews of governmental action plans on disability policy, a report issued by an evaluation and implementation project funded by the government (Aangepast Zorgmodel Slechthorenden - AZOS), and a protocol released by the national committee for audiological assistive technologies (Nationaal Overleg Audiologische Hulpmiddelen -

NOAH). The review of these documents helped me identify key actors and their roles in the new distributive system. Paradoxically, while the documents explicitly deal with hearing aid distribution, the texts make no attempt to problematize the role of technology. Rather, the underlying assumption seems to be that technology has a neutral and/or predictable positive effect. The underlying assumption seems to be that as long as access and availability to more and "better" technology is ensured, the lives of hard of hearing will improve.

I conducted 13 in-depth interviews with actors who were involved in shaping the new Dutch health care policy. The informants were representatives of dispensers and producers (4), audiological professionals (3), user organizations (3), and professionals from the support network (3). All the informants were in some way working with hearing technology had a stake in the reform process. The interviews lasted between one to three hours and were carried out in the offices of the informants. All conversations were recorded with a MP3 player and transcribed. The transcriptions were then sent to the informants for corrections and further comments.

With my exploratory approach, I did not have a predefined hypothesis or theory to test. Instead, it was important that the analysis was grounded in the experiences of the actors. Therefore, I used a semi-structured interview guide, a topical list with open-ended questions where I asked the informants to articulate their situated viewpoints on the reform. The themes for the interview guides were developed iteratively, based on the policy review, issues that had come up in previous interviews and more specific information on the informants gathered from public documents, websites, and research reports. In the interviews, I asked the informants to identify what they considered to be the main drivers in the emergent system: who they saw as the key actors and their role in practice; what role they assigned to technology when it came to enactment of disabled identities and their view on involvement of end users in sociotechnical policy and practice. In addition, I actively encouraged the informants to raise other issues that were important to them. The interviews allowed me to probe theories, analysis, arguments and concepts, by entering into a dialogue with the informants, inviting them to take part in the analytical process and verify my data. Structure and meaning is then constructed in common by the researcher and the informant. In addition to creating room for articulation of what the interview subject has already digested and thought through, the aim was also to facilitate new reflections and open up fresh insight.

In order to trace the enactment of the new policy in practice and learn about how practitioners used hearing technologies, I set up two weeklong visits at an audiological clinic and a hearing aid dispenser. During these visits, I participated in consultations between the professionals and hearing aid users to observe the interactions between humans and technology in an organizational setting. In the time between appointments and during lunch breaks, I asked questions about the distribution process and the professionals explained and demonstrated how they use and their level of experience technological tools. During these visits, I took notes that were later transcribed. During these interviews, emerging tensions in the field were explained as a result of sociopolitical factors. When I started participating in work practices I became aware of the active role of technology. The observations made at the dispenser and clinic gave me empirical examples of the tensions that were brought up during interviews. I use these examples to ground the analysis in practice.

Since the study was undertaken when the health care reform was still in process, there are limitations to the results. The empirical examples that are given are taken from some practices in some locations at a specific time period. I use the empirical examples in order to begin more general discussions on the use of hearing aids as a rehabilitative intervention. Without a doubt, there are several more voices and concerns that should be taken into account in the discussion. For instance, while I have chosen to use examples from one hearing aid dispenser, I could, and perhaps should have used several. However, I do not intend to depict the field as united in definition and practice. Instead, I wanted to explore the complex interplay between social factors and technology in the field of hearing disability. The aim of this qualitative approach is to bring forward and discuss policy related issues as they play out in practice. Differing from (more commonly found) quantitative methodologies in the health care policy field, I wanted to add to the plurality of accounts on hearing disability. As such, the article can be read as a contribution to the bottom-up assessment of the Dutch health care reform.

Results and Discussion

Technological Management of Disability

"The policy on aids is aimed at making necessary care facilities available and accessible so that disabled people can function and participate in society as normally as possible. Fewer rules and a decentralized approach bring the responsibility for providing aids much closer to the parties directly involved. This offers more opportunities for demand-driven care and coordination of the different provisions" (Ministry of Health, Welfare, & Sport, 2005b, p. 10).

One of the ways in which disability is "managed" in our modern, high-tech societies is through the distribution of assistive technologies, as a rehabilitative tool, or, as in the above statement, a "normalizing tool." Following contemporary Dutch health care policy, a demand-driven hearing aid distribution is sought by deregulation of the current distributive system and decentralization of responsibility from the State to the market, assuming that the market is more receptive to the demands of the user. Thus, a new model for hearing aid distribution for adult hard of hearing people with moderate and uncomplicated hearing loss is now being planned and tested. The system is based on a protocol developed by NOAH and the implementation and evaluation project AZOS (AZOS, 2006). Both projects deal with system innovation and quality control in the hearing aid prescription process. Throughout the process three aims were identified:

- Reduce pressure on the specialist service and reduce waiting lists for patients.

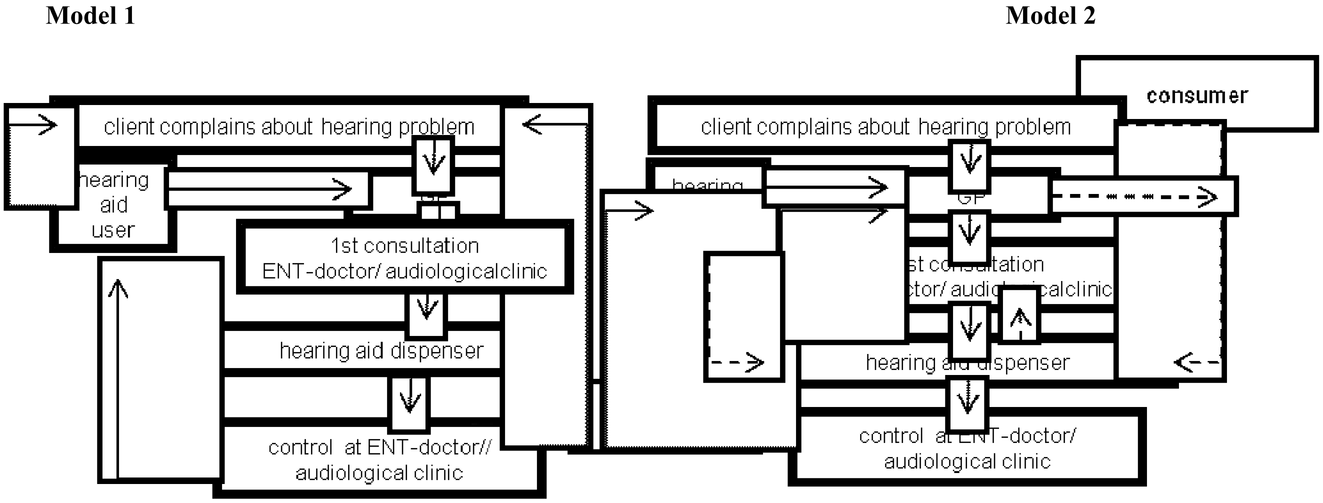

Figure 1: Schematic overview of previous care model (1) and new care model (2). The dotted line in the right hand side figure illustrates the new commercial route. In the new model a specialist instance is only involved when the dispenser detects indications of complications (AZOS, 2006).

- Control cost while maintaining the same qualitative level of service.
- Increase transparency and accessibility for user group.

Before the deregulation, the trajectory a hearing disabled patient had to follow was clearly regulated (see model 1). In order to receive reimbursement for a hearing aid, the patient had to visit an ENT doctor or an audiological center to get a diagnosis and a prescription for hearing aids. With that prescription, the client went to a hearing aid dispenser who selected and fitted a hearing aid based on the prescription from the audiological specialist. Then, the insurance companies required that the client go back to the specialist to have the fitting approved. Only then would the insurance companies reimburse the clients costs.

Following deregulation, a new routing system emerged (see model 2). The goal is to develop a system where the hearing aid dispensers are able to perform rehabilitation with hearing aids without any intervention from a specialist. In the screening process, it is the responsibility of the dispensers to assess whether the clients need treatment from a medical doctor or audiological specialist, or whether they can follow a commercial route. In the new system, the three central entities that are given responsibility for hearing aid fitting are still the ENT doctor, the audiological clinics, and the hearing aid dispensers.[10] The change is that the hearing aid dispensers are now delegated 1st line responsibilities and the required specialist control on hearing aid fitting is lifted.

As a result of the deregulation, NOAH identified a need for a protocol to manage the screening of clients and redirection to the proper service provider. The objective was to develop guidelines for hearing aid fitting that ensures the quality of service without compromising the principles of deregulation. As a co-regulative initiative, the protocol was written by stakeholders from the medical profession, industry, user organizations, and policy advocates. The protocol takes as its starting point the deregulation and a shift of patient streams, and then describes a model including each trajectory for hearing aid fitting in detail and lists the criteria for further routing in the system, when needed. While in the earlier system the routing was regulated, the new protocol is only meant to work as a guide for professionals and has no decisive power. To develop a system that could implement the NOAH protocol on a wide scale basis, the AZOS project was initiated in the beginning of 2005. The project was also set up to evaluate the performance of the new system.

The NOAH protocol emphasizes customer choice. As costs are now increasingly covered by the customer, they should also have a choice of caregiver, hearing aid dispenser, and hearing aid. As regulations are lifted, it is anticipated that competition will rise among hearing aid dispensers. Competition shall in turn, lead to lower prices and increase the quality of service provision. Following deregulation, the commercial routing has become the standard route for the majority of hearing aid users. With the deregulation and the introduction of the NOAH protocol, patients are transformed into consumers and patient organizations to consumer organizations. Sociopolitically speaking, with the reform towards a more demand oriented care system, the consumer becomes more central in the care process. Increasingly, consumer organizations will become important collaborative partners for providers of care, insurance companies, and the government.

Politicians Abdicating?

