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## Forum: Disability Studies Meets Special Education

### Introduction: Disability Studies Meets Special Education

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**Abstract:** An overview of key issues surrounding the intersection between disability studies and special education. Discussed are the history of special education, the role of special education in the quest for equal opportunities, and integrating disability studies and the disability experience into the educational field.

**Key Words:** special education, disability studies, instruction

Special education is perhaps the most well known social science field that concerns itself with the subject of disability, but few scholars in the field of disability studies see themselves as special educators. From the perspective of some disability studies scholars, a “special” education can be equated with segregation, social isolation, and stigma (Barnes, Mercer & Shakespeare, 1999; Irvin, 2004; Linton, 1998). By contrast, many educators maintain that special education represents every child’s right to an education (CEC, n.d.). There is also the question of whether special education “takes away” from regular education and if another solution for the appropriation of resources should be found. Each of these perspectives has a valuable place in disability studies, because they represent the myriad of perceptions of disability itself (i.e. as socially constructed, as a civil rights issue, as a drain on society). Education is in many ways a microcosm of society and its attempt to prepare people for, or fit them into their functional and social roles (Barnes, Mercer & Shakespeare, 1999; Duke, in press; Puri & Abraham, 2004).

Disability studies has much to offer the field of education. The same lens that sees disability as

a cultural, sociological, and historical construct can inform a field that is often criticized for viewing children with disabilities as a problem that will forever need fixing. Over the past decade, disability studies scholars have begun to develop a theoretical grounding and corresponding curriculum that seeks, not necessarily to take the “special” out of education, but to view each child as a “special” individual with a learning style to be nurtured and respected.

Whether looking at education through the eyes of the disability scholar or at disability studies through the eyes of the educator, questions that need to be explored include:

1. What is the history of educational opportunities for individuals with disabilities?
2. Has “special education” helped or hindered people with disabilities in their quest for equal opportunities?
3. How can the field of education better integrate the disability experience and disability culture into its curriculum?

These questions elicited interesting responses when they were posed online for a number of disability studies list-serves. Among the responses:

“I know that educational law [in the United States] did allow for individuals with the correct IQ and the correct behavior to attend school before [the enactment of special education legislation]. The rest of us had to plead and were expected to show the appropriate appreciation just for the opportunity to attend any type of school... [But] special education is looked upon by our youth to mean that you are dumb, you have less value, you do not

belong...disability experience should be life experience..." (Tricia Benefield, Alaska).

"I think every student in public education should have an IEP (Individualized Education Plan)...[Although] I feel blessed to have [special education legislation] in place for [my children]...I have met many adults [with disabilities] who 'graduated' with a certificate of attendance or a special education diploma that isn't worth the paper it's printed on...[They and their parents] didn't know that they had a choice [of a regular diploma]..." (Treva Maitland, Tennessee).

The remainder of this introduction will explore the questions above broadly, and will introduce the five articles in the forum, *Special Education Meets Disability Studies*.

### **The History of Educational Opportunities for Individuals with Disabilities**

As a special educator in the United States, it is easy to slip into the perception that the United States is the international forerunner of special education. While it is true that the United States has been at the cutting edge in terms of establishing government policy and laws that seek to guarantee civil rights for people with disabilities (most notably the Americans with Disabilities Act of 1990, the Rehabilitation Act of 1973, and the Individuals with Disabilities Education Act of 1997), private and public action concerning the education of children with disabilities has been in evidence in Europe for longer than it has in the United States (Disability Social History Project, n.d.). What the United States and many countries in the world share, however, are a progression through various approaches to educating children with disabilities. At first glance these ap-

proaches may appear to be hierarchical, but they are not intended to be so. Various countries may be dominated by a particular approach throughout their history, or may cycle through different approaches (see for example, Quin & Redmond, 2003).

### **Approaches to Educating Children with Disabilities**

#### *No Education or Inclusion of Select Individuals*

Under this approach, most children with disabilities are not educated at all. They may be institutionalized, or remain at home with their family. In some cases, they may contribute to the maintenance of the household and family while other family members work or go to school. A select few children, normally children with well-to-do parents or more "able" children, are educated by tutors or with their peers (Winzer, 1993).

#### *Institutions*

Institutions for the "deaf," "dumb," "blind," "mentally retarded," etc. are often initiated via the benevolence of a charitable organization or individual for the "benefit" of poorer children (Quin & Redmond, 2003). In many cases, these private institutions eventually come under the auspices of the government. Institutions vary in terms of the actual educational benefit that children receive from them. Some institutions function as schools with highly committed educators, others are mere "holding pens," and most fall somewhere in-between (Winzer, 1993).

#### *Special Education Legislation*

Government policy and legislation establishing and regulating special education can result from civil rights awareness and/or attempts to "normalize" people with disabilities (Linton, 1998; Quin & Redmond, 2003). Laws can be general, simply stating that children with disabilities have a right to be educated, or they can be more prescriptive, as exemplified by the Individuals with Disabilities Education Act (IDEA) (1997) in the United States. This law states that children with disabili-

ties are entitled to a “free and appropriate public education” and must be educated in the “least restrictive environment.” In the United States, the IDEA has resulted in the government’s becoming intensively involved in the “special education” process, with resulting policies, procedures and bureaucracy.

### *Professionalism of Special Education*

With special education legislation and policy comes the professionalism of special education. Special education teachers are trained to work specifically with children with “special needs.” Specialists, or “paraprofessionals” in the fields of speech therapy, physical therapy, rehabilitation, orientation and mobility, and the like, are trained to provide services that are deemed to be beyond the realm of the educator’s responsibility or capability (Barnes, Mercer & Shakespeare, 1999; De Poy & Gilson, 2004). University personnel develop personnel preparation and research programs around the study of special education (Winzer, 1993).

### *Special Education Classrooms*

Special education for children with disabilities, with its related policies and professionals, usually takes the form of either (a) a specialized/separate classrooms within a “regular” school, (b) a specialized/separate school, or (c) what is known as “mainstreaming,” where the Special Education student spends all or part of their day being educated with their non-disabled peers, but receives specialized supports and services from a special education teacher and/or paraprofessionals (Barnes, Mercer & Shakespeare, 1999; Linton, 1998; Winzer, 1993).

### *Reaction Against “Special” Label*

Special education has been criticized by some members of the general public, educators, parents, and individuals with disabilities. They argue that special education draws resources away from “regular” education. Others say that special education segregates and labels children with disabilities, perpetuating their status as outcasts in

society. Still others claim many special education classrooms and curriculum are inferior to regular education and do not prepare children with disabilities for adulthood, higher education, and employment (Barnes, Mercer & Shakespeare, 1999; Irvin, 2004; Linton, 1998).

### *Universal Design and Full Inclusion*

The concepts of “Universal Design for Learning” and full inclusion of students with disabilities into the education system are attempts to address concerns about special education. In Universal Design for Learning, curriculum and classrooms are designed to meet a wide variety of learning needs. Thus, every child is “special,” and intervention beyond the regular curriculum or environment is only needed for a small number of children. Ideally, a universally-designed curriculum and classroom means all children can be educated together, or “fully included,” regardless of any disability or other unique characteristic (Barnes, Mercer & Shakespeare, 1999; Center for Human Policy, n.d. [a]; Linton, 1998; Puri & Abraham, 2004; World Bank, 2003).

### **Special Education in Greece and Lethosa**

In *Disability in Greece: Social Perception and Educational Policies*, Stathis Balias and Pandelis Kiprianos trace the history of education for children with disabilities in Greece from the turn of the 20<sup>th</sup> century to the present. This ambitious article describes how civil unrest, war, politics, and educational thought imported from Europe and the United States have shaped Greece’s education system for children with disabilities. “Greece does not stand comparison with the more advanced European nations,” write the authors. Yet the unfolding of events and their effect on education in Greece are not unfamiliar to a majority of countries around the world.

In *Who is Disabled, Who is Not? Teacher Perceptions of Disability in Lethosa*, Christopher Johnstone presents an interesting picture of how intense training efforts can shape the perceptions of teachers about their students with disabilities.



Children with disabilities are, for the most part, educated alongside their peers in Lethosa, not for reasons of inclusive philosophy but because the government lacks money for special education. Efforts to educate children with disabilities in Lethosa have focused on professional training so teachers are accepting and sympathetic to their students. Acceptance and sympathy, as the author points out, do not mean children with disabilities are regarded as “normal” or are necessarily receiving an equal education to that of their peers. However, the author demonstrates these perceptions are a long way from the outcast status that is delegated to many children with disabilities elsewhere in Africa.

### **Special Education and the Quest for Equal Opportunity**

Access to education is paramount to equal opportunities for people with disabilities (Puri & Abraham, 2004). As with women and ethnic minority groups all over the world, people with disabilities have an ongoing fight for the right to be educated and to have the full range of opportunities for employment and daily living that are available to the majority of the population. It can be argued that special education, as we know it today in the United States and in many other countries, has both helped and hindered people with disabilities in their quest for equal opportunity.

#### **Importance to Societal Integration**

It is important to recognize that in many respects special education promotes the right that all children have to an education equal to that of their peers. Under special education programs, children with disabilities may receive the services and supports they need to develop intellectually, emotionally and socially (Barnes, Mercer & Shakespeare, 1999; CEC, n.d.). In many cases, special education is focused on individualized instruction, and teachers are trained to recognize and respect the individual difference of their students.

### **Barrier to Equal Opportunity**

However, because special education often separates children with disabilities from their non-disabled peers, whether physically or nominally, it can also promote the very stereotypes of freakishness, pity, and lack of ability from which people with disabilities struggle to be free. Special education can be a subtle, or not-so-subtle, form of discrimination that tracks children according to their “ability” or other “distinctive” characteristics. Finally, because of all of the “special services” students may receive, special education can value the outside professional (i.e. health, rehabilitation, social work) over the student and the educator (Barnes, Mercer & Shakespeare, 1999; De Poy & Gilson, 2004; Irvin, 2004; Linton, 1998).

### **Educational Spaces and Experiences**

In *Spaces of Education, Finding A Place That Fits*, Nancy Hansen poignantly explores the educational experiences of women with disabilities in Scotland and Canada from a geographical perspective. Through the voices of these women, special education is portrayed as the cause of both their exclusion and their success. The “spaces” of education represent a society where people with disabilities are often not welcome but are ever present as a “problem” to be dealt with.

In *Reflections on Inclusion, Integrating the Disabled Self*, G. Denise Lance describes her educational experiences in the United States before special education became mandatory by law, and then later as an adult pursuing an advanced degree in education. Ironically, the author’s experiences in elementary and secondary school were in many cases quite positive. It was not until she entered college and began studying special education as an adult that her disability manifested itself through other people’s perceptions. Writes Lance, “My area of expertise was assistive technology, and when I attended exhibits at conferences vendors always assumed that I was looking for technology to help myself. The concept that I was looking for ways to help others was beyond their comprehension.”

## Re-framing Special Education and Integrating the Disability Experience into Education

In recent years, increasing numbers of disability studies scholars and educators have begun re-framing education for children with disabilities as a diversity issue rather than as a special issue. These frameworks are focused on both fully including children with disabilities into the classroom and fully including disability studies and the disability experience into the general curriculum. Examples of these frameworks include (a) utilizing Differentiated Instruction and Universal Design, (b) including examples of disability and disabled people as “normal” aspects of the general curriculum, and (c) including disability culture and history in the general curriculum.

### Differentiated Instruction and Universal Design

Universal Design originated as an architectural term and refers to a design that is intended to be usable by a wide variety of people with as little adaptation as possible (Center for Universal Design, n.d.). Universal Design has been adopted by a number of fields beyond architecture, and can be applied by designers of communications, websites and curriculum. The Center for Applied Special Technology (CAST) delineates key differences between the design of existing general and special education programs and programs that implement “Universal Design for Learning” (UDL):

“UDL shifts old assumptions about teaching and learning in four fundamental ways;

- Students with disabilities fall along a continuum of learner differences rather than constituting a separate category,
- Teacher adjustments for learner differences should occur for all students, not just those with disabilities,
- Curriculum materials should be varied and diverse including digital and online

resources, rather than centering on a single textbook, and

- Instead of remediating students so that they can learn from a set curriculum, curriculum should be made flexible to accommodate learner differences” (CAST, n.d.).

UDL heavily emphasizes using multi-media tools to address the needs of a wide variety of learners. Differentiated Instruction is related to UDL and focuses on teaching methods: Examples of Differentiated Instruction methods include having students work in small groups, encouraging cooperative learning, encouraging both verbal and non-verbal means of communicating information, allowing students to present material in a variety of medium, fully utilizing web and computer-based learning, and presenting material to students using a variety of formats and methods (Center on Human Policy, n.d.[a]; Puri & Abraham, 2004).

Both Universal Design for Learning and Differentiated Instruction potentially minimize the need for special education and related services for many children with disabilities. This is not to say that by using these applications the need for some special services (for example instruction in Braille) and adaptations (for example assistive technology) are completely eliminated. However, with an emphasis on the different learning styles and needs of all students, the child with a disability is much less likely to be singled out from other children and is more likely to have their learning needs met in a non-segregated setting.

### Including Examples of Disability in the Curriculum

Disability has largely been absent in curricula at all levels of the educational system (Taylor, 2004). Integrating disability studies into the curriculum provides children with learning tools that are meaningful and provides a realistic view of diversity and society. As with gender, race, and ethnicity, disability can be integrated into a wide range

of curricula and teaching materials. Some examples are depicting people with disabilities doing ordinary things in textbooks, discussing historical figures with disabilities, learning about how people with disabilities contribute to civil rights movements, using symbols of disability (such as wheelchairs) to study scientific principles, and discussing art and literature that is created by people with disabilities (Center on Human Policy, n.d. [b]; Disabled Women's Alliance, n.d.).

### Model for Special Education in Finland

In *Education in the Prevention of Social Exclusion*, Markku Jahnukainen presents a model of education that embodies principles of Differentiated Instruction to establish various levels of inclusion for youth who are at-risk of failure in the general curriculum. Jahnukainen asserts that instruction should initially be designed to address a wide variety of student needs (primary level). The next level (secondary level) involves providing minimal adaptations or services to some students whose entire learning needs cannot be met under the regular curriculum. Only at the last level (tertiary level) is significant intervention needed for a few students whose needs are profoundly different from their peers.

### Conclusion

This introduction is intended to acquaint readers with some of the issues and concepts explored in the forum that follows. These include the history and global status of special education, ways in which special education has helped and hindered people with disabilities in their fight for civil liberties, and innovative models for educating youth with disabilities and infusing disability studies into the general curriculum. The forum articles were selected from the numerous submissions because of their quality, and because they represent a variety of approaches to the meshing of disability studies and special education.

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## Reflections on Inclusion: Integrating the Disabled Self

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**Abstract:** In the following essay, I explain how my experience as an included student with cerebral palsy influenced my identity as an individual with disabilities. I also outline how my discovery of disability studies has influenced my role as a teacher, educator, and researcher in special education.

**Key Words:** disability, identity, inclusion

Since the age of two, I have been in some type of educational setting. Like countless other parents of children with cerebral palsy, doctors told my parents that I likely had severe mental retardation, that I would never walk, talk, or write my name, and they should consider an institutional placement. Thankfully, my parents rejected this negative approach. However, they did believe that getting as much therapy as possible was best, and the best place to receive therapy at that time was in a preschool for children with disabilities. Therefore, my first stop on the “road of knowledge” was a preschool for “crippled” children.

### Not Like “Them”

Most of the other preschoolers had mental retardation, and even at that young age, I recognized that I was different from them. Somehow, I also recognized the negative stigma attached to mental retardation and did everything I could to distinguish myself from “those” kids. With the

speech and physical impairments of cerebral palsy (CP), this was not an easy endeavor.

My preschool days were spent in hours of occupational, physical, and speech therapies, all in an effort to “fix” me, or at least make me as normal as possible. The therapists’ attempts to have me put my tongue behind my teeth to make a perfect “t” sound or scoop food to my mouth without spilling it sent the message that I was not acceptable as I was. The more I could do things in a typical fashion, I subliminally learned, the better my life would be.

### **Not “Handicapped”**

In the summer of 1975, just months before the passage of PL.94-142 (a U.S. special education law now known as the Individuals with Disabilities Education Act), my parents faced a critical decision. I was too old for preschool, and they had to determine where I would continue my education. The most recommended placement for me was a school in the center of a large Midwestern city, an hour bus ride each way from our home. My mother approached the superintendent and asked him to educate me within the district, asserting that she would go to jail before letting me go to the special school.

My parents were not advocating that I be mainstreamed, as it was called then. They simply wanted me to have an education. A district counselor visited our house several times that summer, assessing me, and negotiating my placement.

My first public educational placement was a class for students with learning disabilities and mental retardation, but I only stayed two days. When my mother received a call from the counselor saying I could not stay in that class, she was horrified, her mind racing to think what I had done to be expelled so soon. The problem was that I answered all the questions and would not let the other students have a chance.

Not knowing what to do with me, they gave me a homebound teacher in the morning, and then I

joined a regular first-grade classroom in the afternoon. I was fully included with a full-time aide from second grade until I graduated from high school.

I owe a great deal to my parents for following their instincts and going against the grain. I never regretted being included. Considering the accounts of other included students, I fared well socially. I was very lucky because my peers were rarely cruel or made fun of me. Since I was included from first grade, my peers just got used to me. But the great thing was that I wasn’t tolerated; I was truly included. I had a best friend in every grade and was invited to birthday and slumber parties. When we went to middle school, kids from other schools came together in one school. There were many kids who did not know me and a few seemed unsure, but they got used to me just like the peers I had known for five years.

I think my biggest struggle for acceptance was in Junior High, but that is when everyone feels left out and does not know to which group he or she should belong. It was the mid-1980s and the key to acceptance was designer clothes. So, Mom bought me a couple of pairs of Calvin Klein jeans and I was “in.”

Despite the early messages that my disability made me less worthy, my parents encouraged me to believe in myself and did not place limits on their expectations of me. I knew from my preschool experiences that others might not recognize my intelligence right away. As a result, I often felt I had to prove I belonged in public school by making good grades.

Although I am grateful to have been included, in retrospect, I realize that striving to be “just like everyone else” had some negative consequences. My attempts to distance myself from children with mental retardation left me with a cognitive ablest stance and prevented me from embracing my identity as an individual with a disability. In eighth grade, I recall proudly telling a newspaper reporter who wrote an article about me that I “did not consider myself handicapped.” I fought

efforts to connect me with other people with disabilities. I did not interact with many other students with disabilities in school, and I was the only included student with CP. Therefore, when I met a young man with CP in college, it took some time for me to feel at ease with him.

### **Not Able Enough**

My first semester of college brought about a realization that my physical limitations threatened my ability to achieve academically. I had three courses that required a great deal of writing. Typing eight words per minute on a typewriter with a stylus, keeping up was tough. I could not type as fast as thoughts came, and there were not enough hours to do all the typing. At the end of the first semester, physically and emotionally drained, I gave in. For the first time in my life, I *felt* disabled!

Returning to the “panacea of rehabilitation,” I sought more therapy that would help me do more for myself. In other words, I wanted them to “fix me” so I could continue my life.

Six months of speech and occupational therapy did little to increase the stamina I needed for academic work. I learned to dress and feed myself, but for the price of time. With the amount of typing finishing college would require, time was not something I could expend haphazardly. I realized there was little point in spending three hours dressing myself if I was too tired to do anything else the rest of the day. I made a decision that it was better to have people help me, saving my time and energy for academics and fun.

With nothing to make typing easier, I still decided to return to college. Even if it came to taking one class at a time, it was better than doing nothing at all. I completed two more years of school with the typing stick. The summer before my junior year, my father purchased a computer for me, not really knowing how I would access it. When we brought the computer home I told Dad to put the keyboard on the floor. I had always

used my feet to dial the phone and push buttons on my stereo, so it was just a natural progression to type with my toes. I also discovered the miracle of abbreviation-expansion, software that allowed me to create abbreviations for the words I used most.

My life changed completely when I got the computer and assistive technology. I increased my typing speed from eight to 20 words per minute (still slow, but manageable). Work did not take as long, and I had more time for fun. I completed my B. A. with a double major, English and Psychology, in two more years, graduating with honors.

Toe-typing not only gave me a means to demonstrate academic ability, but it also became means by which to celebrate my differences and begin to embrace and celebrate my identity as an individual with disabilities. I made greeting cards called “Toe-Typed cards by GDL,” complete with a custom logo depicting feet on the keyboard.

### **Graduate School**

At the end of my undergraduate career, I faced two possible areas for graduate study, English, my true passion, or special education, which would fulfill my desire to use my experiences to help others gain access to assistive technology and make their inclusion easier.

I believed that studying special education would be easier, in that the stigma of disability would be easier to overcome. Furthermore, I believed that my opportunities to teach English with a speech impairment would be extremely limited. I had never let others’ perceptions of my abilities stop me before; I cannot explain why I allowed them to curb my ambitions this time.

As a graduate student in special education, I always felt something was amiss, but I was not sure what it was. I assumed my disability would be more understood by my professors and fellow scholars. They, of all people, would see my experiences could have an impact on the education

of children with disabilities. I was an asset, not a threat.

Although I was never mistreated, I felt like an insider forced to look at special education as an outsider. I was trying to understand special education from the perspective of a person with cerebral palsy and to integrate the content with my own experience as an included student. When I attempted to use my personal knowledge to illustrate points in class, I did not feel validated. Many implied that my education was an entirety unique event, never to be replicated again. Someone implied that my success was based on luck, fate, or Divine intervention, having nothing to do with "best practices." Of course, I realized not all students had the family support and exceptional teachers I had, but I felt I still shared much with the current generation of students who have disabilities that would be useful to improving current educational methods.

My area of expertise was assistive technology. When I attended exhibits at conferences, vendors always assumed I was looking for technology to help myself. The concept I looked for ways to help others was beyond their comprehension.

I was discouraged from taking a workshop in augmentative communication because I had physical impairments requiring slight modifications to the computer (putting the keyboard on the floor). The organizers admitted afterward it would have been no problem to accommodate me, but just the idea I was not wanted made me hesitant about viewing them as trusted colleagues.

After reading Linton's *Claiming Disability* (1998), I realized what special education lacked was a disability studies perspective. Linton points out that special education ignores subjective views of disability, failing to see people with disabilities as having power over their own lives, or as important to culture in general. Next, Linton criticizes special education and related disciplines for objectifying people with disabilities, ignoring how personal accounts of individuals with disabilities

contribute to an overall body of knowledge, favoring instead scientifically collected data.

Although my classes denounced the medical model and promoted student-centered approaches, there was little talk of the social construction of disability or encouragement for students to celebrate their differences. In trying to make the education of students with disabilities as typical as possible, the uniqueness of the disability experience and recognition of disability culture became lost.

## Integrated Identity

My identity as a person with disabilities evolved as I progressed from preschool to public school to college and to graduate school. While my misdiagnosis and survival in public school forced me to separate myself from my disability as much as possible, my college years required me to recognize my disability, and my use of assistive technology gave me a means through which to celebrate it. I now consider myself a member of the culture of disability, along with people with cognitive and all other disabilities. I am a fellow soldier in the battle for accommodations, respect, and the freedom to celebrate our differences.

Inclusion has come full-circle for me, progressing from the viewpoint of student to teacher. I now instruct general educators in ways of including students with disabilities, integrating my own experiences into my online course.

As I delve further into the disability studies literature, I continually reconfigure my class to reflect even broader perspectives of disability. Together, I hope that my students and I can discover ways to accommodate disabilities in a manner that honors students' differences, supporting celebration rather than compelling disdain. Students should not have to wait until adulthood to learn disability pride!

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## Who is Disabled? Who is Not? Teachers Perceptions of Disability in Lesotho

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**Abstract:** This paper reports on educational research conducted in Lesotho, Southern Africa. Mixed methods of research were used to elicit and describe teachers' attitudes toward children they perceived as disabled. The study took place in a country where discussions on 'the continuum' of services, specialist diagnoses, and Western notions of assistive technology are largely irrelevant. Over-arching themes are compared to themes that have emerged from special education and Disability Studies literature over the past decade.

**Key Words:** disability, Africa, special education

## Introduction

The fields of Disability Studies and special education have often been at odds with one another. Disability Studies scholars, situated in cultural frameworks, often ask "what" and "why" questions related to the meanings of disability in society. By contrast, much of special education research is concerned with "how to" questions, attempting to understand how to best remedi-

ate perceived shortcomings possessed by students with disabilities.

This tenuous relationship is cause for heated political debates and attempts by scholars of one persuasion to call to question the other. Brantlinger (1997) noted that the present paradigm in special education research (positivism) is a political mechanism to maintain medical models of disability. By embracing positivistic models of research without recognizing their political ramifications, Brantlinger asserts that researchers (either through willful or negligent acts) have discredited important social victories for people with disabilities, such as inclusion in public schools.

Danforth (1997) also criticized modern special education models that focus too heavily on intervention and deficit models of disability. Organizational scientist and special education scholar Skrtic (1995) theorized that the very existence of special (separate) systems for special education implies that students with disabilities are not intended to be part of the regular education system, and that separate provisions, funding streams, and physical environments all act to ensure separate education.

Although the outlook for Disability Studies informing professions like special education appears bleak, there is evidence of improving relations. In the 1990s, discussions about a "merger" of special and regular education (Stainback & Stainback, 1990) and "schooling without labels" (Biklen, 1992) led many professional organizations to embrace the notion of inclusion. Inclusion in theory and practice has been supported by a better understanding of the lived experience of people with disabilities themselves (Ferguson, Ferguson & Taylor, 1992).

Such an understanding is intended to promote better attitudes toward people with disabilities and empower disabled populations. Although empowerment of students with disabilities in K-12 education is still a relatively ignored issue in public schools (Ware, 2001; Ware, Solis, Echeverria, & Stoltz, 2004), research has demonstrated that attitudes toward students with



disabilities matter, both for social and academic outcomes (Jordan & Stanovich, 2001).

The attitudes of “regular education” teachers toward students with disabilities can be seen in the post-industrial world as a special education issue, a regular education issue, and a Disability Studies issue. These fields of study, however, are blurred in societies less apt (by choice or necessity) to be as specialized as countries with high levels of wealth, education, and privilege.

The remainder of this paper will focus on attitudes of regular education teachers toward students with disabilities. The focus of the research will be on teachers in Lesotho, a small country in Southern Africa. Lesotho is considered one of the least economically developed countries in the world (World Bank, 2001) and will be used as an example of countries in the “Majority World,” or countries that are less economically stable, have less physical infrastructure, and are more subsistence-oriented than their neighbors in Europe, North America, and the Pacific Rim. Majority World countries are located all over the world, but are mainly found in South America, Africa, and Asia.

Peters (1993) investigated the notion of special education in Majority World countries and found most countries did not have the “luxury of specialization” that their Minority World counterparts did. For example, disability services were often delivered by family members and lay community members. The concept of domination by the professions (Foucault, 1965) is, according to Peters (1993), not even a choice many nations in the Majority World can make.

