Editor's Page

Welcome to the second issue of *The Review of Disability Studies: An International Journal*. This issue includes a forum on "Postsecondary Education," as well as research articles from a variety of fields, essays, commentary, and book reviews. Thank you to all of our subscribers for your support and patience as we establish ourselves as a new journal! We realize that the first two issues have been produced rather sporadically, and our aim is to produce four issues a year and to establish a regular publication schedule. All subscribers will receive four issues (a year's subscription), regardless of when their subscription started.

If you are not yet a subscriber and are viewing this issue online, note that this is the last issue of *The Review of Disability Studies* that will be available for free online. Our next and subsequent issues will require a subscriber password to access the online version of the journal (subscribers also receive a print edition). See the front cover of the journal for information about how to subscribe or go to www.rds.hawaii.edu.

A final note, although there are several contributions from authors outside of the United States in this issue, our aim is to increase the international flavor of the journal. So let your friends and colleagues around the world know about the journal and encourage them to submit articles, essays, creative works and commentary. Submission guidelines can be found on the back cover of the journal and are also available at www.rds.hawaii.edu.

So please, sit back and enjoy this issue of *The Review of Disability Studies*.

The Editors

Robert A. Stodden, Megan A. Conway, Steven E. Brown

Table of Contents

Research Articles

Upcoming Forums

Forum: Postsecondary Education

Introduction

Robert A. Stodden, Ph.D.
Teresa Whelley, Ed.D.
Center on Disability Studies
University of Hawaii at Manoa

Leadership within the nation's business and education communities has long pointed to the need for highly educated, skilled workers as the nation seeks to succeed in the increasingly competitive global economy. Postsecondary education has been described as, "America's traditional gateway to the professions, more challenging jobs, and higher wages" (U.S. Department of Education Strategic Plan, 1998-2002). Yet, persons with disabilities have often experienced limited access to and success in postsecondary education programs, resulting in poor employment outcomes.

Unfortunately, insufficient information has existed regarding the availability and use of educational supports and how such supports might affect the successful access and performance of persons with disabilities within postsecondary educational and subsequent employment environments. The Center on Disability Studies, University of Hawaii, in collaboration with the Institute on Community Integration, University of Minnesota, Institute on Community Inclusion, Children's Hospital/University of Massachusetts/Boston, Rehabilitation Research & Training Center at Virginia Commonwealth University, and the American Association on Higher Education & Disabilities (AHEAD), have responded to this critical area of need over the past five years with the conduct of a Rehabilitation Research & Training Center (RRTC) focused upon educational supports that increase access and improve outcomes for persons with disabilities in postsecondary education programs.

The focus of the RRTC has been on the following goals: (1) Examine and evaluate the current status of educational supports, including (a) individual academic accommodations, (b) adaptive equipment, (c) case management and coordination,

(d) advocacy, and (e) personal counseling and career advising; (2) Identify effective support practices and models of delivery that contribute to successful access, performance, and retention/completion of postsecondary programs; (3) Identify specific barriers to the provision of disability-related services, including policy and funding requirements; (4) Assess effectiveness of promising educational practices and disability-related services that are important to career mobility and success in the workplace; (5) Test the effectiveness of specific models of delivery that are believed to increase the accessibility of educational supports and innovative technologies; (6) Identify the types of educational and transitional assistance that postsecondary programs provide to improve educational and subsequent labor market success; (7) Provide training, technical assistance, and information to educational support personnel, public and private rehabilitation personnel, career placement specialists, and students with disabilities based on the findings and implications of the proposed research program, and (8) Implement a consumer-driven empowerment evaluation plan.

The RRTC research program was based on an inclusive conceptual framework and the use of both quantitative and qualitative research designs. In addition to conducting national surveys, participatory action research teams conducted field studies within diverse postsecondary educational settings inclusive of all disability types and levels, representative of urban, rural, and suburban sites, and varied across ethnic and racial populations. Further, the RRTC used an innovative and integrated training, technical assistance, and dissemination model to ensure the application and sustainability of research-proven policy and practice.

This forum of papers was developed and peer reviewed for the *Review of Disability Studies (RDS)* and presents a range of findings from studies conducted through the RRTC. These include findings concerning postsecondary support provision in the areas of assistive technology, use of natural institutional and family/community supports, and the preparation of faculty to be universally prepared to support all students with diverse learning and be-havior needs. Several papers focus on those support variables that make a contribution to improved performance and academic success within a postsecondary setting. These papers provide an in-depth view of the struggles and successes of persons with disabilities within postsecondary education settings. Other papers focus on the value and role of advocacy and self-determination skills for persons with disabilities in postsecondary education and employment settings.

Robert A. Stodden is Professor and Director of the Center on Disability Studies and the National Center for the Study of Postsecondary Educational Supports at the University of Hawaii at Manoa.

Teresa Whelley is an Assistant Professor at the Center on Disability Studies and Research Coordinator within the National Center for the Study of Postsecondary Educational Supports at the University of Hawaii at Manoa.

Disability-related Simulations: If, When, and How to Use Them in Professional Development

Sheryl Burgstahler, Ph.D. and Tanis Doe, Ph.D.
University of Washington

Editor's Note - Tanis Doe passed away in her home in Victoria, British Columbia late Wednesday, August 4, 2004 due to a pulmonary embolism. Doe is survived by her daughter, Ann Marie, and a loving community of friends, colleagues, mentees, lovers, dance partners and family in every sense of the word. As a Métis (Ojibway/French Canadian) Deaf woman with other disabilities who was active in disability, queer, and feminist movements internationally, she was widely respected as a disability rights advocate and as an educator.

Abstract: Increasing numbers of students with disabilities participate in mainstream pre-college classes in preparation for higher education. Many educators and administrators have limited knowledge about specific accommodations that can facilitate learning for students with disabilities. Professional development has the potential to increase their knowledge and skills in this area. Simulations of disability experiences, such as completing tasks while covering eyes or sitting in a wheelchair, have sometimes been used to show learners what it is like to have a disability. This form of training has been criticized as inappropriate in the context of emerging paradigms of disability studies, which leads to the question: "Is the use of disability-related simulations ever appropriate?" In this article, we explore positive and negative aspects of disability-related simulations; paradigm shifts regarding approaches to disability studies; implications for training educators and administrators, and examples of disability awareness activities that maximize positive outcomes.

Key Words: postsecondary, simulations, training, disability awareness

Introduction

Despite the participation of increasing numbers of students with disabilities in mainstream pre-college and postsecondary classes, many educators and administrators have limited knowledge about legal issues, resources, and specific accommodations that can facilitate the learning of these students (Burgstahler, 2002; Burgstahler & Doe, in press; Dona & Edmister, 2001; Leyser, Vogel, Wyland, & Brulle, 1998; National Center for the Study of Postsecondary Educational Supports, 2000a, 2000b; Thompson, Bethea, & Turner, 1997). Effective professional development for faculty and administrators may result in increased success for students with disabilities in classroom participation and degree completion.

Training for educators and administrators has taken on many forms, including lectures, workshops and experiential learning. For many years, simulations of disability experiences, such as completing tasks while covering eyes or sitting in a wheelchair, have been used to *show* adult learners what it is like to have a disability. However, the use of this popular form of training has been criticized as inappropriate in the context of emerging paradigms of disability studies (French, 1992; Scullion, 1996). Is the use of disability-related simulations ever appropriate? In this article, we explore positive and negative aspects of disability-related simulations; paradigm shifts regarding approaches to disability studies; implications for training educators and administrators; and examples of disability awareness activities that maximize positive outcomes.

Simulation as a Learning Tool

A simulation creates a representation of elements of reality to develop a learning activity so participants develop skills, gain knowledge or change their attitude about that reality (Duke, 1986; Hertel & Millis, 2002). Learner-centered and engaging, these "problem-based units of learning are set in motion by a particular task, issue, policy, crisis, or problem" (Hertel & Millis, p. 18). During a simulation, participants "carry out functions associated with their roles and with the settings in which they find themselves. The outcomes of the simulation are not determined by chance or luck. Instead, participants experience consequences that follow from the ac-

tions" within the simulation (Hertel & Millis, p. 19). Ideally, the experiences of participants are as realistic as possible.

Simulations are often used to help organizations and individuals tackle challenging issues more quickly and in less risky ways than in real life experiences (Wenzler & Chartier, 1999). Whether delivered in face-to-face meetings or via computers, simulations can provide an engaging learning strategy within academic, organizational and business settings (Hunter & Clark, 1977; Randel, Morris, Wetzel, & Whitehill, 1992). In most simulations participants are given specific roles to play. Examples of simulations include medical education programs that employ computer-based simulations for developing surgical techniques and airplane pilots who "fly" maneuvers in simulator machines before attempting them in the air. In the social sciences and humanities, mock trials, and games are used to develop critical thinking and practical problem solving skills (Karraker, 1993).

Simulations have been found to stimulate interest in a topic and the desire to learn more (Brendemeier & Greenblat, 1981). They are reputed to change perspectives, increase empathy, increase self-awareness, and increase tolerance for ambiguity (Brendemeier & Greenblat). However, a specific simulation experience is not the same for every participant. What any single learner might experience depends on a great number of factors the instructor cannot control. These factors may include the similarity between the simulation experience and the participant's anticipation of the experience, and the cognitive styles, previous experiences, and personality types of participants and instructors. Critics of simulations often point to the lack of valid tools to measure specific outcomes of these experiences (Remus, 1991).

A second criticism of simulations is that even carefully designed tools that measure intended learning may neglect to measure unintended learning, sometimes referred to as the hidden curriculum, that is potentially quite negative (Gay, 2000). For example, in simulations dealing with attitudes towards cultural differences,

ethnocentricity, bias, and phobias can actually be reinforced instead of reduced (Bruschke, Gartner, & Sieter, 1993). An evaluation of an intercultural communications simulation called *BAFA BAFA* (Shirts, 1973) found evidence of a positive change in enthusiasm for learning, an intended result, and an increased ethnocentrism, an unintended result (Bruschke, Gartner, & Seiter). The simulated experience triggered negative and reactionary attitudes toward other cultures, and did not allow for more positive changes that might come from extended interaction across cultures (Bruschke, Gartner, & Seiter). In all types of simulations there is a risk of long-lasting unintended negative results.

Models of Disability

Social workers, medical doctors, special education teachers, disabled student service administrators, vocational rehabilitation counselors, and other professionals have historically focused on an individual's functional limitations and on accommodations specific to the individual in certain environments. Scholars in the field of disability studies have termed models, ideologies, paradigms, and theoretical frameworks based on this focus as *individual, medical,* or *functional-limitations* (Abberley, 1995; Gill, 1987; Hahn, 1988; Jones, 1996; Swain & Lawrence, 1994). In general, individuals who adopt this perspective hold a person's inadequacies responsible for disadvantages that they may experience. The focus of a professional who intervenes is on curing, rehabilitating, and accommodating the individual rather than on changing the individual's environment (Hahn, 1988).

In contrast, the *social* or *minority group* models of disability, which have gained credibility in many fields, argue that disadvantages associated with disabilities are primarily imposed by negative attitudes and systemic discrimination that result in system-wide barriers to information, communication, and the physical environment (Gill, 1987; Hahn, 1988; Jones, 1996; Oliver & Barnes, 1998; Swain & Lawrence, 1994). Proponents of these models of disability challenge perspectives that regard disability as simply an individual's medical problem or personal tragedy. Instead, they view people with dis-

abilities as citizens with civil rights to full access to information, education, public programs, employment, and transportation. Similarly, *interactional* models promote the idea that the interaction between the individual and the environment determines if a disadvantage exists at all. For example, inaccessible facilities create barriers for those who use wheelchairs for mobility, but with appropriately designed ramps, elevators, and physical spaces, the person using a wheelchair is not disadvantaged in this environment when compared to non-wheelchair-users.

Individual, *social* and *interactional* models are consistent with recent legislation such as the Americans with Disabilities Act of 1990, which promotes the participation of individuals with disabilities in the most inclusive settings possible, but also mandates that reasonable accommodations be provided as needed. This legislation promotes both systemic change and individual accommodation.

In educational environments, different models of disability play out in the contrast between providing accommodations and implementing universal design. Individual or functional limitations models are most prevalent in postsecondary education where the disability services counselor recommends specific adjustments to the learning environment for a particular student. Typical accommodations provided by the institution to an individual student with a disability include the provision of extended time on tests, printed materials in alternate formats (e.g., Braille, large print, electronic), sign language interpreters, and assistive technology. They all center on the limitations and needs of the individual student that result from his/her specific disability in relationship to a given learning activity, program, or service. In inaccessible situations, the student with a disability may provide his/her own accommodations as well, such as selecting courses in accessible classrooms, using assistive technology, and allocating extended time to complete reading assignments.

In contrast, proponents of *social* and *interactional* models of disability and of *universal design* suggest instructors and service providers consider diverse characteristics of potential students as they develop their curriculum, information resources, physical environment, programs and services, rather than wait until a student with a disability enrolls in a course or expresses an interest in participating in a program or entering a facility. They should consider the many characteristics of potential participants and make design decisions that produce environments and resources accessible to individuals with a broad range of abilities, disabilities, interests, and other characteristics (Bar & Galluzzo, 1999; Burgstahler, 2001; *Universal design for learning*, 2003; *What is universal design*, 2003). For example, if instructors provide all course materials on a website that employs universal design principles, their course materials will be accessible to almost anyone. Hence, a student who is blind and uses speech output technology will not need to request accommodations. As another example, a student who requires extra time on tests in many classes, may not need an accommodation in a course where the instructor gives take-home tests, in part, to address the variety of speeds at which his students complete their tasks. Employment of universal design principles thus reduces, but does not eliminate the need for "individualized" disability-related accommodations. For example, it is not reasonable to have a sign language interpreter in every class, but it is appropriate to provide interpreters in a class where a student who is deaf needs this particular accommodation.

Disability-Related Simulations

Some scholars and practitioners, including the authors of this paper, believe that in order to maximize the inclusion of individuals with disabilities in all life activities, (a) society must create accessible environments, (b) individuals with disabilities must develop strategies for dealing with functional limitations imposed by their disabilities, and (c) program and service staff must provide reasonable accommodations for people with disabilities. They warn that disability-related simulations as often practiced (a) promote functional limitations models of disability, but ignore social and interactional models of disability, (b) develop a sensitivity to functional limitations but do not provide an awareness of accommodations that, in some cases after a learning

period, increase functionality over time, and (c) ignore altogether the impact of developing a more inclusive environment through employment of universal design principles. Simulations, as often used in disability awareness training, involve "trying on" a physical, sensory, or cognitive impairment for a limited amount of time, and are sometimes followed by a discussion to explore what is learned (French, 1992; Scullion, 1999). Examples of these activities include nurses getting into wheelchairs to "see how it feels" (Scullion), architects with blindfolds navigating through buildings, and educators being assigned disabilities and asked to perform academic tasks like completing a test, performing a lab activity, or taking notes (Semple, Vargo, & Vargo, 1980).

The popularity of disability-related simulations may be due, in part, to how these often lively, entertaining activities engage learners (Clore & Jeffery, 1972; French, 1994). Simulations can create discourses about people with disabilities and social reactions to disability (Kiger, 1992). However, outcomes might also be detrimental. In actuality, most disability-related simulations are designed to result in negative feelings. By *disabling* participants and simulating problematic experiences, given their new limitations (Clore & Jeffery, 1972; French, 1992), participants learn how difficult it is to maneuver a wheelchair, how frustrating it is to be unable to hear or read, how frightening it is to be visually impaired, or how impossible it is to participate in activities without the use of their hands. They focus on what people with disabilities cannot do rather than on what they could do with appropriate access, technology, or skills. Critics of these types of simulations do not deny there are some difficulties associated with living with disabilities. However, they object to simulations that represent only a negative experience rather than a whole, contextual one.

Disability-related simulations, as typically practiced, do not do a good job of "simulating" the disability experience at all. They neither examine the reality of disability nor show how to resolve disadvantages experienced in society (Wilson & Acorn, 1979). Because a participant's "impairment" is for a short period of time, there is no chance for the learner to truly experience real physical limitations, chronic pain or cognitive limitations. More importantly, there is no opportunity for a participant to learn strategies to succeed, given the limitations imposed by disability and society. A person who is blind for 30 minutes will be disoriented. Someone living as a blind adult is able to navigate in familiar situations and even unfamiliar settings after receiving appropriate training. Likewise, pretending to be hearing impaired for ten minutes does not allow time for acquiring lip-reading or sign language skills. Sitting in a wheelchair for twenty minutes does not allow time to develop the upper arm strength necessary to operate a wheelchair efficiently. If the content of the simulation is not a true representation of a given reality, then that simulated experience cannot be expected to allow participants to gain insight into that reality.

Criticisms of disability simulations reach far beyond the limitations of actually simulating a "real" disability. Critics argue that in showing people the negative and difficult experiences of disability in such a way, simulations reinforce individual and medical models of disability. "By reproducing the frustrations of being deprived of sight, hearing, or mobility without the training and socialization that minimize these problems, these exercises [it is argued by critics] reinforce harmful attitudes about disability and disabled people" (Pfeiffer, 1989, p. 53). The experience may reinforce a belief that people with disabilities cannot do basic things such as travel independently, work, or attend school (French, 1992), and that having a disability is a state worse than death (Richardson, 1990). Rather than dismantling stereotypes, such simulations may reinforce these myths as well as feelings of sympathy for people with disabilities. Participants in disability-related simulations may even become frightened by the experience. This limitation of the simulation experience can have undesirable consequences. For example, through a simulation, a faculty member may learn about the challenges faced by a person who uses a wheelchair for mobility, but that faculty member might also conclude that a disability is so intolerable and limiting that s/he might subsequently become less willing to recommend students with this type of disability for a position in their field.

Another limitation of typical simulations is that focusing only on the disability of the individual does not point to the ways the design of the environment discriminates against people with a wide range of differences (Donaldson, 1980; Siperstein & Bak, 1980). This approach "neglects the significance of the built environment, social policies and what some consider to be institutionalized 'disablism'." Inasmuch as the focus of simulations remains at an individual level, political and social structures are not implicated as possible contributing causes of disability" (Scullion 1996, p. 501). For example, simulating the "view" of a web page using a text-to-speech system can demonstrate challenges faced by people who are blind. If the simulation ends without discussing how web pages can be designed to be accessible to visitors who are visually impaired, participants could be left with the notion the disability causes lack of access. This outcome is consistent with the individual or medical model of disability. Instead, proponents of social and interactional models and of universal design point out the web page designer, not the disability, created barriers through poor, inaccessible design. If universal design principles were employed when the web page was being developed, a visually impaired visitor can experience the full benefit of the content. This analysis of the construction of the problem as well as of the solution is more consistent with emerging social and interactional models of disability.

A Successful Simulation

One example of a simulation experience judged successful by the instructor incorporated sustained contact between students and the instructor, who is a wheelchair user. This management professor used a simulation with his students and reported the results of the exercise over a four-year period by conducting a content analysis of student journal entries. The purpose of the exercise was to help students to understand the stigmatization of people with disabilities rather than understand disability itself. One student at a time volunteered to simulate having a mobility impairment by sitting in a wheelchair. The rest of the learners observed how the university community responded to that person.

Students took turns in the wheelchair while conducting basic tasks such as entering buildings, eating in the cafeteria, and using the elevators. The person sitting in the wheelchair discussed the experience with the group, and the class shared what they observed. An extensive analysis of student journal entries concluded the exercise succeeded in improving attitudes about disability. Specifically, participants learned people tended to act in patronizing and demoralizing ways towards people in wheelchairs, and expected that a wheelchair user could not independently perform tasks. For example, student observers in the class were criticized by students not in the class for not "helping" the student in the wheelchair. Through these simulation experiences, students were able to identify stereotypes and myths they held, learn basic facts about disability, and form realistic perspectives on how people with disabilities are treated as a result of societal attitudes, not as a result of the condition itself (Pfeiffer, 1989).

Guidelines for Creating Effective Simulations

While some scholars argue that simulations of disability should never be used (Finkelstein, 1991; French, 1992), we feel carefully designed simulations are effective learning tools in specific situations. Well-designed simulations also reduce potential negative consequences, while they ensure participants explore accommodation strategies, as well as the design of resources and environments that minimize barriers for people with disabilities. Based on a review of the literature and the experiences of the authors, the following suggestions are offered to those who wish to use simulations that maximize positive outcomes for educators and administrators.

State Objectives Clearly

Make it clear to participants at the beginning of the activity what they will do and what they are expected to learn. "Unless the simulation is prefaced with a clear discussion of why we are doing this and what we hope to learn and is followed by a conscientious debriefing about critical thinking processes and values, norms and social change, the simulation has merely served as recreation" (Karraker, 1993, p. 136).

Ensure Voluntary Participation

Allowing people to decline participation eliminates reluctant or resentful participation, maximizes positive outcomes, and creates a sense of safety and trust. Those who choose not to participate may learn just as much from observing the experiences of others and critiquing the simulation activity.

Illustrate Challenges and Solutions Related to Both the System and the Individual

Avoid focusing exclusively on challenges imposed on individuals by a disability, and avoid comparing one disability experience to another in ways that devalue people. In particular, avoid activities that lead to conclusions such as "this disability is far worse than that one," or "I could never live with X, but I could handle Y." Use concrete examples to illustrate both barriers and strategies for overcoming barriers for people with disabilities (Westwood, Vargo, & Vargo, 1981). Some strategies should highlight solutions employed by an individual (e.g., the student's use of assistive technology to access a computer); others can show solutions implemented by other individuals (e.g., accessible Web page design). Make sure when participants learn about the disability experience they learn how people with disabilities cope with inaccessible environments and negative societal attitudes through advocacy, technology and interpersonal skills.

Demonstrate the Value of Universal Design

Simulations and debriefing discussions should examine the way in which a well-designed environment or activity can maximize access for everyone and minimize the need for individual accommodations. A simulation can be used as an opportunity to share information about how civil rights legislation, accessible design of technology and facilities, and inclusive social practices empower people and ensure equal opportunity. "[Administrators], teachers, and curriculum planners should examine learning outcomes closely and consider their role in tackling discrimination…" (French, 1992, p. 263).

Include Consumers in Planning and, When Possible, Delivery of the Simulation

Consult people with disabilities when developing simulations and, when possible, involve them in the delivery, debriefing, and evaluation of simulation activities (Scullion, 1999). By interacting with people with disabilities, learners may realize some of their own assumptions about people with disabilities are not based in reality and that people with disabilities are more similar than they are dissimilar to people without disabilities. By hearing from someone who has experience in being disabled, being discriminated against, and developing coping mechanisms, the learner may be able to understand some of challenges faced by people with disabilities and, more importantly, how these challenges may be successfully addressed. While a training activity involving a person with a disability is not as valuable as long-term contact, it can initiate a consciousness shift for people previously unfamiliar with disability issues (Biordi & Ooermann, 1993). However, when a person with a disability participates in a training activity, it should be made clear that one person cannot represent the views and experiences of all people with the same type of disability, and certainly cannot represent people with all types of disabilities.

Support Positive Attitude Change

Even though it can be awkward, participants should be encouraged to bring up personal beliefs or assumptions, even if negative, without fear of negative repercussions. Such disclosures can help all participants learn what underlying thoughts often inform discriminatory or exclusionary practices. Personal disclosure of changed attitudes provides a good role model to participants. Even for leaders who themselves have disabilities, it is useful to explain how their previous attitudes might have been dis-empowering. Some may be able to share their changed attitudes about people with types of disabilities other than their own. Training facilitators should point out that with changes to legislation, knowledge, and design, new perceptions about disability could emerge. Learners should leave with both knowledge and attitudes that support the rights of people with disabilities to participate in society.

Presenters should be prepared to recognize and handle situations where a simulated disability experience convinces faculty that students with disabilities are not suited to participation in postsecondary programs and careers in their field; when this situation occurs, potential universal design considerations and accommodations should be discussed as well as the essential functions of specific careers within a field of study.

Debrief Thoroughly and Reflectively Acknowledge Discomfort.

An important part of successful simulation activities is a full and meaningful debriefing to disengage participants from what is sometimes an emotional experience, as well as to sort out what was learned (Jones, 1995; Livingston & Kidder, 1993). During debriefing, participants can discuss what they felt and experienced and then reframe new knowledge and attitudes within the context of intended outcomes, perhaps replacing old attitudes and understandings with new. If faculty participants have unanswered questions, fears, and technical difficulties from simulations, they may deal with them in the debriefing instead of carrying them to the classroom. "Some people find the discovery process painful, which is an experience common to all forms of equality training. This is to be expected when exposing societal oppression and the part an individual participant could have unconsciously played in it" (London Boroughs Disability Resource Team, 1991). Trainers should acknowledge that learning about disability and difference can be uncomfortable. Allowing for written responses as well as discussion in small groups and with a larger group may ensure that each person has a chance to reflect on what happened in the simulation, and on what was learned from it.

Examples of Disability Awareness Activities that Maximize Positive and Minimize Negative Outcomes

The following two examples of simulations maximize the positive and minimize the negative outcomes for participants regarding attitudes and knowledge about disabilities.

Example One: Simulation of Computer and Web Access for Students who are Blind

Objective. To increase knowledge of assistive technology and accessible Web design for people who are blind.

Activity. Turning off the graphics-loading feature of your Web browser can simulate the experiences of students who are blind accessing a website, since their speech output systems read only the content presented as text on the screen. Instruct participants to access websites understandable (e.g., universally designed) in this mode and also those that are not. Then have participants access the same sites with the graphics-loading feature of their Web browser turned on.

Debriefing. Discuss the experiences of participants in the activity. They should be encouraged to share how, in the inaccessible site, key content could not be accessed when the graphics-loading function of their Web browser was turned off, and how gaining content from the accessible site in this mode was not difficult. Explain that their experiences were similar to those of individuals who are blind and using text-to-speech technology that can only access text–based elements of a website. Pointing out that the accessible site is a demonstration of universal design, ask how the universal design of a site can benefit people who are not blind (e.g., those using slower, older technology). If possible, have a student who is blind and uses text-to-speech technology and who is not a student of any of the participants demonstrate how he/she can listen to a synthesized voice as it reads text content on the screen. The student should use the system to read the content of the same websites that the participants accessed to show, with speech output, how easy it is to gain content from an accessible site and how some content at an inaccessible website is not available to a visitor who is blind. Encourage participants to ask questions about the assistive technology as well as about the design characteristics of an accessible website. Alternatives such as Braille output can be discussed as well as the application of text-to-speech technology for people with other types of disabilities (e.g., specific learning disabilities).

Example Two: Simulation of Hearing Loss

Objective. To increase faculty knowledge about the impact of hearing impairments on learning and their ability and willingness to incorporate instructional approaches that maximize access to learning for students who are hearing impaired.

Activity. Have participants listen to a tape-recorded mock spelling test and write down the words they hear. On the tape, common words are altered in volume and clarity to represent three types of hearing loss and amplification. One level represents a high frequency loss; some consonants are missing or made difficult to hear. Another level represents a conductive loss where all sounds are reduced in amplification, but somewhat detectable. The third level simulates how sound might be perceived through a hearing aid that amplifies (and distorts). When the spelling test is complete, present the correct answers on an overhead projection system or whiteboard, demonstrating how someone with a hearing impairment may misunderstand spoken words, but have access to them in an alternate, visual format.

Debriefing. The discussion that follows should deal with frustrations associated with straining to hear, and getting wrong answers. Address the need for good acoustics, amplification suited to the individual, and alternative forms of communication (e.g., lip reading, printed documents, and electronic mail). Some specific information about lip-reading, captioning, and technical aids could also be discussed. Participants should be able to ask questions about the mechanics of hearing, but the discussion should be directed at what can be done in a class to ensure a student who has a hearing loss is fully included and has an equal opportunity for success compared to students with hearing abilities within the typical range. The invisible nature of being hearing impaired should also be incorporated to reveal how faculty members might react if they think a student is not paying attention, when the issue is a hearing loss. If individuals who are hearing impaired are involved in delivering this training exercise, they could share how they learn best, alternative methods of accommodation, and answers to questions.

Conclusion

Negative outcomes from the use of poorly designed simulations include unintended attitudinal shifts, increased anxiety about working with individuals with disabilities, and misunderstandings about disability experiences. However, with appropriate designs, careful facilitation, open discussion, and involvement of people with disabilities, negative consequences of simulations can be avoided. Appropriate use of simulations and other exercises can demonstrate the relationships between the environment and individuals with a variety of characteristics, and can show how universal design and appropriate accommodations can enable and empower people with disabilities.

Dr. Sheryl Burgstahler directs project <u>DO-IT</u> (Disabilities, Opportunities, Internetworking and Technology) at the University of Washington. DO-IT promotes the success of students with disabilities in postsecondary programs and careers. DO-IT employs technology to help young people with disabilities achieve success in postsecondary education and careers. It sponsors programs that increase the use of assistive technology and promote the development of accessible facilities, computer labs, electronic resources in libraries, Web pages, educational multi-media and Internet-based distance learning programs.

Dr. Tanis Doe is a trained sociologist who works in education and advocacy with and for people with a range of disabilities. She acts as an external evaluator and research consult for several DO-IT projects at the University of Washington. Her Ph.D. is from University of Alberta in Sociology of Education and she completed a Fulbright session at the University of Washington School of Public Health. She was also the director of the NIDRR funded Research and Training Center for Independent Living and Disability Policy in Oakland California. In her spare time she performs wheelchair ballroom dancing.

References

Abberley, P. (1995). Disabling ideology in health and welfare: The case of occupational therapy. *Disability and Society, 10*, 221-232.

Americans with Disabilities Act of 1990, 104 Stat. 327. Retrieved May 1, 2004, from: http://www.usdoj.gov/crt/ada/statute.html

Bar, L., & Galluzzo, J. (1999). *The accessible school: Universal design for educational settings*. Berkeley, CA: MIG Communications.

Biordi, B., & Ooermann, M. H. (1993). The effects of prior experience in a rehabilitation setting on students attitudes towards the disabled. *Rehabilitation nursing, 18*, 95-98.

Brendemeier, M. E., & Greenblat, C. S. (1981). The educational effectiveness of simulation games: A synthesis of findings. *Simulation and gaming, 12*, 307-332.

Bruschke, J., Gartner, C., & Seiter, J. (1993, March). Student ethnocentrism, dogmatism and motivation: Study of BAFA BAFA. *Simulation & gaming, 23*, 9-15.

Burgstahler, S. (2002). Accommodating students with disabilities: Professional development needs of faculty. *To improve the Academy: Resources for faculty, instructional, and organizational development, 21*, 181-183.

Burgstahler, S. (2001). *Universal design of instruction*. Seattle, WA: DO-IT, University of Washington. Retrieved May 1, 2004, from http://www.washington.edu/doit/Brochures/Academics/instruction.html

Burgstahler, S., & Doe, T. (in press). Improving postsecondary outcomes for students with disabilities: Designing professional development for faculty. *Journal of postsecondary education and disability*.

Clore, G. L., & Jeffery, K. M. (1972). Emotional role playing, attitude change and attraction toward a disabled person. *Journal of personality and social psychology, 23*, 105-111.

Dona, J., & Edmister, J. H. (2001). An examination of community college faculty members' knowledge of the Americans with Disabilities Act of 1990 at the fifteen community colleges in Mississippi. *Journal of postsecondary education and disability, 14*(2), 91-103.

Donaldson, J. (1980). Changing attitudes toward handicapped persons: A review of the literature. *Exceptional children, 46*, 504-545.

Duke, E. S. (1986). A taxonomy of games and simulations for nursing education. *Journal of nursing education, 25*, 197-207.

Finkelstein, V. (1991). Disability: An administrative challenge, the health and welfare heritage. In M. Oliver (Ed.), *Social work, disabled people and disabling environments* (pp. 63-77). London: Jessica Kingsley.

French, S. (1992). Simulation exercises in disability awareness training: A critique. *Disability, handicap and society, 7*, 257-266.

French, S. (Ed.). (1994). *On equal terms: Working with disabled people.* Oxford: Butterworth-Heinemann.

Gay, G. (2000). *Culturally responsive teaching: Theory, research, and practice*. New York: Teachers College, Columbia University.

Gill, C. J. (1987). A new social perspective on disability and its implications for rehabilitation. In F. S. Cromwell (Ed.), *Sociocultural implications in treatment planning in occupational therapy* (pp. 49-55). New York: The Haworth Press.

Hahn, H. (1988). The politics of physical differences: Disability and discrimination. *Journal of social issues, 44*(1), 39-47.

Hertel, J. P., & Millis, B. J. (2002). *Using simulations to promote learning in higher education.* Sterling, Virginia: Stylus Publishing.

Hunter, M., & Clark, R. E. (1977, July). Simulation/ gaming research. *Educational technology, 17*, 44-46.

Jones, K. (1995). *Simulations: A handbook for teachers and trainers (3rd ed).* London: Kegan Page.

Jones, S. R. (1996). Toward inclusive theory: Disability as social construction. *NASPA journal, 33*, 347-354.

Karraker, M. (1993). Mock trials and critical thinking. *College teaching, 41*(4), 134-136.

Kiger, G. (1992). Disability simulations: Logical, methodological and ethical issues. *Disability, handicap and society, 7*(1), 71-78.

Leyser, Y., Vogel, S., Wyland, S., & Brulle, A. (1998). Faculty attitudes and practices regarding students with disabilities: Two decades after implementation of Section 504. *Journal of postsecondary education and disability, 13*(3), 5-19.

Livingston, S. A., & Kidder, S. J. (1993). Role identification and game structure: Effects on political attitudes. *Simulation & gaming, 4*, 131-144.

London Boroughs disability resource team. (1991). *Disability equality training materials guide.* London: CCETSW.

National Center for the Study of Postsecondary Educational Supports (NCSPES). (2000a). *National survey of educational support provision to students with disabilities in postsecondary education settings.* Honolulu, HI: University of Hawaii at Manoa.

National Center for the Study of Postsecondary Educational Supports (NCSPES). (2000b). *Postsecondary education and employment for students with disabilities: Focus group discussions on supports and barriers in lifelong learning.* Honolulu, HI: University of Hawaii at Manoa.

Oliver, M., & Barnes. C. (1998). *Disabled people and social policy: From exclusion to inclusion.* Essex: Addison Wesley Longman Limited.

Pfeiffer, D. (1989). Disability simulation using a wheelchair exercise. *Journal of postsecondary education and disability, 7*(2), 53-60.

Randel, J., Morris, B., Wetzel, C. D., & Whitehill, B. (1992). The effectiveness of games for educational purposes: A review of recent research. *Simulation and gaming, 23*(3), 261-276.

Remus, W. (1991). Experimental designs for analyzing data on games. *Simulation and gaming, 12,* 3-14.

Richardson, M. (1990). Disabled for a day. *Nursing times, 86*, 66-8.

Scullion, P. (1996). Quasidisability experiences using simulation. *British journal of therapy and rehabilitation, 4*, 292-293.

Scullion, P. (1999). Conceptualizing disability in nursing: Some evidence from students and their teachers. *Journal of advanced nursing, 29*, 648-657.

Semple, J. E., Vargo, J. W., & Vargo, F. A. (1980). Disability simulation and its effect on changing the attitudes of physical therapy students towards disabled persons: Some preliminary experimental results. *New Zealand journal of physiotherapy, 8*(2), 6-8.

Shirts, R. G. (1973). *BAFA BAFA.* Lajolla, CA: Simile II.

Siperstein, G., & Bak, J. (1980). Improving children's attitudes toward blind peers. *Journal of visual impairment and blindness, 56*, 132-135.

Swain, J., & Lawrence, P. (1994). Learning about disability: Changing attitudes or challenging understanding? In S. French (Ed.), *On equal terms: Working with disabled people* (pp. 87-102). Oxford: Butterworth Heinemann.

Thompson, A., Bethea, L., & Turner, J. (1997). Faculty knowledge of disability laws in high education: A survey. *Rehabilitation counseling bulletin, 40,* 166-180.

Universal design for learning. (2003). Retrieved May 1, 2004, from the Center for Applied Special Technology web site: http://www.cast.org/udl/

Wenzler, I., & Chartier, D. (1999). Why do we bother with games and simulations: An organizational learning perspective. *Simulation and gaming, 30,* 375-84.

Westwood, M. J., Vargo, J. W., & Vargo, F. (1981). Methods for promoting attitude change towards and among disabled persons. *Journal of applied rehabilitation counseling, 12,* 220-225.

What is universal design? (2003). Retrieved May 1, 2004, from the National Center for Universal Design web site: http://www.design.ncsu.edu/cud/univ_design/ud.htm

Wilson, E. D., & Acorn. D. (1979). Disability simulation and development of attitudes toward the exceptional. *Journal of special education, 33,* 303-7.

Acknowledgement

Improving Implicit Beliefs and Expectations in Academic Achievement for Postsecondary Students with Disabilities

Kelly B.T. Chang, Ph.D. Candidate
University of Hawaii at Manoa

Abstract: In this article, the author introduces the sociocognitive theory of implicit theories of intelligence (developed by Carol S. Dweck and her colleagues) to the field of rehabilitation, and analyzes disability issues in postsecondary academic achievement within this framework. This sociocognitive theory highlights the utility of the social model of disability. People hold two types of implicit beliefs about intelligence. An entity belief can lead to helplessness and negative self-concepts in the face of failure, because it focuses on labels and stable traits. An incremental belief leads to greater resilience in the face of failure by focusing on strategy and effort rather than on stable traits. The value of promoting incremental beliefs about intelligence in youth with disabilities is discussed in light of self-determination training, perception of opportunity, and transition to postsecondary education. Recommendations are presented for facilitating incremental beliefs in students with disabilities and improving the probability of academic success.

Key Words: motivation, academic achievement, students with disabilities, implicit beliefs

Introduction

Attitudinal barriers may disable people by limiting their opportunities to improve. Students with disabilities face low expectations for academic achievement (Berliner & Biddle, 1996; HEATH Resource Center, 1991; Kerka, 2002; National Council on Disability, 2000; R. A. Stodden, Conway, & Chang, 2003), and therefore are less likely to persevere through challenges, and less likely to succeed (Berliner & Biddle, 1996; R. A. Stodden et al., 2003). Attitudes of others affect how students see themselves and what they expect to achieve. Students with disabilities learn to comprehend their situations and abilities through feedback. Their inter-

pretations of this feedback may affect how hard they try and how well they do. In this process, attitudes students with disabilities face can either inhibit or encourage academic achievement.

