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## RDS Editorial

Cheater Pants

Megan A. Conway

I have a “Friend,” who shall remain nameless, who is forever on the Hawaii State List of Persons Who Have Previously Attempted to Cheat the System. A few years ago this Friend was applying for a renewed Disabled Persons Placard (hereafter referred to as DPP in the spirit of true academic devotion) at a Satellite City Hall (SCH). Several months before, Friend had diligently responded to the notice requiring that all persons possessing a current DPP must re-apply and include a new physician’s Verification of Eligibility Form (now known as VOF). This was being done to ensure that all valid DPPs were truly valid and not just fake-valid. Friend went to her physician and her insurance company (don’t tell them) paid Dr. Doctor to sign his name next to a statement that yes, indeed, Friend was still as permanently disabled as she had been on the day she was born. Friend then shoved the VEF for the DPP in a drawer somewhere and forgot about it.

Until the day that Friend realized her placard was about to expire and she would be hoofing it along with the rest of mortal mankind down endless blocks of city street unless she renewed her DPP. So she hunted down the VOF, now quite battered, and went on down to Satellite City Hall (SCH).

Now, I am assuming that in most States, City Hall is populated by people who make their profession out of following the rules. But let me assure you that in Hawaii we have civil servants like no other. Following the rules is like taking your lunch break, it will happen no matter what. After standing in the wrong line at the SCH clutching her VOF for a DPP for 15 minutes and being directed to a new line that she had been standing in for 25 minutes, Friend was idly looking over her VOF for the DPP when she noticed, to her horror, that in very small print at the bottom it read, “VOE only valid for 3 months after signature.” Friend looked at the date beside the signature of Dr. Doctor. It was 5 months old. Friend paled. She imagined actually *extracting* herself from the line at the SCH, actually *leaving* the SCH and walking back to the car. Calling to make *another* appointment with Dr. Doctor, likely in two weeks when her DPP would have expired, getting to the SCH and standing all over again in the wrong line for 15 minutes before she stood in the right line (presumably, who knew?) for another half an hour. Friend imagined all of this and she did what any self respecting person who did not actually grow up in Hawaii would do. She took a pen from her purse, and very subtly, or so she thought, Friend changed the date beside the signature.

You can imagine what happened when Friend reached the friendly Servant of SCH. It took about half a second for the Servant to raise her eyebrows, glower at Friend and say briskly, “Did you change this date?” “No, oh no,” stammered Friend, “I wouldn’t do something like that.” “Well, let’s see,” smirked Servant, lifting up the receiver of the phone by her side and dialing the number of Dr. Doctor printed on the VOF.

Friend (told me later that she) felt like she was in a horror movie that was in slow motion. Servant spoke smugly to a receptionist on the other end of the line, who, being a former SCH Servant herself most likely, confirmed what Friend's SCH Servant had expected. The document had been signed five...months...previously.

Servant hung up the phone. She typed something into her computer. Actually, we know what she typed into her computer. She typed, "This person is a Cheater Pants. In future regard this person with the ultimate amount of disdain and suspicion. In summary, this person DOES NOT FOLLOW THE RULES." We know this because a month later when Friend made it back to a SCH (on the other side of the island), the Servant there made a similar phone call to verify the accuracy of the information presented on the VOE for the DPP. When she handed Friend the new DPP, it was with obvious regret. She knew Cheater Pants was at it again, but she just couldn't prove it.

I hope you have enjoyed this little vignette of how the State of Hawaii foiled yet another attempt by Persons with Disabilities (PWD) to Cheat the System. You can be sure that my "Friend" will never try such a stunt again. But one has to ask, since when does your disability become less permanent over a period of 2 months? How many PWD are actually trying to get away with renewing their DPP with forged VOE at SCH? Why does the University of Hawaii have mirrors on the ceiling of the testing cubicles where SWD (students with disabilities) take their proctored exams? Well, that's another story, and a more titillating one, I'm sure.

## RESEARCH ARTICLES

Navigating the Cultural Landscape towards Self-Determination: Results of an Exploratory Study in American Samoa

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**Abstract:** The American Samoa University Center for Excellence in Developmental Disabilities, Education, Research, and Service (AS-UCEDD) with the University of Hawaii Center on Disability Studies, conducted an exploratory study to better understand how state agencies deliver services, and how disability is perceived by agency staff and consumers in American Samoa. While it initially was envisioned as a needs-sensing study that used surveys and targeted database reviews to systematically capture client needs, the study transformed to a largely qualitative preliminary investigation that was dependent on personal interviews. Findings revealed how contextual, linguistic, and cultural factors play a hugely important role when researching western-based ideals and concepts within indigenous communities.

**Key Words:** culture, self-determination, perceptions, research flexibility

### Introduction

American Samoa in the South Pacific is five hours south of Hawaii by air and includes several outer islands necessitating airline travel from community to community within its boundaries. The largest numbers of people live on the island of Tutuila, with smaller populations on the Manu'a Islands (Ofu', Olosega and Ta'u), Aunu'u Island and Swains Island, with the smaller islands having limited services. This geographic location poses unique challenges for health and human service delivery systems particularly related to serving community members with disabilities.

Coupled with geographic complexities, the cultural context of American Samoa as it relates to disability offers another intricate layer. How the Samoan community responds to disability in the wake of traditional beliefs and practices is seldom studied. Enhanced understanding of cultural effects on service delivery for individuals with disabilities is critical since the territory receives federal funding, yet remains insufficiently documented. The American Samoa University Center for Excellence in Developmental Disabilities, Education, Research and Service (AS-UCEDD) partnered with the University of Hawaii Centers on Disability Studies to conduct an exploratory study. Its purpose was twofold: to better understand how state agencies deliver services and to know how disability is perceived by agency staff and consumers. While it initially was envisioned as a needs-sensing study that used surveys and targeted database reviews to systematically capture client needs, the study transformed to a largely qualitative preliminary investigation that was dependent on personal interviews.

## Objectives

The purpose of this paper is to share the findings of an exploratory study designed to gather more information on services provided for people with disabilities residing in American Samoa. One of the objectives of the UCEDD is to conduct research to improve the quality of life and self-determination of persons with disabilities to live inclusive lives in their communities (Pacific Basin UCEDD Application, CFDA 93.632, 2006). While there are multiple agencies that provide services for people with disabilities, it was unclear how these respective agencies collect complete, accurate, and unduplicated data as well as serve consumers. The majority of these agencies receive federal funding and those that do are therefore subject to the same rules and regulations of other state agencies across the United States.

For this study, of particular interest was the extent to which these agencies support the independence of people with disabilities and how self-determination is interpreted. For example, what types of services are provided? Who are the clientele of state funded services? Do clients receive specific skills training or does the service provider do everything for the client from finding a job to transporting clients? An underlying philosophy about persons with disabilities may affect what specific services exist and how such services are delivered via the individual professional and/or the agency. This underlying philosophy is often shaped by the cultural context and may clash with the intent of the larger organization as well as the funding source. Through surveys and semi-structured interviews with agency staff members and consumers during early July 2009, preliminary information about disability and its relationship to culture sets the stage for further investigation.

We began our inquiry with an overarching research question, “How are existing services perceived and provided for by organizations serving persons with disabilities in American Samoa?” However, over the course of conducting and analyzing interviews and surveys, we felt the need to modify the intended research design and allow the information to derive theory. Thus, the results may not directly apply to the original research question but describes the context by which services are delivered.

## Theoretical Framework

### Socio-Cultural Context

American Samoa is a territory of the United States. Surrounded by island territories that are either French or British along with a rising number of independent island nations, American Samoa is part of a group of nine inhabited volcanic islands known as Samoa. In 1900, Samoa was divided into two separate political entities. The eastern part was named Eastern Samoa and later became American Samoa. The larger and western part was initially called German Samoa, then British Samoa, Western Samoa, and currently the Independent State of Samoa (Ripine, 2008).

According to the 2000 Census, the populace of the US territory American Samoa includes 57, 291 individuals of which 92 % are Polynesian, 2.9% Asian, 1.2% Caucasian 2.8% mixed and .02% other. The primary languages are Samoan and English. The age distribution is

0-14 years 35.7%, 15-64 years 61.3%, and 65 years and older 3%. Sixty-two percent of households that fall below the poverty line include children under 18 years old. The average household income is \$9,349. Based on tri-agency data from the Monitoring and Technical Assistance Review System Report, it is estimated that 16% of the 49,322 persons assessed are considered part of the disability population. Of those with disabilities, 1,014 are between the ages of 5 – 20 years (Administration on Developmental Disabilities, 2008).

Samoa life is structured around the ‘aiga (family), a hierarchical system made up of the nuclear and extended families. Rank or chiefly status as well as age and gender determine the formation. As noted in Mokuau and Tauili’ili (1997), a matai (village chief) is responsible for the welfare of all related families in the village and each household may have its own chief. The females are subordinate to the males and young always defer to the elders. The family works toward the goal of well-being for the entire family which may be as large as an entire village. The values intrinsic in this system include reciprocity, cooperation, and interdependence.

The social and cultural contexts of village life obligate individuals to participate in, and contribute to, a variety of events. Funerals, weddings, religious holidays, and village celebrations can last days or even weeks, and members of the village are expected to provide support. Island politics shape the bureaucracies that control local education, economics, and social welfare. Elections affect all aspects of life, including shifts in jobs and power. In these settings, it is very important to work within the political structures of the community, understanding how familial ties and history play an important role in everyday life. Knowledge of language and behavioral protocols, including how to address both elected officials and traditional leaders, is critical as both a sign of respect and honoring customary practices.

The church is a highly valued institution in Samoan culture that directly intersects with the family. The church affirms the organization and responsibilities of the family and in turn, is supported by family contributions. Religion is one of the most critical features of Samoan culture following various Protestant denominations as well as the Catholic Church. Ministers are ranked higher than chiefs and political leaders.

The cash economy in Samoa has made a significant impact on the lifestyle and language of many Samoans. Such an economy stands in sharp contrast with the traditional land-based system that was at one time the foundation of Pacific society. Although island leaders facilitate the preservation of traditional ways, these practices often contradict other social trends. For example, economic development leads to such non-traditional enterprises as chain restaurants, large-scale fishing and fish packing, tourism, and heavy industry. As a result of commercialization and external influences, structural changes in the society and culture impact the language. The traditional vernacular may no longer be needed or appropriate. The language used at home may not correspond with the language needed in the larger community (Brown, Hammond, and Onikama, 1997). Samoan and English are widely spoken throughout Samoa though a majority of elders speak Samoan language as their first language. Children entering kindergarten are most likely to speak the languages of their village. The vernacular used to describe a person with a disability may not be acceptable by western standards. This representation of disability may impede how one requests or provides services.

Fitzgerald and Anderson (1992) documented several challenges when providing vocational rehabilitation services in Pacific Island communities. Although dated, this record describes the experiences of key informants highlighting issues including transportation, isolation, limited employment opportunities, and cultural and familial considerations. Representatives from the Republic of Palau, American Samoa, Commonwealth of the Northern Mariana Islands, Guam, and four Hawaiian islands (Hawaii, Kauai, Molokai, and Oahu) convened in Molokai, one of the most rural communities in the State of Hawaii. Case studies featured the impact of modernization on sociocentric societies along with exposure to other cultures resulting in rapid change on island life. These changes often conflicted with traditional values and ways of addressing the diversity of the human condition. The issues discussed continue to be relevant within American Samoa.

### Perceptions of Disability in the Pacific Islands

Depending upon where one is from within the Pacific Islands, varying attitudes and beliefs about disability exist. It would be unfair and inaccurate to assume that how one island culture perceives and treats their members with disabilities is the same across all islands. In fact, there exist differences across sociological features such as education level and gender; and depending on whether one resides on a main island or outer island, northern or southern village. We offer a broad view of how disability is perceived based on the literature describing the general context within the Pacific Islands of which we based our inquiry.

According to Locust (n.d.), interactions and influences of other cultures have shaped how Native populations of the Pacific Islands view disability. One of the overarching cultural views is that disability is a punishment for parental sins. It is also associated with the sins of the individual with a disability in a previous incarnation. In her work with rehabilitation of Pacific Islanders, Ratliffe (2005) cites numerous perceptions regarding the causes of disability. For instance, curses or spells laid on the family, ghosts or spirits living in the house or the beach, or parental behaviors such as excessive drinking, spousal abuse, or sexual promiscuity are seen as causes for disability within a family. Likewise, the behaviors of a mother during pregnancy are also taken into consideration, as exemplified in the belief that eating while cooking for elders will cause cleft lip.

While each family responds differently to a child with a disability, it is not uncommon for families to keep a child at home, isolated from community activities. In many traditional Pacific Island communities, families who have children with disabilities are shunned and often blamed for their own situation (Ratliffe, 2005). However, as people become more aware and educated about disabilities, rehabilitation efforts, and medicine, such views are changing and communities are becoming more accepting of children who are different. Yet there is still much work needed in implementing the mandates of ADA. Currently, within many Pacific Island communities an inaccessible environment contributes to the lack of exposure to people with disabilities among the general public.

Ratliffe also cites that, within some families, children with disabilities are thought of as the “most loved ones” or a “gift from God” (2005, p. 45). Thus, family life centers on the child with the disability. Not surprising though, due to shame and social rejection, these families often

avoid bringing their child to social gatherings. By the same token, children with disabilities may also be seen as a result of a poor relationship with God and that God must be displeased with the family (Mokuau & Tauili'ili, 1997). Clearly, perceptions of disability are culture-bound as is the concept of self-determination.

Disability as a word in American Samoa does not exist. Rather, the terms *ma'i* meaning sick or ill; *o le atoatoa o le mafaufau ma le tino* meaning not fully developed; or *gasegase* meaning having a health condition are some of the common vocabulary used to describe a person with a disability. Inquiring about the use and meaning of these terms provided a foundation to better understand how self-determination is defined and valued within this setting. Understanding that disability may be perceived as a topic of taboo, we thoughtfully tried to describe and comprehend self-determination within the Samoan context. Following this contextual framework of disability, the relationship between self-determination and culture was our focus of interest as we gently approached the subject with the study participants.

### Self-Determination and Cultural Congruence

Self-determination is a concept that incorporates cultural beliefs— its definition or value is influenced by one's culture (Frankland, Turnbull, Wehmeyer, & Blackmountain, 2004; Turnbull & Turnbull, 2006; Zhang, 2005). Negotiating the boundaries of traditional culture while adhering to western laws and mandates to promote self-determination often results in dissonance for both the consumer and service provider. Self-determination is a western construct promoting the "individualistic" values of mainstream American culture at the expense of "collectivistic" values characteristic of indigenous cultures (Leake & Black, 2005; Leake, Black, & Roberts, 2004).

Individualism is rooted in the view that people are discrete entities who, as they transition to adulthood, should move from dependence to independence and self-reliance. Collectivism is embedded in the contrasting view that people are connected in some shape or form to others (e.g., family, neighborhood, tribe). As they transition to adulthood they should move from dependence to interdependence (Ewalt & Mokuau, 1995). Individualistic cultures tend to stress individual rights, pursuing personal interests, setting and achieving personal goals, and being true to one's own values and beliefs. On the other hand, collectivistic cultures tend to stress obligations that go along with one's group roles, being an interdependent member of a group, working with others to achieve group success, and adhering to the group's traditional values (Yamauchi, 1998).

Self-determination as related to independence and individuality has been defined, described, and summarized similarly across social science disciplines. For example, as cited by Ewalt and Mokuau (1995), social work construes self-determination in terms of freedom of an individual to apply choice and self direction. Originally defined in the special education field by Wehmeyer (1997) and updated in 2006, self-determination refers to: "...volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life" (p. 117). Turnbull and Turnbull (2006) focused on self-determination funding which emphasized that individuals with disabilities should have more control over the money allocated to serve them than they have had in the past. For the purposes of this study, we focused



on the term as a broad construct integrating the basic tenets of the definitions above, but most importantly, founded on western values and ideals.