This being said, special education in the Majority World is often less “special.” Miles and Miles (1993), for example, found that Pakistani youths were often integrated into schools casually. Because of constraints in local schools, there were no serious efforts to actually include and make accommodations for students with disabilities. However, doors were open to any student that

came to school, and teachers managed diversity as best they could.

Most attitudes about disability, in circumstances such as those described above, are culturally-generated. Experiences of disability are often based on a combination of religious or other supernatural beliefs coupled with day-to-day experiences with people with disabilities (Ingstad, 1995). Situations arise, however, when small or large-scale efforts are made to change attitudes of people toward their disabled community members.

In Southern Africa, attitudes toward people with disabilities have been questioned through large-scale “awareness campaigns” (Ingstad, 2001), conscientization praxis (Peters & Chimedza, 2000), and through training professionals (like teachers) who will interact with students with disabilities (Mariga & Phachaka, 1993). Disability awareness and an understanding of what disability means were selected as major themes for teacher training in Lesotho. Rationale for such training was based on a feasibility study of inclusive education. Mariga and Phachaka found that upward of 15% of students in regular schools had some disability and that teachers lacked awareness. The authors concluded that students were being underserved because teachers could or did not recognize the diversity of learners in their classroom.

Lesotho’s journey into inclusive education began in 1987 when an external consultant concluded the needs of Lesotho’s students with disabilities were best met inclusively (Csapo, 1987). The justification for this recommendation was that inclusion was both more cost-effective and more aligned with Lesotho’s culture of extended family and communal caretaking. A feasibility study performed by Mariga and Phachaka in 1993 determined that schools were at varying levels of “readiness” for inclusion. Some schools appeared to have adequate resources and understanding while others had no idea what disability was and seemed unwilling to accept students

with disabilities. The authors pointed out that enrollment of students with disabilities was actually a non-issue, as schools in Lesotho had always admitted students with disabilities. Because Lesotho had so little infrastructure in place for institutionally based rehabilitation and education, most people with disabilities lived in communities where they grew up. Mariga and Phachaka (1993) reported that lifestyles of community members with disabilities were not always idyllic, but that integration occurred by fiat because no other choices were available.

Inclusive education began in full swing in 1993. During this year the Ministry of Education's Special Education Unit began training at ten "pilot schools." Training was focused on technical skills related to teaching students with disabilities (informal evaluation, learning adaptations, and physical accessibility). A major focus, however, was on conscientizing teachers about disability itself. Trainers believed that Lesotho was rife with superstitions about disability (Ministry of Education, 1994) and that scientific explanations (read: medical model) were necessary to prepare teachers to better educate students with disabilities.

Since 1993 the Ministry of Education has trained over eighty schools using the original curriculum. Peter Mittler, a special education professor in the United Kingdom, evaluated the training program in 1996. Mittler's recommendations were that Lesotho continue training more schools every year and that training programs were successful, especially in the area of attitudes toward students with disabilities.

Lesotho has also currently added a pre- and in-service special education training program at its College of Education. An interesting feature of the Lesotho program is the lack of specialization. From the early days of policy passage, the Ministry of Education has neither budgeted for, nor funded, special education teachers. All teachers of students with disabilities are regular education teachers. Schools in Lesotho, then, have

aspired to the aims of inclusion researchers in the Minority World that advocate for a blurring of special and regular education. Rather than a highly technical merger between two highly bureaucratic systems (Skrtic, 1995), however, Lesotho's streamlined approach is need based, i.e., there is no money for anything other than a unitary system.

The remainder of this paper will focus on field research of this system conducted in Lesotho from January 2004-April 2004. The overall research focused on special educational issues, but a subset of the research examined teachers' understandings of disability. An analysis of teachers' responses is provided followed by concluding comments on the implications of disability awareness training for teachers.

## Methods

Data were collected and analyzed using qualitative research methods. Two main instruments were used: structured questions (found in a questionnaire) and semi-structured interviews. The advantage of using two different methods was an opportunity to reach a large number of teachers while discussing issues, in-depth, with a smaller sample.

The first instrument used was a questionnaire. Twenty schools were visited to examine how special education was being implemented. In those twenty schools, 140 teachers participated in a short questionnaire. The first question on the questionnaire was, "Tell me what it means when a student has a disability."

The questionnaire format was carefully considered because of potential bias created when researchers (author) and participants (teachers) are from different cultural and linguistic backgrounds. All teachers were fluent in English, but two precautions were taken to ensure participants understood questions. First, norm-referenced instruments were avoided. While pre-packaged attitude measurements are available that may have been adapted for this purpose, most normed

instruments found in clearinghouses such as the *Mental Measurements Yearbook* are normed on cultural groups in the Minority World. Such norming may introduce cultural or linguistic bias (Wolcott, 1999).

Rather, the questionnaire used was developed and pilot tested in Lesotho by the researcher himself. Statistical information was not tabulated for this paper, but the information gathered from the questionnaire was used for descriptive purposes. Therefore, the focus of pilot testing was to ensure teachers in Lesotho could understand what was being asked of them.

Second, rather than distributing questionnaires by mail, the researcher visited schools himself. In total, twenty schools were visited. Ten of these schools were the original pilot schools described above. The other ten were recent additions to the list of schools “registered” and having received training in special education. Schools were located in nine out of Lesotho’s ten districts (Thaba Tseka District was omitted because there was no original pilot school in this district). Therefore, urban, rural, and remote mountainous areas were represented in the sample.

Questionnaires were completed face-to-face to ensure the questions were understood. The researcher read all of the items to participants and clarified any misunderstandings. Print was large so all participants could easily read items and language was consistent with plain language guidelines. The entire questionnaire followed the elements of Universal Design of Assessments (Thompson, Johnstone & Thurlow, 2002).

In the tradition of qualitative research, questionnaire responses were read, sorted, and gathered into over-riding themes (Bogdan & Biklen, 1992). Data that emerged from responses were categorized into codes.

The second instrument used was semi-structured interviews. In these interviews teachers were asked to talk about their experiences with students with disabilities and special education. Specific questions were asked, but the format al-

lowed for flexibility so teachers could comment freely and about a variety of topics (Bogdan & Biklen, 1992). Twenty teachers were interviewed using this format; each interview lasted 20-30 minutes. Teachers were interviewed during school breaks and after school.

Interviews took place in English, although Sesotho phrases were used to illustrate points. The author of this paper was proficient enough in Sesotho to translate the phrases into English, but checked with teachers to ensure translations were correct. All participants listened to tape recordings of their interview and approved of its use in research before the results were analyzed.

The researcher transcribed all tapes himself (this was done to ensure data was not lost due to insertion of Sesotho phrases or the accents of the teachers, which may be unfamiliar to Minority World transcriptionists). Data was then carefully read and coded with one and two word codes that described the content. These codes were then clumped into themes that described teachers’ responses (Bogdan & Biklen, 1992). Unlike quantitative research, data was not plugged into a formula to arrive at an instant “answer.” Rather, data was reviewed slowly, themes were considered carefully, then double-checked again to ensure accuracy.

## Results

Five major themes emerged from the data concerning teachers’ understanding of disability. These themes were:

1. Disability as deficit;
2. Protectiveness of students with disabilities;
3. Inability to participate in lessons;
4. Empathy, and
5. Uniformity of response.

Each of the major themes is presented with quotations that illustrate the theme itself.

Sesotho words are translated with English words appearing in parentheses immediately after the Sesotho word.

### Disability as Deficit

Similar to deficit models found in the field of education worldwide, teachers in Lesotho saw disability as a deficit. In virtually every questionnaire, the words “cannot cope” were used in questionnaires, describing children with disabilities as those unable to perform under certain circumstances or unable to manage particular life challenges. Examples of teacher responses were:

“It (disability) means that the student, somehow, cannot cope. Maybe they cannot walk or cannot listen. Maybe they cannot hear properly.”

“A disability means you cannot cope. It means you cannot do certain things that another can do.”

Open-ended interviews yielded similar responses. Often teachers would use specific examples of students they had in class to illustrate what disability meant to them. Responses centered around four major types of impairment: hearing, vision, physical, and learning. Psychological disabilities and/or “emotional disturbances” common in the Minority World were not often given the status of disability by teachers. Likewise, HIV/AIDS was not considered a disability, despite recent Special Education Unit efforts to associate HIV/AIDS issues with disability:

“This one, she can’t hear well. I will say things and sometimes she will just look at me. I have to repeat myself many times because of her disability.”

“I had this one student with mental retardation. He could not do anything. All day he would sit and I would have to find some

stones for him to count or some other material because he could not learn properly.”

“Sometimes the students can’t see. You can see them looking like this (squinting) when they look at the page or at the board. We say they have a visual disability.”

Teachers did not mention words like “cursed” or “punishment” often associated with disability in the Majority World (Ingstad & Whyte, 1995). Rather, teachers viewed disability as an impairment and in terms of the activities of daily life. Teachers associated the etiology of disability with natural or biological events, understanding that disability is often “caused” by explainable events, such as malnutrition or accidents. This type of understanding appeared to normalize disability for teachers, and create a sympathetic response toward students with disabilities.

### Protectiveness of Students with Disabilities

Teachers in Lesotho, despite their penchant for teaching with a disciplinary stick in hand, proclaim a deep love for their students and a protective nature for them. Students, especially in pre-school and younger grades are called *linkua-neana* (little lambs). Teachers in primary schools, who are 85% female (UNESCO, 2002) appear to take on the role of guardian of their students, and want to shield them from harm. This is especially true for students with disabilities:

“We love them (students with disabilities). They are a part of us. We must look after them and help them to be free and be part of everyone.”

“I take them close and speak with them gently. When they are sad I hug them and say to them, ‘don’t cry’.”

The protectiveness of teachers has led to a system with differential expectations. When

students have disabilities they are automatically expected to do less than others. Promotion and grading decisions are made on an individual basis by teachers, and students with disabilities are often exempted from challenging tasks. Protectiveness, then, has mixed results for students with disabilities. In some ways, such students are able to participate in regular school and be part of their peer group without the burden of inappropriate materials. These same students, however, are often pitied and expected to be in child-like roles even as they grow older. What appears as a good-natured relaxation of challenging activities may actually act as a barrier as students with disabilities grow into adults with disabilities (Shapiro, 1994).

### Inability to Participate in Lessons

As would be expected, disability seemed to impact teachers most according to their daily interactions with students. Many teachers defined disability in terms of school-based outcomes, many of which may be completely irrelevant in community life. Regardless, the focus on disability as a barrier to the curriculum demonstrates the converse - many teachers were unable or unwilling to modify their teaching to empower students with disabilities in their classes. The pattern of teacher talks, teacher writes on board, students copy information, students engage in an independent activity, and teacher checks students work was a common finding in observed lessons. Obvious implications for students with a variety of disabilities were present. Nonetheless, teachers saw disability as the inhibiting factor, not the structure of the lesson itself:

“Sometimes they cannot even write. I write things on the board for them to copy into their exercise books and they just sit there. They cannot hold a pencil properly and they cannot make proper letters because they have a disability.”

“This one does not talk. When I ask a question of the class she does not say anything. Sometimes I ask her again, but she says nothing. I think when I am teaching she is not understanding. She can't get it.”

Miles (1999) theorized that inclusive education could be a catalyst to change all education, because the child-centered pedagogy associated with inclusive education has the potential to revolutionize teaching for all students. This revolution, however, has yet to occur in Lesotho. Promising new literacy programs have helped teachers to monitor student progress and prepare individualized and small-group activities based on student need, but lecturing and copying notes from the chalkboard was still the predominant mode of teaching found in twenty classroom observations. Students who cannot participate in this type of learning, then, will be considered “disabled” by teachers, even when other factors, such as the curriculum and pedagogy of the classroom itself, may be more disabling than the student's impairment.

### Empathy

Teachers reported that, as a result of training, they had a better understanding of how they were disabled themselves. Similar to the findings presented above, Ministry of Education training appears to have normalized disability for many teachers. Most teachers even “claimed disability” (see Linton, 1998). From the use of glasses to mild hearing impairments to left-handedness, teachers claimed they too had disabilities and all of humanity at one time or other will encounter disability:

“I too have a disability. I use this *molamo* (walking stick) to walk because my legs have fluid in them. It is a result of sugar diabetes. This is my disability.”

“I cannot be angry at students for having a disability. I use glasses

and sometimes have trouble reading their exercise books myself. Without my glasses I do not see very well. I also am using my left hand to write like you *Ntate* Chris (Mr. Chris – the researcher). We were told when we were younger that this was very bad but now I understand that it is normal and my students should be comfortable writing with either hand, or if they are in a wheelchair, or if they use glasses.”

“I cannot hear out of this ear. Therefore, I have disability.”

These empathic responses demonstrate that teachers abide by the principles, found in disability literature, that state nobody is immune from disability. Researchers like Davis (1998) note that ability and disability are not binary, but are more relative terms. Teachers in Lesotho appear to understand that disability is a lifelong and pervasive experience, one experienced by most everyone.

These empathic responses did not appear to overhaul the dominant pedagogy in Lesotho, but affected how teachers approached students with disabilities. Interactions with students were often peppered with teachers noting their own “disabilities” and challenges in life. Such interactions appeared to create a more welcoming environment for students with disabilities in the regular classroom.

### Uniformity of Response

The final theme that arose from the data was that responses were homogeneous. The themes noted above were described in every school and by practically every teacher interviewed. Teachers appeared to take pride in their new consciousness about disability, deriding their community members for knowing less than they did:

“These Basotho (Basotho is the plural of Mosotho, or a person in the Sotho ethnic group) in the

villages, they hide their children with disabilities. They don’t know that they can learn.”

Teachers heavily praised Ministry trainers for helping them to understand what disability is. In truth, there are words in Sesotho for disability, but these words are often viewed as derogatory or demeaning. The English word “disability” appeared to have provided a sense of legitimacy to the teachers about the experiences of their students. Such legitimizing seems to have appealed to teachers, as responses were similar across schools found in nine different districts and three different geographical areas (urban, rural, and remote). Implications of these findings are useful for both understanding what disability means across cultures and professions, and how disability-related training can be used to conscientize educators or other service providers.

### Implications

The Lesotho model of teacher training, which focuses on attitudes toward students with disabilities, demonstrates how a professional field can incorporate a philosophy, or outlook, into training programs. Critiques of current special education practice assert that special education is mired in a paradigm of intervention, focused on fixing the problems of students with disabilities (Danforth, 1997). Fields like special education, according to Danforth (1997) and Brantlinger (1997) too infrequently consider the perspectives, rights, and experiences of people with disabilities.

Lesotho’s Ministry of Education has not provided a model for changing this paradigm (disability-related training still is centered in a deficit/medical model), but originally provided opportunities for understanding issues like marginalization and exclusion. These themes all open a space for exploring the place of perspective in teacher training. Mariga and Phachaka (1993) set out to change (or develop) teachers’ attitudes about disability and apparently have succeeded. Teachers in Lesotho (who have received special education

training) have remarkably similar attitudes about disability. Although partially based on a much-criticized discrepancy model (Danforth, 1997), teachers do show empathic reactions and inclusive behaviors toward students with disabilities. Such attitudes guide day-to-day interactions with students with disabilities.

These data demonstrate that, despite ongoing pedagogical weaknesses in Lesotho, attitudes towards students with disabilities can be shaped by training. This being said, possibilities open up for missing empowerment models to be included in teacher training. Peters and Lubeski (2002) noted one method of evaluating education is through a Disability Rights Model. One aspect of this model is conscientization at the local level. Such conscientization could easily include teacher training about attitudes toward students with disabilities. Furthermore, as countries in the Majority World develop inclusive and special education programs, Lesotho's example demonstrates that attitudes can make a difference. A model of disability rights, inclusion, and perspective would include an interaction between disability awareness and pedagogical considerations. Lesotho has provided a first step for Disability Studies approaches, disability advocacy and special education to proactively co-exist in the Majority World.

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## Spaces of Education: Finding a Place that Fits

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**Abstract:** The fluidity of disability, and impairment emerges through a series of interviews developed with, and involving, forty women in Scotland and Canada. Their educational experiences are explored. The voices of women with disabilities in this article are important, and what appears are rich contextual profiles of women making spaces on their own terms.

**Key Words:** women, disability, education

### Introduction

Human Geography explores the use of space, time and place elements in various aspects of daily living. The geography of disability is a comparatively new and emerging field within this discipline. Geographers are escaping the rigid disciplinary isolated “boxes” of medical geography in favour of a multi-dimensional approach incorporating the more flexible social and cultural aspects of human geography. In this article, a more detailed picture of disability in daily life emerges, looking at the everyday reality of disability in primary, secondary, college and university “educational spaces” as experienced by women with physical impairments in Scotland and Canada. The women range in age from their early twenties to their mid-sixties. Through a series of in-depth qualitative interviews, the author moves well beyond individual incapacity to look at wider social perceptions, attitudes and the interconnections of education and community. Much can be learned from the phrase, “Tell me about your education experiences.” This question elicits the dignity, self-respect, and quiet courage of disabled women making space in public places where they must take pains to gain peripheral access every day.

## Primitive Beginnings, Primary Elements

Non-disabled people perceive access to education as a natural rite of passage into the adult world. However, education for disabled people is not viewed as a usual element, but rather as a privilege granted on a highly contingent basis (Gleeson, 1999). Indeed, the very presence of disabled people in educational space is often perceived as unnatural and disruptive (Chouinard, 1997). Access points to education are therefore limited, strictly regulated, tentative, peripheral, often medicalized, always on approval and subject to withdrawal. Whereas early education for non-disabled children nurtures creativity, where expectation develops potential, the situation for disabled children commonly entails a narrow focus on physical deficit correction (Rioux, 1999). The space itself is frequently removed from, or on the fringes of, public mainstream spaces. As a result, it has been customary practice to educate disabled people, even more notably disabled women, separately from their non-disabled counterparts. Often the space itself is residual, and devoid of intellectual stimulation, reflecting a lack of expectation.

Audrey provides a telling account of what was common practice half a century ago:

“That’s obviously a long time ago but when it came time for me to go to [mainstream] school, I was just about to go to school, and the education authorities at home said ‘don’t let her go’ I wasn’t educable ... Hadn’t done any tests or anything, they just looked at my medical condition and said ‘people like that are not educable.’”

*(Audrey, 55, Scotland)*

Babette’s experience further underscores the impact of the medicalized approach to school admission:

“I was misdiagnosed as ‘mentally retarded’ because of the condition, it was quite a severe condition, it was diagnosed at the age of 9 months and my vision problems, although they are congenital as well, they weren’t diagnosed until I was 5 and went to school, where a very attentive teacher said ‘this child isn’t mentally retarded she’s blind!’”

*(Babette, 47, Canada)*

What has been the purpose of this segregated or “special” education to which many disabled people have been consigned? It appears the focus of “special” education is geared to obtaining an arbitrary standard commonly known as “normalcy,” which is largely unattainable for this population group, thus firmly attaching to these individuals the label of different. This is perhaps directed at addressing the projected discomfort of the social majority in schools and beyond around physical difference, rather than improving the quality of life for disabled individuals. The aim is to develop a socially acceptable appearance rather than to improve and to develop intellect. Consequently, the education that is provided appears to be adapted to occupy time in a limited space, rather than to foster intellectual stimulation:

“I used to go to boarding school special school in Edinburgh ... physical activity was the focus and you had to walk better, talk better and sit right. I remember once I missed my English class because they made me walk to class unaided [Stacey uses a metal walking frame], so by the time I got there it was finished! ... I just thought the English was more important. Who cares if you can walk unaided but I needed to write.”

*(Stacey, 29, Scotland)*

“[B]ut at the time there wasn’t many people as young, ... with a spinal cord injury, it’s more of a thing, that happens when you’re out skiing, doing things ... really at that time there wasn’t a lot of special schools, special schools were really ... if you had a disability you got shoved into a special school ... It was very much emphasis on physiotherapy, speech therapy or occupational therapy, which is good, but there was practically no emphasis on education.”

*(Elise, 35, Scotland)*

Segregated education did have a positive impact on the lives of some disabled women, particularly in circumstances where medical treatment was required in conjunction with educational requirements, and some women felt the special school environment may have provided the support, formal and also more informal (through friendship networks), that was non-existent in mainstream spaces. This underscores the lack of accommodation provided to disabled people in public mainstream spaces. Often, one is faced with choosing between two extremes, neither one of which is really acceptable; a segregated environment, which has some support but little stimulation, or an integrated mainstream environment with no support. The following quotes capture something of this ambivalent attitude toward special schools, indicating a few positive assessments, but even here the key message seems to be that the women found the schools ultimately limiting in academic terms:

“I went to a special school until I was 11, and it was a wonderful experience in terms of the range of subjects, it was like primary school, we got a different teacher for every subject at primary level and we had languages and all sorts. I was totally challenged by

the curriculum... I became very unsettled I think it was because my sisters had gone to the local grammar, and so their mates were around in the community and I wanted to be part of that as well and also I felt that academically I had been challenged and stretched to the age of 11/12 and then the pace was slowing and I was very unhappy.”

*(Kim, 49, Scotland)*

“I went to a special school, didn't feel particularly special! I hated it, just found it like lack of stimulation, over protective... I just found it limiting academically.”

*(Vicki, 29, Scotland)*

Interestingly, a few women did wonder if experiences may have been better for them had they attended special school:

Interviewer: “Did you ever go to special school?”

“No never. When I went to primary school I was fine, 5 –11 that was fine I got on great but when I went to high school, because I have got like my processing of stuff is not as good because there has been some light brain damage... but I just felt that in high school I could have been doing with extra help.”

*(Brenda, 28, Scotland)*

“It was very difficult, I couldn't take notes, I wasn't sure what the teacher was saying so I was studying by myself, I was coming home and was studying, I was only 10 years old but I was up until midnight studying... I would have felt uncomfortable

with hearing people, I wouldn't have learned how to communicate. I'm glad I went to a regular school, what I miss a lot is if I had gone to a deaf school I would have learned sign language, but I don't know.”

*(Sahara, 40, Canada)*

The overwhelming impression is nonetheless that segregated education served as a holding area for entry into the rehabilitation and social service agencies designed for subsequent entry into suitable disabled spaces such as sheltered or segregated employment. For many of the women whom I interviewed amendments to education legislation have come too late. The measure of success is dependent upon how legislation is interpreted and applied (Gleeson, 1999). Segregated education has in effect, arguably acted as a diversion programme, keeping disabled individuals out of the mainstream economy or at the very most directing them into vocational spaces deemed by others to be “appropriate”:

“When I left special school they didn't really stretch your mind as to what you would like to do, it was all about what you could do. It was mainly guiding you into office work and office technology. At that time I just thought I'll do this because that's what I can do but I find it so boring!”

*(Stacey, 29, Scotland)*

## **Making Primary Spaces in Public Places**

The arrival of disabled children in “public” education space is seen as an anomaly (Kitchin, 2000). Making space for them in the mainstream places of learning is not expected or welcomed, and is perceived as disruptive to the “natural” social order. Those individuals entering into this environment are usually championed by a non-disabled advocate, often a parent demonstrating exceptional personal fortitude to fight against bar-

riers of fear, ignorance and simple lack of imagination (Rioux, 1999). Ariel's story in this respect is telling:

“My mother had to fight like hell to get me... into regular school... they thought that I should be placed in a special school. So the very next day my mother pulled my sister out of school and when the Principal called to find out why my sister hadn't attended school that day... my mother said 'well if you're not equipped to take care of one of my daughters, then you're not equipped to take care of either of my daughters', so they said... 'ok we'll pay for an attendant'... but they wouldn't have done that if my mother hadn't pushed the envelope.”  
*(Ariel, 27, Canada)*

The physical difficulties of accessing and moving around in the mainstream school environment were often stressed, and the teachers clearly worried about the different ways in which disabled children had to move, but the following two quotes demonstrate how, with a little open-mindedness and readiness to accept “unusual” practices, successful integration can be achieved:

“I didn't have a wheelchair until I was 7! ... They didn't give out wheelchairs to children in those days, and that was another fight!... I only lived around the corner, and they eventually got agreement that I could go for a trial period, by this time I was 8 and they put me in with the 7 year olds, and that lasted a day, and the teacher of the 7 year olds said 'ah ah, she's far too fast for this.’”  
*(Audrey, 55, Scotland)*

“I think they had to fight quite a bit to get me in the local school... but really I was going to be happier in the local school, I was lucky it was a small community, it was a small convent, I had two sisters at the school and there was loads of stairs to classrooms, there wasn't going to be a problem with lifting me up the steps or anything, because... I was always quite light, so my classmates just lifted me, carried me up...  
*(Kim, 49, Scotland)*

However, once in mainstream education things are certainly not always straightforward for disabled children. Candi's and Joyce's experience reveals much about the everyday problems of bullying, trying to fit in, teachers' suspicions and the like:

I was in a regular school all of my academic life... When I went to school, I was very clumsy and so I got teased a lot because I didn't know that things were that close and I would trip over them or I would run into somebody and I'd get smacked, or... somebody would hit me... because they just thought I was doing it on purpose. I always sat at the back of the class, I didn't sit at the front of the class and they would force me by the end of the year to go back to the front of the class which would single me out all of the time, because I wasn't seeing so therefore I wasn't learning, but I didn't want to be singled out but I also wanted to be part of the group, so I tried to sit at the back like everybody else... I quit school when I was 16.  
*(Candi, 45, Canada)*

I always remember the teacher saying 'look at your sister she can't see and she's streets ahead of you, how come you can't do this?' and sort of making out to ... that she was really bad and here I was, I couldn't see, and I was doing better than her..."  
*(Joyce, 34, Scotland)*

The difficulties in mainstream education of adapting to the needs of disabled children is evident in many ways, often in the creation of well-meaning regimes which nonetheless still set the disabled child apart or seek to be overly helpful to the point of "cocooning" (Holt, 2003):

"They were very understanding, I think perhaps too much, I think what would happen a lot of the time was if I was having difficulty in a particular area they would just take my hand and walk me along and give me a passing grade, you know sometimes I did really well like English grammar and social studies, but it was the Maths, Geography, those areas, so I never learned how to think for myself like other people do, I had help all the time, I learned helplessness."  
*(Dolly, 34, Canada)*

It as if the mere presence of disabled people is somehow threatening to, or compromising of, the academic standard of non-disabled students (Rioux, 1999). Again, this lack of willingness to accommodate disabled children within mainstream education is due in part to a lack of exposure to disabled people or disability issues (Kitchin, 2000). As a result, disabled children can feel isolated and alone in mainstream education:

"My first year at school kindergarten was not a happy time for me. My teacher didn't know how to treat me she didn't

know how to treat any of the students! She pretty much made a big thing that I was not co-ordinated and she tried everything in the book to get me out of school ... Finally, in grade 1 ... they basically put me in the library on my own with a [non-professional helper]."  
*(Patsy, 25, Canada)*

The mainstream primary education experience of these women can best be described as an interesting dichotomy. Although they felt fortunate to have avoided or limited their exposure to segregated school, at the same time they were often painfully aware that their presence in the regular school environment was perceived as a source of tension and conflict. Indeed, the necessity to provide adaptation is frequently perceived as disruptive, and seemingly compromises the education standards of non-disabled students. Difference is often emphasized by education authorities in a negative fashion, a sign of intellectual limitation rather than a failure on their part to provide effective accommodation (Rioux, 1999). Consequently, most of the women rarely felt welcome in these spaces, although they believed they had the right to be there. The women also identified the need to struggle against "common knowledge" or negative social perceptions of difference in disability. In their efforts to gain approval, many of the women identified an internalised feeling of personal inadequacy taking root during this period in school at the primary level. To "fit in," much physical and academic effort was spent trying to pass as non-disabled, or to blend in with their non-disabled counterparts, often at great personal cost and minimising their own needs. There was a necessity to prove their right to be in the "regular" space, particularly since in childhood there is limited awareness of a larger social or environmental inflexibility, yet at no time did the women ever express the wish to be non-disabled as a means of dealing with their physical reality. What can also be added is that from a very early age essential lessons were being learned about navigating in an essentially

hostile environment, concerning the realities of making space and using time in “public” places, minimising difference in order to gain approval or acceptance.