There is no doubt students with disabilities are at greater risk of lower academic achievement than their peers without disabilities. One study found 22% of students with disabilities drop out of high school, compared to 12% of students without disabilities (Benz & Halpern, 1987). Youth with disabilities also attend postsecondary schools at lower rates than do those without disabilities. In a national longitudinal study, 19% of students with disabilities who graduated from high school went on to postsecondary education, compared to 53% of youth in the general population (Wagner & Blackorby, 1996). Of these, only 16% of students with disabilities who start postsecondary education finish with a bachelor's degree, compared to 27% of students without disabilities (U.S. Department of Education & National Center for Education Statistics, 1999). Achieving a postsecondary degree is important because the relationship between higher education attainment and positive employment outcomes is even stronger for people with disabilities than for people without disabilities. The more education they have, the more likely they are to be employed, especially in their chosen profession, and to earn higher wages (Hoyt, 2001, October; *Ladders of Opportunity*, 2001).

Changes in laws and the accommodation process from secondary to postsecondary school (Stodden, Jones, & Chang, 2002), attitudes of faculty and other students (Conway & Chang, 2003), and lack of resources and resource coordination (Whelley, Hart, & Zafft, 2002), as well as effects of disability on everyday postsecondary educational frustrations, all present barriers and challenges to students with disabilities. To succeed in postsecondary education, and in subsequent employment, students must overcome and persevere through these barriers. Therefore, it is important that educators, service providers, and families of students with disabilities become aware of the motivational factors that influence perseverance and success in postsecondary education. Motivational factors play a key role in

the completion of a degree, subsequent employment, career longevity and advancement.

In mainstream American society, where individual resolve and resilience are often necessary for success and pursuit of the "American Dream," how do environmental and attitudinal barriers influence people's self-concepts and motivation? Do students with disabilities internalize outside barriers and give up? How can they be helped to persevere in the face of such obstacles? Psychological research on motivation may provide some answers. In particular, research on resilience and perseverance in the face of failures, such as the work of Carol S. Dweck (1999) and her colleagues, point to several aspects of motivation to consider in efforts to improve students' chances of academic achievement and subsequent employment. The purposes of this article are to (a) describe Dweck's theory of implicit beliefs about intelligence and how these beliefs influence academic persistence and achievement and (b) apply this theory to issues affecting students with disabilities, such as self-determination, perception of opportunity, and transition into postsecondary education.

The Role of Student Expectations of Intelligence and Effort on Achievement: Implicit Beliefs About Intelligence

Psychological research may be useful when considering how to improve postsecondary outcomes. However, this wealth of knowledge about student motivation and perseverance appears untapped in much of the literature on disability issues. The author's goal is to apply important motivational concepts to the real world situations of postsecondary students with disabilities. Dweck's theory on the processes underlying persistence in performing difficult tasks is highlighted below, followed by an application to challenges faced by students with disabilities when they transition into postsecondary education.

People tend to view intelligence implicitly in two different ways, as established and validated by Carol Dweck and her colleagues (Bandura & Dweck, 1985; Dweck & Leggett, 1988; Elliot & Dweck, 1988; Henderson & Dweck, 1990; Mueller & Dweck,

1998). People with *entity beliefs* think intelligence is fixed. Therefore, they believe that one's level of intelligence is sustained over time, and that effort will not improve intelligence. People with entity beliefs tend to avoid challenges, because the risk of failure poses a threat to their perceived level of intelligence. In contrast, people with *incremental beliefs* think intelligence is malleable and that, with effort, intelligence can improve through practice. People with incremental beliefs tend to welcome challenges and perceive failure as part of the growing process. Both entity and incremental beliefs about intelligence have been demonstrated in elementary school students (Zietgert, Kistner, Castro, & Robertson, 2001), college students (Robins & Pals, 2002), and adults (Lim, Plucker, & Im, 2002), and in different ethnicities (Billings, 1999) and different countries (Lim et al., 2002; Silvera, Moe, & Iversen, 2000). Implicit beliefs about intelligence have been measured in different ways, depending on the population under study. A common method for measuring beliefs in adults is a questionnaire asking people to rate their agreement with statements like "you have a certain amount of intelligence, and you can't really do much to change it" (entity belief), or "you can change even your basic intelligence level considerably" (incremental belief).

Work on implicit beliefs about intelligence stemmed from observations of how people react to failure. "Failure" is usually represented in these studies by receiving a low score on a test, receiving feedback that performance on a task was poor, or hypothetical vignettes. Dweck and her colleagues (Diener & Dweck, 1978, 1980; Dweck, 1975; Dweck & Reppucci, 1973) described two distinct reactions to failure: the helpless response and the mastery-oriented response. *Helpless responses* include a sense of lack of control, self-degradation of intelligence, lower expectations, lower performance, and giving up. Helpless responders tend to attribute failure to their level of intelligence. People with the entity perspective often exhibit helpless responses to failure. In contrast, people with the incremental perspective often exhibit mastery-oriented responses to failure. A *mastery-oriented response* includes problem-solving for improvement, and focusing on trying harder, rather than on attributing blame for failure. In Zhao, Dweck, & Mueller's study (1998) comparing responses to failure between people with incremental beliefs, people with entity beliefs, and students who expressed depressive symptoms, college students were presented with hypothetical vignettes of failure, including failure on the Graduate Record Exam or in a class presentation. These students were then asked what they would think, how they would feel, and what they would do. Students with the entity perspective responded in exactly the same way as depressed students, and both groups were significantly different from students with the incremental perspective. People with entity beliefs and depressed students were more likely to make judgments of their entire intelligence on the basis of failure, saying things like, "I would think I was dumb." These two groups were also more likely to say they would be devastated and feel worthless and hopeless. Finally, they were more likely to report they would quit. In contrast, students with the incremental perspective talked about their strategies to turn failure into success or to increase effort.

Dweck and her colleagues also proposed the two different responses to failure are a result of different goals students emphasize when approaching a task. Again, two distinct types were identified; performance goals and learning goals (Dweck & Elliot, 1983; Elliot & Dweck, 1988). While both types are natural and can coexist, they sometimes conflict when students face decisions regarding tests of their intelligence. *Performance goals* involve a desire to achieve positive appraisal of competence, that is, to look smart. *Learning goals* involve a desire to learn new things and develop skills. Both types of goals may motivate students to achieve, but learning goals tend to lead to more mastery-oriented responses to failure, while performance goals tend to lead to more helpless responses to failure. Students who view a task as a means of learning new things welcome challenges and see mistakes as part of the learning process. However, when students view a task as a means of appearing smart, they don't want to risk making mistakes. They see failure as an indication of low intelligence. People can have both kinds of goals, but people with entity beliefs tend to have more per-

formance goals and people with incremental beliefs tend to have more learning goals.

Implicit beliefs about intelligence and achievement goals influence the meaning of effort. Students with incremental beliefs tend to see effort as a natural part of learning, while students with entity beliefs and performance goals see effort as an indica-

the person led to entity beliefs, performance goals, and helpless responses to failure. Praise such as "you are smart" or criticism such as "you are stupid" facilitates belief in a fixed level of intelligence. In contrast, praise or criticism that focused on strategy or effort led to incremental beliefs, learning goals, and mastery-oriented responses to failure. Praise such as "you used a good strategy" or criticism such as

Table 1
The Effects of Implicit Beliefs About Intelligence on Achievement Goals and Response to Failure

Belief about Intelligence	Achievement Goal	Response to Failure	Meaning of Effort

Incremental:
    Intelligence can
    be improved
    with effort
	Learning:
	    Tasks are a
	    means to gaining
	    knowledge and
	    developing skills
		Mastery-oriented:
		    Mistakes are part of
		    the learning process,
		    and the focus is on
		    trying harder and
		    problem-solving
			Effort is a natural
			part of the
			learning process.
			Even geniuses have
			to work hard.

Entity:
    Intelligence stays
    the same
	Performance:
	    Tasks are a
	    means of judging
	    or displaying
	    intelligence
		Helpless:
		    Mistakes are an
		    indication of low
		    intelligence, and the
		    focus is on failure and
		    negative emotions
			Effort is an
			indication of a lack
			of intelligence.
			Smart people can
			pass tests without
			working hard at it.

tion of low intelligence. "If you have to work hard to understand something, you're probably not very smart." The beliefs, goals, responses to failure, and meaning of effort described above are illustrated in Table 1.

If beliefs about intelligence influence goals, effort, and coping, then what, one might ask, influences beliefs? To answer this question, several studies were done on the effects of praise and criticism (Kamins & Dweck, in press; Mueller & Dweck, 1998). The results of these studies indicate that as children are raised, praise or criticism that focused on stable traits (i.e., something about the person that cannot be changed and is stable over time) within

"you need to try harder" indicate that the result of a task—whether successful or not—can be improved and is not bound to a stable level of intelligence. The implications of this research are that people learn either an incremental or entity perspective of intelligence as they grow through feedback from family, teachers and peers and that feedback can also play a vital role in changing beliefs about the stability of intelligence.

Conclusions drawn from this research contrast today's popular trend of praising innate intelligence to increase self-esteem. It is widely believed that if you praise students for their intelligence and attribute

their successes to their good traits (smart, good, etc.), then they will be more likely to perform well. This may be true, but problems arise when those students face failure. Since they have learned to attribute outcomes of their behavior to inner traits, they also attribute academic failure to lack of intelligence, and therefore respond to failure poorly by giving up or degrading themselves, even though they had high self-confidence and success before the failure.

Implicit theories also influence whether students acquire and use learning strategies (Chang, 2003). College students who were taught various strategies for better learning and test performance reported using strategies more in their studies if they had incremental beliefs, focusing on learning, effort, and practice. Students who reported using strategies less, believed that their need to use strategies indicated they were not smart, and they preferred to do what "felt natural," even if they knew the strategies worked. Their adherence to the entity perspective of intelligence prevented them from taking advantage of interventions meant to help them improve academic achievement.

Specific Issues in Postsecondary Education for Students with Disabilities

Self-Determination

A current priority in disability research and practice is preparing students with disabilities with the skills they need to manage their lives after high school. Self-determination has been viewed as vital to success for people with disabilities when they transition into postsecondary education (Izzo & Lamb, 2002). When introducing their concept of intrinsic motivation to the developing field of disability studies, Deci and his colleagues emphasized the importance of choice and control for people with disabilities, and the potential limiting effects of a system that does not allow them to make decisions for themselves (Deci & Chandler, 1986; Deci, Hodges, Peirson, & Tomassone, 1992). The area of self-determination has since evolved into a collection of skills and knowledge in which researchers suggest all youths with disabilities be trained. This collection includes self–awareness, self–advocacy, self-ef-

ficacy, decision-making, independent performance, self-evaluation and adjustment (Martin & Huber-Marshall, 1995). There are several programs, funded by the American government, that are meant to develop and implement programs to prepare students with disabilities for postsecondary education through self-determination training (Izzo & Lamb, 2002). Programs in America and other countries have been developing ways to enhance consumer self-determination (Callahan & Mank, 1998; Kilsby & Beyer, 2002; Rumrill, 1999; Wehmeyer & Bolding, 2001) and their involvement in developing their rehabilitation plan (Flannery, Slovic, Treasure, Ackley, & Lucas, 2002; Kilsby, Bennert, & Beyer, 2002).

These efforts to teach and implement self-determination skills must take into account implicit beliefs. Students with incremental beliefs about intelligence are more likely to acquire and use new strategies and skills than are students who have internalized entity beliefs (Chang, 2003). There may be a cyclical relationship between implicit beliefs about intelligence and acquisition of self-determination skills. Students with incremental beliefs may be more likely than students with entity beliefs to make self-determined choices based on higher expectations for improvement and academic achievement. Similarly, students with less knowledge of the influence of their disability on academic achievement and the effectiveness of accommodations may be more likely to believe they are "just stupid" and exhibit helpless responses to challenges. Students with entity beliefs about intelligence may be more likely to make choices based on their 'label,' fear of failure, and past successes.

With rapidly improving technology and a growing knowledge base about services and accommodations that improve the quality of life for individuals with disabilities, the potential for academic success for otherwise disabled people is stronger now than ever before. Unfortunately, many students with disabilities are not aware of this potential, either because they have not received appropriate services to help them succeed, or because of the low expectations of others. Ineffective accommodations—or no accommodations—can lead to academic failures, which students may

attribute to their disability. Low expectations of others can lead students to expect less of themselves. One student with a severe physical disability said:

> "In my senior year, I thought I didn't want to go to college, because some people in my high school told me that I might not be able to do it. So I stayed home for a year, and by the middle of February I was bored to death. So I called my rehab counselor and talked with him while my mom was at work. In March, I went to rehab evaluation, and they said I probably couldn't do it…" (National Center for the Study of Postsecondary Educational Supports, 2001, p. 1).

This student nearly gave in to the low expectations of others, but did not. He attended college, and at the time of his interview, had two years until graduation. He acted on an incremental belief and determined for himself that he would take on the challenge of going to college. Other students facing similarly low expectations may not have the resilience to persist if they believe intelligence is an unchangeable entity.

Perception of Opportunity, Choice and Control

A concept closely related to implicit theories of intelligence (i.e., belief in the ability to improve one's self is the concept of perception of opportunity (i.e., belief about the ability to improve the situation). Perception of opportunity is the degree to which an individual believes there are opportunities in the environment to achieve certain goals. Individuals who perceive opportunities to improve their situation (i.e., career advancement, educational attainment, etc.) may be more likely to exhibit mastery-oriented responses to situations than those who do not perceive such opportunities. Individuals who perceive an opportunity for innovation or advancement in their careers are more satisfied with their work (Derecho, 1996) and have a higher sense of subjective well-being and satisfaction in life (Catsis, 2002; Harlow & Newcomb, 1990). Perception of opportunity correlates positively with educational

expectations in secondary school students, which in turn correlates with educational aspirations and career expectations (Wall, Covell, & MacIntyre, 1999). And socially, perception of limited opportunity predicts adolescent alienation, even more so than socioeconomic status (Han, 1971).

Negative influences on perception of opportunity include stereotypes, lack of successful role models, and experienced or observed limits on opportunities (Durodoye & Bodley, 1997). External variables that have a positive effect on perception of opportunity include access to education, informal support (York, Henley, & Gamble, 1985) and formal efforts to improve career choice patterns (Dunn & Veltman, 1989).

While most research on perception of opportunity has been conducted in the context of gender and minority differences, it may also be an important factor for individuals with disabilities. Due to attitudinal and physical barriers, low expectations from others, and societal stereotypes, students with disabilities may have a lower perception of opportunity than students without disabilities. This can contribute to lower attainment in education, dropping out, and low persistence in careers. When individuals with disabilities perceive barriers to success (i.e., they have a low perception of opportunity), they are more likely to quit. Rumrill, Roessler, Longden, & Schuyler (1998) found perceived barriers to worksite accessibility and performance of essential functions related negatively to feelings of job mastery and job satisfaction.

Students who have met with many failures and who attributed those failures to limits within themselves rather than to the environment may have a lower sense of opportunity. Entity-oriented students would more often blame themselves for failures, even to the point of experiencing feelings of worthlessness and helplessness (Diener & Dweck, 1980). Therefore, when such students fail in their first college exams, they are less likely to recognize opportunities to improve the situation. Such maladaptive cognition can result in lower success rates. If students with disabilities are encouraged to see situations through the incremental perspective, they may

be more likely to set higher expectations and aspirations in education, experience a higher sense of well-being, and achieve more academically and vocationally than they would if they continued to interpret their situation through an entity perspective. Efforts to train consumers in strategies for expanding opportunities (i.e., job search skills, social skills necessary for requesting accommodations, etc.) and to expand perceptions of opportunity (i.e., through introduction to role models, job shadowing, and internships) have resulted in higher self-efficacy and increased motivation to study and pursue career options (Burgstahler, 2001; Rumrill, 1999).

Transition to Postsecondary Education

The transition from high school to postsecondary education is often complicated, for anyone. Going to a college or university often involves more freedom, and with it, more responsibilities. For example, students in high school are used to being reminded if they have homework due, but in college, they are responsible for remembering important dates themselves. Also, the entire grade for a course often depends on one-to-three tests and perhaps a paper. Whereas in high school, students have many opportunities to build up their grades through multiple homework assignments, and making mistakes on one of them does not make much of a difference. In college, most measures of student competence are highly concentrated. The amount and depth of material and the context in which tests are taken, and in which papers are written, tend to be very different from what students are used to in high school. In situations where students transition to a more demanding environment with higher stakes in performance, they are more likely to exhibit the differences in thinking between entity beliefs and incremental beliefs. In a study done by Henderson and Dweck (1990), students transitioning into junior high school showed significant differences in academic achievement between those with incremental and those with entity perspectives. Because of the higher standards, more difficult curriculum, and less personalized instruction, it was predicted that increased challenges and failures would result in helpless responses and lower

achievement for students with entity beliefs. Researchers found students with entity beliefs who did well in elementary school actually declined in class standing when faced with the challenges of junior high school. In contrast, students with incremental beliefs about intelligence did well in junior high school. This finding is important to remember for people who serve postsecondary students with disabilities, because for these students, the transition between high school and postsecondary education is even more difficult (Stodden et al., 2002).

Laws which protect the rights and services of students with disabilities change drastically from secondary school to postsecondary school. In high school, students are protected by the Individuals with Disabilities in Education Act (IDEA) of 1997, an educational act establishing federal programs that provide assistance, initiated and paid for by the government, and purposing to benefit the student and improve post-school outcomes. In postsecondary school, students are no longer served under the IDEA. Instead, they rely on civil rights laws, Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) of 1990, which primarily aim to ensure equity and nondiscrimination. In section 504 and the ADA, the government does not provide funding for support, but requires "reasonable accommodations" from government, private, and public organizations, including postsecondary institutions.

Under the IDEA, in high school, teachers are very aware of the special needs of their students and are part of a team which helps decide how best to meet those needs. However, in college or university, students are required to identify themselves as having a disability and to request accommodations from student services personnel and from faculty who are usually ignorant of disability issues (Stodden et al., 2002). While individuals with disabilities may get services from vocational rehabilitation, postsecondary support personnel and vocational rehabilitation services rarely work together the way teachers, related services providers, and parents in high school do. Therefore, students with disabilities not only have to cope with the traditional changes between secondary and postsecondary edu-

cation, but also with major changes in the process of accommodations.

Another transition issue is late diagnosis: 31% of students with disabilities have reported that their disability had not been diagnosed until college (Sharpe, 2003). These students are likely to have little understanding of accommodations that could assist them in postsecondary studies. If these students are not given enough counseling and information about coping with their disability, they may see their new label as just another word for "slow," and attribute their difficulties in class to a fixed amount of intelligence they cannot overcome. However, if they are introduced to strategies and technology to help them process information, they may learn to cope through a mastery-oriented response to challenges.

Effective coping is necessary for any transition to a new environment. When transition involves a change in academic standards, effective coping is affected by students' implicit perspectives of intelligence. Even students who are "gifted" high-achievers in high school may not cope well. If they have developed entity beliefs—trying to preserve their "gifted" label for self-worth—they may be threatened by an environment where they are no longer the smartest in the class, and exhibit helpless responses to the change (Dweck, 1999). All of the changes mentioned above could lead to either helpless or mastery responses, depending on whether the student believes intelligence to be malleable with effort or assumes it to be a fixed trait.

Vocational rehabilitation personnel, disability student services personnel, and transition specialists often find themselves counseling students who are learning to cope with all the new challenges in their environment. Although they have no control over the way in which students were raised and taught with entity or incremental beliefs about intelligence, they may notice how these beliefs affect student persistence or defeat. This may be a time of life when counseling toward an incremental perspective can impact the outcome of postsecondary education for students with disabilities.

Can anything be done for students who have entity beliefs and helpless responses to challenges? Motivational studies say yes. Although a study done by Robins and Pals (2002) indicated that implicit theories are relatively stable over the college years, another study by Aronson and Fried (1998, as cited in Dweck, 1999) revealed that interventions can be effective. A group of high-achieving students and a group of at-risk students, who exhibited a gap in achievement, were shown a film that taught an incremental perspective of intelligence. The film gave evidence that showed that biological changes in the brain result when people meet challenges and exert mental effort and that they become smarter because of it. Student GPA data, which was collected at the end of the term and again at the end of the school year, indicated that students who had seen the film showed a significantly reduced achievement gap between the achieving and the at-risk groups, compared to similar students who had not seen the film. In other research, Burgstahler (Burgstahler, 2000; Burgstahler & Cronheim, 2001, Fall) uses the internet to connect students with disabilities with mentors who are examples of how challenges can be overcome. With effective interventions, students with disabilities can be taught incremental beliefs about intelligence and effective coping strategies for the challenges they face as they transition to postsecondary education.

The application of implicit theories of intelligence to these key issues is summarized in Table 2.

Conclusion and Recommendations

Psychological research and theory in the area of education and motivation have greatly advanced. Theories about what motivates an individual to desire achievement, choose challenges, get up again after failing, and enjoy the educational process can make a difference for people if these theories are applied by service providers. Many instructional methods have their origins in psychological theory, and have been shown to work (Stipek, 1996). Other attempts to shape rehabilitation efforts according to psychological theory have resulted in improved out-

Table 2. Application of implicit beliefs about intelligence to transition issues

Implicit Beliefs	Self-determination	Perception of opportunity	Transition to postsecondary education
	A set of skills, including an understanding of oneself and one's disability, and the ability to control outcomes according to individual decisions, efforts, and preferences.	The degree to which an individual believes there are opportunities in the environment to achieve certain goals.	The change in environment, academic norms, legal entitlement, and supports that students with disabilities must cope with when moving from secondary to postsecondary education
Incremental	Individual with more choice and control in the academic setting is more likely to believe in the ability to change and learn mastery-oriented responses to challenges. Individual is more likely to make choices based on high expectations for improvement and academic achievement if he or she has an incremental perspective of intelligence.	Individual who has been taught to approach challenges and barriers with creative problem solving may experience a greater sense of opportunity and exhibit mastery responses to failures.	Individual who has an incremental perspective adjusts well to higher academic standards and challenges. Effective counseling and training in the use of accommodations can encourage a mastery approach to challenges.
Entity	Individual with less knowledge of the influence of their disability on academic achievement and the effectiveness of accommodations is more likely to believe they are "just stupid" and exhibit helpless responses to challenges. Individual is more likely to make choices based on his or her 'label,' fear of failure, and past successes.	Individual who has met with many failures and attributed those failures to limits within the self rather than the environment would have a lower sense of opportunity	Individual who is used to easy grades in high school may interpret lower grades in college as a judgment of real intelligence and respond helplessly to the loss of his or her "gifted" label. Inadequate accommodations and training can contribute to an entity belief about intelligence.

comes (Bell, Lysaker, & Bryson, 2003; Rumrill, 1999).

To promote incremental beliefs in students with disabilities and the people who work and live with them, recommendations for policy, practice and research are presented follow.

Recommendations for System Enhancement: Improving the Possibility of Success in Postsecondary Education

- Make universal design of instruction and universal design of technology a national priority. Students with disabilities will be able to achieve more if their environment facilitates their efforts to do the same things as people without disabilities.

- Improve technical assistance and training for students with disabilities to increase opportunities for academic achievement through the use of different strategies.

- Improve accountability and funding for effective accommodations in postsecondary schools to make the above recommendations possible and efficient.

- Improve collaboration between Vocational Rehabilitation, secondary and postsecondary schools to make the transition from secondary to postsecondary education smoother and to improve choice, control, and self-determination of consumers.

Recommendations for Rehabilitation Counselors and Postsecondary Education Disability Services: Taking an Incremental Approach to Service

- Emphasize the belief that students can improve. Know yourself — do you believe students can improve their performance or do you prejudge them based on their label?

- Assess incremental beliefs as part of the counseling process.

- Participate in incremental belief training. Promote personnel development on facilitating incremental beliefs, so students are taught to emphasize strategy and effort rather than fixed traits.

- Focus assessment feedback on incremental improvement rather than on labels or judgments of a fixed ability. Always present assessments of challenging areas with possible solutions. Do not just tell a person he is dyslexic, but also recommend technical assistance such as screen-reading software, books

on tape, note-takers, etc. If students still have difficulties, even with accommodations, try a different approach.

- Teach learning disabled (LD) students strategies for learning, with an emphasis on improving possibilities, rather than on deficiencies.

- Encourage students to analyze the processes involved in challenging situations, so potential changes in strategy or accommodations can be made.

- Connect students with mentors or role models who encourage incremental beliefs. Provide role models in the form of older students, graduates, adults in the same field, or even video stories. Hearing the success stories of people like themselves can help students to improve their self-efficacy and their belief that they can improve academically.

Recommendations for Further Study

- Research societal and educational factors that contribute to the development of implicit beliefs in students with disabilities.

- Research effective ways to facilitate and sustain incremental beliefs.

- Research implicit beliefs of various cultures and minority groups, and their effects on students at risk.

- Research potential for changing implicit beliefs in adults with disabilities.

- Pilot programs in vocational rehabilitation offices and in disability services offices to assist in creating a climate of incremental beliefs.

- Infuse incremental belief training in self-determination curricula.

The theory outlined in this article has implications for the academic success of students with disabilities. Promoting an incremental perspective of intelligence could help students with disabilities overcome attitudinal barriers and setbacks in classes, and

take on the challenges they face while navigating through systems and between educational settings. Among educators, families, and service providers, an increased understanding about the difference between entity beliefs and incremental beliefs could equip them to help students move from helpless responses to mastery-oriented behavior.

Kelly Bow Tsin Chang has an M.A. in Psychology in the area of Teaching, Learning, and Cognition, with an emphasis on student motivation and self-regulated learning, and is a Ph.D. candidate in the same field at the University of Hawaii at Manoa. She works as a research assistant for the National Center on Secondary Education and Transition, Post Outcomes Network, where she focuses primarily on issues of transition from secondary to postsecondary education. She can be contacted by email at Kelly.Chang@cds.hawaii.edu.

References

Americans with Disabilities Act of 1990, 42 U.S.C.A. 12101 *et seq.* (1993).

Aronson, J., & Fried, C. (1998). *Reducing stereotype threat and boosting academic achievement of African Americans: The role of conceptions of intelligence.* Unpublished manuscript.

Bandura, M., & Dweck, C. S. (1985). *The relationship of conceptions of intelligence and achievement goals to achievement-related cognition, affect, and behavior.* Unpublished manuscript.

Bell, M., Lysaker, P., & Bryson, G. (2003). A behavioral intervention to improve work performance in schizophrenia: Work behavior inventory feedback. *Journal of Vocational Rehabilitation, 18*, 43-50.

Benz, M. R., & Halpern, A. S. (1987). Transition services for secondary students with mild disabilities: A statewide perspective. *Exceptional Children, 53*, 507-514.

Berliner, D. C., & Biddle, B. J. (1996). Standards amidst uncertainty and inequality. *The School Administrator, 53*(5), 42-47.

Billings, B. L. (1999, April 15-18). *Ethnicity and individual differences in achievement goals in kindergarten children (ED 436288).* Paper presented at the Biennial Meeting of the Society for Research in Child Development, Albuquerque, NM.

Burgstahler, S. (2000). *Opening doors: Mentoring on the internet.* Seattle, Washington: University of Washington.

Burgstahler, S. (2001). A collaborative model to promote career success for students with disabilities. *Journal of Vocational Rehabilitation, 16*, 209-215.

Burgstahler, S., & Cronheim, D. (2001, Fall). Supporting Peer-Peer and Mentor-Protege Relationships on the Internet. *Journal of Research on Technology in Education, 34*(1), 59-74.

Callahan, M., & Mank, D. (1998). *Choice and control of employment for people with disabilities*, Paper prepared for The Robert Wood Johnson Foundation Self-Determination Initiative.

Catsis, C. T. (2002, March). Perception of opportunity for innovation and productivity in relation to subjective well-being of interior design educators at major universities in the United States. *Dissertation Abstracts International Section A: Humanities & Social Sciences, 62*(8-A), 2693.

Chang, K. B. T. (2003). *A Grounded Theory of the Acquisition of Learning Strategies in College Classrooms.* University of Hawaii, Manoa, Honolulu, Hawaii.

Conway, M. A., & Chang, K. B. T. (2003). *Personnel and Student Perceptions about the Role of the Postsecondary Disability Support Provider.* Unpublished manuscript, Honolulu, Hawaii.Deci, E. L., & Chandler, C. L. (1986). The importance of motivation for the future of the LD field. *Journal of Learning Disabilities, 19*, 587-594.

Deci, E. L., Hodges, R., Peirson, L., & Tomassone, J. (1992). Autonomy and competence as motivational factors in students with learning disabilities and emotional handicaps. *Journal of Learning Disabilities, 25*, 457-471. Derecho, C. N. (1996, March). Situational and dispositional factors in affective responses to work. *Dissertation Abstracts International: Section B: The Sciences & Engineering, 56*(9-B), 5206.

Diener, C. I., & Dweck, C. S. (1978). An analysis of learned helplessness: Continuous changes in performance, strategy and achievement cognitions following failure. *Journal of Personality and Social Psychology, 36*, 451-462.

Diener, C. I., & Dweck, C. S. (1980). An analysis of learned helplessness: (II) The processing of success. *Journal of Personality and Social Psychology, 39*, 940-952.

Dunn, C. W., & Veltman, G. C. (1989, October). Addressing the restrictive career maturity patterns of minority youth: A program evaluation. *Journal of Multicultural Counseling & Development, 17*, 156-164.

Durodoye, B., & Bodley, G. (1997, March). Career development issues for ethnic minority college students. *College Student Journal, 31*(1), 27-32.

Dweck, C. S. (1975). The role of expectations and attributions in the alleviation of learned helplessness. *Journal of Personality and Social Psychology, 31*, 674-685.

Dweck, C. S. (1999). *Self-theories: Their role in motivation, personality, and development.* Philadelphia: Psychology Press.

Dweck, C. S., & Elliot, E. S. (1983). Achievement motivation. In P. Mussen & E. M. Hetherington (Eds.), *Handbook of Child Psychology* (pp. 643-692). New York: Wiley.

Dweck, C. S., & Leggett, E. L. (1988). A social-cognitive approach to motivation and personality. *Psychological Review, 95*, 256-273.

Dweck, C. S., & Reppucci, N. D. (1973). Learned helplessness and reinforcement responsibility in children. *Journal of Personality and Social Psychology, 25*, 109-116. Elliot, E. S., & Dweck, C. S. (1988). Goals: An approach to motivation and achievement. *Journal of Personality and Social Psychology, 54*, 5-12.

Flannery, K. B., Slovic, R., Treasure, T., Ackley, D., & Lucas, F. (2002). Collaboration and partnership to improve employment outcomes. *Journal of Vocational Rehabilitation, 17*, 207-215.

Han, W. S. (1971, March). Alienation, deviation-proneness, and perception of two types of barriers among rural adolescents. *Social Forces, 49*, 398-413.

Harlow, L. L., & Newcomb, M. D. (1990, July). Towards a general hierarchical model of meaning and satisfaction in life. *Multivariate Behavioral Research, 25*, 387-405.

HEATH Resource Center. (1991). *Career planning and employment strategies for postsecondary students with disabilities*. Retrieved January 2, 2003, from http://www.heath-resource-center.org/PDFs/CareerPlanningandEmploymentStrategiesforPostsecondaryStudentswithDisabilities.pdf

Henderson, V., & Dweck, C. S. (1990). Motivation and achievement. In S. Feldman & G. Elliott (Eds.), *At the threshold: The developing adolescent* (308-329). Cambridge, Massachusetts: Harvard University Press.

Hoyt, K. (2001, October). Helping high school students broaden their knowledge of postsecondary education options. *Professional School Counseling, 5*(1), 6-13.

Individuals with Disabilities Education Act, 20 U.S.C. 1400 *et seq.* (1997).

Izzo, M., & Lamb, M. (2002). *Self-determination and career development: Skills for successful transitions to postsecondary education and employment.* Unpublished manuscript, A white paper developed for the National Center on Postsecondary Education Supports at the University of Hawaii at Manoa. Available online, at: http://www.ncset.hawaii.edu/Publications/Pdfs/self_determination.pdf

Kamins, M. L., & Dweck, C. S. (in press). Person vs. process praise and criticism: Implications for contingent self-worth and coping. *Developmental Psychology.*

Kerka, S. (2002). *Learning disabilities and career development*: ERIC.

Kilsby, M. S., Bennert, K., & Beyer, S. (2002). Measuring and reducing acquiescence in vocational profiling procedures for first-time job-seekers with mental retardation. *Journal of Vocational Rehabilitation, 17*, 287-299.

Kilsby, M. S., & Beyer, S. (2002). Enhancing self-determination in job matching in supported employment for people with learning disabilities: An intervention study. *Journal of Vocational Rehabilitation, 17*, 125-135.

Ladders of opportunity. (2001). California: California Community Colleges, Sacramento. Office of the Chancellor.

Levy, S. R., & Dweck, C. S. (1996, June). *The relation between implicit person theories and beliefs in stereotypes.* Paper presented at the Paper presented at the Annual Convention of the American Psychological Society, San Francisco, CA.

Lim, W., Plucker, J. A., & Im, K. (2002). We are more alike than we think we are: Implicit theories of intelligence with a Korean sample. *Intelligence, 30*, 185-208.

Martin, J. E., & Huber-Marshall, L. (1995). Choicemaker: A comprehensive self-determination transition program. *Intervention in School and Clinic, 30*(3), 147-156.

Mueller, C. M., & Dweck, C. S. (1998). Intelligence praise can undermine motivation and performance. *Journal of Personality and Social Psychology, 75*, 33-52.

National Center for the Study of Postsecondary Educational Supports. (2001). *Focus group discussions on supports and barriers in lifelong learning.* Honolulu: University of Hawaii at Manoa, Rehabilitation Research and Training Center.

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

Robins, R. W., & Pals, J. L. (2002). Implicit self-theories in the academic domain: Implications for goal orientation, attributions, affect, and self-esteem change. *Self & Identity, 1*(4), 313-336.

Rumrill, P. (1999). Effects of a social competence training program on accommodation request activity, situational self-efficacy, and Americans with Disabilities Act knowledge among employed people with visual impairments and blindness. *Journal of Vocational Rehabilitation, 12*, 25-31.

Rumrill, P., Roessler, R., Longden, J., & Schuyler, B. (1998). Situational assessment of the accommodation needs of employees with visual impairments and blindness. *Journal of Visual Impairment and Blindness, 92*(1), 42-54.

Sharpe, M. (2003). *Project Grad preliminary analysis, Institute on Community Integration.* Retrieved June 25, 2003, from http://www.rrtc.hawaii.edu/documents/products/phase2/pdf/059b(2)-H02.pdf

Silvera, D. H., Moe, S. K., & Iversen, P. (2000). The association between implicit theories of personality and the attributional process. *Scandinavian Journal of Psychology, 41*, 107-111.

Stipek, D. J. (1996). Motivation and instruction. In D. C. Berliner & R. C. Calfee (Eds.), *Handbook of Educational Psychology (pp. 85-113).* New York: Simon & Schuster Macmillan.

Stodden, R., Jones, M. A., & Chang, K. B. T. (2002). *Services, supports and accommodations for individuals with disabilities: An analysis across secondary education, postsecondary education and employment.* Unpublished manuscript, Honolulu, HI.

Stodden, R. A., Conway, M. A., & Chang, K. B. T. (2003). *Professional employment for individuals with disabilities.* Unpublished manuscript, Honolulu, HI.

U.S. Department of Education, & National Center for Education Statistics. (1999). *Students with disabilities in postsecondary education: A profile of preparation, participation, and outcomes (NCES 1999–187).* Washington, DC.

The Vocational Rehabilitation Act, 29 U.S.C. 701 *et seq.* (1973).

Wagner, M., & Blackorby, J. (1996). Transition from high school to work or college: How special education students fare. *The future of children: Special education for students with disabilities, 6*(1), 103-120.

Wall, J., Covell, K., & MacIntyre, P. D. (1999, April). Implications of social supports for adolescents' education and career aspirations. *Canadian Journal of Behavioural Science, 31*(2), 63-71.

Wehmeyer, M. L., & Bolding, N. (2001). Enhanced self-determination of adults with intellectual disability as an outcome of moving to community-based work or living environments. *Journal of Intellectual Disability Research, 45*, 371-383.

Whelley, T., Hart, D., & Zafft, C. (2002). *Coordination and management of services and supports for individuals with disabilities from secondary to postsecondary education and employment.* Unpublished manuscript, Honolulu. HI.

York, R. O., Henley, H. C., & Gamble, D. N. (1985, Fall). Barriers to the advancement of women in social work administration. *Journal of Social Service Research, 9*(1), 1-15.

Zhao, W., Dweck, C. S., & Mueller, C. (1998). *Implicit theories and depression-like responses to failure.* Unpublished manuscript.

Zietgert, D. I., Kistner, J. A., Castro, R., & Robertson, B. (2001). Longitudinal study of young children's responses to challenging achievement situations. *Child Development, 72*, 609-624.

Case Studies that Illustrate Achieving Career Success in Postsecondary Education through Self-Determination and Problem-Solving Skills

Peter W. Dowrick, Ph.D.
Center on Disability Studies, University of Hawaii

Elizabeth Evans Getzel, M.A.
Lori W. Briel, M.Ed.
Virginia Commonwealth University

Abstract: Conditions for students with disabilities in postsecondary education are improving and numbers are increasing. The potential for better outcomes may well be addressed through personal examples of effective support and accommodations. This article presents three case studies across a spectrum of conditions. These adults, with sensory, emotional, and/or cognitive disabilities, were 29 to 44 years of age, with a variety of life choices. They sought participatory guidance and support from a program at Virginia Commonwealth University. They explored career options around which to build degree programs in administration, exercise science, and photography. The emerging theme was the ability to create personal futures through self-determination and problem-solving.

Key Words: post secondary education, career planning, students with disabilities, self-determination, problem solving

Introduction

Research to identify strategies and practices that contribute to improved employment outcomes are imperative for enhancing career opportunities and quality of life outcomes for people with disabilities (Sharpe, Johnson, Mavis, & Rosen, 2001). The participation rate of these individuals in the United States (U.S.) labor force is alarmingly low compared to employment rates among people without disabilities (Gilmore, Schuster, Zaft, & Hart, 2003). In addition, individuals with disabilities experience lower average earnings, limited access to employee benefits, disproportionately high representation in low skilled jobs, and higher rates of poverty (Stodden & Dowrick, 2000). The completion of a postsecondary education that includes vocational training significantly improves the chances of employment success for men and women with disabilities (Gilson, 1996). Indeed, employment and salaries in the workforce have become increasingly skewed in favor of adults with a higher education (Dowrick & Crespo, 2004), and this difference is exacerbated for people with disabilities. Overall, educational opportunities maximize preparedness for careers in today's changing economy when students with disabilities learn higher order thinking and technical skills necessary to take advantage of current and future job market trends (Stodden, 2001).