The research on self-determination spans numerous disciplines and continents as well as culturally diverse populations (Field, Sarver, & Shaw, 2003; Hardre & Reeve, 2003; Serna, Forness, & Nielsen, 1998; Wehmeyer, 1997; Zhang & Benz, 2006; Zhang, Wehmeyer, & Chen, 2005; Zhang & Law, 2005). Stanhope (2002) compared psychosocial rehabilitation in India and the United States, exploring how cultural beliefs and practices influenced the recovery of people with psychiatric disabilities. The Indian emphases on interdependence, externalized locus of control, and family involvement were found to be significant factors in the care of people with psychiatric disabilities. Rehabilitation goals in the United States, by contrast, concentrate on independence and individual productivity.

Frankland, Turnbull, Wehmeyer, and Blackmountain (2004) described how the Dine (Navajo) enacts key elements of self-determination according to their cultural perspective. While the Dine people value self-regulation and autonomy, the importance of interdependence and group unity take precedence over independence and autonomy. This study of self-determination within the Dine culture and traditions illustrated the application of particular aspects of self-determination and pointed out the need for services that reflect cultural, racial, and familial values of clients.

Ewalt and Mokuau (1995) discussed self-determination from a Pacific perspective and offered implications for social workers working with migrant Pacific Islanders. However, studies within a Pacific Island community rooted in traditional beliefs and mandated western practices related to self-determination are sorely wanting. More specifically, research conducted by indigenous investigators who possess the insider's knowledge of cultural nuances is considerably deficient (Mohatt, Hazel, Allen, Stachelrodt, Hensel & Fath, 2004; Norton & Manson, 1996).

## Methods

This exploratory study was loosely based on the methods described by Tuhiwai Smith (1999). The techniques for gathering evidence became the means and procedures through which the core issues of the research were addressed. In other words, during the data collection activities, the pre-determined interview questions became secondary to the rich stories and testimonies that emerged. Thus, responses to the interview questions were analyzed in accordance with the overarching paradigm that materialized.

### Recruitment

The second author played a crucial role in facilitating study recruitment as her insider knowledge, information about cultural etiquette, and local connections were invaluable particularly when setting up and conducting the interviews. Informants were recruited from member agencies within the Interagency Council on Disabilities and consumers of these services. Participation was voluntary. Individuals were provided a survey along with an information letter outlining the scope of the project and their rights as participants. The letter served as an invitation and consent to participate. The University of Hawaii's Institutional

Review Board approved the study. Participants did not receive monetary compensation for their participation.

## Sample

Purposive sampling allowed us to target a particular group of service providers relevant to this study which included directors and professional staff (n = 17). Twelve of the 17 service providers completed follow-up interviews. We were scheduled and confirmed to interview staff at the Department of Education-Special Education and Early Childhood Education Departments. However, upon arrival at these agencies, staff was not available to meet or complete the surveys. As a result their viewpoints are not represented in this sample.

Consumer interviews and surveys were limited based on a convenience sample of respondents who were willing to participate because of their acquaintance with one of the researchers. Scheduled meetings with a parent organization were cancelled since staff was unable to obtain approval from their director. One parent consumer was not able to attend a scheduled meeting; this absence reduced the sample to three participants. By far, results based on this sample of consumers cannot be generalized to the wider population. However, we were grateful for the conversation and insights that these three people shared as we inquired about services, self-determination, and culture. We believe their stories offer an intimate profile of what it is like to have a disability while living in American Samoa.

## Procedure

Two separate standardized surveys were administered to agency representatives and consumers, respectively. The questions were co-developed by both researchers, one of whom is a member of the Interagency Council on Disabilities and also the Director of the AS-UCEDD. The surveys were written in English and completed on site by agency staff at the following:

1. Hope House Hospice
2. Department of Vocational Rehabilitation
3. Office of Protection and Advocacy for the Disabled
4. Early Intervention (Part C) – Helping Hands, and
5. Department of Health-Children with Special Health Care Needs/Maternal and Child Health

In addition, we conducted interviews using slightly different protocols for the service provider or consumer. The interview served as a follow up to the survey. Both authors conducted the service provider interviews at the individual agencies. We completed two consumer interviews at the AS-UCEDD office (American Samoa Community College campus) and one at the consumer's residence per his request. All of the participants were fluent in English. However, for those who preferred to converse in Samoan, the second author conducted or led the interview.

To capture responses to the interview questions, we relied on handwritten notes. The interviews were not audio-taped for several reasons: (1) we were concerned about the comfort level of participants speaking candidly, (2) we wanted to gauge the tone and pace of the

interviews for cultural sensitivity and the possibility of recording future interviews, and (3) these initial interviews were exploratory, designed to gain a global conception of services, disability and self-determination. Exploratory interviews encourage respondents to converse freely and emotionally with candor and authenticity as opposed to collecting facts and numbers. Audio-taping could have inhibited the richness of responses.

During the interviews, participants were asked to respond to questions about general service requests, limitations of services, and perception of self-determination. The interview protocol consisted of semi-structured open-ended questions. However, the interviews themselves were conversational, flexible, exploratory, and informal. As noted in Merriam (1998), one of the goals of the unstructured interview is to learn enough about a phenomenon to devise questions for future exploration. Participants were encouraged to talk about the Samoan culture and how it influenced the provision or perception of services. The interview protocol was used as a guide to facilitate conversation. Depending on the flow of the discussion, questions were determined relevant or not.

The interviews provided a forum to “represent” voice and expression as noted by Tuhiwai Smith (1999). While we utilized the pre-developed interview protocol, we also strayed from asking some questions depending on the respondent and flow of the conversation. These diversions proved fruitful. We were enlightened with personal narratives experienced in this cultural context which served as a canvas to better describe how agency services intersect with culture. These stories served as a catalyst for more questions regarding the availability and quality of services for persons with disabilities residing in American Samoa. The interviews led to a much-needed contextual description of how the culture influences action. Interviews also contributed to a much-needed comprehensive picture of community services, systems of care, and perceptions of these systems. A follow up study is planned that will build upon this exploration.

### Analysis

To analyze interview data, we employed the method of grounded theory. Grounded theory is a specific methodology in which the researcher attempts to develop a theory by using several stages of data collection and refinement, making the inter-relationship of information categories explicit (Strauss & Corbin, 1990). Two primary features of this design are the continual comparison of emerging categories and the theoretical sampling of different groups to enhance the similarities and differences of information (Creswell, 1994). In other words, through the process of collecting, coding, and analyzing data, we generated theory. For the purpose of answering the research question, we used the first feature of conducting simultaneous data collection and analysis to generate categories and build thematic strands as recommended by Merriam (1998) and Creswell (1994). Similar to other forms of qualitative research, the investigators served as the major instrument of data collection and analysis, assuming an inductive posture and aiming to gather meaning from the data. The end result of this type of research was a theory that emerged from, or was grounded in the data.

As data were coded, the information was compared within and between categories. Also termed as constant comparative analysis (Glaser & Strauss, 1967), this technique occurred as

data were compared, and categories and their properties emerged or were integrated (Anfara, Brown, & Mangione, 2002). This process included initially identifying the surface content topics followed by classifying emergent themes and defining final categories. No codes were assigned a priori, but rather “induced” from the data. The researchers consistently read through the interview notes and debriefed after the interviews in an effort to reframe the discussions. Reframing refers to defining the problem or issue and determining how best to address that problem (Tuhiwai Smith, 1999). We wanted to make sure that we understood the information within the wider socio-cultural context. Because the interviews were a combination of unstructured and semi-structured, the first cut included coding only the responses to questions from the original protocol. The interview questions provided the organizational foundation to initially code responses. Open codes were then grouped into themes. Through inductive reasoning, the categories and their properties were classified (axial coding). Core categories were identified and formed the crux of the narrative.

## Findings

For the purposes of this paper, only the results relevant to this study will be discussed. Data collected from the survey included basic demographics and are presented in [Table 1](#).

**Table 1.** Description of Participants.

		Service Providers (n=17)	Consumers (n=3)
Mean Age		45.23 (SD = 9.80)	29.67 (SD=8.65)
% Female		88	33
% Race/Ethnicity			
	Samoan/Pacific Islander	82	100
	Other	18	0
% Highest Degree Obtained			
	High School	24	67
	Graduate/GED		
	Associate Degree	29	33
	Bachelor’s Degree	12	0
	Master’s Degree	24	0
	Doctorate’s Degree	6	0
	Other	6	0
% Number of Years at Current Employment			
	0-5 Years	35	N/A
	6-10 Years	12	N/A
	11-15 Years	18	N/A
	>16 Years	35	N/A
Mean # Years Working in Disability		11.25 (SD = 8.46)	N/A

Agency staff survey respondents were asked to rate the degree to which they coordinate with other disability service provider agencies on a scale of 1 to 4 (1 = Never, 2 = Seldom, 3 = Sometimes, 4 = Often). Staff responded with a mean rating of 3.11 (range = 3). Another item asked staff to rate the extent to which requests for services were made directly from potential clients. The mean rating was 2.94 (range = 3). To understand the process towards self-determination using the same scale, staff rated the extent to which clients independently complete applications for service. Mean rating for this item was 2.18 (range = 3) implying that clients rarely fill out the application on their own for services.

While only three consumers completed the survey, responses regarding services requested and not provided had a mean rating of 2.66 (range = 1). A mean of 2.66 (range = 3) was noted for requests for services made through other parties (not by the consumers themselves). In response to working with other agencies to support their individual needs, consumers had a mean rating of 3.66 (range = 1) implying that they are aware and have accessed other avenues towards receiving services.

Of special interest to the researchers were consumers' perceptions about disability and disability in general. The staff survey, using the same rating scale described above, asked respondents, "How do clients refer to themselves in terms of being 'disabled' as noted by their self descriptions (ma'i meaning sick or ill, o le atoatoa o le mafaufau ma le tino meaning not fully developed, or gasegase meaning having a health condition)?" Their mean rating of 3.29 (range = 3) is similar to that of consumers when asked, "How do you refer to yourself in terms of your disability (ma'i meaning sick or ill, e le atoatoa le mafaufau ma le tino meaning not fully developed, or gasegase meaning having a disease)? The mean rating was 3.00 (range = 3). These select survey results coupled with the interviews elicit additional questions to further understand disability and culture within an indigenous Pacific setting.

## Service Providers

### Service Delivery

Based on interview responses, two major themes emerged for each identified category. **Table 2** illustrates Category 1: Service Delivery which includes the themes of Resources and Coordination with other agencies. As perceived by the service providers, service delivery seems to be an area of great challenge in terms of resources. Transportation problems ranging from availability to accessibility was echoed throughout almost every interview. Many families do not have cars and rely either on relatives or modified buses that are not accessible for people with physical disabilities. For those who reside in remote parts of the island getting around is an even bigger challenge since most wage labor opportunities are located in the "urban" or central areas.

Equipment such as voting machines for government elections is not available. Votes are done via paper and pencil and are hand counted. Therefore, people with visual disabilities often need a family member to cast their votes for them. This calls into question the issue of privacy as well as validity of the voting process. At other agencies, equipment such as shower chairs is needed to provide clients basic care. Like many small island communities, a limited economic

base makes it difficult to find employment opportunities that provide training or job coaching. At the same time, an insufficient number of qualified people are available to provide comprehensive services to a population of people most in need. Similarly, we heard that appropriate and relevant training of staff pertaining to proper assessment, diagnosis, and treatment was a dire need. For instance, a service provider shared that inaccurate or unqualified diagnosis of specific disabilities often leads to inappropriate medical treatment or services.

Coordination was another theme that came out in the interviews. In speaking with the various service providers about working with other agencies, there appeared to be a disconnect with the public school system, particularly the special education department. Informants shared a desire for better follow through as clients moved through the various agencies and were linked to special education. They also mentioned a need for more communication in situations when agencies have the same clientele.

**Table 2.** Category 1: Service delivery – Service providers

THEME	FACTORS
Resources	Limited transportation Limited equipment Limited employment Limited number of qualified people
Coordination with other agencies	Inconsistencies within the special education department Undefined priorities about training needs

### Self-Determination

Through our inquiries with staff about self-determination and agency clientele, it became apparent that many staff respondents did not have a solid understanding of the concept until we further clarified it and related it to independence. This in itself was fascinating. To facilitate germane responses pertaining to clients, service delivery, and personal beliefs, we provided examples. For instance we exemplified independence by clients' behaviors such as completing an application on their own, requesting for services without parents or other family members speaking for them, or working to support themselves. All of the staff interviewed agreed with the idea or concept but in the course of discussion we heard much about how traditional and religious beliefs and practices underlie services. For example, many families seek alternative methods such as herbal medicines or lomilomi (massage) from traditional healers to address a disability. In some situations, independence is not seen as a possibility by some parents because of the cultural aspects of dependency and inter-dependency within the matai structure. Often, parents are over-protective of their child with a disability.

In other cases, language can be a barrier where formalities are important to acknowledge the status of those communicating with each other. Furthermore, if agency providers do not thoroughly check for understanding of specific instructions or care provision directions, families' perceived unresponsive or non-compliant behavior may be misinterpreted as not caring. One of the directors we interviewed emphasized the importance of knowing how to communicate as a

critical part of the services they deliver. By the same token, parents of children with disabilities often do not ask questions pertaining to rights or services, frequently leaving program staff to assume that the information was understood or comprehended. In many instances, parents place their trust with the service provider to provide what is “best.” These types of communication mismatches can lead to barriers in providing effective services.

Disability may carry a stigma in which parents may not be receptive to home visits. Having a service provider arrive in a government car is often cause for concern, particularly if neighbors see the car. In these circumstances, self-determination takes a backseat or no seat to saving face. For young adults, family dynamics in situations such as voting may interfere with enacting self-determined choices. Because the election system relies on paper and pencil, for the sight impaired, ballots must be read to the voter and the actual voting cast done by designee. This practice defeats the effort to vote independently and confidentially. For situations where political party lines are drawn in the household, and proxy voting may be questionable, service provider staff will depend on legal, religious and familial reasoning to encourage parents to respect their children’s choices.

**Table 3.** Category 2: Self-Determination – Service Providers

THEME	FACTORS
Self-determination concept	Limited understanding of the concept Agreement with the concept
Cultural (in)congruence	Traditional beliefs and practices Religious beliefs and practices Linguistic aspects Perception of disability Communication patterns Family dynamics

### Consumers

As noted previously, we were able to interview only three consumers during the data collection timeframe (July 6-10, 2009). Tables describing specific categories as presented above will not occur in this section because of the limited number of respondents. In order to thoroughly conceal their identities, we will provide a broad summary of their responses.

### Service Delivery

All consumers had experience requesting services through a state agency. All consumers shared that their requests for services in general were met by a lengthy response period specifically regarding one particular agency. However, some requests were fulfilled within a matter of months but the service itself (transportation) was limited to certain hours. Requests ranged from transportation to and from work or school to assistive technology and equipment. One consumer shared that a request for accessible daily living equipment made three years ago continues to be open. Per his understanding, although the equipment is at the agency, there is no

one available to install it. Another consumer mentioned a request for specific equipment made about five to six months prior. He did not appear aggravated and believed it was his responsibility to follow up with the agency regarding his request.

### Self-Determination

When talking about self-determination, consumers understood the term in relation to independence and being able to do things for oneself. All three consumers commented positively about engaging in activities on their own such as traveling or attending college. One consumer stated that attending school provided a sense of being “normal” and that “I can do things normal people do.” In addition, service requests that were implemented allowed opportunity to become more independent and fully participate in activities.

The conversation about self-determination naturally flowed into questions pertaining to family and culture. Two of the consumers reside at home with their parents and families. One consumer resides at home on weekends, but during the week days lives at Hope House Hospice, where 21 residents (elderly and individuals with severe physical disabilities) are sheltered. The two who reside at home expressed that they receive much family support for being independent while at the same time the instinct to protect often eclipses autonomy. In regards to culture, another consumer shared that being independent came at the cost of politely disrespecting elders. While traveling alone at the airport going back to American Samoa, several Samoan elders recognized this consumer and sincerely wanted to help. However, in his determination to be independent, he respectfully declined their offers of assistance careful not to offend the elders since culturally one must listen to direction of those older in age.