## Secondary Spaces

In the higher school grades, the pressing realities of time and space and difference are more acute on a number of different levels. The nature of study changes in secondary school, both in the increased volume of work to be done and the demands on the amount of time required for completing it. Movement of disabled students between classes is also a change, placing far greater demands on physical effort and navigation skills. The speed/time management skills developed to pass and function to this point no longer work to the same extent as before. Academic mainstreaming is also a part of high school, and in several instances slower physical processing of material was often interpreted as a lack of intellectual ability. Women who could not keep pace were placed in less challenging academic or vocational classes. As was the case in primary school, few if any changes were made to the existing academic environment, and adaptation was left to the women themselves. As a result, many of the women again felt alone or isolated. Feelings of isolation were accentuated because notions of body difference and physicality become more fixed and acute in teenage years, as does the need to gain social acceptance. Joyce and Brenda’s experiences provide a fitting illustration of the need to “fit in” in the midst of demeaning attitudes and bullying at secondary level. The women internalised a sense of what is “normal” and of one’s distance from that:

“We went to secondary school, the blackboard was used a lot for everything and I fell way behind, [Joyce has a vision impairment], and then when people are saying to you you’re just thick, well you’re told that so often, that if you’re told it often enough you just begin to believe

it, well I’m thick, but I used to feel so frustrated because I could understand what was going on but I just couldn’t ...”

*(Joyce, 34, Scotland)*

“They tended to send you to remedial classes which made you feel thick or stupid and I knew I wasn’t ... There was a lot of bullying and name-calling. I had my own friends, when you are that age, it is sort of like if you don’t fit in you’re not worth knowing... I think it made me more timid, more self conscious and more unaccepting of who I was because I wanted to fit in with everybody else.”

*(Brenda, 28, Scotland)*

Several women gave accounts of missing school or being taken out of school to undergo surgical procedures. None of the women questioned the need for the surgery, although, upon reflection, many women expressed regret concerning the impact of hospitalisation on attaining long-term educational qualifications. The medical model appears to remain paramount to decisions around education, and the quest for “normalisation” took precedence over qualifications. The purpose here is not to berate or to downgrade the importance of medical intervention, but it is to wonder if more care should be taken to co-ordinate better these medical elements to lessen the negative educational impact on the young individual. There was little thought given to assisting the women in a manner that best suited them, and it was left to the individual women to deal with the situation with limited information or resources. Placing medical matters before educational ones clearly had enormous and often-negative implications for several of the women who I interviewed, as these quotes reveal:

“I left school at 15 to get an operation, it was my bladder

problems, I was incontinent at school [spina bifida]. I left in March... because I was going to get an operation.”

*(Brenda, 28, Scotland)*

“A hip operation put me back a year, the school was wanting me to not go back a year, I went no, so it was me that had a choice of whether I could go back a year or not to do the year’s studying, but I didn’t want to, so I should have but I didn’t ... life may have been different now if I did but I never, so I only really did three years instead of four at High School, even though I did sort of do four... but I wasn’t there for a full year.”

*(Rhonda, 31, Scotland)*

“The Secondary school ... was simply not accessible ... so I went to special school a boarding school for the severely disabled children, and I was there until I was 16, ... but I spent two and half years of that in hospital ... So I came out of school with pretty well not a lot of qualifications.”

*(Audrey, 55, Scotland)*

Various women had a positive experience in high school because of a positive self-image and an effective support system enabling them to study effectively and to more fully integrate into the social academic environment. Patsy gives one example:

“In high school ... they had an orthopaedic unit in the school itself, which integrated disabled students in the regular curriculum. I was lucky people didn’t judge me. The teachers didn’t judge me because of the chair [Patsy uses a

wheelchair]. They judged me for my potential and what I did.”

*(Patsy, 25, Canada)*

Unfortunately, several women did not have a positive experience. Secondary education proved to be a turning point for many women, providing a crucial marker for adulthood:

“I actually filled in an application to go to Teachers College, and it had to go through the Principal’s office for them to sign and the Guidance Counsellor... The Principal, the Vice Principal and the Guidance Counsellor called me in for an interview in their office, and ... didn’t they say they were very sorry that they couldn’t sign the application ... [but] I may as well not waste my time because they certainly wouldn’t have hired me to be a teacher in their school system.”

*(Alice, 51, Canada)*

“I desperately wanted to be like whoever ... I was just so glad to get out ... I didn’t realize it would affect the rest of my life. I was going for jobs and I had no formal qualifications. I had no confidence and I no self-esteem. It took me until I was in my 20’s to accept who I was.”

*(Brenda, 28, Scotland)*

It is important to recognise that even a poor initial school experience can eventually build a bridge to fulfilled later education:

“When I was 16 and they let me go to this other, a different secondary school, I went there for a year to sort of catch up on some things and then I left still without qualifications apart from shorthand and typing and things

like that, then I went to college to further that in book keeping and then in the 80s, late 70s, I ended up at University, applied to do that, and then after eight years I got an honours degree.”

*(Audrey, 55, Scotland)*

### **Post-Secondary Spaces: College and University Places**

“I’ve actually been told to my face that I shouldn’t be complaining so much because a couple of years back I wouldn’t have even been allowed into the university! So yes, I’ve actually been told to my face you know that I should think myself quite lucky because a couple of years back I wouldn’t even be allowed in, so it’s like ‘I am not worthy.’”

*(Trudy, 33, Scotland)*

Remnant elements of the medical model still remain as part of the procedure at this level of the educational system. Indeed, frequently, the medical profession provides the gate-keeping access mechanism to the process of entering further or higher education (Michalko & Titchkosky 2001). Academic qualifications are often secondary to the need for an arbitrary level of physicality, which is another manifestation of an exceptional status provision. The individual is faced with having to prove an everyday coping ability to undertake the course before it has even begun (Michalko & Titchkosky). Whereas non-disabled people are provided access without this added hurdle, it is as if disabled students must provide this assurance as added proof of the right to be in the space concerned. Access to academic space is hence conditional and regarded as a kind of privilege, which is yet another manifestation of an “on approval” mechanism which is all too often subject to withdrawal:

“I filled out my application for college when I was in hospital and I remember having this enormous debate...with a friend of mine who had come to give me a hand... because I had just had surgery on my spine and I was completely flat out... I was in plaster from my neck down to my knees, completely flat out in bed, but I felt fine... was just literally recovering, waiting on the bones to knit together. And I was filling out this form and it said ‘are you in good health?’ and I ticked ‘yes,’ and [my friend] was like how can you write ‘yes,’ you are lying in a hospital bed, and I was like fine there was nothing wrong with me.”

Interviewer: “They wouldn’t have let you in otherwise?”

“No, I actually wanted to be to be an occupational therapist for a profession and I wanted to do physiotherapy, but I couldn’t have got into physiotherapy, I wasn’t deemed fit enough at that time. I think maybe things are different now, but at that time I wouldn’t have got in...”

*(Marilyn, 39, Scotland)*

Marilyn’s story reveals many points, such as the gulf between her understanding of herself, her body and her intellectual potential and what others, the gatekeepers of post-secondary spaces, may perceive in terms of her as a viable applicant for a place at college.

Other issues, of course, arise to do with institutional concerns about an individual’s “fitness” and the clichéd problem of wheelchair accessibility as a reason for blocking someone’s application cannot be avoided:



“They said that my academic qualifications were fine but they just couldn’t have somebody in a wheelchair on their premises because it wasn’t accessible at all, so obviously I didn’t accept that at all, so they had to move lectures from one building to another, it was ok, I mean it wasn’t fantastic for getting about but I got by.”  
(*Vicki, 29, Scotland*)

“I’m doing an undergraduate course in community education and that’s been a real struggle, they did say, they knew I was coming four months before I came, they told me it would be an accessible course... I got there and some of the lectures we had were like three flights up with no lift, so I couldn’t attend them, so then they suggested we had a video link and I said I didn’t want to be in the library on the video link, what if I wanted to ask questions... there would be me viewed to 300 other students and there was no way I was going to do that and it would cost more, so I just said why don’t you just move it to a lecture theatre that’s accessible, so they did move one of them, there’s one of them I can’t attend because I just can’t get up three flights.”  
(*Trudy, 33, Scotland*)

Preconceptions of physical incapacity and access may be used as a convenient means to mask the deeper underlying social insecurities or objections about sharing non-disabled spaces with disabled people. Echoing earlier comments, it is almost as if the presence of disabled people compromises or contaminates these higher education elite “public” able-bodied spaces:

“I had applied to and was accepted into a Masters programme... in Speech Pathology, and the day after I was accepted is the day I had my haemorrhage and I had already had a stroke when I was 18 and I had a little bit of neurological residual damage, and they said that they shouldn’t but they would be willing to overlook it because my application was strong in other areas, so they overlooked that and they accepted me into the programme, but then when I called them and told them I’d had a haemorrhage they said you can’t come in.”  
(*Babette, 47, Canada*)

“Well at first they turned me down, they said they couldn’t provide facilities for somebody in a wheelchair... even after I’d been accepted... Well the Head of Department came to my house and he said... ‘do you actually know what Psychology is?’ ... I did say to him... do you think I would have fought this hard and not found out that’s what I wanted to do? Of course I found out what it was about,’ and he said ‘oh you have to be really good at maths and biology,’ and I said ‘yes well that’s my best subjects’...”  
(*Vicki, 29, Scotland*)

Even in supposedly mainstream post-secondary education, “special needs” segregation still occurs. There appears to be a will to “teach” life-skills to people with disabilities (Barnes, 1991), and perhaps this is a continuing reflection of the desire to “normalize” this population group in an appropriate vocational manner:

“I was at College three days a week in administration. The whole course was inaccessible to me. It was a very frustrating experience in college. I was in a ‘special needs’ class (teaching basic life skills) and it was awful.”  
*(Stacey, 29, Scotland)*

“Wednesday when all the other students from mainstream would have a day off to study, we would have to participate in some special class [such as] cookery and woodwork. It was so hideous I used to not go and lost the time. They would complain because that was part of the condition you were at college.”  
*(Vicki, 29, Scotland)*

Disabled students are sometimes called upon to enlighten other students about the realities of life with a disability, another manifestation of the novelty and the “public property” of disability in the academic sphere. Disabled students remain very much “on display” much of the time. Trudy’s experience illustrates the central role that Academics play in a student’s experience:

“I’m the only disabled person in the class... She said to me, ‘I want to ask you what has your life been as a disabled person, have you had hard times?’ And I said ‘well I’m not going to answer that,’ and she said ‘why not?’ and I said ‘because you just said to the class that you shouldn’t assume that everybody’s experiences are the same, so no matter what I tell you about what my experience is, every other [disabled] person’s experiences will be completely different’... she was really embarrassed, and I also said ‘I also don’t appreciate the fact

that you’ve drawn me as the centre of attention.’”  
*(Trudy, 33, Scotland)*

Patronising comments from non-disabled people appear to be an everyday occurrence in academic life. Often disabled students must justify accommodation requirements while proving individual academic competence in the face of social stereotypes:

She [disabled student services advisor] got me a reader... and she got me somebody to do my exams with me the person who did my exams answered the questions for me in a way that he thought was appropriate, not the way I answered them... I was stunned because I did really well in university and I got a D in the exam, and the Professor’s read of it was that my vision must really be interfering and I said ‘no that’s not true,’ so I said ‘I need to go over the answers with you,’ and he started to give me the answers and I said ‘I didn’t say that, I didn’t say that,’ and... so I got to redo the exam but I mean that was just a horrific experience...  
*(Babette, 47, Canada)*

The thing that they keep firing back at us is ‘well you know it’s only a couple of years since we’ve had disabled students,’ and... I’m one of the first couple of wheelchair using students and it’s all very new to them and they’ll learn by their mistakes...  
*(Trudy, 33, Scotland)*

Some of the interviewees were far more willing to bring these and other shortcomings to the attention of education authorities and to make their own suitable arrangements. Progressing through the academic environment, such individuals have

refined and developed more skills necessary to manage in a largely inflexible academic environment:

“[A]t first I didn’t get into the Fine Arts because there were concerns that I was not able to handle the physical aspects or demands of the programme, so firstly what I ended up doing was majoring in Art History... but I exceeded the requirements, so I had to demonstrate... not only that I have the talent, but I was able to meet programme requirements. I got accepted into second-year status and I was fine after that, so there was very little modification that was needed for me to do the programme.”

*(Lilly, 34, Canada)*

Although many of the women did not relish the idea of drawing attention to themselves, they were aware of the type of accommodation and support they needed to study effectively. Although the larger environmental framework remained quite rigid, within individual educational spaces, the nature of study could be somewhat flexible. Again, it was left to the individual to negotiate with instructors or to form alliances with fellow students to build supports into the environment, thereby increasing the likelihood of success. Candi’s and Stephanie’s accounts in this respect demonstrate this aspect, but, as ever, things were never ideal or plain sailing:

“I went back to school when I was 18, and went through adult education... which was a learn at your own pace so it was a lot better for me because I could sit and read the stuff, I didn’t have to follow along and I didn’t have to read off the board and I didn’t have to worry about being asked to read something in class and

things like that, because I wasn’t able to read at the same pace as everybody else was.”

*(Candi, 45, Canada)*

“When I was in school [college] I had a lot of doctor’s appointments... but every time I came back from an appointment he made me feel guilty... He was very unforgiving. But most of the time they were okay... If I couldn’t hear I’d move up [Stephanie has a hearing impairment]. If I couldn’t understand the teacher I would ask about it.”

*(Stephanie, 29, Canada)*

The fact that obstacles are always waiting to ‘trip you up’ is strikingly revealed by Babette, who also shows the profound frustration associated with trying to secure assistance, even from professionals who are supposed to be specialising in assisting students with disabilities:

“My undergraduate years were wonderful up until I had a haemorrhage in my eye, and I was at university... and I had a massive haemorrhage that was responsible for knocking the vision out... I couldn’t see a thing, and of course I didn’t have a cane or any training at that time, and I got to the university and I asked somebody to take me to the disabled students office and I got there, to be told that they wouldn’t do anything for me until my disability had been in place for three weeks...”

*(Babette, 47, Canada)*

“I got really annoyed... because there’s all the stress about exams and I couldn’t get to the study room because the lift was broke,

and they didn't have another area that I could go to and I said 'well can't I just use one of the empty rooms?' And they said 'oh well,' but I said like I need a computer in it and as soon as I said 'computer in it,' they said 'oh no we can't do that.'"  
*(Trudy, 33, Scotland)*

Lilly's and Joyce's experiences illustrate the vital importance of supportive social networks as a means of working around the wider inaccessible geographies that often intertwine with the academic experience:

"I had a difficult time there, I couldn't cope with the change in the environment just because I was going through a new course of study and the transportation system was terrible at the time... I just ended up dropping out and coming home... feeling defeated. At that time I didn't understand that having a well established social network and also having the resources were important to my academic success, I took that for granted... I came back... worked for a year and applied to... University, got accepted and moved into residence and did fine, no problems."  
*(Lilly, 34, Canada)*

"I actually started to speak to people collectively, there was like five people that I was really close friends with, and they said 'right let's look at how we can do this,' so when lecturers wrote diagrams on the board what they did, out of the five of them they would take a week each one, and they took carbon copy paper and they just drew the diagram and gave

me the carbon copy and they described things to me."  
*(Joyce, 34, Scotland)*

As we have found talking about schools, the individual must fit into the existing and established criteria, and it seems that access is controlled and allowed so long as non-disabled students are not inconvenienced. The crisis response approach to policy development and protocol, which is rarely produced by or in consultation with individuals who need or use them, is a manifestation of the singular approach to the accommodation of disability. The presence of disability within the academy is still viewed as an anomaly and disruptive to established routines. Frequently it is left to the student to take the initiative to resolve situations, and commonly this will mean trying to figure out micro-level organisational matters - often to do with "time-space relations" - in such a way as to accommodate the disabled student but without inconveniencing anybody else too much:

"I found that they had no initiative, like they had to be told things, you know I would always have to be thinking ahead, like what I needed rather than them saying 'oh you've got exams coming up or you've got labs coming up, what do we need to do?' They never asked me that, I always approached them ... so I always had to be more organised than other students had to be."  
*(Vicki, 29, Scotland)*

"I sometimes feel angry at the university because I feel as if I'm doing twice as much work as I have to because I'm fighting and I don't want to be fighting, I just want to do a degree, and I don't want to come in and worry about whether or not the lift is

working so I can actually get to the lectures...”

*(Trudy, 33, Scotland)*

Babette’s experience also shows how tentative and peripheral accommodation for disabled students can often be very much secondary to able-bodied aesthetics to do with what environments should physically look like:

“I went and got hooked up with the disabled students office and asked them if they could paint the strips along the kerb yellow, so that people like me with vision impairment could see where the indents were and that the kerb was there, and they thought that was a really good idea, and they did it, and I went back, I was very grateful and thanked them for it, and they said ‘well we have bad news for you, it’s coming off today,’ and I was quite puzzled by that, and they told me that they had had complaints from faculty members that it wasn’t aesthetically appealing so they removed it. So I was left again with no awareness of where kerbs were and what not.”

*(Babette, 47, Canada)*

### **Positive Spaces**

Respect, acceptance and support, both environmental and ideological, has a significant positive impact on individual educational experience:

“Everything at medical school within the university with colleagues, I mean medical students, has just been brilliant... If ever I need any help at all... the only help I need is physical

help... the time I am walking with someone, I take their arm...”

*(Lynda, 23, Scotland)*

“The Prof’s were really good, I was allowed to tape record my classes without any difficulty at all ... I never felt badly about it and students were really open to extra support and I didn’t have any problem.”

*(Babette, 47, Canada)*

“The other students I’ve had a great time with, they just treat me as me, there’s no leeway for me whatsoever, which is brilliant it’s just like other students, same as them... Which is fine you know, I don’t want them to tip toe round me.”

*(Trudy, 33, Scotland)*

### **On Approval: the Stress of Tentative Acceptance in Academia**

Trudy’s experience illustrates the stress often experienced by disabled students having to deal with countless individualised “small” access issues that are a vital necessity to the actual study process. It is interesting that the study process itself is supposed to be central to the post-secondary education experience, yet it is often secondary to the on-going quest for an accessible educational environment. One wonders what the outcome would be if students were able to use the bulk of their physical and mental energy solely on study:

“I said to my director of studies, ‘look I don’t have time to keep writing complaint letters, I’m here to be a student and get a degree and writing complaint letters to you is actually taking up my time, I need to be studying not writing bloody complaint letters! No just

fix it, I'm not asking for much just sort it out."

*(Trudy, 33, Scotland)*

The presence of disabled students in elite academic space is not commonplace. In many ways disability is still looked upon with suspicion or at the very least a curiosity. Perhaps on a much deeper primitive level, it is indeed a threat to the "spatial control" imposed by the dominant non-disabled social order. A peripheral acceptance is palpable. As a reflection of this phenomenon, many women identified the need to perform at an exceptional level as a means of validating their presence in the academic environment, gaining acceptance and approval, and thereby affirming their right to be present in these spaces.

### Conclusion

The women that I interviewed felt the need constantly to work on several levels at the same time simply to be present in the academic environment. Many women spoke of having to maintain an exceptional academic standard to be perceived as competent. This situation was of course coupled with the need to "pass" or minimize one's disability according to non-disabled perceptions of physicality or aesthetics. There is a type of reflexivity here rarely discussed: the energy used to be present both within and outside the academic environment. Established boundaries or comfort zones are constantly challenged by the outsiders having a tentative presence on the inside of academia. Such efforts use large amounts of physical and emotional energy for a population where energy is often at a premium. The question remains what could be accomplished if we as a society could move beyond such a grudging acceptance of disability in our mainstream educational spaces. Revolutionary changes are needed to achieve substantive results. To facilitate this process, the depth, texture and complexity of disability in a relational context must be fully understood. A grounded sensitivity to the timings and spacings of everyday life for people with disabilities is needed, without which much thinking

and policy on disability, education, and social participation seems to be limited in scope.

The knowledge and experience of persons with disabilities has to date been largely discounted by mainstream society. Knowledge has in effect been imposed upon them with diagnostic, bureaucratic and other labels. Legislation and related disability policy, informed by this knowledge, while appearing to serve an ameliorative function, has in reality maintained and reinforced existing barriers to full participation by people, especially women, with disabilities. The traditional medicalized approach to disability places the onus on the individual to fit into a social structure and system to which access for people with disabilities has been tightly controlled from the outset.

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## Education in the Prevention of Social Exclusion

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**Abstract:** Social exclusion is a frequently used concept in different youth programs in the European Union. Schools have participated in projects for the prevention of social exclusion. However, the definition of social exclusion is still unclear and it could be used also as a stigmatising label. In this article, the nature of social exclusion as a social phenomena and the preventive, non-stigmatising potential of education will be discussed.

**Key Words:** social exclusion, prevention, special education

### Introduction

Concern over the welfare of children and young people is frequently voiced both in expert forums and the media. Various programmes to foster their welfare are also being implemented by different sectors of the government in Finland. In

these contexts, the concept of social exclusion is often used<sup>1</sup>. The process of social exclusion should be seen as linked to the operating environment in which the individual exists or from which s/he is excluded. The risk of social exclusion exists for individuals whose life situation includes serious risk factors for the accumulation of disadvantage, whereas socially excluded individuals are the ones for which the risks have become a reality. In discussing, for instance, dropping out from education in the framework of exclusion one should specify that the concept dealt with is educational exclusion, not social exclusion per se, which is accompanied by an accumulation of many other elements of disadvantage (such as poverty, health problems, loneliness, drug problems) (Järvinen & Jahnukainen, 2001). Correspondingly, unemployment can be defined as exclusion from the labour market, which in itself is not a sufficient condition for social exclusion.

The prevention of the process of educational exclusion contains several levels. Certain measures are targeted for entire age groups and thus non-stigmatising. This article deals with these several levels and conceptually links the prevention of educational exclusion to the wider debate on social exclusion.

### Exclusion from the Societal Context

According to Tuula Helne, "When speaking of [social] exclusion we always speak of society" (Helne, 2002). This is a simple but crucial observation: in social exclusion talk we<sup>2</sup> very often speak of social exclusion as a characteristic defining the *individual*, without paying more attention to the crucial role of the operating context in the definition. Community and its norms have a crucial role in producing social exclusion: without community and society there is no possibility of social exclusion. By definition, social exclusion is linked to interpersonal relationships, societal actor positions and the values and norms defined by those representing the *dominant* culture in society<sup>3</sup>.

Thus, as a *concept*, social exclusion is much more difficult than could be expected when looking at the word alone (see Järvinen & Jahnukainen, 2001). As it is, social exclusion – and the prevention (or even eradication) of exclusion – is a catchword employed particularly in projects targeted to the young, without a more precise definition of the precise nature of the concept itself and the causal relationships eventually linked to it. In everyday speech certain activities and expression belonging to youth culture – and consequently regarded as marginal and deviant by adults and proponents of middle-class lifestyle – are easily seen as characteristics linked to social exclusion on too flimsy grounds: for instance, tattoos and piercings, heavy black metal music and recreational drug use are matters of (life) style and cannot serve today as a basis for defining the risk of social exclusion. Stylistic trends may be outside the mainstream (compared with the arts and the development of different styles) and challenge the more established concepts on values, norms or aesthetics, but they do not necessarily have any links with social exclusion in the short or the longer term. As is suggested by Tuula Helne, the marginal actor position, being at the edge, does not yet signify being outside (or in the excluded position); instead, “if someone is at the edge, they are inside, at the periphery of the centre” (Helne, 2002, 174). Deviation from the mainstream, or marginality, should actually be distinguished from the concept of social exclusion<sup>4</sup>, which is a process and leads to a societal actor position that is unsatisfactory from the viewpoints of both the individual and society (Jahnukainen, 2001e; Järvinen & Jahnukainen, 2001; Helne, 2002).

### **Educational System and the Process of Exclusion**

Participation in, or exclusion (voluntary or involuntary) from, education is an exceptionally strong societal signal, especially in the Finnish culture: a high value is set on acquiring as high a level of education as possible – even as an end in itself<sup>5</sup> – and, on the other hand, dropping out

of a course of study or being pushed to less appreciated fields of education are taken as signs of failure (see, e.g., Markku Vanttaja’s 2002 analyses of the “failures” of high achievers). It is the purpose of our educational system to provide, on the basis of equal opportunity, an education that is of as high a level as possible to as many citizens as possible. The youngest generation in particular has also been able to utilise this opportunity to an excellent degree<sup>6</sup>.

At the risk of overstating the case one can also say that, applied in their current target scope, the principles of educating the entire age group and providing them with lifelong learning, while admirable, may accelerate the birth of an educational lower class of individuals who have, for instance, severe learning difficulties or a culturally and socially deprived background. Moreover, the adult population with deficient basic education (as regards foreign languages, for instance) may be pushed to a secondary position in the labour market due to the lack of formal educational qualification. If participation in education was less frequent or less typical, being uneducated would not in itself become a stigmatising factor to the present degree.

On the other hand it is clear that, at least in the comprehensive school, an attempt is made to provide everyone with the opportunity to succeed: evaluation is no longer carried out<sup>7</sup> in the tight format of normal distribution (based on the so-called bell curve), but every child has the opportunity of progress as compared to his or her previous level and as compared to the age group. Teaching suited to the “good ones” – or to the average at least – has been abandoned in favour of taking account of the learning capabilities of each individual pupil, thanks to individual study plans and, in special education, the Personal Plan Covering the Organisation of Education (commonly known by its Finnish acronym HOJKS).

Despite the procedures described above, some of our schoolchildren still do poorly in the comprehensive school (Jakku-Sihvonen & Kuusela,



2002). Actually, gaps in basic knowledge and skills may be among the primary reasons<sup>8</sup> for dropping out of further education or not entering post-comprehensive education. The crucial division into educational achievers and educational losers happens at the transition stage between basic and secondary education, even though the roots of the choices actualised at this stage can be tracked further back, to success during the first years of comprehensive school and also to the pupils' family background (Kuusinen, 1986; Kuusela, 2002). The children of educated parents do better in school than those of uneducated parents, which continues to be seen in the students' skills levels and their confidence in their own abilities in secondary education (Hautamäki et al., 2002).