In the 1990s, there was a 90% increase in the number of universities, technical institutions, community colleges, and vocational technical centers offering supports for adults with disabilities to continue their education (Stodden & Dowrick, 2000). In our best estimate, the percentage of students with disabilities enrolled in postsecondary education doubled in the late 1990s. In a National Center for Educational Statistics (NCES) study of 16 million U.S. students, 9% reported a disability in 1999-2000, although NCES (2002) cautioned this figure may not be comparable to previous years when a different set of questions was used. While increasing numbers of individuals with disabilities enroll in postsecondary education, many individuals experience difficulty continuing or completing their program of study (Heiman & Precel, 2003; N.O.D., 1998; Witte, Philips & Kakela, 1998). Factors contributing to low enrollment and high dropout rates for students with disabilities are not limited to the need for supports or services – they also include a host of systemic, socio-cultural, financial, and personal factors that impede academic progress (Stodden, 2001). While a considerable body of theoretical knowledge exists regarding the effectiveness of various services, supports, and programs in postsecondary education for persons with disabilities, much less information is available about the personal attributes that facilitate career growth and those that lead to successful futures (Dowrick & Skouge, 2001; Gartin, Rumrill, & Serebreni, 1996; Tindal, Heath, Hollenbeck, Almond, & Harniss, 1998).

In the last decade, there has been a substantial increase in the promotion of self-determination throughout the disability community. In their review of the link between education and employment, Stodden and Dowrick (2000) note "self-advocacy and self-determination—the abilities to express one's needs and to make informed decisions—are considered to be among the most important skills for students with disabilities to have before beginning their postsecondary educational experience" (p.21). The main elements of self-determination applicable in this context are typically described to include: Self-awareness (including self-assessment); Self-advocacy (recognizing and acting upon one's rights); Self-efficacy (a person's belief that he or she can perform an identified task); Decision-making (goal-setting and planning), and Independence (initiating tasks and adjusting goals) (Yuen & Shaughnessy, 2000).

Educators who facilitate self-determination for people with disabilities enable those individuals to play an active role in developing their own careers (Kilsby & Beyer, 2002). Similarly, goal-setting, problem-solving, and decision-making and other skills that lead to enhanced self-determination enable students to assume greater responsibility and control over their lives (Ward, 1996). Multiple studies indicate that students who obtain self-determination skills while attending school have a greater chance of achieving positive post-school outcomes than do students who have not acquired these skills (e.g., Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1998).

Today's growing body of knowledge suggests that providing opportunities for teaching and demonstrating decision-making and problem-solving skills greatly enhances a person's sense of self-determination. In the field of disabilities research, frameworks have been developed for teaching students self-determination. For example, Wehmeyer and Palmer (2003) describe students being taught to solve a series of problems to construct a causal sequence to move them from where they are to where they want to be. Research on academic success and problem-solving skills indicates that teaching problem-solving skills, such as the ability to devise strategies, techniques, and compensatory methods to adjust for a particular disability, greatly enhances students' ability to perform well in their present situations while building potential resolutions for encountering future obstacles (Columbus & Mithaug, 2003).

Case Studies on Disabilities in Postsecondary Education

Case studies may "put a human face on the postsecondary education issues" (Dowrick, 2000) and give full voice to consumer perspectives on topics such as postsecondary supports, scope and effectiveness of services, and employment outcomes. In particular, case illustrations offer details not available in surveys or aggregated data. The following three case studies emphasize how attributes such as self-determination and problem-solving may be fostered through postsecondary educational services. These traits may then promote career mobility and create foundations for future career success. The underlying themes of each case are presented and discussed, offering conclusions and recommendations for future teaching, policies, and research efforts.

The Career Connections Program at Virginia Commonwealth University (VCU) offers students with disabilities access to services and supports, provides internships, and maximizes university and community services (Briel & Getzel, 2001) to encourage positive career outcomes. Students are self-identified in their need for assistance and they direct the implementation of services provided. The VCU program offers job placement assistance, on-site strategies to facilitate learning, and coordination of community supports. The following three case examples illustrate the significant impact of VCU support services on access to career opportunities and life-long goals. These studies also demonstrate the strategies used in creating futures through problem-solving skills to attain career success and improved quality of life.

Case Example #1

"Dawn," 36 years old, completed her undergraduate degree in history with a minor in political science. Dawn obtained services through the federally funded comprehensive VCU Career Connec-

tions Program for postsecondary students with disabilities. Dawn developed Stargardt's Disease at a young age and became legally blind. While attending VCU, she contacted the Career Connections Program for assistance in securing employment. Dawn had minimal financially compensated work experience, but she had gained 10 years of leadership background in a volunteer organization. Dawn was frustrated with her lack of opportunity for professional employment. She had applied for many positions, but thought employers, after they discovered her visual impairment, would not call her for a second interview, let alone hire her.

The VCU staff worked with Dawn to develop an Individualized Career Plan to help focus on areas she needed to strengthen. Two primary areas emerged. First, she needed to revise her resume to emphasize her skills and abilities gained through her volunteer experience. The second area was learning how community services (e.g. The Virginia Department for the Blind and Vision Impaired) could assist with the provision of computer technology at the work site and how to communicate this information during an interview. She also took the initiative to research the skills requested by employers and gained proficiency in a variety of computer programs.

With assistance from the VCU Career Connections staff, a job lead was identified through the university career center. The VCU Career Connections staff contacted the employer and arranged a short meeting to establish a supportive relationship, further identify job duties, clarify work processes, assess the work environment of the company, and determine if the position would be a good match for the student. Information gathered reflected an independent position in which the employee would have his or her own computer and would communicate with representatives in 22 states. It was learned that the employer, a VCU alumnus, had never worked with anyone with a visual impairment and had little understanding of how technology could be used to enhance production. After a brief explanation of magnification software and closed circuit television screens, the employer reviewed Dawn's resume and eagerly set up an interview.

As a result, Dawn secured a 30-hour per-week position as a research associate for a non-profit organization that served over 400 cities, counties, and towns in 22 states. Dawn worked for the organization for almost 2 years. She remained in contact with the VCU Career Connections Program keeping them informed on how she was performing in her position. While in this position, Dawn enrolled in a Master's degree program at VCU and reconnected again with the Career Connections staff.

While working and going to school, Dawn decided to pursue another position and leave her Master's degree program. After resigning her position and before leaving her degree program, Dawn expressed an interest in pursuing a position in events planning and sought to capitalize on her strengths, her personal communication skills, ability to coordinate details, and ability to organize multiple levels of information. She wanted to see if ultimately she would seek an advanced degree to help her in this field. Several informational interviews were arranged for Dawn to learn more about the events planning field. Dawn secured a position on a medical campus coordinating physicians' schedules and education rotations. She brought with her the closed circuit television screen she had used in her previous position, and she installed Zoom Text software on her computer. Less than a year later, Dawn secured another position at the corporate headquarters of a company that manufactured and distributed credit cards. She was hired as an administrative assistant and received a salary $10,000 greater than in her previous job. Dawn worked in the distribution department, still using the closed circuit television screen originally purchased by the Department for the Blind and Vision Impaired. She then considered supplementing her education with a post-baccalaureate certificate in business management.

Dawn's example of career success illustrates the self-advocacy skills that are essential to the development of self-determination—for example, the ability to express her needs, to make informed decisions, and to advocate for those decisions (Yuen & Shaughnessy, 2000). Dawn also demonstrated the ability to "reframe" her disability experience through the understanding of her strengths and limitations,

and her belief in herself as being able to overcome the challenges by moving from a reactive to proactive stance (Shessel & Reiff, 1999). The promotion of self-determination was further nurtured through Dawn's encounters with the VCU Career Connections staff, which modeled effective education and advocacy skills with employers and consistently provided Dawn with opportunities to choose her goals according to her own interests. The VCU staff worked to maximize her strengths and problem solving. By providing connections to appropriate supports and opportunities for potential jobs relevant to Dawn's own interests, the staff worked to foster Dawn's persistence in pursuit of future success. The Career Connections program was able to identify locations for informational interviews using the VCU alumni office, the university career center, and other business contacts established through the program. This assisted Dawn to network with individuals in the field and offered an opportunity to discuss her strengths in a more comfortable setting than a formal job interview. Dawn often expressed that the VCU Career Connections program provided her an upper hand in the job market by educating employers about individuals with disabilities. The program staff members had the expertise about accommodating individuals with disabilities in the workplace and to work with these students on developing skills to manage their careers.

Case Example #2

"Bill," 29 years of age, had been diagnosed with anxiety and depression while in high school. In college, he majored in community wellness and exercise science. Bill contacted the VCU Career Connections Program after reading an article published in the local newspaper. He had experienced difficulties getting an internship site for his senior year and had chosen not to receive support through the college's services for students with disabilities.

Bill participated with the Career Connections staff to develop an Individualized Career Plan that focused first on securing an internship site. His work preferences were based on his recognized abilities and he was provided with direct assistance to secure a suitably appropriate internship. When the employer asked about learner accommodations, Bill was taught to indicate how important it was for him to repeatedly practice a new skill and to proceed at a moderate pace. He communicated how he could become easily stressed and that he dealt with stress through physical reactions. Previously, Bill had held a position as a grocery bagger for 2 years before being fired for a public outburst. Bill was not aware of stress management techniques and was unsure of what strategies to apply when under stress.

The VCU staff supported Bill and provided him with appropriate coaching to secure an internship at a local athletic club. On the second day of work, Bill asked the fitness director if he could go home, as he was not "feeling well." On the third day, the VCU Career Connections staff came on-site to assist Bill in structuring his time at work. They identified specific duties that could be completed throughout the day, such as helping at the front desk or cleaning the equipment. It soon became apparent to the Career Connections staff that when Bill had any idle time, he became agitated and wanted to leave the work place. To alleviate this problem, the staff modeled certain strategies for Bill including greeting customers, talking to co-workers, and taking a break in the staff office.

VCU staff again intervened when Bill had difficulty explaining how exercise machines worked. After repeated observations of workouts, Bill still could not explain how the machines worked. The Career Connections staff recommended Bill actively participate. To help him learn about the weight machines, Bill was asked to write the name of each machine and muscle group strengthened by it on a 3" x 5" card. He would then identify something important to remember about the specific machine and note it on the card. A refined strategy was later developed in which VCU staff modeled the explanation and demonstration of each machine, followed by Bill performing the same functions. The VCU staff also brought in customers to participate in sharpening Bill's skills.

Later in the year, Bill walked out of the club after a verbal exchange with the fitness director. Bill was frustrated with his inability to understand a spe-

cific job function he needed to complete. VCU staff encouraged Bill to identify potential stress management strategies including exercise, taking a break, and reading. With support from the VCU staff, Bill initiated a discussion with the fitness director about his disability and his need for accommodations when feeling stressed. He selected the tactic of excusing himself for a few minutes and walking outside in the parking lot as one primary strategy for coping with stress. The VCU Career Connections staff modeled this behavior for Bill and he later initiated this strategy independently while prodding a student with an introduction to the weight machines. Another useful strategy suggested for Bill by VCU staff was keeping a daily log of his activities and feelings to identify potential stressors. He was taught to review the previous day's entries and to remember the frequent stress-free days he had experienced to support his growing self-efficacy.

As Bill neared the completion of his internship, the VCU staff and the Virginia Department of Rehabilitative Services helped Bill to arrange informal interviews at health clubs, YMCAs, and recreational centers to network with employers and provide opportunities to practice his interviewing skills. He also received services from a job coach. Bill obtained a part-time position as a program assistant at a local YMCA near his home. Bill and the Career Connections staff discussed successful support strategies identified during Bill's internship at an informal meeting with his job coach. They then modified these effective strategies to fit the environment of Bill's new job in the aquatic department. For example, Bill's stress management technique of taking walks was modified at his new site to include swimming laps in the pool between aquatic sessions. Bill also maintained a journal and received one-on-one instruction from his job coach. Overall, Bill enjoyed his new job, demonstrated consistent attendance, and participated in various employee social activities on the weekends.

This case study illustrates the concept of *creating futures,* which includes divergent approaches to problem-solving and requires a person to invent new approaches that capitalize on the individual's strengths and that are not jeopardized by the individual's weaknesses (Dowrick & Skouge, 2001). Such strategies can be employed by adults with disabilities to enhance long-term employment success. When individuals generate unique solutions to fit their individual learning styles through brainstorming and problem-solving, they create images of future success that they have not previously achieved—known as *feedforward* (Dowrick, 1999).

Bill's ability to collaborate and problem-solve with his VCU Career Connections team and health club staff resulted in the development of unique methods and interventions specific to his challenges. Activities such as role playing, stress management, tasks development, and memorizing exemplify methods to facilitate success on multiple levels. Successful interventions and strategies were transferred into the subsequent work environment to ensure ongoing success.

Case Example # 3

At 44 years of age, "Steve" elected to pursue a career in professional photography. He had previously completed several years of coursework at a college in Rhode Island and later moved with his parents to Virginia. He transferred to Virginia Commonwealth University to complete his degree. In his late thirties, Steve was in a car accident and subsequently experienced depression. He was later diagnosed with attention deficit disorder and a learning disability. Steve's psychiatrist prescribed medication to assist with managing the attention deficits.

Steve contacted the VCU Career Connections program, wanting a part-time job in photography, his main field of interest. His long-term goals revolved around photography at special events, for magazines, or in studio work. He also had an interest in filmmaking. Steve felt intimidated by the interview process and lacked confidence about his ability to be successful in the photography field. He had not been interviewed in a long time and was uncertain about expectations in that profession.

Steve registered with the Disability Support Services on campus and received accommodations in his classes. He received extended time for tests and

assignments and he taped his lectures, but still struggled to maintain a grade point average of 2.3. He had difficulty with short-term memory and he transposed letters when reading and writing. Steve learned best in his "hands on" classes and he benefited from immediate feedback on his performance. His technical skills were excellent.

Steve's work history included several years of service in the Navy after high school, mill operator for 10 years, and a variety of odd jobs, including work as a substitute teacher and security officer. He reported that he required extra time to learn job tasks and that he used strategies to assist himself with learning (e.g., he wrote out formulas on 3" x 5" cards for mixing dyes at the mill). For recreation, Steve enjoyed camping, fishing, scuba diving, and boating. He had also been an assistant Scoutmaster for several years during which he taught boys photography and electronics for their merit badges.

To address Steve's academic issues, the Career Connections Program provided Steve with information about other campus resources such as the Writing Center, and regular workshops on topics including how to decode textbooks or prepare for finals. Fortunately, many of Steve's classes focused on technical skills. Since Steve's diagnosis had been relatively recent, contact information was also given regarding a support group for adults with attention deficit disorder.

It was agreed that participation in informal interviews would be a less threatening way for Steve to explore the photography profession. Steve preferred not to disclose his disability to his employers. VCU staff arranged several informational interviews with photographers, including specialists in a private studio, in a fine arts museum, and in aviation photography. The interviews were informal and included a review of Steve's portfolio, a review of his photographic equipment, and discussions concerning career options. VCU Career Connections staff provided Steve with suggestions of organizations to join and ways to get started in the field. The process built Steve's confidence in his abilities and his career choice.

Next, a summer internship was secured for him at a local newspaper by the Career Connections staff. The VCU School of the Arts encouraged qualified students to enter into limited and carefully selected internship arrangements, but did not have any available for the summer. The Career Connections staff and Steve felt that an internship opportunity would greatly assist him in learning more about the photography field and to gain further experience. Steve was provided with assistance in identifying opportunities and completing the application process. He took full advantage of the potential networking opportunities. He initiated travel to a local movie set connected with a film photographer. Steve's photograph of the movie set made the front page of the local newspaper and he delivered several copies to the film photographer. He developed and maintained a friendship with the film photographer, learned about additional ways to get started in the field, and job-shadowed this photographer at another movie location.

Throughout the next year, Steve participated in additional informational interviews with free-lance photographers, university media services, newspaper photographers, field producers, and job fair representatives. He eagerly followed suggestions made by employers, such as joining the National Press Photographers Association, a local film office, and the International Freelance Photographer's Organization, which enabled his photos to appear on their website. Through Steve's multiple contacts, he secured a position working as a photographer for a large agency through which he had the opportunity to photograph Rod Stewart and Reba McIntyre in concert. Steve now plans on marketing his photographs to various magazines to continue building his reputation and personal business.

The previous case scenario demonstrates how an internship setting can be an optimal place for developing self-determination skills. There is a positive relationship between individuals who develop an internal locus of control and the demonstration of self-determination. Research has indicated that as people have the opportunity to choose, and to make decisions and actions according to their own environment, they develop an internal locus of control

(Lefcourt, 1984) and individuals with disabilities gain control over major life events (Wehmeyer & Garner, 2003). Several researchers have questioned the possibility of developing self-determination for some individuals with disabilities who are consistently limited or denied the opportunity to make their own decisions (see Dowrick & Skouge, 2001). Steve's decision to enter the field of photography was an *internally driven* choice that was based on his interests and skill level. With the assistance of the VCU staff, Steve was able to self-advocate for his needed supports and to gain access to opportunities within his chosen field. Steve also demonstrated decision-making skills (e.g., setting goals and standards, identifying information upon which to base his decisions, generating new solutions when needed, and choosing the best option to develop a plan).

Discussion

This article summarizes experiences in the lives of three individuals. In each situation there were moments in which the system could have worked better for these students. In each case, the individuals were able to avail themselves of staff and other advocates from within their environment to give leverage to their own self-determination, often through considerable problem-solving and experimentation to find out what worked as a solution acceptable for them. There were instances of making connections between early employment experiences and current opportunities. Here it was mostly university-based staff who initiated a series of experiences that proved substantially responsible for the success of the graduating student in the workplace. Another evident theme which emerges is the students' considerable inner strength, perhaps the biggest factor in achieving their educational goals.

"Dawn" benefited from an early job success in launching a career. Her story illustrates the way in which prior employment can help employers focus their attention on previous work qualities, instead of her disability. This focus was partially brought about with Dawn learning about community supports available to her, and informing a potential employer about how technology enhanced her work performance.

Postsecondary educational training that provides internship experience can be crucial to preparation for employment. "Bill" succeeded in adapting to and compensating for his psychiatric disability. He benefited from working with support through on-the-job training situations that differed from college training. He was able to practice disclosing his disability, incorporating strategies into his work routine to help him learn a new work routine or to reduce his stress.

"Steve" elected not to disclose his disabilities to employers; however, he worked with the Career Connections staff to establish informational interviews to learn as much as possible about his profession. Steve's internship proved to be an invaluable experience for him. It enabled him to learn how to assess the demands of his work environment, and to determine if supports were needed to assist him in successfully meeting these demands.

The case studies presented in this article provide examples of students with disabilities who needed varying levels of support to better understand how to problem solve and request accommodations within their work environments. Each student needed to affirm their strengths and abilities, and used informational interviewing, job shadowing, or internships as mechanisms to test new strategies to effectively interact in the work place. As a result, these three students were able to pursue their chosen careers.

Peter W. Dowrick, Ph.D., is Professor of Disability Studies and Psychology at the University of Hawaii. He has wide experience working with people marginalized by culture, disability, mental health, and other considerations. His overarching contribution has been in the concepts of *feedforward* and *creating futures,* applied in situations of personal safety, serious mental illness, social behavior, sports and recreation, daily living, literacy, academic skills, health, housing, management, and jobs, among others. Correspondence concerning this article can be sent to: Dr. Peter W. Dowrick, 1776 University Av. UA 4-6, University of Hawaii, Manoa, HI 96822, USA, (808) 956-8741 (telephone), (808) 956-4371 (fax), or dowrick@hawaii.edu.

Elizabeth Evans Getzel, M.A., is the VCU-RRTC Director of Postsecondary Education Initiatives at Virginia Commonwealth University in Richmond, Virginia. She has over 20 years of experience conducting research, evaluation, and training in the areas of transition planning for secondary students with disabilities, postsecondary education for student with disabilities, and career planning/employment for individuals with disabilities.

Lori W. Briel, M.Ed., is a Research Associate at the VCU-RRTC in Richmond, Virginia. Currently, she provides comprehensive career planning and placement services for postsecondary students with disabilities. Additionally, she assists with the development activities for university faculty. She has co-authored several journal articles and a book chapter in these areas.

References

Briel, L., & Getzel, E. (2001). Internships in higher education: Promoting success for students with disabilities. *Disabilities Studies Quarterly.* Retrieved February 2004, from http://www.cds.hawaii.edu/dsq/_articles_pdf /2001/Winter/dsq_2001_Winter_06.pdf

Columbus, M. A., & Mithaug, D. E. (2003). The effects of self-regulated problem-solving instruction on the self-determination of secondary students with disabilities. In D. E. Mithaug & D. K. Mithaug (Eds.), *Self-determined learning theory: Construction, verification, and evaluation* (pp. 172-189). Mahwah, NJ: Erlbaum.

Dowrick, P. W. (1999). A review of self modeling and related applications. *Applied and Preventive Psychology, 8,* 23-39.

Dowrick, P. W. (2000). *Research findings brief: Case reports on students with disabilities in postsecondary education*. National Center for the Study of Postsecondary Education Supports, University of Hawaii at Manoa.

Dowrick, P. W., & Crespo, N. (2004). Prevention and treatment of school failure in adolescence. In T. Gullotta & G. Adams (Eds.), *Handbook on the treatment and prevention of dysfunctional behavior in adolescence.* New York: Kluwer/Academic (in press).

Dowrick, P. W., & Skouge, J. (2001). Creating futures: Potential of video empowerment in postsecondary education. *Disability Studies Quarterly, 21,* 59-76.

Gartin, B. P., Rumrill, P., & Serebreni, R. (1996). The higher education transition model: Guidelines for facilitating college transition among college bound student with disabilities. *Teaching Exceptional Children, 28*(5), 30-33.

Gilmore, S., Schuter, J., Zaft, C., & Hart, D. (2003). Postsecondary education services and employment outcomes within the vocational rehabilitation system. *Disabilities Studies Quarterly, 21.* Retrieved September 2003, from http://www.cds. hawaii.edu/dsq.

Gilson, S. F. (1996). Students with disabilities: An increasing voice and presence on college campuses. *Journal of Vocational Rehabilitation, 6,* 263-272.

Heiman, T., & Precel, K. (2003). Students with learning disabilities in higher education: Academic strategies profile. *Journal of Learning Disabilities, 36,* 246-256.

Kilsby, M. S., & Beyer, S. (2002). Enhancing self-determination in job matching in supported employment for people with learning disabilities: An intervention study. *Journal of Vocational Rehabilitation, 17,* 125-135.

Lefcourt, H. M. (1984). New directions in research with the locus of control construct. *Psychological Studies, 29,* 107-111.

National Center for Education Statistics. (2002). *The 1999-2000 National Postsecondary Student Aid Study*. Washington, DC: US Department of Education.

National Organization on Disabilities. (1998). *N.O.D./Harris survey of Americans with disabilities.* Washington, DC: Louis Harris & Associates.

Sharpe, M., Johnson, D. A., Mavis, A., & Rosen, D. (2001). Individual experiences of persons with disabilities with state employment systems. *Journal for Vocational Special Needs Education, 23*(2), 32-41.

Shessel, I., & Reiff, H. B. (1999). Experiences of adults with learning disabilities: Positive and negative impacts and outcomes. *Learning Disability Quarterly, 22*, 305-316.

Stodden, R. A. (2001). Postsecondary education supports for students with disabilities: A review and response. *Journal for Vocational Special Needs Education, 23*(2), 4-10.

Stodden, R. A., & Dowrick, P. W. (2000). Postsecondary education and employment of adults with disabilities. *American Rehabilitation, 25*(3), 19-23.

Tindal, G., Heath, B., Hollenbeck, K., Almond, P., & Harniss, M. (1998). Accommodating students with disabilities on large-scale tests: An experimental study. *Exceptional Children, 64,* 439-450.

Ward, M. J. (1996). Coming of age in the age of self-determination: A historical and personal perspective. In D. J. Sands & M. L. Weymeyer (Eds.), *Self-determination across the life span: Independence and choice of people with disabilities* (pp. 1-16). Baltimore: Paul H. Brookes.

Wehmeyer, M. L, & Garner, N. W. (2003). The impact of personal characteristics of people with intellectual and developmental disability on self-determination and autonomous functioning. *Journal of Applied Research in Intellectual Disabilities, 16*, 255-265.

Wehmeyer, M. L., & Palmer, S. B. (2003). Adult outcomes for students with cognitive disabilities three years after high school: The impact of self-determination. *Education & Training in Developmental Disabilities, 38,* 131-144.

Wehmeyer, M., & Schwartz, M. (1998). The self-determination focus of transition goals for students with mental retardation. *Career Development for Exceptional Individuals, 21*(1), 75-86.

Witte, R. H., Philips, L., & Kakela, M. (1998). Job satisfaction of college graduates with learning disabilities. *Journal of Learning Disabilities, 31*, 259-265.

Yuen, J. W. L., & Shaughnessy, B. (2001). Cultural empowerment: Tools to engage and retain postsecondary students with disabilities. *Journal of Vocational Rehabilitation, 16*, 199-207.

Author Note

Research Synthesis on Assistive Technology use by People with Learning Disabilities and Difficulties

Kelly D. Roberts, Ph.D., ATP
Robert Stodden, Ph.D.
Center on Disability Studies
University of Hawaii, Manoa

Abstract: In this article, we provide a synthesis of the literature available on the use of assistive technology (AT) by elementary through postsecondary education students with learning disabilities and/or difficulties. The synthesis addresses the following questions: 1. What types of AT are being used in educational and workplace settings? 2. What are the outcomes for students with learning disabilities and difficulties who use AT? 3. What types of AT, as used by students with learning disabilities and difficulties, necessitate additional research, and 4. Does the use of AT improve performance and retention rates? Answers to these questions are based upon analysis of seven articles found through an extensive literature search based upon the following criteria: (a) Empirical studies on AT; (b) Studies published in refereed journals; (c) Study participants attending elementary through postsecondary educational institutions; (d) Non-mainstreamed technologies (i.e. technology not used regularly by people without disabilities such as spell checkers, grammar checkers, word processing software, educational software); (e) Technology that is used to compensate for learning difficulties and not used to remediate, and (f) Study participants identified as having a learning disability or learning difficulty. Overall, the use of AT as a compensatory strategy by students with learning disabilities and/or difficulties was shown to be effective.

Key Words: assistive technology, learning disabilities or difficulties, voice recognition software

Introduction

The United States Office of Education (1977) defines "specific learning disability" as: "A disorder in one or more of the basic psychological processes involved in understanding or in using language, spo-ken or written, which may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations. The term includes such conditions as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. The term does not include children who have learning problems that are primarily the result of visual, hearing, or motor impairments; mental retardation; emotional disturbance; or environmental, cultural, or economic conditions." For purposes of this literature review the terms learning disabled and learning difficulties were both used in the search process as current research indicates that it is virtually impossible to differentiate between those labeled slow learners and those labeled learning disabled based on tests of cognitive functioning (Lyon et al., 2000).

It is estimated that 15% of all school-aged children have one or more type of learning disability (Johnson & Blalock, 1987). Research indicates that the academic difficulties experienced by these children in elementary and secondary school persist into adulthood (Gerber, Ginsberg, & Reiff, 1992; Johnson & Blalock, 1987; White, 1985). Yet, an increasing number of secondary students are choosing to continue their education (Higgins & Zvi, 1995). In 1991, 8.8% of full-time college freshmen reported having some form of disability, compared with 2.6% in 1978. Of the types of disabilities reported, learning disabilities were the fastest growing group, increasing from 15% to 25% of all students with disabilities over the 13-year period (Henderson, 1992). These data demonstrate an increase in the number of people with learning disabilities attending college, but they do not show the number of students graduating. Vogel and Adelman (1992) indicate that young adults with learning disabilities have low postsecondary graduation rates and tend to take longer to complete their program of study compared to their peers without disabilities.

Even though people with learning disabilities often form their own compensatory strategies (ways to circumvent deficits) through "trial and error" or via "training," which then helps them to counterbalance their learning disabilities (Schumaker, Deshler, & Ellis, 1986), there may still be persistent

areas of difficulty. Estimates of the number of adults with learning disabilities who exhibit written language disorders range from 80% to 90%. Eighty percent of people with learning disabilities are estimated to have a reading disability (Blalock, 1981).

For persons with learning disabilities and or learning difficulties, AT may provide a new compensatory strategy for reading and writing (The Alliance for Technology Access, 1994). Raskind (1993) indicated that although remedial and compensatory strategies are beneficial for adults with learning disabilities, the compensatory approach "may offer the most expeditious means of addressing specific difficulties within particular contexts" (p. 159). Raskind (1993) also points to the frustration and burnout adults with learning disabilities experience as a result of years of remedial instruction that yielded little benefit, and the appeal of immediate solutions to particular problems as reasons to support the use of AT.

The purpose of this synthesis is to examine articles on the use of AT as a compensatory strategy by persons with learning disabilities and learning difficulties in elementary through postsecondary settings, thus answering the following questions:

1. What types of AT are being used in educational and workplace settings?

2. What are the outcomes for students with learning disabilities and difficulties who use AT?

3. What types of AT, as used by students with learning disabilities and difficulties, necessitate additional research?

4. Does the use of AT improve performance and retention rates?

Overview of Assistive Technology

AT is defined as any item, piece of equipment, or product system, whether acquired commercially off-the-shelf, modified, or customized, that is used to increase, maintain or improve the functional capabilities of individuals with disabilities (The Technology Related Assistance for Individuals with Disabilities Act of 1988).

In reviewing the literature on AT for people with learning disabilities no articles included empirical data on any types of learning disabilities other than those related to reading and writing. Three forms of AT seem to be particularly suited to advancement of the reading and writing process for individuals with learning disabilities and/or learning difficulties. These include (a) optical character recognition (OCR), (b) speech synthesis (SS), also known as screen readers, and (c) voice recognition software (VRS), also referred to as speech recognition.

OCR software is used with a scanner to convert images (i.e., text material such as chapters from books, newspaper articles, and other printed material) to text and create documents, which can be "read" back to the user, using SS. SS provides auditory feedback via the computer. Some SS programs actually highlight the text, word for word, as it is being "spoken." The premise is that persons with learning disabilities often have phonetic awareness problems that negatively influence their ability to decode words, thus affecting their ability to comprehend written text (Stanovich, Cunningham, & Freeman, 1984; Adams, 1990). Having text read out loud should increase comprehension.

VRS allows the user to operate the computer by speaking rather than using the keyboard and mouse. Using VRS, the user speaks into a headset-mounted microphone; the system then converts the spoken words to electronic text displayed on the computer screen and entered into a word processing document (Riviere, 1996). The document can be saved and edited. It can also be read back using a speech synthesizer. For persons with learning disabilities and/or learning difficulties, who often face difficulties with written language and spelling, voice recognition allows them to use their oral language abilities, which frequently precede and exceed their written performance (King & Rentel, 1981).

To best employ these forms of AT as compensatory strategies for persons with learning disabilities and/or learning difficulties in multiple settings, an understanding of the research and strategies applied

to date is imperative. What has and has not been effective in the past needs to be evaluated so effective strategies and AT devices can be implemented to a greater degree and ineffective strategies eliminated or revised.

Method

This literature synthesis reviews six studies from peer reviewed journals. The criteria used for article selection was that they be (a) empirical studies on AT, (b) published in refereed journals, (c) based on study participants who are in postsecondary educational institutions and workplace settings, (d) focused on non-mainstreamed technologies (i.e. technology not used regularly by people without disabilities, such as spell checkers, grammar checkers, word processing software, educational software), (e) focused on technology that is used to compensate for learning difficulties and not used to remediate, and (f) based on study participants identified as having a learning disability or learning difficulty. Originally, the intent was to review articles on the use of AT by persons with learning disabilities in postsecondary education and in the workforce. Due to the limited number of articles that met the criteria, however, the synthesis was expanded to include three articles that investigated the use of AT by students in grades 4 through 12 (Leong, 1992; Leong, 1995; Wetzel, 1996). Two of these articles (Leong, 1992; Leong, 1995) also investigated students with learning difficulties rather than diagnosed learning disabilities. Because there are questions as to whether there are psychometric differences between the two groups (Ysseldyke, et al. 1983) these studies were deemed acceptable for inclusion in this synthesis.

For this literature synthesis four databases were searched: Educational Resources Information Center (ERIC), PubMed (MEDLINE), Info Trac (Expanded Academic Index ASAP), and PsyInfo. Ancestral and hand searches were also performed. The timelines specified did not include a beginning or end date. Ancestral searches were performed by reviewing the reference lists of articles that met the criteria as well as articles that reported anecdotally on the effectiveness of AT. Hand searches of the *Journal of Learning Disabilities*, *Exceptional Children*,

and *Learning Disabilities Quarterly* were performed for the years 1999 to 2003 and yielded no additional articles. Search terms included "learning disabilities", "assistive technology," "learning difficulties," "postsecondary education," "adults," "workplace," "workforce," "employment," "technology," "speech recognition," "university," "voice recognition," "reading," "text-to-speech," "dictation," and "college." These terms were searched for individually and in combination. A total of 53,753 articles were found with a search in ERIC using the keyword "technology." Due to this high number, "technology" was combined with "learning disabilities" and 427 articles were found. Many of these articles appeared in search results from all four databases. There were no articles found when the keywords "technology" and "learning disabilities" were used that did not appear in the search when the keywords "assistive technology" and "learning disabilities" were used. When the terms "learning disabilities" and "assistive technology" were used, ERIC yielded 49 articles, PSY INFO found 13, ASAP found 11, and PubMed found 53. Fewer articles were found with a keyword search using "assistive technology" and "learning difficulties," with all articles found under this search included in the keyword search for "learning disabilities" and "assistive technology." Ancestral and hand searches did not yield any articles that were not included in the database searches. After reviewing the articles found by the database, ancestral, and hand searches, six articles met the criteria for inclusion in the synthesis. While there were numerous articles that reported on the use of AT as a remedial tool the intent of this synthesis was to investigate AT used as a means to compensate for learning disabilities and difficulties.

Results

This section reports on the results of the literature synthesis including demographics, study variables, and literature review questions.

Demographics

Table 1 shows the demographics of the participants in each study reviewed. The number of participants in each study ranged from 1 to 192. In the

Table 1. Demographics

Author(s)	#	M/F	AGE/ Grade	Disability	IQ/ mean/ range	ESL/ ethnicity	Achvmt scores	SES
Higgins & Raskind, 1995	29	17/ 12	15% Fresh, 17% Soph., 29% Jr. 27% Sr. 12% Grad. Avg. age 24.9yrs	LD	Mean 97	3 Af-Am 23 Caucas. 3 Hispanic	Mean Written Lang. Score 83.5	On a 1-5 scale (1=low SES & 5=high SES) 1=1, 2=3, 3=16, 4=9, 5=0
Higgins & Raskind, 1997	37	N/A	N/A	LD	Mean 97	4 Af-Am, 27 Caucas, 5 Hispanic, 1 Asian-Am	Mean rdg. comp. 88.0 on Woodcock-Johnson Psycho-Educational Battery part I	On a 1-5 scale (1=low SES & 5=high SES) 1=1, 2=3, 3=23, 4=10, 5=0
Leong, 1992	67	N/A	32 grade 6, 27 grade 7, & 8 grade 8 Avg. age 12.5 yrs	Learning difficulties	N/A	N/A	N/A	N/A

studies that indicated gender there were more males than females with a ratio of approximately 3 to 2. Age and grade ranges were from age 9 to 37 and grade 4 to graduate school respectively. Disability categories were learning disabled with two studies (Leong, 1992; Leong, 1995) identifying students as having learning difficulties. IQ's ranged from 74 to 137. Ethnicity was varied. Achievement scores were reported from a range of tests. In general the reported achievement levels were average. In the studies that indicated socioeconomic status (Higgins & Raskind, 1995; Higgins & Raskind, 1997; Raskind & Higgins, 1995) the majority of participants self-identified as middle class.

Study Variables

Table 2 shows the various types of interventions used, the methods of selecting subjects, study design and analysis, study variables, and the findings for the six studies reviewed. Two studies investigated the use of VRS (Higgins & Raskind, 1995; Wetzel, 1996) and four studies researched the use of SS and OCR software (Higgins & Raskind, 1997; Leong, 1992; Leong, 1995; Raskind & Higgins, 1995). The duration and quantity of intervention ranged from three essays being written over an unspecified time to 18 weeks of intervention. Selection of subjects was not indicated in the six studies. Design and analysis of the studies varied with one study using a post-test only (Higgins & Raskind, 1995), two using ANOVA (Higgins & Raskind, 1997; Leong, 1992), one using ANCOVA (Leong, 1995), one using z-scores (Raskind & Higgins, 1995), and one not indicating a method of analysis (Wetzel, 1996).

Dependent Variables

Dependent variables in the articles reviewed were; composition performance, reading comprehension, spelling, word recognition, proofreading, long-term effects on academics, behavior, attitudes and retention, and written language difficulties. The most frequently reported dependent variables were reading comprehension, which was investigated in

Table 1 (continued). Demographics

Author(s)	#	M/F	AGE/ Grade	Disability	IQ/ mean/ range	ESL/ ethnicity	Achvmt scores	SES
Raskind & Higgins, 1995	33	19/ 14	College age range 19-37 Avg. age 24.9	LD	88-116 mean 101	3 Af-Am, 25 Caucas, 4 Hispanic, 1 Asian-Am	Range 72-108 avg. 86 on the Woodcock-Johnson battery part II	25 mid/ up-mid class, 1 lower SES, 1 Upper Class
Wetzel, 1996	1	1/0	Grade 6	LD	Full scale 111	N/A	Wood-cock Johnson Achvmt at grade 5.7- rdg 4.0, mth 5.8, splg 3.9 & word attack 3.0	N/A

# = Number of study participants   LD = Learning Disability   Caucas = Caucasian   M/F = Male/Female
Achvmt = Achievement Af-Am = African American   Asian-Am = Asian American   ESL = English as a second language
SES = Socioeconomic status   Fresh = Freshman   Soph = Sophomore   Grad = Graduate student
LD = Learning Disabled   splg = spelling

three studies (Higgins & Raskind, 1997; Leong, 1992; Leong, 1995), and written language/composition performance, which was investigated in two studies (Higgins & Raskind, 1995; Wetzel, 1996). The sixth study investigated proofreading (Raskind & Higgins, 1995).