In terms of how the concept of disability and culture intertwine, one of the consumers supported the perception about the cause of disability being a result of a cultural belief. Although he did not provide more detail, he translated the term disability to mean, “...for those not strong enough,” or tino vaivai referring to those weak in spirit, body, or mind. The other two consumers related personal stories about having a disability in their community. For instance, with friends and peer groups, a consumer shared how she is encouraged to take risks and go beyond her comfort zone. In so doing, she feels that she is the same as her friends when they are together. Yet on a particular afternoon when arriving at a park to eat lunch with friends, she was unable to leave the car and enjoy the park because it was inaccessible. She and her friends ate their lunch in the car. Although her friends did not mind being in the car with her, she said that incident made her feel different and that she really is not independent.

### Implications

The findings in this preliminary study set the groundwork for future inquiry pertaining to service delivery, self-determination and culture within American Samoa. The interview results appear to be consistent with those of previous investigations where issues of transportation, limited resources and cultural complexities inhibit the provision of comprehensive services (Fitzgerald & Anderson, 1992). The coordination of services among various provider agencies is an area that needs further examination. Although survey respondents believed that coordination



sometimes occurred, it is unclear which agencies coordinate and in what ways they work together. It would be useful to understand the quality of these collaborations.

As perceived by service providers, clients' requests for services and application completion are other areas that warrant scrutiny. Just about every professional we interviewed agreed with the concept of self-determination after we clarified and provided a definition. However, we do not know whether agency staff members encourage clients to speak for themselves or when possible, fill out agency forms. Cultural aspects such as age and status may come into play if parents accompany their children to the various agencies.

Residing on a small island presents many challenges as highlighted by the interviews. Services may not be effective or timely if there is not enough qualified staff. Along these lines, we heard that appropriate and relevant training of professionals to accurately diagnose and treat clients is a significant need. This dovetails with the necessity for coordination and collaboration amongst agencies.

Agency staff highlighted the lack of equipment such as computerized voting machines as a luxury that Americans probably do not even think about when we cast our vote. Yet, in rural societies such luxuries are still absent. Inaccessible public transportation or public parks particularly in rural settings continue to present challenges for people with disabilities wanting to be self-determined.

The reliance on customary healing methods is part and parcel with indigenous cultures and cannot be overlooked. In the same way, language protocols must also be integrated within a responsive system of care that accounts for a culturally determined ideal of independence. Through our interviews we unearthed what appears to be some ambivalence with values and beliefs. Service providers on the one hand are socialized in these traditional contexts, yet many obtain their education from American universities and are employed as public servants following American legislation and laws. While agency staff agreed with the concept of self-determination is it really something that is contextually compatible in this setting? The fact that many staff professionals did not have a comprehensive understanding of self-determination provides reason to pursue this line of investigation. In several interviews we had to re-phrase or define the term itself. Additionally, is self-determination an appropriate value or goal for traditionally collectivist cultures?

Our inquiry also uncovered some areas necessitating additional research relating to the perception of disability. We were especially interested in understanding how people with disabilities in this population refer to themselves. Both staff and consumer survey respondents believed that the various local terms (ma'i, o le atoatoa o le mafaufau ma le tino, gasegase) were used sometimes. In fact, o le atoatoa o le mafaufau ma le tino (not fully developed) is used in public service announcements. Through a western lens this definition of not being whole or half of a person seems appalling, as it overtly promotes power and privilege. Yet, within a culture rich in tradition and religious doctrine, what expression is deemed appropriate? How do these societal values coincide with western laws, rules, and regulations? Do age, gender, and socioeconomic status of both consumers and service providers impact perceptions? And if so, how do these perceptions play out in everyday life?

In his inquiries with the Carolinian atoll dwellers, Marshall (1994) explored the western concept of disability through their ideas about personhood. Personhood refers to the fundamental need of persons to be with other people. The core of personhood reflects the extent that one is able to participate in the hierarchical and interconnected social relationships. The measure of a person's "disability" then, is the degree to which that individual is able or not able to participate in the on-going everyday network of social relationships. Even physical impairments such as quadriplegia or blindness are not necessarily a "disability" in these communities provided that the person with a "disability" can construct new roles that enable active contribution to the household and community. Much like Samoans where life revolves around the aiga or family, factoring in contribution and relationships in the coordination between agencies may facilitate better and appropriate services.

This preliminary study provides insight towards a more targeted study. More research is needed on how culture and language influence the perception of disability and resultant services. We hope to enrich the sparse knowledge of culture and disability related to self-determination. There is a significant gap between what we know from western-based research and paradigms and the actual application across indigenous cultures. Future studies of this nature may inform federal legislation regarding appropriately defining specific activities within a culturally diverse community, as mandated by IDEA or ADA.

#### Limitations

The authors would like to acknowledge the limitations inherent in this study. Noted previously, sampling for the service providers was purposive. Although necessary and chosen for a specific purpose, it does not represent the wider population and may be selective and biased. Sampling for the consumer group was convenient or opportunistic, based on the ease of access. The parameters of generalizability are highly negligible since only three consumers were interviewed and surveyed. As a result, conclusions drawn represent the three consumers and cannot be generalized across the Samoan community members with disabilities.

We were not able to meet with the Special Education and Early Childhood Education staff from the Department of Education to hear their perspectives regarding services and self-determination. This paper does not provide a balanced view of the issues since we did not obtain responses from these departments.

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## The Experience of Active Wheelchair Provision and Aspects of Importance Concerning the Wheelchair Among Experienced Users in Sweden

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**Abstract:** This qualitative study describes the experience of active ultra lightweight rigid frame wheelchairs (active wheelchairs) provision. Eleven interviews with experienced users showed that the wheelchair should support physical as well as social functioning, but that users experienced injustice and unfairness when negotiating their wheelchair needs and felt insecure within the system. Changes of attitudes and organization are suggested.

**Key Words:** negotiation, qualitative research, wheelchair prescription

### Introduction

Active wheelchairs are a sub-type of wheelchairs mostly used by younger persons living active lives with career, family, and leisure activities. But, without an optimized wheelchair, everyday life activities become difficult to maintain (Batavia, 1998; Cooper, 1998). In Sweden, municipalities are responsible for the provision of assistive devices, such as wheelchairs (Arnell, 1999). However, as most wheelchairs are used by persons over 65 years of age, active wheelchairs represent only a fraction of all wheelchairs (Frick-Meijer, 2005). Meeting the demands of a small group of young active users, as compared to older persons with different demands, may pose a problem. Active wheelchairs have to meet other requirements than other manual wheelchairs, for instance, to facilitate active means of ambulating. Compared to other types of wheelchairs, an active wheelchair is less a tool for a person being transported (Cooper, 1998; Batavia, 1998; Bergström & Samuelsson, 2006). Active wheelchairs are more hard-wearing, can withstand higher strains than other manual wheelchairs and can be used for up to 16 hours a day, 365 days per year, a degree of usage few other devices are required to withstand (Cooper, 1998; Cooper, Boninger, & Rentschler, 1999).

In Sweden, 6.5% (or 575,000 persons) of the population between 16 and 84 years have a physical disability (defined as the inability to take a short walk); about 25% are under 65 years of age. Further, a person is considered severely physically disabled if an assistive device is needed for ambulation. About 1 % of the Swedish population (90,000 persons) uses manual wheelchairs. Among those, the proportion of active wheelchairs is unknown. There is no centralized gathering of data from the 21 county councils or 290 municipalities regarding prescription and utilization of models and brands of active wheelchairs (Arnell, 1999). However, in the year of 2004/05, the number of manual wheelchairs reported by the Swedish Handicap Institute (HI) as sold was 19,797, out of which 9.4% (1,579) were active wheelchairs. This data is not based on prescriptions, but on the reported sale by the manufacturers. There is no information concerning

how the number of manual wheelchairs sold is distributed among the various brands or models (Frick-Meijer, 2005).

The Swedish system of government is based on strong and independent municipalities and county councils. Within their respective fields of responsibility, they are relatively free to decide upon taxes and the detailed content of specific services (Lindgren, 2006).

General guidelines for prescription are provided by the Swedish Health and Medical Care Act (HsL) (SFS, 1983). Decisions made based on this act cannot be appealed; neither does the act include any possible sanctions if its intentions are not fulfilled. Instead, HsL states that the obligations of the health-care system to supply the medical care and devices are deemed necessary by the profession. Thus, the legislation endows no rights to the patient to demand a specific medical treatment (or device) (Lindgren, 2006).

The assistive device is a loan and ought to be returned when it is no longer needed (Svensson, Ödegaard, & Persson, 2007). When a user moves from one municipality to another, the device is to be returned, and another device prescribed in the new municipality (Hjälpmedelinstitutet, 2008). Normally, counties are responsible for healthcare at large, and municipalities are responsible for assistive devices used in everyday life (e.g., active wheelchairs). In practice, only assistive devices deemed necessary for everyday life are supplied – assistive devices whose primary purpose is deemed recreational (e.g., a set of wider wheelchair wheels for a walk in the woods or on a sandy beach) are not supplied. The HsL does not regulate the interaction between county councils and municipalities regarding the assortment of devices and potential fees (SFS, 1983; NSH, 2003). Blomquist (2006) found variations between municipalities in the same county, as well as between counties, and increasing fees during later years.

Choices regarding the local selection of assistive devices are guided by recommendations by the Swedish Handicap Institute. One role of the Institute is to test and validate assistive devices, normally by commission of manufacturers, thus establishing a list of validated models (NSH, 2003; Rönnerberg, 2005; Blomquist, 2006). The list includes 17 models from five distributors/manufacturers (Hjälpmedelinstitutet: Webb-HIDA, 2008). The local lists tend to contain fewer models due to economic reasons (Kittel, DiMarco & Stewart, 2002; Wressle & Samuelsson, 2004). However, no legal hindrances have been located regarding neither marketing nor prescription of CE-marked models (not validated by the Swedish Handicap Institute). Validation may therefore serve other purposes, such as a marketing argument.

Previous research has identified the main objective in prescription as the selection of the wheelchair that best allows the user to carry out daily activities and social roles (DiGiovine, Cooper, Boninger, Lawrence, VanSickle, & Rentschler, 2000; Routhier, Vincent, Desrosiers, & Nadeau, 2003), i.e., a satisfied user performing needed and desired activities in varied settings (Scherer, Jutai, Fuhrer, Demers, & Deruyter, 2007).

Wheelchair prescription requires knowledge in many disciplines such as mechanics, anatomy, physiology, kinesiology and technology, but also concerning everyday activities and movement function. Moreover, knowledge concerning available products is needed due to the

constant expansion of available models. It is vital to allow the user to try different models during the prescription process. The wheelchair is an extension of the user's body, and therefore, knowledge about the user's needs and priorities are of utmost importance for the prescriber. Thus, in theory, the most important factor is the user's personal priorities (Batavia, 1998; Cooper, 1998). However, a dilemma in prescription is the traditional view of users as patients, subject to expert assessment and prescription; not as individuals with a right to express preferences or allowed the possibility to choose (Sapey, Stewart, & Donaldson, 2004).

In Sweden, prescription is supposed to be based on the user's entire life situation. The prescriber has to make sure that the user priorities are understood; choice of product ought to be done together with the user, based on individual demands, needs, and priorities. However, this process does not imply that the user has a free choice. The final decision is always made by the prescriber, thus indicating an uneven distribution of power in the relationship. The availability of a certain device may differ between municipalities. Even though a specific device is available on a local list, it may prove impossible to obtain in reality (NSH, 2003; Lindgren, 2006; Svensson, Ödegaard, & Persson, 2007). DHR (2003), the Swedish National Confederation of Persons with Disabilities, conducted a survey concerning users' experience of assistive devices supply. Results indicated that the process was thought to be complicated. This was due to organizational decentralization and widespread responsibilities, making it difficult to find someone with an actual responsibility. Nevertheless, prescription of active wheelchairs in Sweden has only sparsely been focused in earlier research. This may be due to the comparatively small number of prescriptions, therefore a less common task for the average prescriber. Hence, the objective of this study was *to describe the experience of active wheelchair provision and aspects of importance concerning the wheelchair among experienced users in Sweden*. In order to gain a thorough understanding, a qualitative approach based on interviews was chosen.

## Materials and Method

This study utilized qualitative methods for data collection and analysis; more specifically, a thematic qualitative content analysis, as described by Graneheim & Lundman (2004). Through this approach, themes and issues in the interview data were linked, forming a system of categories from which the subject was understood. By employing an inductive approach, the focus was on the "understanding of the nature of a phenomenon on its own terms" (Kilbourn, 2006).

The experiences of the first author as a wheelchair user (not mentioned when recruiting respondents) proved helpful during the interviews. A common ground of understanding emerged due to shared terminology and knowledge. One of the first respondents immediately expressed relief upon noticing the interviewer using a wheelchair and said it was great due to "speaking the same language." However, this also served as a reminder of the need to handle these issues in the following interviews by means of attempting to employ an enhanced naivety for example. This episode also increased awareness (as a form of reflexivity) of researcher triangulation, thus emphasized during the analysis.

## Study Group and Participants



Experienced active wheelchair users can be described as those who are “healthy disabled,” i.e., persons whose impairments are predictable and stable (for instance spinal cord injuries), those who consider themselves to be healthy (as opposed to sick), and those who do not “expect to die any sooner than any other healthy person their age” (Wendell, 2001). An experienced user has passed primary rehabilitation and gained a width of experiences of living with a wheelchair as primary mode of mobility.

An experienced user utilizes the wheelchair in everyday life without specific concentration. Everyday life is “a series of ‘methodic appearances’ through which ‘doing being ordinary’ is mundanely, methodically and reflexively accomplished” (Sandywell, 2004), i.e. daily occurrences where social relations are (re)produced and activities are performed or from which desisted (Burkitt 2004). In this study, criteria for being included as an experienced user were: (1) considering oneself to live an active life with a range of family and leisure activities (e.g. sports or other hobbies); (2) perceiving oneself to be post-rehabilitation, having landed in a reshaped everyday life; and (3) engaging in at least half-time employment, studies, or similar, but preferably full-time. These criteria are based on persons within this group possibly having accumulated a width of experiences of active wheelchair use and provision in the context of an active life with a range of activities, having finished rehabilitation, and having some kind of daytime occupation, studies, or other. Another criterion was the absence of cognitive affect and/or drug abuse. In sum, the phrase “healthy disabled” designates active individuals whose only obvious difference compared to others is wheelchair use.

After establishing inclusion criteria, key persons in disability organizations in southern Sweden were contacted, suggesting potential interviewees. The first author contacted them to validate the fulfillment of the inclusion criteria. This form of community recruitment was complemented with respondent referrals (i.e., snowball sampling). Eleven respondents, eight male and three female, aged between 25 and 52 (median: 41; mean 38.6), and between three and 40 (median: 23) years of wheelchair experience were included in this study. All were gainfully employed or students. Four were civil servants, three were teachers/lecturers, two were students, one was an economist, and one worked with computers. The causes of impairments were spinal cord injuries acquired at birth or later.

## The Interviews

A semi-structured interview guide was used during the interviews. Initially, a structured interview guide was constructed, but after two pilot interviews, this was revised. The interview guide consisted of ten topics concerning experiences of wheelchair prescription and utilization. Each interview started with a basic question of, “What do you do when you need a new wheelchair?” Thereafter, other interview topics were discussed. Please see below for a presentation of the topics:

- 1) What to do when a new wheelchair is needed
- 2) Repairs and maintenance of the wheelchair
- 3) The role of sports
- 4) Sources of wheelchair skills
- 5) Key features of an optimized wheelchair

- 6) The role of the wheelchair in everyday life
- 7) Sources of knowledge
- 8) Sources of news on modern wheelchairs
- 9) The interactional effect of the wheelchair
- 10) Financial factors concerning wheelchair use

During each of the interviews, ideas emerged about what to ask next when following up on specific issues. Sports served a role as a source of information concerning news on the international wheelchair market. Initially, sports was included concerning the personal development of wheelchairs skills, but this proved to be of lesser importance than as a source of knowledge in active wheelchair optimization. Finishing each interview, the informant was asked if something needed to be supplemented. This aimed at giving the interviewee more control of the content of the interview (Beazley, Moore, Benzie, 1997). Interviews were digitally recorded using an mp3-recorder or a mini-DV camera utilizing only the audio recording capacity. Consent from the interviewees was obtained in accordance with valid ethical guidelines. Valid Swedish legislation was followed when conducting this study (SFS, 2003; Gustafsson, Hermerén, & Petersson, 2006).