Thus, stressing the importance of education is a double-edged sword: when success in school is linked to family background, it strengthens the cultural capital of the pupils who are capable of benefiting from education. For a part of the age group, education forms one (more) link in the process of social exclusion. However, it is to be noted that even though a statistical connection exists between such factors as education and employment prospects, there are individual exceptions from the statistical norm both in the positive and the negative direction (e.g., Jahnukainen, 1997, 2004; Kivirauma & Jahnukainen, 2001). Whether dropping out from school leads into deeper social exclusion depends on the demands and support provided by the individual's (close) community and on the compensating factors in the individual's life. Thus, what we are dealing with is the goodness or poorness of fit between the individual's potential for action and the action expected by the community and the support available (for more detail, see Thomas & Chess, 1980).

It is also obvious that school alone cannot influence all factors that affect the process of exclusion. Nevertheless, school is without doubt in a key position for offering activity that can provide compensatory experiences to an individual who

has landed on an unfavourable track. In preventing the exclusion process, school has the crucial task of preventing educational dropping out by ensuring that everyone receives instruction suitable to their level, and of ensuring the acquisition of essential basic skills and knowledge in particular. These also form the foundation for the students' subsequent ability to utilise the channels for further education offered by society (and considered as the default option, at least latently).

## Potential of School to Prevent Exclusion

With the economic depression of the early 1990s, as the social exclusion of the young began to receive particular attention, the typical means of prevention that emerged were various activity projects targeted to young people. To begin with, these projects were organised outside the school, then gradually linked with the educational world, and the target group consisted of what were called "young people at risk of social exclusion." The exact definition of the "risk of social exclusion" at any given instance has remained very vague in practice: what is certain, however, is that the life situation of some participants has been burdened by a great number of risk factors for a considerable time, while others have had the good or bad luck of being involved in the project (and being labelled as being "at risk") with no more than slight grounds. From the viewpoint of prevention<sup>9</sup>, this mode of operation is located in the middle ground between what is called secondary and tertiary prevention: the members of the target group are affected by some risk factor at least, on the basis of which so-called remedial activity is considered necessary (secondary) and, in addition, the difficulties of some are of such a degree or number that a particular mode of operation is applied to reach a state where the individual could not harm him/herself or others any more than is already the case (tertiary).

In fact, prevention is always a relative concept and requires a definition of the thing to be prevented. Speaking of the prevention of exclu-

sion, development processes need to be looked at in longer perspective than simply within the comprehensive school. As was stated above, during the most lively period of youth projects the operating modes in relation to exclusion were located in the framework of remedial action and even action to minimise the damage. In the context of traditional school teaching this task has been handled by special education, even though this has only rarely been defined as prevention (see, however, Ruoho, 1992; Kauffman, 1999). In addition to these operating models, targeted at individuals already at risk – and perhaps, in part, instead of them – special weight should be laid on actual, primary prevention, i.e., on measures affecting the entire age group. From the point of view of education, primary prevention of exclusion consists particularly of concentrating on good basic instruction: teachers should make sure that every pupil in the teaching group acquires the basic knowledge and skills that form the basis of further study. Thus, in the prevention of exclusion the school should aim to work in the primary field that is its natural domain: to ensure that the task of educating the entire age group is accomplished for each individual. The following table lists educational measures to prevent exclusion at different stages of education and different levels of prevention.

Thus, the primary-level services concern the entire age group, while the secondary and, where needed, tertiary services involve a significantly smaller group. In fact, prevention is often described as a funnel where the primary services are located on the rim and the tertiary services at the narrow tip of the funnel (e.g., Nuorten huumeiden käytön ehkäisytoimikunnan mietintö, 2000).

At the **primary level** exclusion is prevented by arranging the most optimal conditions for growth for each child, and by investing in good early education and basic education. Afternoon activities arranged at school can also be included in this category (see Siitari, 2000). Primary-level activity by individual teachers includes the positions as elected municipal officials held by many profes-

sional educators, through which it is possible to promote operating models targeted to improving the situation of entire age groups by influencing municipal family, social and educational policy.

At the **secondary level**, special support is arranged for the children and young people who exhibit difficulties related to learning, development and/or behaviour. The measures aim at circumventing or eliminating difficulties detected at an early stage so that later stages of development are not jeopardised. The secondary stage consists of various short-term interventions such as part-time special education, improved study counselling and transition planning (see Jahnukainen, 2001b and 2001c). Especially at the transition between comprehensive school and secondary education, anticipating the transition of individuals at risk has been found effective (e.g., Benz et al., 1997).

At the **tertiary level**, the activity is targeted to individuals whose development is clearly endangered. Longer-term, holistic rehabilitation, eventually in co-operation with other authorities, aims at reaching the development targets of the age group by using individual means. Several operating models employed at this level require instruction in small groups or even individually, at least at the beginning or for part of the time; this is in the interests of both the child or young person and their immediate vicinity. Nevertheless, the permanent goal is to find an operating model that best avoids any stigmatisation and thus helps to prevent isolation or exclusion from the rest of the age group.

### From Theory to Practice

As was stated above, a lot is *talked* about social exclusion and young people threatened by social exclusion. Since, however, social exclusion is difficult to define on the individual level, it would make more sense to approach the prevention of social exclusion only as a general principle, but especially when talking about children and young people, we should focus on the strengths and de-

**Table 1. Prevention of exclusion at various levels and different stages of education (the measures cumulate from the primary to the tertiary level)**

	<b>Early Education</b>	<b>Comprehensive School</b>	<b>Secondary Education</b>
<b>Primary</b>	<ul style="list-style-type: none"> <li>• good basic care and pre-school education</li> <li>• support to parenting</li> <li>• individual educational plans for each child</li> </ul>	<ul style="list-style-type: none"> <li>• good basic instruction</li> <li>• development of knowledge</li> <li>• individual study programmes for everyone</li> <li>• remedial teaching</li> </ul>	<ul style="list-style-type: none"> <li>• good basic vocational instruction</li> <li>• development of knowledge</li> <li>• individual study programmes for everyone</li> <li>• remedial teaching</li> </ul>
<b>Secondary</b>	<ul style="list-style-type: none"> <li>• various services offered by the special kindergarten teachers</li> <li>• early rehabilitation programmes</li> <li>• transition planning and co-operation with the (special) teacher of early education and primary education</li> </ul>	<ul style="list-style-type: none"> <li>• part-time special teaching</li> <li>• transition planning</li> <li>• improved study counselling</li> <li>• additional instruction (10th class)</li> <li>• HOJKS and integration with general instruction</li> </ul>	<ul style="list-style-type: none"> <li>• part-time special teaching</li> <li>• improved study counselling</li> <li>• monitoring of absences</li> <li>• transition planning (education / working life)</li> <li>• HOJKS and integration with general instruction</li> </ul>
<b>Tertiary</b>	<ul style="list-style-type: none"> <li>• special groups</li> <li>• co-operation with child protection and rehabilitation</li> </ul>	<ul style="list-style-type: none"> <li>• HOJKS and teaching in special classes*</li> <li>• personal career, workshop groups*</li> <li>• reform schools</li> </ul>	<ul style="list-style-type: none"> <li>• HOJKS and special vocational instruction groups</li> <li>• projects for drop-outs*</li> </ul>

\* The inclusion of these operating models in the secondary or tertiary levels depends on the target group in question and the municipal special education strategy. As suggested by Kari Ruoho, it might be more meaningful in general to call the primary level the *general* and the two other levels *special prevention* (Ruoho, 1992, 187).

velopment needs in the individual life situation. Thus, I do not consider it appropriate to set up particular instruction groups for young people “threatened by social exclusion”; instead, I would welcome discourse that prevents social exclusion also in practical teaching in the general primary-level activity of the school. Creating a learning climate in which everyone has the opportunity of studying individually, yet striving to attain the general basic goals, without unnecessary competition or comparison, is one of the most important starting-points of primary-level prevention. Even if learning and adaptation problems are undeniably also linked to the process of social exclusion, schools must primarily target rehabilitative action to whatever problem area is topical, whether this is dyslexia or unauthorised absences. If the teacher takes the trouble to learn to know the pupils in his/her class or group as early as possible, s/he can better identify eventual deviations in learning and behaviour, enabling a rapid intervention and preventing the accumulation of problems. In my opinion, the true prevention of social exclusion consists in the development of the basic task of education, that is, the provision of education for the entire age group, into an entity which is as functional as possible at the level of individual schools and of the municipality. This work has been badly neglected, with projects funded by special arrangements overtaking the “exclusion market.”

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#### (Footnotes)

<sup>1</sup> The Finnish word used to translate the concept *social exclusion* does not contain the dimension 'social', which is why it can, and often is, linked to any and all kinds of exclusion. In the most typical case it is used without defining the particular nature of exclusion.

<sup>2</sup> I include myself in the discussion here, for in my job I deal almost daily with this area, and according to my observation I must all too frequently remind myself and my discussion partners of the complex nature of the definition of social exclusion. It is easy to talk about "the socially excluded young people in our school..." or "operating models targeted to young people at risk of social exclusion..." etc. This means that social exclusion is already being constructed in speech, often with too simplistic grounds.

<sup>3</sup> At a minimum I should say that social exclusion needs three actors. This makes it possible for two actors to form a core on a majority principle, leaving the third one outside the core, in the margin.

<sup>4</sup> It is, however, obvious that the phenomena behind the concepts also have a shared interface; when, for instance, marginality as an individual choice involves the most essential areas of life or covers a sufficient number of less essential social activities, we are coming closer to the definition of social exclusion (for more detail, see

Jahnukainen, 2001e, Järvinen & Jahnukainen, 2001, 138 – 144).

<sup>5</sup> Also among young people (see Nuorisobarometri, 1999). This presents an interesting paradox, for it has nevertheless been noted that school is often experienced as a highly unattractive environment (see Kauppila, 1995; Jahnukainen, 1998; 2001a and 2001d): one is thus forced to go through education, even if with gritted teeth.

<sup>6</sup> In 2000, the proportion of young people between the ages of 15 and 24 that participated in post-comprehensive education was higher in Finland than in the other EU Member States (Järvinen, 2001).

<sup>7</sup> At least this should not be the case, see Opetushallitus (1999) Perusopetuksen päättöarvioinnin kriteerit. The criteria for the grade Good (8) in shared subjects.

<sup>8</sup> On the secondary level – or as the "explanations" noted on the student level – the causes may naturally consist of "frequent absences", "behavioural" and "motivational problems", when, in fact, the student may not be capable of following challenging instruction even when the field is to his or her liking, though on the other hand, teachers may also not be capable of recognising gaps in basic skills.

<sup>9</sup> For more detail on the levels of prevention, see, e.g., Nuorten huumeiden käytön ehkäisytoimikunnan mietintö (2000), and in the context of learning difficulties, Ruoho (1992).

## **Disability in Greece: Social Perception and Educational Policies**

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**Abstract:** This work examines how the Greek state (under multiple types of governmental regimes) dealt with children with disabilities within the framework of educational and political reforms, and how social perceptions of disability have defined – to a lesser or greater degree - the aforementioned policies. This article covers three basic periods: 1) First steps, starting from the turn of the 20<sup>th</sup> century until the 1940s; 2) Minimal state intervention to deal with the issue (1948 – 1985), and 3) the most recent period, where children with a disability are dealt with in a more

comprehensive way within the terms of a social welfare state (1985 – 2004).

**Keywords:** Greece, education, policy

In Western societies the history of state intervention for the protection of disabled children is almost identical with the efforts to provide public education for these children. The richer, industrial West began to provide services much earlier than did poorer, peripheral Western countries, such as Greece, where Western developments were adopted at a much slower pace. Although issues of provisions geared towards people with disabilities, and particularly the need for Special Education, arose at the turn of the 20<sup>th</sup> century, real measures began to appear only after Greece's return to democracy (1974, post junta era).

Greece's return to solid democratic foundations and proper membership in international organizations, particularly the European Union (1981), multiplied the number of communication channels and the voices of influence from Western societies. Progress and processes relative to human rights issues coming from European and international sources led to increased pressure on the social-political life of the country. Thus, ratification of the International Convention on the Rights of the Child by the Greek Parliament (1992), directives issued by the European Minister's Council and the European Commission (European Commission, 2001), and U.N. and UNESCO Resolutions, Declarations and Acts, helped in the development of a new public climate in Greece. Democratic freedoms allowed for the establishment and development of various organizations for people with disabilities and other institutions that were able to apply pressure on the system. This had a positive effect on government policy for the disabled population, including children, which gradually expanded to all levels of education.

In this article we shall examine perceptions of disability in Greece, and resulting educational policies, throughout the 20<sup>th</sup> century. According to these criteria we distinguish three historical

periods. The first, from the beginning of the 20th century up until 1948, concerns initial rather ambitious, but not very successful, steps. The second period, from 1948 until 1980, is when disability was still perceived negatively, but the Greek State provided basic education to children with disabilities through a sparse elementary school network. And finally the period from 1985 up until the present, which is marked by the development of the social welfare state and the emergence of public sensitivity to disability issues, thanks to greater awareness about democratic and human values.

### **The First Steps (1906-1940)**

Following the Greek War of Independence, fought against the Ottoman Empire, and the drafting of the Modern Greek State Constitution in 1828, educational policy was focused on two aims: a) establishment of elementary institutions for the provision of formal education and, b) care for the large number of orphaned children. In this context and, in contrast with many other European countries<sup>10</sup>, no public talks were held on the issue of disability and the education of people with disabilities.

In the beginning of the 20<sup>th</sup> Century, three major trends marked Greek education. Greece was strongly influenced by contemporary educational movements, particularly from Germany, and to a lesser - but growing degree - by developments in the United States. Many social reformers were trying to modernize Greek education and society. On the other hand, participation in two wars - within a decade - changed the country radically. After the victorious Balkans Wars in 1912-1913, the territory almost doubled and the population increased from 2.6 to 4.7 million people. Ten years later the Greek army was defeated severely by the Turks in Asia Minor. In addition to moral, ideological and economical collapse (Campbell & Sherrard, 1968), another 1.2 million refugees arrived from Asia Minor to settle in Greece proper. Thus the population of the country surpassed the 6.2 million mark. School was perceived as the best and the most powerful medium for the

unification of the nation and restoration of state control. However, and while Greece was trying to restore its economy, the Great Depression of the 1930s arrived to drastically limit any possibility for educational reforms.

Under these circumstances it is clear why frequent - and persistent - attempts to reform education met with failure. The same holds true for measures related to disability and the education of disabled people. From the beginning of the 20<sup>th</sup> Century, one of the most widely discussed questions was that of the human body. The aim was to improve the strength of the human body, both through physical exercise (gymnastics), better personal health care, and through a set of hygienic rules (cleaning, medical care for pupils, the architecture of buildings, etc.) (Kiprianos, 2004).

This “body movement” is closely connected with early thoughts and the first steps related to disability and schooling for people with disabilities. Indeed, public debates in the turn of the 20<sup>th</sup> Century about disability resulted in the question of disability being raised in two major attempts at educational reforms in the first half of the century (1913 and 1929).

An early legislative draft (not debated in Parliament), fruit of the progressive educational movement of the time, represents the first official reference to disability and schooling for people with disabilities in Greece (Glinos, 1924). The draft distinguishes two forms of disability: “Students with purely pathological causes, requiring special institutions,” and pupils who, “Because of various reasons, including physiology, lag behind in development.” Without any other comments, the letter of the law deals only with the second group. The legislation aims to a) aid pupils in this category to graduate from school, and b) allow the other children to complete their schooling “without delays.” For this purpose, the draft suggests the establishment of special classes within schools, similar to what was going on in many German cities, with targeted teaching and lighter courses.



The question of disability was also dealt with – although briefly - in the law of 1929. Again, and despite the fact that liberals were in government - as in the previous occasion – the tone was anachronistic. While admitting that education for “healthy children” leaves much to be desired, the reformers argued that it is worthwhile to “take care of the disabled” because “the cost is not high and the number of these children is constantly increasing.”

With the term “disabled” the law described and formed two categories of children: the “dysfunctional children” and the “weak, prone to sickness” children. The former category concerned “children with physical and mental sickness prohibiting them from attending regular schools” and included “some children of alcoholic and prone to sickness parents who manifest psychical abnormalities” who are unable to attend “regular schools.” In addition to the above, there were “many sickness prone children” who did not “manifest any mental dysfunction... yet they bear within the seeds for hereditary disease or they have bodies with obvious inclination towards various diseases” (Bouzakis, 1994).

This law provided for the establishment of a limited number of schools, for “dysfunctional children,” and only in major cities. More attention was given to the children who were “weak and prone to sickness.” To assure their effective schooling and to avoid “contamination” of “healthy children,” it was deemed necessary to set up “outdoor or open air schools.” Since implementation of such a proposal would be expensive it was decided to set-up one or two schools as “test beds” (Bouzakis, 1994).

There is no doubt that popular (and official) perceptions of disability and people with disabilities was, to say the least, very primitive. Despite dubious progress views were generalist and deeply anachronistic. The distinction between the two categories was not clear. Moreover, no clear distinction was made between biological, medical and social grounds for exclusion. In any case,

nothing was done about the law until 1937, mostly for economic reasons.

In contrast to vain attempts by the state to deal with the disabled population and the education of children with disabilities, a large number of distinguished public figures, famous writers, educators, and institutions (i.e. Greece’s royal family, well known statesmen, and others including the Orthodox Church) were driven to stir up public awareness on the issue of persons with “physical” and “mental” disabilities and endeavored to take care of them either through state run programs or the establishment of appropriate institutions (Stasinou, 1991).

In this context and following the intervention of these noted figures, a group of people (the same group of people laboring to raise awareness about pre-school education) founded a philanthropic association aptly named “Home of The Blind” in Athens (1906). This was - and still is – a foundation oriented towards the protection, education and the overall care of blind children between 7 and 18 years of age. The following year (1907), the President of the foundation, Irene Laskaridou, provided her own residence to accommodate the “Home Of The Blind,” the first such institution in the Near East (Stasinou, 1991).

The Home of The Blind began its operation providing 2 years of pre-school care and 6 years of elementary education. As time went on, the school became very popular and attendance steadily grew. The number of attendees increased rapidly following the “national disaster”<sup>11</sup> of 1922 and the large influx of refugees from Asia Minor. The official records report 20 students in 1912, 33 in 1921, 56 in 1922 and 70 in 1931 (Stasinou, 1991).

The example set by the Home of The Blind was soon followed by others. In 1907, Charalabos and Helen Spiliopoulos founded the “Home of The Deaf-Mute,” which remained dormant. In 1923, right after the “national disaster,” the American humanitarian organization “Near East Relief,” (which was founded in 1919 and had been very

active in the area) established in Athens the first school for 10 deaf-mute children from 7 to 15 years of age, refugees from Asia Minor (Stasinos, 1991).

During the 1930s, initiatives for the support of children with special educational needs increased and intensified, coming both from the state as well as from the private sector. This was due in part to the fact that the population of people with disabilities was increasing and because of influences coming from abroad. Governments in Europe and the United States were adopting measures and implementing programs for people with disabilities. So, despite the fact that the provisions of the law passed in 1929 were largely inactive, the Greek government, in cooperation with the Near East Foundation, went ahead to establish the “National Home of Deaf-Mute” in 1932.

A major breakthrough for the development of Special Education in Greece came during the dictatorship of Metaxas (1930 – 1940). During favorable economic conditions the dictatorship decided to appeal to the “weaker” segments of the population through a series of measures. Three major breakthroughs were made in this period:

- 1) In 1936 Metaxas decided to accept the proposal submitted by a renowned educator, Roza Imvrioti, student of Spranger in Germany,<sup>12</sup> to create a school, the first in Greece, for “retarded children” (Kalatzis, 1985). Thus, in 1937, the “Special School for Dysfunctional and Retarded Children,” the first public school in Greece for children with special educational needs was founded. Thanks to Imvrioti’s insistence, a few months later the school was officially renamed the “Model Special School of Athens.” The operation of the school was very successful for three years. It was forced to close down when Greece was invaded by Italy under Mussolini, in October 1940. According to Roza Imvrioti’s

documentation, the school was attended by 94 students during the school year 1938-1939, and showed remarkable activity (Imvrioti, 1983).

Although the Model Special School of Athens was equivalent to similar schools established at the same period in developed countries, it is of note that it quickly deteriorated after Imvrioti’s removal. Roza Imvrioti was the inspiration, the heart and soul of the entire effort. Despite this the Model Special School of Athens left a strong legacy for generations to come. It promoted Special Education in Greece, creating all sorts of repercussions and more importantly so, managing to reach deep into the state bureaucracy and its services. In fact, the Model Special School of Athens was a historic breakthrough for Greek society. For the first time the public became aware of the enormous humanitarian issue presented by the problem of children with mental illnesses. For educators involved in the project it had been a thrilling experience, an “initiation” not only into Special Education but also into “humanity” (Kalatzis, 1985).

- 2) Also, in 1937 and again thanks to governmental intervention, the Spiliopoulos-founded “Home of The Deaf-Mute,” which had been dormant since its establishment in 1907, became active as “The National Home of the Deaf Mute.” The new foundation was organized according to Anglo-French patterns. The foundation was under the control and supervision of the Ministry of Social Affairs and its scope was to promote the education of concerned people through the establishment of specialized appropriate institutions (Stasinos, 1991).

- 3) Two more institutions were established in 1937. In Athens, Asklepeion Hospital of Voula set up an elementary school for its patients. Financing and supervision of the project was under the Ministry of Education, although the initiative for its creation was undertaken by a group of prominent personalities and the support of an Athenian society club, "Rotarianos Omilos Athinon." The other was an initiative by the "Near East Relief" which founded the "Greek Association for the Protection and the Rehabilitation of Handicapped Children." The scope of this institute was to provide care for "handicapped children" from infancy up until their 16<sup>th</sup> year of age.

### **State Policy Between Segregation and Integration (1948-1985)**

The 1940s were a troubled and trying time for Greece. Following the war against the Italian and German invasion (1940 – 1941), the Axis occupation (1941 – 1944), and liberation (1944), the country continued its suffering through a three year long civil war (1946 – 1949). The armed conflicts and the resulting hunger - in addition to the collapse of the entire infrastructure – were very destructive throughout the territory. Hundreds of thousands of children were orphaned and untold scores were disfigured with multitudes of physical and psychological problems. The educational and care systems were also destroyed to a great extent.

Under these trying conditions, the State, because of limited financial resources and in the absence of public pressure for corrective measures, did little towards the protection and education of people with disabilities. Despite major developments taking place in many Western societies, particularly the United States (Winzer, 1993), nothing was really done in Greece. Even educational reforms labeled as progressive (those taking place in 1964 and 1976) made no mention of people with special educational needs. The

only worthwhile mention was made in the report of a "think tank" (so called "wise men"), the "Educational Committee" that had been formed in 1957 to study the situation in the educational system and explore various solutions (Kiprianos, 2004).

The conclusions of the Committee were two-pronged. First, it concluded that "geniuses" were being lost because of social trends and second, that educational care for the estimated 10,000 children with "mental and physical disorders" was lacking. Yet, it stopped short of making specific proposals but rather proposed the Ministry of Education hire a special consultant whose responsibility would be to "coordinate the activities of the Ministry in this sector and to promote closer cooperation between the Ministry of Education and the Ministry of Social Policy" (Bouzakis, 1994).

The vague proposals of the Committee do not allow us to form any substantial conclusions relative to people with disabilities and their education. It should be noted here though that there was a change in the terminology that was used. The negative remarks of the past were mostly absent and new, less derogatory terms were coming into effect ("physically disabled" and "mentally lacking"). This change in attitude, is also present in the majority of writings of that period (Kalatzis, 1985). This could be explained by the general assumption that special education was becoming the domain of experts.

As a matter of fact, the number of private institutions catering to people with special educational needs had increased since the end of WWII, and many of these were funded with public funds. In many cases these institutions were created through initiatives undertaken by specialists, physicians or psychologists, and more often than not they were based inside a hospital. An exception to this rule was the Stoupathion Center For Therapeutic Education, founded in Athens, 1962, by the "Parent Association of Dysfunctional Children." K. Kalatzis, (who had

been an associate of Roza Imvrioti) was appointed principal of the school. Kalatzis worked to achieve the integration of children with special education needs into the mainstream and to avoid the segregation that was the norm in the past (Stasinou, 1991).

Unfortunately, Kalatzis's endeavours were not immediately successful. Yet, the social and economic changes taking place in Greece, as well as abroad, and the increasing number of children with special educational needs, forced the Dictatorship of the Colonels (1967 – 1974) to take into consideration and implement some of the measures proposed by the "Educational Committee" of 1957. Thus in 1969, the Ministry of Education formed the "Special Education Bureau" along the lines proposed by the Educational Committee. This act was followed by two more measures. In 1971, the curriculum in higher education institutes for Elementary and Kindergarten Teachers included a course for the "education of dysfunctional children" and in 1970 the Athens Pedagogical Academy (Teacher School) offered postgraduate classes on special education (Kalatzis, 1985).

These measures mark some notable changes at the organizational level, but by no means in the general perception of disability. Indeed, in 1971, the Dictatorship formed a new Educational Committee to explore the educational system. The report submitted by the Committee, made public in 1971, made extensive mention of children with special educational needs but the language remained pointedly vague. Children were divided into the "socially maladapted" and "mentally retarded." This distinction was also the measure for the proposed "solutions." The propositions included measures that underscored the need for greater involvement with these children and improvements in public awareness. The basic issues, however, those concerning the education and social integration of these children, remained vague and alternated constantly from integration to segregation (Kiprianos, 2004). Basically what the Committee did was return to the Law of 1929, proposing the

establishment of special schools or the creation of special classes inside "regular" schools.

The fall of the military junta and the return to democracy in 1974 is a turning point and marks the beginning of important steps taken towards improved education for people with special needs and their integration into mainstream society. Yet, these steps are still exploratory and slow and seem to vary between segregation and integration.

The first important law concerning the provision of educational services to children with disabilities was law 227/1975, directing educators into post-graduates studies in special education to cover the most elementary of needs. Following the formation of the Directorate of Special Education, under the Ministry of Education (Pr.De.147/1976), procedures in the area of Special Education took a more cohesive shape and things began to move a lot faster.

From this point, and until the closing years of the 20<sup>th</sup> Century, legislative activity proliferates. The new laws deal mostly with concerns for the training of educators, admittance of disabled people in higher education institutions, initiating reforms of Analytical Programs and, to a lesser degree, with a systematic and long term confrontation with the "heart of the problem."