Independent Variables

Independent variables included the three major AT's used; VRS, OCR, and SS. Other compensations used included a human transcriber (Higgins & Raskind, 1995), text read aloud (Higgins & Raskind, 1997), on-line reading (Leong, 1995), explanation of difficult words (Leong, 1992), and metacognitive activities (Leong, 1995). Pre-training was provided in five of the six studies with three using OCR/SS (Higgins & Raskind, 1997; Leong 1992; Raskind & Higgins, 1995) and two using VRS (Higgins & Raskind, 1995; Wetzel, 1996). The pre-training provided instruction and training on the use of the OCR, SS, and VRS before the research began. Researcher and/or assistant involvement was indicated in all but one study (Raskind & Higgins, 1995). When indicated the researchers and assistants were mostly involved in providing training and instruction.

Literature Review Questions

The questions posed previously, and the answers, as determined from the literature reviewed, are answered in the following text.

What types of AT are being used in educational and workplace settings? Based upon the applied literature search procedures and articles reviewed the types of AT's used in educational settings for persons with learning disabilities and difficulties were VRS, OCR, and SS. The purpose of these applications of AT was to improve reading and writing. No research studies were found that met the criteria and were conducted with individuals in the work place.

What are the outcomes for individuals with learning disabilities and difficulties who use AT? Outcomes were positive for most participants in the studies reviewed. Two of the studies (Leong, 1992; Wetzel, 1996) found that the AT intervention did not improve the reading and writing performance of the subjects. In the remaining four articles, the AT intervention was reported as positively influencing the reading, writing, and proofreading performance of the participants.

Table 2. Study variables

Author(s)	Duration & Qty. of Intervention	Selection of subjects	Design/ Analysis	Dependent Variable
Higgins & Raskind, 1995	5.8 avg. hr. of VRS training; 3 essays written: 1 w/ out assistance, 1 w/a human transcriber, 1 w/VRS	N/A	Post-test only	Composition Performance
Higgins & Raskind, 1997	3 sessions, read: w/o assistance, w/human reader, w/ OCR/SS	N/A	ANOVA	Rdg. Comprehension
Leong, 1992	18 wks	N/A	ANOVA Verbal reports & pre & posttests	Rdg. comprehension

What types of AT used by individuals with learning disabilities and difficulties need more research? Additional research is needed on all forms of AT for use by persons with learning disabilities and difficulties. The findings from the six studies reviewed are not definitive, leaving room for additional research.

Does the use of AT improve performance and retention rates? Higgins and Zvi (1995) reported on the findings from the three intervention studies with postsecondary education students (Higgins & Raskind, 1995, 1997; Raskind and Higgins, 1995) reviewed in this paper. In this overall review Higgins and Zvi (1995) reported that retention rates for participants in the studies increased significantly. Higgins and Zvi (1995) also reported that the grade point averages (GPA) for courses with heavy reading and or composition requirements improved significantly with a pre-study GPA of 2.20 and post study GPA of 2.63 (one-tailed t = 1.76<.05). In the same review Higgins and Zvi (1995) also reported that the dropout rate for persons in the studies

dropped to 1.4% compared to 34% for the match control group and 48% for the non-disabled population. No studies reported workplace outcomes.

Overall Findings

Study results (see Table 2) were consistent with all except Wetzel's (1996) indicating positive outcomes for AT use. The studies by Higgins and Raskind (1995 & 1997), and Raskind and Higgins (1995) are the most extensive studies reviewed. They researched the use of OCR, SS, and VRS by university students. Over a period of three years they researched reading comprehension, proofreading and written composition, long-term effects on academic success and retention, and behavior and attitudes. All forms of AT were found to be effective compensatory strategies.

Raskind and Higgins (1995) also found VRS to be an effective tool for improving holistic written scores. They found that when learning disabled students used voice recognition their written performance was not significantly different from their non-

disabled peers whereas without the VRS their written performance was significantly lower. Higgins and Raskind, (1997) also found a significant correlation between silent reading scores and improvement under the technology conditions such that the greater the difficulty the more the technology enhanced performance.

Of the four studies (Higgins & Raskind, 1997; Leong, 1992, 1995; Raskind & Higgins, 1995) that investigated the effectiveness of OCR and SS three of them (Higgins & Raskind, 1997; Leong, 1992, 1995) explored its use and its effects on reading comprehension. In all three cases it was found to be effective. In the fourth study (Raskind & Higgins, 1995) SS was used to research proofreading ability. Raskind and Higgins (1995) indicated that the study participants found more errors when using the SS compared to having the material read to them, or when reading it themselves. Leong, in her 1995 study with younger children, obtained similar results when investigating the use of SS for increasing comprehension. This result was different from Leong's 1992 findings where SS did not prove statistically significant but where it still indicated positive results in 10 of the 12 passages read.

Discussion

The following section will discuss the literature synthesis findings as they relate to the search procedures, demographic variables, and study variables. In addition to these areas the overall findings, limitations, and direction for future research will also be discussed.

Demographics

As seen in Table 1 the known demographics of the study participants indicated that there were more males, Caucasians, and individuals from middle income levels. In the field of learning disabilities there are more males than females diagnosed (Murray, et al., 2000), which is a likely reason for why there are more males in the studies reviewed. IQ's and achievement scores, when indicated, varied. This is typical of persons with learning disabilities (Lyon et al., 2000).

Mean IQ scores were average to low average with a range of 74 to 137. A range of IQ's from 74 to 137 is large but does align with the current literature on learning disabilities (Lyon, et al., 2000; Murray, et al., 2000) that indicates persons are being identified as learning disabled when they may actually be slow learners. For example, a person with an IQ of 74 is functioning in the low range as the average range of IQ scores is from 85 to 115 (American Association on Mental Retardation, 2002). If a person has an IQ of 74 they could possibly be considered borderline mentally retarded depending upon their functional abilities (Diagnostic and Statistical Manual of Mental Disorders-DSM-IV, 2000), which implies that they are a slow learner.

Study Variables

None of the six studies reviewed indicated subject selection procedures, but based on the information provided it is likely that the selection of subjects was convenience sampling. For example, Leong (1995) indicates the sample consisted of 64 grade 4 students, 68 grade 5 students, and 60 grade 6 students. It is possible that these numbers represent students with learning difficulties from two classes at each grade level who were selected because they were members of the class.

The design and analysis procedures varied from study to study, which posed difficulty in performing statistical comparisons of the results. Thus, overall outcomes, rather than specific outcomes, are presented. The lack of continuity in the findings leaves room for future replication studies that may validate the findings in the studies reviewed.

Each article analyzed presented a range of characteristics and variables. Because of this, the data are difficult to categorize yet provide insight into the previously posed questions, as discussed in the following text.

The dependent variables were similar across studies with two investigating written language difficulties (Higgins & Raskind, 1995; Wetzel, 1996), three investigating reading comprehension (Higgins & Raskind, 1997; Leong, 1992; Leong, 1995), and one investigating proofreading (Raskind & Higgins,

Table 2. (continued) Study variables

| Author(s) | Independent Variable | | | | Findings | |
	Major AT	Other Compensation	Pre-training	Researcher involvement	Overall	Specific's
Higgins & Raskind, 1995	VRS	Human transcriber	5.8 hr. on Speech Recognition	Study/ Instructions	VRS +	VRS improved written composition when compared to no assistance; positive outcomes may be due to the use of longer wd.
Higgins & Raskind, 1997	OCR/ SS	Passages rd. aloud	45 min. training, avg. time 23 min.	Study/ Instructions	OCR/ SS +	Inverse correlation between silent rdg. comprehension and OCR/SS
Leong, 1992	Text-to-speech (SS)	Explanation of difficult wd.	Practice ex.	Guided participants Through practice exercise	Text-to-speech (SS) Not significant	Improvement in rdg. comprehension. For 10 of 12 passages

1995). It is clear that the AT currently being used by persons with learning disabilities is of the three types mentioned previously. VRS is being used to compensate for written language difficulties while OCR and SS are being used to compensate for reading comprehension and proofreading difficulties.

Overall Findings

Overall, the results indicated that the types of AT investigated (i.e., OCR, SS, and VRS) are effective compensatory tools for persons with learning disabilities and or learning difficulties. The difficulty most frequently experienced by people with learning disabilities is phonetic awareness (Stanovich,

Cunningham, & Freeman, 1984; Adams, 1990). With a lack of phonetic awareness the ability of individuals to comprehend written material is reduced. By using OCR and SS electronic text can be "read" to an individual. This appears to minimize the required decoding while improving comprehension. Speech synthesis was also found to improve proofreading abilities when compared to reading alone or having text read by a human reader to an individual (Higgins & Raskind, 1997). This again is not unexpected, as people with learning disabilities have difficulty reading and are so focused on the words that they often do not comprehend the larger meaning. Speech synthesis was found to be more effective than reading alone or using a human reader for proof-

Table 2 (continued). Study variables

Author(s)	Duration & Quantity of Intervention	Selection of subjects	Design/ Analysis	Dependent Variable
Leong, 1995	4 months	N/A	ANCOVA	Comprehension, Word recognition
Raskind & Higgins, 1995	Proofread 3 essays, 1 SS, 1 read aloud, & 1 with no assistance	N/A	z-scores	Proofreading
Wetzel, 1996	Fourteen 30-minute sessions spent with the researcher	N/A	N/A	Written language difficulties

reading text (Raskind & Higgins, 1995). This may be due to the independence provided by the use of AT as the person doing the proofreading does not have to be concerned with bothering the reader. The individuals using the software can replay the text as many times as they like, thus possibly catching more errors.

Higgins and Raskind, (1997) found a significant correlation between silent reading scores and improvement under the technology conditions such that the greater the difficulty the more the technology enhanced performance. This implies that students with the most severe learning disabilities and/or learning difficulties will benefit the most from the use of AT. This finding is supported by Raskind's (1993) statement that although both remedial and compensatory strategies are beneficial for adults with learning disabilities, the compensatory approach "may offer the most expeditious means of addressing specific difficulties within particular contexts" (p. 159). This finding may also have implications for self-esteem and self-confidence.

Higgins and Raskind (1995, 1997) and Raskind and Higgins (1995) as reported by Higgins and Zvi (1995) found a decrease in the dropout rate for persons in their studies when compared to a control group and to students from the non-disabled popu-lation. While the increase in retention for students in the three studies may be partly due to the use of AT there are additional variables that may have influenced participants' retention rates, with one possibility being they were part of a 3-year study that provided supports that students not in the study did not receive. Based on this it cannot be assumed that the use of AT alone decreased the drop out rate, but it may have influenced it.

Although VRS did not prove to be an effective compensatory strategy in one study (Wetzel, 1996) it was in one other (Higgins & Raskind, 1995). A possible reason for VRS not being effective in the 1996 study by Wetzel is that voice recognition software and hardware was in its infant stages. It has improved since then. Dragon Naturally Speaking (DNS) can now be minimally trained in about twenty minutes. With this minimal training DNS has about 98% recognition accuracy (S. Krysler, personal communication, April 30, 2001). This is providing the computer has a good quality sound card and a fast processor. The 98% recognition accuracy is also based on the users consistently and clearly enunciating their words. VRS has improved since the studies reviewed were performed. Thus, today, the implications for persons with learning disabilities and or learning difficulties are far greater.

To be able to speak ones ideas and not get caught up in the intricacies of spelling and grammar can, as indicated by Higgins and Raskind (1995), improve written composition.

There are numerous weaknesses in the studies reviewed. For instance, three of the studies (Higgins & Raskind, 1995; Leong, 1992; and Leong, 1995) did not indicate pertinent demographic information. Likewise, effect size was not indicated in any of the studies reviewed. In addition, if there were more empirical studies available there may be more variety in the populations investigated that may provide different results. For example, persons with learning disabilities from culturally and linguistically diverse backgrounds may not fare as well with VRS, OCR, and SS due to their linguistic differences.

In addition, the study variables include a wide range of ages, academic levels, and research procedures that make it difficult to compare studies. Small sample sizes in all of the studies inhibit the ability to generalize the results to other settings and demographics.

Limitations

Overall, the greatest limitation of this literature synthesis is that there are so few empirical studies investigating the use of AT as a compensatory strategy for persons with learning disabilities. One reason for the lack of research may be that the technology is relatively new. Other possible reasons may include lack of teacher experience in using technology and a lack of awareness in the workplace. With the lack of empirical research available it is necessary to keep in mind that the results indicated in this synthesis cannot be considered conclusive.

Direction for Future Research

As indicated by Raskind (1993) the appeal of immediate solutions to particular problems is a very good reason to begin researching the use of AT. This is particularly true in employment settings when individuals need to perform and do not have time for remediation. Many (Day & Edwards, 1996; Golden, 1998; Riviere, 1996) have indicated the effectiveness of AT, but research supporting this is limited.

The problem of determining whether AT is consistently an effective compensatory strategy for persons with learning disabilities and difficulties, thus enabling them to succeed in educational and workplace endeavors, requires ongoing, systematic investigation. Future research should replicate the current studies in multiple settings to determine if the results are generalizable. This may include a larger mix of ethnicity, gender, and socioeconomic status.

In addition, researchers need to begin to assess the use of AT in the workforce. Individuals with learning and other types of disabilities use AT, but its effectiveness and the variables that influence its use have not been researched. The technologies investigated, as they continue to improve, should be incorporated into the workplace and educational arenas. Voice recognition may also be beneficial for individuals with quadriplegia, visual tracking problems, fine motor control problems, and cerebral palsy. Additional research is needed to document effective and ineffective strategies across all disability categories and in multiple settings.

Conclusions

Research studies investigating the use of AT as compensatory agents in the work place are more limited than studies done in educational settings. In fact, the researchers were not able to find any research studies that investigated the use of AT in the workplace. The studies implemented with postsecondary education students offer the closest similarity to work settings but are still significantly removed. While generalizations can take place they should be made with caution. For example, in the studies reviewed the research participants were provided with support that would not necessarily be available in non-research based settings. If VRS, SS, and OCR software programs are to be used in educational and work settings, facilitators and or potential users should be aware that ongoing support and training might be necessary for the AT to be used consistently and effectively. In addition, the use of VRS may interfere with other employees or students as the person using the software is speaking into the microphone. Likewise, using SS in a shared space may annoy others as the com-

puter "reads" back what has been scanned or typed. This could be avoided by using headphones.

Based upon the findings from the articles reviewed it is apparent that AT should be used by persons with learning disabilities and difficulties as a compensatory strategy in postsecondary educational settings. AT should also be used, but with greater caution, in K-12 settings. The need for caution is due to the concern that compensating for a learning difficulty may interfere with remediation. The benefits of compensation need to be weighed against the benefits of remediation. As indicated by Raskind (1993) years of remediation often lead to frustration that the use of AT may be able to alleviate.

The use of AT has been shown to improve postsecondary education outcomes for students with learning disabilities. If AT increases the retention and graduation rates of postsecondary education students with learning disabilities these individuals should be able to transfer the use to work settings thus increasing employability and retention in the work force. Perhaps more importantly, if people with learning disabilities are able to complete postsecondary education, statistics show they have a better chance of obtaining gainful employment.

Individuals need to understand their own strengths and weaknesses to know which types of assistive technologies may be beneficial. In addition a determination of what tasks the individual cannot perform should be assessed prior to any AT recommendations and implementation. For example, in the studies reviewed that used VRS a determination was made that the subjects were deficient in written composition performance. Logic dictates that if there is not a deficit then the AT will not be necessary. This is aligned with the Higgins and Raskind (1997) finding that a significant correlation existed between silent reading scores and improvement under the technology conditions such that the greater the difficulty the more the technology enhanced performance. It is important to remember that there is great variance between individuals diagnosed as learning disabled. Determining an individual's strengths and weaknesses should be the first priority. Using AT to compensate for the deficient areas should be the second consideration.

Kelly Drew Roberts, Ph.D., ATP holds a Ph.D. in Education (Exceptionalities) with an emphasis on learning disabilities and assistive technology (AT). She has nearly 20 years experience working in the education field with 12 of those years spent working in the AT field. She holds an Assistive Technology Practitioners Certificate from the Rehabilitation and Engineering Society of North America (RESNA) and is well versed in AT application.

Robert A. Stodden, Ph.D. is Director and Professor at the Center on Disability Studies at the University of Hawaii at Manoa, and is current past president of the Association of University Centers on Disabilities (AUCD) Board of Directors. Professionally trained in Psychology, Special Education, and Rehabilitation, he has served more than twenty-five years as a national leader in the fields of special education, school to adult transition, postsecondary education, and employment for persons with disabilities.

References

Adams, M. J. (1990). *Beginning to read-thinking and learning about print.* Cambridge, MA: MIT Press.

Blalock, J. (1981). Persistent problems and concerns of young adults with learning disabilities. In W. Cruickshank & A. Silvers (Eds.), *Bridges to tomorrow: Selected papers from the 17th international conference of the Association for Children with Learning Disabilities. The best of ACLD, Vol. 2* (pp. 31-45). Syracuse, N.Y.: Syracuse University Press.

Gerber, P. J., Ginsberg, R., & Reiff, H. B. (1992). Identifying alterable patterns in employment success for highly successful adults with learning disabilities. *Journal of Learning Disabilities, 25*, 475-487.

Henderson, C. (1992). *College freshmen with disabilities: A statistical profile.* Washington, DC: American Council on Education, HEATH Resource Center (ERIC Document Reproduction No. ED 354 792).

Higgins, E., & Zvi, J. (1995). Assistive technology for postsecondary students with learning disabilities from research to practice. *Annals of Dyslexia, 45*, 123-142.

Higgins, E., & Raskind, M. (1995). Compensatory effectiveness of speech recognition on the written composition performance of postsecondary students with learning disabilities. *Learning Disability Quarterly, 18*, 159-174.

Higgins, E., & Raskind, M. (1997). The compensatory effectiveness of optical character recognition/speech synthesis on reading comprehension of postsecondary students with learning disabilities. *Learning Disabilities, 8*(2), 75-87.

Johnson, D. J., & Blalock, J. W. (Eds.). (1987). *Adults with learning disabilities: Clinical studies*. Orlando, FL: Grune and Stratton.

Leong, C. K. (1992). Enhancing reading comprehension with text-to-speech (DECtalk) computer system. *Reading and Writing: An Interdisciplinary Journal, 4*, 205-217.

Leong, C. K. (1995). Effects of on-line reading and simultaneous DECtalk YESauding in helping below-average and poor readers comprehend and summarize text. *Learning Disability Quarterly, 18*, 101-116.

Lyon, G., Fletcher, J., Shaywitz, S., Bennett, A., Shaywitz, B., Torgesen, J., Wood, F., & Olson, R. (2000). Rethinking learning disabilities. Retrieved on December 8, 2001 from http://www.edexcellence.net/library/special_ed

Murphy, H., & Higgins, E. (1994). *An investigation of the compensatory effectiveness of assistive technology on postsecondary students with learning disabilities*. California State University Northridge (ERIC Document Reproduction Service No. ED 414 681).

Murray, C., Goldstein, D., Nourse, S., & Edgar, E. (2000). The postsecondary school attendance and completion rates of high school graduates with learning disabilities. *Learning Disabilities Research & Practice, 15*(3), 119-127.

Raskind, M. (1993). Assistive technology and adults with learning disabilities. *Learning Disability Quarterly, 16,* 185-196.

Raskind, M., & Higgins, E. (1995). Effects of speech synthesis on the proofreading efficiency of postsecondary students with learning disabilities. *Learning Disability Quarterly, 18,* 141-158.

Raskind, M., & Higgins, E. (1999). Speaking to read: The effects of speech recognition technology on the reading and spelling performance of children with learning disabilities. *Annals of Dyslexia, 49,* 251-281.

Riviere, A. (1996). *Assistive technology: Meeting the needs of adults with learning disabilities*. Retrieved June 8, 2002 from, http://www.ldonline.com/ld indepth/technology_/nalldc_guide.html.

Schumaker, J., Deshler, D., & Ellis, E. (1986). *Intervention issues related to the education of LD adolescents*. In J. Torgesen & B. Wong (Ed.), Psychological and educational perspectives on learning disabilities (pp. 329-360). Orlando, Florida: Academic Press.

Stanovick, K. E., Cunningham, A. E., & Freeman, D. J. (1984). Intelligence, cognitive skills, and early reading progress. *Reading Research Quarterly, 21,* 360-406.

The Alliance for Technology Access. *Computer resources for people with disabilities.* (1994). Alameda, CA: Hunter House Inc.

The Education of the Handicapped Act of 1975, Pub. L. No. 100-407. U.S. Department of Education.

The Technology Related Assistance for Individuals with Disabilities Act of 1988, Pub. L. No. 100-407,29 U.S.C. 2201, 2202.

The United States Office of Education. (1977). Register, 42:250, p. 65083. Washington, DC: U.S. Government Printing Office.)

Vogel, S., & Adelman, P. (1992). The success of college students with learning disabilities: Factors related to educational attainment. *Journal of Learning Disabilities, 25,* 430-441.

Wagner, M. (1992). *Being female - A secondary disability? Gender differences in the transition experiences of young people with disabilities.* Menlo Park, CA: SRI International.

Wetzel, K. (1996). Speech-recognizing computers: A written-communication tool for students with learning disabilities? *Journal of Learning Disabilities, 29,* 371-380.

White, W. J. (1985). Perspectives on the education and training of learning disabled adults. *Learning Disability Quarterly, 8,* 231-36.

Ysseldyke, J. E., Thurlow, M., Graden, J., Wesson, C., Algozzine, B., & Deno, S. (1983). Generalizations from five years of research on assessment and decision making: The University of Minnesota Institute. *Exceptional Education Quarterly, 4,* 75-94.

Fostering the Self-Determination and Self-Advocacy Skills of College Students with Disabilities through a College Success Class

Peg Lamb, Ph.D.
Holt Public Schools, Michigan

Abstract: Students with disabilities are entering postsecondary education in greater numbers; however, they experience great difficulty in completing their programs. One factor contributing to their lack of success is the discrepancy in the laws that govern educational support in secondary and postsecondary education. An additional factor is limited development of self-determination/self-advocacy skills when students exit high school. Bridges, a National Science Foundation three-year transition project, piloted a College Success Class at Lansing [Michigan] Community College with the dual purpose of supporting student transition to college and developing self-determination and self-advocacy skills. Data suggests that through classroom activities and follow-up meetings, students developed a greater understanding of these concepts, more confidence, and the ability to advocate with college instructors for their accommodations.

Key Words: self-determination, self-advocacy, postsecondary success

Introduction

The demands of the twenty-first century workforce include advanced training, technical skills, and high standards of productivity, problem solving, and teamwork. McCabe (2000) found that 80% of the new jobs in the 21st century will require some postsecondary education and that only 20% will be for unskilled labor. In their Strategic Plan of 1998-2000, the United States Department of Education reported postsecondary education is the entryway to professional and technical training and higher wages. In order for young adults to gain economic independence they must pursue some form of education and training beyond high school to develop the technical skills necessary to enter the workforce of the 21st Century. Furthermore, President Bush's New Freedom Initiative, 2001, declares that all

Americans with disabilities must have the opportunity to learn and develop skills and engage in productive work. This means that postsecondary institutions are faced with the challenge of finding ways to successfully educate all youth, including those with special needs.

Many studies report that enrollment rates of students with disabilities in postsecondary education increased from 2.6% in 1978 to nearly 19% in 1996 (Blackorby & Wagner, 1996; Gajar1998). According to HEATH Resource Center, between 1988 and 1998 there was an increase of 173% for students with disabilities entering college (Henderson, 1999). In spite of these increasing numbers, students are experiencing limited success and exiting college without completing their programs (Blackorby & Wagner, 1996; Witte, Philips, & Kakela, 1998). The percentage of students who are successful remains low, with only 25% of students with disabilities awarded an associate degree after five years at a community college (Burgstahler, Crawford, & Acosta, 2001). This is partially due to the number of remedial courses students with disabilities take prior to beginning their college curriculum. Adelman (1998) found that students who need to take remedial courses reduce their probability of achieving a college degree. Students with zero remedial courses had a 60% graduation rate, those with 2 remedial courses resulted in a 45% completion rate, and students who took 5 or more courses had a 35% completion rate. Several other issues that diminish the probability for success for students with disabilities in postsecondary education include: organizational barriers, pace of instruction, and expectation of independent learning (Vogel, S. & Adelman, P. 1993).

Statement of the Problem

The transition from high school to college for many students is complicated and challenging. For students with disabilities it is even more demanding, in part because of the dramatic differences in the laws that govern high school and postsecondary settings. In high school, under the Individuals with Disabilities Education Act (IDEA) of 1997, students with disabilities are entitled to individualized supports and services provided by an array of special education staff that provide and coordinate specialized instruction and accommodations in both general and special education classes. One result of these services is many students with disabilities exit high school with limited self-determination and self-advocacy skills, because their service providers and parents assume responsibility for advocating for their educational needs rather than fostering the development of these skills (Izzo & Lamb, 2002).

Postsecondary settings are governed by Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) of 1990 that mandate only access to higher education, not a vast array of services and support personnel to meet the students' academic and emotional needs.

Students must present the college with documentation of their disabilities. The college determines if they meet the criteria for educational accommodations. These accommodations must be requested by the students; otherwise the college is under no obligation to provide them. Thus, in order for college students with disabilities to be able to learn successfully in postsecondary settings, they must assume full responsibility, often for the first time, for securing any accommodations necessary for success in their college studies.

Consequently, skills such as self-determination and self-advocacy, or the ability to articulate ones strengths, challenges, and necessary supports, are critical when entering postsecondary settings. Wehmeyer (1998) has written extensively about the need for people with disabilities to become more autonomous, to learn how to make choices, and to advocate for their wishes and needs. Stodden (2000) and Izzo and Lamb (2002) indicate that self-determination/self-advocacy are critical skills for the success of students with disabilities in postsecondary education and employment. However, many college students with disabilities report they are uncomfortable requesting accommodations from faculty (Izzo, Hertzfeld & Aaron, 2002). Often they must advocate for themselves with faculty who have limited knowledge of the ADA, the characteristics of specific disabilities, and appropriate accommodations.

The Bridges Study

Overview of the Project

Bridges, a three-year transition project funded in 2000 by the National Science Foundation, was a collaborative approach to transition involving college disabilities counselors, vocational rehabilitation counselors, a transition specialist and a group of high school and college mathematics and science teachers. The project was implemented by Holt High School, a large suburban district in a tri-county area of mid-Michigan, in the Great Lakes region of the United States, and Lansing Community College. The major goal of the *Bridges* project was to increase accessibility to a community college for students with disabilities pursuing scientific and technical careers. One feature of the project was a *College Success Class* piloted with the dual purpose of supporting students in the project in their transition from high school to college, and developing their self-determination and self-advocacy skills. Students with disabilities were recruited from Holt High School and twelve other county high schools. Participation in the *Bridges Project* was based on three criteria: A documented disability; Enrollment in the community college, and A career interest in science, technology, engineering or mathematics. High school special education teachers, rehabilitation counselors, and parents referred students to the project. The class was required for the students in the *Bridges Project* and was also open to other community college students with disabilities who had various career interests and who had been recommended by their college disabilities counselor.

The class was a two credit, one-semester course co-taught by a College Disabilities Counselor and the *Bridges Project* Director, a transition specialist. The College Disabilities Counselor is a certified counselor who has worked with college students with disabilities for more than ten years. The transition specialist taught students with disabilities K-12 for twenty-five years and spent the last ten years developing and researching transition programs for high school youth. The state vocational rehabilitation agency, which serves people with all disabilities except for those who are blind or visually impaired, paid tuition for the *College Success Class* for all students as a part of their collaborative partnership in the *Bridges Project*. The class met once a week for a two-hour class period offered in the fall of 2002 and 2003 to two different groups of students. In addition to the semester class, students were required to meet individually with instructors at the midterm and end of the fall semester. During the spring semester they were scheduled to meet twice with the instructors to follow-up on their academic progress, problem solve, and provide encouragement and support for their self-advocacy. At the end of the spring semester, students participated in a final interview to discuss their college success and their thoughts about the impact of the *College Success Class* on their self-determination skills and their ongoing support. Whenever, possible vocational rehabilitation counselors participated in the follow-up conferences with their students.

The curriculum of the *College Success Class* consisted of 10 major components (See Addendum 1). All activities focused on developing one or more aspects of self-determination skills. The instructors utilized the comprehensive definition of self-determination developed by Martin and Huber Marshall (1995), which consists of seven components; self-awareness, self-advocacy, self-efficacy, decision-making, independent performance, self-evaluation, and adjustment (See Addendum 2 for detailed descriptions developed by Izzo & Lamb, 2002). The class emphasized development of self-awareness, self-advocacy, independent performance, and self-evaluation. In one class session students learned about both internal and external "locus of control" and were asked to provide examples of both from their personal experiences. In another they investigated different learning and teaching styles and developed their personal profile of learning and accommodations. Following these sessions, students were given an outline for developing a written self-advocacy plan. The plan included a description of the student's learning styles, learning strengths and challenges, accommodations needed, and their responsibility as a student. Students practiced sharing their self-advocacy plans with classmates of their own choosing.

In the next class session, instructors invited college faculty to listen to students present their plans

on an individual basis and ask them questions about their needs. Each student was required to share his or her plan with at least two faculty members or more, if time permitted. Following their presentations, faculty members provided students with written feedback on the clarity of their explanations concerning their learning challenges, the accommodations they needed to be successful, their responsibilities as students, and their demeanor throughout the presentation. In the last part of this class session, instructors invited students to discuss their experiences in this process, what they learned, and how they felt the college instructors had responded to their advocacy. As a follow-up activity, students were assigned a reflective journal consisting of four questions concerning their feelings about their preparation to self-advocate, their learning difficulties and accommodations, whether the experience was good preparation for future discussions with instructors, and the helpfulness of faculty feedback.

At mid-semester, the instructors held individual student conferences to encourage students to meet with their own instructors and share the information they had written in their self-advocacy plan. In subsequent student conferences, instructors focused on student self-evaluation, self-awareness, student responsibility, and decision making about academic progress. Instructors assisted students in developing problem solving strategies and making adjustments in their goals as necessary.

Research Questions

The specific questions the study on college success investigated are:

1. What impact, if any, do the class activities have on the students' ability to define in their own words the concepts of self-determination and self-advocacy?

2. What impact, if any, does the course have on the students' confidence, ability, and willingness to self-advocate with their college instructors?

3. What class activities, if any, would students identify as most beneficial in assisting them

in becoming more self-determined and better advocates?

4. What benefits, if any, would students report from participation in this type of college class?

Research Method

The qualitative method was used primarily to understand the effect of the intervention, i.e., the *College Success Class*, by listening to the voices of the students over time and analyzing the changes in their thinking and actions related to self-determination and self-advocacy. Qualitative methods are interactive and therefore better able to provide insights into the complexities and processes involved in developing self-determination and self-advocacy skills (Marshall & Rossman, 1995). Since the development of these skills is process oriented, a qualitative approach offers an opportunity to examine the context and the players from a holistic perspective and to view them and the process as a whole without reducing them to variables (Taylor & Bogdan, 1984). According to Borg & Gall (1989), a qualitative inquiry methodology is appropriate when attempting to understand what is happening in a field, in this case the development of self-determination and self-advocacy skills for college students with disabilities. Some quantitative data was also collected (i.e., student ratings of the value of the class activities and the ways class experiences and interviews assisted them during their first year in college).

Three guidelines that govern the value and usefulness of this type of study include credibility, dependability, and transferability (Guba, 1981). Credibility refers to the congruence between the intended meanings of participants and how those meanings are interpreted and represented by researchers. Having two researchers (the two instructors) read and analyze the data and agree on the interpretations increased study credibility. "Crucial to inter reliability is inter-rater or inter-observer reliability—the extent to which the sets of meanings held by multiple observers are sufficiently congruent so that they describe the phenomena in the same way and arrive at the same conclusions about them" (LeCompte & Goetz, 1982, p. 41).

Dependability involves maintaining stability and consistency while allowing for an emergent study design. This project's dependability was strengthened through the verification of the two researchers in weekly discussions about students' progress in developing self-determination/self-advocacy skills, by reading students' pretests and course evaluations, and by discussing students' conversations and detailed notes of students' responses during the follow-up interviews. A third researcher with knowledge and experience in transition was secured to evaluate and rate the pre/post data on students' definitions of self-determination and self-advocacy for the purposes of inter-rater reliability. Further, Lincoln and Guba (1985) also recommend triangulation of data as a way to build the credibility and validity of data. Triangulation of data involves collecting multiple sets of data to develop accurate representations for corroboration. The college students with disabilities wrote individual pretests and course evaluations and were interviewed separately about their experiences in the *College Success Class*. It is believed these measures to ensure credibility and dependability diminished the drawbacks cited about case study methods (i.e., a perceived lack of rigor because the researcher may allow "biased views to influence the direction of findings and conclusions") (Yin, 1994, p. 9).

Transferability refers to the generalizability of results—whether they will apply to another situation. Since the majority of colleges and universities provide support services to students with disabilities, the outcomes of this study may be of interest to support services professionals as they counsel and support students to advocate for themselves. The study may also be of interest to secondary transition specialists who work with students with disabilities to develop these skills and assist them in identifying postsecondary institutions that will provide the support necessary for their college success. The outcomes may be of value to vocational rehabilitation counselors who provide supports and services to youth with disabilities and encourage students' self-advocacy and independence.

Design of Study and Site Selection

This study investigated the development of the self-determination and self-advocacy skills of college students with disabilities through their participation in a *College Success Class* taught by a college disabilities counselor and a transition specialist.

Sampling Procedures and Recruitment

Twelve students enrolled in the 2001 *College Success Class*. Nine students completed all course components and participated in second semester follow-up meetings. The instructors believed the follow-up meetings were critical in assisting students to apply the self-determination and self-advocacy skills addressed in the class. Two of the twelve students dropped the class and one student did not participate in the follow-up meetings. In the 2002 course, sixteen students enrolled in the class. Three students dropped the class and two did not participate in the follow-up meetings. In both years, the primary reason that students gave for dropping the class was they felt they did not need further assistance in developing their skills in self-determination and self-advocacy. Thus, a combined total of twenty students with disabilities completed the College Success Class and the follow-up meetings. The results of this study are based on the data from these twenty students. The numbers and types of disabilities or federal/state categorical certifications of the twenty students were as follows; 6 Learning Disabled (LD) and Attention Deficit Disorder, 5 LD, 3 Emotionally Impaired, 2 LD and Attention Deficit Hyperactive Disorder, 1 Autistically Impaired, 1 Hearing Impaired, 1 Visually Impaired, and 1 Traumatic Brain Injury.

Data Sources and Collection

Students completed a pretest and a posttest on self-determination and self-advocacy. In these tests students were asked to explain self-determination and self-advocacy, their disability, and accommodations they needed. The tests were read aloud and answers were transcribed as necessary for any of the students. On the last day of class they completed a course evaluation. They were asked the following: to indi-

cate two things they liked best and least about the class, to evaluate on a scale of 1 (least) to 5 (most) the activities that were of most value in helping them become more self-determined and better at self-advocacy, whether they would recommend the class to other college students with disabilities, and why or why not. At each individual student meeting at midterm and at the end of class, students were asked about their academic progress, their efforts in self-advocacy, accommodations they had requested, their use of assistive technology, their career planning and employment to date. Notes were taken in each of these areas and after each conference the instructors compared notes about student progress.

Two weeks after the semester ended, students were scheduled for a comprehensive interview with the instructors and with their vocational rehabilitation counselor to discuss their freshmen college experience. Students were asked to describe their successes and areas they needed to improve. They were again asked what it means to be self-determined and to self-advocate. Then they were asked to rate their ability to self-advocate, the number of instructors they talked with about their learning styles and accommodations they needed. Finally, they were asked in what ways the College Success Class and the individual meetings had assisted them in college that year. They were read a list of skills related to self-determination and asked to rate the impact of their experience on a scale of zero to two; 0, not at all, 1, somewhat helpful, 2, very helpful. Some of the students responses include, "The class helped me to solve problems," "focus my attentions," "get more organized," "become more responsible," "self-advocate," "meet my goals," or "advocate for myself." The project director wrote the student responses on the interview form. The pre/post tests, course evaluations, interview data, and student journals on self-advocacy were the primary data sources for this study.

Data Analysis Procedures

Student definitions of self-determination and self-advocacy were copied from their pre/post tests and their final interview for comparative analysis. A rating scale of zero, one, and two was developed to evaluate the quality of their definitions of these con-

cepts. A list was made of phrases used in curriculum materials and by instructors to describe concepts of self-determination and self-advocacy. For example, in materials used on goal setting, students learned about standards, timelines, supports, and motivation. In the unit on locus of control, students learned about taking personal responsibility for their actions and operating independently. In the self-advocacy discussions, students learned about being assertive rather than aggressive, about their legal rights, and about asking for accommodations they needed for academic success. In analyzing their pre/post definitions, evaluators used this list of phrases to rate student answers. A zero rating indicated a vague definition with none of the phrases on the list or their equivalent, a rating of one indicated there was one element from the list, and a rating of two indicated two or more elements from the list of phrases defining these terms. The class instructors and an independent researcher rated student definitions. The inter rater reliability was 95% for definitions about self-determination and 85% for definitions about self-advocacy. In instances where one evaluator had a different rating, ratings given by both evaluators were used.

In the class evaluation for each student, ratings of class activities were charted and totals tabulated. This same type of analysis was used in the final interview ratings where students indicated which skills in self-determination and self-advocacy were developed through the class and follow-up meetings. Student journals about their experiences in self-advocacy simulation with college instructors were then examined to identify any patterns of feelings regarding preparation, confidence, and instructor responses to their advocacy. On the initial reading, key phrases were noted and formed into groups. On the second reading of journals, student responses were categorized.

Findings

Changes in Description of Self-Determination

An analysis of student pre/post tests reveal that 11 of 20 student definitions (55%) changed from a level 1 on the pretest to a level 2 on the post test. Level 1 rating indicated that a student had one ele-

Table: Course Evaluation

The class helped me to:	Students rating item 0 Not At All	Students rating item 1 Somewhat Helpful	Students rating item 2 Very Helpful
1. Feel support and encouragement.	0	0	20
2. Self-advocate.	0	12	8
3. Get more organized.	2	10	8
4. Become more responsible.	2	10	8
5. Think about future career.	3	8	9
6. Meet my goals.	3	11	6
7. Focus my attention.	4	7	9
6. Plan my schedule.	4	13	3
9. Become more independent.	5	7	8
10. Understand my disability.	6	10	4
11. Solve problems.	6	13	1

ment describing self-determination in the definition; level 2 rating indicated two or more elements, such as goal setting, taking action, operating independently, or advocating for him or herself.