A central issue following deregulation is who should control access to hearing aids. While insurance companies have attained an increasing role within the new health care system, it has become clear that more freedom and power will be given to dispensers as designated gatekeepers to ownership of hearing aids. A pivotal question surfaces, “Within the new Dutch system, is there an adequate system in force to supervise the functioning and behavior of these powerful actors?" What we observe is that if the State commercializes service provisions, there is a shift from the State actually "fulfilling" a right to the State obligation to offer "protection" against possible abuses by the private actor who becomes the provider of the service. It is unclear what should be the roles of different actors. What is clear is that the State leaves much up to self-regulation by private firms in the hearing aid market and the active citizenship of hearing disabled people. Robison (2006) has argued that inherent to neo-liberalism is a distrust of politics. In the argument for deregulation of the hearing aid system, it is possible to trace an underlying lack of trust in politicians and their ability to manage complex professional practices. In an interview, one of the NOAH committee members explained the rationale behind the deregulation as follows:

> "In parliament a lot of the voting is done on matters that each politician does not know comprehensively. But that is the system, right. The policy-makers do not have the knowledge to oversee all the consequences of their reforms. For the government it is just a financial problem, they want to cut the overall costs of health care, they are less concerned about the practical details on the local level. Maybe it is not all bad that the government is for liberalization of the market. Because I think that the consumers will start to claim better quality and make up a counterforce to get it right in the end. But nowadays it is very much left up to the insurance companies and the professionals to set minimum standards for quality" (I. Olaussen personal communication, January 20, 2006).

The complexity of the issues at stake is used to justify exclusion of the State as a regulator, while distributing new roles and responsibilities to others. In line with current neoliberal creed, the management of hearing disability through hearing aid dispensing is depoliticized; removed from political influence or control because it is not seen as something that politicians can have sufficiently detailed knowledge about. Regulation of practice should be left to corporations, professionals and consumers in the market, so the argument goes. As patients transform into consumers, new roles and responsibilities are given to hard of hearing people. While the politicians are seen as unfit to regulate detailed processes, consumers are expected to act as organized, unified and (pro)-active contributors to the regulatory process.

According to background documents for the health care reform (Ministry of Health, Welfare, & Sport, 2004), it is problematic that citizens hardly pay a direct contribution to the cost of health care and therefore often are unaware of its costs and quality. As a result, it is assumed that the citizen has no direct interest in choosing the most efficient or effective treatment. By introducing the principle of cost-sharing, this is expected to change. In line with this assumption, in his analysis, the NOAH representative narrates the management of hearing disability in terms of exchanges occurring in a market. The hearing aid consumers are assigned the role of regulators, as they are expected to act in accordance with this notion of "reciprocity" and "vote with their feet" (Homans, 1961). The consumers will seek to fulfill their self-interests in the hearing aid market by selecting providers who offer the best balance between service and price and thereby, play their part to make it right in the end." Thus, in the process of shifting from patients to consumers, hard of hearing people become instruments for a market-oriented policy. Rose (1999) notes that it involves considerable work to be free to choose and participate in the re-working of governance under the rubric of industry self-regulation. In the Dutch case, we find evidence of Rose's perspective on the new ways in which "advanced liberal forms of government" rest upon the activation of the powers of the citizen:

> “Citizenship is no longer primarily realized in relation with the state, or in a single public sphere, but in a variety of private, corporate and quasi public practices from working to shopping. The citizen as consumer is to become an active agent in the regulation of professional expertise... Even in politics... the citizen is to enable his or her democratic obligations as a form of consumption” (Rose 1999, p. 166).

Thus far, I have noted that in the emerging corporate discourse on disability, deregulation takes the responsibility and control from the State and places them on professionals, corporations, and consumers to self-, or co-regulate.

Shifts in Expertise - The Dispenser as Regulator

As a result of a new stream of hearing aid consumers and increased competition, the number of hearing aid dispensers has grown significantly over the last few years. Today there are around 300 stores nationwide. In this highly competitive market, dispensers seek to sharpen their brand image, the corporate identities that make them stand out in the market. “Beter Horen”[11], the largest Dutch dispenser, has gone for a high quality product range and extensive service for a higher price. But there are also new players entering the field, the discount dispensers. “Hans Anders,”[12] originally a Dutch optician chain, is now also competing in the market for hearing aids. The strategy of this firm is to offer low price hearing aids that are fully reimbursed by insurance. Such competition and market segmentation based on price is in line with the governmental policy of generating more choice for the consumer. Especially now, as the consumer is made to cover larger parts of the costs themselves, it is considered important that there are affordable generic alternatives on the market. But, this policy is not undisputed. As the hearing aid dispensers become the 1st line of service, the initial meeting a hard of hearing person has with the hearing field is with an actor who primarily seeks profit. There are concerns among the actors in the field that the focus on price and profit may overrule the requirement for quality and competence. Also, for the government it is considered important that the quality of the hearing aid fitting should not decrease as a consequence of the reform. As to quality, there is a risk that health insurance companies, in their search for the cheapest option, will not always contract health care services and products that are the best for their customers.

Another concern among key actors has been how to safeguard and supervise quality within the new system. A particular problem has been how to maintain the quality of dispensing personnel. There are institutions offering audiological education both at a vocational and higher level in the Netherlands, but formal training is not a requirement for the practice of hearing aid fitting at a dispenser. Without standard educational requirements, there are different practices for hiring and training of personnel among the firms. Most dispensers offer some sort of internal training with recruitment, but the length and content of these courses varies considerably. At a professional level, there are concerns that professionalism may decrease as a result of the commercialization of the sector, as explained by a senior audiologist:

> “I am afraid that if you compare the hearing aid fitting these days with the way that it was done say ten years ago, the people involved right now are much more commercial people, and also not what you would call craftsmen. The number of potential clients is increasing along with the demographic trends. As a result, the shops are looking for personnel that have to be very good at dealing with people. But, what do they have to know about hearing aids, only that which is of absolutely necessity. So some shops only have a minimal interest in having highly educated personnel, it will only mean higher costs having them educated, trained and

> hired, it just is not in their commercial interest" I. Olaussen (personal communication, January 20, 2006)

Also among the hearing aid dispensers a shift in priorities is noticeable. A manager at a "Beter Horen" dispenser points out that the commercialization rearranges forms of expertise. Sales and marketing skills become more important drivers in a terrain earlier dominated by audiological and medical competence:

> "I would describe our organization as a pyramid, on top is sales, we are a sales organization, and marketing is also important. Then at the lower levels are the staff with technical competence, we try to have this expertise represented also on the upper level of the organization, but sales are dominating" (I. Olaussen personal communication January 11, 2005)

In contrast to the rational assumption in policy, there are actual concerns among the actors in the field about how to safeguard quality when competition among dispensers increases. The actors worry that as specialist control is lifted in the new model, an important quality control will disappear. The challenge is noted in the evaluation report from the AZOS group (AZOS, 2006). Despite offering additional training for the dispensers participating in the trial development project, they could not deliver the quality of service that was required by the NOAH protocol. As a response the "StAr" (De Stichting Audicienregister) initiative[13] was organized. "StAr" constitutes a quality assessment and approval foundation whose purpose is to safeguard the objectivity, quality, and professionalism among the dispensers in the field. An instrument for assessment and approval of quality has been developed. A so-called "stamp of approval" to be assigned to the dispensers that manage to maintain the agreed upon quality standards. The quality control involves the technical aspects of the hearing aid fitting, as well as financial aspects of the prescription and customer satisfaction.

Nederlandse Vereniging Voor Slechthorenden (NVVS)[14], the Dutch organization for hard of hearing people, has been involved in the planning for this "stamp of approval" but its director is concerned with the criteria for such a self-regulative instrument:

> "They seek to establish some procedures and criteria that will give the shops a 'stamp of approval,' a sticker that they can put on their window to demonstrate that they operate in a professional manner. We of course welcome this initiative, but we are also critical. Maybe it will only be a self-confirming process where the criteria are based on what already exists" (I. Olaussen (personal communication December 14, 2006).

The comment made by the NVVS director echoes a consistent problem with neoclassical theory (Hecter, 1987) - and the policy reforms they foster - of how to motivate people for collective actions. Can the appeal to interest alone motivate people to adopt great reforms, whether this appeal is embodied in the legal codes, in the freedom of the market, or in schemes for new rules of the social game? It is the old question, "Who guards the guardians?" With the retraction of the State as an objective third party and the lifting of professional control, what prevails seems to be lack of control leading to a lack of trust among the actors in the field of hearing disability.

Along with the call for cost efficiency, rapid technological development is an important justification for the liberalization of the market and the new delegations of roles and responsibilities in the emerging system. The aim is to reduce pressure on specialist services. At the same time, General Practitioners are no longer seen as able to give expert advice on hearing aids because of the complexity of the technology involved. Therefore, a lot more of the consultation and detailed assessment with regard to finding hearing aids for the customer is now assigned to the dispensers. They have the time to do it, and they claim the competence. The insurance companies seem to be for it because they see that a consultation for a hearing aid fitting takes time, an hour in general. The doctors are already pressed for time and, in addition, their time is more expensive than the dispensers. There has been a shift in expertise. But, what type of expertise does the new 1st line service offer? What implications arise for service provision when rapid technological development and increased corporate control are becoming the main drivers of the field? And, how does this emerging corporate order interrelate with the technologies at work in this new system for hearing aid distribution? According to policy, it is proverbial that businesses are closer to the customer, and in a better position to know their desires.

Organizing Skills

For "Beter Horen," a focus on sale is coupled with a focus on service, and what the manager calls the human factor. In the recruitment and training of personnel, they are emphasizing the social evaluation as the most important part of their consultation. In the course of training, they are not primarily occupied with the technical side of the job, but the human side. This example discusses how to deal with the clients:

> "Many people come here and they are in tears, it is hard for them to accept that they need hearing aids, they feel ashamed. When we recruit people we look for people with people-skills. For us being in the hearing aid business is about a lot more than technical products" (I. Olaussen personal communication, January 11, 2005)

This focus on social interaction does not mean that there is no technology at work. On the contrary, the entire process of getting an appointment, the hearing test, fitting a hearing aid, and administration is all conducted by means of technologies.