It is true that from the early 1970s a growing number of countries began to follow the example of Scandinavian countries, which were the first to adopt "the principle of normalization" (i.e. of the disabled population) with its attendant concept of integration (Mazurek & Winzer, 1994). This principle enacted in the United States in November of 1975, by the enacting of the Education of All Handicapped Children, required "a free, appropriate education for every child with a disability" (Hallenbeck & Kauffman, 1994). Integration was also the principle of the report of the Warnock Committee in the United Kingdom and the ensuing 1981 Education Act.<sup>13</sup>

Under the strong influence of the aforementioned developments, the trend towards integra-

tion became stronger and stronger in Greece, particularly after 1981. From 1983 onwards the Ministry of Education formed special classes for children with disabilities within schools, particularly for those children with learning difficulties, instead of the establishment of special schools that had been normal in the past, aiming towards the integration of these children into the mainstream and to develop a more acceptable climate of “social approval.”

Law 1143 was approved in March of 1981, with the eloquent title, “About Special Education, Special Vocational Training, Employment and Social Care of Persons Deviating from Normal and Similar Educational Provisions.” The law received intense criticism for discrimination, e.g. separating “normal people” from “abnormal people” (Xiromeriti – Tsaklaganou, 1986). On the other hand, and despite the justifiable criticism, the law was in fact the first comprehensive approach to the issue of Special Education in Greece. For the first time Special Education fell into the jurisdiction of the Ministry of Education. Additionally, the law mandated obligatory education for children 6 to 17 years of age.

### **Children With Disabilities During the Development of the Social Welfare State (1985-2004)**

Law 1566/1985 made a breakthrough in policy for the education of children with disabilities. For the first time, a law had a separate chapter for Special Education and introduced the internationally-accepted term “children with special educational needs” instead of the anachronistic “abnormal,” “retarded,” etc. This demonstrated a shift in the overall perceptions about disability towards a socially sincere and more humane treatment people with disabilities.

In fact, the law recognized as disabled all those children who “show delays, disabilities or disorders in their overall physical or mental condition or in particular functions to a degree that hinders or seriously disrupts their ability to

follow through with general or vocational education, their ability to enter into the production process and their acceptance into mainstream society” (Law 1566/1985). Even a simple glance at the above text shows that the overall government philosophy on the education of people with disabilities had shifted towards the realization of their human rights, rights that were recognized mainly due to international obligations undertaken by the country.

It is also true that under the influence of European social policies, pressure exercised on the government by organizations for people with disabilities, and a more sensitive public opinion, the state was forced to promote measures for children with disabilities in a more organized way. On the practical side, more decisive measures were taken through law 2817/2000, which regulated various education issues for children with special education needs and set up 54 Diagnosis Evaluation and Support Centers (KDAY in Greek). Also, in November 2003, the Greek Parliament regulated the establishment of 4 more such centers in major cities of the country to cover additional needs and specified that preference should be given to appoint or hire staff with specialization in the area of special education. The same law stipulated the terms for the establishment and operation of special education schools in the primary and secondary education levels, and the creation of a Special Education Department in the Pedagogical Institute, proof that the political will of the government has turned towards a more coordinated intervention into the issues of special education.

In regards to higher education, from 1980 (law 1035/1980) people with disabilities were accepted into higher education institutions, Universities and Higher Technical Institutes, without prior admission examination. Another law introduced in 1998 specified that greater numbers of people with disabilities be admitted into these schools, lifting to a greater degree the social isolation suffered by this segment of the population. Many higher education institutions have gone further by introducing measures to improve higher edu-

cation for schooling for students with disabilities (Psilla et. al, 2003). Also, due to the fact that enrollment of students with disabilities grew disproportionately for the supporting infrastructures in higher education institutions, another regulation was legislated in 2000 specifying the admission of disabled students to 3% of the total number of students admitted in each university department.

The KDAYs, however are faced with important problems, primarily having to do with infrastructure. In addition to shortages in specialized staff and technical infrastructure, what has become quite obvious is that there is no comprehensive scientific approach into the various shapes and forms of childhood disabilities, one that could combine and coordinate the knowledge of various scientific sectors towards a common problem and offer a case by case solution (Drosinou, 2004). Also, in light of the fact that scientific research undertaken by the Pedagogical Departments on such issues is relatively recent, and that it does not relate to the practical operation of KDAYs, the result is a huge gap separating research from the application of theoretical conclusions. This creates an important obstacle in their effectiveness.

Beyond the KDAYs, it appears that the overall legislative framework of special education is less capable of dealing with the variety and additional needs of students and that there are substantial indications for a crisis in the education of students with disabilities. This becomes apparent from the flawed organization of Special Education Schools, shortcomings in the advanced training of educators, and the deficiencies of law 2817/2000, which can be described as vague and generic, since it assumes an all around similar treatment of all children with disabilities (e.g. enrollment of deaf, physically disabled and autistic children in common schools).

The most obvious example of such glitches is the program for the deaf, which – despite the fact that it is considered a full program starting from kindergarten all the way to special high school and Special Technical Training, produces students

with low reading efficiency. Of course the current policy of the state is to improve – at least - the existing infrastructures, but educational efficiency is a combination of the work and the ethics of the teachers themselves, who, in many cases, are bringing with them antiquated ideas and prejudices.

We should mention the important role played by the movement of people with disabilities, which has developed rapidly over the last ten years and forced the state to enter more actively into the issues of children with disabilities. The successes scored by the movement are particularly notable in the measures taken by the state for deaf children. Special Schools for the education of the deaf have multiplied all over Greece (7 kindergartens with 45 pupils, 12 elementary schools with 145 students, 3 junior/high schools with approximately 240 students), while the movement of the deaf managed to gain recognition for Greek sign language (Law 2817/2000) as the “language of the deaf” and make it a required skill for teachers appointed in schools for the deaf (Lampropoulou, 2001).

The major success of the movement of the deaf is that it managed to alleviate public discrimination to a degree where being deaf is no longer considered a “handicap” by Greek society, at least not as much as it used to be in the recent past, and that society has an obligation to deal with deafness with positive measures. A disability is no longer an excuse for social segregation, but it may be soon seen as a reason for reverse discrimination, something that is quite apparent in all levels of education where Special Education is gaining ground at an accelerated pace (Psilla et. al, 2003).

## Conclusions

It may be true that state education policy for children with disabilities in Greece has been, and remains to a large degree vague, uncoordinated and patchy, because of historical and cultural reasons as well as limited financial resources.

Indeed, the Greek state of more than twenty years ago was not in a position to set into place the necessary infrastructures for special education. The institutions founded by the state prior to 1974 were more of an attempt to “pacify” the social consciousness and much less an effort to provide a comprehensive solution to huge social and humanitarian issues. During the last few years the state has embarked on an unprecedented effort in terms of educating children with disabilities. However, the structures put into place are still lacking, given that the number of children who need some type of special education number more than 200,000 throughout Greece. Furthermore, educational schemes for people with disabilities suffer from deficiencies, having to do mostly with the vast organizational problems of the state itself.

The most important issue though, is that for people with disabilities within the framework of a developed, democratic society, removal of the barriers prohibiting their full and unhindered integration into the social fabric has yet to be achieved. This, of course, is not restricted to Greece alone, and may well be considered as a European phenomenon. Although the number of people with disabilities enrolled in higher education institutions at the European level has risen substantially over the last few years, there is no corresponding rise of these numbers in employment (Svalfors, 2000). The education of children with disabilities in Greece does not compare well with the more advanced European nations. Despite breakthroughs achieved recently, there is still a great distance to cover towards a more comprehensive, better organized and socially efficient system of Special Education.

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**(Footnotes)**

<sup>1</sup> The first schools for people with disabilities in Europe were established in France, 1784 and 1790; and later in Britain, 1846 (Winzer, 1993). The first special education classes in schools were founded in Halle, Germany, in 1863 and some years later, 1881, in Switzerland (Descoedres, 1948).

<sup>2</sup> Following the defeat and withdrawal of the Greek army from Asia Minor the entire Greek population of the area was forced to abandon their homes and sought refuge in Greece. For more information see C. M. Woodhouse, *A Short History of Greece*, pp 187 - 211.

<sup>3</sup> It is of note here that Roza Imvrioti was a prominent personality with strong communist affiliations. Despite this fact and given that the dictatorship was hard at work persecuting communists, it is surprising that Metaxas agreed to her proposal. Perhaps he acted so due to the fact that he had become an avid admirer of Spranger while following postgraduate studies in Germany where he had enrolled in his classes.

<sup>13</sup> “The Committee recommended that the term ‘children with learning difficulties’ should replace the term ‘educationally sub-normal’ which had been introduced in the 1944 Education Act” (Copeland, 2002).

## Research Articles

### “Colorless in a Rainbow” An African American Female with Albinism in the Hawaii Public School System

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**Abstract:** Culture, ethnicity and ability: these are just three attributes that encompass the life of a female African-American student living with albinism and attending a local Hawaii public school. From February 2003 – April 2004, through personal and family interviews, a personal journal and autobiography, field notes, observations at home, school and in extracurricular activities, the personal perceptions and experiences of what it is like living with albinism and being African-American surfaced for this student. This article addresses identity issues regarding race, gender and ability, and discusses two theories: Critical race theory (CRT) and disability theory to answer the questions, who and what defines this female’s identity?



Utilizing the lens of critical race theory and disability theorists, the following case study will examine issues related to being an African-American female student with albinism in Hawaii. The complexities of issues that make up Taylour's life include: 1. The societal definition of her race and the implications of stereotypes and name-calling that reflect these views; 2. The issue of how society defines her disability, which often excludes blindness, but focuses on albinism and finally; 3. Self-identity and personal reflection and how Taylour relates to being African-American and having albinism.

**Key Words:** Critical Race Theory, African-American, Albinism

“Just as our skin provides us with a means to negotiate our interactions with the world – both in how we perceive our surroundings and in how those around us perceive us – our language plays an equally pivotal role in determining who we are.”

(Lisa Delpit)

### Taylour

Taylour's skin is as white as snow and her eyes are light gray. However, her other physical features are African-American. She has albinism, a deficiency of pigmentation in the skin, hair, and eyes affecting one in 20,000 individuals in the world. Taylour is the youngest of three children in her family, and the only girl. At home she is surrounded by culture - the walls are covered with African, Hawaiian and Japanese masks and African-American and Japanese furniture; paintings and sculptures fill each room.

Taylour's family has long been associated with the military. Her father is a Gunner Sergeant in the United States Marine Corp, and has served for twenty years. Her mother is a Chief Petty Officer in the United States Navy Reserve; she served active duty for twenty-two years. Both of

her brothers attend military academies. Her oldest brother is at King's Point Military Academy and the other is at West Point Military Academy, both on the mainland. The family has lived in several US states and in Okinawa. Taylour spends a lot of time with her parents going out to dinner, sewing and going to the movies. She says her mother is her best friend because she can talk to her about any and everything.

Taylour loves to sew and the family business, “Taylour Made Embroidery” is named after her. She is very creative with her hands. The first time I went to her home, she showed me quilts, pillows and a jean skirt she had sewn out of two pairs of old jeans. For the past two years she has been taking Karate and in April 2003 she earned her green belt. Over the past ten months she was awarded two additional stripes. When she grows up, she wants to be a Navy attorney because she feels that people are mistreated in the world for being different with regard to their culture and ethnicities, and she knows she will come in contact with many cultures if she stays connected to the military. The following is a composite narrative of Taylour's experiences from birth to present. The words are taken from her personal journal, a written autobiography, personal interviews, and interviews with her family and teacher conducted over the past 16 months. The words of Taylour's parents are also interwoven throughout the narrative. The University of Hawaii Human Subjects Board, and the permission of the student and parents granted permission for this case study. Actual names are used because the family wanted their true identities and voices heard.

Taylour:

*“I was asked to describe myself as an African-American female living in Hawaii. I thought about it for a long time and I had to ask Mrs. Hairston to rephrase the question to: What is it like to be an African-American female with albinism living in Hawaii. I added the albinism because even though my family and friends don't talk about it everyday, I see it every time I look in the mirror. When I think*

*of who I am, I often don't mention the albinism though. I'm not ignoring it. I've just gotten used to it so when people call me names because of it, that's when it bothers me. So, what is it like here in Hawaii? I'm colorless in a rainbow. There are so many people and cultures here, so many tans, shades and colors, and then there is me. My color is inside and I am filled with African-American culture, but I am white on the outside. I hate the sun because it burns my skin and eyes. Although I could say that I'm white because of my skin, it is still a color that no one else relates to me when they call me names like ghost and banshee. These things are invisible, so, I say I am colorless in a rainbow!*

*My life story starts as far back as I can remember clearly, at the age of five. First, I'll start with my family and the way I feel more than half the time about things that deal with my family. I am the youngest of three kids. My mother's name is Jill and she is 41 years old. My father's name is Antonio and he is 38 years old. I have two older brothers, Allen, 23, and Jermaine, 21.*

*The relationship I have with my parents is getting stronger each passing day. I know they do what they do for a reason (to prepare me for life), but I'm scared to grow up and the changes that are happening to me are happening so fast. I want so much out of life - to go to the prom, get a driver's license, and go to college and become a lawyer. Sometimes I feel like I just can't do it, but my mom and dad keep me focused. Life for me has been better than this past year, but I have tried to stay far away from complaining so that I can build a good strong system of discipline. I have been feeling sort of sad thinking about my life. Sometimes I just don't fit in. All people, including black people, often say I'm not black because I have white skin. They reject me. One thing for sure is that my family will never reject me. When I need them and when the world gets overwhelming, they will always be there and I am thankful for that. That's how I feel about my family and myself.*

*I often get stares on the street from strangers. It's different in Hawaii. The people talk about me right there in earshot, and they can't even wait until I've*

*passed. I face the biggest problems of people treating me different and talking about me in school. When I moved to Hawaii the second time, (we have lived here twice), the most unexpected turn in my life happened (my parents tell me that it was worse the first time we lived here, but I can't remember). I was in the 5<sup>th</sup> grade, and the first day of school was awful. Never in my life, including all the other schools I had attended, did so many classmates talk about me like they did in Hawaii. That much I can remember. I was called so many names and it was because they didn't know me. My parents remember every incident that happened to me. They remember all the tears that I cried. I try to forget them as much as I can.*

*Now I am in the 8<sup>th</sup> grade and I'm almost a freshman. I asked my parents if we could move from Hawaii and go to New Baltimore, Michigan. I want to go to school there, or at least be there my senior year so that I can graduate from a good school like my brothers did. It is a very clean place and everyone is nice and knows everyone else. It's beautiful and to think about graduating there is wonderful. Although this year has gotten better for me, I am so ready to leave Hawaii.*

*I know I'll do fine when I get older as long as I study and work hard. The only person keeping me from my work is myself. The only reason why anyone is afraid of me is because they never take the time to get to know me. I may be different on the outside, but on the inside I am a person who wants to do the same things that every teenager wants to do. If black people with dark skin think it's hard in America, it's twice as hard for a black person with white skin because it just is."*

Mrs. Smith:

*"Taylour was born on September 10, 1990 and I kind of knew I was having a girl, even though I didn't have any tests, ultrasounds or anything to find out what I was having. When she was born, I looked at her and her hair was beak red and her face was so bright. I asked the doctor right away, does my baby have albinism? At the time I asked if my baby was an albino. I didn't know that saying 'albino' was*

*politically incorrect. The doctor said no and that she was just fine. So they only gave her to me briefly because they had a six-hour waiting time before the mother could see the baby again. All the time that they were cleaning her up, my husband Antonio was over her taking pictures. I kept telling them that I needed to see my baby again and that my baby was albino.*

*During my waiting period, I was supposed to relax, but I couldn't because I kept wondering if my baby was going to be blind, and why wouldn't anyone listen to me? Finally it was about the fifth hour and I asked the nurse to check on the baby and she said that she was all cleaned up. I said that I saw my baby and she has albinism. The nurse kept saying no, no she's fine. So, they brought her to me, and I asked to see a physician, the one that was on duty. The nurse wanted to know why? I said because I am concerned about her vision, can she see? The nurse then looked at me, she looked at Taylour, then looked at me and then looked at Antonio, and then she said, 'all black babies come out light.' I responded that they may come out light, but they don't come out with blond hair. This made me think that maybe she thought something else was going on in my marriage. So, she took Taylour back. A few minutes later, the doctor came in and said, 'I hear you have a concern.' I asked him if he had seen Taylour. He said no. I told him that my baby has albinism and I asked him if she could see? I was so frustrated by then. So, he went out of the room and when he came back he had Taylour and he said, 'Yes, I do think she's albino and I'm going to be back with you in few moments.' Then the same nurse who had been with me all day became so apologetic to me, and she said that she had never seen an albino baby before. She explained that this was the first child born with albinism at this hospital."*

During the next two years, the family educated themselves and joined the National Organization for Albinism and Hypopigmentation, which is a support organization for people with albinism. During Taylour's infant and toddler years, her parents dealt with the stares and questions from people they came in contact with about their

daughter's albinism. It wasn't until Taylour turned three that her parents began to see how she understood her albinism:

*"On Taylour's third birthday, I asked her what she wanted as a gift. She said a baby doll. I was so excited because I had been waiting for this moment. I could remember when I was little and I collected baby dolls. They were all African-American and I kept them clean and organized in my room. So, as we were walking through the aisles of dolls in the toy store, I immediately stopped in front of the black baby dolls. I began to point to this one and that one, and when I looked around, Taylour's focus was on the white baby dolls. I can remember asking her, 'Taylour don't you want to get a black baby doll?' She replied, 'I want this one, (she was pointing to a white Barbie with blond hair), it looks more like me.' I realized that she wasn't choosing the doll because it was white; race had nothing to do with it. She chose the doll because it resembled a person with albinism. At that point, I realized that my child related more with having albinism than I thought. You have to understand that although Taylour has albinism, we still focused on our culture and ethnicity at home and never thought about the white skin as a factor."*

Over the next three years, the Smith family moved both within the US and outside the country as a result of military relocations. Taylour began kindergarten in a local Hawaii public school. She attended the same school in Hawaii through second grade:

*"Taylour had become so defensive and built a wall around herself because of the hateful words that students at school have said to her. Not one day passed during kindergarten through second grade that my daughter did not come home crying or upset because of the other children teasing her. All the kids made fun of her, white and local students called her names like, albino nigger, white nigger, snowball, black ghost, banshee and powder puff, and black students told her that she is not black. If people could just look past the albinism, they would see the strong willed, sweet, pretty and courageous daughter that*

*we have raised. During her second grade year, we had a conference with the principal and teachers at the school. I have to say that the teachers and principal were very supportive and protective of Taylour, so when problems did arise, they immediately handled them. But, this particular year, we (me, my [wife?], the teachers and principal) all decided to get a professional speaker to come in and talk to the student body about albinism. We all agreed that maybe if the students were educated about albinism and could ask questions, they would be less hateful toward Taylour. Unfortunately, this plan backfired; it made it even worse for Taylour. The teasing increased. Kids can be so cruel.”*

During the next three years, the Smith family went to California for two years and spent one year in Okinawa. During her time in Okinawa, Taylour attended a Department of Defense (DOD) school. In Okinawa, Taylour had a different experience. Taylour explains in the following excerpt:

*“I liked living in Okinawa. I know that I am different because I have albinism, but for some reason the people didn’t stare as much there. In school, the kids made jokes and still called me names, but it wasn’t as bad as when I was in Hawaii the first time. In Hawaii, people pass me on the street and talk about me right there. I can hear every word and every comment. In Okinawa, if they were talking, they spoke Japanese, or they just waited until I was out of their hearing range. I guess it was good that I didn’t understand Japanese; that way I didn’t know if they were talking about me or not. School was fun. We learned about all the cultures in the world; we celebrated Black History Month, along with other cultural holidays, and I felt safe. Maybe it was because it was a DOD school (Department of Defense) and all the students were military dependents. I remember the day my parents told me that we were moving back to Hawaii. I was a little anxious. I mean it was exciting because I loved the weather, even though the sun is terrible on my skin because I burned so easily and it hurt my eyes. But, the last time I was in Hawaii, school was not a good place to be. I was not looking forward to returning to*

*school, being the brunt of the black ghost jokes, and crying everyday in my mom’s arms when I got home from school. But what could I do? We are military and we go where the U.S. Marine Corp says we go. I had no choice, so I planned to make the best of my return.”*

On July 5, 2000, the Smith family returned to Oahu, Hawaii. Taylour began the fifth grade at a local school because the enrollment on the military base school was too high.

Mr. Smith:

*“These past three years have been the hardest years of my daughter’s life. From our end and the school’s end, we have established what Taylour needs with regard to her eyesight. She has been declared legally blind, so in school she uses a special device to help her read. She likes this because it looks cool and the kids like it too. Anyway, when we arrived back in Hawaii, we immediately went in and advised the teachers and administrators about Taylour’s needs. Once again they were supportive and she received the necessary services. But, we cannot stop the mistreatment that comes from the other kids. This is where a lot of the social problems come in. From fifth to sixth grade, Taylour got into trouble at school for defending herself. She has an attitude, but the attitude is a defense mechanism. Elementary school was hard, but the past two years of middle school have been a little better. In seventh grade she did get into a fight with a boy for calling her an albino nigger. The boy was suspended for two days, and she had two days of detention. This really upset her, but she managed to get through it. She came home about two weeks ago and told us that a rumor started at school by some local kids that she was from another planet. They called her an alien freak, and told her she was different, so she had to be from another planet. This devastated Taylour for a few days, but she jumped right back on the horse and held her head high. On a positive note, she did say that she has made friends who like her, take up for her and accept her. This summer (2003), Taylour made more friends on the military base and these relationships carried over to school. She’s not crying all the time anymore. I know that*

*she is growing up and the kids have been around her now for almost three years, so they are getting used to her, but most important she is being accepted for who she is and that makes us all happy.”*

This go-around in Hawaii, Taylour has developed some good peer relationships. Taylour has one “true” friend, as she puts it. She is an African-American and she lives on base. She and Taylour see each other in and out of school. Her other friends are also African-American military students who she rides the bus with and/or has classes with at school. Taylour says that she gets along very well with some of the African-American males from base too, most of them are in the 7<sup>th</sup> grade and younger than her. She says that they laugh and joke about everything, and they even take up for her when some of the local boys make fun of her. She has two other friends who are Mexican females. They live on base too. She goes to their house after school and on the weekends and sometimes they go to the movies together. Outside of base kids, Taylour does not have any peer relationships with the local students at school. She speaks to them in class, they talk in the hallways, however she does not consider any of them close acquaintances. As Taylour transitions into the 8<sup>th</sup> grade, her current friendships grow stronger and Taylour’s acceptance and self-esteem levels begin to increase. The remaining narrative is from August 2003 – April 2004, Taylour’s 8<sup>th</sup> grade year at a local intermediate school in Hawaii.

August and September 2003:

*“The year has been going well. It’s so good to be back in school and see my friends. A lot of them moved during the summer. I hate when my friends move away because that means I have to wait for new friends to get used to me. This is the worst part of being in the military! My teachers are okay, so far. I’ve been in school three weeks and I am already the victim of a rumor. It never fails. Someone starts saying I’m a “black ghost” or “banshee” because I look different. Yesterday (September 10, and my birthday) at school, my friend got into a fight with a local*

*boy on the basketball court because he was making fun of me. He called me a freak and an albino nigger. When he was down, I ran over and kicked him in the stomach! It felt so good. I got in trouble and had to have a parent/teacher conference, but it was great to have someone else take up for me and it was great to kick him. He did apologize later. The kick had to hurt because I just earned my green belt in Karate. My sensei would really be upset with me if he knew I did it, but hey self-defense is self-defense – words hurt just as bad as punches sometimes. Anyway, we both got in trouble. First nothing happened, then, I went home and told my parents. They were upset about the incident and not too mad at me. They went to the school and had a conference with the principal. She gave the local boy, my friend, and me detention. Although the other boy started it, my friend and I got in trouble for hitting and kicking him.*

*After this incident, everything seemed to cool down at school. If rumors were still spreading, I wasn’t hearing them. People think I’m mean because I defend myself and speak my mind, but I can’t change who I am.”*

October, November, December 2003:

*“In October, my mom came to school to teach embroidery to my Home Economics class. All of my classmates said that she was so beautiful. Some of them asked me if I was adopted because I looked nothing like her. I pretty much said, ‘duh I have albinism!’ Other students said that she was a beautiful black woman. When I told my mom this, she laughed. That night we sat down in front of the mirror and looked at the things we had in common. The only difference we both saw was the color of our skin. My mom is such a great mom, hard at times, but great!*

*November was a sad month because my mom was gone most of the month to conferences and reserve duty leave. I am glad my dad is home now and he doesn’t have to deploy this time around, but my mom leaves a lot. I want to tell you what it feels like when your parents go away. It is really hard. Sometimes I can’t concentrate on my homework and when I come*

home from school and she's not here, I get sad sometimes. My dad is so cool though. Usually it's my mom who is at home with me, so now my dad is here. At school when I don't have my homework, the teachers get mad and call home. They just don't understand that I miss my mom. I know I have to keep on track, but I'm just saying, it's hard!

December is coming and that means Christmas break and my brothers are coming to visit. I cleaned for two weeks straight and cooked for a week straight to get ready for their arrival. I was so excited about seeing my brothers, but when they were here, one blew me off and the other was never at home. On January 3, 2004, I broke down in tears because Jermaine was ignoring me and Allen made so many plans outside the house, I hardly saw him. I guess I'm too young to hang out with them, and it hurts really bad!"

January and February 2004:

"January 10 had to be the coolest day of my life. Today Mrs. Hairston took Symone and me to Valerie's house. We got to eat and talk about life as African-American females in Hawaii. I feel that today was a good day. I am happy that I am participating in Mrs. Hairston's study; it gives me a chance to tell my story about how I feel. Sometimes I feel that people don't really care about my feelings. Anyway, today was great. Mrs. Hairston picked me and Symone up, and we drove to the other side of the island to meet Valerie. Symone and I are pretty good friends; she really speaks her mind. Valerie was so cool and she cracked me up. As I listened to them talk, all I could do was nod my head, especially when we were talking about how the local kids wear the same clothes as us, walk and talk like us, but they are still racist. It does seem like me and Symone see racist acts at least once a week at school while Valerie doesn't. Regardless, I know that what we all said today was true and I don't think, no, I know I'm special and that I'm wonderful. I don't need anyone to tell me that much – I wish we could have had a sleep over!

February has been the worst two months of my life. At home, I'm in trouble for everything - at

school, I just wish that people would leave me alone and give me my space. Sometimes I just want to go up to them and scream in their faces, 'Leave me alone, just let me breath[e]!' If I do or say one thing wrong to anyone, there will be fireworks; I'm just trying to stay to myself!

At school, sometimes it would be nice to learn about other cultures. When we talk about history, it is usually Hawaii, but I love my history class and the teacher is my favorite teacher. She is cool and she lets me bring in African-American information and artifacts. For Black History Month, I brought in information on famous African-Americans, but whenever I bring in anything at anytime, she lets me share it. The other students are really interested in the things I bring in. At the beginning of February to acknowledge my history, I brought in an African-American Trivial Pursuit board game. No one knew the answers, not even the black kids, so we all ended up reading the cards instead. It was cool because we were learning about so many African-American contributions to American history. Finally we were talking about my culture. I need these connections in my life; cultural heritage is important to my family, and me and it is great to share with other people."