### Analysis

Thematic qualitative content analysis seeks to link themes and issues in the interview data forming a system of categories from which the subject can be understood. In this study, the inductive analysis focuses the manifest, as well as the latent content, of the interview transcripts. Manifest analysis aims at the obvious and visible components in the text being analyzed, and latent analysis aims at interpreting the embedded and underlying meaning of the text. According to Berg (2001), manifest and latent analysis should be used in combination when possible. The detailed analysis was performed in several steps, the first step being readings of the whole text in order to gain an overall understanding of the text. After this, the meaning units in the text were identified, and the text was condensed and coded for content (Graneheim & Lundman, 2004). Thereafter, the second and last authors independently generated their own category system from the data, i.e., a form of researcher triangulation (Curtin & Fossey, 2007). The coding and interpretations of the text were discussed; thereafter codes with similar content were clustered and named based on their meaning, then assigned to categories. The last step was to confirm the categorization by means of comparing and contrasting the categories to the codes, and the codes to the text.

### Results

The main and subcategories emerging from the interview data is presented in **Table 1**. Within the first part of the aim of this study (users' experiences of wheelchair prescription), one main category ("to negotiate") emerged, and within the second part of the aim of this study (aspects of importance concerning the optimal wheelchair), two main categories ("support physical function" and "support social function") emerged. In the following, the content of these categories are discussed in detail.

**Table 1:** Main and sub-categories of the interview data

Part of aim	Main categories	Sub-categories
Experiences of the wheelchair prescription	To negotiate	To experience injustice and unfairness To feel insecure within the system
Aspects of importance concerning the optimal wheelchair	Support physical function  Support social function	Easy to handle  Comfortable seating Stand high strains and be trusted Identity and self image  Social capital and agency

### Experiences of the Wheelchair Prescription

Interviewees described two main actors in wheelchair prescription: (1) the prescriber and (2) the manufacturer's sales representative. The sales representative was described as the one having deep knowledge in technical aspects, as well as a clear sales motive. The prescriber represented the municipality in the prescription process and was described as being in power, i.e., the gatekeeper of an optimal wheelchair, denying solutions outside the absolute minimum. Examples given included not being listened to, or even answered, when providing arguments for a wanted wheelchair. Other arguments could be answered as being outside the municipal budget, which evoked feelings of uncertainty and frustration. Users based their arguments on being post rehabilitation and having gained a range of experiences and knowledge. There were also examples of when a prescriber could support almost everything the interviewee said, and even ask the interviewee to gather information and arguments concerning various models. However, these experiences were most common when the prescriber was described to lack knowledge on even basic aspects of an active wheelchair:

“When the prescriber was demonstrating the wheelchair he read the manual and said... ‘back here, on the back, is a cord’ [...] ‘and when you drag the cord, the back is folded’ ... [laugh] [...] well, it has been like that on my seven latest wheelchairs... [laugh].”

The division of responsibility between the prescriber and the manufacturer was sometimes unclear during the prescription process. In some situations, the informants found themselves in a position of reaching a conclusion with one of them, a conclusion questioned by the other. In theory, the prescriber decided on the configuration and type of prescribed wheelchair, but in reality, parts of this decision seemed to be subject to negotiation between the interviewee and the manufacturer, leaving the prescriber outside.

#### *To Negotiate*

In general, interviewees found prescription to be a process of negotiating their needs:

“It is a negotiation, and if you are a poor negotiator you do not get anything.”

“The weird thing is...with the prescribers...at last, you often end up with what you wanted, if you are persistent and can really motivate.”

A negotiation with a prescriber was seen as problematic due to the prescriber not having the sufficient knowledge to be an effective counterpart. Interviewees saw arguments on municipal economy to be used when arguments based on technical knowledge were lacking:

“They do not know that much I think...you have to keep informed yourself...”

The personal cost in terms of invested energy in negotiating one’s needs was experienced as high:

“I experienced a radically decreased quality of life by this...this way of behavior.”

A general argument from the interviewees was that negotiations should not be needed at all if prescribers had sufficient technical knowledge and understanding of wheelchair needs. Different experiences of negotiations could be identified: (1) to experience injustice and unfairness and (2) to feel insecure within the system.

### *To Experience Injustice and Unfairness*

An experience of injustice and unfairness in contacts with the prescriber was emphasized by many of the interviewees. Examples included experiences of a high cost in terms of personal energy when the expressed needs were not considered. To obtain a new wheelchair was described as a long and tedious process. Therefore, it was something to engage in only when it was needed. Informants expressed one reason for needing a new wheelchair to be the introduction on the market of a new model that might solve issues with the model used at present. Even so, the prescriber did not always accept arguments of a new wheelchair solving problems with the current one. Informants even expressed fears of a potential injustice for other active wheelchair users perhaps not persistent enough in fighting for their needs, thus ending up with wheelchairs less optimized. However, some interviewees expressed that they were generally uninterested with the wheelchair:

“So, I just drive on... I think I get used to both how it works and how it does not work, and how poor I sit because it is nothing that changes from one day to another but gradually.”

The sense of injustice was also described in relation to economical prerequisites. Some of the informants with stable financial situations had abandoned the public system of prescription and bought wheelchairs themselves in order to avoid having to discuss every detail with the prescriber. Interviewees stressed that already today the cost of rear wheel tires is, in many municipalities, a personal responsibility for the user. In many cases, interviewees with

wheelchairs prescribed within the public system used alternative, and privately funded, rear wheels and hand rims. Other examples were privately funded ways of attending wheelchair service and maintenance.

Family members were described as a buffer in contacts with the prescriber. One informant described when a prescriber discussed matters of cushion covers with a family member, where the family member in vain tried to convince the prescriber of the need for a spare cushion cover.

### *To Feel Insecure Within the System*

Interviewees described a sense of insecurity when in contact with the prescriber. To feel insecure and powerless was due to not knowing what to expect in terms of wheelchair optimization and assortment, or the prescriber's negotiation starting point, or how difficult the negotiation was going to be, i.e., the unpredictability of the process. Nevertheless, informants could contact the prescriber to discuss the need for a new and better wheelchair:

“I have hesitated all this time because, no one really likes to change wheelchair... due to it is so tough to change.”

Hesitance could be based on a new wheelchair taking time to get used to. Hesitance was further increased by the insecurity of not knowing what to expect. One informant described that the prescriber asked her/him to check what was available on the wheelchair market and then return with a decision. For the informant, this resulted in insecurity due to a feeling of not being taken seriously and the presumed expert's lack of expertise.

“The prescribers were very passive at the side... [...] it was more like a dialogue with the manufacturer sales representative.”

A further source of insecurity described by the interviewees was differences between municipalities. Some municipalities had widespread restrictions concerning active wheelchairs, adding to increased unpredictability:

“My experience here in [in this municipality compared to where I used to live] is not good... it is probably the worst I have experienced since I got injured.”

Another source of insecurity was when they tried to locate the prescriber in a system in which it was difficult to navigate. One informant described this as difficult due to not having had any contact with the prescriber for some time, the municipal organization was altered, new persons were employed, etc.:

“I started by calling my health care centre in X-town and then they wanted me to call the municipal local organization and then they told me to contact X [the prescriber] and then X came home to me, made a home visit, they like making home visits...”

However, one informant described the prescription of a new wheelchair as an easy and unproblematic process:

“Actually relatively easy... among the easiest I have been through concerning... the jungle of societal support... [laughs].”

### Aspects of Importance Concerning the Optimal Wheelchair

A picture emerged in the narratives of how the optimal wheelchair should be constructed and what needs it should fulfill. The role of the optimal wheelchair was described as supporting: (1) physical function (technical aspects) and (2) social function (identity, self-image, and agency).

#### Supporting Physical Function

Technical aspects of importance were described as the wheelchair should: (a) be easy to handle, (b) have comfortable seating, and (c) stand high strains and be trusted. The prescriber was expected to give an account for these aspects. The technical perspective on wheelchairs involved mobility:

“It should make it possible for me to ambulate as freely as possible from my physical... prerequisites.”

An optimal wheelchair was described as tailor-made to fit the user perfectly. Some interviewees expressed plans of buying such a chair, built from personal measurements, as such a wheelchair was not prescribed within the Swedish prescription system.

#### *Easy to Handle*

An aspect of importance was that the wheelchair should be easy to handle in varying environments. One main criterion is that it should have low weight:

“It should weigh nothing, preferably minus...”

However, some informants expressed that the hunt for low weight seemed to have gone a little too far:

“I think it is ridiculous, this hunt for... hectograms of the wheelchair when you are sitting with...one of these...[points at his paunch] [laughs].”

Low weight was also associated with easiness of loading and unloading the wheelchair in and out of a car. Informants described that in relation to weight, a wheelchair that was a little heavier could still be easier to drive if it was better adjusted. However, when loading the wheelchair into the car, extra weight could cause problems.

To be easy to drive, the wheelchair had to be optimized to the user. Functioning friction hand rims were important for interviewees with limited hand function. Aspects of optimization included rear wheels, as lightweight fiber spoke rear wheels were lighter, easier to maintain, and more hard-wearing than other types. Cast magnesium rear wheels were preferred by a user wanting a narrower wheelchair in order to not smash into doorposts.

An optimal wheelchair was described as not having too many possibilities to adjust. Each site of adjustment tended to make the wheelchair heavier, and in time break easier. Less possible adjustments made the wheelchair more rigid according to some of the interviewees; a rigid frame makes the chair more stable, hence easier to operate.

Informants expressed that side guards could be too hot in the summer, but used during the winter to prevent clothes from being stained. For a user with lower hand function, side guards could be omitted due to being in the way during transfers, and being time consuming to remove or mount when loading/unloading the wheelchair in or out of the car.

### *Comfortable Seating*

One key aspect emphasized by the interviewees was seating properties, including aspects of the cushion. Informants expressed that the wheelchair had to be adjusted in a way facilitating both driving the wheelchair and sitting in one place. This could lead to compromises – optimal seating positions when driving and when remaining in one place were different. For example, driving was easier sitting lower with the knees more flexed, whereas for static sitting, a more upright position was more practical. Nevertheless:

“Comfortable seating is almost never present in a wheelchair, but you can sit more or less stable and good.”

“Good seating is possible, but not as in an armchair... [laughs].”

The cushion was described as important for prevention of pressure ulcers and had to keep the rear parts cool and provide an even pressure. Other demands included low weight, easiness of putting in and removing from the chair when loading in or out of a car. Informants expressed that the cushion must be easily washed (both cover and cushion) in case of incontinence. Under these circumstances, an extra cushion cover was convenient.

However, a wheelchair not selected and adjusted from the beginning to fit the user was not easily optimized. Therefore, informants emphasized the need to keep informed about developments and new products. This included, but was not limited to, trade fairs, magazines (both local and international), as well as information obtained via peer-to-peer networks.

### *Stand High Strains and Be Trusted*

Another issue of importance emphasized was that the wheelchair had to be trusted to stand strains from everyday use. In general, wheelchairs could stand many demands, but when the demands exceeded the capacity of the wheelchair, accidents could happen. One of the

interviewees mentioned a travel abroad, where curbs were higher than at home, thus breaking one of the rear wheel axles of the wheelchair. However, accidents were described as generally rare, and were expressed as partly understandable due to the demands put on the wheelchair:

“When the frame... if it starts to crack, then it is time to get a new wheelchair, then the metal is exhausted and will soon start to crack also in other places...”

Interviewees expressed that rear wheel tires could be more or less sensitive. Some types, especially ones sold via the prescriber, were of low quality, prone to puncture. Therefore, more expensive, but less sensitive tires were preferred. One interviewee described a potential problem of tires being too knobby, thus bringing grit and gravel indoors during the winter.

The alternative to a one-hand operated two-wheel brake was brakes in a standard one per side configuration. However, these could widen the chair and be in the way, snagging clothes when lifting in and out of a car. Another problem was the one-handed brake sometimes coming loose during transfers to and from the wheelchair. Some interviewees preferred to not use any brake at all, and when needing to stay in one place instead placed a foot on the floor.

## Supporting Social Function

The second perspective of the optimal wheelchair was to support social function in terms of identity and agency. Social functioning was also described in relation to technical aspects. For example, lightweight fiber spoke rear wheels were not only lighter and more durable. They were also considered to be better looking, nicer in color, and providing a more active appearance. A 12-spoke model of these rear wheels was expressed as the “top of the line,” even though they had to be privately imported at a high cost.

### *Identity and Self-Image*

In general, the wheelchair could be a part of one’s identity and self-image, but the importance differed between the interviewees:

“It should not be seen, the wheelchair is not me; it is me who should be noticed.”

“It is still a part of me, even though it is not a part of my body.”

Interviewees saw the wheelchair as not only a means of mobility, but as a part of the presentation of self. A wheelchair had to be properly cleaned, e.g., hair around the front wheel axles was seen as sloppy, and a stained cushion cover as disgusting. The cushion and its cover were washed once every month, sometimes a little less often.

A good-looking wheelchair was described to be as discrete as possible, but at the same time good-looking and signaling an active lifestyle. For example, a black wheelchair was described as easier to match with clothes. Colors and looks were generally described as important, and even though one interviewee saw matters of trends, colors, and image as being



less important, this interviewee clearly expressed a will to not settle for any possible color without having the possibility to make an active choice:

“I will be using this chair almost 24 hours a day, well... almost... and, am I not supposed to have... to be satisfied with my chair then?”

Informants expressed differences between municipalities concerning both possibilities to choose color and making other choices. In some municipalities, the standard assortment consisted of only one or two models.

Even though a wheelchair should be perceived as discrete, some accentuation of design features was not negative. For instance, black tires were described as better looking than the ordinary “municipal gray,” whereas too wide or knobby tires made the whole wheelchair look clumsy. Nevertheless, informants emphasized that design ideals differ with age, insofar as they preferred more brightly colored wheelchairs when they were younger, but during later years had begun to use more discrete color and design.

### *Social Capital and Agency*

Interviewees expressed that one social function of an optimized active wheelchair was to make activities and roles possible, i.e., increase agency. Among peers, agency could be expressed by the optimized wheelchair and the skills of the user, i.e., how to use the wheelchair as a means of living an active life. Agency was further understood and evaluated in terms of ascribed social capital based on individual prerequisites, for example, level of spinal cord injury (SCI). A lower level of SCI implied managing activities not expected with a higher level of SCI.

Interviewees explained that features ascribed to a high social capital were often features that increased optimization of the wheelchair, thus increasing personal function and agency in everyday life. On the other hand, features only meant to improve looks were considered ridiculous, for instance casters (front wheels) with built in flashing lights of different colors:

“Design is enormously important actually... Some [i.e. out-group] may not be conscious about the importance but I see the importance among, among... all, all conscious wheelchair pilots that the design is... and the function of course... they are of course intertwined the two... [i.e. design and function].”

Informants described the role of the wheelchair concerning how others treated the wheelchair user. Differences were described between peers and outsiders (persons outside the group of conscious users). Reactions among peers concerned mainly functional aspects. Outsiders tended to react on the occurrence of a wheelchair *per se*, understanding the wheelchair as signaling absence of autonomy and agency. Interviewees referred to the wheelchair as a disabling attribute among outsiders, and an enabling device among peers.

An example of a negative impact on the social capital of an active wheelchair user can be to use an electric scooter:

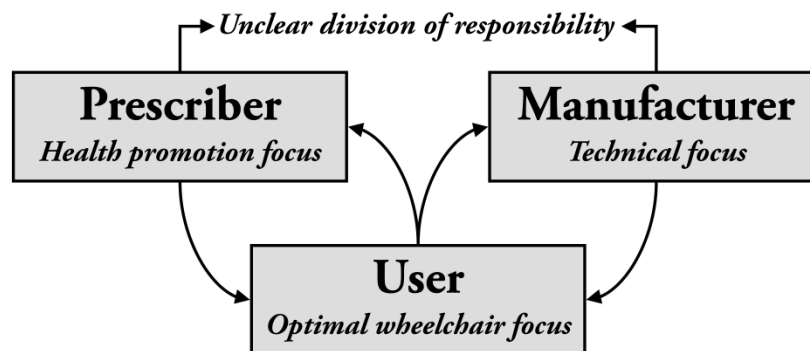
“... Some party in X-town ... where someone had used a moped ... electric scooter ... to get there ... [Interviewer: Right, yes...] and then it was the talk of the party of who’s it was... it stood outside and no one wanted to admit [that it was hers/his] [laughs].”