Six of the students (30%) changed from a 0 to a level 2. One student was rated a 2 on both the pre/post tests, one student changed from a 0 to a rating of 1, and another student remained a zero on both the pre and post test. Overall, 18 of 20 student (90%) definitions were rated at level 2. For example, "Lucas" described self-determination before the class as "wanting to push your self" (level 1). After the class he wrote that a self-determined person "doesn't waste a day, sets goals, has time management, assertiveness and asks for help or assistance" (level

2). On his pretest, "Josh" described self-determination as "motivation to want to finish something" (level 1). On the post test, he stated someone who is self-determined has "goals and a plan to meet those goals, is organized, has good time management, doesn't give up, and takes responsibility for himself" (level 2). "Liz" was unable to define self-determination on her pretest, however, on her post test she wrote, "Self-determination is where you advocate for yourself and you have a set plan of action to go by. They are motivated in what they're doing to get things done. They have goals and push towards the goals" (level 2).

Changes in Description of Self-Advocacy

In the analysis of the pre/post test on student definitions of self-advocacy, 8 of 20 students (40%) changed from level 0 to level 2. The same number (40%) changed from level 1 to level 2. Two students (20%) changed from level 0 to 1 and an equivalent number had no change (0 to 0). In all, 16 of the 20 students (80%) were found to be at a level 2 in defining or explaining self-advocacy. Their definitions incorporated two or more phrases, such as "tell people what you need," "speak for yourself," "ask for help," and "accommodations." "Kris" could not define self-advocacy on the pretest but provided this description on the posttest, "To talk with your instructor for feedback about your work in class, and to ask for assistance when you don't understand, and for accommodations for your disability" (level 2). "Zach" clarified his understanding of self-advocacy between the pre and post test. On the pretest he defined self-advocacy as "making the right decision without help from outsiders" (level 1). On the post test "Zach" reported that, "You talk with the instructors about your disability, about the class style, and the types of homework, and about the accommodations that you need" (level 2). "Nikki" wrote on her pretest, "Self- advocacy is where you do what other people used to do for you" (level 1). On the post test she indicated, "If you need help you ask for it and don't rely on someone else. It is knowing what rights you have, and what helps you learn" (level 2).

In the *College Success Class* students developed a self-advocacy plan describing their abilities, challenges, and accommodations, and then discussed the plan with college instructors who volunteered to attend class, listen to their plans, and provide them with feedback. Only 16 of the 20 students participated in this activity; the other four were absent. In an analysis of their reflective journals on this experience, 12 of the students (75%) reported they felt more confident and better prepared to talk with college instructors after this experience. "Nikki" wrote, "This put my mind at ease and helped me understand the process I will take and what I will need to do." "Jacquee" reported, "I gained in my confidence as I talked to more instructors. I learned teachers really care about students." "Kris" wrote about the value of the activity: "It gave me the confidence to explain my disabilities and my needs to future instructors. I did not feel instructors intimidated me."

Not all students reported feeling this way; 4 of 16 (25%) reported that it did not prepare them for advocating with their instructors. Two of the students reported they were nervous and the experience did not prepare them for doing this in the future because they will still be nervous when they talk with their instructors about their disabilities. "It didn't help prepare me," "Matt" commented, "Since the teachers knew in advance what the purpose the meeting was about. But they won't know that in the future." "Tammy" felt it had not prepared her at all. "When I did my meetings with each instructor," she said, "I was basically reciting what I did whenever I talked to my real instructors."

In the course evaluation, 65% of the students rated this activity as average or above average and ranked it fourth of the six major activities. In the final interview, students were asked how many instructors they talked with about their disabilities and the accommodations they needed. Nearly half of the students (40% or 8 of 20) reported speaking to all their instructors during both semesters. In some cases (35% or 7 of 20) students reported speaking only to those instructors in whose classes they felt they needed assistance. One student reported speaking to one instructor in the first semester and all of them in the second semester. Some students (20% or 4 of 20) did not speak to their instructors at all. In two of these cases, students had emotional rather than learning impairments and reported they did not feel they needed accommodations. "Kris", who did not self-advocate, stated in his interview, "That was my downfall. I would have done better in physics if I had talked with him about my progress in his class and asked for more time on the tests. I won't make that mistake again."

Students were also asked in their last interview to rate their self-advocacy skills on a scale of 1-5. The students rated themselves as follows; 6 students, "Excellent", 4 students, "Good", 7 students, "Fair", 2 students, "Poor", and 1 student, "Not At All." In sum, it appears the activities related to development of self-advocacy benefited the majority of students

in feeling more confident and better prepared to talk with their instructors about their learning and their accommodations. Further, by the second semester of their freshmen year, 15 of the 20 students spoke either with all of their instructors or with instructors in courses in which they needed accommodations for their learning needs. Ten students rated their self-advocacy skills between excellent and good, and seven more indicated they were fairly good at the process. Further, 75% felt more confident in their abilities to self-advocate, and 80% of them reported speaking to either all of their instructors or to the ones who they felt needed to provide them with accommodations by second semester of their first year.

Student Commentary on the Class

What types of comments did students write in their final evaluation of the class? Students were asked to complete a written evaluation listing things they liked best and least about the class, and the one major thing they learned in the class. They were also asked to rate the value of the major activities of the class on a scale of 1 (least) to 5 (most). Of the 20 students, 8 wrote about the friendly, "laid-back atmosphere of the class" and about the opportunity to meet other students with disabilities. Five of the participants identified the *Faculty Workshop on Teaching College Students with Disabilities* developed by students as the best activity. Five students reported they learned a great deal about their disabilities and accommodations, especially through self-advocacy plans. Four students reported the class gave them the support they needed to be successful in college. Three other students reported they felt this class helped them become more independent, responsible, and in control.

In terms of what students liked least about the class, three students felt the group project to develop a *Faculty Workshop* was "stressful in trying to meet with everyone and getting people to work together." Another three felt the unit on goal setting was overemphasized. One student reported he felt the atmosphere of the class and the curriculum was too much like high school and the students were immature.

When asked in the course evaluation if they would recommend the class to other students with disabilities 15 out of 20 (75%) indicated yes, 2 indicated maybe, and 3 indicated no. "Rick" wrote, "It will teach them what college is all about, and give them a support base." "Joe" felt that "it would help them more getting through the first semester of college." "Ashley" wrote in her evaluation, "You know you're not alone. It's helped to establish a support network and to get focused." "Dale" wrote, "I learned things about advocating, how to manage time, and setting priorities." "Lyle" noted, "Some things can't be taught they have to be experienced, maybe if it were more of a guide." "Kris", however, felt differently, "I didn't learn much, but some students will find it helpful." However, in the final individual meetings at the end of the spring semester all 20 students said they would recommend the class and the meetings. "Kris" rethought his position and shared in the last meeting, "Having this program has kept my mind on my long term goals and helped me stay focused on school. The encouragement has been very helpful." "Kris" stated the course and supports during his second semester "helped me quite a bit and I would recommend it to other students." Two students in their last interview shared they would have quit college before the end of their second semester had they not had this class and the follow-up support.

Student Ratings of the Course Activities

In their evaluation of the class, students were asked to rate the major activities of the class for their value in helping them to become more self-determined and better at self-advocating. The majority of students rated the course activities between average value (3), to above average (4), or most valuable (5). The student-led *Faculty Workshop on Teaching College Students with Disabilities* was rated the highest by 18 of the 20 (90%) students, even though it was the most complex and challenging. This was the culminating activity of the course. The students were divided into two groups based on student input, and assigned the task of developing an hour-long workshop for college faculty on disabilities. The workshop had to include information on the Americans with Disabilities Act, information on one or

more disabilities, accommodations that would assist students in class, and suggestions on how college faculty could help students with disabilities feel more comfortable in class. Students were required to develop a handout and visuals related to their presentations. All students were required to present a part of the workshop. Since they were given only one hour of class time to discuss and plan, student groups were expected to meet outside of class. Fifteen to twenty faculty members attended each session in both years. All workshop participants reported the student presentations were some of the most valuable and meaningful they had attended on the topic.

Two other activities were rated by majority of students as most valuable activities. The unit of *Goal Setting*, in which students learned the elements of a goal, the process for developing goals, and where they developed an academic goal for the semester, was the unit rated most valuable by 85% (17 of 20) of the students. The *Research and Presentations on a Person with Disability Unit* was rated most valuable by 75% of the students (15 of 20). In this project, students had to identify someone with a disability, research that person's life story, and identify which self-determination skills contributed to that person's success. They were required to present their findings to the class and to accommodate student learning styles by including a visual and a hands-on activity. The presentation of their self-advocacy plan to college faculty was rated as a valuable activity by 65% of the students (13 of 20).

Two other activities rated by over half the students (55%, 11 of 20) as important were writing their self-advocacy plans and researching their personal career interests. In this latter activity, students had to find information on education and training required, future demand for that career, salary, etc., and then had to develop a set of questions, to interview someone in the career, and present their findings to the class.

Based on the outcomes of their evaluations, both groups (Year 1 and Year 2) participating in the *College Success Class* felt core activities of the course contributed to development of their self-determination

and self-advocacy skills. Further corroboration of these findings was revealed in their final interviews when students rated the ways the class and follow-up meetings assisted them in their first year of college. Students were asked to rate the helpfulness of the class on developing a series of skills related to self-determination on a scale of 0 (not at all), 1 (somewhat helpful) or 2 (very helpful). The following table lists their ratings:

This table reveals that the majority of students felt the *College Success Class*, including follow-up meetings was either somewhat or very helpful in assisting them in the development of the above skills. All 20 students felt the class was very helpful in providing them with a great deal of encouragement and support. In terms of self-advocating all felt the class was somewhat or very helpful in this area. Between 40-45% felt the class was very helpful in assisting them in self-advocating, getting more organized, becoming more responsible, thinking about their futures, focusing their attention, and becoming more independent. In other skill areas, i.e., meeting their goals, planning their college schedule, understanding their disabilities, and solving problems, 50-65% of the students rated the class as somewhat helpful. When combining the ratings of 1 and 2, the College Success Class was rated as fairly helpful to very helpful in the first nine areas on Table 1 by 75% to 100% of the students. In the last two areas, helping students learn more about their disability and problem solving, 70% rated the class as somewhat to very helpful.

Discussion

Data from student journals, class evaluations, and final interviews indicated the activities implemented through the *College Success Class* were beneficial in helping all twenty students develop skills in self-determination and self-advocacy. While these findings are limited by the small number of participants and are based on the self-report of students, the findings provide valuable information concerning the types of activities that students find most valuable in assisting them in becoming more independent and responsible learners. First, based on student reports, a *College Success Class* with the types of activi-

ties described in this study can increase college students' understanding of the concepts of self-determination and self-advocacy, and it can strengthen the development of these skills. Second, when students are given opportunities to practice self-advocacy with college faculty, the confidence of students with disabilities increases and they are more likely to take the initiative and talk with their own instructors. Third, the opportunity to develop and present their own workshop on disabilities empowers students through the process of providing faculty with information on their leaning needs. Also, in many cases, they examine their own personal experiences in trying to learn and discover how teachers could support their efforts. Fourth, in the 11 areas of support, 70% or more of the students in this study rated the class as helpful to very helpful. The fact that all students would recommend this course to other students with disabilities as a means of support to assist them during their first year in college is an indicator that courses like these offered on college campuses may be of value in teaching such students how to self advocate and become more self-determined. In the long term, courses like this may increase the capacity of students with disabilities to remain in college and to achieve their postsecondary goals. Of the 20 students involved in this project, 16 are still in college, one relocated to another state, one joined the military, and two are working full-time without completing their program.

Limitations

In spite of the careful design of this study, gathering and analyzing the data resulted in some limitations. First, the study focused on twenty college students with disabilities. Such a small sample raises questions about generalizability, credibility, and dependability of the findings. The intent of the study, however, was less to produce generalizable results and more to learn about the impact of a college class focused on developing student understanding of the concept of self-determination and self-advocacy, and the development and application of these skills. A second purpose was to determine what types of activities students would find most beneficial in developing these skills.

A second limitation is that the author of this paper was the major architect of the curriculum and co-taught the class. However, several measures were taken to moderate the bias. The data was analyzed and reviewed by the author and the other co-teacher, a third researcher was secured to rate changes in student definitions of self-determination and self-advocacy, and the inter-rater reliability between the three researchers was 85-90% respectively. In addition, the paper was reviewed by the co-teacher of the course for her input and verification.

Conclusion

A major purpose of this study was to find out the impact a college class might have on the development of student understanding and development of self-determination and self-advocacy skills. The findings revealed that at the end of the course, 90% of the students were able to describe self-determination in more specific detail and 80% were more explicit in describing self-advocacy. When given the opportunity to practice their self-advocacy skills with college faculty, 75% felt more confident and 80% spoke either to all their instructors, or to faculty of the classes in which the students needed accommodations, by the second semester of their first year. Students found the most beneficial course activities involved their active participation and presentation of information, i.e., the faculty workshop, goal setting, research and presentation on a person with a disability, and practicing self-advocacy with college faculty. These were the most challenging activities to execute, yet in spite of the complexity and risk-taking involved in these activities, students rated them as most beneficial in developing their self-determination and self-advocacy skills. This raises the question for educators as to whether the bar is raised high enough in high school by expecting students to operate more independently in advocating for themselves. All students reported in their final interview that the class was somewhat to very helpful in assisting them in developing their skills in self-determination and self-advocacy, and all of them said that they would recommend it to first year college students with disabilities. The results of this study indicate that it is indeed possible to strengthen the

understanding and development of self-determination of college students with disabilities through a class of student-driven activities. Further, the scheduling of follow-up meetings involving the student's college disability counselor and their vocational rehabilitation counselors were critically important in assisting these students in the further development and application of these skills. Providing students with disabilities with a course such as the one described in this study in their first year of college was crucial in helping them become their own advocates and learn how to navigate the rough waters inherent in postsecondary institutions as independent learners. In the words of "Kris," "I learned that I am able to be what I want, but it is my responsibility to make it come to pass."

Implications for Policy and Practice

Implications for Policy

1. Policymakers need to require postsecondary institutions to support the continued development of the self-determination/self-advocacy skills of students with disabilities.

2. Vocational Rehabilitation Agencies need to provide tuition for courses offered by colleges to foster student self-determination, self-advocacy, and independent learning skills.

Implications for Practice

1. Disability professionals in postsecondary settings need to identify ways they can further develop the self-determination and self-advocacy skills of students with disabilities through pre-college workshops or student success classes, incorporating the activities similar to those described in this study.

2. College disabilities professionals and vocational rehabilitation counselors need to work collaboratively to provide supports and services to students with disabilities and to strengthen the development of their skills in self-determination/self-advocacy in postsecondary education.

Addendum 1: Ten Major Activities of College Success Class

- Write four *Reflective Journals* related to class activities.

- Learn about goal setting and develop personal goals.

- Research and present a biography on a person with a disability.

- Participate in a panel discussion with veteran college students/faculty with disabilities.

- Complete a unit on *Internal and External Locus of Control*.

- Write a *Self-Advocacy Plan* including information about academic strengths, challenges, learning style, and accommodations for success.

- Present *Self-Advocacy Plan* to college faculty.

- Research career interest and interview a person in the career.

- Develop and present a *Workshop on Disabilities, the Law, and Accommodations* to college faculty.

- Participate in scheduled meetings with instructors and rehabilitation counselor dur-

ing the first semester and follow-up meetings the second semester.

Addendum 2. Descriptions of the Seven Components of Self-Determination

- Self-awareness begins with the ability to identify and understand needs, interest, strengths, limitations, and values.

- Self-advocacy refers to the ability to assertively state wants, needs and rights, determine and pursue needed supports, and conduct your own affairs.

- Self-efficacy often is referred to as self-confidence—the belief that you expect to obtain your goals.

- Decision-making is the complex skill of setting goals and standards, identifying information to make decisions and considering past solutions, generating new solutions if needed, and choosing the best options to develop a plan.

- Independent performance refers to the ability to initiate and complete tasks by using self-management strategies.

- Self-evaluation includes monitoring task performance and determining if the plan has been completed and the goal met.

- Adjustment is the process of changing goals, standards, and plans to improve performance so that the person ultimately develops a better understanding to their needs, strengths, and limitations. Thus, the self-determination process continues to cycle through a self-improvement process.

Source: Izzo & Lamb, 2002 p. 6

Dr. Peg Lamb is the Director of the National Science Foundation Bridges Transition Project awarded to Holt Public Schools. She is the author of several articles about the role of the rehabilitation counselor in transition, self-determination, career development, and strategies for including students with disabilities in secondary mathematics and science courses. She is affiliated with the National Center for the Study of Postsecondary Education Supports at the University of Hawaii at Manoa and the National Center on Secondary Education and Transition at the University of Minnesota. Contact her at drpeglamb@yahoo.com.

References

Adelman, C. (1998). Kiss of death? An alternative view of college remediation. *National Crosstalk, San Jose National Center for Public Policy and Higher Education, 6*(3), 1-3.

American with Disabilities Act of 1990, 794. (1990). *Americans with disabilities act (ADA).* Dewitt, NY: The Guildford Press.

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

Borg, W. K., & Gall, M. D. (1989). *Educational research: An introduction* (5th Ed.). White Plains, NY: Longman.

Burgstahler, S., Crawford, M., & Acosta, J. (2001). *Transition from two-year institutions for students with disabilities.* Retrieved on November 18, 2003 from http://www.rrtc.hawaii.edu/documents/products/phase2/pdf/030a (2)-H01.pdf.

Gajar, A. (1998). Postsecondary education. In F. Rusch & J. Chadsey (Eds.), *Beyond high school: transition from school to work* (pp. 383-405). Belmont, CA: Wadsworth.

Geertz, C. (1973). *The interpretation of culture: Selected essays.* New York: Basic Books.

Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Communication and Technology Journal, 29,* 75-92.

Henderson, C. (1999). College freshmen with disabilities statistical year 1998: A biennial statistical profile. Washington, DC: American Council on Education, *HEATH resource c*enter.

Individuals with Disabilities Education Act Amendments of 1997, PL.105-17, 20 U.S.C. $$1400 *et seq.*

Izzo, M. V., Hertzfeld, J. A., & Aaron, J. H. (2002). Raising the bar: Self-determination + universal design = success. *Journal of vocational special needs educators, 24*(1), 26-36.

Izzo, M., & Lamb, M. (2002). *Self-determination and career development: Skills for successful transitions to postsecondary education and employment.* A paper retrieved July 28, 2003 from http://www.nceset.hawaii.edu/Publications/index.html#papers.

Kaye, H. S. (2000). Disability and the digital divide. *Disability statistics abstract.* San Francisco, CA: Disability Statistics center, University of California, San Francisco, and Washington, D.C.: U.S. Department of Education National Institute on Disability and Rehabilitation Research.

LeCompte, M. D., & Goetz, J. P. (1982). Problems of reliability and validity in ethnographic research. *Review of educational research, 52,* 31-60.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry.* Beverly Hills, CA: Sage Publications.

Marshall, C., & Rossman, G. B. (1995). *Designing qualitative research* (2nd Ed.). Thousand Oaks, CA: Sage Publication.

Martin, J. E., & Huber Marshall, L. H. (1995). *Choicemaker self-determination transition assessment.* Longmont, CO: Sopris West.

McCabe, R. (2000). *No one to waste.* Community College Press. American Association of Community Colleges, One Dupont Circle NW Suite 410, Washington DC 20036.

Rehabilitation Act of 1992. Retrieved on February 23, 2003 from http://ihru.org/ilnet/files/faqs/coverrehab.html

Stodden, R. A. (2000, March). The study of postsecondary educational supports: A formative approach to an emerging area of study. In *The national review forum briefing materials.* Conference held March 9-10, 2000 at the Center for the Study of Postsecondary Education Support, Rehabilitation Research Training Center, University of Hawaii at Manoa.

Taylor, S. J., & Bogdan, R. (1984). *Introduction to qualitative research methods: The search for meaning* (2nd Ed.). New York: John Wiley and Sons.

U.S. Department of Education Strategic Plan 1998-2002-September 1997. Retrieved on March 10, 2003 from http://ed.gov/pubs/StratPln/goal_3.html

Vogel, S., & Adelman, P. (1993). *Success for college students with learning disabilities.* New York: Springer-Verlag.

Witte, R., Philips, L., & Kakela, M. (1998). Job satisfaction of college graduates with learning disabilities. *Journal of learning disabilities, 31*, 259- 265.

Wehmeyer, M. L. (1998). Self-determination and individuals with significant disabilities: Examining meanings and misinterpretations. *Journal of the Association for Persons with Severe Handicaps, 23*(1), 5-16.

Yin, R. K. (1994). *Case study research: Design and methods.* (2nd Ed.). Applied social research methods series, Volume 5. Thousand Oaks. London: Sage Publications.

Success for People with Disabilities after Postsecondary Education

Jennifer A. Graf, Ph.D. Candidate
Teresa Whelley, Ed.D.,
Linda Jones
Center on Disability Studies
University of Hawaii at Manoa

Abstract: Success may be defined in numerous ways and may be linked to quality of life. Individuals with disabilities often find success difficult to achieve. Postsecondary education has been shown to improve individual quality of life. Does a professional life obtained through postsecondary education provide individuals with disabilities entree to a better quality of life? How does this play out in the life of a person with a disability? This study reports on interviews with both people with and without disabilities and their perceptions of both success and quality of life. The findings stress how important it is to facilitate access and support in the pursuit of a postsecondary education for individuals with disabilities.

Key Words: quality of life, individuals with disabilities, postsecondary education

Introduction

Success is a concept that may be linked to the quality of ones life. When one reaches a level of accomplishment in life, ones quality of life may increase because of a sense of achievement, and one may have right of entry to opportunities previously off limits Indicators, such as financial independence, a pleasurable working environment, employment with a prestigious company, or enjoying a healthy, happy family life may define "success" for different individuals. For people with disabilities, just as for people without disabilities, achievement of success and thus an enhanced quality of life is partly dependent on self-determination. Wehmeyer (1996, p. 24) describes a definitional framework in which self-determination refers to "acting as the primary causal agent in ones life and making choices and decisions regarding ones quality of life free from undue external influence or interference." Concepts of success have generated a substantial amount of discussion in research literature. Studies have focused on success by examining numerous categories including successful businessmen, successful female executives, and successful black women as well as various achievement-related factors. What is success and how does one determine when it has been achieved? Further, how does this relate to people with disabilities and the quality of their lives? There has been comparatively little research on success relevant to the personal and professional lives of individuals with disabilities and the subsequent effects upon their quality of life.

What is quality of life? Quality of life is a concept that exists without a concrete, agreed upon definition. Is it contingent on some level with economic status, education, physical health and functional ability, or mental and emotional well-being? Is it having a loving family, friends, freedom and being self-determined? Might quality of life be seen as what people do with their free time, where and how they participate in recreation and leisure? Or is quality of life some combination of these factors; a subjective appraisal made by each individual about whether he or she is truly happy and satisfied with life and its opportunities? Does having a disability make achieving a high quality of life more or less difficult? Scholars and practitioners are challenged by the task of studying these questions.

While quality of life (QOL) has no single uniform definition (O'Boyle, 1997) it is closely related to success and has received attention as of late. One definition of QOL is: "A general wellbeing synonymous with overall life satisfaction, happiness, contentment or success" (Stark & Goldsbury, 1990). Taylor and Bogdan (1990) believe the concept of QOL has no meaning apart from what a person feels and experiences. Furthermore, people may evaluate

the same experiences differently. What enhances one person's quality of life may detract from another's. Some may see having children as a welcome addition to their lives while others may see the responsibility as a burden. Goode (1990) thought a higher quality of life to be more likely when an individual, with or without disabilities, is able to meet needs in major life settings (work, school, community, home) as well as satisfy the normative expectations that others hold for them in those settings. When one is able to consistently produce superior work as well as form successful relationships at the workplace, then one is able to obtain a higher quality of life in this life setting. Goode also echoed Maslow's (2003) hierarchy of needs stating an enhanced QOL is experienced when a person's basic needs are being met and when he or she has the opportunity to pursue and achieve goals in major life settings.

Current and ongoing research in this area identifies eight core quality of life dimensions (Schalock, 1996a):

- emotional well-being

- interpersonal relationships

- material well-being

- personal development

- physical well-being

- self-determination

- social inclusion, and

- individual rights.

These eight core dimensions vary slightly among investigators but are based on the work of Cummings (1997), Felce (1997), Hughes and Hwang (1996), Parmenter and Donelly (1997), and Renwick and Brown (1996). There is an emerging consensus, when referring to these eight core dimensions that each person values them differently, and the value attached to each varies across ones life (Wehmeyer & Schalock, 2001). Therefore success, and consequently quality of life, regardless of ability, occurs when a person's needs and desires are experienced

with some control and meaning in their environment.

Persons with disabilities often find success difficult to achieve. It is plausible that some variables that effect success are locus of control, communication skills (accommodated and not accommodated), socioeconomic status, type of disability and when disability occurred (at birth or later on in life), social supports, community involvement, history of employment and range of settings/responsibilities (Schalock, Keith, Hoffman & Karan, 1989). According to Sands and Wehmeyer (1996), "Most people with disabilities who are living, working and participating in the community have stories about the obstacles that they have overcome to achieve a personal degree of independence" (pp. 15). This is similar for people without disabilities, but people with disabilities have more obstacles in their way, i.e. discrimination, stigma, stereotypes, etc. Furthermore, a person's relative self-determination is a strong predictor of his or her quality of life: People who are highly self-determined have a higher quality of life, and people who lack self-determination have a less positive quality of life (Wehmeyer & Schalock, 2001). Those with a higher quality of life should have substantial freedom and dignity and be actualizing his/her potential to achieve maximum independence, self-acceptance, and social acceptance (Felce & Perry, 1995). However, persons with disabilities continually encounter forms of discrimination in many facets of life including postsecondary education and employment that may be barriers to self-determination.

Gretzel, Briel and Kregel (2002a) present obstacles people with disabilities face, including negative employer attitudes, architectural barriers, and lack of necessary services and supports, when attempting to access employment or pursue their careers. Further barriers people with disabilities face are lack of work experience opportunities, networking skills, and job-seeking skills. Additionally, they can lack information about available careers, knowledge on how to identify what modifications are necessary to perform a job, and knowledge on how to request needed modifications from an employer (Gretzel, Briel & Kregel, 2002b). These factors,

which hinder a person with a disability from being successful in life, also affect that person's quality of life. For these reasons, it is critical to provide greater opportunities for inclusion and choice, employment, living in a residence of ones choice, and social integration (Sands & Wehmeyer, 1996).

A central issue when examining definitions and descriptions of success and QOL is the discrepancy between subjective and objective criteria. Subjective refers to the individual's point of view whereas objective refers to the societal point of view. Subjective and objective criteria are akin to concepts of internal and external locus of control as elements of self-determination. While there may be no definitive classification for "quality of life" (Dennis et al., 1993) researchers agree that any assessment for quality of life is essentially subjective (Blatt, 1987; Edgerton 1990; Schalock, 1990; Taylor & Racino, 1991). One may assume another person has a high quality of life by observing where they live or if they have a prestigious job, but the person observed may not feel those material trappings contribute to a superior lifestyle. They may compare themselves to another with even more material wealth and feel they are truly lacking. Therefore, because quality of life is something experienced subjectively by the individual, the individual's perspective must be the primary focus of any study of quality of life (Taylor & Bogdan, 1996; Yuen & Shaughnessy, 2001).

Education is considered one way to empowerment and a higher quality of life. Statistically significant relationships between disability, level of education, and employment outcomes have been established (Benz, Doren & Yovanoff, 1998). Employment rates for people with disabilities are closely related to their level of education (Stodden & Dowrick, 1999/2000). The rate of unemployment for individuals with disabilities has hovered at around 70% for the past 12 years (New Freedom Initiative, 2001). Even with a postsecondary education, only 50% of individuals with disabilities are employed (Swenson & Richards, 1999). Despite these horrendous employment statistics, for people with disabilities, overcoming obstacles encountered in postsecondary education and graduating from college can be a major accomplishment and a significant step towards con-

trolling his/her environment and ultimately obtaining a higher quality of life.

Why would anyone attempt to study the elusive concept of success and quality of life? Perhaps because one of the most significant changes recently in the study of QOL has been the shift toward quality-of-life oriented, outcome-based evaluation rooted in person-referenced outcomes (Wehmeyer & Schalock, 2001). This development, from the sometimes ambiguous and subjective study of QOL to the more structured results orientated study, has focused the field of study upon the effects on the people being studied. According to Halpern (1993), the purpose of measuring quality of life is to assist people to establish an enhanced standard of living and lifestyle.

Research Questions

1. Does a professional life obtained through postsecondary education give people with disabilities access to a better quality of life?

2. What does it mean/look like for a person with a disability to have a positive quality of life experience?

3. Is this the same meaning/picture of quality of life as for a person without a disability?

Method

Some researchers believe that quality of life, by its very nature, is an individually unique and subjective concept that defies objective measurement and demands qualitative approaches (Edgerton, 1990). Qualitative methods offer significant advantages to the understanding of such poly-dimensional human experiences as the one being studied (Krueger, 1988; Morgan, 1988).

In-depth interviews explored the thoughts of people with and without disabilities about success. Qualitative interviews offered a number of advantages when compared with quantitative surveys of the target population. First, they allowed members of the target population to express their ideas in a spontaneous manner not entirely structured accord-

ing to the researcher's prejudices (Bertrand, Brown & Ward, 1992). Participants were free to volunteer information on points important to them, or which the researcher may not have anticipated. Second, such interviews provide more in-depth insights into how people felt about specific issues, and more importantly, why they felt this way.

Successful professional people were identified and approached to serve as participants. Purposeful sampling began with people with disabilities who have successfully negotiated postsecondary education, are employed, and who were known to the Center on Disability Studies, University of Hawaii, Manoa. Professionals in the field of human service management identified additional research subjects. Four people with disabilities were matched to four similarly employed people without disabilities.

Interviews took place over lunch or dinner. They lasted up to two hours. Selected informants revealed and described both objective and subjective quality of life indicators. Using the same indicators of objective quality of life indicators and subjective probe questions enhanced the reliability of the study.

With the permission of the interviewee, all interviews were tape recorded and transcribed. Notes were taken on relevant information, verbal and nonverbal. The data was entered and analyzed with the help of a computer software program for qualitative data analysis, NVivo. This enhanced the reliability of the analysis process by recording an audit trail of the findings (Fielding & Lee, 1998; Richards & Richards, 1994). The researcher analyzed the transcripts and notes carefully, finding themes using the constant comparative method (Glaser & Strauss, 1967; Taylor & Bogdan, 1984).

Results were offered to informants for feedback and participants were able to validate or refute the accuracy of the researcher's interpretations and conclusions (Kotre, 1984; Stiles, 1993; Lincoln & Guba; 1985). Testimonial validity was achieved in all themes.

Significant Findings

The findings of this study could be classified in three different theme areas; themes by ability, themes by gender and common themes.

Research participants related their experience of quality of life through the findings and the themes. A postsecondary education contributed to participants with disabilities' sense of ability and their self-concept of success. This is a demonstration of person referenced outcomes of quality of life. Gender is a highly personal issue and interacting with disability affected the success of women with disabilities in this study. Finally, there were some common findings among participants with and without disabilities who attended postsecondary education and were now practicing human service professionals. Postsecondary education in and of itself is seen as a credential, a building block for future development by all. These professionals also recognized that their success was due in part to family support, but it continued to be a challenge for all to balance professional life and family responsibilities. All participants needed great personal commitment to complete their education.

Themes Varied By Presence of a Disability

Successful people with disabilities in our study appear more self-reliant and see themselves as an agent of change in their own lives, more so than their non-disabled counterparts. It seems they realize they must determine what they want and how to get it:

> "…And again because of my disability, even though I can bend down and pick something up on the floor, if I drop a piece of paper and I need it, and I need it bad enough I will find someone to pick it up for me. So much of it depends on the need or priority."

> "Well, I think the education alone or the combination of the education and the professional has given me the self-confidence to make me feel like I could conquer the

world. I can get married, I can have kids, and I can run away and live in a tropical island in the Pacific. I can do anything I want because I have confidence that I'll land on my feet…"

Related to this last finding is the issue of control and choice, which seems to be more important for research subjects with disabilities than for non-disabled research subjects. This indicates that people with disabilities appear to need to strive harder and be more self-reliant in achieving success. Again, this reinforces the fact that quality of life is tied to self-determination. Self-determination is important for everyone, but in this study it was more important for people with disabilities. (PWDs):

> "I think it's a matter of how you perceive yourself and how you perceive your environment. And so if you perceptually change that and you start to create action steps then you can have tremendous amounts of control. But a lot of times people don't want control because with control comes responsibility."

> "I realized that no matter where your path takes you, from that point, wherever you are, you have an infinite set of choices, even though the ones behind you were limited."

> "There was a pervasive attitude there, that 'you get on with it' that I think really stood me on good stead."

Some people with disabilities in this study felt highly regarded by others. They indicated these opinions are sometimes exaggerated, which made them feel they were being overvalued. This suggests that while non-disabled people are aware of the obstacles persons with disabilities face, they may feel the need to be over complimentary. PWDs in this study felt that others would overestimate the effect of their disability on their lives and that their successes and small achievements in their life were over inflated:

> "There are a few people…who just have this total inflated notion of who I am, they think I walk on water and everything I do is a miracle…"

> "I say this because I've been told by a number of people…I think people give me way more credit than I deserve."

Other misconceptions had detrimental effects on people with disabilities and their careers. Both women with disabilities had career plans altered by someone with influence and a limited view of disability:

> "I had wanted to go into some type of medical profession and I was told that I couldn't do that…just forget that."

> "My high school guidance counselor did not know any better and it was just like you were told 'no you can't do that, no nursing school would take you, no medical school would take you'…and then when I got the master's degree in counseling, it was like well, it's the easiest thing to do…"

Themes Varied By Gender

The women spoke of how mentoring helped in their success. All the women had someone to call a mentor, who they could go to for advice and/or encouragement and who was a role model:

> "I would tell someone nowadays to get a mentor. Find someone to teach you the ropes…that will stick with you because I think that's what worked for me- finding a couple of people I could always count on to be there."

> "Someone who never says 'I can't' or 'You can't'…I would advise people to look for someone who is

genuinely interested in who they are on the inside and what they have to offer on the inside…"

The women also spoke of the importance of mentoring others:

> "I think I feel successful when…I have had an opportunity to mentor and …watch them go on to bigger and better things. And they come back to me and say, 'Oh that was so useful and I learned so much.' That feels wonderful."

> "Success is…being able to mentor people and help them see themselves as leaders in the field."

Mentoring is a changing concept. All people have peer relationships that are valuable as supports both professionally and personally. Most people have role models who they aspire to be like. Advisors are more formal relationships that assist people in making decisions and choices. But the most formal is a mentoring relationship. Originally, this was a relationship between an older adult and a younger person designed to teach the younger person about the world. It was assumed to be long lasting. More current applications of the mentoring role include mentors for specific tasks in employment and schooling (Whelley, Radtke, Burgstahler & Christ, 2003).

Men mentioned the overlapping of personal and professional lives more than the women did:

> "In a sense, my personal success is pretty much in my professional side, so it's made everything much more…It's made me able to succeed professionally, which makes me more satisfied personally."

> "There is a real merge of what I do socially, personally- they are all interrelated."

Women and men agreed that it is important to have a plan. The women emphasized a vision while men thought having a plan would be key to achieving their goals: "It is good to have an idea, a vision, of where you would like to go."

In a slightly different way, men talked about goal setting: "It is important to set goals for yourself and be able to meet those goals."

Common Themes

Most participants felt that credentials earned were a large part of the importance of postsecondary education. It is a societal standard that demonstrates a level of ability and can open the door to further possibilities:

> "It gives you a basic framework for someone to realize maybe there is a common body of knowledge that you share with others in the profession."

> "I guess I'd say that from the standpoint of being taken seriously, …it's like who you are, where did you go to school, what's your background, what experience have you had, what makes you worthy of doing this type of job."

Family support was also common to all our successful professionals:

> "My family was extremely supportive during the time I was growing up…"

> "Those were all fundamental necessities in terms of my being able to accomplish what I had accomplished. Family is probably the foremost variable, strong parental support, a lot of people coming to bat for you when you require help."

All of our participants showed a high level of determination. They kept trying despite various setbacks in their lives:

> "The things that led to success? For one, sheer determination to succeed."

Perhaps because of their field of study, the human services management field, all were interested in making a difference:

> "The other part of personal success is feeling like I can help make the world a better place."

> "Professional success means that the activities I do on my job or in my job has impact, there are outcomes and there are impacts on the kinds of systems that I work with."

All participants indicated a struggle for balance in their lives and the feeling of not having enough time:

> "Well, I'm struggling with work/family balance; I guess right now at this time in my life, I feel most successful when I'm not feeling torn apart by struggling with this balance."

> "I think I've been talking about, I'd like to be more diversified, and I'd have more time to do social things…"

All participants saw postsecondary education as a foundation on which to build their lives and a great opportunity to broaden their worldview:

> "I think it was Einstein who said that 'as the circle of light expands so does the circumference of darkness' so the more we know, the more we realize we don't know and so that the knowledge that we gain, more and more knowledge, whatever it is that we gain, creates this change in terms of how we see things, how we perceive our world, how we perceive others, how we perceive ourselves, so sure, expansion of knowledge is going to create changes all over the place."

> "I think it's broadened my knowledge. I mean, lots of times skills are transferable, what you use in business and what you use in your professional, take people skills, or counseling skills, you might learn in your profession, but it goes a long way."

Limitations/Suggestions for Future Research

The findings in this study come from a very small group and cannot be generalized widely. The scope of this study could be expanded to include more diverse people, especially those who are culturally diverse, adding another dimension to compare themes. Additionally, a comparison study done on the themes of those with postsecondary educations and those without would allow for further contrast. As a final limitation, the study was limited to Hawaii and to the field of human resource management.

For future research an interesting possibility would be to identify others close to those interviewed about their perspectives on the already identified successful case study and to do more of a complete case study. This could be expanded to an ethnographic study, observing the subjects at home and work and drawing conclusions from the combination of the perspectives. These methods would give depth to the findings and add validity to the subjects' reports.