In fact, also the social evaluation is technology driven. At "Beter Horen" they have their own protocol which uses an interactive computer based tool, the "Amplifit."[15] The dispenser sits down with the clients and guides them through the assessment of their social needs. As needs are identified they are registered in the program. The result is an auditory profile and a suggestion for a hearing aid. When asked whether this tool risks dislocating the decision making process, the store manager explains that the technology today is so complex that they have no chance in tackling what goes on behind the interface. It would take too much time. Instead, they follow a standardized assessment scheme that makes the customer aware of their needs. They do not sit down and talk to them about technical details. It used to be like that, that the dispenser was all about technical things. Today, it is the opposite. Now they start out asking the client whether they watch television, whether they are active socially and so on, what they want to use their hearing aids for. Then, they select the right device. But, it is the software that makes the technical assessment. It is the machine that suggests the most adequate hearing aid.

Within the health profession, there have been some vocal efforts at curbing excessive scientific and technological zeal and "treating the patient as a person." Katz (1984) argued that the practice of patient-doctor communication has been given short shrift in this age of science, in the expectations that treatment only requires silent scalpels, wordless monitors, and mute pharmaceutical agents. Often, hard of hearing people feel they lack a language to communicate their experiences of disability, the technical terminology of medicine seems unfit for social talk and their hearing aids, they are often told by advertisement is something to hide away. What may ensue is a cultural void of gestures and words that communicate experiences of disability in everyday settings, thus, lack of public awareness and social understanding necessary for the sociocultural accommodation of disability may prevail. The incommunicability of disability may work to isolate hard of hearing persons and strip them of cultural resources, especially the resource of language. It is therefore, worth noting that according to research and studies on service provisions among dispensers user satisfaction is quite high.[16] The dispensers believe that the satisfaction is due to their focus on the human factor: the time and space they offer for a holistic assessment of needs and aspirations. It seems that the language and interaction oriented toward the client as a social person is hitting the target with consumers.

Dispensers inform us that hearing aid fitting is increasingly about the ability to assess the social needs of the clients, engage with their life situation. In fact, the rapid developments and constant renewal of programs and artifacts makes it hard for the dispenser to follow the technicalities of the procedures and products, it is preferable to use an interface, considered more accurate, safe, and efficient. Following the increased complexity of the fitting procedure, dispensers have made it a strategic choice to rely on the producers and their software when handling the technical aspect of the hearing aid fitting. The producers follow up by designing assessment programs that give dispensers a user-friendly tool that allows for rapid adaptation by personnel and an efficient answer to the administration of a growing client base. At the same time, the technical skills are downplayed. The packaged assessment software reduces the complexity of the fitting procedure, but it also limits the number of factors it assesses, (e.g., focusing on volume, but ignoring speech discrimination). According to dispensers, the rapid technological development is a challenge for formal education within the field. Formal training programs do not manage to keep up with the specialized developments as new models are introduced on an annual, sometimes biannual basis. In my interviews with dispensers in the field, I have asked how they acquire the competence needed for their practice. Most favor the in-house training and the training offered by producers. The following response is typical:

> "Everything I have learnt I have learnt here at my work. Then we learn a lot from the producers of course. They travel around and demonstrate new devices and train staff, so that is the most important source of new knowledge" (I. Olaussen personal communication, January 11, 2005)

Paradoxically, the same argument about the rapid and complex technological development that was earlier used to legitimize the pivotal role of the hearing aid dispensers in the new system is now justifying the dislocation of technical competence and decision-making from the same practice. The audiologist does not see technical or audiological knowledge as their foremost competence; it is their social skills that are essential for their work. Apparently, a consequence of the rapid technological development is that producers become the beholders of knowledge that is considered relevant and desirable among the practitioners in the field. It is their knowledge that is transformed into assessment schemes, fitting procedures, and products and services for hearing aid users. What then is the link between the way corporations organize research and design (R&D), specifically, the choice of multinational companies to operate centralized R&D structures and the type of innovations they produce? A critical question is whether the centralization of R&D will let their commercial interests and the dispensers interrelated needs for efficient service delivery overrun the sensibility towards clients needs and aspirations at the local level. There is a risk involved in using standard assessment software. It may lead to reduced sensibility for the ongoing social interaction if the personnel start taking their eyes off the client and leave the assessment and decision-making to programmers situated at international R&D units.

Given the centralization of R&D processes, I argue that the market is not, as assumed by policy, necessarily closer to the hearing aid users than the State, and thereby, not automatically in a better position to pick up on their demands for service provisions. Rather, following the multinational character of the hearing aid producers, the local practices and R&D are in fact being separated, and so are users and producers. Such separation can be problematic since there is not necessarily a unilinear correlation between the social assessment of needs and aspirations at the local level and the materialization of knowledge through technology at the central level. The interactive consultation of social needs may work well, but this is not necessarily securing the technical solution. And vice versa, a sophisticated technological product may be developed, but there might not necessarily be an actual social need for it.

Technology at Work

Commercialization and shifts in expertise seem to create tension at the organizational level of the dispensers. Following the increased competition, sales, and marketing skills now gain importance, sometimes at the cost of audiological competence. This shift in priorities is also reflected at the level of the technology at work in these organizations. When the producers launch a new model of hearing aid, fitting software follows. This interface often comes with different layers in which the dispenser can choose to operate. The layers have varying degrees of complexity with regard to what kind of adjustment that can be done on the hearing aid. In the simpler version of the program, you upload the client's audiogram and adjust volume according to it. The procedure is fast and simple. But, as already mentioned, there are also limits to such fittings, something that specialists have become increasingly aware of, as explained by a senior audiologist at an audiological clinic:

> "The most common problem we have with the fitting done by the dispenser is that they adjust the volume, but do not adjust the discomfort level on the hearing aids accordingly. This happens if the dispensers base their fitting only on the client's audiogram. Many clients complain about the volume, they cannot hear, "could you please turn up the volume a little bit", they ask. But with a high frequency loss, you cannot hear vocal sounds very well. The vocals are important for our speech understanding. Then adjusting volume will not improve the client's hearing. You need to fine tune the hearing aid, try to optimize the fitting according to what hearing the client has left. At the dispenser they do not measure speech understanding or discomfort level, they lack the expertise and they do not have the equipment for these tests. Consequently, they cannot fine tune the hearing aids" (I. Olaussen personal communication February 3, 2006).

In order to fine tune the hearing aid, one must use the advanced layers in the fitting software where other parameters than volume are adjustable. When personnel are not educated audiologists, they are often not aware of or trained to operate these interfaces because it demands a higher level of audiological competence. In order to serve the client's needs, the fitter must understand the interrelatedness of elements of sound, for instance between volume and discomfort. While a user-friendly interface might be an efficient tool, it is also crucial that personnel are aware of its limitations and know how to interpret the client's complaints and when to use the more complex layers. In some cases, when dispensers cannot maximize the technical potential of the hearing aid, the moral responsibility to adapt is passed on to the client, as we hear from the senior audiologist:

> "Many of the clients coming here are frustrated because they can not get their hearing aids to work properly. They have been told by the dispenser that it is them who have to be more active in their listening, position closer to the person speaking, use the volume control more and so on. I think that is bad because then it is

> the dispenser who tries to conceal their lack of competence by blaming the users, making them compensate for a poor fitting job. The producers know that the personnel at the dispenser have to like their software in order to sell their hearing aids. If the personnel struggle with the fitting they will not use that program and they will not sell the hearing aids. Therefore, the producers make simple software, even though it might not be the optimal for clients" (I. Olaussen personal communication February 3, 2006).

Ironically, clients who start in the commercial routing system can end up in the specialist system because of the lack of technical expertise at the level of the dispenser. Because of long waiting lists, many clients are happy they now can go directly to a dispenser. It is easy to make an appointment and the consultation does not take much time because the dispensers only set the audiogram. The risk is that the quality of the fitting is reduced. But, for most clients it is hard to assess the quality of the service they receive. The dispensers are seen as the experts and the clients trust them to be competent. In order to manage a growing customer base, and without formal requirements for training, what results is increasingly that dispensers use programs that reduce the complexity of the fitting. Thus, allowing more clients to get service, but at the same time, compromise the opportunity for fine-tuning of hearing aids. Through the design of different layers for hearing aid fitting, producers actually invite such a shift in quality.

While I have proposed that the two dominant drivers in the deregulated system for hearing aid dispensing are rapid technological development and increased competition, it is also my supposition that these cannot be seen in isolation. They are co-producing the emerging system. Technology is not inevitably leading to less local knowledge and control. However, when intensively used as an administrative tool, in a commercial system where the priority is sales and personnel that can attract customers, this lack of knowledge and local control may be the result. Emphasizing the human factor, assessing a hearing aid fitting according to lifestyle and individual preferences and the context of use at first seems as a progressive move in the direction of a more user driven development. However, the administrative framing involved in implementing a standard assessment tool risks dislocating expertise and decision-making.

The result is that dispensers weaken their sensibility for the local context and the ongoing social interaction with clients. The way that the corporate order intertwines with technology at work in these practices offers possibilities for new relational forms between dispenser and clients, but the same tools may also compromise the quality of the service provisions. There is potential tension between standardization and flexibility, between profiting on a growing customer base, while offering high quality service provisions, tension that is not addressed by policy. What is further thought provoking is that the new system thus far, has not proved to be cost efficient. Because of unsatisfactory fitting jobs, many hearing aid consumers end up in the specialist system after all. Therefore, the cost of hearing aid distribution is today the same as before the de-regulation at the same time as there has been a slight overall decrease in the quality of service provisions (AZOS, 2006). The difference is that now the consumers increasingly contribute to cover the costs.