March 2004:

"This month (March) I have been doing some soul searching. I need a spiritual connection, so Lent is coming and I am giving up meat and chocolate-OUCH! I have been going to church on base. I am really enjoying church. It is a time for me to sit, listen and reflect on who I am and what I really want out of life. My parents have always taught me to treat people with respect. When we were on the mainland we used to go to church a lot, but now with the family business it is hard for my parents to go every Sunday. I think I'm going to keep going. At church I feel safe and connected to God."

April 2004:

"A lot of people say that I am mean. I guess I come off that way sometimes because I speak my mind. My parents have always taught me to speak my mind, so I do, but when I overdo it, I get in trouble. My

*mom keeps telling me to choose my battles wisely, but sometimes it's hard. I am trying to control my actions. I've been going to church and I really want to be baptized. I memorized the Lord's Prayer and I feel pretty good about myself.*

*When I am in church or with people from church I feel safe. During this time, I don't have to defend myself or worry about people calling me names. This is one reason why I love going to church. When I learned the Lord's Prayer, it reminded me that God is with me at all times and no matter how evil people can be, he will protect me. My favorite part of the prayer is – 'and lead us not into temptation but deliver us from evil, for thine is the kingdom and the power and the glory forever.' That is real. No meanness, no hurtfulness, just peace for me to be who I am – Taylour!"*

From a local and teacher perspective, Taylour's "favorite teacher," offers her perspectives about African-American military children, the local culture and Taylour's experiences in school.

A Teacher's Perspective:

*"I am a local. I was born in Hawaii, attended the public school system here, graduated from a local college, and now I am a teacher of nine-years in the Hawaii school system. When I was growing up I rarely came in contact with any African-Americans or military people. If I did, I don't remember anything about them. In school everyone was local, so all of my friends were local. If I were to define racism, it would be a little different from the mindset of those that come from the mainland. Racism is putting someone down based on their race, but in Hawaii often it is taken lightly through joking and laughing at stereotypes. I don't think it's right, especially now as a teacher and I see how it affects the students. However, in school, I stay to myself, so I have not really witnessed any issues of racism firsthand; I only get the rumors and tales from my students.*

*As Taylor's teacher I see her as a child who handles herself very well. She is very respectful and I know that this has been instilled in her through her parents. They are both very involved and good people.*

*Socially, Taylour has a lot of friends, but when there is a problem she doesn't back down. She speaks her mind and stands up for what she believes in and she doesn't hide her ethnicity. I mean she wears her hair in braids, she is always bringing in information to share about different African-Americans and she is very proud of who she is. In my class, the albinism is not an issue, but I know that she has had some incidents in school where kids called her names and were very cruel to her. She doesn't really talk about it with me.*

*One thing that I don't understand is the military transitions. Why do they move these poor families at a moment's notice? I mean the kids are coming in the middle of the year, during a quarter term, at the end of a quarter term and some even come with a week or two left in school at the end of the year. As a teacher it is very hard to catch these students up or even get them prepared to test. To me it just seems like the military should take this into consideration when they move the families. Why not shoot for the beginning of a school year or in January after Christmas break?*

*I think the students handle the transition better than I do, I guess because they are used to it. At least most of them handle coming into a new school. They usually have one or two other students who are just arriving. The parents are pretty involved. I have noticed that the military students and especially the African-American kids have a hard time with it. They seem to have more social problems. It is hard for African-American military children because they are only here for a short time and really don't get a chance to learn and experience the different cultures and us locals really don't know that much about their culture either. I think they come with a lot of negative preconceptions of Hawaii and this often hurts them socially because it is almost like they are looking for something to happen. They bring their mainland ideas about racism. Every thing isn't always about race, but sometimes I think they may feel that it is.*

*Overall, I think Taylour is happy. I don't think she wants to live in Hawaii forever, but she seems to be*

*dealing with it pretty well. If I had known her before she came and could have given her some advice, I probably would have told her several things. First, stand back and observe and don't take everything so personal. Second, try not to be so outspoken because a lot of locals are not used to it, and third be proud of who you are regardless of the stereotyping. The stereotyping is often in fun; it does hurt, but try to remember that most of the people who are using the stereotypes don't know the history behind them."*

Taylor's Final Reflections:

*"In Hawaii, it is really hard to be African-American and a military dependent. The local and Hawaiian kids don't like us (military kids) because they blame us for taking their land. I know what racism is; because the kids here judge me before they even know me. I used to think that it was just because of the albinism, but I know it's because I'm African-American and military too. I have some really cool friends this year; they are all black and I think it's because we have more in common and we band together whenever there is a racial incident at school. I have been called so many names in my life. The one's that hurt the most, and the ones that I remember the most are white nigger, albino nigger and black ghost. The local and white kids that called me these names realized that I'm African-American and that I don't just have albinism. What they don't realize is that I have been declared legally blind. Do they even care? I have to wear contact lenses and use eyeglasses and special magnifying scope, and when I read a book it takes a long time. This summer I read the Harry Potter books, and it took a long time because my eyes hurt if I try to read too much at one time. But, I don't think that I have a disability because I can see and I know that having albinism doesn't make me disabled, I'm just different.*

*I am your typical teenager; I have my ups and downs. The end of the school year is coming so quick and a lot of my friends are leaving. It's so sad! My parents told me that we would be leaving soon too, possibly this summer. I am excited about moving because that means I can go to a good school on the mainland. When I say a good school I mean, no dirt*

*flying all over the place, air conditioner, classes about black people and our history, and a school building that you don't have to walk outside of to get to your next class. We are going to buy a house too! I can't wait. I hate living on base; the house is too small and I miss living in a big, unattached house.*

*Doing this study with Mrs. Hairston has taught me some things that I never really thought about before. I do realize that you have to be willing to forgive other people especially when they don't have a clue about who you really are. I'm getting baptized in three weeks (May 1, 2004) and as a Christian, I have to be able to forgive and change my ways too. My mom and dad are very happy and very proud of me because I made this decision on my own. I also realized that I know that I have the ability to do whatever I want and I will do whatever I want until I die. I am an African-American, and being an African-American and living in Hawaii means having to adjust to the culture and the way they do things here, but also remember my own culture. I am African-American, it's my specific culture, I don't care what others feel, I'm African-American, military dependent, female, person with albinism, and I will soon be a Christian. Although 60 percent of the time it is tough, I'm happy with who I am."*

## Theoretical Analysis

Since the early eighteenth century showmen have exhibited African-Americans with albinism and vitiligo in circus sideshows, taverns, and dime museums. The mystery of the African-American with skin as white as snow challenges the color line and clearly implies that an African-American can be white. Martin (1962) explains, "The term 'white Negro' has served to describe an individual born with albinism as well as those who have vitiligo, a disorder that robs the skin of its pigment in ever-growing patches." Today in America people are judged by their race and ability. An African-American who has albinism faces many challenges and issues with regard to self-identity and cultural assimilation. The experiences of a person with albinism in Hawaii are unique and



complex, especially for Taylour who is an African-American military student attending a local public school. The experiences she faced in her life, though similar to other African-American females in Hawaii public schools, are different because she is an African-American in a white body and she has a visual impairment.

Race and disability theories offer evidence for factors in which society judges and defines people based on these attributes. Along with other contemporary theorists, it has been concluded that what constitutes a disability, as what constitutes a racial category, is socially constructed (Asch, 2002). Asch goes on to explain that, critical race and feminist theories contend that the viewpoint of the discriminated-against, oppressed individual or group must be better understood by the larger society. Race and gender discrimination have become a normal part of societal views, and in order to reprimand society, the law should look not to the wrongs of perpetrators but to helping those who have been victims of discrimination. In addition, disability theorist Harlan Hahn (1988) characterizes, "Disability as eliciting existential and aesthetic anxiety in others. Notable in the history of governmental discrimination and segregation documented in the Garret Case is that people with only certain conditions received some of the most isolating and demeaning treatment."

### **Societal Definitions of Race and Ability**

#### *Who Defines Race*

During the first five hours of Taylour's life, issues of race and ability began to shape her identity. From the nurse who stereotyped all black babies as coming out light to her mother's concern about if her daughter was blind. The questions raised here are how does race define Taylour if she is with white skin in an African-American body and how has albinism become the disability, when in fact the impairment is her eyesight?

The first sign of society defining Taylour came through racial epithets and stereotypes. Parts of the names that students called Taylour referred

to the color of her skin (white, albino, powder), other parts of the names referred to her race (nigger, black). Stereotypes and name-calling are defining Taylour's race. Racial slurs and stereotyping others are amongst the two most common forms of racism. Stereotypes come in many forms, from verbal implications about ones culture and character, to negative depictions of them in literature and pictures. Racial slurs are direct words aimed to wound and humiliate a person based on their ethnicity.

Critical Race Theory scholars focus directly on the psychological harm of racial issues toward children of color. One of the most painful racial slurs for African-Americans is the word "nigger." Delgado (1982) explains that race-based stigmatization is one of the most fruitful causes of human misery and that poverty can be eliminated, but a person's race cannot. He goes on to say that stereotyping and racial slurs can injure a person's dignity and self-regard because the listener who "internalizes" the message can suffer both mental and emotional distress, and often due to retaliation, physical harm to their target. In addition, he states that, "Subtle racial stereotypes transmitted through films, television, videotapes, and other popular media can leave deep emotional and psychological scars on children of the targeted ethnic group, and on others as well" (129). Both writers agree that racial slurs and stereotypes may cause long-term emotional pain. In addition to pain, Delgado expresses that children come to question their competence, intelligence and worth. Waugh (1999) adds that teasing and name-calling a child with albinism is very dehumanizing and, "Almost all children will encounter this during the school years, and they need to develop positive coping strategies." She goes on to say that parents and the school should increase education about albinism to help with the problem.

Although Taylour was called an albino and white nigger, the African-American stereotype of the word attached itself to her identity. The students looked passed her white skin, and found her ethnicity. In addition, during the second grade

when her parents brought in a person to discuss and educate the students about albinism, it actually made Taylour's situation worse. Stereotypes overpowered education with regard to albinism in this particular case.

### *Who Defines Disability?*

Racial epithets were not the only derogatory actions Taylor faced; she was also told that she was from another planet and singled out as being a freak. This implies that she is not normal. Waugh (1999) explains:

“Albinism carries with it myths in cultures throughout the world. These run the spectrum from the notion that those with albinism have magical powers to the belief that they are retarded... The media including literature and film, have contributed to stereotypes of albinism. The character with albinism is often portrayed as villainous, deviant, supernatural or sadistic. Also some news reports and encyclopedia articles have included false or incomplete information about albinism. It is difficult for the public to know what is true and untrue about albinism” (2).

During the 1800s African-Americans with albinism were considered as disabled freaks. Martin (1962) explains that, “It is important to note that at this point in time the bodies of African-American men and women... qualified as disabled under this rubric (the disabled body is not self-reliant) since they were deemed incompetent to perform the rites of citizenship” (3). The Americans with Disabilities Act (ADA) defines a disability as an impairment that limits one or more of the major life activities of an individual. However, disability theories, which consist of many definitions and paradigms, do have one commonality. Pfeiffer (2001) explains, “Many people with disabilities live lives not acting as if

they are disabled. It is only when they encounter acts of discrimination based upon artificial barriers that they feel disabled... They are not being treated fairly and not being treated as other, non-disabled people” (41). Neither the general public nor those with albinism agree about whether to identify albinism as a disability. This ambiguity creates a problem in the language used to talk about albinism. The disability is the eyesight impairment, not the lack of pigmentation in the skin, however the appearance of a person with albinism draws more attention and less attention is focused on the concept of legal blindness. Martin (1962) concludes:

“Current critical discussion of the extraordinary body identifies vitiligo and albinism as a disability... these skin conditions cause little or no physical debilitation, yet the stigma assessed to them is the same as those that more greatly hinder negotiation with the world. Our language acknowledges this. We call albinism a disease, a disorder, we consider a person to ‘suffer’ from vitiligo” (187).

Disability theorist, Thomson (1996), in her book, *Extraordinary Bodies: Figuring Disability in American Culture and Literature*, discusses a critical rubric that defines “normalcy” in American society. Thomson explains, “Disability is not bodily insufficiency, but instead arises from the interaction of physical differences with an environment... Disability is unorthodox made flesh” (187). In Taylour's experience, society decided that albinism was the disability, and relied on stereotypes and myths to justify their actions toward her.

### **Self Identity: Taylour Defines Who She Is**

For over thirteen years of Taylour's life, her identification with being African-American and with having albinism has intersected. When Taylour was three she chose a white Barbie Doll

because it had similar features to her, however, now at the age of 13, the majority of her friends are African-American military dependents. She says. *“We have more in common and band together whenever there is a racial incident at school.”*

Throughout her adolescent years, some African-American students have rejected Taylour stating that because she did not have black skin, she was not a black person. Taylour explained that in 7<sup>th</sup> grade a group of African-American girls refused to talk to her because they had decided that Taylour was trying to “act black,” by wearing her hair in braids, listening to hip-hop music and having other African-American friends. She could not convince this group of girls that she was black because her skin color was white. She asked the girls, *“If I’m not black, then do you think I’m white?”* One of the girls replied, *“We don’t know what you are, you’re just different.”* Another time a group of local kids were teasing Taylour and calling her black ghost. They told her she wasn’t white or black. Taylour said these two incidents were the most hurtful times in her life. She explained that she did not feel like a person. For a brief moment, Taylour questioned who she was and if she fit in anywhere.

Unfortunately, the lack of education about albinism led to discrimination and placed her into the category of disability based on societal perceptions, myths and stereotypes. Neither the general public nor those with albinism agree about whether to identify albinism as a disability. This ambiguity creates a problem in the language used to talk about albinism. In Taylour’s case, race (African-American) and disability (albinism) intersected in ways that dehumanized her, and constructed her as a racial and social outcast.

### Final Thoughts

The mystery of the African-American with skin as white as snow challenges the color line and clearly implies that an African-American can be white, if affected by albinism. Critical race theory, feminist, and disability theories discuss

the ways in which society objectifies people based on their race, gender and ability. For Taylour, this occurred primarily through being the recipient of racial epithets and stereotypes. The names she was called referred to the color of her skin (white, albino, powder), and to her race (nigger, black). In addition to the racial epithets, Taylour was also told that she was “from another planet,” and called a ghost, a banshee, and a freak, implying that she was other than normal or human. Peter Putman (1963) wrote:

“Blindness is a confining handicap, but it would not confine the boy to the life in the Negro ghettos that are the shame of our cities, North and South. If he had a Seeing Eye dog, he would be excluded for his dog, not for his skin. In blindness, he would know moments of humiliating helplessness, but not so bitter as the practice of Jim Crow, the loss of civil rights, or the experience of police brutality Baldwin describes, not in the South, but in New York City. Yet, blindness is a genuine handicap. Blackness is not. The blind man has lost an important sense. The Negro has all his faculties. The handicap of blindness is intrinsic. The handicap of blackness comes from the outside, imposed by force of the threat of force. The handicap of the American Negro has been the American white.”

In other words, race and ability are two components used by society to judge and dehumanize individuals, but strong individual will and determination can only determine how they will be defined and how they will maintain control over their lives and personal choices. Being blind and Black in America opens doors for discrimination, racial conflicts, stereotypes and racial epithets.

This case study and the many issues it raises can be addressed and resolved through disability awareness and multicultural education. Such awareness is essential for children, teachers, parents, and administrators in America's schools. I conclude with a poem I wrote the day I met Taylour. These words are my first impressions of Taylour and my personal perceptions of who defines me.

*Who defines me?*

*My race, my gender, my ability, my ethnicity?*

*African, Negro, Colored, Black, Afro-American, African-American, Nanny, Gal, Female, Woman.*

*Who determines who I am?*

*The state I live in, demographics, economics, the government, the law, the census bureau, the man, my boss, my teachers, my colleagues, my family, my friends?*

*Who labels me?*

*Liberal, radical, extremist, loud, out-spoken, aggressive, strong-willed, determined, proud, ready to fight for what's right, ready to lead a revolution, scared, scorned, angry.*

*I am defined by the color of my skin, the texture of my hair, the tone in my voice. I am defined by my femininity and grace, my sexual preference and the way I walk into a room or invade someone's space.*

*I am defined by my history and past. Stereotypes that were created based on hate and ignorance but linger and linger and linger - day after day - as the years pass.*

*I am defined by my financial status, the job I hold, my education and where I live, what type of car I drive, how I eat, who my husband is, his rank in the military, where my children go to school, the degrees I hold and my grade point average.*

*Who defines me?*

*What do you see?*

*If you didn't know who I was, how would you define me?*

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## **Evaluation of Master of Arts Program in Rehabilitation Counseling and Guidance Service for Persons with Disabilities in Thailand**

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**Abstract:** This research examines the positive and negative aspects of the Master's Degree in Rehabilitation Counseling and Guidance for persons with disabilities in Thailand, since it began in 1997. A CIPP model was utilized for the program evaluation. Multiple methods were used to collect the data, and both retrospective and prospective data collection were undertaken. The research results indicated many positive outcomes. They also indicated certain features of rehabilitation within the Thai context differed

significantly from traditional rehabilitation counseling programs in Western countries.

**Key Words:** counseling, disability, Thailand

Ratchasuda College of Higher Education and Research Center for People with Disabilities at Mahidol University in Thailand was founded in 1993, by Her Royal Highness (HRH) Princess Mahachakri Sirindhorn, daughter of His Majesty (HM) the King of Thailand. HRH has held a lifelong interest in, and has a deep concern for, people with disabilities. It is the Princess's conviction that given proper training and opportunities, disabled people will lead lives which are productive and rewarding, both personally, and to society as a whole. Because of the Princess's commitment, HRH has graciously consented to patronage of the Ratchasuda Foundation, which was established to assist in the building and the operation of Ratchasuda College. Several programs have been provided to promote and enhance the quality of life of persons with disabilities. Since 1997, the Master of Arts Program in Rehabilitation Counseling and Guidance Service for Persons with Disabilities has existed for both persons with and without disabilities who want to be rehabilitation counselors. However, this program has never been evaluated to determine its strengths and weaknesses. There have only been evaluations of specific aspects of the program, such as the role and functions of the rehabilitation counselor and employment outcomes for graduates (Scorzelli, 1999). Some research methods used to conduct these studies may not have been sufficiently rigorous. For instance, one evaluation was based on self reports of participants at a workshop at Ratchasuda College, but most samples were from personnel not directly involved in the program. Further systemic program evaluation is therefore needed. This research utilizes a CIPP (Context, Input, Process and Product, explained more fully below) model (Stufflebeam, 1973) to conduct such analysis.

The CIPP model provides a comprehensive framework for guiding evaluations of programs,

projects, personnel, products, institutions and systems, and it has been a popular tool for evaluation of many programs including education, art, business, nursing, medical, engineering and other particular vocational areas in Thailand and other countries (Waraporn, 1999; Wasorn, 1998; Nipawan, 1997; Nuananong, 1995; Tumnu, 1994; Somwang, 1979; Evans, 1969). Part of the rationale for conducting evaluations of this type is to provide important information about the organisation's needs, so it can improve services and personnel decisions to more effectively serve clients (Stufflebeam, 1997). It is the evaluator's job to provide information to management, to help them in making decisions about programs, products, etc. (Stufflebeam, 2002; Payne, 1994).

This paper applies the CIPP model to the Master of Arts Program in Rehabilitation Counseling and Guidance Service for Persons with Disabilities to determine the strengths and weaknesses of the program, to provide a comprehensive plan for further curriculum development, and to assure educational quality.

## Methods

### Research Design

The research project involved program evaluation using the CIPP model of Daniel L. Stufflebeam (1973, 1997, 2002). Stufflebeam suggests that CIPP involves evaluation of four elements: context, input, process and product. Context evaluation involves assessing the needs, assets and problems within a defined environment and also determining whether the proposed objectives are sufficiently responsive to the identified needs. For this study, context evaluation involved examining the program's philosophy, objectives, course descriptions and study plan, as well as legislative frameworks, such as the Rehabilitation for Disabled Persons Act 1991 and the National Educational Act 1999. The program was also understood in the context of the Thai disability movement. A comparison with other rehabilitation counseling programs in Western

countries, particularly in the United States, was also undertaken. Input evaluation involves assessing the competing strategies, work plans and budgets of the program and also involves drafting a prospective cost-benefit analysis. In short, this type of evaluation examines what the program planners want to do. Six major program inputs and resources were identified and assessed: 1) student profiles, such as admission, selection and academic qualifications of students; 2) teacher profiles, such as recruitment, numbers, qualifications, and developmental plans of teachers or lecturers; 3) educational media and technology resources, such as textbooks, journals, computers and assistive devices for students with disabilities; 4) budgets and financial management; 5) the place/physical environment; and 6) support personnel. Process evaluation monitors documents and assesses program activities. It examines how a program is being implemented, monitors how the program is performed, audits the program to make sure it follows existing guidelines and identifies defects in the procedural design or in the implementation of the program. In this case, three major areas were assessed: study and teaching processes (i.e., study contents, teaching styles, measurement and evaluation); program administration, and extra-curricular activities. Product evaluation means determining and examining the general and specific outcomes of the program, measuring anticipated outcomes, attempting to identify unanticipated outcomes, and assessing the merit and cost/benefit as summative evaluation decisions. Thus various characteristics of students who have graduated were also assessed (including grade point average, knowledge, attitudes and skills, length of study, work trends, and so on).

### Participants

Among the 73 participants selected by purposive sampling were 30 students of all 3 groups who started to enroll in the Master of Arts Program in Rehabilitation Counseling and Guidance Service for Persons with Disabilities in 1997, 1998 and 2000 (the program did not pro-

vide for students in the year 1999 due to program preparation and development) respectively, and 43 teachers/lecturers who taught those students. Furthermore, a wide range of documents related to the program were also collected and analyzed, including curriculum meeting records, student backgrounds, and student admission exams.

### **Instrumentation and Data Collection Methods**

Evaluation research, by its very nature, involves many stakeholders and uses a wide variety of methods. This study used four data collection methods. First, four questionnaires were developed. Second, participatory observation by the researcher as one of the college's lecturers and program committee members has been undertaken. Third, videotaping was used for monitoring the teaching and learning styles of teachers and students, after informed consent had been obtained. Fortunately, most teachers and students showed their willingness to be monitored. Fourth, supplementary documents were also collected, concerning such matters as admission examination scores of students, program meeting records, and statistics of library users.

Questionnaires developed were the program evaluation questionnaire for students, the program evaluation questionnaire for teachers, the student evaluation questionnaire for teachers, and the work trend open-ended questionnaire. The program evaluation questionnaire for students consisted of 41 items. It covered six aspects of the program's administration: characters of teachers; the learning process; program objectives/contents/subjects; educational media/study facilities; place and environment, and communication and relationships. The program evaluation questionnaire for teachers consisted of 60 items regarding seven aspects of the program administration. The first six elements of this questionnaire were similar to the program evaluation questionnaires for students, and the last one particularly revealed expectations about the competencies of graduated students. The student evaluation questionnaire for teachers consisted of 25 items regarding the competencies of students as rehabilitation coun-

selors in terms of affective, cognitive and psychomotor domains. Those questionnaires involved self-reporting and utilized a 5 point Likert-scale (ranging from poor, fairly poor, moderate, fairly good, to good, respectively), with a reliability of .80, .76, and .75 respectively. The open-ended questionnaire for students regarding work trends consisted of 7 items which explored the employment of students after graduation.

### **Procedures**

This research was undertaken over an 18-month period – using both retrospective and prospective data collection methods. The first two questionnaires were given to all students and teachers after the final examination of each subject. The third questionnaire was simultaneously used by teachers or supervisors to assess students during the practicum course in the first semester of the second year. The last questionnaire was given to 18 students who finished all course work and attended a student meeting at Ratchasuda college.

The third group of students, who enrolled in the program in 2000, were videotaped in both study and teaching situations. This videotaping occurred after the researcher distributed letters to teachers and students asking for their consent and they agreed to participate in the research. Even though all teachers and students agreed to such records, if they felt uncomfortable or threatened during any session (such as in the context of counseling or examinations) the videotaping was stopped immediately.

Participatory observation and document collection and analysis were undertaken both retrospectively and prospectively for 4 years, starting when the program was established in 1997 through 2000.

The data was then analyzed using the SPSS (Statistical Package for the Social Sciences) for Windows program. A number of statistical operations were performed on the data (including fre-

quency distributions, percentages, means, standard deviations, and two tailed t-tests).

## Results

With regard to context evaluation, it is important to acknowledge the program was established by considering the needs of persons with disabilities, the legislative framework such as the Rehabilitation of Disabled Persons Act 1991 and the National Education Act 1999, and by examining the nature of rehabilitation counseling programs in the United States. The National Education Act 1999 was important in terms of promoting awareness of professional ethics and skills, ensuring compatibility with social and institutional needs, and addressing the necessity of individual educational plans. The Rehabilitation of Disabled Persons Act 1991 has also influenced program establishment. The needs survey of 2,968 respondents who work with disabled persons in both public and private sectors in Thailand showed that 39.6%, 30.4%, and 30.0% of respondents needed to enroll in the program as part of a major of rehabilitation counseling, access technology and rehabilitation administration respectively. As a result, four seminars were held to collect suggestions and feedback from disabled persons and personnel involved in rehabilitation services within both public and private agencies. The comparisons with rehabilitation counseling programs in the United States suggested that the study courses and credits were similar to many other programs (Table 1). This could be seen as confirming this program addressed both the needs of clients and Thai society, within the context of globalization. In contrast, some of the negative aspects of the program included the fact that there was no clear written philosophy of the program. Such a philosophy is probably implied in some statements of program rationale such as “enhancing quality of life and social integration of persons with disabilities” and to “produce professionals to work with persons with disabilities.” The program also excluded sufficient participa-

tion and feedback of disabled persons and their families at community or grassroots levels.

Regarding the input evaluation, there was also systematic examination of students in terms of general knowledge of current important events, English proficiency, and particular knowledge of disabilities and basic rehabilitation issues. Student admission exams were also continually analyzed in terms of their difficulty index (P) and in terms of a discrimination index (r). Of those exams, 36%, 22%, and 42% were determined as good, fair, and poor respectively. Applicants who performed well on a written examination would be interviewed by a committee responsible for selecting those applicants who had both appropriate academic performance and attitudes towards disabled persons and rehabilitation services. In addition, due to a variety of academic backgrounds of applicants, intensive tutoring courses for students were provided before actual study to provide knowledge in three basic areas - psychology, computer sciences and medical sciences. Such tutoring courses helped students to be significantly more knowledgeable. There was also new educational and audiovisual equipment, as well as additional money for program development. Unfortunately, the number of applicants was not increasing each year, and as a result, opportunities for student recruitment were limited. For example, in 1997, 1998, and 2000, there were 24, 14, and 17 applicants who turned into 10, 11, and 12 students respectively. The background knowledge and work experiences of students varied and influenced the workload for student tutoring (Table 2). In addition, the score weight of written examinations by students in each year was different, suggesting that the written examination may have been inconsistent in some ways. As well, textbooks and journals were restrictively available. Also, qualified thesis advisors who had obtained a doctoral degree or higher in rehabilitation services were not available.