Discussion

In each angle of analysis there were clear and common themes. People with disabilities are not so different from those without in their determinants of success. But they do see themselves as more self-reliant and as being rated higher by others. Having control and choice was clearly a theme for people with disabilities, yet did not emerge as a theme for those without disabilities. Another unique theme for people with disabilities was having their career plans altered by someone with influence and negative view of being disabled.

Postsecondary education appears to make a difference for people with disabilities. The major find-

ing in this research was that postsecondary education makes more of a difference in quality of life for those with disabilities than for those without in regard to employment. Having success in one milestone in life, i.e. postsecondary education, may pave the way for further success in an array of outcomes: employment, status, sense of accomplishment and productivity. It was also found that completion of a postsecondary education was not as much of an expectation for those with disabilities as for those without disabilities. For this reason, self-determination and other self directed skills should be taught for all, but especially those with disabilities, and should begin as early in high school. Once on a college campus, supportive access to postsecondary education for those with disabilities must be provided.

The theme area of gender also proved interesting. Women thoroughly believed one reason for their success was being mentored and mentoring others. As mentoring changes in today's society, opportunities for being mentored and mentoring should become part of the movement to include diverse peoples. Both genders talked about the importance of having a plan, but the women talked more broadly and philosophically, about having a vision and dreams, whereas men talked more about concrete goal-setting.

Themes common to all levels of analysis were also found. Postsecondary education was seen as a credential in American society almost necessary to be successful. Credentials are seen as being important in themselves but also as a strong foundation. Higher education has opened avenues to millions of Americans. Students with disabilities must be provided the same opportunities and access as their non-disabled peers. The importance of family support is also unambiguous. All of our interviewees listed their families, both birth families and created families as a determinant of their success. Support can also come from elsewhere (disability service providers, friends, etc.) and seems to be most effective when there is a triangle of support (Whelley & Graf, 2003) with the family, disability support providers and the student all working toward the shared goal of a college education for the student. All of those studied pointed to their own determination as a reason for their success. Another commonality was the goal of making a difference in the world. This may be because of the more socially conscious group (human service professionals) chosen for the study. Not surprisingly, all participants felt there was not enough time do all they would like to do and to achieve a balance between work and family. Post- secondary education was clearly seen as a building block on which to begin the road to success. Overall, definitions of success need to be more encompassing. For individuals with disabilities, barriers need to be recognized and removed. As shown in this study, postsecondary education opportunities may make a difference in the success of people with disabilities and contribute to their quality of life.

Jennifer A. Graf is currently working on her doctorate in Community and Cultural Psychology at the University of Hawaii, Manoa. Her interest areas are in diversity (including disability), multiculturalism, HIV/AIDS, and women's studies.

Teresa Whelley, Ed.D. is an Assistant Professor with the Center on Disability Studies and at the University of Hawaii at Manoa. Her research includes, transition, postsecondary education, families of people with disabilities and developmental disabilities. She has taught in the areas of secondary education and transition, families and in community social services.

Linda F. Jones received her B.A from the University of Hawaii in Speech Communications with an emphasis on theory and research. She currently teaches children who have autism in the private sector. She continues to explore her education in the field of autism through specialized seminars, conferences and workshops.

References

Benz, M., Doren, B., & Yovanoff, P. (1998). Crossing the great divide: Predicting productive engagement for young women with disabilities. *Career Development for Exceptional Individuals, 21*(1), 3-16.

Bertrand, J. T., Brown, J. E., & Ward, V. M. (1992). Techniques for analyzing focus group data. *Evaluation Review*, *16*, 198-209.

Blatt, B. (1987). *The conquest of mental retardation*. Austin, TX: Pro-Ed.

Cummings, R. A. (1997). Assessing quality of life. In R. I. Brown (Ed.), *Quality of life for people with disabilities: Models, research and practice* (pp. 116-150). Cheltenham, UK: Stanley Thornes (Publishers) Ltd.

Dennis, R., Williams, W., Gioningangrego, M. F. & Cloninger, C. (1993). Quality of life as context for planning and evaluation of services for people with disabilities. *Exceptional Children*, *58*, 499-512.

Edgerton, R. (1990). Quality of life from a longitudinal research perspective. In R. Shalock & M. J. Bogale (Eds.), *Quality of life: Perspectives and issues* (pp. 149-160). Washington, D.C.: American Association of Mental Retardation.

Felce, D. (1997). Defining and applying the concept of quality of life. *Journal of Intellectual Disability Research, 41,* 126-135.

Fielding, N. & Lee, R. (1998). *Computer analysis and qualitative research*. Thousand Oaks, CA: Sage.

Glaser, B. & Strauss A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.

Goode, D. (1990). Thinking about and discussing quality of life. In R. Shalock & M. J. Bogale (Eds.), *Quality of life: Perspectives and issues* (pp. 149-160). Washington, D.C: American Association of Mental Retardation.

Graf, J. & Whelley, T. (2003). *The role of families of students with disabilities in postsecondary education*. Manuscript submitted for publication.

Gretzel, E. E., Briel, L. W., & Kregel, J. (2002a). Comprehensive career planning: The VCU career connections program. *Work*, *14,* 41-49.

Halpern, A. (1993). Quality of life as a conceptual framework for evaluating transitional outcomes. *Exceptional Children*, *59,* 486-498.

Hughes, C., & Huang, B. (1996). Attempts to conceptualize and measure quality of life. In R. L. Schalock (Ed.), *Quality of life: Conceptualization and measurement* (pp. 51-62). Washington, D.C.: American Association of Mental Retardation.

Kotre, J. (1984). *Outliving the self: Generatively and the interpretation of lives*. Baltimore: John Hopkins University Press.

Krueger, R. A. (1988). *Focus groups: A practical guide for applied research*. Newbury Park, CA: Sage.

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.

Maslowv's Pyramid. (October, 2003). Retrieved March 8, 2004. Available: http://www.cyber-gish.com/Blogger/archives/000722.html

Morgan, D. L. (1988). *Focus groups as qualitative research*. Newbury Park, CA: Sage.

O'Boyle, C. A. (1997). Quality of life assessment: A paradigm shift in healthcare?

The Irish Journal of Psychology, 18, 51-66.

New Freedom Initiative. (2001). *Executive summary of the New Freedom Initiative*. Available: http://www.whitehouse.gov/news / freedominitiative/freedominitiative.html.

Parmenter, T., & Donelly, M. (1997). An analysis of the dimensions of quality of life. In R. I. Brown (Ed.), *Quality of life for people with disabilities: Models, research and practice* (pp. 91-114). Cheltenham. UK: Stanley Thornes.

Renwick, R., & Brown, I. (1996). The Centre for Health Promotion's conceptual approach to quality of life. In R. Renwick, I. Brown, & M. Nagler (Eds.), *Quality of life in health promotion and rehabilitation: Conceptual approaches, issues, and applications* (pp. 75-86). Thousand Oaks, CA: Sage Publications.

Richards, T., & Richards, L. (1994). Using computers in qualitative analysis In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (pp. 445-462). Berkley, CA: Sage.

Sands, D., & Wehmeyer, M. (1996). *Self-determination across the lifespan*. Baltimore: Paul H. Brookes Publishing Co.

Schalock, R. (1996a). Reconsidering the conceptualization and measurement of the quality of life. In R. L. Schalock (Ed.), *Quality of life: Conceptualization and measurement* (pp. 9-26). Washington, D.C.: American Association on Mental retardation.

Schalock, R. (1990). Attempts to conceptualize and measure quality of life. In R. Shalock & M. J. Bogale (Eds.), *Quality of life: Perspectives and issues* (pp. 141-148). Washington, D.C: American Association of Mental Retardation.

Schalock, R., Keith, K. Hoffman, K. and Karan, O. (1989). Quality of life its measurements and its use. *Mental Retardation, 27* (1), 25-31.

Stark, J., & Goldsbury, T. (1990). Quality of life from childhood to adulthood. In R. Shalock & M. J. Bogale (Eds.), *Quality of life: Perspectives and issues* (pp. 71-84). Washington, D.C: American Association of Mental Retardation.

Stiles, W. (1993). Quality control in qualitative research. *Clinical Psychological Review, 13*, 593-618.

Stodden, R. A., & Dowrick, P. (Winter 1999/2000). Postsecondary education and employment of adults with disabilities. *American Rehabilitation, 25*(3), 19-23.

Swensen, S., & Richards, C. (1999). *Report from the subcommittee on expanding opportunities for young people with disabilities*. (OSERS). Washington, DC: U.S. Department of Education.

Taylor, S., & Bogdan, R. (1996). Quality of life and the individual's perspective. In R. Shalock & G. Siperstein (Eds.), *Quality of life: Conceptualization and measurement* (pp. 87-102). Washington, D.C.: American Association on Mental retardation.

Taylor, S., & Bogdan, R. (1984). *Introduction to qualitative research methods: The search for meanings*. New York: Wiley.

Taylor, S., & Bogdan, R. (1990). Quality of life and the individual's perspective, In R. Shalock & M. J. Bogale (Eds.), *Quality of life: Perspectives and issues* (pp. 304-312). Washington, D.C.: American Association of Mental Retardation.

Taylor, S., & Racino, J. (1991). Community living: Lessons for today. In L. Meyer, C. Peck, & L. Brown (Eds.), *Critical issues in the lives of people with severe disabilities* (pp. 235-238). Baltimore: Paul H. Brookes.

U.S. Department of Education. (1991). *To assure the free appropriate public education for all handicapped children: Thirteenth annual report of Congress on the implementation of the Education of All Handicapped Act*. Washington, DC: U.S. Department of Education, Office of Special Education and Rehabilitation Services.

Wehmeyer, M. L., & Schalock, R. L. (2001). Self-determination and quality of life: Implications for special education services and supports. *Focus on Exceptional Children*, *33*(8), 1-15.

Wehmeyer, M. L. (1996). Self-determination as an educational outcome: Why is it important to children, youth and adults with disabilities? In D. J. Sands & M. L. Wehmeyer (Eds.), *Self-determination across their life span: Independence and choice for people with disabilities* (pp. 15-34). Baltimore: Paul H. Brookes.

Whelley, T., & Graf, J. (2003). *The role of families of students with disabilities in postsecondary education*. Manuscript submitted for publication.

Whelley, T., Radtke, R., Burgstahler, S., & Christ. T. W. (2003). Mentors, advisers, role models and peer supporters: career development relationships and individuals with disabilities *American Rehabilitation, 17*(1), 42-50.

Yuen, J., & Shaughnessy, B. (2001). Cultural empowerment: Tools to engage tools to engage and retain postsecondary education students with disabilities. *Journal of Vocational Rehabilitation, 16*, 199-207.

A Beautiful Story: A Dream Realized through the Power of Natural Supports and Faith in Oneself

Anona K. Napoleon, Ph.D. and Cindi Sherman
University of Hawaii at Manoa

Abstract: At a very young age, Shirley Doneza was diagnosed with developmental delay and a learning disability. Her parents, Ed and Martha, recall the obstetrician telling them in the vaguest of terms: "Something is wrong with her." However, Ed and Martha knew the person that Shirley was becoming and never doubted her potential to work hard and realize whatever dreams she might hold dear. With their faith and support, Shirley passed through the grade levels in school apace with her peers and ultimately graduated from college with a degree as an Educational Assistant. Today, she has achieved a high quality of life with a competitive, and exceptionally gratifying, employment and a high quality of life. Her story is a model of the power of natural supports—defined as the people surrounding a person, not as professionals but as personal associations, i.e., family and friends who believe in the person (Stodden & Leake, 1994) —to impart self-confidence and self-efficacy, and the success that that belief can bring.

Key Words: postsecondary education, natural supports, transition to employment

While still a very small child, Shirley Doneza showed signs of developmental delay. "When someone spoke to her," her parents, Ed and Martha, remember, "She would just look at the person and, sort of, not hear or understand." At the prompting of her kindergarten teacher, Shirley was tested and diagnosed as having a learning disability.

The authors purposely are not being more specific about Shirley's disability because, like others currently working with people with developmental disabilities, we try not to apply disability labels. Since the stigmas attached to these labels have been so harmful in the past, many of us have found that it is most important to form relationships with the people we are associated with, rather than focusing on any

label. In addition, Shirley's family wants her to be viewed as a person, not as her disability. A significant factor in Shirley's story is that Ed and Martha Doneza are rooted in a Filipino community. They identify with traditional Filipino culture and attitudes and they raise their children in accordance with the heritage they hold dear, a heritage wherein children with disabilities are often stigmatized and seen by the community as evidence of transgression in the spiritual life of the family (MDAA, n.d.). Family members with disabilities are kept highly sheltered, sometimes even hidden, and viewed as the responsibility of parents and siblings, not as independent agents. To a lesser degree, the female members are also considered less capable of self-governance and more in need of protection than male counterparts. Therefore, as a female child, and one with a learning disability that might suggest a life of dependence and light domestic duties, it is remarkable that Shirley eventually came of age with the commitment to education that she did. This familial commitment, along with Shirley's willingness to learn and everyone's efforts to invoke her rights, propelled her through high school and on to college, where she ultimately earned the credentials to take on competitive employment as an educational assistant in a local school. Shirley is proud to relate that the vital factor in her success was her family's unwavering belief in her and in her potential. Shirley's story is a testimony to perseverance, self-efficacy, faith in oneself, and the indispensable benefit of natural supports.

At the outset of her formal education, Shirley's teacher suggested holding her back for a second year in kindergarten and limiting the expectations put upon her. This position conveyed to Ed and Martha that the well-meaning teacher was less convinced of Shirley's potential than they were. Ed and Martha sought the help of a Special Education advocate. They were determined to become involved in Shirley's education, even if it meant they were occasionally perceived as meddlesome. Ed remembers how he inadvertently acquired a reputation for "making trouble" because he asked so many questions. When a parent has a child with a disability, there are many things to learn, such as state laws and federal Acts. Suddenly there is a lexicon of terms and phrases—IEP's, Section 504, No Child Left Behind, and so forth—in which to become conversant. In addition, there are issues of curricular content and delivery that parents of a student with a learning disability must inquire about and advocate for. Ed and Martha recognized early on that they must be proactive if they were to garner a free and equal public education (which the Donezas came to know by yet another common acronym, FAPE) for Shirley.

For instance, they insisted Shirley be given the opportunity to learn new material that would emphasize concepts, underlying meanings, and critical thinking, rather than the rote memorization and "drill" activities that too frequently, they believed, defined Special Education classrooms. Specifically, they advocated through the Individuals with Disabilities in Education Act (IDEA) and, armed with the full awareness of the rights that Act conferred, obtained curricular and instructional modifications and supports. They called meetings with Shirley's teacher, the principal, representatives form the district SPED office, and local, government-funded disability support agencies and advocacy groups. The school, although located in Hawaii where various Polynesian cultures are widely represented, had never seen such involvement and assertiveness from a traditional Filipino family, where individual needs are typically subordinated to the larger community and girls' educations are not prioritized. Ed and Martha knew they had to defy traditional mores in the service of launching their daughter into satisfying, independent adulthood. They had to adapt as people, and they rose to the challenge.

With such firm parental support, Shirley's own faith in herself strengthened. She studied with the diligence and consistency of one resolved to defy typical expectations for someone with so significant a learning disability. This is a woman who was essentially written off as *uneducable* at birth. "I was determined," she says, "That I was going to finish." That determination, which had always been so supported at home, was beginning to convert the doubters. One teacher in particular, Shirley recalls, seemed to have a mantra just for Shirley: "You can do it, you can do it…"

Another factor that fueled Shirley's inner drive was the realization that her parents would not be with her forever. Even though she is a member of a strong Filipino community and can depend on members of that community for continued support, Shirley felt a need to exercise some independence from her family. In a sense, she felt that she owed it to them to become self-reliant and thus free them of the need to extend their parental responsibility into her adulthood, and to free them from worry. It was her way of thanking them. That impetus never let her down. "It's like a voice within," she recalls, "Saying: 'You can do it, keep going, hang in there…'" After persevering in postsecondary education for eight years, taking the full number of credits per semester that her disability allowed (which was considerably fewer than the standard 15), Shirley obtained her Educational Assistant (EA) certificate in Early Childhood Education, where she could best impart to children with learning disabilities that they too must believe in themselves, and must find supporters who also believe. In Shirley's own words: "I was in special education, and I know how frustrating it is when you have a teacher who doesn't really understand you." She explains, "I am at a point in my life where I want to encourage others to keep working and learning so they can feel great and support themselves."

When asked if they could provide any advice for special education teachers, parents of youth with learning disabilities, and the youth themselves, the Doneza family underscored the need to find natural supporters who could convey to the student their belief in the student's ability to achieve dreams and aspirations. These natural supporters can be family, friends, clergy, community groups, and so forth. Shirley reflects that it was through seeing others' faith in her, and being continually encouraged, that her own self-efficacy never flagged. She adds that while she is not "happy" to have the weaknesses that she possesses, it is by virtue of having those weaknesses that she discovered and cultivated her strengths. She is steadfast, she celebrates herself and those around her, and she understands that everyone has something to offer. She feels humbled by the help she has received from her parents, who flouted the school's "not so great expectations," and by the support of her teachers. She is determined, now, to spread that to others.

Anona K. Napoleon, Ph.D. is a recent graduate of the College of Education, University of Hawaii. She was a leadership trainee in the area of Disability Studies. Her research areas of interest include Hawaiian Studies.

Cindi Sherman has been a high school teacher, and is currently a senior writer/editor with the National Center for the Study of Postsecondary Educational Supports at the Center for Disabilities Studies at the University of Hawaii.

References

Multicultural Disability Advocacy Association. (n.d.). *Ethnic communities and disability*. Retrieved March 15, 2004, from http://www.mdaa.org.au/ethnic/filipino/general.html.

Stodden, S. A., & Leake, D. W. (1994). Getting to the core of transition: A re-assessment of old wine in new bottles. *Career development for exceptional individuals, 17*(1), 65-76.

Research Articles

Asian Americans with Disabilities: Influence of the Disability Rights Movement on Culturally Competent Social Work Practice

Christine N. Langworthy, LSW
School of Social Work
University of Hawaii at Manoa

Evaon C. Wong-Kim, LCSW, MPH, Ph.D.
College of Social Work
San Jose State University

Abstract: This article discusses the implications for culturally relevant social work practice with Asian Americans with disabilities based on the goals and philosophy of the disability rights movement. Standards of practice within the social work profession, especially in the health care and rehabilitation settings, have included changes in conceptual framework and practice roles in response to the disability rights movement. Using a case study as an example, the article focuses on the cultural values of Asian Americans with disabilities to identify obstacles to incorporating mutually shared premises into social work practice. Some of the concepts of the disability rights movement need to be redefined in a culturally competent way so that social workers can respond appropriately to the needs of Asian Americans with disabilities. The implications are that social work practice must integrate and apply cultural values with support of the full functioning of people with disabilities.

Key Words: social work, culturally relevant approach, Asian Americans with disabilities

Introduction

In 1990, the United States Congress passed the Americans with Disabilities Act (ADA). This landmark legislation, designed to promote and protect the rights and interests of all people with disabilities, was one of the most significant pieces of legislation in the history of the disability rights movement. It is often referred to as the "emancipation procla-mation" for persons with disabilities. The significance of this act is that it provided the full range of protections and rights as the 1964 Civil Rights Act did for other minorities (Meinert & de Loyola, 2002). The disability rights movement arose to respond to a newly identified social problem of oppressive marginalization of people with disabilities. The movement sought to empower people with disabilities to take control of their own lives and create public policy and practices that would eliminate or at least ameliorate the problem of systematic exclusion from mainstream society.

The movement embraced the social barriers model as one of several new models of disability, replacing the medical model as the existing framework. This model contends that it is society's response to an impairment that disables a person, not the impairment itself (the actual bio-physical condition). Furthermore, this societal response limits disabled people's ability to fully participate in society and to exercise their rights. From this perspective, disability is seen as a social justice issue; a societal induced oppression that could be remedied by societal action such as passing appropriate laws that would reduce or eliminate the oppression (Winter, 2003).

Another model developed during the disability rights movement was the minority group model. This model emerged as an alternative to the deficit orientation (Mackelprang & Salsgiver, 1996). The minority group model asserts that discrimination against people with disabilities is rooted in the cultural beliefs and values of the culture. From this perspective, the major problems confronting people with disabilities are similar to other disadvantaged groups that have encountered discrimination as a result of race, ethnicity, gender and age.

The expansion of the independent living center concept was a natural progression in the disability rights movement – the concept that people with disabilities can practice self-governance by making their own life decisions. Independent living centers define independence as the "freedom to choose". The goals of the independent living center for people with disabilities are to increase self-determination and minimize dependency on others by offering services

in the community that are consumer controlled (Winter, 2003). Consumers of these programs and services should be involved in their planning and implementation (Brown, 1994). Centers seek to minimize dependence on the intervention of professionals and maximize the use of advocacy, peer support, and self-help by assisting people with disabilities remove barriers that undermine the ability to carry out one's own decisions (Winter, 2003).

The social work discipline shares many values parallel to the disability rights movement such as the focus on changing the environment and providing resources to clients based on an empowering process. Given the fact that the core values and underlying conceptual and philosophical underpinnings of social work and the disability rights movement are basically compatible, social work policy and practice should be more closely aligned with disability rights advocates in upholding ADA definitions of disability rights and moving toward the common goal of supporting the full functioning of people with disabilities. However, the social work discipline has not been committed to serving people with disabilities. Many students are ill prepared to work with this population.

Besides training to prepare social workers to work with people with disabilities, cultural competent social work practice with minority persons is virtually an untouched area of training and research in the social work profession. Most research on culturally competent social work practice focuses on how cultural norms, beliefs, and behaviors impacted the minority client's interaction with the mainstream environment. There have not been many social work studies focused on working with minority clients with disabilities. It is unclear if the approach to assist clients with disabilities will be appropriate for minority clients with disabilities. By using client self determination as an example, the authors will illustrate how this widely accepted social work value that is consistent with the disabilities movement may actually be in conflict with providing culturally competent social work practice.

We ask the question: "What are the issues that must be addressed to 'fit' culturally competent so-cial work interventions with Asian Americans with disabilities?" We use some of the concepts of the disability rights movement and redefine them in a culturally competent way so that social workers can respond appropriately to the needs of Asian Americans with disabilities. The focus on Asian American people for the discussion is mainly due to the growing number of this population nation-wide, and because some of their values conflict with those of the disability rights movement.

Using a case study, this article suggests some ways to make social work practice more culturally competent when working with Asian Americans with disabilities. The lack of disability rights perspectives in social work practices will also be discussed. Finally, a culturally competent social work model that focuses on self-determination and other concepts of the disability rights movement are redefined in a culturally relevant way so that social workers can respond appropriately to the needs of a diverse population group with disabilities.

Case Study

Mrs. Tran is a Vietnamese-Chinese woman diagnosed with stage-two breast cancer who was referred to the oncology social worker after her initial appointment with the oncologist. As part of the case management services in oncology, the social worker routinely assesses clients newly diagnosed with cancer. After a full assessment of her family situation and other psychosocial issues, the bilingual oncology social worker asked if Mrs. Tran had any concerns. Mrs. Tran started became to become tearful and very upset. Mrs. Tran calmed down after some grief counseling and then asked the social worker, "How am I going to tell my daughter about my cancer?" The oncology social worker tried to work with Mrs. Tran regarding issues of communication within the family and suggested some ways of approaching such an important issue. Mrs. Tran then said to the social worker, "You don't understand, my daughter is deaf and she cannot understand me!" Mrs. Tran explained that she moved to San Francisco from China about 15 years ago. At the time of the immigration, her daughter Lia was one years old. Due to a high fever, Lia subsequently lost her hear-

ing. Lia was referred to an agency that serves people with disabilities and a social worker was assigned to her case. Lia was admitted to a pre-school for deaf children when she was three years old.

When Lia was at home, Mrs. Tran tried to speak with her even though she was fully aware of Lia's disability. Due to long working hours and a lack of resources, Mrs. Tran did not learn to sign in English. As a matter of fact, to be able to sign Mrs. Tran would first have had to learn English. Mrs. Tran became frustrated in the process of learning English and gave up after a few months in the ESL classes. Although Lia was learning fast and able to adapt in the pre-school environment, both Mr. And Mrs. Tran communicated with Lia using some simple gestures. Lia was fourteen years old at the time of Mrs. Tran's diagnosis and was doing very well at school but basically didn't have any substantial communications with her parents.

Mrs. Tran also asked the oncology social worker why misfortunes had to happen to her family. She answered the question herself by saying it must be the punishment of their ancestors' sins. She believed in reincarnation and how the crimes and sins one committed in his/her last life could come back to haunt him/her. When asked if the case worker assisting Lia could provide her with resources to learn how to sign and teach Lia to write in Chinese, Mrs. Tran said that there was no social worker assigned to Lia anymore because Lia was doing well in school and seemed adjusted. Now Mrs. Tran was wondering how she could tell Lia about her diagnosis and how Lia would feel about it.

In order to provide a culturally appropriate intervention, the oncology social worker contacted the school Lia was attending and discussed the situation with her teacher. The teacher referred the oncology social worker to a bilingual classroom assistant who also knew how to sign. A family meeting was set up for Mr. and Mrs. Tran, Lia, the oncology social worker and the bilingual classroom assistant. Many issues were discussed and many questions regarding Mrs. Tran's diagnosis were raised. Another family meeting was scheduled with the Tran family, the classroom assistant, the oncology social worker and

the oncologist to further explore Mrs. Tran's treatment options and the care she might require once she started treatment. Although the long-term communication problem was not resolved, Mr. and Mrs. Tran were encouraged to learn simple sign language that is internationally used and easier to remember. By learning this kind of sign language, they did not have to be so fluent in English.

This case illustrates some of the barriers a monolingual Chinese family experienced when their child became deaf. A systems approach or "person-in-environment" perspective that emphasizes environmental influences on personal functioning should have taken into consideration the family structure and communication when the child was diagnosed with a disability. In this case, if Mr. and Mrs. Tran were taught to sign in Chinese and if Lia had learned both English and Chinese, the family might have been able to communicate with each other after Lia became deaf. By treating the individual only and not considering the functioning of the family as a unit, we risk minimizing the support family members can offer each other, especially when working with a culture that values family and interdependence.

Lack of Disabilities Rights Perspective in Social Work Practice

This case illustrates the lack of a social work case management model to work with this family that would promote not just personal adjustment, but the well-being of the family. There are other indications that the social work discipline is not well prepared in this area. Social work policy and resulting services to people with disabilities continues to be fragmented and contradictory in spite of the momentum of political and social changes that occurred as a result of the ADA in the 1990s. Long before the ADA, Howoritz (1959) recommended that social work should serve to enhance the social functioning of a person with a disability. However, social workers did not take leadership roles in the field of rehabilitation at that time and continued to focus on a more treatment-oriented casework model. This approach, based on the medical model, limited the role of the social worker and the scope of the in-

volvement in advancing the disability rights movement.

Although some believed that social work was one of the few professions ready to assist with the complex needs of a person with a disability and the family (Quinn, 1995), the role of social workers in rehabilitation diminished in the 1970s and 1980s, neglecting a population that was severely lacking in services that could be provided by social workers (Meinert & de Loyola, 2002).

The lack of social work involvement in the disability area was due, in part, to the lack of a sufficient knowledge base about people with disabilities (Horowitz, 1959, Meinert & de Loyola, 2002). Furthermore, social workers were not trained to view disability using a human diversity perspective. Long held attitudes and perspectives needed to be realigned to view disability from other perspectives rather than just using the medical model. Social work educators needed to remind students to overcome their own biases and prejudices and be aware that even when overt discrimination is not evident there is often a culture of benign neglect for persons with disabilities.

Today, there is evidence that more experienced and educated social workers generally recognize and accept change in their role and their relationships with their clients from one characterized more by paternalism and control to one of equality and partnership. However, an exploratory study of disabled individuals' experiences with social workers indicates that concerns remain about stereotyping and the lack of a focus on autonomy, self-determination, privacy, and equality. Specifically, less experienced social workers prejudge individuals on the basis of the disability label and fail to seek the advice of consumers themselves (Gilson, Bricout & Baskind, 1998). This suggests that social work training in this area should include the leadership role of people with disabilities, an approach that would include support for self-determination and empowerment of people with disabilities in a collaborative effort with the social worker (Stainton, 2002). Solomon (1976) defines empowerment as "aiming to reduce the powerlessness that has been created by negative valuations based on membership in a stigmatized group," and identifies several elements of social work practice that may enhance empowerment. These include collaborative partnerships, a focus on client strengths and a person's environment, and ensuring that people are active participants in determining their future direction.

Culturally Competent Social Work Practice and the Disability Rights Movement

The Asian American and Pacific Islander (AAPI) population (reported as an aggregate group until Census 2000) has doubled each decade from 1.5 million in 1970 to nearly 10.7 million in 2000. Since 1990, the APPI population has grown 41 percent, faster than any other racial/ethnic group in the United States. Although often combined for political or data reporting purposes, Asians Americans and Pacific Islanders are, in fact, two distinct population groups, both of which encompass more than 35 distinct ethnicities, each with its own traditions, culture, and languages. More than 3,000 distinct languages and dialects are spoken by both Asians and Pacific Islanders and more than 100 languages are commonly spoken in the United States. In Hawaii more than 70% of the population is classified as Asian, or mixed Asian (Census Bureau, 2000). This large number of Asians living in Hawaii calls for special attention from social work providers to deliver culturally appropriate interventions. Several concepts pertinent to working with people with disabilities, and how these concepts are suitable to use with Asian Americans with disabilities, will be analyzed in the following sections.

Self-Determination, Individualization

Person-centered planning is a concept in the field of mental retardation that identifies a new approach (Russo, 1999). Brown & Ringma (1989) point out that a major review of disability services in Australia clearly promotes a consumer perspective in planning and managing services. The social work values of individual self-determination and promotion of social justice stress a commitment to identifying and acting upon a person's needs and expressed preferences in order to empower consumers toward self-

development and actualization (NASW Code of Ethics, 1996). The concept of autonomy, defined as the individual's capacity to formulate and act on plans and purposes that are self-determined, is a fundamental concept in most theories of rights and an explicit goal of the disability rights movement (Stainton, 1994).

It is important to recognize that the disability rights movement has historically been a self-help movement, and has sometimes taken an adversarial role toward professionals, including social workers, who disabled advocates perceive as consultants who are often unsupportive of self-determination (Mackelprang & Salsgiver, 1996). One of the main premises of the independent living philosophy is that people with disabilities are the true "experts" regarding their own needs and issues, and that those who have disabilities are best suited to understand and guide someone else in a similar situation through peer support (Brown, 1994). Independent living encourages people with disabilities to assert their capabilities and feel empowered enough to take control over their lives. Whether people with disabilities do in fact choose to act autonomously is not as important as that they have the means and capacity to do so if they wish. More recent studies in social work discipline indicated a change in how to work with people with disabilities. Beaulaurier & Taylor (2001) suggest that effective social work practice is going to require a refocused conceptual framework that will support and promote self-determination and respect for the uniqueness of each individual. They suggest that community organization, advocacy skills, and the role of the educator should take on more importance in working effectively with people with disabilities.

Within Asian American culture, the family provides an expanded version of "self" for many disabled individuals and is the largest single provider of support within the home and the community (Hsu, 1985). Social work practice can be consumer driven and still include the family as part of the treatment team, by incorporating a holistic view which focuses not only on the individual with a disability but also on the needs of the entire family unit. A holistic approach implies that the social worker practice from a family strengths perspective, especially in the presence of severe disability. It also validates the Asian American value of interdependence rather than independence (Triandis, et al., 1988). The social worker should facilitate identification of the unique needs, strengths, and cultural values of the family. A customized person-centered plan that incorporates this information can then be created. In particular, the role of the social worker as an educator would be more fully utilized. Many individuals and families need assistance in developing skills to explore the range of options and choices available, including community-based services and natural support systems such as churches, recreation centers, social organizations, etc. The family system would become the "experts" in identifying resources, services, and supports that would meet their needs. Individuals and families can then make decisions based on their own cultural values and identified natural supports. The social worker can act as a service broker, the "expert" in guiding the person-centered plan toward the goals in a collaborative partnership with the individual and the family (Kaplan, 1999). However, the Asian American individual or family may place a higher value on respect for authority and professional expertise than acting autonomously and may choose to exercise their option of deferring to the social worker as the decision-maker (Hirayama & Cetingok, 1988).

Social Barriers Model, Empowerment

Systems change should be another level of social work practice that could be incorporated into this model of responding appropriately to the needs of Asian Americans with disabilities. Social workers must gain knowledge about how particular issues are viewed by Asian American individuals with disabilities and their families, such as concerns about isolation and a lack of connectedness and support in the community.

Full inclusion into society and the community is a goal of the disability rights movement. For many families and individuals, "person with a disability" has gone from meaning "person with severe limitations" to "person with rights to accommodation and inclusion" (Beaulaurier & Taylor, 2001, pg. 84). This

change in perception has resulted in a shift in the expectations of individuals and their families regarding the concept of quality. No longer are a majority of families satisfied with supports based on segregated custodial models. The demand is for individualized models that maximize the individual's abilities, and full participation in home, school, work, and relationships. Families have also come to expect more teamwork from other professionals and community members who are involved in the life of the disabled individual in eliminating barriers to community inclusion (Gilson & DePoy, 2002).

Bradley (2000), discusses "inclusion" as a transforming goal directly related to the movement of people with disabilities out of institutions and re-entry into communities and families. Families are the largest single providers of support to people with developmental disabilities (Fujiura & Braddock, 1992, cited by Freedman & Boyer, 2000). Family members, usually parents, are the backbone of their community support system, often serving as an alternative to institutionalization. The notion of inclusion shifts the delivery of service from a system that was challenged to provide better surroundings and opportunities than those available in institutions to one that supported involvement in typical community activities based on the needs and choices of the individual. The goal is to help connect and support individuals with disabilities in school, home, community and work (Knoll & Peterson, 1992 cited by Bradley, 2000). This approach has as its basis individual self-determination and includes "circles of support;" friends, neighbors, family members, and the presence of brokers or facilitators. Circles of support can assist individuals in making social connections and getting access to other needed services and natural supports in the community.

The social worker should act as a facilitator and liaison to eliminate barriers to community participation. This should be a collaborative teamwork effort with the person with a disability, the family, community members, and other professionals who are involved in the life of the individual. The Asian American value of collectivism or shared responsibility validates the community as an important source of support. Inclusion and integration of the person with a disability into the community and settings that promote self-determination benefits the family as well, because others will support them as they provide stimulation, socialization, and assistance. Linking disabled people to community-based services and natural support systems may require outreach that is sensitive to Asian American cultural values of "shame" and a view of disability as a family matter. More traditional Asian families, as well as some newly immigrated families less acculturated to Western thinking, may still perceive disability as a punishment due to some wrong doing of their ancestors (see case study for details). This can be perceived as the negative effect of interdependence, that the family is also stigmatized. This perception may prevent families from seeking assistance or declining services due to fear of losing confidentiality.

Lack of information due to language difficulties will require that interpreters and written material be available in an individual's and family's native language. Social workers must also be aware of the health literacy level of the Asian American individual or family, which is a measure of the ability to understand technical terms and professional jargon that goes beyond a basic ability to speak English (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999). Besides familiarizing themselves with the disability literacy and correct language to use when working with people with disabilities, social workers should also have an open mind regarding learning the experiences of the Asian American history of immigration and how this experience may impact the client's functioning and their perception as well as the community's perception of disability. Being cultural competent does not mean social workers have to speak all of the languages that their clients speak. It means an attitude of willingness to learn from their clients and to use critical thinking to analyze their clients' issues using a person-in-environment perspective. Social workers need to understand the reasons why clients decline services to rule out any reasons such as shame and fear rather than attributing refusal to a lack of self-determination and self-sufficiency.

The social work role of advocate should also be expanded. The individual and the family may need

preparation to be more effective in dealing with professionals, agencies and bureaucracies in shifting the power of decision making from the professionals to consumer control. Intervention on a systems level often requires empowerment strategies such as advocacy to assure civil rights, eliminate oppression, and reduce marginalization. Helping Asian American individuals with disabilities and their families eliminate barriers to community inclusion may require a culturally sensitive redefinition of the empowering process. The cultural value of respect for authority may seem incompatible with self-advocacy. It is important to understand that questioning the judgment of professionals such as physicians might seem uncomfortable for individuals raised in a culture that emphasizes obedience. Issues of power and authority differentials between professions and consumers may not be a matter of concern to the Asian American. An important principle in social work is "start where the client is" which implies that the person with a disability gets to decide what he/she wants help with. Social workers who are experts in the disability field will have to learn more about culturally competent approaches to working with Asian populations. Likewise, social workers who are experienced in working with Asian Americans will need to familiarize themselves with the disability literature, to serve the Asian client with a disability in an appropriate manner and connect them to resources. Having a culturally appropriate attitude, and awareness of the perception of disability in a different culture, will help social workers to provide culturally competent services that will maximize the functioning of the person with a disability.

Conclusion

The profession of social work reflects selected social values and norms of our society. The philosophy of social work, which is based on altruistic values of helping people, needs to maintain this humanitarian philosophy (Pillari, 2002). Historically, social work was embedded in a social and moral philosophy of help being "handed down" by the social worker who acted as the moral agent of the community. Through the years, social work practice has evolved to a more humanitarian philosophy based on the dignity and worth of individuals regardless of their issues or circumstances. But because the profession is still viewed as an agent of society in carrying out some of its responsibilities, it likewise has the potential to be a vehicle for influencing the attitudes and values of society. A stronger commitment to educating professional social workers in specific content about people with disabilities and the issues they face might enable the profession to become a stronger advocate for needed systematic and societal changes.

Passage of the Americans with Disabilities Act in 1990 provided the American with a disability the right to equal access and opportunity to be integrated into all areas of society. However, it is important to understand how each subculture in America, such as Asian Americans, interprets the meaning of disability as a cultural concept and views the implementation of the law through the lens of the culture's value system. It is important to remember that all Asian Americans with disabilities are not the same nor do they all share the same values, norms, and beliefs. Asians are diverse peoples whose origins are of the Far East, Southeast Asia, and the Indian subcontinent. Generation and age are also factors in determining an individual's particular value system. Independent living philosophy encourages people with disabilities to assert themselves and take control over their own lives. How and if this opportunity is acted upon by an Asian American person with a disability requires knowledge and sensitivity to the cultural nuances that are part of that person's particular makeup. Social workers must be careful not to stereotype Asian American responses and respect individual differences.