Summary

Market-oriented policies are currently involved in the shaping of a new system for hearing aid distribution in the Netherlands. In this system, a large part of the expertise and control over hearing disability has shifted from the medical field into the market. Rather than depoliticizing issues, negotiations over criteria for protocols and procedures are brought out of the central political body and down to the level of stakeholders operating in the market. One of the problems with “light-touch” regulation is that the market is narrowly conceptualized in terms of neoclassical economics, a form of economics that assumes that competition inevitably leads to lower price and increased quality of services. By using the concept of co-production to follow this policy in practice, I have tried to show that this assumption is not necessarily the case. Profit drive inspires development and use of standardized assessment programs and bureaucratic tools for the administration of a growing customer base.

These types of programs are designed to evaluate and systemize the human factor and reduce the complexity of individual cases of hearing loss and translate their characteristics into suggestions for hearing aids. With regard to knowledge and control in relation to these tools, it seems that dispensers do not always need to understand the audiological calculations that these suggestions are based upon. In an evaluation report, AZOS (2006), explains the shortcoming of the new system as dispensers’ lack of competence. Consequently, more training is recommended to improve the situation. With the notion of co-production, I have strived to show that technology at work in the practice of hearing aid distribution also plays an active role in the production of the new Dutch system, and actually supports the shift in quality.

To what extent commercialization makes both practitioners in the field and consumers of hearing aids more dependent on a technology driven industry, is a question for further investigation. However, as producers increasingly are seen as key experts within the sector, their control over the sociotechnical aspect of rehabilitation is expanding. While hearing aid dispensers, audiologists, and insurers are identified as central actors in policy documents, the role of the multinational corporations and their interventions in the field is not discussed. Yet, given that the transnational competition model has been adopted by the Dutch government, it is the policy of these corporations that grows in importance since decisions made by transnational corporations in the hearing aid industry directly affect the lives of hard of hearing people. In an epoch in which the State is being reshaped and the market takes on additional significance as the distributor of welfare services and identities among disabled people, the corporate discourse on hearing disability, including its ordering of hard of hearing people and the audiological practices that surrounds them, must be opened up for public scrutiny in order to prevent institutions from forming a self-governing consensus that disregards the well being of the community. Herein lies a challenge for the hard of hearing community to explicitly address the issue of technology, to organize on an international level, and to conduct independent research that will enable them a powerful voice in the future development and distribution of hearing technologies.

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Acknowledgments

The author would like to thank the Faculty of Arts and Culture at the University of Maastricht for providing me with excellent office facilities during my fieldwork in the Netherlands. I am also grateful to Dr. Roland Bal and colleagues from the Institute for Health Policy and Management at Erasmus University in Rotterdam

for their helpful comments on an earlier draft of this paper. I want to thank the anonymous reviewers for carefully reading the text and offering valuable corrections and suggestions. Last, but not least, I am tremendously grateful to the informants who patiently shared their time and experiences with me.

End Notes

[1] For more information about the Dutch health care system please visit the website of the Dutch Ministry of Health, Welfare and Sport: http://www.minvws.nl

[2] As determined by the EC Treaty, the principle of solidarity governs the funding and organization of health care whereby to improve efficiency, while guaranteeing access to high quality healthcare services for all citizens. The Netherlands has also adopted the UN declaration on health in its national legislation (For more information on the charter please visit: http://www.unhchr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En?OpenDocument). Through this charter, the Dutch government is committed to maintaining a health care system that provides people with access to essential medical care of good quality.

[3] So far the Ministry has not released any overall or conclusive assessment of the reform. In provisional statements, the Ministry has pointed out that throughout the 1st year (2006) of the new Health Insurance Act, there was a decrease in the average nominal premium and 18% of the policy holders switched to another insurance company. According to the Ministry, the number is an indication that the policy market has become competitive and that the consumers are today more aware of health care cost. The Dutch model has also generated international attention. The Minister for Health has given official speeches both in Germany and Hungary regarding the opportunity for these countries adopting similar approaches to health care reforms (Ministry of Health, Welfare, & Sport, 2007a; 2007b).

[4] Sound varies in amplitude (loudness) and frequency (pitch). With sounds and spoken language as a primary means of communication our hearing is most sensitive for the pitches that are produced in speech. A hearing loss entails that while some will hear the sound loud and clear, for others, the very same sound will be muffled or even completely inaudible. Generally, if the gain is increased, a pitch is more likely to be perceived. The degree of a hearing loss is categorized according to how much louder a sound must be made over the usual levels before the listener can detect it. Hearing sensitivity is generally indicated by the quietest sound that an individual can detect, called the hearing threshold. This threshold can be measured by an audiogram. In profound deafness, even the loudest sounds that can be produced by the audiometer, the instrument used to measure hearing, may not reach threshold. There is another aspect to hearing that involves the quality of a sound rather than amplitude. That aspect is usually measured by tests of speech discrimination. For more information about hearing disability, hearing tests, and hearing technologies the reader may find the UK website of The Royal National Institute for the Deaf and Hard of Hearing (RNID) helpful: http://www.rnid.org.uk/information_resources/ However, if you are looking for country specific information, it might be best to consult the web site of the international federation for hard of hearing people and access your country's organization from there: http://www.ifhoh.org/

[5] Audiologists have a clinical/educational background that emphasizes diagnostic testing, amplification technology, hearing science, and assistive device fitting. Audiologists also dispense hearing aids. In the Netherlands, the title Audiologist is protected by law, which puts a restriction on the number of specialists operating in the field. Hearing aid dispensers (hearing aid dealers) are traditionally different from Audiologists because they do not diagnose hearing loss or balance disorders and deal strictly in hearing aids only. For more information about Audiology you can visit the website of the American Academy of Audiology: http://www.audiology.org/

[6] In addition, digitization has also made hearing aids compatible with solutions based on blue tooth technology, allowing the users to integrate their hearing aids their mobile phone or MP3 players, and FM listening systems and a separate wireless microphone transmitting voices wirelessly to the hearing aids reducing the effects of distance and background noise.

[7] The authors are not explicit in their definition of "corporate." Herein lies a potential weakness of their theory since the term corporation has different meanings in and between different national contexts. While in the US, the predominant form of corporation is the privately owned business corporations. In the UK, on the other hand, corporations are more often publicly owned businesses. Corporations may also be formed for local government (municipal corporation), political, religious, and charitable purposes (not-for-profit corporation), or government programs (government-owned corporation). I use the term "corporation" here to refer to the modern business corporation, a privately owned company pursuing profit in the market for hearing technology.

[8] Take for instance "Beter Horen," a hearing aid dispenser chain in the Netherlands. The company is owned by the Italian based "Amplifon Group," which operates throughout European countries under different local names. "Amplifon" develops hearing test

software and hearing aid fitting processes that are used in these countries. In addition, “Beter Horen” has a deal with “GN Resound” and markets their products as their “house brand.” ”GN Resound” has roots in the telegraph industry and is now also a global manufacturer of technology headsets, hearing instruments, and audiological diagnostic equipment. “GN Resound” is listed on the Copenhagen Stock Exchange. The company has almost 40,000 registered shareholders and the foreign ownership in the company is estimated at more than 50%. The majority of “GN Resound’s” manufacturing is located in China, with more than 95% of sales generated outside of our company headquarters in Denmark. The corporation currently employs approximately 4600 employees worldwide, with the majority of employees based overseas in North America.

[9] The empirical material is from an ongoing Ph.D. project investigating use of technology among hard of hearing people in the Netherlands and Norway. The core of this project is an ethnographically inspired study of hard of hearing users. Although the results of this study are not an explicit part of this article, the concerns that are raised were identified partly through my interaction with hearing aid users. The users’ needs and aspirations thus form an important background for this article.

[10] Additionally, the GPs are often important actors for the initial screening

[11] For more information on “Beter Horen” please visit their website: http://www.beterhoren.nl

[12] For more information on “Hans Anders” please visit their website: http://www.hansanders.nl/

[13] For more information, please visit the Star website at: http://www.audicienregister.nl/

[14] For more information on NVVS please visit: http//:www.nvvs.nl

[15] For more information, please visit: http://www.amplifon.com/wps/wcm/connect/SiteCompanyCom/en/Professionals/Professional+Organisation/The+Protocol/Amplifit/

[16] For more information on this study, please see: http://www.oorakel.nl/shownieuws.php3?id=740

The Role of Non-Profits in Shaping Civil Rights: Understanding of Disability in Families of Children with Autism

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Abstract: Challenges associated with disability are increasingly linked to civil rights oriented policy solutions. Nevertheless, public policy theory suggests that issue definition includes competitive promotion of preferred linkages of problem definitions to policy solutions among stakeholders. In this article, we use the case of autism to examine the role of nonprofits in shaping understandings of disability.

Key Words: Autism, nonprofits, families

Introduction

The extent to which framing of rights through social movements benefits all members of society, including the disadvantaged, creates enduring questions for political science (Lichbach, 1998). Such questions surround how and whether adoption of a rights-based problem definition for disabilities correlates with differences in income and geographic location, and in tandem with interactions with non-profit and private groups. Although the distribution of a rights-based orientation helps to determine citizen demands and subsequently whether citizens benefit from public programs, scholars have paid little attention to how rights-based framing of problems varies across individuals within the United States. This article employs the case of autism to examine how recognition of disability as connected to rights-based policy challenges is related to individual connection to nonprofit organizations. It is our core hypothesis that nonprofits play a formative role in the dissemination of the rights-based understanding of disability.

Social Movements: Making the Personal Public

During the late twentieth century, many social policy arenas were newly constructed as rights-based issues. How a social problem is defined in public discourse directly affects both the policy making process and the substance of public policy (Baumgartner & Jones, 1993; Rochefort & Cobb, 1994). Furthermore, problem definition also impacts policy implementation by influencing potential clients of public problems and the administrators who run public programs.