The results of process evaluation suggested that teachers were concerned about their roles as facilitators. They allowed students to do research



**Table 1**

**Comparison of Study Courses and Credits of Master's Degree of Rehabilitation Counseling Program in Selected Universities in the United States and Thailand**

**Study Courses and Credits**

University	Counseling	Rehabilitation	Practicum	Thesis	Others
1. State University of New York at Buffalo	15	9	15	2	7
2. University of North Florida	12	15	15	-	15
3. The University of Texas Western Medical Center at Dallas	21	8	15	7	9
4. Northeastern University	12	15	9	-	12
5. Georgia State University	16	15	8	-	9
6. Arkansas State University	9	18	12	-	9
7. Mahidol University					
Pattern A (thesis)	12	6	3	12	9
Pattern B (non thesis)	12	6	3	-	17

*Note: Others = other courses such as research methodology, statistics, addiction, individual study, multicultural issues, elective subject.*

related to the student's interests. Most teaching hours corresponded to the policy of University Affairs and involved a set course/credit hour. The program administration was conducted by the particular program committee consisting of at least five lecturers from the college and two external lecturers. Since such committees had a monthly meeting, the meeting record was beneficial in terms of illustrating the processes of the program. This program was also monitored by the Quality Assurance Committee of Ratchasuda College. In terms of the negative aspects of process evaluation, the content of each subject varied due to the interests of lecturers who taught subjects which probably differed from original course description. Also, practice or internship hours were provided for students only for 3 credits or

90 hours (Table 1). The teaching style mainly utilized straight lectures, and approximately half the teaching was conducted by teachers/guest lecturers from outside Ratchasuda College. The experience, or academic background, of teachers sometimes was not consistent with the areas in which they taught. In addition, the research productivity of teachers was low (0.28 article/person/year). In terms of student theses, the majority of them were descriptive or employed survey studies. Difficulties writing theses in English and the lack of qualified advisors were the main problems leading to delayed graduation of the students.

Based on product evaluation, students showed good academic achievement. The first and second group of students obtained a grade point average

(GPA) of 3.59 and 3.50 respectively. (The third group could not be obtained due to limited time of research). They also showed good achievements in terms of affective and psychomotor domains. In addition, 57.9 % of questionnaire respondents stated that they effectively applied the knowledge gained in their degrees to their rehabilitation services. However, in terms of negative aspects, stu-

dents were assessed by their teachers or supervisors as having a moderate level cognitive domain. Forty-two percent of those who completed their coursework studies did not obtain jobs or were not working in the field of counseling or rehabilitation services.

Additionally, the majority of students and teachers gave a good rating to the context, input and process aspects of the program, but they suggested textbooks, journals, and rehabilitation and counseling resources should be more available.

**Table 2**

**Students Characteristics, Frequencies and Percentages**

	<b>Number of Students</b>	<b>Percent Total Students</b>
<b>Admission Year</b>		
1997	10	30.3
1998	11	33.3
2000	12	36.4
<b>Gender</b>		
Male	4	12.1
Female	29	87.9
<b>Disability</b>		
Yes	4	12.1
No	29	87.9
<b>Age</b>		
21-30 years	24	72.7
31-44 years	9	27.3
<b>Bachelor Degree</b>		
Nursing	7	21.2
Physical therapy	6	18.2
Special Education	5	15.2
English Education	4	12.1
Psychology	2	6.1
Mass Media communication	2	6.1
Administration	2	6.1
Politics	2	6.1
Physical Education	1	3.0
Social Work	1	3.0
Nutrition	1	3.0
<b>Experience In Rehabilitation Service</b>		
Directly service	16	48.5
Partially service	9	27.3
None	8	24.2

## **Discussion**

This research project examined the Master of Arts Program in Rehabilitation Counseling and Guidance Service for Persons with Disabilities at Ratchasuda College in Thailand in terms of its strengths and weaknesses, as a part of establishing a comprehensive plan for further curriculum development. The curriculum development for the program at Ratchasuda College is time consuming and ongoing. However, this need for program development should be understood in context - in the United States, rehabilitation counseling has been developing for approximately 40 years and it still faces a number of challenges (Leahy and Szymanski, 1995). Therefore, the Thai program seems to be in quite a strong and fortunate position, as it is already quite well integrated into Thai society.

In general, data collection methods for this evaluation involved a process of self-reporting

and questionnaires (Wasorn, 1998; Nuananong, 1995; Tumnu, 1994; Pornprasert, 1990; Auchala, 1987; Somwang, 1979; Evans, 1969). This research methodology involves an effort to obtain data from many kinds of stakeholders and the particular methods used in this program were consistent with those recommended by Brooker and Macdonald (1999) for obtaining representative data. Videotaping of classes and teaching situations, participant observation, questionnaires, and the use of retrospective and prospective data collection methods were used. There were, however, some reservations which should be mentioned about this data. The program was so new, there were no students who had graduated, so there was no feedback from graduated students or their employers. As such, product evaluation could not be clearly assessed.

This research has led to five critical recommendations. First, every opportunity for maximizing enrollments in the program should be taken. Active public relations strategies should be developed to promote society's concern about disability issues, and stimulate interest in this program. As Young and Shaw (1997) indicate, perceptions about the value of the course were the most important predictors for student enrollments. Second, student selection should be improved. Even though there were two systematic examinations - a written examination and an interview, these two examinations were considered separately by different committees. Furthermore, the correlation between those examinations and other components of program evaluation may not be immediately apparent. In response to this dilemma, program officials must make sure that each admission requirement is educationally defensible and that the applicant's capacities are not evaluated based on any single piece of information. It is also necessary to identify any informational, ethical and attitudinal barriers among applicants which might affect their understanding of disability issues and rehabilitation services (Pullin and Heaney, 1997; Bento, 1996). Attitudinal barriers can result in subtle forms of discrimination which prevent disabled individuals from being able

to realize their full potential (Hunt and Hunt, 2000).

Third, teachers or lecturers have to be recognized and promoted according to their knowledge and experience in the rehabilitation counseling area. Moore, Porter & Flower (2000) have indicated that rehabilitation faculty reported a need for counseling courses/laboratories to improve curriculum. However, there are few qualified thesis advisors with a doctoral degree or associate professor rank, and many teachers did not graduate in rehabilitation counseling. As a result, contents of coursework was often adjusted by the personal interests and specialties of principal teachers of such subjects. Also, productivity on research programs and publications of teachers were low. These disadvantages probably reflected inadequate qualifications and performance abilities among teachers or lecturers. Thus, effective instructors seems to be an important issue for meeting the program objectives, providing quality assurance and attracting individuals to the program. Nasser and Glassman's study (1997) revealed that many of the students took the course because of the instructor's reputation. Therefore, there is a need to address the academic promotion of teachers. A human resource department which is responsible for this matter must be implemented.

Fourth, the rehabilitation counseling skills of students should be enhanced. Experience in counseling are important for counselors to become more effective professionals, because learning from experience and using scientific reasoning to adjust one's practice is the mark of a true professional (Corey, 1995; Jacobs, Harvill, & Masson, 1994; Dewey, 1933, cited in Koch, Arhar, Wells, 2000). So far, this program has provided students with only 3 credits or 90 practice hours, in a subject named "RSRS 514: Practicum in counseling and guidance." In contrast, rehabilitation programs in the United States and CORE recommendations are for students to have 600-700 hours of practicum and internship (CORE, 2001). A lack of practical experience may reduce

student's skills and confidence. To solve this problem, the credit hours associated with the practicum, or internship, should be maximized, and the credits associated with the thesis should be minimized. Finally, this program should be broadened and have the flexibility to include more information relating to the culture, politics, economy and other contexts which influence disability and rehabilitation in Thailand.

The body of knowledge of rehabilitation counseling and the central role of the rehabilitation counselor in the United States has remained quite consistent over the years (Leahy and Szymanski, 1995). In contrast, the body of knowledge of rehabilitation counseling in Thailand is inconsistent and still in a developmental process. Although the Rehabilitation for Disabled Persons Act 1991 exists, its implementation is a sensitive and critical issue in terms of its effectiveness. There is a lack of punishment for noncompliance.

It is also important to note the terms "counseling" and "rehabilitation services" are difficult to understand for the public and society in Thailand and seem to differ from traditional meanings of rehabilitation counseling in America and Europe (Cheausuwantavee, 1997). Because of the nature of Thailand as a developing country and the need for immediate help, rehabilitation counselors often help disabled persons by addressing basic concerns such as food, clothes, medicine and housing. Thus, the role of rehabilitation counselor is likely to be focused on consulting, coordinating and supporting, rather than on giving counseling.

There are strong associations and clubs of people with disabilities (such as the blind and the physically disabled) and these groups were the originators of the Rehabilitation Act for Disabled Persons 1991.

Recently, the Association of Autistics' Parents was founded by the parents and families of autistic children to help and rehabilitate their children. People with disabilities and their families are therefore very important in terms of shaping the nature of service delivery within Thailand.

According to Hershenson's (1998) model, within the Thai context, influence tends to move in an outward direction rather than inward. Therefore, participation and feedback by disabled persons at a grassroots level, as well as their families and community, are necessary for long-lasting development of rehabilitation curriculum. The principle that no single theory can provide an adequate foundation for the design of curricula, and that educators need multiple perspectives, multiple research findings, practical experiences and extensive deliberations to change classes into communities of inquiry (Terwel, 1999), is still valid here.

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## Essays And Creative Works

### “Normals, Crazies, Insiders, and Outsiders”: The Relevance of Sue Estroff’s Medical Anthropology to Disability Studies

Diane R. Wiener

**Abstract:** This essay explores the promising interdisciplinary connections between Disability Studies and Medical Anthropology by examining the work of long-time ethnographer and activist Sue Estroff in the context of a Disability Studies perspective and philosophy. The author provides an array of examples of how Estroff’s historical, and more recent scholarship, is relevant to Disability Studies praxis today, and suggests that Medical Anthropology as a field would benefit from utilizing a Disability Studies orientation in its own scholarship and practices.

**Key Words:** medical anthropology, psychiatric survivor movement, interdisciplinary

First, a note of appreciation. Sue Estroff’s work is methodologically and theoretically indispensa-

ble to my study of psychiatric discourse, women’s first person narratives of “mental illness,” and representations of female “madness” in mainstream Hollywood cinema. I am grateful to Ana Ortiz and Mark Nichter of the University of Arizona Department of Anthropology for introducing me to Estroff’s writings.

Second, the sharing of a compelling citation – employed here as part cogitative fulcrum and part assertive plea – from feminist philosopher Andrea Nicki (2001). While I differ from Nicki in my views on “the mind,” “truth,” and “mental illness,” her article’s concluding words are striking, and help to situate my discussion. She remarks:

“Feminist theory of physical disability focuses on society’s oppression of the body, of the alternate bodily states found in the physically disabled. Similarly, feminist theory of psychiatric disability concerns the oppression of the mind by a society that rejects and despises the alternate mental states found in the psychiatrically disabled. The history of Western thought has not truly been about the glorification of the mind. True appreciation will come when there is no more oppressive talk of some mental island called madness to which one in illness goes, no more morbid romanticizing of offshoots of oppression and abuse – of “mad starving artists” – or scientific mystification of fettered minds. Let there be no more beliefs that partition the complex wheel of the mind or that enforce the isolation of those suffering from oppression and mental illness” (p. 100).

Nicki’s phrasing seems to naturalize the terms and concepts “mental illness,” “the mind,” and “truth,” as if they are able to be described as sta-

ble categories with persistent and clear cultural meanings. In contrast, I believe these terms and concepts are contested, and cannot be readily interpreted through language, as their meanings depend on the context and are thus not merely transparent. I cite Nicki's work here because I appreciate her attitude toward refuting the romanticizing of "madness" and "mad starving artists," and her questioning of what she terms "scientific mystification of fettered minds." Her apparent intention to undo the societal "partition[ing]" that accompanies references to "the mind" is crucial to discussions of Disability Studies in the context of Medical Anthropology and vice versa.

For thirty years, Medical Anthropologist Sue Estroff's scholarship has accentuated the relationships between psychiatric consumer/survivor/ex-patient or "c/s/x" identity formation, social constructions of emotional difference, and public policy concerning mental health and emotional disability. Her assertion that "our psychiatric belief and treatment systems and our interactions as community members can contribute not only to the amelioration of patienthood but to its perpetuation" (1981, p. 174) directly relates to two of Disability Studies' primary objectives: to improve the lives of disabled people; and, as advocate Simi Linton puts it, to "serve both academic discourse and social change" (1998, p. 1).

Among our multiple projects and varied stances, promoters of Disability Studies encourage individuals and groups who self-identify as disabled to self-empower. This is partly accomplished by de-linking emotional, cognitive, and corporeal identities of "difference" from explanatory models that individualize "illness" – and by moving away from the often disturbing advancements of medicalization and "patient" dependency models – to critique and deconstruct power structures and combat stigmatization. For these reasons, I believe that Estroff's stance regarding "patienthood" and its "amelioration" versus "perpetuation" within capitalist society may be used to build promising bridges between Medical Anthropology and Disability Studies.

In her piloting book *Claiming Disability*, Linton remarks:

"A disability studies perspective adds a critical dimension to thinking about issues such as autonomy, competence, wholeness, independence/dependence, health, physical appearance, aesthetics, community, and notions of progress and perfection – issues that pervade every aspect of the civic and pedagogic culture... Scholarship in the field addresses such fundamental ideas as who is considered a burden and who a resource, who is expendable and who is esteemed, who should engage in the activities that might lead to reproduction and who should not, and, if reproduction is not the aim, who can engage in erotic pleasures and who should not" (p. 118).

Linton rightly insisted "the voice of disabled people should be present in both disability studies and applied approaches to disabled people, but the voice should take different form in each" (p. 141). Disabled individuals must be included on curriculum committees, welcomed as leaders in the rehabilitation movement and the applied fields that affect their lives, and respectfully incorporated – rather than shunned, ignored, made exotic, or tokenized – within all societal spheres. As many Disability Studies advocates maintain, images, stories, and other representations of the disabled fashioned *by* disabled people must be centrally featured in all domains that pertain to disabled people's experience. The presence of these representations ought to also help the non-disabled learn about and gain sensitivity to the disabled experience.

The mental health industry in particular needs to increasingly acknowledge, respect, and make



changes based upon the powerful contributions to social justice and the critiques of the psychiatric status quo offered by members of the Disability Rights movement and the psychiatric survivor movement. Thankfully, it appears that these movements may indeed be influencing the worlds of mainstream rehabilitation and treatment. In an article published in the Spring 2001 issue of the *Psychiatric Rehabilitation Journal*, progressive social worker Priscilla Ridgway remarks, “To understand and facilitate processes of resilience and recovery, we must end the silence imposed on people with psychiatric disabilities, attend much more carefully to their personal and collective voices, and value and honor their stories” (p. 341).

The trajectory of Sue Estroff’s writing, theorizing, and advocacy was brought to public attention in the late 1970s, when she completed her dissertation on the experiences of outpatient clients in a community mental health program in Madison, Wisconsin. This work was later published as *Making it Crazy: An Ethnography of Psychiatric Clients in an American Community* (1981). One of its chapter headings is the source of the quote in my essay’s title.

In *Making it Crazy*, Estroff sought to fairly (and as accurately as possible) depict the complicated and interactive positions and perspectives of an outpatient mental health program’s staff and clients, rather than demonizing the former or patronizing the latter, as some of her professional predecessors in medical anthropology and sociology had understandably been accused of doing. The descriptive cultural study of psychiatric survivors in the wake of de-institutionalization was radical for its time. As Disability Studies emerged, in part, from the Disability Rights movement, the *c/s/x*, anti-psychiatry, and Disability Rights movements simultaneously influenced Estroff’s early work, and continue to influence it today. In her introduction to *Making it Crazy*, she explains some of her motivation to do the project as follows: “If Goffman and Kesey can do it in an institution, someone ought to try it

outside” (( p. 3). As a cultural artifact, the study may be read as a critical commentary on the era of post de-institutionalization.

Years later, Estroff returned to the Madison field site for a follow-up study, and subsequently published *Identity, Disability, and Schizophrenia: The Problem of Chronicity* (1993), a piece well-known within medical anthropology for its continued attention to her theory of role engulfment, a conceptual framework for explaining the differences between and reasoning behind what she terms “I have” versus “I am” illnesses. According to her distinctions, one does not have schizophrenia, but is (labeled) a schizophrenic. One is not an arthritic, but has arthritis – although one could say that he “feels arthritic,” meaning that a bout with arthritis is in full swing.

Per Estroff, believing that one “has” or “is” something, and the linguistic conventions that label and express these states of being, are strongly influenced by the length of time one experiences symptoms, pain, difference, and so on. Thus, chronicity makes it “less and less possible to separate one’s self from the stubborn presence of the impairment and resulting altered level of functioning” ( 1993, p. 258-9). Estroff’s “sociocultural understanding of the process of chronicity” (p. 274) is aimed to “reclaim medical anthropology from biomedicine,” (p. 277) but this approach “does not mean... that one rejects the call for salience in the realm of healing and suffering” (ibid.). The connections Estroff draws between disabled bodies and disabled identities may have resonance for those Disability Studies advocates who seek to simultaneously honor and complicate the identity politics around disability and difference while acknowledging that disabling moments materially happen to disabled and non-disabled people. As Laurence Kirmayer (2000) helpfully summarizes, “Medical anthropology is concerned with the interaction of social and personal constructions of illness meaning” (p.174). Estroff’s attention to the daily practicalities of mental health has influenced both the tone and style of medical anthropology scholarship. In the intro-

duction to their foundational anthology *Disability and Culture* (1995), anthropologists Benedicte Ingstad and Susan Reynolds Whyte remark, “Sue Estroff finds it characteristic of anthropology to show how people identified as deviant ‘adopted, elaborated, and/or rejected their deviant identities while interacting with the culturally defined values and actions of others’ [*Making it Crazy*, p. 211]. She examines the cultural values and practices of American society toward ‘crazy’ people and the way those so defined manipulate and use the dominant values” (p. 19).

According to Estroff, there are numerous ways that people labeled “mentally ill” strategically utilize the idea of their “deviant identities” to their advantage, and they may embrace such identities as meaningful and complex, rather than just imagining these identities as wholly problematic or as merely disruptive and difficult. Estroff asserts that “craziness” may be a choice for some and can become an ongoing performance of identity. She explains there are “rules for making it crazy,” particularly if one is compelled to seek what she calls “career options” as a way of negotiating life within the realms of mainstream clinical psychiatry, and within a larger society that punishes people with stigmatic consequences for doing what they are in some ways set up to do.

In *Making it Crazy*, Estroff lists the specific “Rules for Making it Crazy” (pp. 189-190), which are assembled “to clarify the clients’ perspective and working dynamics” (p. 189). Estroff notes that there are both pros and cons, and what she terms “comfort and agony,” in the choice of “making it crazy” (p. 190). Before listing the 12 “rules,” she remarks:

“The real cultural craziness here is that not only do we describe these persons as pathologically dependent but we contribute to their dependencies. Not only do we view them as un-integrated within the community but we isolate them by constantly

reminding them of their incompetence and by introducing them to peers [in treatment programs] with whom they may be more comfortable. We provide professionals to help these persons, as [our] society seem[s] to prefer to pay others to deal with them and thereby undermine any motivation that community members or other clients might have to participate in the caring and treatment process... We negatively value these persons, collectively and as individuals, for their differentness and their dependencies, but we leave them little chance to give us anything except ‘getting better’ (which means being more like us)” (pp. 188-189).

Importantly, after listing the 12 “rules,” Estroff provides four “criteria for making it without craziness” (pp. 190-191), to acknowledge that some mental health clients “made it out of the system” or “reconstruct[ed] a well self” (pp. 191-191), despite what she describes as the “failures, both of persons and of the sociocultural system within which they operate” (p. 190).

I believe that the “system” to which she is referring here is the American mental health system of the mid- to late 1970s. Unfortunately, in my estimation, our current mental health system – including many (but not all) of its policies, administrators, and practitioners – is differently (if not more) problematic than it was during the 1970s.

Estroff points out that engaging with “craziness” as a disabled “identity” or “role” is often “the means by which [mental health clients] ‘make it’ or survive” in a fraught system and beyond (1981, p. 38). She notes that many psychiatrically diagnosed individuals pursue entitlements benefits based upon their strategic employment of a “mentally ill” identity (Estroff, et. al., 1997).

Attempting to use a stigmatized identity to one's advantage and finding other ways to strategically survive in a society that stigmatizes those labeled "mentally ill" are complicated choices, and there may be serious "costs" to those who accept or who negotiate stigmatizing labels in order to claim financial benefits. However, these choices can be some among many ways of managing within an unsettling society whose hardy and ubiquitous mental health industry aims to "serve" but often simultaneously harms individuals who are labeled "mentally ill" by "experts" in that industry.

Instead of negatively judging people for making complex choices in a laborious system, Estroff is aware of – and advises that others should become more aware of – the myriad facets of adapting, working with, denying, combating, or embracing a "deviant" identity or role. She remarks that "we must remind ourselves that we are trying to understand persons who are absorbed in the creation of day-to-day living that, though negatively valued and often painful, is nonetheless rewarding" (1981, p. 198). This observation about emotionally disabled individuals mirrors one among many Disability Studies approaches toward reading triumph narratives – disabled people, psychiatric survivors among them, do not necessarily or only imagine themselves as disempowered victims of oppression who seek to heroically overcome obstacles, but are individuals with abundant identities, living with nuances and in ways that are agentive.

Estroff's commitment to respecting the rights of consumers/survivors/ex-patients and the *c/s/x* movement overall promotes a heightened awareness of the obligation to go beyond condescending care and well-meaning empathy to valuing the emotionally disabled within local communities and professional rehabilitative circles, and in not disrespecting individuals and groups via unethical ethnographic projects (see 1999). As someone trained in cultural anthropology, Estroff is extremely concerned with the connections between the realms of the "macro" and the "micro," and she thus engages cultural patterns while be-

ing mindful of individual uniqueness. Estroff believes in an anthropological enterprise that goes beyond studying people in context to pragmatically serve them. She is one of those rare activist scholars who actually puts into practice the idea of "giving back to the community," an approach that sometimes seems like a promise or sentimental avowal on so many scholarly lips.

Among Estroff's major concerns are the relationships between and health care seeking patterns among chronic psychiatric patients, and the ways these crucial life facets are forged in part by the mental health industry's resource allocations and professional players, and larger social policies. She asserts, "social welfare and health policies codify cultural ideas about identity, illness, and productive activity. These are then expressed in mental health care systems that – in the U.S. in particular – facilitate, indeed operate a political economy of disability construction among severely mentally ill persons" (1993, p. 251). The premise of "disability construction" is familiar to many disabled people, and has sometimes been used by Disability Studies scholars to advance a politicized social critique. While "severely mentally ill" may not be a welcome descriptor for some self-identified psychiatric survivors, Estroff's definition of disability construction could prove useful for forwarding Disability Studies and *c/s/x* critiques.

I interpret Estroff as envisioning a politically engaged mental health care system that is effective but that does not have its own perpetuation as a primary goal. She likewise does not want to foster a system that hinges upon the creation of patient dependencies. In her extensive work on *c/s/x* subjectivities and narratives, it is clear that she believes psychiatric survivors are experts within the system and ought to have the opportunity to run some things for themselves, despite the frequent and ongoing resistance to this stance on the part of many mental health administrators and professionals (see 2004). Importantly, psychiatric survivors have not waited for opportunities to be handed to them but have created op-

portunities for themselves through activist means. The international clubhouse movement begun by New York City's Fountain House, a rehabilitative location mostly governed by c/s/x individuals for c/s/x individuals, and other patient-led advocacy efforts have blossomed and grown and will hopefully continue to flourish in the future. Of course, there is enormous variation in what psychiatric survivors want and need, not to mention the diversity in the c/s/x world regarding political orientations, beliefs, perceptions, and feelings about being (or being labeled) "mentally ill."

In the absence of a monolithic leftist patient-led revolution that some would welcome but others would not applaud, and given ongoing capitalist realities, Estroff works to critique the mental health system from within. Her efforts invoke a savvy combination of epidemiology, patients' rights, expert attitudes, and public health policies, and she provides insights into how the mental health system – alarmingly interwoven with the prison industrial complex – could and should change, with an awareness that merely good intentions won't get us far, and there must be a profit motive behind any systemic alterations.

Disability Studies scholars and activists who are attentive to emotional and cognitive disabilities issues might benefit from surveying Estroff's reflections on the social and political-economic underpinnings of consumer/survivor/ex-patient identity formation, the pros and cons of narrative constructions of mentally ill selves, the anthropological incorporation of illness narratives and life stories, and activist anthropology's potential impact on policy making.

Although modern ethnographic work cannot be utterly disentangled from its deeply fraught socio-political history, a self-reflexive Medical Anthropology approach that is accomplished with a Disability Studies stance at its core, and a Disability Studies practice that is influenced by an anthropological orientation like Estroff's, could each offer a great deal to discussions and understandings of the connections between gen-

der, class, sexuality, ethnicity, nation, and race in relation to disability, difference, and deviance, particularly in the scholarly and "treatment" arenas around, and the daily living of, those labeled – and/or self-identified – as "mentally ill."

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## Book, Art And Film Reviews

### Book Review

**Title:** *Implementing the Social Model of Disability: Theory and Research*

**Author:** Colin Barnes and Geof Mercer, Eds.

**Publisher:** The Disability Press, 2004

**Cost:** \$30.00, paperback (20% discount for orders of four or more).

**ISBN:** 0952845083

Available from

Centre for Disability Studies,  
School of Sociology and Social Policy,  
University of Leeds,

A CD ROM of the book may be requested at the time of book purchase and is supplied free of charge.

**Reviewer:** Liat Ben-Moshe

The title of this book is slightly misleading, if you are thinking of implementation in a policy or practice oriented way. The book should be called "Everything you ever wanted to know about the social model and its critiques." The book contains 13 chapters written mostly by theorists and researchers from the UK. Each chapter offers some critique of the social model and calls for changes, points out omissions in the theory, or tries to move beyond it while reflecting on its historic relevance.

The book provides, in a number of chapters, a comprehensive history of the creation of the social model (if you ever wanted to know what UPIAS, DIG and BCODP stand for, you'll have no problem finding it here). Some of it helps to explain arguments that underpin its usefulness. For instance, the fact that people with physical disabilities drove its inception, and it was later on

generalized, inadequately, to include the experiences of people with various disabilities.

As a whole, there are some recurring critiques of the social model that resurface throughout the book: its essentialism (the disabled/non-disabled binary is real); it rejects accounts of personal experience; it insufficiently theorizes impairment; its assumed universality; and its exclusion of psycho-emotional aspects as well as structural/global aspects of disablement and impairment (best theorized by Carol Thomas in chapter 3 here).