More research is needed to understand how subcultures such as Asian Americans interpret concepts as "disability rights" and how a person with a disability is viewed within the family structure. Because there have not been many social work studies on working with minorities with disabilities, it is unknown if approaches and interventions that support and promote self-determination and empowerment to assist clients with disabilities are appropriate for minority clients with disabilities. This lack

of knowledge must be addressed if social work practice with Asian Americans with disabilities is going to become a better cultural fit. Social work has the potential to bridge the gap between supporting the goal of self-enhancement by empowering people with disabilities to choose, and providing the cultural context of what that freedom of choice means to a particular Asian American with a disability.

Christine N. Langworthy, LSW is Assistant Director of Practicum at the School of Social Work, University of Hawaii at Manoa. She has extensive social work practice experience in the areas of mental health and gerontology.

Evaon C. Wong-Kim, LCSW, MPH, Ph.D. is an Assistant Professor at the College of Social Work, San Jose State University. Dr. Wong-Kim practiced medical social work for ten years before joining the faculty.

References

Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs. (1999). American Journal Association: Health Literacy: Report of the Council on Scientific Affairs. *JAMA, 281*, 552-557.

Beaulaurier, R. L., & Taylor, S. H. (2001). Social Work practice with people with disabilities in the era of disability rights. *Social Work in Health Care, 32*(4), 67-91.

Bradley, V. J. (2000, August). Changes in services and supports for people with developmental disabilities: New challenges to established practice. *Health and Social Work, 25*(3), 191-200.

Brown, C., & Ringma, C. (1989, December). The myth of consumer participation in disability services: some issues for Social Workers. *Australian Social Work, 42*(4), 35-40.

Brown, S. E. (1994). *Independent living: Theory and practice*. Retrieved from 4/1/03 http://hometown.aol.com/sbrown8912/page9.html

Freedman, R. I., & Capobianco Boyer, N. (2000, February). The power to choose: Supports for families caring for individuals with developmental disabilities. *Health and Social Work, 25*(1), 59-68.

Gilson, S. F., Bricout, J. C., & Baskind, F. R. (1998, March/April). Listening to the voices of individuals with disabilities. *Families in Society, 79*(2), 188-96.

Gilson, S. F., & DePoy, E. (2002, Winter). Theoretical approaches to disability content in Social Work education. *Journal of Social Work Education, 38*(1), 153-165

Hiayama, H., & Cetingok, M. (1988). Empowerment: A Social Work approach for Asian immigrants. *Social Casework, 69*(1), 41-47.

Howoritz, J. J. (1959). *Education for social workers in the rehabilitation of the handicapped*. New York, NY: Wolff Book Manufacturing Co., Inc.

Hsu, F. L. K. (1985). The self in cross-cultural perspective. In A. Manella, G. Devos, and F. Hsu (Eds.), *Culture and self* (pp. 24-55). New York, NY: Travistock.

Kaplan, R. M. (1999). Shared medical decision-making: A new paradigm for behavioral medicine. *Annals of Behavioral Medicine, 21*(1), 3-11.

Mackelprang, R. W., & Salsgiver, R. O. (1996, January). People with disabilities and Social Work: Historical and contemporary issues. *Social Work, 41*(1), 7-14.

McCallion, P., & Toseland, R. W. (1993, December). Empowering families of adolescents and adults with developmental disabilities. *Families in Society, 74*(10), 579-89.

Meinert, R., & de Loyola, S. (2002). The national protection and advocacy system: What Social Workers need to know. *Journal of Social Work in Disability and Rehabilitation, 1*(1), 15-26.

National Association of Social Workers (1996). *NASW code of ethics.* Washington D.C.: Author.

Pillari, V. (2002). *Social Work practice theories and skills.* Needham Heights, MA: Allyn & Bacon Spearson Education Company.

Quinn, P. (1995). Social Work and disability management policy: Yesterday, today, and tomorrow. *Social Work in Health Care, 20*(3), 67-82.

Quinn, P. (1995). Social Work education and disability: Benefiting from the impact of ADA. *Journal of Teaching in Social Work, 12*(2), 55-71.

Russo, R. J. (1999, January/February). Applying a strengths-based practice approach in working with people with developmental disabilities and their families. *Families in Society, 80*(1), 25-33.

Soloman, B. B. (1976). *Black empowerment social work in oppressed communities.* New York, NY: Columbia University Press.

Stainton, T. (2002, September). Taking rights structurally: Disability, rights and Social Worker responses to direct payments. *The British-Journal of Social Work, 32*(6), 751-763.

Triandis, H. C., Bontempo, R., Villareal, M. J., Asai, M., & Lucca, N. (1988). Individualism and collectivism: Cross-cultural perspective on self-intergroup relationships. *Journal of Personality and Social Psychology, 54*(20), 323-338.

U.S. Department of Commerce, Bureau of the Census. (2000, March). *The foreign-born population in the United States.* Washington D.C.: U.S. Government Printing Office.

Winter, J. A. (2003, Winter). The development of the Disability Rights Movement as a social problem solver. *Disability Studies Quarterly, 23*(1), 33-61.

From Charitable Relief to Social Control: The Criminalization of People with Disabilities in Nineteenth Century Canada

Roy Hanes, Ph.D.
School of Social Work
Carleton University, Canada

Abstract: In recent years, academics interested in the field of disability studies have argued that the disability category is a socially constructed category influenced by historical, social, political, cultural and economic factors. In the present era a dominant social construction of disability is that disability is primarily a "personal tragedy" (Oliver, 1990) requiring medical intervention. Prior to the medical model social construction of the disability category, disability was primarily defined as a social and legal category linked to social welfare and charitable relief (Stone, 1984). These two social constructs of disability (social/legal and medical model) have received a great deal of attention in recent years but there is at least one social construction of disability that has not received as much investigation and that has to do with disability as a criminal category. The following article attempts to examine the criminalization of people with disabilities by using the case example of the care and treatment of people with orthopedic disabilities living in the province of Ontario, Canada, during the 19th Century.

Key Words: disability, cripples, history, Canada

Disclaimer: Common terms used in the 19th century to denote persons with orthopedic disabilities were "physical defectives" and "cripples." For the purposes of historical accuracy, these terms will be used in context in this the article.

Introduction

In recent years, academics in the field of disability studies have argued that the disability category is a socially constructed category influenced by historical, social, political, cultural and economic factors (Wilson and Lewiecki-Wilson, 2001; Marks, 1999; Mitchell and Snyder, 1997; Ingstad and Reynolds

Whyte, 1995). In the present era, a dominant social construction of disability is that disability is primarily a medicalized problem (DeJong, 1978; Stone, 1984) and a personal tragedy (Oliver, 1990). Prior to its medical model construct, the disability category was primarily defined as a social and legal category linked to social welfare and charitable relief (Stone, 1984).

By using a historical lens one can examine how social, political, cultural and economic factors have helped construct the disability category over time. For example, during the 19th Century, public opinion toward disability, charity and dependency shifted and the disabled population, once considered a deserving population, came to be viewed as a nuisance population. The shift in public opinion led to the creation of government policies that established draconian measures to control this "unwanted" population. In effect, many people with disabilities were treated as common criminals and they were sent to local jails, provincial lock-ups and in some situations to the federal penitentiary in Kingston, Ontario.

The era between the mid and the late 19th Century is the focus of this article. It is during this era that we find a shift in public attitude away from community social support, known during the era as "outdoor relief", toward institutional warehousing known as "in-door relief". It is a period in Canadian history during which concerns about care and relief were replaced by concerns about moral decay, moral reform, individualism, production and independence. Similarly, it is an era wherein we find the legislative origins for institutional confinement, the origins of modern social welfare programs, as well as the beginnings of the eugenics and sterilization movements in Canada.

Early Government Support

During the 18th and 19th Centuries, when the colonies of British North America (later Canada) were granted provincial status, many of these provinces adopted the British parliamentary system as well as Britain's legal system. This included adopting English Poor Law as a means of regulating support for people unable to provide for themselves. During the reign of Elizabeth 1, England established a system of support and relief for needy individuals known as Poor Law (1601). Poor Law distinguished between deserving poor and non-deserving poor populations. Non-deserving poor were unemployed, able-bodied individuals and deserving poor were unable to work or fend for themselves: "Lepers, bedridden creatures, persons being impotent to serve and persons over the age of sixty" (Stone, 1984, p. 36). In brief, the statutes of the era permitted assistance for people unable to provide for themselves, but these statutes also determined very harsh punishments for able-bodied people who were not working.

Louis Hartz has referred to this adaptation of "old world" values, culture and ideology onto the "new world", as the influence of the "politics of point of departure" (Hartz, 1955 in Guest 1980, p. 16). While it is true that "old world" influences often determined colonial law, it is evident that provinces, including Ontario, did control the extent to which "old world" values were applied. Ontario, for example, did not incorporate English Poor Law as part of its provincial legislation (Splane, 1965). Instead, when Ontario was granted its provincial status in 1794, the provincial charter made all forms of social relief a local responsibility. In fact, all provinces directed their own social relief programs and the federal government, beginning with Confederation in 1867, remained out of the direct provision of social relief well into the 20th Century. When Ontario (Upper Canada) joined with other colonies of British North America to form the country of Canada in 1867, social welfare, health care and education were designated to come under provincial jurisdiction. As a result of this decision, Canada did not create a universal set of principles pertaining to the care and treatment of people with disabilities, and to this day policies regarding the care and treatment of this population varies from one province to the next (Hanes and Moscovitch in Puttee, 2002).

The government of Ontario adapted Poor Law for its own purposes and it made municipalities and counties responsible for the care and maintenance of the poor, the sick, the elderly and the disabled.

These populations were often referred to as the dependent and defective classes (Henderson, 1904). Throughout much of the 19th Century, the provincial government instituted various forms of legislation which further ingrained its position of no direct responsibility and therefore no direct assistance. The Charity Aid Act, 1837, the House of Industry Act, 1837, the Municipal Corporations Act, 1849, the Municipal Institutions Act, 1866, and the Royal Commission on Prisons, Asylums and Public Charities, 1891, are examples of provincial legislation which reinforced the provincial government's position that the provision of care to dependents and people with disabilities was a local responsibility (Splane, 1965).

Ontario's approach towards welfare relief during the 19th century is often referred to as "reluctant welfareism." This doctrine highlights the province's position regarding all forms of care and relief, which emphasized the opinion that support for needy individuals was first and foremost a family responsibility. And, if family members were not able to provide for the individual in need then it fell upon local authorities to provide the required assistance (Wallace, 1950). In circumstances where the local municipalities were unable to, or refused to provide care and assistance, then private philanthropy and the use of charitable institutions were encouraged. "This doctrine," Wallace suggests, "Largely ignored the special needs of such groups as the old, the sick, the widowed, the orphaned and the mentally and physically incapacitated" (Wallace 1950, p. 382). This hands-off approach of "reluctant welfareism" established in the 19th Century guided the direction of providing care and support to people with disabilities well into the 20th Century. As far as the care of "cripples" was concerned, the province saw its role as one of a residual funding body only. Fundamentally, the province held the position that it had no direct responsibility for the care and maintenance of any dependent populations. The province did establish guidelines for the establishment of poor houses, jails and asylums but it did not provide direct financial support to these institutions and their inmates. As far as the province was concerned, the care and support of needy populations was first and

foremost a family responsibility and if families could not provide the support, then such support fell onto local charities and municipalities. This system of reluctant support began in the late 1700s and lasted well into the 1900s.

Influences of the Economy on the Social Status of "Cripples"

Similar to other settlers throughout North America, 19th Century settlers in Ontario were very much influenced by their Christian faith, and charitable relief was viewed as a positive virtue. For many settlers, opportunities to provide support in time of need and to show kindness to one's neighbor were viewed as opportunities to serve God and community. In many ways social dependency was a mechanism which brought individuals from different social strata closer together.

John Winthorp observes the following:

> "... According to God's scheme, a well ordered society was hierarchical; it had a series of ranks from top to bottom. Some men, the great one's, high and eminent in power and dignity, were at the top, others, the poor and inferior sat at the bottom. Each had special privileges and obligations, the poor to show respect and deference to those above them, the well-to-do to aid and care for those below them. Disparities in wealth and condition existed not to separate and alienate men from one another but to make them have more need for one another - - to bind them closer together so that they might improve their lives to serve the Lord" (John Winthrop, in Trattner 1984, p. 16).

In addition to this Christian influence, Ontario's settlers were very much influenced by the reality of the North American environment, and a pragmatic approach to providing assistance to one's neighbors and kin was essential. In an environment where neighbor knew neighbor and each had to rely on

the other, assistance was provided when needed. Settlers realized that ones own survival as well as the survival of ones family was based on reciprocity of support, therefore denial of support to kin or neighbor was rare.

Support was provided as needed, but this did not mean that "cripples" and other populations of "physical defectives" were always in need of support. In fact, because of the province's agrarian economic base it was quite likely that many "cripples" required little or no support and it was likely that they contributed to their families and communities. In other words, an individual could have a physical impairment, but the individual was not considered a burden and in economic and social terms the individual was not considered disabled.

From 1790, when Ontario received its provincial charter, to the late 19th century Ontario primarily remained a rural province with an agrarian economy. For example, at the time of Confederation in 1867, the population of the province was close to 1,525,000 people, and nearly four fifths of the population lived in rural communities, small villages or towns, or on farms. Toronto at the time was the largest urban centre and its population was approximately 30,000 people (Varga 1983, p. 9). Within 15 years, there was a major shift in the economic base and between the early 1880s and 1900 Ontario became the industrial centre of Canada. This change from a predominantly agrarian economic base to an industrial economic base had a significant impact on the social status of people with disabilities living in Ontario.

In his research on the care of "cripples," Finkelstein (1981) argued that the social consequences of industrialization actually made people with disabilities out of "cripples." Finkelstein's point stresses the significance of disability as a social construct. From his research pertaining to the care of "cripples" in England during the rise of industrialization, he concluded that this population came to be viewed as a problem population. He makes the argument that during a period wherein the economy was based on agriculture, most "cripples" made and repaired products. He concluded that "cripples"

contributed to the income of their families and to the economic well being of their communities.

Finkelstein stresses the importance of the informal face-to-face contacts of the rural agrarian communities of England and his analysis can be applied to 19th Century Canada. Finkelstein argued that in small rural communities, people with disabilities were not considered a problem population, nor were they considered burdens on family and community. The nature of an agrarian way of life, according to Finkelstein, allowed people with disabilities to contribute to the family and community. "Cripples" repaired farm implements, made clothing and helped with household chores. This is not to suggest that life was easy for them, because it was not, but as Finkelstein points out, life was difficult for most working poor people: "Conditions of life were extremely harsh for cripples but in a context where life was harsh for all the common people, the circumstances for cripples would not seem significantly worse" (Finkelstein 1981, p. 60). In short, according to Finkelstein's argument, "cripples" existed but not necessarily as part of a category of people with disabilities.

Finkelstein's social history of "cripples" reveals the connection between changes in economy (agrarian to industrial base) and changes to the social status of individuals with disabilities. He concluded that prior to the onset of industrialization and a waged based economy, "cripples" were very much part of the family and community. Moreover, Finkelstein argued that it was because of a significant shift in social and economic relations brought about by industrialization that led to "cripples" becoming part of the undesirable class. He concludes that prior to the onset of industrialization with its wage based economy "cripples" were not necessarily viewed as being disabled. The social creation of the "disabled" came hand in hand with demands of an emerging urban and industrialized society.

The plight of people with disabilities living in Ontario was not much different from the plight of people with disabilities living in Britain or the United States during the 19th Century. An examination of the linkages between Britain and Ontario indicates

that the development of institutional care in late 18th-century Britain, later transplanted to Ontario, was closely linked to broader social, political and economic changes brought about by the development of a wage-based economy.

Changes in the social, political and economic spheres led to changes in the social status and the social role of "cripples" (Finkelstein, 1987). Of significance was the change in the social importance of "cripples" to their families and their communities. With the displacement of the rural- agrarian economy by a wage-based economy, there was a major shift in the perception of the social importance of the individual, and the individual replaced the collective, as well as the family, as the predominant unit of production. Over time, the relative social and economic importance of the individual increased and greater social value was placed on able-bodied individuals, and less value was placed on individuals with disabilities that limited them in their ability to earn wages (Oliver, 1990).

Although custodial institutions were not used in all parts of Ontario, indoor relief in the form of asylums, alms houses and houses of industry came to dominate the provision of care and relief for dependent and "defective" populations in the larger towns and cities of the province. Similar to other approaches of confinement that existed throughout North America at the time, institutions in Ontario made no distinction on the basis of need, age, or gender in these institutions: "There the old and sick were thrown together with tramps and vagabonds, with the blind, deaf mutes, cripples, idiots, epileptics and insane people. Children, orphans, foundlings, unmarried mothers with children, prostitutes and criminals were put in these houses" (Trattner 1984, p. 44).

By the mid 19th Century, the notion of deserving poor was removed from the social consciousness and no distinction was made between deserving and non-deserving poor. All manner of people with disabilities who are unable to care for themselves were often forced to live in institutions that were ill - equipped to look after them.

Reports from the Inspector of Prisons, Asylums and Public Charities indicates the desperate situation for many "cripples" who needed continuous care. The following example refers to a patient of the Toronto Lunatic Asylum:

"In cases of paralysis of the lower body, the patients are in a pitiable condition, lying quite unable to turn in bed, and having lost control over bladder and bowel, faeces and urine are constantly passed without the knowledge or command of such patients. They are entirely dependent on the care and attention of the attendant for everything. They are very troublesome and wearying cases for the attendant as well as for the patient, the cause of the disease usually being from bad to worse" (Sessional Papers, Province of Ontario, 1880, p. 20).

As the provincial economy shifted from a predominantly agrarian economy to a predominantly industrial and waged-based economy, there was a greater need for able-bodied workers. Moreover, wages were often so low that all capable family members had to work to support the family. It was very common to find men, women and children of the same family working in the mills and factories of Ontario. Looking after a disabled family member had serious consequences for working class and poor people. For example, if a family member was required to remain at home to provide care for someone who was infirmed and/or disabled, this meant there were fewer workers in the family and fewer workers meant less income for the family.

The rise of industrialization not only had a negative impact on the social status of individuals with disabilities, but industrialization also contributed to an increase in the size of the disabled population. Factors such as unsafe working conditions, child labour, poor sanitation, lack of public health, and poverty contributed to an increase in the numbers of people with disabilities. But, despite the increase in the disabled and dependent population, there were

few suitable resources from which these populations could receive assistance.

The Ontario Royal Commission on Labour and Capital in 1889 shows, in great detail, the consequences of this lack of support for injured employees. One young man, who lost an arm and a leg as a result of an accident, reported to the Commission that following his discharge from the hospital, his mother had to pay for all further medical expenses. The only compensation he received for his injuries was $10.00 above the wages owed and $25.00 collected for him by his fellow workers. The young man reported to the Royal Commission that he was 12 years old at the time of the accident (Kealy 1973, pp. 196-197). Another witness at the Royal Commission reported that at the age of 12 he had his arm severed as a result of an accident in a saw mill. At the time of the accident, he was earning 25 cents per day, he received no compensation and he was never re-employed by his employer (Kealy 1973, pp. 196-197).

People With Disabilities: Changes In Social Role From Deserving Poor To Non-Deserving Poor

While English Poor Law was not incorporated into the provincial charter of 1794, some elements of poor law are nevertheless evident in the systems of relief that emerged in 19th Century Ontario. For example, two primary forms of relief to emerge out of poor law were "outdoor relief" and "indoor relief."

Initially, people with disabilities unable to care for themselves or to be cared for by family members were allowed to seek out alms through a system referred to as outdoor relief. Outdoor relief was a common form of assistance provided to deserving poor populations since the onset of English Poor Law of 1601. Outdoor relief was a system of charity wherein deserving people in need were allowed to receive relief through public charitable measures. For example, deserving poor people were allowed to receive alms by begging, or they received support from religious institutions, or from landowners or wealthy merchants. Outdoor relief also allowed private homeowners to house infirmed, elderly, disabled boarders, and for doing so they were given a stipend from municipal governments. In most instances, outdoor relief measures allowed deserving poor people such as "cripples" to remain part of the community. Outdoor relief was effective, at least by the standards of the era, as long as the population remained small and stable and there were no huge demands for assistance (Guest, 1980). Outdoor relief remained the dominant form of public assistance for needy populations from the 1790s to the mid 1800s, at which time public support for outdoor relief declined and there were demands for the establishment of institutions to segregate all needy persons from the general population.

This shift from outdoor relief to indoor relief represents a significant change in public attitude toward the provision of relief, and this shift in the public domain led to a shift in provincial government policy. The shift in attitude toward supporting people in need was connected to broader changes in public attitude to all forms and methods of assistance. To begin with, there was a shift in the notion of Christian charity. The ethic of hard work and individualism of Protestantism influenced a change in attitude toward social dependency. Secondly, the cost for providing care and relief to needy individuals was a municipal responsibility, and many of an emerging middle class argued that they should not have their hard earned money spent on people who could not or would not take care of themselves.

Indoor relief was introduced as a mechanism that was intended to discourage people from seeking public support and to control an undesirable population. Indoor relief measures were intended to remove undesirables from the community and to instill a new moral code into the inmates. The replacement of outdoor relief with indoor relief did away with the distinction between the deserving poor and the non-deserving poor, which had been at the core of English Poor Law since 1601. As a result of these changes in public attitude and public policy, "cripples" lost their social status as deserving and many were forced to live in workhouses, asylums or jails if they wanted to survive.

In addition to Victorian middle class concerns about the dire consequences of providing charity and support to the poorer and defective classes, Victorians began to develop an interest in health and physical prowess. Indeed, Haley (1978) argues that the attainment of good health was considered by middle and upper class Victorians to be a moral obligation and a measure of one's character. According to Haley, many Victorians were consumed with pursuing good health and he suggested that discussions about health outranked discussions about war, politics and science. It is an era where we find the emergence of spas and country clubs, as well as an interest in physical activity including hiking, biking, and swimming. In addition to physical activities, Victorians experimented with medications, opiates and other remedies as they strived for a healthy body. "Total health or wholeness- means sana in corpore sano," argued Haley, "Was the dominant concept for Victorians, as important in shaping thought about human growth and conduct as nature was to the Romantics" (p. 17).

Victorians did not pursue physical activity and good health merely for the sake of feeling better. The desire for good health shaped Victorian bourgeois images of themselves as physically, morally and spiritually virtuous persons. Similarly, it was this notion that good health was connected to good virtue which helped to construct Victorian attitudes toward poor, sick, and disabled people. Although middle and upper class Victorians were aware that disease and disability were not necessarily the fault of the individual, they still held the opinion that ones character was shaped according to ones bodily make-up and physical health. "Victorian intellectuals insisted on the reality of the spiritual life higher than that of the body, but they all thought physiologically: they adapted the well knit body as their model of the well formed mind and the mind- body harmony as their model of spiritual health" (Haley, 1978, p. 4). In brief, Victorians held the view that "cripples," because they were defective in body, were also defective morally, mentally and spiritually. Moreover, Victorians believed that most people with disabilities could not emotionally adjust to their lot in life, and because of this inability to accept their situation they developed a bitter and resentful moral character which in turn contributed to a life of vice and deceit. Considering these prevailing concerns about social charity, as well as concerns about the moral character of "cripples" and the repugnance that Victorians held toward them, it is little wonder that laws were passed to remove this population from society.

The first legislation put forth by the government of Upper Canada (Ontario) to end outdoor relief measures was the House of Industry Act of 1837. This legislation was intended to discourage social dependency and to introduce methods to reform the moral character of dependent persons. The House of Industry Act was never implemented on its own merit, but instead it was linked to other custodial legislative measures, including the Municipal Corporations Act of 1849 and the Municipal Institutions Act of 1866, which dealt with the establishment and maintenance of hospitals, poor houses and houses of industry (Splane, 1965). Although the House of Industry Act was not enacted on its own, it was an important piece of legislation, as it signified a new era for the provision of relief and care to all needy and dependent populations, including people with disabilities, and set the tone for the type of care that was provided for these populations from the late 1830s into the 1900s (Splane, 1965).

Provincial legislation such as the House of Industry Act was intended to remove "destitute," "defective" and "dependent" persons from the community and the legislation was applied to a very wide population:

> "All poor and indigent persons who are incapable of supporting themselves; All persons, able of body to work and without any means of maintaining themselves, who refuse or neglect to do so, all persons living a lewd dissolute vagrant life or exercising no ordinary calling or lawful business sufficient to procure an honest living; all such persons who spend their time and property in the Public House to the neglect

of their lawful calling" (Splane 1965, p. 71).

Over time, outdoor relief measures became very expensive for municipalities to maintain and working citizens resented people who could not or would not care for themselves or their families. While financial concerns represented a significant factor pertaining to the decline in support for outdoor relief measures, other social concerns emerged. Some of these concerns included concerns about wide spread misuse of charity; the opinion that charity led to individual laziness and laziness led to moral decay which in turn led to social, political and economic upheaval. The ethic of Christian charity was replaced by the ethics of rugged individualism, the virtues of hard work, independence from charity, and the connection of strong moral character to a strong economy. Outdoor relief, it was believed, eroded these important characteristics and contributed to the moral decay of the community, thus eroding a strong economy and a strong nation. As a consequence of these changes in public attitude toward social dependency, institutional approaches to the provision of care and relief of all dependent populations became the preferred method of relief. If relief was to be provided it was provided reluctantly, and it was provided in an institutional setting.

Although primarily directed at curtailing costs of maintaining the able-bodied poor, demands for an end to outdoor relief had a direct impact on people with disabilities who could not be cared for by their families. This former deserving poor population came to be treated no differently than the non-deserving poor population. The lack of differentiation between the deserving and the non-deserving poor represented a radical departure from the original intent of English Poor Law, which differentiated between the two populations and allowed for the provision of relief to populations who were unable to care for themselves.

The "Cripple" As Public Outcast: Controlling an Unwanted Population

"Jails were destined to be put to
a number of uses other than the
primary one of detaining persons charged with or convicted of a crime. Among those who were crowded into them were persons whose only crime was their inability to care for themselves" (Splane 1965, p. 68).

Much of the literature pertaining to the institutional confinement of poor and dependent populations makes reference to the use of custodial institutions such as Poor Houses and Houses of Industry (Baehre, 1981; Irving, 1987; Pitsula, 1979; Rooke and Schnell.1983; Splane, 1965; Wallace, 1950) but in Ontario, jails and prisons were also used to contain people unable to care for themselves. "Cripples," as well as "infirmed persons," the poor and the elderly who were unable to care for themselves and had no family to care for them were either brought to the jails by local authorities, or they went voluntarily. Jails were "filled with men out of work and elderly and infirm people without homes, who, seeking food and shelter, flocked to prisons where they shared cells with those awaiting trial or already convicted of offences" (Wallace 1950, p. 387).

The use of jails as shelters for the "aged," "infirm" and "crippled" populations became so wide spread that some jail superintendents complained openly about the inappropriate use of jails as places of refuge for the "defective" population. The Superintendent of the Hamilton jail, for example, made reference to the misuse of his facility as a shelter for those who were unable to care for themselves. According to reports by the superintendent, a high number of "physically defective" persons were living in the Hamilton jail, and he proposed that they would be more appropriately cared for in a poorhouse (Sessional Papers, Province of Ontario 1891, p. 129). Examination of primary documents, such as the Report of the Ontario Royal Commission on Prisons, Asylums and Public Charities (Sessional Papers, Province of Ontario 1891) provides numerous examples of "infirmed" and "defective" persons in need of support resorting to the local jails for food and shelter. The above Royal Commission found many needy, disabled and infirmed persons not only sought out jails, but, in many cases, often did not leave because they had nowhere else to go.

From a legal point of view, people with disabilities were treated as a class of undesirables subject to municipal morality and vagrancy laws. The City of Toronto, for example, introduced vagrancy laws in 1847, and a section of these vagrancy laws was instituted to control the disabled population of the city. By-laws linking the control of people with disabilities with vagrants stems from English Poor Law which in turn grew out of earlier British laws to control vagrancy (Stone, 1984).

The Act to Provide for the Arrest and the Punishment of Vagrants (1847) is very clear in its intent to control people with disabilities:

> "That all persons openly exhibiting or exposing themselves in any street, road or public place of the said city or liberties, any indecent exhibition, and all persons wandering abroad or placing themselves in the streets, public places, highways or passages to beg or gather alms or causing or procuring any child or children so to do or endeavoring by the exposure of wounds or deformities to affect the same purpose" (City of Toronto, Municipal By-laws, 1847).

The bylaw was later amended in 1890 and again in 1904, but the inclusion of people with disabilities remained part of these amended bylaws. The By-Laws Relating to the Public Morals (1890 and 1904) was specific in its condemnation of people with disabilities:

> "... Nor shall any malformed, deformed, or diseased person expose himself or be exposed in any street or public place in order to excite sympathy or induce help or assistance from general or public charity" (City of Toronto, Municipal By-laws, 1904).

In today's society, laws pertaining to indecent assault and indecent exposure refer to sexual offences falling under the Criminal Code of Canada. In lat-ter part of 19th-century Ontario, however, laws pertaining to indecent assault and indecent exposure, it appears, were applied to "malformed, deformed or diseased" persons and they were indicative of the repugnance that able-bodied Victorians felt toward disabled individuals. In other words "physical impurity" was an assault on middle and upper class Victorian sensitivities and as such Victorians felt they should not have to come into contact with the so-called impure. One way to ensure non-contact was the removal of the source of the displeasure by creating laws which banished some groups from the public view. Moreover, it appears that morality laws banning people with disabilities from public places may have been widespread across North America during the 1800s. Frank Bowe (1978) provides the example of the "Ugly Laws" of Chicago established during the 19th Century, which were similar to the municipal by-laws of Toronto:

> "No person who is diseased, maimed, mutilated or in any way deformed, so as to be an unsightly or disgusting object, or improper person, is to be allowed on the public ways, or other public places in this city, nor shall therein or thereon expose himself to public view" (Bowe 1978, p. 186).

In Ontario, it appears that statutes pertaining to public morals and vagrancy came under the jurisdiction of crimes associated with morality, including "indecent exposure and indecent assault," and persons who were found guilty of transgressing these laws were sent to jail. Annual Reports from the Inspector of Prisons, Asylums and Public Charities to the Province of Ontario, covering the years 1880, 1885 and 1890, indicate that 150 people were charged with indecent assault and exposure, of which 100 were sentenced to provincial jail (Hanes, 1995). Moreover, many people with disabilities who were charged under these morality laws were repeat offenders and records indicate they were well known to the authorities. In fact, many were often re-arrested for violating morality laws within hours of their release from jail and then returned to the insti-

tution (Sessional Papers, Province of Ontario 1891, p. 113).

The criminal prosecution and the incarceration of people with disabilities provide an example of the cultural relevance of the disability category. For example, a once contributing population came to be seen as a nuisance population. Begging as a legitimate means of self support for people with disabilities was banned. Community support was replaced by institutional mechanisms of control. Social acceptance turned to repugnance and laws were passed to prevent cripples from the public view.

By the early 1890s, the confinement of people with disabilities in jails and prisons had reached a critical point and social reformers in Ontario began to condemn the practice. Goldwyn Smith, Chairman of the Royal Commission on Prisons, Asylums and Public Charities (1891), for example, proposed that more suitable means of support for the disabled and the dependent populations had to be found. "The gaol (jail)," argued Goldwyn Smith, "Should under no circumstances be used as an almshouse or place of refuge. It ought to be used as a penal institution. My recommendation is that the House of Industry should be a refuge for the old, feeble and disabled" (Sessional Papers, Province of Ontario 1891, p. 112). While Smith drew attention to the inappropriate use of jails for housing poor and destitute populations his "reforms" remained institutionally based and he advocated for the construction and development of more poor houses, not fewer. In fact, the Royal Commission proposed that poorhouses be made compulsory in all counties, and "defective" populations who were unable to care for themselves or be cared for by family be sent to the poorhouses.

Some of the recommendations of the Ontario Royal Commission on Prisons, Asylums and Public Charities of 1891 included many of Goldwyn Smith's proposals as they pertained to the social support of "defective" and dependent populations. The Royal Commission advocated many reforms pertaining to the care of dependent and disabled populations but it still upheld the principle that the relief of people with disabilities remain a local responsibility and not

a provincial government responsibility. While Royal Commission put an end to the placement of people with disabilities into jails and prisons, it recommended that the practice of placing this population in institutions such as Poor Houses and Houses of Industry be continued.

Interestingly, the reforms proposed by this Royal Commission were viewed as being very progressive, but in reality the reforms merely shifted the means of social control away from jails and back to other institutions such as poor houses and chronic care facilities. The reforms of 1891 set in place the mechanism where institutions of social control such as poor houses for people with disabilities and dependent persons had to be constructed in every county of the province. Such measures did not create an environment wherein people with disabilities were brought back into society – instead these measures contributed to their further isolation. For example, by the mid 1890s we find the development of more and more institutions such as the Toronto Hospital for Incurables and the Bloorview Home for Incurable Children (also in Toronto). The province continued with its policy of reluctant welfareism well into the 20th Century. Meeting the needs of people with disabilities remained first a family responsibility, and only in circumstances where the family could not look after the individual were public charities involved.

Conclusion

As the 19th century made way for the 20th century, provincial policies remained relatively unchanged and the province took no direct responsibility for the direct care of people with disabilities. Municipalities such as Toronto continued with vagrancy laws which banned many "cripples" from going out in public. Even educational and vocational training programs that were introduced by the early 1900s had a moral ethic of developing productive citizens out of cripples. The Charity Aid Act, the Prisons and Asylums Inspection Act and the Municipal Institutions Act, which dominated 19th-century policies, continued to exhibit their influence until the Great Depression era of the 1930s. The municipalities, not the province, provided the

bulk of the funds to provide support to people with disabilities.

Nineteenth Century policies of the Province of Ontario pertaining to the care and treatment of people with disabilities requiring public support emphasized four primary themes. First, the provincial government took no direct responsibility for the care and maintenance of people with disabilities. The provincial government saw its role as one of a residual funding body and the province made the provision of care for "physical defectives" a local municipal or county responsibility. Second, the lack of direct provincial responsibility and the lack of universal policies led to a collection of diversified institutional programs throughout the province. Third, the provincial government maintained an arm's length approach in funding local institutions, but it did establish mechanisms for the annual inspection of these institutions. Fourth, the care of "cripples" reflected the ideology of the era, which changed from a system of community based support (outdoor relief) to a system of institutional control (indoor relief). Fourth, the establishment of institutions and the removal of people with disabilities from society that took root during the 19th Century lasted well into the 20th Century.

In conclusion, we find that the social construction of the "cripple", and the provision of care and relief to this population in Ontario during the 19th Century, was closely linked to social, cultural and economic factors including: the transition in the economy from an agrarian based economy to a wage based market economy; changes in public attitudes toward dependency; development of middle class notions of aesthetics and good health, and the reluctance of the province to provide direct support for the care and well being of all citizens in need.

Roy Hanes, MSW, Ph.D., teaches social work courses School of Social Work, Carleton University, in the area of people with disabilities. The author has done extensive historical research into the development of late 19th and early 20th services for children with disabilities in Canada. He is a founding member of the People with Disabilities

Caucus, Canadian Association Schools of Social Work.

References

Albrecht, G., Seelman, K. D., & Bury, M. (2001). *Handbook of disability studies*. Thousand Oaks, California: Sage Publications.

Baehre, R. (1981). *Paupers and poor relief in upper Canada*. Paper presented at the meeting of the Canadian Historical Association, Learned Societies Conference, Halifax, NS.

Brown, T. (1980). *Living with God's afflicted: A history of the Provincial Lunatic Asylum at Toronto 1830-1911*. Unpublished master's thesis, Queens University.

Bowe, F. (1978). *Handicapping America: Barriers to disabled people*. New York: Harper and Rowe.

Finkelstein, V. (1981). Disability and the Helper/ Helped Relationship: An Historical View. In A. Brechin, P. Lidiard, and J. Swain (Eds.), *Handicap in a Social World* (pp. 58-65). Suffolk, UK: Chaucer Press.

Guest, D. (1980). *The emergence of social security in Canada*. Vancouver, BC: The University of British Columbia Press.

Haley, B. (1978). *The healthy body and Victorian culture*. Cambridge: Harvard University Press.

Hanes, R. (1995). *The medicalization of disability: The rise of the crippled child saving movement in Ontario, 1880-1940*. Unpublished doctoral dissertation, McGill University, Montreal, Quebec.

Hanes, R. (1996). Linking physical defect to physical deformity: The case of crippled children in Ontario: 1880-1940. *Journal on Developmental Disabilities, 4*(1), 23-40.

Henderson, C. (1904). *An introduction to the study of the dependent, defective and delinquent classes*. London, UK: D.C. Heath.

Ingstad, B., & Reynolds Whyte, S. (1995). *Disability and culture.* Berkeley: University of California Press.

Irving, A. (1987). *From no Poor Law to the Social Assistance Review: A history of social assistance in Ontario, 1791-1987.* A Study Prepared for the Ontario Social Assistance Review.

Jennissen, T. (1991). *Regulating the workplace in industrial Ontario: The origins of occupational health and safety policy, 1880 –1914.* Unpublished master's thesis, McGill University.

Kealey, G. (1973). *Canada investigates Industrialism: The Royal Commission on the Relations of Labour and Capital.* Toronto, Ontario: University of Toronto Press.

Marks, D. (1999). *Disability: Controversial debates and psychological perspectives.* London: Routledge Publishing.

McMurtrie, D. (1914). The care of cripples. In C. L. Stedman (Ed.), *The reference handbook of the medical sciences* (pp. 366-367). New York: William Wood and Co.

Mitchell, D., & Snyder, S. (1997). *The body and physical difference: Discourses of disability.* Ann Arbor: University of Michigan Press.

Oliver, M. (1990). *The politics of disablement.* London, UK: Macmillan Educational Ltd.

Pitsula, J. (1979). *The relief of poverty in Toronto, 1880-1930.* Unpublished master's thesis, York University.

Safilios-Rothchild, C. (1970). *The sociology and the social psychology of disability and rehabilitation.* New York: Random House.

Scull, A. (1979). *Museums of madness: The social organization of insanity in nineteenth century England.* London, UK: The Trinity Press.

Splane, R. B. (1965). *Social welfare in Ontario, 1791-1893: A study of public welfare administration.* Toronto, ON: University of Toronto Press.

Stone, D. (1984). *The disabled state.* Philadelphia: Temple University Press.