Because problem definitions are temporal and fluid (Stone, 1988), interest groups and social movements play a large role in influencing problem definitions. The influence of interest groups varies, however, across citizens with some citizens adopting a particular problem definition while others do not. Furthermore, social movements and interest groups play an essential role in determining whether support exists for the idea that a particular problem requires governmental response (Lieberman, 2002). As a result, programs implemented in a rights-based policy environment might be expected to actively encourage a rights-based engagement on the part of clients and other stakeholders.

The creation of social policy arenas involves an exercise in problem definition wherein what was once a personal issue is recast as a public one (Freeman, 1975; Yongjoo & Haider-Markel, 2001). Up until the twentieth century, disability represented an extremely private and all too often shameful experience (Ward & Meyer, 1999). Individuals with disabilities were systematically excluded from participating in the defining activities of citizenship. Children with disabilities were routinely barred from public schools, regardless of their capabilities, until the 1970s. Adults with disabilities often experienced disenfranchisement as a result of either logistical difficulties, such as inaccessible transportation, or being illegally denied the right to register to vote. Furthermore, the unemployment and underemployment rate of adults with disabilities greatly exceeded that of the general population (O'Brien, 2003; Krieger, 2003).

In the western democratic context, when a society excludes a particular segment of the population due to an unfair or irrational response to the individual characteristics of that sub-population, civil or human rights-based solutions tend to be favored (Dowding & Van Hess, 2003). Whereas human rights-based strategies use the society at large as the unit of focus, civil rights-based policy solutions depend on individualized remedies. In the United States, civil rights-based solutions tend to be favored. In a civil rights-based context, citizens are protected against violations of their rights and liberties, assuming that the individual fulfills his or her side of the social contract by acting as a responsible, law abiding citizen. To protect human rights, positive policy solutions are most often employed, meaning that a society takes it upon itself to create the conditions under which all individuals can exercise the right. To protect civil rights, on the other hand, society takes it upon itself to ensure that those who violated the rights of others are punished.

Limitations on social and political participation persist despite ongoing governmental efforts directed at improving the inclusion of individuals with disabilities. Many disability activists and advocates consistently question the efficacy and integrity of governmental programs designed to support the efforts of individuals with disabilities and their families in securing full participation in society. Others, however, criticize the civil-rights basis of many disability policies, especially the Individuals with Disabilities Education Act and the Americans with Disabilities Act, as unnecessarily litigious, counterproductive, and not representative of all stakeholders' interests. These differing interpretations of policy effects highlight the need for a better understanding of the relationships between differences in stakeholder's perception of rights and personal characteristics.

Construction of Rights: Class, Communities, and Nonprofit Participation

The impact of social movements and interest groups on issue definition varies across individuals. Adoption of particular problem definitions takes place differently at the individual level depending on the ecology of the given person (Rochefort & Cobb 1994). Why does one individual view their social problem as a public one, while another does not? The scholarly literature points to three types of variables that might affect the influence of social movements on shaping problem definitions among individual citizens including income, community setting, and involvement with non-profit organizations.

Income

One dominant theme in the literature on social movements in the United States is that they are class based (Hooks, 1981). First, research indicates income correlates with general political participation. Higher income people engage in political activity of all types at higher rates (Milbrath & Goel, 1977; Verba, Scholozman, & Brady, 1995; Wolfinger & Rosentstone, 1980). People with higher incomes develop more civic skills to participate in politics (Verba, Scholozman, & Brady 1995).[1] Political participation develops alongside a more intense, if not necessarily more accurate, understanding of the political environment, including the construction of civil rights in a given social context. Because of this, personal investment or involvement in the political process likely improves with an individual's increased understanding of negative experiences such as social exclusion, policy implementation failures, or even violence, as violations of individual rights. As a result, in the disability policy arena, we would expect that higher income would be positively correlated with a tendency to report the violation of rights as a result of disability. Presumably, an individual must adopt a rights-based construction of disability in order for them to feel that a right has been violated on the basis of disability. In so far as the disability social movement includes a class basis, we would expect that middle and upper income people are more likely to have adopted the social movement's rights-based problem definition than those with lower incomes.

Securing rights often involves not only an awareness of these rights, but also the investment of personal resources, such as lawyers' fees associated with costly court battles surrounding the specifics of individual's publicly provided services. Families with higher incomes are more likely to be able to spend resources in an effort to secure rights. However, those with middle incomes might be expected to be most likely to expend these resources because the wealthy may elect to pay for services privately rather than fight for access to publicly provided services. Facing such adversities, those with less resources, unless particularly fortunate, are likely to go without.

Community Setting

In addition to income, the influence of many social movement groups is expected to vary by community location. The experiences of individuals living in rural settings are increasingly understood as different from those in cities, and different again from those living in suburban settings. As is discussed above, issue definition generally involves the reconstruction of an understanding of a transcendent element of human experience as a problem to be addressed by a favored policy solution. This efficacy of and response to this type of social construction likely depends not only on the larger society, but also on the community into which policies using a particular definition of the issue are implemented. To the extent fundamental differences exist between types of communities in the United States, the conception of civil rights is likely to be observably different.

Two competing possibilities exist for the nature of this difference. The first, which draws more heavily from social movement theory, is that individuals living in rural settings would be less likely to have transitioned toward a rights-based understanding of a once-personal challenge. The theoretical assumption driving this expectation anticipates a relative lack of advocacy and activist groups in rural settings. From this perspective, one might easily derive the expectation that a higher density of civic organizations will make citizens more informed and effective in their efforts to gain responsiveness from government. Unfortunately, this possibility has received little attention: most research on civil society and political participation tends to ignore citizen demands aimed at government programs (Anechiarico, 1998, but see Soss, 2000 as an exception).[2]

Nevertheless, one might expect that in order to maximize their influence on the larger society, interest groups tend to concentrate in areas with high population. This expectation leaves people in rural areas with fewer opportunities to become involved, or at least makes participation more time consuming and expensive for each individual. Even those interest groups focusing on rural issues tend to be headquartered if not in the largest of cities, at least in medium sized cities, such as state capitals. Furthermore, given the limited budgets of most nonprofit organizations, it is often in the best interest of groups to concentrate their efforts in areas with denser populations. This is especially the case for groups seeking to affect changes in policy, such as those dedicated to the advancement of the (newly-constructed) rights of individuals with disabilities. After all, both the representatives and institutions of political power tend to be located in urban settings. Given this urban concentration, it might be expected that individuals in rural communities would be less likely to understand negative experiences resulting from disabilities as being violations of their civil rights.

On the other hand, a rural community might be more likely to be a setting in which an individual might develop a rights-based conception of disability in the current era. Rural settings are archetypically understood as locations where individuals have a deeper level of interconnectedness. Especially in the case of differences that do not necessarily require (medical) treatment for survival, rural communities might be less likely to see a given human difference as one that cannot be accommodated. Furthermore, exceptions to a convention of inclusion—however real or imaginary in the historical experience of the particular community—would be less likely to be excused or tolerated by the individual and his or her family.

As a result, violations of the rights of individuals with disabilities or their families could become both more remarkable and more public than would generally be the case in an urban or suburban environment. Furthermore, with the increasing availability of the Internet, access to information about the basic elements of disability rights, including the unique right to a free and appropriate education for children with disabilities, became more universal. To the extent that the implementation of these rights depends more on an inclusionary disposition on the part of the public and public infrastructures than on material resources, rural communities could be a more likely setting for the development of a rights-based understanding of disability on the individual level.

Nonprofit Participation

As mentioned earlier, nonprofits played a role in advocating for a rights-based view of disability. We would expect interactions with nonprofits to increase the likelihood that citizens will adopt a rights-based problem definition of autism. We also expect such interactions make individuals more likely to assert those rights.

Civic organizations facilitate demands on government by providing them with information about public programs and by informing citizens of their rights (Soss, 2000). Participation in civic organizations make it more likely that citizens will assert their rights because organizations build political skills, bring individuals into contact with others in similar circumstances, and provide opportunities for recruitment into the political process (Verba, Scholman, & Brady, 1995). As a result, participants gain a better understanding of government and government programs. Particularly when disability programs are designed in the context of a rights-based understanding of disability, participation in disability oriented nonprofit organizations is likely to promote the development of a stakeholder's rights-based understanding of negative experiences associated with disability. Indeed, states with a higher density of civil society organizations produce more applications for cash assistance for disability in the Social Security Disability Insurance and Supplemental Security Income programs (Soss & Keiser, 2004).

Finally, nonprofit organizations engage actively in not only the promotion, but also the construction of disability-specific information. When individuals and families become personally connected with a particular type of disability, they likely seek information not only about disability in general, but also about the specific disability affecting themselves or their families. For example, Organizations such as Cure Autism Now, the Organization for Autism Research and Families for the Early Autism Treatment help shape knowledge about autism, as either sponsors or promoters of the development of selected types of information about autism. Because much of the discourse used to argue for the expenditure of more resources toward the development of specific knowledge is expressed in the language of disability rights, stakeholders who rely more heavily on nonprofit organizations for disability-specific information might be more likely to develop a rights-based understanding of negative experiences associated with disability.

Method

As mentioned earlier, we are interested in explaining variation across individuals in adopting a rights-based approach to disability as it relates to their interaction with nonprofit organizations. While we are particularly intrigued by the role of nonprofits, we will also examine the roles of income and geography, as more established explanations of such variations in the acceptance of the rights-based paradigm in our sample.

Case Description

Autism is a neurological disorder of unknown cause, manifesting itself along a spectrum ranging from relatively minor social impairment and behavioral differences (typically called Asperger's syndrome) to a complete withdrawal from interpersonal interaction combined with a tendency toward self-injury. When autism was first identified in the 1940s, it was believed to affect approximately 1 in 10,000 individuals (Feinberg & Vacca, 2000). During the past 15 years, the reported incidence of autism increased dramatically worldwide and, in recent years, autism became the fastest growing disability reported within public schools in North America. Though the prevalence of autism is hotly debated today, the more conservative estimates suggest that at least 1 in 500 children have an autism spectrum disorder (Newschaffer & Curran, 2003). Whereas autism was once believed to affect predominantly Caucasians, the reported cases of autism currently distribute relatively evenly across socioeconomic and ethic groups. Boys are approximately 4 times more likely to be affected than girls. Most children with autism first develop symptoms some time between their first and third birthdays (Rutter, 2000).