To use an electric scooter was explained as to give up autonomy by making oneself dependent upon technology.

## Discussion

The aim of this study was to describe the experience of active wheelchair provision and aspects of importance concerning the wheelchair among experienced users in Sweden. The process of prescription was experienced as a negotiation with a prescriber having the power to decide. During this process, feelings of injustice and unfairness were frequent, associated with feeling insecure and powerless within the system. The main aspects of importance concerning the wheelchair were supporting the user’s physical as well as social functioning. Important aspects concerning the physical function were that the wheelchair should be easy to handle, provide comfortable seating, be easy to maintain, and stand high strains in order to be trusted to function, while important aspects concerning the social function were to support the identity and self-image of the user and be a means of agency.

**Figure 1:** Model of understanding user perceptions of negotiating needs



From a user perspective, the process of wheelchair provision can be seen as a triad of relations between the wheelchair user, prescriber, and sales representative as described in **Figure 1**. The goal of the wheelchair user was to obtain an optimal one. The goal of the sales representative was described as proposing a wheelchair optimized for the user, thus also in many cases more expensive rear wheels for example. The goal of the user in this negotiation (to obtain an optimal wheelchair) and the goal of the sales representative (to sell) appeared intertwined concerning optimization. The goal of the prescriber was described to be health promotion and rehabilitation, which was not very well received by the users, as they considered themselves to be post rehabilitation, having landed in a reshaped everyday life, i.e., in line with the inclusion criteria of this study. The prescribers were further described to have a clear cost-cutting goal, in conflict with the users’ needs and expectations. The informants instead expected the prescriber to have expert knowledge of technical aspects, e.g., material strength and pros and cons of a great

variety of aspects. This can be seen as a role conflict for the prescriber to have a health promoting and rehabilitating perspective that is not requested and a cost cutting perspective that might contradict what the user deems optimal for his wheelchair. From the users' perspective, the division of responsibilities between prescriber and sales representative remained unclear.

For a wheelchair user, the prescription was a process of negotiating basic needs. Efring (1999) discusses assistive devices and needs as based on the desired activity of the user and the capacity of the device in this activity. The desired activity defined by the user, what remains to be negotiated with the prescriber is the capacity of the device. The optimal wheelchair fulfilling these demands can be a wheelchair with a high degree of useworthiness (Efring, 1999), i.e., a device perceived as not only possible to use, but also worth using due to the qualities of the device corresponding with the user's needs. This does not always mean a prescription of the most advanced chair or equipment as, "The most advanced application of technology is not necessarily the same as the application of the most advanced technology" (Childress, 2002). "Needs" have been discussed by Hallström & Elander (2001), utilizing a definition by Georg Henrik von Wright, i.e., as something "bad for the person to be without." By not recognizing perceived needs, the prescriber was seen as exercising power, repressing the functioning of the user. However, prescribers are an executive part of the municipal organization, not the ones making the rules they are following. The general argument from interviewees (that negotiations should not be needed at all if prescribers had sufficient knowledge) is therefore an argument pertaining to the societal organization the prescriber represents, and not only the individual prescriber. Consequently, even though a prescriber has the knowledge and wants to prescribe an optimal wheelchair, the prescriber may be hindered by regulations.

On a general level, societal organization of assistive devices supply is mainly arranged to facilitate the demands of persons with longstanding, sometimes progressing, diseases, and less to facilitate the demands of persons with stable conditions (i.e., "healthy disabled"). This is supported by findings from Wressle & Samuelsson (2004) including a random sample of adult wheelchair users where approximately four in five users were satisfied with their wheelchairs, indicating that today's municipal system is sufficient for persons with a more general demand of assistive devices supply. One way to handle the specific needs and demands of the group of "healthy disabled" could be to locate and/or construct an alternative track through the system, a track with optimal wheelchair provisioning as its only goal. Until the mid 1990s, specialized assistive devices centers existed within each county, but after assistive devices became a municipal responsibility, the centers were closed and competence disappeared. As this is a relatively small group, the supply can preferably be organized on a regional rather than a local level in order to enable provision based on specialized knowledge.

Differences described by the interviewees between in-group and out-group attitudes towards the wheelchair can be discussed in Goffman's (1990) terms of back stage and front stage, i.e., the back stage being where information can be exchanged freely among peers, and the front stage being where self is presented to others, i.e., out-group persons. Front stage, technical aspects could be emphasized from a perspective of physical function, with social aspects often left aside. Back stage, particular aspects are ascribed a certain value among peers, for instance, having a certain model of rear wheels or a wheelchair that is properly maintained. Persons not members of the in-group are neither aware, nor know of the existence of these values. According

to the informants, outsiders tended to react on the wheelchair *per se* as signaling absence of autonomy and agency. Among peers, social capital emerged from the functional value of the optimized wheelchair and the skills of the user as a means of agency, where user skills were understood and evaluated based on individual prerequisites, for example, function based on the level of spinal cord injury (SCI). In sum, a person's agency can be understood based on both a physical level of ambulation based on personal prerequisites and optimization of the wheelchair, and a social level of self-image, identity, and social functioning in everyday life.

Thus, the combination of physical and social aspects is vital when optimizing a wheelchair as a means of agency. For an experienced user, the wheelchair has become integrated into the user's body image—a person's mental picture of her or his body. This was seen in a person's body image as a dynamic construction based on internal and external stimuli, understood as the compatibility between the actual and mental pictures of the body (Breakey, 1997; Desmond & MacLachlan, 2002). The body image of a wheelchair user can be affected by attitudes and values projected back stage concerning aspects of the wheelchair and parts thereof, as the wheelchair can be a means of expressing one's self. However, this was not mentioned as an aspect expressed to the prescriber during a process of prescription and thus remained undisclosed for the prescriber. Instead, the negotiation was mainly kept on a technical level by the interviewees, a level where prescribers were unable to respond due to lack of knowledge.

Some users had abandoned the public system of prescription as a consequence of not getting the expressed needs met. Instead, personal financial capacity was used to obtain an optimal wheelchair or complementing a prescribed wheelchair with other rear wheels, etc. This can be seen in Bourdieu's (1984; 1991; 1992) terms as a transformation of economic capital into social capital, where one's financial assets are used as means of gaining a higher degree of social capital valid among peers back stage, where matters of, for instance, rear wheels are ascribed a certain value. Consequently, a person without the financial capital is unable to obtain the social capital desired. On a general level, abandonment of the public system raises the question of financial differences within the group of users when a person's need of an optimal wheelchair becomes less important than her or his financial strength.

## Methodological Considerations

There is a risk that the first author's experience as a wheelchair user has affected the interviews and the analysis of the interview transcripts. To balance this risk, two coanalyzers also generated their own category system from the data, i.e., researcher triangulation. The first coanalyzer (Ph.D. in Occupational Therapy) had experiences from a prescribing perspective, while the second co-analyzer (Professor, Ph.D. in Nursing) had no previous experiences of the prescription process. Through comprehensive discussions, an increased awareness emerged where the included perspectives added to a wider understanding of the subject. Furthermore, personal experience of wheelchair use mainly proved positive concerning the possibility to gain a more thorough understanding of key issues, at the same time as increasing awareness of potential researcher bias *per se*. Other means of triangulation employed in order to enhance trustworthiness included attempts to make a "thick description" by providing extensive quotes from the interviews and a comprehensive description of the research process. Ultimately,

triangulation aims at enhancing trustworthiness, i.e., establishing arguments for the interpretations most probable (Graneheim & Lundman, 2004).

Transferability of the findings in this study can be discussed from a wider perspective in terms of other types of assistive devices or other groups of users. As shown by Bergström & Samuelsson (2006), satisfaction in general may be higher when focusing a wider group of users. Hypothesizing that knowledge among prescribers of wheelchairs is roughly the same as indicated by the experiences among users in this study, one possible consequence is that the larger group of users utilize wheelchairs that are less than optimal.

Transferability to similar groups in other countries for example, countries where health care services and assistive devices are not financed through general taxes, can be discussed. The results may have limited transferability to countries where funding of assistive devices are based on insurances and/or private funding.

### Conclusions

In general, experienced users of active wheelchairs were not satisfied with active wheelchair prescription. The process was described as negotiating one's needs of an optimized wheelchair as a means of physical and social functioning. The counterpart in this negotiation, the prescriber, was perceived to have a low level of knowledge concerning important aspects of the wheelchair from both physical and social perspectives and was working within a cumbersome system of budgets and regulations. Prescribers emphasized a health promotion focus instead of a user requested technical focus. This left the user feeling insecure within the system. As a consequence, a question can be raised whether users have realistic expectations regarding the prescribers' resources to meet their needs of an optimal wheelchair. Another question can be raised concerning prescribers' knowledge of the social function of active wheelchairs, i.e. prescribers' access to, and use of, back stage information in wheelchair prescription. In the interaction between the agents of the user-prescriber-manufacturer triad presented here, efforts by the prescribers to express and utilize knowledge of these conditions, purposes and norms therefore seem highly warranted. Even in a changed organization, to accomplish a better fit and satisfaction within the prescription process in the future, users, in turn, have to inform the prescriber about everyday life and personal needs, also back stage.

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## Empowering Women with Disabilities in Northern Ghana

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**Abstract:** Women with disabilities in Ghana experience the triple disadvantage of sexism, ableism, and poverty, curtailing their visibility in society and their access to rights and sustenance. This article describes a program implemented to empower women with disabilities in Northern Ghana, the country's poorest region.

**Key Words:** Ghana, women with disabilities, empowerment

### Introduction

Women with disabilities all over the world experience multiple disadvantages due to gender and disability. For instance, the United States Bureau of Census indicates that men with disabilities have an employment rate of 59.9% while that of women with disabilities is 45.7% (Waldrop & Stern, 2003). Women with disabilities who work often experience unequal opportunities at their workplaces, including less pay for equal work (United Nations Enable [UNE], 2008). Additionally, men with disabilities tend to have more years of education compared to their female counterparts (Waldrop & Stern, 2003). In developing countries, they experience “triple jeopardy” as they face discrimination on account of gender, disability, and geographic region. The various forms of oppression women with disabilities encounter reinforce each other, thus resulting in unequal opportunities for women and men with disabilities (The Disabled Women’s Network [DAWN], 2007). In Ghana, the situation could be worse for women with disabilities due to cultural beliefs and practices that exist to perpetuate these vulnerabilities.

This article describes a program implemented to empower women with disabilities in Northern Ghana, the country's poorest region. It begins with an overview of the Republic of Ghana and then discusses the situation of persons with disabilities in general and women with disabilities in Ghana, the empowerment program, and its outcomes.

### The Republic of Ghana

Ghana is located in Western Africa, bordering the Gulf of Guinea, between Cote d'Ivoire and Togo, with Burkina Faso to the north. It is 239,460 square km in area, with a population of approximately 23 million. The median age is 20 years and life expectancy is 59 years. The literacy rate for those 15 and over is 66% for males and 50% for females (Central Intelligence Agency [CIA], 2008). This former British colony gained independence in 1957. There are five major ethnic groups and 100 spoken languages in Ghana, but English is the official language.

One of the least developed countries in the world, Ghana's Human Development Index reported by the United Nations is 0.532, ranking it 135<sup>th</sup> out of 177 countries (United Nations Development Program, 2008). This rating reflects Ghana's poor performance in meeting the health, sanitation, education, employment, and nutritional needs of its citizens. The GNP per capita was \$452 USD in 2005 (Students of the World, 2005). The majority of Ghanaians are living in poverty with 42% classified as "extremely poor" and unable to meet basic human needs including food. The unemployment rate is 23% and the minimum wage earned per day is about \$2 USD (Ghana Statistical Service [GSS], 2008a; 2008b).

Northern Ghana is more economically disadvantaged than southern parts of Ghana. According to the 2000 census, approximately 3.3 million people live within 97,000 square km. The literacy rates are lower than those in the general population: 42% for males and 15% for females (GSS, 2008a). Recurring drought in the north severely affects their economic situation given that 90% of the residents engage in small-scale agriculture (CIA, 2008). As the southern regions have more favorable climates for agriculture and there are opportunities for residents to engage in other industries such as mining and international and urban commerce, the disparity between the northern and southern regions of Ghana continues to widen.

### People with Disabilities in Ghana

Little study has been conducted in Ghana concerning disability issues in general. Therefore, little hard data exist on disability scope and trends in Ghana, as it is the case for many developing countries (Emmett & Alant, 2006). In the United States, approximately 20% of the non-institutionalized civilian population over the age of five has some type of impairment (Waldrop & Stern, 2003). In Great Britain, approximately 20% of the adult population has some type of impairment (Tibble, 2004). One may expect that the rates in developing countries are higher than those of industrialized nations as economic and social conditions are worse in the former. However, the figures reported by governments in developing countries are significantly lower than those of their industrialized counterparts. For example, in Ghana, the Ministry of Employment and Social Welfare (2000) reported that the rate of persons with impairments is 10%, of those 55% are female and 45% are male. Possible reasons for this discrepancy may include higher rates of premature death of children with disabilities, inaccurate counts of the disabled population in censuses, and higher thresholds for the identification of impairments in developing countries (Albert, McBride, & Seddon, 2002; Emmett & Alant, 2006).

People with disabilities struggle with poverty and ableism in Ghanaian society. Low societal expectations of their capability combined with architectural barriers, limited access to transportation, lack of information, inadequate medical systems, and few social welfare benefits propel many people with disabilities into marginal and unproductive social roles such as begging on the streets for survival (Kassah, 2008; Appiagyie, 2006). However, there are policies in Ghana that could improve the situation of people with disabilities.

The Persons with Disability Act was enacted in 2006 to provide a framework for protecting the rights of Ghanaians with disabilities, after a series of lobbying by both the disability organizations and other interest groups. It exists to ensure people with disabilities to

participate fully in mainstream society. However, implementation of this law has not been realized.

A poverty reduction strategy program, the National Health Insurance Scheme, was enacted in 2004 to provide health insurance to Ghanaian citizens upon payment of a premium (United Nations Office for the Coordination of Humanitarian Affairs, 2004; Physicians for a National Health Program, 2003). This policy recognizes the need to waive the premium for some categories of indigent people. However, the definition of “indigent” is very ambiguous and subject to the discretion of individual government employees who are responsible for implementing the program. They may not be sympathetic to the situation of people with disabilities. As a result, the majority of people with disabilities might be considered ineligible for the waiver by those employees and yet find it difficult to pay the premium. Consequently, many are disinclined to enroll in the program. Hence, they are unable to enjoy the benefits of the health insurance.

The National Youth Employment Program is another poverty reduction strategy, launched by the government of Ghana in 2006 (Ghana News Agency, 2006). The objective of the program is to empower youth to contribute meaningfully to the socioeconomic development of the country. The program has six modules: agriculture, waste management and sanitation, health assistance, rural education, information communication technology, and industrial internships. As the unemployment rate of Ghanaians with disabilities is 45% while that of the general populations is 23% (GSS, 2008b), it is crucial to implement the program in ways that help unemployed Ghanaians with disabilities. Employment generates income, but it also provides opportunities for social participation which lead to increased psychological well-being and improved life satisfaction of employees. Employment also contributes to increased self-esteem of women with disabilities (Lonsdale, 1990; Boylan, 1999). Unfortunately, the program is largely incompatible with the employment of persons with disabilities. For instance, most persons with physical disabilities cannot work in the physically demanding agriculture or waste management and sanitation modules. As barriers to lower education continue to deprive them of obtaining higher education, most persons with disabilities do not qualify for the education module. Furthermore, the attitudinal barriers ubiquitous in society are also prevalent among program administrators; these prevent youth with disabilities from obtaining employment in other modules (Geng-qing & Qu, 2003). The program, therefore, has not resulted in employment for persons with disabilities.