I found most chapters to be thought-provoking and well written. This book should definitely generate interest among ‘social modelists’ (as Barnes and Mercer refer to them) and people interested in current research in Disability Studies (DS) in the UK, since most of the authors engage with theories of other authors in the book or other leading DS scholars that are UK-based. This book is of particular interest to activists and Disability Studies scholars who want to take the social model further and engage with new ways of thinking about the relations between people with disabilities, the environment, and their relation with each other as well as with non-disabled people.

The cover is very plain and the extra thin and relatively poor quality of paper adds to its low-tech feel, but also makes it a more affordable buy.

**Liat Ben-Moshe** is a Ph.D. student in Sociology, Women’s Studies, and Disability Studies at Syracuse University, and a member of Beyond Compliance (BCCC), a student advocacy group at Syracuse University aimed at raising awareness around disability, as a form of diversity. The BCCC website is: [http://soeweb.syr.edu/thechp/beyond\\_compliance.html](http://soeweb.syr.edu/thechp/beyond_compliance.html). She can be contacted at: [lbenmosh@maxwell.syr.edu](mailto:lbenmosh@maxwell.syr.edu)

## Book Review

**Title:** *Deaf Side Story: Deaf Sharks, Hearing Jets, and a Classic American Musical*

**Author:** Mark Rigney

**Publisher:** Gallaudet University Press

**Cost:** \$19.95 US paperback

**ISBN:** 1-56368-145-5

**Reviewer:** Alex Lubet

*Deaf Side Story* chronicles a 2000 production of *West Side Story* at MacMurray College in Jacksonville, Illinois. The rival youth gangs were portrayed by hearing students from “Mac” and deaf high schoolers from Jacksonville’s Illinois School for the Deaf.

Rigney is a playwright and it shows. He knows much about theatre and is a compelling storyteller. Unfortunately, as a case study in Theatre and Deaf Education, the book comes up short.

Rigney never reveals how he was able to provide a seemingly eyewitness account of a production whose book-worthiness would have been apparent only in its late stages. Rigney was likely not present at all, relying on the account of director Diane Brewer who now lives, like Rigney, in Evansville, Indiana. Lack of balanced perspective is worsened by non-disclosure of method.

Rigney knows no sign language, but claims to have represented Deaf culture as well as any hearing person could. I disagree. He vividly portrays many “Hearies,” but almost no Deaf personnel. He renders Jacksonville drably Midwestern, a perspective native “Flat-landers” and “Hearies” like myself will recognize. But with its large Deaf school and Deaf community, and Mac’s prestigious Deaf Education program, Jacksonville might appear to Deaf readers like Mecca on the prairie.

Rigney seems to laud pro-Deaf director Brewer’s rejection of the suggestion that a bass drum be used to assist Deaf dancers as a “crutch” that

would reflect badly upon them. In reality, this device is used by the Gallaudet University Dance Company (Hottendorf & Gill-Doleac, 2003). The suggestion Brewer nixed almost certainly came from a Deaf member of the production team, although s/he is never identified.

Much of the drama of Rigney's tale revolves around the many cast members, who dropped out throughout the production. These are young people, largely minors, some apparently quite vulnerable. Rigney impugns these and others mercilessly, using their real names when permissions could be obtained. Comparable ethnographies of schools (Nettl, 1995; Kingsbury, 1988) protect even the names and locations of their institutions.

Rigney's descriptions of music range from muddled to incorrect. His transcriptions of e-mails of a Deaf production team member whose English is imperfect are inadequately contextualized and unempathic.

*Deaf Side Story* is intended for students of theatre and Disability Studies. It is mostly an easy "read," although issues of theatrical production and Deaf Culture present challenges. Scholars of Deaf Culture will find it disappointing in ways others may not notice.

*Deaf Side Story* needs to be read with a background in Deaf Studies and a dose of skepticism. There is a revival of Roger Miller's musical, *Big River*, in an ASL/English production currently running on Broadway and on tour. Perhaps from that a truly distinguished chronicle of an ASL/English musical production will finally be written.

Hottendorf, Diane & Susan Gill-Doeac (2003, November 18). *Dance Techniques for Deaf and Hard of Hearing Dancers*. The Gallaudet Dance Company, Gallaudet University. Retrieved July 8, 2003, from <http://depts.gallaudet.edu/dance/techniques.html>.

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**Alex Lubet, Ph.D.**, is Morse Alumni Distinguished Teaching Professor of Music, American Studies, and Jewish Studies at the University of Minnesota. A musician, theatre artist, and educator, he has written on numerous aspects of disability studies in music and is currently completing a monograph entitled *Crip Notes: Towards a Disability Studies of Music*. Contact him at [lubet001@umn.edu](mailto:lubet001@umn.edu) or School of Music, University of Minnesota, Minneapolis, MN 55455.

## Monograph Review

**Title:** *Understanding and Accommodating People with Multiple Chemical Sensitivity in Independent Living*

**Author:** Pamela Reed Gibson, Ph.D.

**Publisher:** Independent Living Research Utilization (ILRU)

**Cost:** Up to 20 at no cost, \$3 apiece after

From Dawn Heinsohn at [ilru@ilru.org](mailto:ilru@ilru.org) or phone 713/520-0232 ext. 130 (V), or 713/520-5136 (TTY).

Via the web at <http://www.ilru.org/Publications/dateShelf.html>

**Reviewer:** Susan Molloy

Chemical and electrical exposures methodically incapacitate thousands of individuals a year, and slam them into isolation. Pamela Gibson, of Virginia's James Madison University, has written several outstanding books describing the emer-

gence of this burgeoning population, and the crisis of accessibility it raises.

Now she gives us an on-target guidebook, part of ILRU's "Bookshelf" series, to make plain the access and advocacy requirements of these individuals who are being driven away from society at large, and possibly out of your office and your campus.

Dr. Gibson offers a succinct, straightforward primer, a foothold in this version of reality. She describes the rapid emergence of this illness in the U.S., and internationally, what many people with multiple chemical sensitivities and electrical sensitivities (MCS/ES) seek and what protections they must have to survive daily chemical and electrical assaults.

This monograph offers a way to grasp the emergence of people with MCS/ES. She explains what to call this illness and where these people come from, then offers some interpretations of what they want and what they can offer. She backs up every point she makes with solid references, as well as practical suggestions about how to get started and what to expect.

Today, people with MCS/ES have no orientation or rehabilitation programs, no occupational or physical therapy, scant, if any, legal precedents, no accessible housing, and no hospitals to break the fall. This includes Gulf War veterans with MCS/ES – the armed services don't offer them much either.

Wrongly perceived as latecomers or even "non-contributors" to the Disability Rights Movement, people with MCS/ES don't understand why they are not welcomed with open arms into today's disability rights programs and campaigns, let alone Universities and community colleges.

I don't just recommend you get this book. My own survival may depend on your awareness of what this book offers: an overview of the essential components of MCS/ES from Assistive Technology and Durable Medical Equipment to

accessible housing, adaptive equipment, personal assistance, and safety from incapacitating electrical exposures and chemical assault.

**Susan Molloy**, M.A. in Disability Policy, San Francisco State University, Department of Public Administration, lives in the high desert of rural N.E. Arizona on several hundred acres with a dozen households of people with chemical and electrical sensitivity disabilities. Most of the houses are fully wheelchair accessible as well as being constructed and maintained with nontoxic materials. Susan has hammock hooks and plenty of room in the driveway, and welcomes non-smoking, fragrance free, traveling scholars. She can be contacted at: [susanm@cybertrails.com](mailto:susanm@cybertrails.com)

## Book Review

**Title:** *The Labor Market Experience of Workers with Disabilities: The ADA and Beyond*

**Author:** Julie L. Hotchkiss

**Publisher:** W. E. Upjohn Institute for Employment Research, 2003

<http://www.upjohninst.org/publications/titles/lmewd.html>

**Cost:** \$20 paperback, \$40 hardcover

**ISBN:** 0-88099-251-4 paperback or 0 88099-252-2 hardcover

**Reviewer:** Cal Montgomery

Julie Hotchkiss asks whether the Americans with Disabilities Act (ADA) has made any difference in the labor market experience of people with disabilities and concludes that it has not. Moreover, she argues, it is unlikely that this is due to employers' failure to comply with the law nor that people with disabilities' labor market experience doesn't need to be improved. "It is probable ... that the lack of notable impact of the ADA ... implies that, like many other pieces of legislation with a strong social and moral content, it was



adopted in an environment that had already embraced its principles and mandates, for the most part” (p. 142).

The former argument is backed up by statistical analysis and may prove useful to American policymakers, Hotchkiss’s target audience, and to researchers looking at disability and employment (following the argument closely requires familiarity with statistics). The latter argument is a quick sketch and not a major contribution to debates about how best to address the employment crisis for Americans with disabilities.

In other words, readers interested in whether the ADA has “worked” for workers and jobseekers with disabilities – and who can follow statistical arguments – will find this book worth considering.

But to evaluate current and proposed policy it isn’t enough to ask *whether* the ADA has changed anything; one has to ask *why*. There is no consensus among those concerned with disability policy that by 1990 employers had embraced the idea that disability discrimination is wrong, much less the idea that the barriers that provoke reasonable accommodation requests constitute discrimination, and *The Labor Market Experience of Workers with Disabilities* will not satisfy readers on this point unless they have already independently arrived at Hotchkiss’s conclusion.

John Jay Frank (2004), to give one example, has called for more research into what happens when people ask for accommodation and barrier removal. Calling the attempt to challenge discrimination through the Equal Employment Opportunity Commission and Department of Justice “ineffective,” Frank says that “the issue for those of us facing barriers is the way the law is circumscribed and ignored.”

The issue for Hotchkiss has nothing to do with the law being circumscribed or ignored; and her recommendations for improving education, training, and job matching and for restructuring the incentives and disincentives are not atypical. But

she does not adequately answer those disability advocates who believe that evidence of widespread discrimination was provided to Congress when it was considering the ADA and that if little has changed for workers and jobseekers with disabilities, discrimination clearly persists.

Frank, J. J. (2004). *Time to gather our own evidence*. Retrieved July 29, 2004, from <http://www.raggededgemagazine.com/focus/frankADAAres0704.html>

**Cal Montgomery** is a disabled reader, a writer, and an activist living in Chicago, who writes regularly for *Ragged Edge* magazine.

## Book Review

**Title:** *Damned for Their Difference: The Cultural Construction of Deaf People as Disabled*

**Author:** Jan Branson and Don Miller

**Publisher:** Gallaudet University Press, 2002

**Cost:** Paperback \$34.95

**ISBN:** 1-56368-121-8

**Reviewer:** Albert B. Robillard, Ph.D.

A linguist and an anthropologist from Melbourne, Australia produced this finely written book. They have done a marvelous job of a kind of Foucaultian discourse analysis of how deaf people were framed, talked about, and physically handled since the 17th century in Europe and beyond. The early focus is on France and Britain, examining the texts from institutions for the deaf.

The authors take us through the early development of natural sign language and the subsequent institutionalization of standard sign languages. They also take us through an attendant institutionalization of careers and bureaucracy in the teaching of the deaf. The conclusion, found in chapters 8 and 9, is that the standardization and the natural incrimination of associations of teach-

ers of the deaf, either deaf themselves or hearing and speaking, have unconsciously limited the free expression of deaf students. This is not unique to deaf people and affects everyone who goes through a system of education that forgets the irruptive and dynamic structure of life.

The authors are acutely sensitive to the reflexive effect of language and writing on how deaf people have been treated through history. They have several horror stories. The first is insistence by teachers of the deaf that deaf students learn to speak. The writers describe the history of oralism and lip-reading. The second horror story is the history of the cochlear implant, a surgically implanted mechanism to let the wearer receive the vibrations of conversation. The vibrations are transmitted to the wearer's skull.

In the last two chapters, the authors make a strong plea for letting deaf sign language and deaf culture flower, be appreciated, encouraged, and left alone. The plea also includes a request that the so-called "normals" not impose their imperialist culture on the deaf, feeling the deaf need improvement, that they are disabled.

**Albert B. Robillard, Ph.D.**, Professor of Sociology, University of Hawaii, has a neurological condition that has robbed him of speaking. He has his own system of lip-reading. However, despite the academic success of writing books, articles, and actively teaching, he is not immune from the constant onslaught of people who are trying to standardize, digitize, and otherwise remove the spontaneity from language.

### Book Review

**Title:** *Cochlear Implants in Children: Ethics and Choices*

**Authors:** John B. Christiansen & Irene W. Leigh

**Publisher:** Gallaudet University Press, 2002

**Cost:** \$49.95, hardcover

**ISBN:** 1-56368-116-1

**Title:** *Ethics in Mental Health and Deafness*

**Author:** Virginia Gutman (editor)

**Publisher:** Gallaudet University Press, 2002

**Cost:** \$65.00, hardcover

**ISBN:** 1-56368-120-X

**Reviewer:** Simo Vehmas

These two recent books treat ethical issues of immense importance related to working with deaf clients in mental health practice, and to the facts and controversies associated with cochlear implants. The titles of these books may be misleading though since the actual ethical discussion found in these books is scarce and shallow. The focus regarding ethics in these books is very practical. They deal with issues that professionals, parents and deaf people themselves may confront in different stages of life. In both books the ethics part is more an introduction to various ethical questions, rather than scrutinizing them and finding sound bases for ethical judgments.

The authors do not discuss the issues philosophically. Gutman, for example, mentions in *Ethics in Mental Health and Deafness*, that her focus is not on providing the "right answers" but on helping readers ask the *right questions* leading to ethically sound clinical decisions (p. 12). This may reflect a conscious methodological approach to examining ethics where the point is to enlighten moral philosophical reasoning to people unfamiliar with it. But presenting questions in itself is not very helpful if they are not discussed properly. To help readers make their own conclusions, one should provide them with arguments of the strengths and weaknesses of various possible normative judgments. In this sense, the ethical argument in *Ethics in Mental Health and Deafness* seems to cease before it has even properly begun.

Christiansen and Leigh fortunately present the ethical dimensions related to cochlear implants in a more versatile manner. They provide readers

with at least one possible tool for solving ethical problems: the four-principles approach developed by Tom Beauchamp and James Childress. However, the principles of autonomy, justice, beneficence and nonmaleficence do not in any manner constitute an unproblematic, indisputable foundation for resolving ethical dilemmas. The theory of four principles has been strongly criticized. Whether one finds it plausible is not the issue. The ideal in books like *Cochlear Implants in Children* is to give readers alternative ways to solve ethical issues. When only one philosophical tool is presented, the ethical reasoning is limited.

Thus, from the viewpoint of philosophical ethics, these books do not seem to have too much to offer. However, one crucial element in applied ethics is the consideration of empirical knowledge. The use of empirical data gives a framework to the normative arguments and directs the conclusions. In this sense, these books provide some invaluable material to both academics and lay people. Many academics and professionals may not have even thought about many of the issues related to cochlear implants, deaf people in mental health care, the Deaf culture and so on. Regarding the awareness of the ethical issues related to deafness, these books give a useful overview of the field (this applies especially to *Cochlear Implants in Children*). Since many professionals, like the general public, do not have much time for complicated philosophical arguments, these books may be very useful to parents and professionals who have not encountered deafness and the related ethical issues.

**Simo Vehmas, Ph.D.** in Education, specializes in ethical issues related to disability. The subjects of his publications include practical topics such as the morality of selective abortion, as well as more general theorization about the concept of disability. He may be contacted at Dept. of Moral and Social Philosophy, PO Box 9, 00014 University of Helsinki, Finland, or [simo.vehmas@helsinki.fi](mailto:simo.vehmas@helsinki.fi); [njet.net/users/vehmas](http://njet.net/users/vehmas)

## Book Review

**Title:** *You're Going to Love this Kid!: Teaching Students with Autism in the Inclusive Classroom*

**Author:** Paula Kluth

**Publisher:** Paul H. Brookes Publishing Co., 2003

**Cost:** \$27.00, paperback

**ISBN:** 1557666148

**Reviewer:** Patricia Wright

Students with autism are becoming more frequent members of general education classrooms. *You're Going to Love this Kid!: Teaching Students with Autism in the Inclusive Classroom*, a work by Paula Kluth, Ph.D., provides a unique resource dedicated solely to inclusion and individuals with autism. Kluth's book is engaging and informative. The intended audience of this book is classroom teachers; however, parents and other professionals who are working towards inclusive schools will find this book to be an excellent resource. The opening chapter of the book includes first-person accounts of students who experience autism. These individuals give the reader clarity and insight from a first-person viewpoint about the experience of having autism. Kluth then addresses inclusive schooling and the ins and outs of the Individuals with Disabilities Education Act (IDEA). A chapter is dedicated to the role of a teacher; emphasis is placed on an educator's ability to support inclusive schooling. Another chapter addresses collaboration, describing how all members of an educational team can cooperate to promote an inclusive school. Kluth provides practical and creative methods for solving some of the challenges that individuals with autism present in an inclusive environment. Solutions for adapting classrooms to support student participation in classwork, as well as school routines and social activities, are provided. An excellent chapter addresses literacy and the importance of literacy instruction for students with autism. Another chapter, addressing challenging behavior, emphasizes a positive approach and encourages

environmental and sensory accommodations to promote positive behavior change. Kluth provides helpful hints from veteran teachers and individuals with autism throughout the book. This book is vibrant and provides a positive view of how inclusive education can be achieved for learners with autism. The mixture of practical solutions with inspiring real-life stories provides the reader with an excellent resource.

**Patricia Wright, M.A.**, is an educator who is a zealous supporter of inclusive education. She is a graduate student at the University of Hawaii and has an active private practice as an educational consultant.

## Disability Classics

**Editors Note:** This section of RDS is intended to highlight “classic” articles or commentary that helped to lay the foundation of disability studies and disability rights, or, as in the case of the article reprinted below, simply make a point that never tires from being repeated! Reprints can be from journals, newsletters or other media. If you have ideas for material that would fit in this section, please contact Associate Editor Megan Conway at [mconway@hawaii.edu](mailto:mconway@hawaii.edu).

### Dee [Lesneski] Says

#### Josie Byzek

Reprinted with permission from *Mouth: Voice of the Disability Nation*, XI (5) (Jan.-Feb. 2001), 12-13, 44-45. This is a slightly edited version of a January 2001 interview by Josie Byzek with Dee Lesneski, who became known as “the flagpole mom.” It begins with an explanatory paragraph, followed by the interview. More about *Mouth* is at: <http://www.mouthmag.com/>

**Dee Lesneski** chained herself to a flagpole in the parking lot of her son’s elementary school. The school had refused to provide a sign language interpreter, as ordered by the court, and would not allow her son Max access to his own asthma

medication. Due to their denseness at missing his distress and his signed need for his medication, he suffered a life-threatening asthma attack. Outraged, Dee stood her ground at the flagpole for 20 days, until the school backed down and agreed to do as the court had ordered them to do. The police would not arrest her because they viewed the flagpole as US property, not school property. Nonetheless, in vigilante fashion, the “good citizens” of Pennsylvania, USA expressed their displeasure at her daring to stand up for the rights of her son by shooting at her, and trying to gas her in her tent with automobile exhaust fumes.

#### Josie Byzek (JB): *Dee, what made you do it?*

#### Dee SAYS

For three years I had battled the school district for what my son needs. And I’d won...We went to due process three times. I’ve filed numerous state complaints. We went to mediation. Every process we’ve gone through has said the school district must put someone proficient in sign in class with Max.

Max is in a regular classroom. He has a hearing impairment, and Down Syndrome, and asthma. He knows how to sign. What he needs is someone to communicate with. In the beginning of his schooling, no one signed or interpreted for him when he signed.

At that point, Max’s life was in danger. He had no one to communicate with if he needed his asthma medicine. The last hearing was in February, 2000, and the hearing officer said to the school, finally, “I’m a little tired of this. This has got to happen, and I’m giving you thirty days to have it in place.” That meant by the end of March. In May, nothing was in place, so I went to federal court. And the federal judge told them that they needed to do everything that had been ordered in February.

Come the first day of school in August this last year, Max had an asthma attack. No one knew what it was. I had gone to the school to check on

him. He was blue. He was telling them, in sign, “Call Mommy please!” They said, “He’s been doing that all morning. We have no idea what he’s saying.” No one there knew sign. No one.

I medicated him, he was stabilized, he went back to his classroom. And I was so angry. I didn’t know what to do. I had done everything I could. I had gone all the way to federal court, and a federal judge, Judge Cindrich, had told them what they had to do. What could I do that a federal judge can’t do? For God’s sakes, what could I do?

I said, “This is it. I am not leaving this building until my son has what the court ordered.” Well, they got me out of the building. When I got outside, completely frustrated, I realized I could make a stand. I have a ten-year-old who plays baseball, so I carry a lawn chair in the car to watch his games. And Max was learning to jump rope, so I had a rope in the car.

I went up to the flagpole — which is the only thing standing near the school besides a dumpster — and I tied myself to the flagpole.

I said, “I am not leaving here until my son gets the services he needs.” That’s how it started. I thought I’d be out there three hours, tops.

**JB: *What did you expect would happen?***

In an hour or so, I thought, somebody will be out here saying, “Okay, we’ll do what the court ordered.”

Well, they didn’t. They sent a police officer to arrest me. But they couldn’t arrest me, because the flagpole made it my first amendment right. I did not know that.

Thank God I didn’t tie myself to the dumpster. They could have arrested me. I would have been trespassing. The flagpole made it freedom of speech.

I wasn’t prepared. The flagpole was on blacktop in the middle of a large parking lot. It was hot, 85 degrees that day. No trees, no shade, no nothing. I wound up staying for twenty days and nights.

The media showed up almost immediately, and came back every day. The school hated that.

I was shot at from the wooded area by the school. The shot that was fired hit my girlfriend’s van. She had brought her daughter, who has spina bifida, and she had to take her girl home. We didn’t know if they were going to shoot again or not.

Then a truck tried to run me over, at about three in the morning. It was an older, black truck with Confederate flags in the windows. The form of muscular dystrophy I have is called channel myopathy. When I get cold, I tense up and stay like that. So when it rained or got cold, I got in the tent.

My daughter had come to spend the night with me and it was starting to get cold. The truck couldn’t get close enough to the flagpole to run us over, so it backed up and filled the tent with exhaust fumes.

**JB: *Didn’t you call the police?***

The police? They did absolutely nothing.

They didn’t try to find out who shot at me, or who drove the truck. The security guard the school put there told us, “You’re not going to die while the kids are here at school. But when we leave at four o’clock, there will be no protection.” They didn’t want me dying during school hours, but it was okay afterwards.

There would be school buses pulling up and kids would have flags hanging out the windows with little signs saying, “Justice For Max,” “Go Max!” And busloads of kids would be cheering.

And then there would be other buses with kids giving me the finger, saying, “Go home!”

After the school closed at four o’clock, clear through the middle of the night, people would drive by, circling the flagpole, gawking and heckling.

**JB: *Why did you stay?***

Because instead of me being dead in the parking lot it could be my son dead at school from not getting an asthma treatment.

As long as I was in their face, they were cautious about what care my son got.

**JB: *How did the press treat you?***

I did talk-radio shows and a local talk show host told me he would put a drive on to get money if I would consider institutionalizing my child.

I had probably a hundred people say that what I was doing by putting him out into public school was humiliating and degrading to him, that it was a very aggressive idea to bring to a small town. That I actually was sick and “in denial” because I “didn’t recognize his needs.”

**JB: *You didn’t know about the disability rights movement?***

I knew there was a disability movement. I just didn’t know there was anybody that would actually work for me right now!

Then my kids started making phone calls, saying, “My mom’s tied to the flagpole. She’s getting into a lot of trouble. Can you come help?” I have five children. One of my oldest called here [Tri-County Patriots for Independent Living, the CIL in Washington, Pennsylvania]. He talked to John Lorence. John said, “Absolutely. We’ll be there.”

People from TRIPIL came out and stayed the whole 20 days with me. I was never by myself. I owe these people my soul. They went through everything that I went through. The rain, the cold, the harassment, the sun, not having bathroom facilities, days without eating or drinking.

They fully supported everything I decided to do. The school would come out and say, “We’ll put somebody with him. Why don’t you go home and rest up?” Well, next week wasn’t going to serve the purpose.

I wasn’t wanting piloting lessons, I was just wanting what a federal judge said was necessary for my son.

**JB: *Where do you see yourself and Max in our history?***

I’m not comparing myself on any level to Rosa Parks, but when she got on the bus, she wasn’t leaving the front seat. I wasn’t leaving that flagpole until the school did what a federal judge ordered for my son’s education.

It is a damn shame that a little boy who wouldn’t say a bad thing (loving someone to death would be the biggest harm he could do) that there would be a protest about him being in a public school!

I was asked by a number of interviewers, what could be gained by what I did. The only thing I know is that kids are kids. It’s what we teach the children that makes a difference.

Max does have a signing aide with him at all times now. He’s in second grade, with the other second graders, doing regular science and health. He gets help with reading and math. But other than that, he’s doing the same curriculum as the other second graders.

It’s harder for him. I spend three hours a night working with him because they don’t modify the communication on his subjects to allow for his hearing loss. It’s like all they can see is the Down Syndrome.

I still get mail saying to remove him from school. The school district made me explain why I wanted him in public school, to parents who wanted to sue me to have Max removed. All they kept saying was, “That animal needs to go home.”

And I still cannot go to open house like any other parent. His Christmas program is next Monday. I will be heckled the whole time.

It’s still there. Standing in line at the grocery, people will leave the line when I have Max with me so they don’t have to look at him. Being the last one into the doctor’s office but the first one called. It’s there.

**JB:** *You work at TRIPIL now. What are you learning?*

You know how when you wake up in the spring, you can just smell that spring is here? You can smell the rain? It's like all of a sudden, I realize what it's about. My eyes are opened.

I had no idea I was going through life with my eyes closed.

## Correspondence

Letters to the Editors and brief commentary are included in this section and can be addressed to Dr. Megan Conway, Associate Editor, Review of Disability Studies, Center on Disability Studies, 1776 University Avenue, UA 4-6, Honolulu, HI 96822, U.S.A. or emailed to [submissions\\_rds@cds.hawaii.edu](mailto:submissions_rds@cds.hawaii.edu).

## Announcements

**21st Annual Pacific Rim  
Conference on Disabilities  
February 28<sup>th</sup> – March 1<sup>st</sup>, 2005  
Honolulu, HI  
<http://www.pacrim.hawaii.edu/>**

Since the first Pacific Rim (Pac Rim) Conference in 1985, the scope and size of this premier event has grown to include participants from the U.S. Mainland, Alaska, Pacific Islands Nations, Japan, Australia, the Philippines and numerous other countries. Persons with disabilities, family members, researchers, and service providers join policymakers and nationally recognized speakers in the field of disability to share resources for communities to fully include and support persons with disabilities. Sponsored by the Center on Disability Studies at the University of Hawaii at Manoa and various community partners.

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

The Center on Disability Studies is the umbrella for some 25 funded projects. It originated as the Hawaii 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 Hawaii, and the State Planning Council on Developmental Disabilities.



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

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

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