Since in the past individuals with autism tended to be institutionalized or otherwise removed from social participation and access to education and employment, the prognosis of the current generation of children with autism is largely unknown (Ward & Meyer, 1999; Bryson, Rogers, & Fombonne, 2003). Furthermore, many more of the children identified as having autism in the current era are so-called "higher-functioning" and presumably, therefore, less likely to need intensive social services as adults (Newschaffer & Curran, 2003). As a result of the growing pressures on school and other systems serving a ballooning population of children with autism, an ever-improving understanding of the types of programs and treatments for autism, and the changing population of children with autism, an improved understanding of the construction of civil rights with regard to neurological differences becomes important (Kohler, 1999; Bryson, Rogers, & Fombonne, 2003).

Research Design

To explore variation in the use of a rights-based understanding of disability, we use the Families' Experiences with Autism Survey (FEAS). FEAS was developed specifically for use with families with children with autism and is correlated to similar surveys used to collect stakeholders' impressions of the relationship between disability and public infrastructures, especially the Participation and Activities Limitation Survey (PALS) first implemented by Statistics Canada in 2001. FEAS includes 45 questions on aspects of families' experiences including perceptions of disability, disability history, participation in public programs, economic effects of disability, and general socioeconomic indicators.

FEAS was launched in Missouri in July, 2003. 452 responses were collected. Because children with autism constitute a "rare" population, purposive sampling techniques were more appropriate than random sampling (Hinton, 2003). A snowball sampling methodology with multiple entry points was used. Responses were collected both online and on paper.

The survey posed two questions that are especially relevant to our purposes here. First, the survey asked respondents whether their child's rights have ever been violated as a result of his or her autism or related condition. According to a rights-based problem definition, most children with autism have had their rights violated in some way either by having activities or speech restricted when not absolutely necessary, through social exclusion by their peers, failure on the part of social and public infrastructures to accommodate differences, or through more traditional violations such as becoming targets of violence or abuse motivated by discriminatory intent. In addition, children with autism were expected to have experienced illegal limitations of their right to a free and appropriate education under the Individuals with Disabilities Education Act, as interpreted by their parents or other stakeholders (Scherer, 2003).

It is important to note, however, that this measure does not capture the severity of a rights violation or even if a rights violation as it is currently defined by law or other standards in formal public policy occurred. Rights violations such as peer victimization motivated by differences, represent a near universal experience for individuals with disabilities. Previous research documented the pervasive nature of these experiences for the subpopulation of individuals with disabilities as a whole (Li, Ford, & Moore, 2000; Walden, 1996). For example, one study found that 94% of children with Asperger's Syndrome or nonverbal learning disability experienced peer victimization in a single year (Little, 2001). In the absence of a rights-based understanding of disability, however, these experiences are not necessarily understood as a violation of civil rights. A measure of perception is most appropriate for our purposes because we are interested in explaining variation in problem definition, which by nature is due to perception. Respondents who answer affirmatively on this question have adopted a rights-based orientation.

Findings

38% of the parents and primary caregivers reported their child's rights had been violated as a result of their autism or related condition. Furthermore, approximately 50% of the respondents reported that their children were not in inclusionary educational settings, one of the basic tenets of the educational rights of almost all children with disabilities. Parents and primary caregivers who reported that their child's rights had been violated were asked to describe the most recent incident. The descriptions were almost universally related to negative rights. Some of the more extreme examples involved the misapplication or misinterpretation of physical discipline. For example, one parent wrote:

> "He was put in foster care for a week by the Department of Family Services because his self-abusive picking at his skin all the time was reported as child abuse. It took $1200 in attorney fees and 5 months for that to be cleared up. At school he has been spanked, sent to the police station, put face down on the floor with his hands behind his back, been restrained with plastic restraints, and spent the last 4 weeks of this school year in the timeout room in the high school classroom."

Similarly, another parent related that the "teacher and aide bruised and assaulted my son, family doctor confirmed abuse, DFS (Department of Family Services) found our complaint to be unfounded." Another mother explained, "Because of the lack of understanding on the juvenile officer's part and the Department of Family Service's part the family has been put through hell with dad being kicked out of the home for a month only to find out he did nothing."

In addition to civil rights violations in the form of direct physical harm, various overt violations of specifically protected civil rights were also reported. Many parents described situations in which schools or school officials did not follow the Individualized Education Program (IEP) plans established as a civil right of children with disabilities under the Individuals with Disabilities Education Act. For example, one parent stated that the "school did not learn about Asperger Syndrome nor follow the IEP. He was harassed by others and picked on by certain teachers." Several parents reported that their children, as young adults with autism, had been denied voter applications at the Department of Motor Vehicles. Another parent reported "my dependent coverage life insurance at work (work for State) denied me obtaining a life insurance policy for my child, citing reason being a preexisting medical condition of autism. I contacted Division of Insurance stating it was discrimination, that autism is not life threatening, etc. To make a long story short, he now has a policy the same as my other two children (I won)."

In addition to these instances interpreted by parents and primary caregivers as violations of their children's rights, a lack of protection of positive rights was frequently experienced by families with children with autism. 78% of the parents and primary caregivers reported that their community activities have been restricted as a result of their child's autism. These restrictions often included a failure on the part of privately run businesses and activities to include individuals with autism. For example, several parents and primary caregivers explained that their children were not allowed to participate in church activities due to their autism or related condition. Another reported that her family was "kicked out of the children's zoo because child (24 months) was stimming (making repetitive noises) during a sea lion show." Others had difficulties with extracurricular activities. For example, one primary caregiver reported, "I enrolled our grandson in swimming lesson classes last year and they flat out told me that they didn't think he should stay in the group classes because they just didn't have time to spend with him. I then tried to get him in private lessons and the person they gave me to contact never returned the phone call."

When the children with autism discussed by the respondents escaped civil rights violations, it was often described as having less to do with accommodation on the part of public infrastructures than with preventative effort on the part of parents. For example, when responding to the question asking whether her child experienced violations of his rights as a result of autism, one mother responded, "Oh hell no. Not while I am alive and breathing." Another suggested that "an agency must be established with the authority, courage, and the ability to actively and effectively sanction, monitor, and punish those people and agencies who deny and/or abuse the civil rights..." The descriptions provided by parents were varied and in keeping with previous research indicating situations that are interpreted under a civil rights-based understanding of disability. Violations of civil rights are as commonplace for this minority group, as for other subpopulations with a history of oppression.

However, the results of the cross-tabulations of the indicators of an adoption of a civil rights-based understanding of disability and the selected independent variables are mixed. Most of our preliminary findings match our expectations whereas others are more surprising.

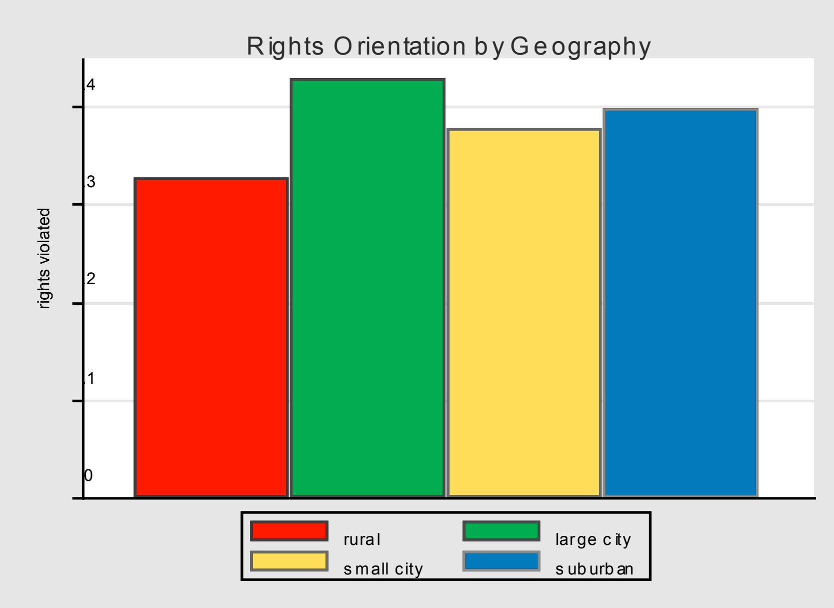
Income

As is described above, one of our hypotheses was that higher income would be correlated positively with the adoption of a civil rights-based understanding of disability. Individuals with higher incomes (upper middle class and above) were expected, therefore, to report a higher incidence of civil rights violations and to be more likely to have their child included in a general education setting.

The results of a cross-tabulation of answers to the question, "Have your child's rights ever been violated as a result of his or her autism?" and reported income for 2002 showed the group most likely to report that their children's rights had been violated were those in the middle class, with incomes between $40,001 and $60,000. The second group most likely were those living in poverty with incomes below $20,000. These findings suggest that income may be less significant as a determining factor of the adoption of a rights-based understanding of disability than other characteristics. These income results may also reflect a difference in reasons for the perception of rights-based violations. Those in the highest income category may in fact, be removing their children from settings, such as public schools, where the violations are most likely to occur. The lower middle class income group may be the least engaged in public programs due to incomes above program limits as well as less likely than the slightly wealthier to become civically engaged.

Community Setting

Our second variable of interest was whether the type of community setting was correlated with the adoption of a rights-based understanding of disability. As is discussed above, previous scholarship suggests competing hypotheses about the effects of community setting on the conception and perception of civil rights.