### Women with Disabilities in Ghana

Women with disabilities worldwide endure ableism and sexism. For example, in the United States, having impairments and being a woman are the strongest predictors of unemployment. Women with disabilities are at higher risk of being unemployed than men with disabilities regardless of categories of impairments. In their investigation, Randolph and Andresen (2004) found that the unemployment rate for women with disabilities (55.1%) was much higher than their male counterparts (45.3%) and higher still than men without disabilities (11.7%) and women without disabilities (25.1%). Similarly, D. L. Smith (2007) echoed these finding. Smith showed that between 1995 and 2002 in the United States, the average unemployment rate for women with disabilities was 55.2%, while the rates for women without

disabilities was 30.3% and for men with disabilities was 44.8%. Women with disabilities are not only less likely to be employed, but also earn less than their male counterparts (United Nations Enable [UNE], 2008). For instance, Elwan (1999) notes that women with disabilities in full-time jobs earn only 56% of the wage of men with disabilities.

In developing countries, the situation is worse. Emmett and Alant (2006) explore multiple disadvantages that women with disabilities endure in developing countries and note that attitudes towards people with disabilities in developing countries, especially women with disabilities, are considerably more prejudicial than those in industrialized countries. They conclude that the impact of ableism and sexism are intensified by the poor economic standard of the countries. However, there is a dearth of literature from developing countries, including Ghana, to estimate the scope of the problem.

In Ghana, sexist beliefs and practices prevail. Men are regarded as productive members of society in their roles as workers and professionals. Women are expected to submit to men in general and their husbands in particular, regardless of issues at stake. Men are allowed to have multiple sexual partners, while women are expected to marry, have children, and assume the nurturing roles as mothers and wives. Their contribution in their homes is not recognized. They are blamed for the breakdown of the marriages and the absence of children. While the primary roles of women without disabilities are those of wives, mothers, and sexual partners, women with disabilities are not even allowed to have this inferior status. They are regarded as asexual, unproductive, and useless (Lonsdale, 1990). They are excluded from education, health care, and employment opportunities, which leads them to severe poverty. The Coalition on Women's Manifesto for Ghana (2004) emphasizes that gender inequalities in Ghanaian society result in violations of the basic human rights of women with disabilities in all spheres of life.

### Sexism in the Disability Movement in Ghana

Under the umbrella of the Ghana Federation of the Disabled, there are three major national disability organizations: the Ghana National Association of the Deaf (GNAD), the Ghana National Association of the Blind (GAB), and the Ghana Society for the Physically Disabled (GSPD). The disability movement was not immune to sexist beliefs and practices. Although all three of these disability organizations had women's groups called "Women's Wings," originally formed to organize women and advocate for the rights of women and children, they had little voice in the organizations and were virtually inactive. Issues that were important for women with disabilities were sidelined to the Women's Wings where they disappeared. Thus, little attention was given to women's issues in the disability movement (Naami, 2006). This supports the argument of Deegan and Brooks (1985) that the disability movements dominated by men focus their attention mainly on male concerns while little attention is given to women's issues such as sexuality, relationships, and motherhood.

Further, the Women's Wings programs in the different disability organizations existed separately from one another without a network for collaborative work on common issues. As they had been marginalized for a long time, women had accepted inferior positions in the movement. Their acquiescence to their marginalization exacerbated their low self-worth and impeded their full participation within the movement and in society as a whole.

There was an urgent need to empower women and boost their self-confidence to increase their representation and participation in the disability movement, to create a system that would enable women's organizations to work together and support one another, and to raise awareness about women's issues in the male-dominated organizations.

### Empowering Women with Disabilities in Northern Ghana

Between November 2004 and August 2007, one of the authors worked as the gender program officer for Action on Disability and Development (ADD) Ghana. ADD is a British based non-governmental organization that seeks to build strong organizations of persons with disabilities in Africa and Asia. It aims to influence policy and practice in order to end social exclusion and poverty (ADD, 2008). ADD-Ghana was established in 1994 and works in Northern Ghana because poverty is concentrated there as discussed earlier. The relationship between poverty and disability is not unidirectional. Poverty causes disability or makes it worse as a result of barriers such as inadequate health care, lack of access to services, education, and employment, which perpetuates poverty (Harris & Enfield, 2003). There are 134 ADD branches in Northern Ghana. At the national level, ADD works with the Ghana Federation of the Disabled and its three member organizations (GNAD, GSPD, and GAB) to influence national policies (ADD, 2006a).

ADD had two main objectives. One was to help build strong disability organizations to advocate for persons with disabilities and influence social policies. The other was to support the inclusion of marginalized groups within the disability organizations. Women were recognized as one category of marginalized groups (ADD, 2008). In 2000, ADD started a gender program to end exclusion of women in the disability movements. The goals of the gender program are twofold: (1) to empower women with disabilities to increase their representation and participation within the disability movements and in society, and (2) to work with disability organizations to change their discriminatory practices against women.

The first step was to encourage the various Women's Wings from different disability organizations to collaborate in order to promote their issues and needs. This led to the 2002 formation of the Alliance of Women with Disabilities (AWWD), a cross-disability organization of women from various disability groups. Local chapters were formed in 34 towns and villages in Northern Ghana as well as a national chapter. The Alliance's mission was to resolve gender issues within disability organizations as well as address issues faced by women with disabilities in the society at large. Issues of women with disabilities should be recognized within the disability organizations and extended to greater society when women with disabilities learned their rights and advocated for themselves (AWWD, 2002).

In order to empower women with disabilities in Northern Ghana, five major strategies were adopted. The ADD gender program officer, herself a Ghanaian woman with a disability, would provide: (1) workshops to enhance gender sensitivity within disability organizations, (2) capacity-building training for self-advocacy, (3) training follow-ups, (4) assistance in establishing advocacy committees, and (5) support for networking with other organizations.

## Gender Sensitivity Workshops for Men in Disability Organizations

The first strategy was to create awareness about women's issues among male leaders of disability organizations. In order to do so, the program officer provided workshops to the leaders. The themes of the workshops included how to make the mission statements of disability organizations gender sensitive, how to use the gender lens in planning and monitoring organizational programs and activities, how to analyze the inclusion of women, and how to mainstream women's issues in their programs. In the workshops, the leaders had first-hand experiences of making changes in their writing, planning, and thinking, as well as benefits that could accrue to the movement by practicing these concepts. Expectedly, the program officer was met with resistance and criticism from workshop participants at the beginning. However, by the end of the intervention, there were some moderate changes in the perception of male leaders about the need to include women's issues in their activities.

## Capacity Building Training

A series of capacity-building training sessions was provided for women at the AWWD local chapters. The sessions included assertiveness and confidence building training that aimed at equipping women with disabilities with skills necessary to stand up for their rights and express their opinions, needs, and feelings without ignoring or hurting those of others. Women also learned the differences between assertive, aggressive, and passive behaviors. They role-played assertive behaviors in groups. The sessions also included group dynamics training. It provided knowledge and skills on group formation and development, maintaining group cohesion, conflict management, leadership, and effective communication. Finally, the sessions provided skills necessary for advocacy, public speaking, and community organizing (Alliance for Nonprofit Management, 2008). After these training sessions, the groups elected their regional executives to advocate for the group in Northern Ghana.

## Follow-up Support

Realizing that training alone was not enough to improve the self-advocacy skills of women with disabilities, the program officer visited the AWWD chapters at least once every two months for two years and provided follow-up support and consultation. She reviewed every activity undertaken by AWWD members and evaluated the effectiveness of the training sessions. She also shared with members important information such as government policies that concern women with disabilities and women in general. She used these follow-up sessions to strengthen the bonds among members. The women realized the importance of the group and why they should own and sustain the group's development. They also realized the importance of breaking the cultural norms that encouraged passivity and inferiority by cultivating skills of assertiveness, self-advocacy, and group advocacy (ADD, 2007).

## Founding Advocacy Committees

As the next step for the women to work collaboratively to make changes in the society, the program officer provided members assistance for establishing advocacy committees. The committee members studied the various injustices that women with disabilities had been

experiencing in their daily lives, the causes of discrimination and oppression, and the institutions where human rights abuses had occurred. They identified problems and planned new initiatives to solve those problems. The advocacy committees started demanding that government and other organizations protect the rights of women with disabilities in health, education, employment/skills training, and social services. Twenty-four advocacy committees were formed in Northern Ghana in 2005. At the beginning, the committee encountered some resistance from within the disability movement, but due to the sensitivity workshops, male leaders of the disability movement eventually supported the committee in its fight for women's human rights.

### Networking with Other Organizations

The final strategy was to provide support for members in networking with various governmental and non-governmental organizations to promote issues important for women with disabilities. Mainstream women's organizations were also targeted for networking. The women's organizations were asked to include women with disabilities in their memberships and to consider joint activities with the AWWD. The networking also provided opportunities for the AWWD to build a financial base to support small-scale businesses pursued by members such as dressmaking, soap and pomade making, weaving, batik, and dyeing.

### The Program Outcomes

The five strategies discussed in the previous section have resulted in empowerment of women with disabilities in Northern Ghana. Through advocacy, confidence building, and assertiveness training, women with disabilities have gained control over their lives. They have developed better strategies in advocating for their rights, as demonstrated in the following examples:

- Gina gained admission to Anglican Women's Center at Sirigu to obtain vocational training. However, upon recognizing her disability, the center administrators revoked her admission. In the past, Gina would have given up the opportunity. But she now had the support of the AWWD. AWWD leaders in Bolga approached the center administrators and the case was amicably resolved. Gina is now in the school and about to complete her studies (ADD, 2006a).
- Christiana in Lawra had an ex-husband who had neglected his responsibilities as the father of her five-year-old son. After the training, she gathered the courage to summons him to government's Department of Social Welfare office and successfully negotiated to obtain monthly child support (ADD, 2006b).
- Martha at Chereponi wished to attend a naming ceremony of a baby. The naming ceremony is an important custom in Northern Ghana when a newborn is presented in the community. But, her family told her that she would have no role to play in the ceremony because she was disabled and they tried to discourage her from attending. Martha in the past would have given up and just cried. But after the training sessions, she understood that it was her right to participate in the ceremony and did so (ADD, 2006c).



- Fati in Daffiama and some members of the Alliance were returning from a meeting. As they were approaching the market area, they heard some women making derogatory comments about their impairments. One woman said, "Look at those cripples. Nowadays they are proud." Fati approached them and said, "In those days we didn't know our rights. That was why we kept quiet. But now we will not let anyone who makes such comments go free" (ADD, 2006d).

Currently, there are 34 AWWD branches in Northern Ghana advocating for the rights and needs of women with disabilities. There is one AWWD at the national level working for policy changes within disability organizations as well as in Ghanaian society. The AWWD boasts 24 Advocacy Committees that are responsible for advocacy on health, education, employment/skills training, social services issues, and conduct fundraising for the organizations in Northern Ghana. By the middle of 2007, the advocacy committees successfully handled 26 cases that involved women's rights violations, accessibility issues, and violence against women.

A case in point occurred in the town of Jirapa. Upon seeing a credit union building under construction that was not accessible, the local advocacy committee met with the manager of the credit union. The committee members argued that they were part of society and that accessibility would be essential as customers of the business. The building has been completed with accessibility in place. In another case in Gushiegu, the advocacy committee advocated for ramps to be built at the audit service office and schools. Changes were successfully implemented (ADD, 2007).

AWWD members are also making good use of the funds that the group has. In 2006, the committees raised GHcedis 27,000 (\$2,800 USD) for small businesses of their members for the first time and started a microcredit program (ADD, 2006b; ADD, 2008). The economic situation of the women who are beneficiaries of the funds has improved along with the lives of their family members. The women, many of them single parents, have established small businesses with the fund that enabled them to feed and clothe their children, pay their school fees, and take care of their houses (ADD, 2006b). For example, Ayi, a single mother of four, started a small trading enterprise with GHcedis 6 (less than \$10 USD) that she obtained from her group. She purchased sugar, bagged it in smaller bags and sold it GHp 0.5 each. With the profits she accumulated, she expanded her business to sell matches, candies, and other small goods. She was very happy that she could provide food for her children with the proceeds from this small entrepreneurial venture.

Other women started their businesses without the funding assistance of the AWWD. For example, groups of women in Savelugu-Northern Region, Bole-Northern Region, and Daffiama-Upper West Region started their own credit venture. Each woman contributes a small amount of money at every group meeting. The collection of money is given to one member at the end of each meeting. The process continues until every member receives their turn. The women are able to start their small businesses with the amount they receive from the credit venture. These strategies have not only helped the women to generate their own incomes, they have provided the opportunities for social participation and they have increased psychological well-being as well as self-dignity, and self-esteem (Lonsdale, 1990; Boylan, 1999).

AWWD members have gained visibility in the disability movement. As of December 2006, women held 19% of the leadership positions such as president or vice-president in the disability organizations in towns and villages in Northern Ghana (ADD, 2006d). Although men still dominate the disability movement by holding the majority (81%) of the major leadership positions, women's progress will not be stopped as AWWD continues to educate and empower women.

Some AWWD members became active participants in other mainstream organizations, including the Ghana Hairdressers and Beauticians Association, Orphans and Widows Ministries, Single Mothers Association, Knights and Ladies of Marshall of the Catholic Church, and the National Commission on Women and Development. Some of them hold leadership positions in those mainstream organizations. Furthermore, some mainstream organizations such as German Development Services, Non Formal Education, African Development Fund, Ghana Institute of Linguistics Literacy and Bible Translation, and the SEND Foundation have started to include women with disabilities in their programs. In 2006, nine AWWD members ran for local government offices and one of them was elected into the office (ADD, 2006c).

Largely as a result of these successes, disability organizations in Northern Ghana have recognized the need to include women's issues in their plans and activities, as well as including women in their committees. The equal representation and participation of men and women has gradually become a norm. For example, the fundraising committee in Bongo in Upper East Region has 3 women and 4 men, the advocacy committee in Savelugu in northern Region has 4 women and 5 men, and the planning committee in Bolga in Upper East Region has 5 women and 3 men (ADD, 2006e).

### Conclusion

Women with disabilities in Ghana experience the triple disadvantage of sexism, ableism, and the poor economic standard of the country, as do other women with disabilities in developing countries (DAWN, 2007). Consequently, they were invisible in society and their rights and needs were ignored over the years. Strategies to empower women with disabilities were implemented between 2002 and 2007 in Northern Ghana, the country's poorest region. These strategies included assertiveness training for women, follow-up support, advocacy committees for women to advocate for themselves, networking initiatives with other organizations, and education of male leaders of disability organizations about gender equality issues. As a result, women demanded their rights in their daily lives and their participation in both disability and civic organizations (with some women assuming leadership positions in those organizations). They founded a cross-disability organization of women to advocate for women's issues at the local level, and they raised funds to improve the economic condition of their members. Male-dominated disability organizations became aware of their groups' practices of gender inequality and began including gender issues in their planning and activities. These advances bode well for the future of Ghana, and provide a template for the empowerment of women with disabilities.

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## A "Visible" Woman: Learning with a Student who is Deaf-blind at University

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**Abstract:** This article presents a case study of an undergraduate student with Deaf-blindness working with an interpreter and an academic skills adviser to develop her writing for the disciplines. It highlights the mutual learning this involves: about strategies for communication, issues of inclusion, and perspectives on disability.

**Key Words:** deaf-blind, disability, voice

For people who are Deaf-blind to undertake university study requires the involvement of a wide range of people, including (in addition to their subject lecturers) technicians who provide texts in an accessible form, sign language interpreters, librarians, and, if possible, academic skills advisers to help with composing and editing. It is usual to refer to these as support “services,” but as participants we find this concept inadequate to encompass the kinds of mutual engagement that can develop as staff members in various roles accompany students through their course of study. The literature on studying with a dual sensory impairment does not as yet offer an account of what staff and students have learned from one another, as far as we are aware. We would like to move the discussion from *service* to *learning* by recounting the experience of one such student – Elizabeth – and the staff involved in her efforts to learn how to write for the purposes, and in the discourses, of a Bachelor of Arts degree course in an Australian university. This piece is narrated by Kay, the academic skills adviser for Elizabeth’s Humanities and Social Science Faculty, in concert with Elizabeth and Sarah, our Deaf and Disability Liaison Officer, and drawing on interviews with technical staff and subject lecturers who have taught Elizabeth. She has, with the utmost good humour, unsettled our assumptions, expanded our knowledge, and improved our practice. One lecturer told me she had learned “that adjusting teaching/learning experiences for a student with special needs is beneficial for everybody’s learning and interactions in the classroom. There are many ways of learning, and sometimes students are the best guides ...”