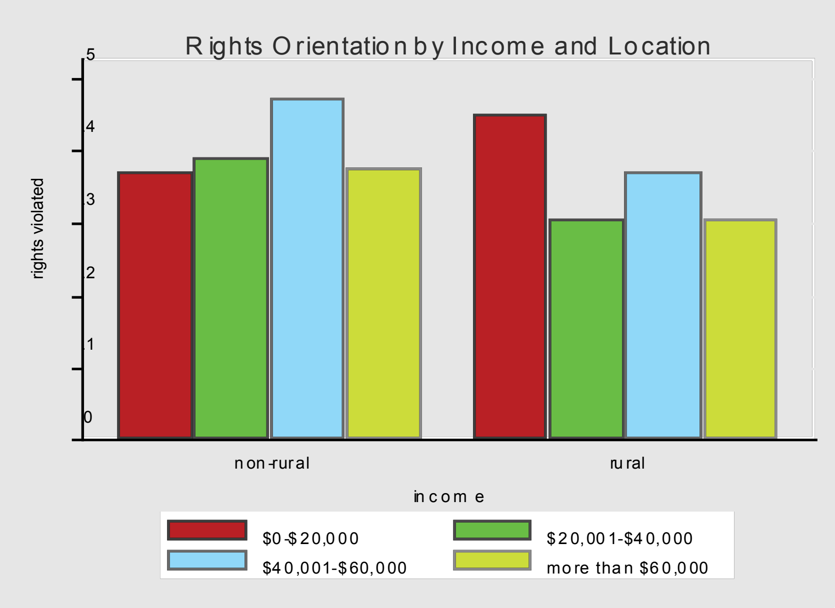


The result of a cross-tabulation between the reported experience of civil rights violations and rural vs. urban community setting suggests that those living in urban settings are more likely to be have adopted a rights-based understanding of disability than those living in rural environments. This finding is in keeping with the argument that barriers, including distance and a less intensive presence of advocacy effort, have impaired the development of a rights-based understanding of disability in rural areas.

Closer examination of the urban responses also proved interesting, in that there was some difference in the reported rate of civil rights violations. Table 1 shows these results.

Respondents were asked to identify whether they lived in a big city, small city, or suburban environment. In each of these categories, a higher percentage of respondents indicated that their child had experienced rights violations due to his or her autism than the rural respondents (34%). However, the percentages were slightly different across urban categories with 42% of those living in big cities, 40% of those living in suburban settings and 37% of those living in small cities reporting that their child's rights had been violated as a result of his or her autism.

Analyzing the variable further showed more dramatic differences. The percentage of parents and primary caregivers reporting that their child's rights had been violated varied more by income in rural than in non-rural communities. Whereas the $40,001-$60,000 income group was the most likely to have reported violations due to autism in non-rural areas, in rural areas, the highest percentage of reported rights was in the lowest income group. Acceptance of the rights based paradigm of disability depends on differenc-



es in circumstances above and beyond a family's income. These results are shown in Table 2.

Nonprofit Participation

Nonprofit participation was also expected to play a role in the development of a rights-based understanding of disability. Nonprofit organizations, especially those surrounding emerging disabilities such as autism, tend to encourage their clients to adopt a rights-based understanding of disability. It was our hypothesis that nonprofit participation would be correlated positively with the adoption of a civil rights-based understanding of disability. The cross-tabulation of answers to the question related to who usually provides families with needed assistance, and the reported experience of civil rights violations was in support of this hypothesis. Whereas only 1/3 of parents not reporting help from nonprofits reported rights violations, close to 1/2 of those with nonprofit help reported rights violations.

The relationship between types of organizations that families reported they usually depended on for assistance and the reported violation of their child's rights was different for different types of communities. The gap in percentage for non-rural respondents was almost four times larger than the one reported by rural respondents. Engagement with a nonprofit organization appears more likely to motivate acceptance of a rights-based paradigm of disability in those living in non-rural environments. This finding may be related to the level or nature of involvement with the nonprofit, as well as to the types of nonprofits extant in different types of communities. Residents of non-rural communities presumably tend to be proximate to a greater and more diverse set of organizations with which they can participate in person. While residents of rural communities can participate in a great variety of organizations electronically, it is less likely that a large number of nonprofits will be directly engaged in the provision of programs and services close to their homes. Nevertheless, increased electronic participation in nonprofit organizations is correlated positively with a tendency to perceive disability issues as being rights-based. Those who reported that they most often used nonprofit organization sources were 10% more likely to report that their children's rights had been violated than those that did not.

Conclusion

The tendency to understand disability as a rights-based issue varies between individuals, with some citizens adopting the problem definition and others not. Since the problem definition influences whether or not, and how, citizens make demands on government, whether or not individuals adopt a social movements problem definition has consequences for whom benefits from government policy. The observed differences in the adoption of a rights-based paradigm of disability among parents and primary caregivers of children with autism suggests that variance in issue definition among stakeholders is affecting the implementation of public policy for children with disabilities.

In the case of parents and primary caregivers of children with autism, engagement with a nonprofit organization tended to be associated with a greater likelihood that the parent or primary caregiver would perceive their child to have experienced discrimination as a result of his or her disability. Nonprofit organizations have a key role to play in shaping stakeholders' understanding of basic philosophies underpinning issue related public policy. While the influence of this role is not constant across socioeconomic circumstances, the results suggest that involvement with nonprofit organizations is deeply connected to an understanding of disability rights.

In continuing our analysis of this question, we will be looking at other individual characteristics (such as type of autism) and their experiences (such as the specific description of rights violations) in order to expand our understanding of the construction of rights vis-_-vis the specific experiences of individuals. After all, one of the most optimistic interpretations of the data would be that the civil rights-based paradigm of disability has been phenomenally successful in that certain characteristics, such as income, participation with advocacy groups, or inclusionary communities, insulate some children with autism from the discriminatory circumstances that have been discussed as pervasive to this point. Continued investigation of the specifics of the respondents' understanding of their children's rights alongside additional family characteristics will shed further light on the mechanisms and impressions of the construction of rights in disability policy problem definition.

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End Notes

[1] Interestingly, lower income individuals have similar amounts of free time as higher income individuals (Verba, Scholozman & Brady 1995).

[2] Putnam's study of Italy offers a partial exception to this pattern. His index of institutional performance incorporates one indicator of bureaucratic responsiveness – the ways in which health, vocational, and agricultural agencies responded to inquiries requesting information (Putnam with Leonardi and Nanetti 1993, p. 73).

The Autism Mantra

Rama Cousik, Ph.D. Candidate
Indiana University, Bloomington

Autism Asperger's spectrum of disorders
Atypical autism PDD (NOS)
Savant autistic
Idiosyncratic eccentric

More than enough labels
To give me a nervous tic!

Rocking flapping tip toeing
Spinning stimming persevering
Echolalia puzzle mania
OCD insomnia

Methinks the world is affected
With acute paranoia!

Selective reaction
Photographic imitation
Hidden emotion
Musical intonation

Boundless imagination
Not hallucination!

Frontal lobes
Who knows
Amygdyla
Phobia

Take a break or you may
Get dyspepsia!

Mindblindedness
Weak central coherence
Executive dysfunction
Auditory processing

Chaotic theories
Think overstimulation?

Sensory integration
Chelation
Facilitative communication
Medication

Without any of these
Am I doomed to damnation?

Casein free gluten free
Allergy mercury
Music therapy horse therapy
Canine therapy dolphin therapy

Leave those poor animals alone
If you ask me!

Brushing Holding TEACCH squeeze machine
PRT REI marijuana megavitamin
Daily Life ABA Floortime Option
Special education General education

(I) understand you mean well
But do think about my avocation

Social skills training
Behavior modification
Speech modulation
Auditory integration

All are nothing but
Fruits of civilization!

MMR
Trigger
Culture
Disaster

What were you thinking?
Leo Kanner? Hans Asperger?

Also see my strengths
Not only my weaknesses

Leave me alone
If you can't do that

A curse a blessing
Don't bemoan!

Autos means self, yeah! sure
Oblivious to your world
(You) think I need a cure
Your line of reasoning's a tad obscure

I prefer to be me
Enigmatic, but secure!

Rama Cousik is a 3rd year Doctoral student in Special Education at IU Bloomington. Rama has worked with children with developmental disabilities for 20 years, 6 of which were with children with autism. Rama is doing a minor in Ethnomusicology. Her interests are in the teacher and in children. Rama is exploring the use of creative and performing arts in teaching children with varied learning styles. Rama believes that all children can learn, if only the teacher knows different ways of teaching them. She has adopted the motto, "Label jars, not people."

Book Review

Title: *Leave No Nurse Behind: Nurses Working with disAbilities*

Author: Donna Maheady

Publisher: iUniverse, 2006

Paper, ISBN: 0-595-39649-6, 146 pages

Cost: $14.95

Reviewer: Alice Tse, PhD, APRN, RN

This is a collection of eleven inspirational stories of nurses finding purpose when disability strikes later in life. It is a rich ethnography of the psychological battle and societal reactions of several individual nurses living with a disability. This book presents an interesting oxymoron; nursing as a helping profession outright rejects those who fight to enter the discipline. Eleven different nurses describe the denial to accessing the profession that they admired and sought, the frustration, and their breakthrough to rediscover their own creative expression and professional engagement. The issue in common was always how to assist the able bodied receiver (e.g., administrator, employer, counselor) to see Abilities without having their disAbility become blinders for the other. In addition to having to face the intricacies of regular working requirements, these nurses mustered the energy and persistence to negotiate through well-intended systems that hindered rather than helped via the intention of "helping" those of their own with disAbilities. The result is a fascinating book, which examines how nursing, as a seemingly "caring" profession, still strongly creates its own mainstream culture.

The individuals in the text each describe how they experienced an unconscious effort of the "caring profession's" attempts to maintain its standards by rejecting their joining into the profession because of their disabilities, even after they had been nurses. Overall the text describes an interplay between individuals who, for the most part, create and propose their own accommodations and those members of the profession whose good intentions end up restricting rather than accommodating. All of this takes an inordinate amount of energy that could be better spent providing quality patient care.