We would like to develop two themes which reflect the two kinds of learning in which we have been engaged. First, as we have grappled with the practicalities of sustaining participation without sight or hearing, we have found ourselves questioning common assumptions about the boundaries of our professional roles. The other theme traces the development of Elizabeth’s thinking about issues of difference or diversity, discrimination or inclusion, as she has moved through her course. Her continuity of focus on such related issues is a product of Elizabeth’s self-consciousness as a person with a disability, which drives her to make connections among diverse kinds of marginalisation and self-assertion. Selecting from subjects offered in the BA – in English, history, sociology, and gender and diversity studies -- Elizabeth has constructed a curriculum which has introduced her to ways of seeing these issues through different disciplinary lenses and with reference to different bodies of knowledge, while she has enriched each subject with her expert knowledge of disability.

Elizabeth’s Education as a Person who is Deaf-blind

Elizabeth was born prematurely in 1958, and the oxygen administered to keep her alive damaged her retinas. She attended Blind School up to year seven, and during that time, ear infections and cholesteatoma also damaged her hearing. Elizabeth speaks of her frustration with the methods of education for people with her disabilities (her terminology reflecting usage at that time).

“[In the] 1960s [and] 70s, it was ... [decided] that Braille would no longer be taught to children with partial sight and they started using tape recorders, [and] large print, no matter how little vision you had. [Also at this time] oralism education for Deaf children was being taught [based on the idea that Deaf people should learn to speak, and to comprehend speech by lip reading]; and cued speech and signed English, which is a hearing person’s means of sign language, became popular for teachers of the Deaf [rather than sign languages developed by Deaf people themselves].

Children’s expectations were very low. For example it was felt that I should go to Blind rehabilitation services at...16 ... [and] then into the sheltered work shops for the blind. This [was] frustrating ...because I knew I could do a lot better for myself. ... academic expectations of my abilities [were not] very high. In fact, I did very little reading and writing because I thought that was only for school and ... I had a very unhappy childhood at school being away from my family -- apart from music, [which] was one thing I really excelled at. I would lock myself into one of the practice rooms at school to lock the outside world away.”

Moving to England, Elizabeth studied music at the Royal National College for the Blind, and graduated with credits. However, her hearing deteriorated until in 1992 she was given one of the early cochlear implants. She says:

“During this time I was working for Guide Dogs Victoria in Public Relations and Fundraising. And I had to learn Auslan (Australian Sign Language) very quickly because I had no means of communication.

In 1993 I worked for The Deaf-blind Association as Community Liaisons Officer. During this time I went to many schools teaching children about Deaf-blindness, and my time in Public Relations and Community Education gave me a love for teaching children.

It was not until 1998 that my friend Andrea encouraged me to read for relaxation. It would take me ages to read a large print book. It was at this time [that] I started to use some Braille.”

In 2005 Elizabeth took an online course designed for students with Deafness to improve their English, and then studied senior secondary level English, followed by a Diploma course to improve her Auslan so she could go on to further study. Elizabeth says, “[If you search,] you will find many things on Deaf-blind children’s education but not much on University or tertiary education for adults. This is because the expectations of Deaf-blind people are still quite low in many people’s views.”

People who are Deaf-Blind in Higher Education

Indeed, there is little information about people who are Deaf-blind in higher education. According to Everson and Enos (1995), “[a]lthough many young adults who are Deaf-blind could potentially benefit from postsecondary education, currently very few” enroll, and “very little has been written or researched about students who are Deaf-blind and their postsecondary education experiences” (p. 1). There are, however, some documents that offer advice to prospective students about assessing the suitability of institutions they may be considering, and advice to staff about meeting the needs of students who are Deaf-blind (e.g. Enos & Jordan, n.d.; Transition guide for students who are Deaf-blind, n.d.; Jordan, 2001; Everson & Enos, 1995; Talbot-Williams, 1996; Ingraham, Belanich, & Lascek, 1998; Orlando, 1998; Lago-Avery, 2001).

Spiers and Hammett (1995) have written a very useful paper addressed to students, lecturers, administrators and disability support staff, explaining the causes, kinds, and combinations of impairment that come under the general description of Deaf-blindness, and recommending services and accommodations to support their studies. They emphasise that each person is different in the degree of their impairment of either kind, when and how they acquired it, their cultural identification, if any, with the Deaf community, their awareness about their own disability, and their awareness of services. Conway concurs: “In my case, the answer to the question ‘What do you need?’ cannot be achieved simply by skimming down the list of what to provide for people who are blind and what to provide for people who are deaf. . . . Vision loss plus hearing loss manifests itself differently for each individual” (Stodden & Conway, 2003, p. 5; cf. Spiers & Hammett, 1995, p. 2).

The “individual nature of each student’s accommodation needs” is similarly stressed by Anindya Bhattacharyya (1997) in his address to the Sixth Helen Keller World Conference (online). He emphasizes the importance of (1) consultation to determine how a student prefers to access and communicate information in texts, lectures, and discussions (2) forward planning, to ensure that texts are made available in accessible formats, and that interpreters and note-takers, if needed, are available and (3) arrangements for orientation and mobility training, so that students know their way around campus. Bhattacharyya (1997) understands the initial difficulty, for most institutions, of working out accommodations when “they have not yet experienced serving this unique population of students.”

It is not only support staff who must rise to this challenge, as Bhattacharyya (1997) notes, but teaching staff as well:

”When first exposed to a post secondary environment, a Deaf-blind student presents unique challenges for support services to meet his or her needs. Faculty are also challenged with learning effective methods to help Deaf-blind students to successfully complete academic endeavours.”

Nor does this encompass the full constellation of people involved in any student’s efforts to succeed at university. Enos and Jordan (n.d.) point out, in *A guide for students who are Deaf-blind considering college*, that “All college students have a support network, which can include family members, academic advisors, study partners, tutors, and friends. Often students take a team approach to completing a course, relying on the assistance of these and other supports.”



Their advice, at this point, resonates strongly with our own experience: “By taking this team approach to your entire college experience, you will help ensure your success.”

### Elizabeth’s Team

Elizabeth uses our university’s alternate format service, which provides the readings she needs in formats that she can access; the note-taker service, which provides a record of lectures and tutorials; the university librarians’ assistance in finding readings; and the interpreting service, which provides tactile sign Auslan interpreters in settings requiring real time, face-to-face communication. The Deaf and Disability Liaison Officer, Sarah, arranges the provision of all of these services, as well as liaising with teaching staff to provide information about Elizabeth’s needs and how to accommodate them and to set up meetings as needed with teachers, the academic skills adviser, or the technical staff.

The alternate format staff welcomes Elizabeth’s feedback to tell them what works for her and what does not, and they are very flexible about converting texts quickly. As Elizabeth’s vision and hearing have deteriorated during the course of her studies, her preferences for different formats have changed from large print to Braille, because, as she says, “reading is extremely stressful for the little vision I have. And I am so pleased I made that decision.” An attachment to her computer keyboard turns whatever is on the screen into Braille under Elizabeth’s fingers, allowing her to read materials that have been scanned into the computer as well as those that are already available in electronic form, on websites or as e-books (Ingraham, Belanich & Lascek, 1998; for more on technology, see Pasupathy, 2006).

To communicate with others, Elizabeth has the options of typing (to email other people, and to produce assignments), or signing, or speaking, and in conversation she switches between sign and speech or uses them simultaneously. Elizabeth is fluent in English, because she was not Deaf at birth, and her speech is not noticeably affected by her Deafness except when she is also signing, as often happens. Then, her speech adapts itself to the morphology and syntax of Auslan (for information on this, see Johnston & Schembri, 2007). This has the effect of simplifying spoken utterances, because much of the meaning of Auslan is conveyed in non-lexical ways, such as use of space or facial expression, or shared knowledge of context. Elizabeth is aware of differences between English and Auslan, and has told me that she used to think in longer concepts, but now she “tend[s] to think in short Auslan concepts, then fill in the gaps”. This suggests that her written composition, as well as her conversation, may be affected by the change to thinking in her additional language.

With Sarah, Elizabeth meets regularly with her lecturers, to check her understanding, and they help her to choose readings or films relevant to her assignments (for film, an interpreter watches with Elizabeth and signs what is on the screen). During these sessions with lecturers, Elizabeth can let them know what is unclear to her, and keep them informed of her ideas for her assignments. These meetings serve to keep Elizabeth “on track,” conceptually and practically. For example, when her interpreter missed a lecture, she got the lecturer’s notes to fill that gap.

Then, Elizabeth and Sarah and I also meet each week, and Elizabeth tells me what her lecturers have emphasised as important in her assignments. Elizabeth often refocuses a question

to allow scope for her to use and to extend what she knows about disability, which in turn enriches the learning of her fellow students and her lecturers. For example, for the History subject “Myth, Memory and History,” which touches on oral traditions, Elizabeth designed her own topic, “What significance does the history of oralism have in relation to Deaf politics and identity in the present?” For her subject in “Writing Fiction,” she wrote a tale of “reversals,” about lost travellers who encounter a community where it is normal to be born with Usher’s Syndrome – a condition of deteriorating vision and hearing – and the few people who have sight and hearing are kept as slaves to serve the dominant Usher population (for an extract from this story, see Appendix One). In most cases, this strategy of focusing on disability to explore her subjects’ themes of division, inequality, or construction of identity works well, but her lecturers are mindful that her studies should also take her beyond what she already knows, so negotiating the focus and scope of each assignment involves considerations of flexibility, inclusivity, and standards.

### Blurring the Boundaries between “Support” and “Direction”

In our weekly meetings, we talk about the readings and the lectures, and in this respect, the way I work with Elizabeth is different from the way I work with students who can see. With a sighted student, we make brief notes of what the student says, for him to elaborate on later. He will do that with his books and notes all around him, drawing evidence and quotations from this or that different source and putting them together in an outline plan or a mind map where he can see, at every stage, what he is compiling, how all the bits relate to each other, where the gaps are, and so on. Lacking this visual dimension, Elizabeth finds it helpful to talk while I function rather like a mind map, noting ideas and examples as she recalls them, asking her how they relate to each other, identifying gaps where I ask her to elaborate, or contradictions which she will need to resolve. Then I email a summary of the session to Elizabeth, to remind her of what we said, and to pass on to her lecturers if she wants to check that we are on the right track.

Some readers may be uncomfortable about the amount of direction offered in these sessions, contrasting with the non-directive ethos prominent in writing tutoring. Writing tutors generally try to focus on *how* students write, not *what* they write; if we venture into matters of content, we may be suspected of misleading the student (because we know too little), or of leading them (because we know too much). (For this debate, see Clark, 1990 and 2001; Harris, 1990.) However, directive teaching does not have to give answers; it can encourage habits of questioning that will help students to succeed in the kinds of enquiry fostered by their disciplines. Those who fear that this is likely to make students dependent on their tutors may be reassured by Elizabeth’s experience. She has told me that increasingly, when she is working by herself, she asks herself questions because she has got used to me asking so many when I am with her (for more on this, see Chanock, 2010).

Sarah’s role, similarly, often goes beyond the limits of exact translation that interpreters are conventionally bound to observe. She asks occasional questions of her own (beyond the questions about arrangements which are her responsibility) or suggests a new approach. For example, when Elizabeth could not find a way into understanding how poetry works – “maybe,” she said, “because it’s so visual” – Sarah suggested that she use what she knew about music. Right away, we could talk about stress and rhythm, the structure of verse, and recurring themes

(“like a melody”). Sarah also draws Elizabeth back to the central focus of discussion when she wanders, and if Elizabeth’s response to one of my questions suggests that the purpose of the question has not been understood, Sarah says to me, “That’s not what you meant, is it?” and rephrases the question. Without this collaboration, I would be much less effective, because despite taking a brief beginner’s course in Auslan, which introduced me to the ways in which signs express ideas, I have very limited understanding of the range of ways in which my utterances might be given meaning in the language.

In these sessions, we cannot do close work on drafts, as I would with a hearing student, saying “This bit here, where you say [blah blah blah], it’s a bit unclear....” To do this in a session with Elizabeth and Sarah, I have to wait while she signs every word of the passage I want to talk about, and Elizabeth has to hold it in memory at the same time as receiving and considering the question I want to ask her about it. Usually, therefore, I save this for our electronic exchange of drafts and comments.

### Commenting on Writing

How to comment upon drafts when a student cannot see was a problem for Elizabeth’s lecturers as well as for me, and our methods have evolved, as we have learned more about how Elizabeth works. When I began working with Elizabeth, I found it difficult to move beyond my previous experience of working with students with a vision or hearing impairment. I responded to the challenges of her situation not with imagination or resourcefulness, but only, initially, with dismay. I had learned ways of working with students with a hearing impairment, such as using the “track changes” tool on my computer to comment on their drafts, making mind maps, and constructing written conversations as we sat side by side, looking at their essay plans; but these were no good to Elizabeth, as they depended upon vision. Conversely, the methods I had learned to work with students with vision impairment were no use either, as they relied on hearing: for example, I might read a student’s work aloud and comment on it, or recommend that he use screen-reading software at home to hear what he was writing as he wrote it. Working with Elizabeth, I could no longer rely on the strategy of shifting the load from one sense to another.

At first, because Elizabeth still had some, albeit very limited, vision and hearing when she began her studies, I tried to use “track changes,” as did her lecturers. However, it relies on colour to flag corrections, and it puts comments in the margin where a student who is blind cannot easily find them. Fortunately, as Elizabeth’s sight deteriorated, she switched to the Braille display on her computer, which does not use vision at all, and our communications improved as I was forced to find a way to put comments where they were needed, in such a way that they were readily noticed and easily understood. The key, I have learned, is simplicity. What I want Elizabeth to consider may be complex, but the way I express this request should be as simple as possible. I decided to place corrections in square brackets immediately after the thing that they referred to, and to use a few consistent directions such as *add*, *delete*, *change*, or *replace*. Where it is a comment or a question, rather than a correction, I begin each one with “Elizabeth”, to flag the difference. At various times we have worked on topic sentences, cohesive devices, and transitional phrases, and I have modeled the phrasing and location of these in academic writing. Over time, Elizabeth asked me to use capitals for my interjections, so that she could tell them apart from her own writing:

“Deaf people were made to feel unequal and lesser to [CHANGE TO TO THAN] their hearing counterparts under the education of oralism, [CHANGE COMMA TO FULL STOP AND CAPITALISE NEXT WORD] because they couldn’t learn to speak, they were placed in a category of intellectually disabled which is particularly true for the children who were pre-lingually Deaf.

...The knowledge of suppression of Deaf people arises from the reading of histories such as [ADD THAT OF] oralism which has in turn proceeded [ELIZABETH, DID YOU MEAN PRODUCED?] a mission of Deaf empowerment and the resistance of Dominant cultural forces. It is the History itself that catalyses social [ADD AND] political change.”

Once we had worked out this method, I suggested that Elizabeth circulate it to her lecturers and to her peers in the fiction writing subject when they were workshopping her drafts, so all of them became more aware of how Elizabeth works and what they could do to help.

### Faults or Strategies?

When I notice a pattern of errors, like incomplete sentences or apostrophes, I write an extended message to Elizabeth, explaining the problem and solution with examples from her draft. One pattern that lecturers have noted as a fault is Elizabeth’s use of repetitions and redundancies, and clichés. But I have wondered whether we ought to look at these from another perspective if they are characteristic of the writing of a person who is Deaf-blind. They are, after all, commonplace rhetorical devices in oral traditions, where redundancy serves to maintain the prominence of themes as the composition proceeds, and to remind listeners (and, no doubt, speakers) of events recounted earlier in the piece. In oral traditions, repetition is an aid to memory, rather than an irritation, and clichés, too, have their uses. Homer used epithets such as “wily Odysseus” and “wine-dark sea” to conjure character and scene economically, by drawing upon listeners’ familiarity with the phrases. We might reflect that the world of the Deaf is like an oral culture, in its reliance on ephemeral signs, and that stock phrases and repetition may serve similar purposes in preserving its traditions. If so, we might see their appearance in Elizabeth’s writing as rhetorical devices, rather than faults to be overcome.

### Faculty Response to Challenges of Inclusion

For the faculty who teach Elizabeth, it is not only her written work that challenges them to think about the implications of disability for inclusive thinking and practice. Having Elizabeth in their classes has stimulated a good deal of creative adaptation. In answer to my interview question, “What challenges have you encountered in this work [with Elizabeth],” a Gender and Diversity Studies lecturer volunteered:

“I use a lot of audio/visual material in lectures in particular, so I needed to think of ways for Elizabeth to access this information....In lectures, I got students to describe visuals, before I spoke to them. This would also set [the] context for interpreters before I launched into explanations. This worked well for everyone. Elizabeth and [the] interpreters were very proactive if clarification was needed, and we also met outside of

lecture/tutorial time. . . . Documentaries [and films] were the biggest challenge, particularly if they did not follow a straightforward narrative. Sometimes what is going on visually is different from what is being spoken, and can also be different from subtitles.”

To facilitate communication more generally, this lecturer found that “It is very important to send interpreters the lectures ahead of time. It was also helpful to meet with the student and interpreters outside of lecture/tutorial time, to check in on what is going on.”

Similarly, another lecturer felt that “It was really valuable to have an introductory session with Sarah and Elizabeth at the start of the semester -- half an hour chatting about Elizabeth’s background and needs, etc.” Both lecturers mentioned that they would have liked to learn a few signs, to be able to greet Elizabeth in Auslan, and that they did learn this eventually.

### Social Challenges of Communications in the Classroom

Thus far we have been looking at the roles of various staff members in working with Elizabeth, but fellow students are another important part of the learning community, and they need guidance, too, in how to make it work. Isolation can be a problem for people who are Deaf-blind, as others do not know, at first, how much they perceive or how best to communicate with them. One student who is Deaf-blind attending an Art college in Britain recalls that her peers did not initially make the effort to include her:

“They had not seemed to realise that when they got up and said generally ‘Let’s go to the pub,’ that I could not hear what was going on. I seemed to be the last person to know what was going on. In a group I would feel left out, but I do try my best to make an effort and get involved. Another time when I felt left out was when we had essays and other students would get ideas from each other or hear useful tips, while I tried to struggle on in my own way. Now I have built up my self-confidence and directly ask friends more” (Emma Hancock, interviewed by Sarah Talbot-Williams, 1996, p. 25).

This student’s advice to others was “Make good friendships/relationships with tutors and students. . . . Be bold” (p. 26). Similarly, a student in the U.S. who is Deaf-blind advises others to “learn to educate people not familiar with vision/hearing losses. . . . and let friends know now – not later – what you need” (Erik Hammer, quoted in Everson & Enos, 1995, p. 6). While self-advocacy is strongly emphasized by writers in this field, including students who are Deaf-blind themselves (see Stodden & Conway, 2003, p. 2), it is also helpful if lecturers and peers do their part in facilitating the full participation of a student who is Deaf-blind in the life of the class. Elizabeth’s lecturer who worked at mediating the challenges of audio and visual materials was also concerned to work out ways of managing classroom communications so that Elizabeth would be included. She got:

“...all students to adjust the speed in which they speak and identify who they are before they speak (for interpreters). . . . As time went on, I got more of an idea of what needed to be finger spelt, and so would spell out the words [or] names that I thought would have no

sign. If I forgot, an interpreter would remind me. In tutorials, I would repeat what students would say, to give interpreters more time to translate.”

Another lecturer found that her students were “a little uncertain about how to interact with Elizabeth early on in the semester,” but that “they eventually learned more about Elizabeth over the semester through experience,” and “by the end of the semester, most of the other students understood Elizabeth, and interacted with her easily.” She notes that “the real breakthrough with the other students came after Elizabeth gave a tutorial paper. They finally saw her expressing herself in relation to the course, and this led to greater understanding.”

### Our Learning about Inclusion

This brings us to what Elizabeth has learned, and taught us all, about inclusion. So far we have highlighted many things that Elizabeth has taught us about herself and her own situation. More broadly, however, Elizabeth has pursued her interest in inclusion – or the lack of it – through her choice of subjects and her sustained focus on what each subject could teach her about this. In sociology, she has learned about divisions in society along fault lines of class, race, culture and ethnicity, gender, and generation, as well as disability, and she carried those concepts into her other subjects, where she learned about discrimination and about the construction of identity not only by one’s own community, but by outsiders via stereotyping and “othering” – a familiar experience to a person with a disability. In Gender and Diversity studies, Anthropology, History, and English, Elizabeth’s understanding of the experience of disability was expanded by the concepts she was learning. At the same time, because she applied them to the topic of disability in her writing, her lecturers, as well as Sarah and I, were able to benefit from her insights and the information she presented. When she made oral presentations to her class, her peers too were included in her learning, as the lecturer noted above.

In Elizabeth’s English essay on Ralph Ellison’s (1952) novel about racism in America, *Invisible Man*, we find these sorts of connections again. The essay was about race, not disability, but in her final section, having dealt with race in the novel, Elizabeth reflects upon its relevance to disability. She writes:

“...In the sort of society where black people were discriminated against, the only way for black people to get along was to deny their blackness and live as white people. Similarly people have tried to make deaf children who were born pre-lingually deaf learn oralism to try to become involved in the hearing world. This is similar to black people denying their background. Their real culture and their real identity is exactly the same as Ellison’s character – invisible.”

For all of us, Elizabeth has made disability visible.

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## Appendix

### Extract from Elizabeth's Story about Pilots Crash-landing in a Community Dominated by People with Usher's Syndrome

As we accompanied the Usherians to their village we felt so amazed how the Deaf-blind community was normal in every way. They are the insiders, and we are the outsiders and we with hearing and sight were the ones with a disability.

As we walked through the streets, looking into the shops, everyone was using this strange language they call tactile sign language. As the Usherians were told of our presence they were very unsure about us. As we saw a car come from around the corner, driven by one of the Deaf-blind people, we both immediately stopped to let him pass. I asked our host, "How can a Deaf-



blind person drive a car?” This made me feel quite mystified. She explained, “We have developed cars that have inbuilt navigation systems and the person uses a special on-board navigation computer which automatically drives the car for them.” “Why do you need the hearing and sighted people to guide you around?” I asked her. Our host went on to say, “We must keep our hearing and sighted people to be our servants and they are here to accomplish our every need. If we do not give them a job they will get bored and sit round and waste away. We have special hearing and sighted centres where they learn to be integrated into the Deaf-blind community.”

The Usherian said, “Come on, I am going to be late for the Doctor’s appointment.” Jones wondered, “Are you sick?” The Usherian answered, “No, one of our children is visiting the doctor to see if he will be normal or have a disability of hearing and sight. We will ask one of our hearing people to interpret for you”.

We both were amazed to learn even their Doctors are Deaf-blind; they carry out their duties with the assistance of their hearing and sighted servants.

The doctor greeted the parents. We have never seen a doctor use sign language before. I was astonished to see how the conversation flowed. The language seemed so natural and it was not out of place. “Hello,” the doctor said. “We have the results back from your child’s test, and I have some very bad news.” The parents’ faces turned white, “Oh no what is it?” The doctor went on to say, “Unfortunately your child is hearing and seeing.” The parents replied in a shocked manner, “Oh no that is terrible news – really?” The doctor said, “Yes I’m afraid so, however we can help your child to lead a normal life. He will go to a special school just for Hearing and sighted children; they will learn a special language known as English. It will not interfere with their usual sign language.” The parents wondered whether they will have to go and learn this special language known as E.N.G.L.I.S.H. The Doctor added, “I will ask the visiting teacher for the hearing and sighted to visit your home so she can begin to teach you how to communicate through English”. The doctor was quite firm in explaining to them, “It is important that their primary language must be sign language so they can be as normal as possible.”

The doctor continued, “They will even learn how to communicate with each other by using English, and we have special teachers who will help them to be as normal as possible.” The parents seemed amazed there could be so much help available for the newly disabled child. The parents left the Doctor’s room and we accompanied the Usherian to see if we could find a way to get help.

## **BOOK AND MEDIA REVIEWS**

### **Book Review**

**Title:** *The Church of 80% Sincerity*

**Author:** David Roche

**Publisher:** Toronto: Penguin, 2008

**Paper:** ISBN: 978-0-399-53390-7

**Cost:** \$19.95, 147 pages

**Reviewer:** Laura Kati Corlew

The Church of 80% Sincerity, by David Roche, is a charming and heartwarming look into the mirror by which we view ourselves. Roche is a motivational speaker and a person who is facially disfigured. He begins the book with a description of face, to satisfy audience curiosity from the get-go. Three paragraphs later, Roche is free to dive into the good stuff: namely, a life philosophy in which people strive to be good, but go easy on themselves when that does not work out. Roche's metaphorical church was built slowly throughout his life after learning such valuable lessons as "The principle of delayed understanding... [which] states that you cannot understand what is going on while it is going on" (p. 50). Rather, understanding happens long after (sometimes decades after) events have passed. Thus, perfect understanding within the moment is simply beyond the reach of humanity. Roche argues that people should not feel incompetent by this lack of perspective, but should take comfort in the fact that perspective comes to us all, eventually.

The philosophy guiding Roche's church is that we can get it right about 80% of the time, at best. "It's in that 20 percent area where you get some slack and you can be yourself" (p. 7). Roche lays forth this philosophy of self-acceptance while narrating his own winding path. As a child he experienced nothing but warmth and love from the adults around him, but from them he also learned denial—that he must never talk about his face. As an adult he was unequipped to express his experience or emotions regarding his disfigurement; he struggled to stand up for himself when confronted by the random cruelty of strangers or the dispassionate "care" of doctors who looked at his face without seeing a person.

The audience follows Roche on his journey as he learns the importance of compassion, fleeting moments of grace, and a healthy dose of cutting yourself a break. At every turn, the reader empathizes with Roche because his conversational style calls to mind the audience's own trials and triumphs. He tells the story of love at second sight, an endearing tale of love winding its roundabout way through years of friendship before evolving into a loving marriage. He talks about learning to speak out, which helps him recognize and conquer humanity's most powerful

motivation – to avoid embarrassment. Roche explains how people often see themselves in his life story even when he himself can see no such similarity. But through connection to others, one can come to see oneself.

*The Church of 80% Sincerity* is at turns thought-provoking, poignant, and wickedly funny. The book provides a new outlook on life for those of us (humans, that is) who never quite manage perfection. It is an easy, lighthearted text that is written with a frank style and everyday language which gives the reader a sense of sharing stories over coffee. This is a greatly enjoyable book.

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## **Book review**

**Title:** *Seeing All Kids as Readers: A New Vision for Literacy in the Inclusive Early Childhood Classroom*

**Author:** Christopher Kliever

**Publisher:** Baltimore, MD: Brookes, 2008

**Paper:** ISBN: 978-1-55766-901-8

**Cost:** \$24.95, 160 pages

**Reviewer:** Julie Smith

Christopher Kliever takes us on a timely and scenic ethnographic journey in his book, *Seeing All Kids as Readers: A New Vision for Literacy in the Inclusive Early Childhood Classroom*. Kliever encourages educators and society to reflect on our educational system, including what we perceive as literacy, how we facilitate meaningful literacy skills, and how those perceptions affect all students in our schools.

Perceptions of who we consider competent students have enormous effects on individual student lives. They can make the difference between students becoming more active and fulfilled members of society, or being left out of full literate citizenship. Kliever's observations and recommendations may resonate with anyone who has spent considerable time in classrooms from pre-school through high school over the past several years.

Over the last decade many early childhood classrooms have transformed. Some of the greatest changes have occurred in Kindergarten, which used to be a place of great activity and unbridled learning. Young children took great joy in making sense of their worlds through countless discoveries. Classes were focused more on the overall cognitive, social, emotional, and physical development of children. Test scores and developmentally inappropriate standards and practices have overshadowed many early childhood classrooms. Unfortunately, the pressures of accountability have made some good schools and many great teachers vulnerable to poor practice. As Kliever points out, some of that poor practice has led to fewer opportunities for students with disabilities to develop their literate citizenship to the fullest potential.

Kliever introduces the concept of local understanding early in his book. He defines local understanding as "the capacity to recognize the intelligence, imagination, and drive to make sense of the world within all children, *and* it is the structuring of thoughtful, inclusive educational contexts that foster, deepen, and expand children's intelligence, imagination, and sense-making" (p. 4). This concept is woven throughout the book, challenging the current medical model of disability that drives most segregated educational placements. In a broad sense,

children's discoveries and attempts to understand and navigate the world are what Kliever calls "local understanding." Local understanding in a classroom acknowledges that all children construct knowledge, utilizing intelligence, imagination, and drive as they strive to make sense of their worlds, not just children without identified disabilities.

Although Kliever rightly points out common literacy assumptions that guide current policy are based in phonetic, linear skills that allegedly build to reading, followed by comprehension, he also recognizes there is no one universally accepted definition of literacy. Kliever acknowledges an important role for print-based literacy, but invites us to think more broadly about how we define literacy and how we encourage it in our students. In addition to (and facilitating) what we commonly assume as literacy, Kliever expands literacy to what he calls literate citizenship, which includes: children's "symbolic presence . . . extraordinary motivation to imagine, make sense of the surrounding world, and develop a connectedness with others; children's crafted stories and narratives during interactions, used to construct meaning and relationships, and children's multiple systems of symbols and signs created and enacted for the development of stories and narratives" (p. 17).

Kliever does not limit literacy to sound-symbol relationships commonly found in "pre-reading" or "reading." Frank Smith (2003) took a similar position, challenging what he saw as the fallacy of "scientific" approaches to reading instruction. Like Kliever, Smith states we "read" all manner of things in our world to make sense of it, and effectively interact with the world: "Trying to make sense of any facet of the environment, including print, is a natural activity (p. 9)" and part of literate citizenship. After laying the foundations for local understanding, literate citizenship, and the many ways in which children construct meaning using visual, orthographic, and tactile sign systems, Chapter 5 lays out practical activities for teachers to use in their classrooms to enhance the literacy experiences and opportunities for all students.

The literacy action of developing vocabulary through word and word knowledge can be designed so children with disabilities will expand vocabulary through exposure to, and experience with, complex descriptive language. An example below is summarized from one sample of his ten-page Table of skills and possible activities, which is designed as a useful reference for teachers.

Kliever suggests discussing, writing, creating poetry, acting out, playing, dancing, and reading about every topic available. As children question, they should be encouraged to research through books and the internet, then share with others the question and discoveries. His specific example is around making French toast, and a teacher questioning where syrup comes from. With adult support, children with disabilities, along with peers, explore the question using the internet. They may print, then cut and paste the information on a poster that explains the answers they found, and present it to the class. As children express interest in particular topics, the teacher can develop themes around which classroom lessons and highly engaging student activities are designed to expose children to as much vocabulary as possible.

Kliever ends his book with a compelling argument for literacy as a civil right. He challenges educators to look past labels and low expectations for students, especially those with

significant disabilities, and use dynamic and imaginative approaches to help all students become the literate citizens they deserve to be in our world.

Kliewer's book is not a beachy read. You will have to think, and perhaps challenge some taken-for-granted assumptions, but it is an important book for educators. His message of achieving literate citizenship for all students within inclusive classrooms is important to teachers and teacher educators beyond early childhood or special education. Many of us have seen the devastating effects of students' lack of literacy opportunities, struggling within a system that rarely acknowledges more unique forms of literacy. We have seen adults give up on them. Expanding our perceptions of what constitutes literacy, and how to achieve it to become more inclusive in the broadest sense of the word, can only broaden opportunities for students.

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## DISABILITY STUDIES DISSERTATION ABSTRACTS

### Disability Studies Dissertation Abstracts

Editor's Note: The information for this section of RDS is provided by Jonathon Erlen of the University of Pittsburgh. A full list of disability-related dissertation abstracts may be found at <http://www.hsls.pitt.edu/guides/histmed/dissertations/>

*A counterstory to master narratives for persons with disability: Carolyn Scheidies' life history*  
Sherwood, Laura Ackerman. Proquest Dissertations And Theses 2009. Section 1058, Part 0708  
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Sweeney, Patrick. Proquest Dissertations And Theses 2009. Section 0010, Part 0514 218 pages;  
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*ADHD in black and white: A comparative inquiry in narrative and photographs examining the social construction of Attention-Deficit/Hyperactivity Disorder in poor African American and affluent White American families*

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*General and special educators' attitudes toward students with severe disabilities included in the regular education classroom*

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

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

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

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