Disability makes non-disabled people anxious. Although nursing is deemed a "caring"' discipline, the professional stance taken by the nursing profession is not friendly to individuals with disabilities. The individuals in this book describe transformations they undergo while pursuing their nursing dreams/careers. Each nurse choosing to enter the profession had no prior role model. As each story is told through each author's experience, the text integrates an undercurrent of the disability world within the nursing profession. The authors provide an analysis of how professionalism and activism mesh to create something new; that is, the realization that it is possible for the person with a disability to be a health care professional.

Attempts of a profession to maintain its "standards" can happen to any discipline. The text sheds insight into why for so long nurses with disabilities have been missing from the nursing profession. The common thread to each author's description is garnering their own professional survival in a restrictive and unbending culture.

A strength of this book is the ability of the authors to address issues associated with reclaiming his/her own life, navigating and facing the uncertainty of not knowing what is coming next. Issues of vulnerability are subtly brought out. Although this text does not offer any new medical knowledge, it serves as a positive resource on disability culture. Many disability theories are developed in universities and via research. The text incorporates the real-life daily stories of nurses with disabilities as a legitimate voice as a source of knowledge within a culture of professionals.

The appendices broaden awareness of reciprocal responsibilities between nurses and their employers. They provide a sample accommodation request letter, guidance on the action of disclosing, dealing with difficult supervisors, and selected resources. The application of this array of samples is referred to in the text.

Although the book is written for nurses with disabilities who wish to join the discipline or change their activities within it, the concepts are applicable to individuals who want to join the ranks of any profession. The message is clearly that disability does not mean the end. Rather it is the beginning; how it is handled will inform and shape the disciplines' practices.

This book is highly recommended for those seeking mentorship while facing stigma and discrimination. It provides an inspiration and practical guide for nurses and students with disabilities. The concepts addressed are applicable to individuals of other professions who have the ability to successfully meet the hurdles put forth by their discipline as well.

Book Review

Title: *Face On: Disability Arts in Ireland and Beyond*

Author: Kaite O'Reilly, Ed.

Publisher: Arts & Disability Ireland, 2007.

Paper, ISBN: 978-0955474903, 159 pages

Cost: $20.00

Reviewer: Steven E. Brown

This book came across my desk while I worked on a paper about disability culture across the globe. One comment from the later 1990s that has stuck with me from a trip to Germany recurred while I read this volume. In both cases, individuals lamented the lack of a disability culture in their home countries. But from my vantage, this book is full of examples of the existence of a culture of disability. Maybe some of this disconnect arises from the American belief that Europeans are much more supportive of artists than are we. While art is hardly the only marker of disability culture it is one of the most visible and accessible to many of us.

There are many different kinds of stories in this book. More than twenty authors and artists are represented. I read Davoren Hanna's 1990 "Notes from a Bone Fragment" and I returned to it again and again for two reasons. I came back first because Hanna's words hit me like a sledgehammer: "A brain scan taken when I was five years old showed an abnormality consistent with severe physical disability. My brain's ability to signal my distress at being intellectually undermined did not register on the C.A.T. scan" (pp. 29-30). When I finished the piece I received another blow. Hanna lived from 1975 to 1994. His perceptiveness within his short lifetime, and his facility with words, again hammered at me.

Other pieces in the book were equally eye-opening. I learned not only how the Graeae Theatre Company began, but how to pronounce it (gray-eye). Beyond Ireland not only ranged to England and Wales, but all the way to New Zealand, whose comic genius, Philip Patston writes about his alter ego, Philly Delphia, in an essay that analyzes disability, drag, and deviance.

My two frustrations with the book were the assumption that some words would be understood across continents. For example, what is a "traveller?" The word is used in a context new to me, but not explained for those who might be unfamiliar with the term in the context used in this book. Even more frustrating is the lack of a "Resources" section. Many resources are mentioned within various articles, but there is no follow-up on how to find them. Still, this is a book well worth having in any library that wants to demonstrate how disability arts and culture are being demonstrated in the early twenty-first century.

Book Review

Title: *Disability Harassment*

Author: Mark C. Weber

Publisher: New York University Press, 2007

Cloth ISBN: 9780814794050, 240 pages

Cost: $42.00

Reviewer: Anna Kirkland

Mark C. Weber's *Disability Harassment* is a detailed account of the full range of legal options for combating harassing conduct directed at adults and children with disabilities in the contemporary United States. Weber's goal is to convince the general public that disability harassment is a significant problem of injustice, and then to show how the legal tools we already have in place could be used much more robustly than they currently are in order to decrease harassment. The first three chapters set out first, the evidence that harassment on the basis of disability happens and that it causes great trauma and limitations in the lives of the people who endure it. Weber argues next that harassment can be understood through a disability studies framework that identifies isolation and segregation as the primary forms of subordination for people with disabilities and that harassment helps accomplish that subordination. The third chapter explains that disability harassment is not the same as sexual and racial harassment and thus should not simply be shoe-horned into preexisting legal analysis.

The primary arguments of the book come in Chapter Four, in which Weber notes that there is actually more expansive anti-harassment language in the Americans with Disabilities Act (ADA) than there is in Title VII of the 1964 Civil Rights Act, the antidiscrimination law that covers race and gender harassment. Weber's target is then the federal courts, where Weber argues judges have interpreted this anti-harassment language too restrictively. Later chapters move from the workplace context to explain the legal terrain for lawsuits against public schools for harassment of students with disabilities and also detail other less-well-known legal options for suing for disability harassment.

Disability Harassment laudably draws scholarly attention to an issue that has been widely overlooked but is surely central to any social justice movement for people with disabilities. The dense discussions of legal cases and statutory provisions, however, make it difficult for anyone not trained in the law to decipher. The book is probably more helpful as a resource for disability rights lawyers than as a general academic book for activists, people with disabilities who are not lawyers, or scholars in related disciplines like political science and disability studies. Weber also asks us to assume that if judges were to listen to him and follow his suggestions in their rulings, the groundwork would be laid for significant improvements in the lives of people with disabilities. This lawyerly perspective is complicated by evidence that the vast majority of ADA plaintiffs lose their cases as it is , by much interdisciplinary work showing that even successful lawsuits have limited impact on people's lives and, even if law does have some impact, being part of a successful lawsuit is not necessarily the most important thing . Weber acknowledges the limitations of the formal law as a route to social change while sticking to his doctrinal arguments. Though it is certainly a worthy project to lay out the legal landscape in all its complexity, this focus limits the book's ambitions.

While *Disability Harassment* is the first and last word on the current law for anyone who is a part of disability harassment litigation or considering it as an option, it can only fulfill one small part of a multi-faceted program to remedy isolation and segregation in the lives of adults and children with disabilities. Because the book is not currently available in an affordable paperback version (and because anyone with access to law journals can find much of the material previously published) and because of its highly specific legal aims, *Disability Harassment* is not particularly accessible to people with disabilities generally. It fills a crucial niche for legal practitioners, disability law scholars, and potential plaintiffs.

Book Review

Title: *Meaningful Exchanges for People with Autism: An Introduction to Augmentative and Alternative Communication*

Author: Joanne Cafiero

Publisher: Woodbine House, 2005

Paper, ISBN: 978-1-890627-44-7, 174 pages

Cost: $17.95

Reviewer: Patricia Wright

Joanne Cafiero, Ph.D. has provided a wonderful resource for individuals interested in providing effective language and communication interventions for individuals with autism. *Meaningful Exchange for People with Autism: An Introduction to Augmentative and Alternative Communication* should be considered a go-to resource for developing and implementing communication interventions. Approximately 50% of individuals with autism do not develop effective spoken language (National Research Council, 2001). Augmentative and alternative communication (AAC) provides a means to communicate for those who do not have spoken language. AAC is any tool, device, picture, word, symbol or gesture that compensates for expressive and receptive communication deficits. Individuals with autism who are not able to effectively utilize spoken language can use AAC to communicate.

Cafiero opens her first chapter with an explanation of why the AAC tools and strategies discussed are important for individuals with autism. This content is provided with descriptive stories and scientific data. Cafiero's writing style is immediately accessible to both the skilled AAC professional and novice reader. The first two chapters provide an introduction to the strengths and challenges that individuals with autism experience in regards to communication.

Chapter 3 is highly informative, covering AAC tools, devices and strategies used to promote effective communication for individuals with autism. Cafiero covers the range from the low-tech picture communication symbol through high-tech electronic systems and everything in-between. In addition to descriptions of available tools and devices there are personal stories of how these tools are used by individuals with autism to promote effective communication. And, most importantly, Cafiero provides direct guidance to professionals in the delivery of effective instruction and strategies to encourage individuals with autism to use AAC. The importance of direct instruction and intervention is advocated for strongly within this chapter. Cafiero emphasizes the importance of quality instruction for communication success. A large section of this chapter is dedicated to descriptions of how communication partners and those providing communication interventions can promote learning and skill development of individuals with autism.

AAC assessment is addressed in chapter 4. Three distinct models of assessment are described and examples are provided. The necessity of a quality assessment is highlighted. Cafiero states that the nature of learners with autism and the continued progress of technology require that the AAC assessment process be dynamic. Assessment decisions may need to be modified as the learner with autism gains skills and/or as technology development advances.

Chapter 5 is an overview of AAC and the law. Cafiero provides a comprehensive list of the laws that support the provision of AAC tools and supports. The majority of the chapter addresses the needs of children; however there is some content for adults as well.

Chapters 3, 4 and 5 each include a helpful section entitled "frequently asked questions." This content captures many common areas of concern that a reader might ponder from the content provided in the previous chapter. This question and answer format is reader friendly and allows for quick access to common areas of concern.

Meaningful Exchanges for People with Autism is an excellent resource for AAC intervention for people with autism. The content is provided in a user-friendly format that includes qualitative stories, quantitative data and pictorial representations. This book would be particularly helpful to those new to the field of AAC or new to the delivery of AAC service and support to individuals with autism.

Reference

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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 Hawaiʻi, 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.

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cds

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University of Hawaiʻi at Mānoa

Building an accessible, inclusive community for all

www.cds.hawaii.edu

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