Trattner, W. (1984). *From poor law to welfare state: A history of social welfare in America.* New York: The Free Press.

Valverde, M. (1991*). The age of light, soap and water: Moral reform in English Canada, 1885-1925.* Toronto, ON: McClelland and Stewart Inc.

Wallace, E. (1950). *The changing Canadian State: A study of the changing conception of the State as revealed in Canadian social legislation, 1867-1948.* Unpublished master's thesis, Columbia University.

Williams, G. (2001). Theorizing Disability. In G. Albrecht, K. D. Seelman, & M. Bury (Eds.), *Handbook of disability studies.* Thousand Oaks, CA: Sage Publications.

Zola, I. K. (1972). Medicine as an Institution of Social Control. *Sociological review, 20*(4), 487- 504.

Government Documents

City of Toronto (1847). *An Act for the Arrest and the Punishment of Vagrants.* Toronto, Ontario: City of Toronto By-Law.

City of Toronto (1890). *A By-Law Relating to Public Morals.* Toronto, Ontario: City of Toronto By-Law 2449.

City of Toronto (1904). *A By-Law Relating to Public Morals.* Toronto, Ontario: City of Toronto, City of Toronto By-Law 4305.

Province of Ontario (1891). *Report to the Royal Commission on Prisons, Asylums and Public Charities.*

Province of Ontario (1880-1900). *Annual Report of the Inspector of Asylums, Prisons and Public Charities.* Toronto, Ontario: Province of Ontario. Ontario Sessional Papers.

Homeschooling Children with Disabilities: Balancing Freedom and Responsibility

Merope Pavlides, Ph.D.

Abstract: Increasing numbers of children with disabilities in the United States are being home educated. Many parents of children with special needs have elected to homeschool their children out of frustration with the public school system, while educators express concern about the quality of education homeschooled children receive. This article discusses the need for regulation which assures that these children are receiving services consistent with the Individuals with Disabilities Education Act. As an example, proposed changes to Home Instruction regulations in the State of Maryland are included.

Key Words: Homeschooling, home instruction, disability, Individuals with Disabilities Education Act

Introduction

Families reach the decision to homeschool children in many ways. For some, homeschooling is viewed as a spiritual necessity, a way to insure that specific religious or philosophical values receive primary attention in a child's education. Other homeschooling families simply do not find that the public or private educational opportunities available to them can provide their children with the rigor or flexibility that is possible in home education. Still others fear for their children's safety, either physical or emotional. Demographic studies in the United States show that although home educators are most frequently Caucasian, middle-class parents with education beyond high school, increasingly diverse populations are choosing home education (Mayberry et al., 1995). In fact, homeschooling as a national movement in the U.S. is on the rise. A 1997 study indicated that approximately 1.23 million children were being educated at home (Ray, 1997) and the Home School Legal Defense Association (1997) estimates that the practice has increased at the rate of 15% per year since 1990.

For families of children with disabilities, the decision to homeschool may not come as a first choice in education, but as a result of feeling that other avenues of schooling are closed to them. Some parents turn to home education out of frustration and desperation at the lack of affordable services that adequately address the individual education needs of their children. Many parents who homeschool children with special needs do so after dismal experiences with public education, after becoming dismayed and disheartened at how little academic progress their children make in public schools. Frequently, they are saddened by the school's inability to create a well-functioning inclusive environment, either academically or socially. Often, they simply grow weary of the intense level of advocacy they must maintain in order to assure that public schools are providing the services their children are guaranteed under American law:

> "It is becoming increasingly common for parents to pull a miserable LD or ADD youngster out of school in the middle of the academic year. It is as though something suddenly snaps. The family may have quietly endured years of IEPs, long conferences, tears from the child, notes from the teacher, promises from the administrators, and bad report cards in spite of all the energy they put into running a nightly study hall. They may have come to think of it as normal to feel trapped and helpless..." (Stevens, 1996, p. 1).

Although parents may wish to remove a child from public school, private schooling for children with disabilities is often only financially possible for parents if the child's Local Education Agency (LEA) agrees to fund a private placement. Homeschooling becomes, in the view of many parents, the only viable option for providing their children with truly individualized approaches to learning. And so they back into becoming home educators, unsure of their relationship to either public or private services. The Council for Exceptional Children (2000) recently

estimated that 10 percent of the children being homeschooled in the United States have a disability.

Home educators of children with special needs are often confused about their own role in the educational system, and with good reason; most state regulations governing home schooling do not contain references to special education (Leppert & Leppert, 1999). The U.S. Federal requirements regarding special education set forth in the Individuals with Disabilities Education Act (IDEA) apply only to children in publicly funded placements. Interpretation of state regulations is necessary to determine how these affect homeschoolers (Turnbull & Turnbull, 2000). Although a 1993 policy statement from the U.S. Department of Education, Office of Special Education Programs (OSEP), encouraged school districts to " ... include home educated children in their child find activities" (National Association of State Directors of Special Education, 1998, p. 1), only 12 states apply IDEA mandates to homeschooled children with disabilities. Six states have regulations with restrictions limiting options to homeschooled children with special needs:

> "Two states require a specific "approval" as a condition of allowable participation in home schooling. In Iowa, written approval of the director of special education of the area education agency is required. In Pennsylvania, a student identified as in need of special education can be home schooled only if the instruction is approved by a teacher certified in special education by the state or by a certified school psychologist" (National Association of State Directors of Special Education, 1998, p. 2).

From a legislative point of view, parents who choose to utilize home education for their children with disabilities seem to do so with either no state guidance or support or with paralyzing state control. As a nation seemingly concerned about the quality of education that our children are receiving, and about our commitment to those individuals previously disenfranchised by social institutions, the lack of state validation in the U.S. of the growing community of families involved in the home education of special needs children is both unwise and unjust.

Individual Rights vs. State Interest

Nothing in the U.S. Constitution or its Amendments guarantees the nation's children an education. Yet by the mid-nineteenth century, the federal government was sufficiently desirous of a populace receiving a "common" education that laws were enacted mandating school attendance:

> "Political, economic, social, and religious factors all contributed to the common school movement of the 1830s and 1840s. The faith in public schooling has, among other factors, been closely tied to national identity... With the emergence of the nation-state came the triumph of an ideology of faith in the state as the source of ultimate social value, with national values transcending those of family, community, and even religion" (Kirschner, 1991, pp. 139-140).

A country that requires its children to attend school must then provide those schools at its expense; hence the machine of public education was fired up right alongside its industrial counterparts. For approximately a century, that machine ran best as the tool of a specific class of people, with discrimination against minorities abundant. Then in 1954, the U.S. Supreme Court's decision in Brown v. Board of Education, determined that the system was in need of an overhaul in order to serve all Americans adequately (Turnbull & Turnbull, 2000). Out of civil rights, anti-poverty legislation, and case law came reforms for people with disabilities. In 1970, the Education of the Handicapped Act demonstrated governmental commitment to providing educational services for children with special needs. The subsequent 1990 Individuals with Disabilities Education Act (IDEA), with its central tenant of the impor-

tance of the Individualized Education program, implied a renewed and reformulated governmental commitment to providing educational services for children with special needs. Unfortunately, the more complex the public education system became, the more complications arose in its governance.

Homeschooling, of course, did not become an "alternative" method of education until compulsory public education was well entrenched in American society. Early practitioners were primarily families who were geographically isolated, or whose religious beliefs encouraged keeping children at home during some or all of their first sixteen years (Lines, 1991). However, by the middle of the twentieth century, as critics of the public school system became increasingly vocal, home education began to appear as an alternative to public education. In 1982, education reformer John Holt published *Teach Your Own: A Hopeful Path for Education*, in which he rejected the notion that the state should in any way have supremacy over a parent's right to decide how to educate a child. According to Franzosa (1991):

> "Holt's conservative libertarianism defines a society in which the individual's welfare is not the legitimate concern of the state, one's children can be thought of strictly as one's own, and the individual need feel no responsibility for the good of all. The best and wisest parent within this ideological context chooses to reject social participation in favor of personal independence and autonomy" (p. 123).

Included in Holt's argument for parental control of education is the assumption that "parents of exceptional children can adequately meet their children's therapeutic and educational needs themselves" (Franzosa, 1991, p. 129), an assertion which is disputed by many public school systems.

For a democratic nation, political and ethical conflict arises when the legislated or perceived rights of the individual run counter to the interest of the state. In the United States, the conflict is compli-cated by the issue of States' Rights. The lack of Constitutional commentary on education has historically meant that the schooling of the public has been the province of the states. Each state is responsible for providing and administering public education. Thus, regulations governing home education vary from state to state. In Alaska, for example, where home education is a desirable fiscal alternative to transporting children great distances to public schools, homeschooling families are granted complete educational autonomy as well as a reduction in taxes (Leppert & Leppert, 1999). Conversely, Nebraska home educators are only sanctioned by the state when they have demonstrated "sincerely held religious beliefs" (Leppert & Leppert, 1999, p. 566). The level of actual regulatory involvement varies dramatically from state to state, and frequently from school district to school district within a state. Because home education is frequently regarded as operating outside the compulsory school attendance laws, conflict often arises between parents, who view making any and all decisions regarding how their children are educated as a fundamental right, and school districts, which maintain that, under compulsory attendance laws, children receiving home education still fall within their jurisdiction. Opposing interests can become even more polarized in the case of children with special needs for whom educational goals and methods may be more difficult to determine and implement. Is it possible then, to create a system in which both the rights of the parents to determine how to best raise and educate their children, and the States' interests in educating individuals with disabilities to become contributing members of society, are protected? It is difficult, but absolutely possible. Balance can be achieved if the individual needs of the child with disabilities are truly made paramount, and if well-considered and well-implemented measures are taken to assure each child the opportunity to reach his/her educational potential.

Outcome and Assessment

Professional educators repeatedly articulate their concern that children who are being home educated are receiving an inadequate education. The National

Education Association stated in its 1999-2000 Resolutions that it "believes that home schooling programs cannot provide the student with a comprehensive educational experience" (National Education Association, 2000, p. 1). Yet no outcome data exists indicating that homeschoolers fall behind their publicly educated peers, either in terms of academics or social skills. In fact, a 1998 study, which utilized standardized testing to measure outcome, showed that home schoolers' test scores were "exceptionally high" and that children receiving a home education often work above grade level as compared to students enrolled in public or private school (Rudner, 1999). According to a 1999 study conducted by the Home School Legal Defense Association involving 20,000 homeschoolers:

> "... Students taught at home scored higher than their public- and private-school counterparts in every subject of the Iowa Test of Basic Skills... By eighth grade, the average home student performs four grade levels above the national average" (Cook, 1991, p. 2).

In addition, although critics of home education frequently question home educators' ability to provide ample opportunities for social experiences, this concern also seems unwarranted:

> "The home schooled also appear to be at no great risk with respect to socialization. The research indicates that their self-concept is high; they are socially/emotionally well-adjusted; they are involved in many activities that are predictors of adult leadership; they are consistently engaged in social activities with peers and adults" (Ray & Wartes, 1991, p. 57).

Furthermore, Ray and Wartes found in a 1987 sampling of homeschoolers in Washington that neither level of parent education nor formality of curriculum structure impacted upon successful educational outcome (1991).

Most of the research that has been conducted on homeschooling, however, does not examine the success rate of children with special needs. A 1997 study published in the journal *Education & Treatment of Children* demonstrated that children with special needs who were home educated "made more progress overall than public school students as measured by standardized tests," improving in skill acquisition across the curriculum (Duvall, 1997, cited in Home School Legal Defense Association, 1997, p. 1). The parents of the children involved in Duvall's study did not receive, or have prior training in special education. No related services were provided for the families involved in the study by their public school systems.

While no data exists showing homeschoolers with special needs are at risk, educational critics question whether the needs of children with disabilities are indeed being met in public schools. Public school systems are being urged to examine both their accountability and assessment procedures for children with special needs in order to comply with the 1997 Amendments to IDEA (Erikson, 1998). Under federal law, public school systems must "include students with disabilities in general state and district-wide assessment programs" (Erikson, 1998, p. 4). Yet, Erikson found that many school districts are not including children with special needs in assessment programs-either with or without accommodations, in spite of federal mandates:

> "Since the passage of P.L. 94-142, special educators and administrators at local and state levels have been accountable for complying with many state and federal regulations overseeing the delivery of services to students with disabilities... Unfortunately, this focus on inputs and processes has drawn the field's attention away from expectations of results for students with disabilities" (Erikson, 1998, p. 12).

The lack of accountability and assessment measures at the state level prompts many home educators to fear that state regulations which focus spe-

cifically on homeschoolers with special needs will mean that they will be held to a higher standard than their public and private school peers.

Giving the IEP Meaning for Home Education

So how do the states assure the quality of education for children with disabilities at the same time they refrain from requiring stricter accountability measures from home educators than from professionals? A good place to start is with IDEA itself. The philosophical essence of IDEA certainly lies in its recognition of learning differences. The fulcrum of this legislation is the requirement that all children with disabilities must receive an Individualized Education Program, that the plan must be approved by a professionally diverse team which includes the child's parents, and that any changes in the IEP are subject to due process. Few would argue that the intentions of this legislation are in the child's best interest. In practice, however, the mandates of IDEA and the implementation of the IEP have often simply created a legal instrument with which professional educators and parents do battle for control of the child's education. Professional educators intimidate parents with their knowledge of the intricacies of the public education system, sometimes not providing parents with a clear understanding of the extent of their rights to involvement in their child's education. Parents, on the other hand, are able to force the IEP approval process to grind to a halt by electing to undertake expensive and time-consuming due process mediations and hearings. Whenever there is conflict in approving or changing an IEP, the child suffers educationally, and sometimes, emotionally.

For those children not enrolled in publicly funded schools-including private schools that accept federal funding of any kind-IEP concerns are virtually nonexistent. Technically, under IDEA, any homeschooled children with disabilities who are supervised by their local district should have IEPs (Turnbull & Turnbull, 2000). However, because specific mention of children with disabilities frequently does not occur in state regulations of home schools, few districts seem to follow through with this mandate. From the perspective of the public education system, providing and assessing IEPs for homeschoolers would tax an already overburdened system. Home educators do not push for—or even desire—their children to have IEPs because they believe this would mean further unnecessary and unwelcome involvement in their educational choices on the part of the state. Yet it also means that children with disabilities may not be receiving all of the educational services-such as speech therapy or occupational therapy-they require and are entitled to at public expense. In a few instances, it may mean that children with disabilities are not truly being given the education and training that would allow them to fulfill their personal potential for independence in adulthood.

Before home and professional educators can establish a system which best allows children with disabilities to be educated in the manner most suited to their learning needs and to specifics of family priorities, it is necessary for these two interests to establish a more cooperative view of home education. Those on both ends of the spectrum hinder attempts to create an educational system which prioritizes the individual needs of the child. Misperceptions abound. A 1996 study (Mayberry et al.), which surveyed 118 school superintendents in Washington, Nevada and Utah, reflected the widely held professional opinion that homeschooled children receive an inadequate education, although the superintendents admitted to ignorance regarding actual data on homeschooling. Likewise, some homeschool proponents, such as the editors of *Home Education Magazine*, urge parents to shun any relationship with the public education system, including screening and special education services, without providing data:

> "By undermining confidence of both parents and children, screening actually makes it less likely that children will be able to develop their strengths and abilities. Ironically, rather than supporting children and helping them develop their abilities to the fullest potential... it interferes with and hinders their development" (Kaseman & Kaseman, 1993).

In order to formulate policy that best serves children with special needs, it is incumbent upon both home and professional educators to request and access accurate outcome data, and to use this data to design programs which make it possible for children with special needs to learn in a manner which is suited to individual learning style.

An Example of Proposed Regulation

In the State of Maryland, there are three possible options for the home education of children. A parent may choose to homeschool his/her child under the guidance of a church group. The Constitutional separation of Church and State means that this option for home education takes it out of the province of the state altogether. If, however, a home educator does not choose to use a church-affiliated umbrella group, two other legal avenues to home education remain. An approved, nonpublic school may be employed to provide curricula and guidance. Only two nonpublic schools have been approved by the State of Maryland to provided Home Instruction. Neither has curricula designed for children with special needs; it is up to the parents to make acceptable modifications to meet the needs of the child with learning differences. The ease of this task is frequently dependent on the type and level of involvement of the child's disability, and upon the parents' access to supplemental resources for educating a special needs child. Finally, homeschooling may be under the supervision of the child's local school district. No state regulations govern how this supervision will be conducted, thus quality of supervision varies greatly from one school district to the next.

The following is a proposal for amendments to the existing Home Instruction regulations in Maryland (COMAR 13A). The intention of this proposal is not to create hurdles for home educators, but rather to help assure that the needs of the child with disabilities are addressed. Under these guidelines, it is the responsibility of the parents to articulate appropriate educational goals for the child and assure that they are being met; conversely the state must demonstrate that an acceptable Individualized Education Program is not in place in order to inter-

fere with the child's homeschool curriculum and placement. All changes and additions to existing regulations are highlighted in bold italics.

Title 13A

STATE BOARD OF EDUCATION

Subtitle 10 HOME INSTRUCTION

Chapter 01 General Regulations

Authority: Education Article § 7-301, Annotated Code of Maryland

.01 Home Instruction Program

A. Purpose. The purpose of this regulation is to establish a procedure to be used by the superintendent of each local school system to determine if a child participating in a home instruction program is receiving regular, thorough instruction during the school year in the studies usually taught in the public schools to children of the same age. *It is the responsibility of the local superintendent or superintendent's designee to supply evidence demonstrating lack of compliance with this policy in order to instigate a student's change of placement from a home instruction program to a public school placement.*

B. Written Agreement. A parent or guardian who chooses to teach a child at home shall sign a statement of a form prescribed by the State Department of Education which:

(1) Indicated consent to the requirements set for in §§ C, D, and E; and

(2) Shall be submitted to the local superintendent at least 15 days before the beginning of a home instruction program.

C. Instruction Program. The home instruction program shall:

(1) Provide regular, thorough instruction in the studies usually taught in public schools to children of the same age *and ability level*;

(2) Include instruction in English, mathematics, science, social studies, art, music, health, and physical

education *unless otherwise indicated in the child's Individualized Education Program*;

(3) Take place on a regular basis during the school year and be of sufficient duration to implement the instruction program.

D. Educational Materials. A parent or guardian who chooses to teach a child at home shall maintain a portfolio of materials which:

(1) Demonstrates the parent or guardian is providing regular, thorough instruction during the school year in the areas specified in § C(1) and (2);

(2) Includes relevant materials, such as instructional materials, reading materials, and examples of the child's writings, worksheets, workbooks, creative materials, and tests;

(3) Shall be reviewed by the local superintendent or the superintendent's designee at the conclusion of each semester of the local school system at such times as are mutually agreeable to the local superintendent or designee and the parent or guardian.

E. A parent or guardian shall agree to permit a representative of a local school system to review the portfolio of educational materials, discuss the instructional program, and observe instruction provided that all of the following requirements are met:

(1) The review is at a time and place mutually agreeable to the representative of the local school system and the parent or guardian;

(2) The purpose of the review is to ensure that the child is receiving regular, thorough instruction as set forth in § C;

(3) There are not more than three reviews during a school year.

F. Children with Special Needs. All aspects of Part B of the Individuals with Disabilities Education Act (20 U.S.C., Ch. 33, §§ 1400-1491) and its implementing regulation (34 CFR 300) shall apply to children receiving home instruction who have a disability as defined therein. Each child shall have

an Individualized Education Program as mandated in IDEA, written and approved by an IEP team. Any related services specified in the IEP shall either be provided and funded by the county or provided and funded privately according to the determination of the parent or guardian. Related services which may be funded by the parent or guardian and provided either by the home teacher or independent contractor include, but are not limited to, special education consultation, speech and language therapy, occupational therapy, physical therapy, functional behavior assessments and academic tutoring.

G. Additional Requirements. A local school system may not impose additional requirements for home instruction programs other than those in these regulations.

02. Voluntary Participation in Standardized Testing.

Upon request of a parent or guardian, a child receiving home instruction may participate in the regularly scheduled standardized testing programs that are administered in the public school the child is eligible to attend. *Children with special needs as defined in the Individuals with Disabilities Education Act must be allowed "appropriate accommodations" as mandated by that Act [612(a)(17)(A)].*

03. Noncompliance with Requirements.

A. Failure to Consent. If a parent or guardian does not agree to the requirements of Regulation .01B, C, and D, above, a child shall be enrolled promptly in a public school or nonpublic school as defined in COMAR 13A.09.09.02B(4)(a).

B. Deficiencies in the Program. If a local superintendent determines on the review of the home instructions program or inspection of the portfolio that a child is not receiving a regular, thorough instruction program in conformity with Regulation .01C and D, the local superintendent shall notify the parent or guardian in writing of any deficiencies in the program.

The following apply:

(1) Within 30 days or receipt of notification of any deficiencies, the parent or guardian shall provide evidence to the local superintendent that the deficiency has been or is being corrected.

(2) If a local superintendent determines there is not a satisfactory plan to correct a deficiency or if a deficiency is not corrected, a child shall be enrolled promptly in a public school or a nonpublic school as defined in COMAR 13a.09.09.02b(4)(a).

(3) For children with special needs, it is incumbent upon the superintendent or superintendent's designee to demonstrate that progress toward the goals set forth in the child's Individualized Education Program has not occurred in order for the program to be considered deficient. Removal of a child with special needs from a home instruction program is considered a "change of placement" under the Individuals with Disabilities Education Act, and may only occur after the parents have been given an opportunity to contest the decision through a due process hearing as stipulated in the IDEA Part B regulation (34 CFR 300).

04. Placement in Public School

Upon application of a child for admission to a public school from a home instruction program, the local superintendent shall determine by an evaluation the placement of the child and any credits to be awarded toward high school graduation. The evaluation may include administration of standardized tests and examinations and interviews with the child. *Children with special needs shall be placed according to the Individualized Education Program. Any standardized tests administered to children with special needs must include appropriate accommodations as mandated by the Individuals with Disabilities Education Act.*

05. Home Instruction Under Supervision of Nonpublic School

A parent or guardian may provide instruction for a child at home without compliance with the requirements of this regulation, other than the requirements of Regulations .01B(2) and .04, if that instruction is offered through correspondence courses and is under the supervision of a:

A. School or institution offering an educational program operated by a bona fide church organization, and the supervision includes at a minimum all of the following components:

(1) Preenrollment conferences with parents or guardians, (2) Textbooks, lesson materials, and other instructional materials or equipment designed to be used independently by the pupil at a site other than a school, (3) Annual visits by supervisory personnel to the site where the pupil is receiving instruction and (4) Conferences with parents or guardians at appropriate intervals during the period of enrollment; or

B. Nonpublic school with a certificate of approval from the State Board of Education, and the supervision includes at a minimum all of the following components:

(1) Textbooks, lesson materials, and other instructional materials or equipment designed to be used independently by the pupil at a site other than a school, and (2) Assignment of a school-based teacher to assist the home teacher in using the correspondence courses and to assist the pupil by issuing progress reports, marking papers, and grading tests.

Accommodations for children with special needs, including whether an Individualized Education Program will be utilized, will be made at the discretion of the supervising organization. Related services will be either provided and funded by the supervising organization or the parent or guardian, and may include, but are not limited to, special education consultation, speech/language therapy, occupational therapy, physical therapy, behavioral assessments and management, and academic tutoring. (COMAR 13A, 10.01).

Merope Pavlides, is an independent scholar working in the area of Disability Studies. She holds a Ph.D. from the University of Wisconsin-Madison in Dramatic Literature and is currently pursuing a M.S. in Special Education from Johns Hopkins

University. In 2000, she co-founded a center for children with learning disabilities. She is the mother of two children with disabilities.

Correspondence regarding this manuscript should be sent to Merope Pavlides, Ph.D., Independent Scholar, TEL: 410-750-8728, FAX: 410-750-0170 or email: merope1@aol.com.

References

COMAR 13A 10.01, Home Instruction.

Cook, S. (1999, March 25). Report card on homeschooling in the U.S. *Christian Science Monitor*. [Online]. Available: http://www.csmonitor.com/durable/1999/03/25/p3sl.html.

Council for Exceptional Children. (2000). Home schooling-A viable alternative for students with special needs. *Today, 7*(1), 1, 5, 15.

DuVall, S. F., Ward, D. L., Delquardri, J. C., & Greenwood, C. R. (1997). An exploratory study of home school instructional environments and their effects on basic skills of students with learning disabilities. *Education and treatment of children, 20*(2), 150-172. [Home School Legal Defense Association (1997, September 4). Press release. (Online). Available: http://www.hslda.org/media/releases/docs.09-04-97.html].

Erickson, R. (1998). *Accountability, standards and assessment. Special education in an era of reform*. Washington, DC: Federal Resource Center.

Franzosa, S. D. (1991). The best and wisest parent: A critique of John Holt's philosophy of education. In J. Van Galen & M. A. Pitman (Eds.), *Homeschooling: Political, historical, and pedagogical perspectives* (pp. 121-135). Norwood, NJ: Ablex.

Home School Legal Defense Association. (1997, May/June). Across the states. *Home school court report, 13*(3), 11-19.

Kaseman, L., & Kaseman, S. (1993, November/December). Why are not for screening. *Home education magazine*. [Online]. Available: http://www.home-ed-magazine.com/INF/SPCL/spcl_screen.html.

Kirschner, J. (1991). The shifting roles of family and school as educator: A historical perspective. In J. Van Galen & M. A. Pitman (Eds.), *Homeschooling: Political, historical, and pedagogical perspectives* (pp. 137-157). Norwood, NJ: Ablex.

Leppert, M., & Leppert, M. (1999). *Homeschooling almanac: 2000-2001*. Rocklin, CA: Prima.

Lines, P. (1991). Home instructions: The size and growth of the movement. In J. Van Galen & M. A. Pitman (Eds.), *Homeschooling: Political, historical, and pedagogical perspectives* (pp. 9-41). Norwood, NJ: Ablex.

Mayberry, M., Knowles, J., Ray, B., & Marlow, S. (1995). *Homeschooling: Parents as educators*. Thousand Oaks, CA: Corwin.

National Association of State Directors of Special Education. (1998, April). *Home schooling and students with disabilities. Quick turn around project forum*. (ERIC Document Resources Service No. ED 418 544).

National Education Association. (1999). B-67. Home schooling. *NEA 1999-2000 resolutions*. [Online]. Available: http://www.nea.org/resolutions/99/99b-67.html.

Ray, B. (1997). *Strengths of their own*. Salem, OR: National Home Education Research Institite.

Ray, B., & Wartes, J. (1991). The academic achievement and affective development of home-schooled children. In J. Van Galen & M. A. Pitman (Eds.), *Homeschooling: Political, historical, and pedagogical perspectives*. Norwood, NJ: Ablex.

Rudner, L. M. (1999). Scholastic achievement and demographic characteristics of home

school students in 1998. *Educational policy analysis archives, 7*(8), 1-34. [Online serial]. Available: http://epaa.asu.edu/epaa/v7n8/.

Stevens, S. (1996). Homeschooling LD/ADD children: Great idea or big mistake? Reprinted from *The LD child and the ADHD child: Ways parents and professionals can help*. [Online]. Available: http://www.ldonline.org/ld_indepth/parenting/homeschooling.html.

Turnbull & Turnbull. (2000). *Free appropriate public education: The law and children with disabilities*. Denver, CO: Love.

Essays and Creative Works

A Little Story to Share

Lee-chin Heng
Malaysia

Abstract: An autobiographical article of a physically disabled person from Malaysia.

Key Words: Malaysia, education, equal rights

I have Osteogenesis Imperfecta, also known as Brittle Bone Disease. Wheelchair user since a very bad fall at the age of 7. As a person with only a physical disability, my parents couldn't enroll me in the existing schools that the Malaysian government provided. There are special schools for the visual and hearing impaired, and spastic centres for the mentally impaired. But as there are no special schools for the physically disabled, and most "normal" schools are unequipped with facilities for the wheel-chairs, like ramps or special toilets, people with only physical disabilities are often being slighted or left out. And often, as in my case, no school even dared take me in for fear of having to shoulder the responsibilities should any accident or mishaps happen to me in their compound.

Within the Malaysian education system, without a high school qualification, my hope of entering into colleges or universities to do a full-time degree course in music will never be realized, whether or not I'm musically qualified to do so.

I'm now an Associate diploma holder in music, under Trinity College of Music, London's external diploma programme. Most music centres hired teachers even before they reach diploma level, but knowing the discrimination I'll face, I only started job hunting when I got my diploma certificate in hand. With the numerous interviews and auditions that I've gone through, what is most disheartening is not the people who turned me down straight for reasons of inaccessibility, as most class rooms are on the upper floors of shophouses, but the hypocrites that never forget to be understanding, but never from the very start intended to hire me. It's not just dis-heartening but worrying that people who are sup-

posed to guide and develop the talents and potentials of young minds are themselves judging by the disabilities and not the capabilities of an individual.

A friend whom I just got to know related her experiences to me as a way to encourage me not to give up or feel disheartened by the little setbacks that I've faced. The first thing she said to me was, "There's nothing as called fairness or justice in this world. And being disabled, this is the reality that we have to face, and fighting back for our rights is our only options next to giving up."

As a person with physical deformity herself, she's had her fair share of difficulty in finding jobs. When she finally found herself hired by a small manufacturing plant, her boss was so nice to her up to the point of asking her to stay for dinner. But with the intention of wanting her to help tutor his son afterwards. Which often extends to 8 at night, when her job as a clerk only runs till 5PM. Not only was she taken advantage of for doing the jobs of both clerk and home tutor for the pay of one, her boss eventually insisted on her doing his son's homework instead of only guiding him. And that's when she put both her feet down and quit in the name of integrity and dignity. She's now working in a rehabilitation organisation, from a clerk to her post as assistant manager now. A place she's devoted herself to for the past 30 years, where the disabled people she has worked with has grown to love and trust her like a friend and family and a job in which she'd garnered both self-esteem and respectability from her superiors.

And this is the reason she fully encourages me to take up the challenge of music tutor in a disabled centre. Not only would I have the chance to fully utilize and develop my love of music, being disabled myself, I would also have the chance to share my sentiments with so many other disabled people and bring our music to another level where we can establish a performing troupe for ourselves as well as the plan of setting up a new art centre specially for the disabled in the future.

My hope as a disabled person for all disabled people in Malaysia is the right to be treated equally. And to ceased being regarded as the less fortunate or the needy, terms which are not just belittling but totally disillusioning the public into perceiving the disabled as objects to be sympathised with or a burden to the society and community at large. And being a person deprived of education, I plea the need of providing education to all people, the physically, mentally, as well as the socially discluded. And a barrier free environment that not only goes to enforcement of ramps and accessibility in public buildings but also in all public facilities like roads and transports. As well as educating the public about the existence of the disabled, like creating more programmes and campaigns that allows the disabled and the able-bodied the opportunity of working together as equal. And one very sad fact in Malaysia is the lack of chance for the disabled people to represent themselves in disabled society and communities.

Often people with no experiences of working with the disabled are elected or selected to represent us in committee meetings, and often proposals are only good on paper, but totally impractical and not really serving to disabled peoples' needs and benefits. And the saddest circumstances are the organisations or foundations that started out with good intentions but slowly got into the wrong hands and more often than not either turned out to be social gatherings for the upper classes, where fundings are often squandered on the numerous dinings and discussion meetings on ways to help the needy but always end up with no result whatsoever, or where money raised in fundraisings or charity events are being corrupted by conscience-less people for their own personal gain.

I hope to see the swift enforcement of education to all people. I hope just as much that disabled persons will be given the power and funds to act on behalf and represent their own disabilities. No matter how much an observer claims to understand the person that's being observed, the observer still stands an observer. And what gives anyone the right to observe another person in the first place?

Lee-chin Heng is a Certified associate diploma holder in music. She is currently working as a piano accompanist in a ballet school. Lee-chin will be tak-

ing up the post as music tutor in a disabled centre, that will be giving free music tuition to all disabled people. She will also oversee the music department of an art troupe that plans to travel to Taiwan by the middle of 2004, and the music department of an art centre for the disabled to be ready by 2005. We welcome people from all walks of life, disabled or otherwise, to join our music classes. Anyone interested in visiting our centre or just to know more about us can email Lee-chin at lc_h02@yahoo.com or our centre at bgcentre@yahoo.com.

Frightnight

Monty Anderson
University of Hawaii at Manoa

Abstract: At some point in the life of every disabled person, discrimination will be experienced in one form or another. Sometimes that discrimination may take the form of something minor like cutting in line in front of a blind person or talking to a paraplegic as though he/she was a child. At other times the discrimination is more serious: preventing access to a public event or establishment, or harassing them into leaving. On October 27, 2003, I was harassed into leaving a public event, an elaborate haunted house, because I am blind. After several minutes of harassment, instead of fighting my way inside, I decided to leave. I still question whether or not that was the correct decision, but I felt compelled to share my story with others so if they have a similar experience, perhaps they will be more prepared to make their own decision.

Key Words: discrimination, blind, harassment

"How ya doing bud?" he asked as he walked by, patting me on the arm. From the deep resonance of his voice, he sounded like a big guy.

"All right," I replied and waited for his instructions. I was sitting in a group of seven people waiting to enter the haunted house at the Waikiki Shell. My friend Tasha and I had been talking about it for days. We hadn't been to a haunted house since we were kids, and on the drive over we were laughing and shivering like high schoolers.

The man started telling the group what to expect. There would be a lot of large stairs and a lot of low places where we would have to duck. He pointed the flashlight at me, the light glowing off of my cane, and said, "Especially you." I smiled and nodded. For one thing, I'm six foot eight, so I'm used to ducking through doorways and dodging ceiling fans. For another, I'm blind. Well, not completely blind, but close enough. I still have some sight at the periphery of my vision, but I carry a cane and borrow an occasional shoulder when walking through unfamiliar territory.

"We're together," I said, gesturing toward Tasha. "She'll help me through."

"This is a dangerous place," he said, and I couldn't help but wonder why anyone would create a public event that was dangerous—especially an event where there was sure to be children. The flashlight beam moved from me to Tasha. "You did see the sign out front, right? Enter at your own risk." Tasha shook her head. He turned to the group. "Okay all you people hear me telling this guy that he's entering at his own risk. This is a dangerous place, and we're not responsible for anything that might happen." I cringed. Was this guy for real? I understood his concern, but why was he involving everybody else? Did he want witnesses?

"Don't worry," I said, "No lawsuits."

Finally I was out of the spotlight. He told the group that we needed a leader, and asked for a volunteer. One of the group members said, "I want him," and gestured to me. I laughed and said "At your own risk pal." And the mood began to lighten.

He handed the flashlight to Tasha. "You be the leader."

She handed the flashlight back. "I can't lead these people and help my friend at the same time."

"Then you two need to leave. Go back to the ticket counter and try to get your money back." I thought, "Leave? This guy was kicking us out?" Tasha calmly explained to him that she could guide me, but not the rest of the group.

"You know," he said, again pointing the flashlight at me, "I don't know why they even sold you a ticket. Why did you even come here in the first place? You're blind."

My arms were trembling and my face was hot. I had two choices: I could either stand up and tell this guy off, or I could leave. I considered sticking around, but by that point the fun was gone. Trying to remain calm, I turned to my friend and said, "Let's go." On the way out, Tasha made a point of telling the ticket takers and those at the ticket counters what had just happened. We were met with silence. There were no apologies. Were they shocked? Were they embarrassed? Or were they silently wondering what a blind guy was doing at a haunted house.

Indeed, what was a blind guy doing at a haunted house? To me, the answer is obvious: to have fun. Of course I wouldn't experience the event on the same level as a sighted person; I would experience the event on different levels. I still have other senses, and when I'm with a friend, they usually describe the visual things. People are often perplexed that I enjoy movies, theater, baseball games. There's more to a movie than just spectacle. There's more to a play or baseball game than just action. There's a universe of sounds: laughing, talking, the crack of the bat, and the excited cheers of those sitting around me. There's a garden of aromas: the warm buttery smell of popcorn, the sharp tang of mustard on hot dogs, and hot, crispy French fries. These may not be experiences most would consider fun, but I do.

Everyone has the right to participate in society, and if they want to participate, they should be encouraged, not shamed. There's no shame in wanting to enjoy life. Organizers of public events need to understand that society consists of many people with disabilities, and these people need to be considered when events are being organized. Arrangements should be made to allow them to participate. It's no fun to have someone tell you that you're not welcome because of a physical attribute, something which one has no control over. A person with a disability is not an alien, not a creature from another planet, not subhuman or less worthy of dignity and respect than any other person. The bottom line is that people with disabilities are people, and the only thing separating the abled from the disabled is a split second: the crunch of metal in an intersection, a slip on wet concrete, a misjudged dive in shallow water and your life could change forever.

Disabilities are an issue of civil rights. The ADA has been in effect for nearly fourteen years now, making it illegal to discriminate against someone on the basis of their physical ability, or lack [thereof]. With a little assistance and ingenuity, a person with a physical impairment can overcome any obstacle. Just a few years ago, a gentleman who is totally blind climbed to the top of Mt. Everest. As the immortal philosopher John Lennon once said, "There are no problems, only solutions."

The haunted house at the Waikiki Shell was a public event, and I'm a member of the public. I should not have been bullied and made to feel stupid for wanting to join in. Was he wrong for his concerns? Absolutely not. It was perfectly reasonable for an employee of a major event to check in with me and ask if I knew the risks. The problem was that even after I made it clear that I knew the risks and was willing to go on, he continued to bully me, even at one point questioning why the ticket sellers had let me in. He put the spotlight on me and kept it there, embarrassing me in front of a group of people... I guarantee you that if someone talked to him the way he talked to me, he would have belted them. For the most part, this is an issue of communication and respect, and not so much intent; however, I did certainly get the feeling that he wanted me gone.

Did I do the right thing? Should I have told him where to go? Should I have stormed up to the counter and demanded to see the manager? Would any of that have improved anything? Who knows? I did what I did. I'm not a hostile or confrontational person, but I feel it is important to speak out against discrimination wherever it may be lurking, for one day it may be lurking for you.

"Frightnight" was originally published in *Ka Leo*, the University of Hawaii at Manoa student newspaper.

Monty Anderson is currently a candidate for graduate school at the University of Hawaii at Manoa in the departments of both Speech Communication and Clinical Psychology. He has a BS in Human Services and a BA in Psychology. Additionally, he has a license in Massage Therapy. He plans to obtain a Masters in Speech Communication, and a Masters/Ph.D. in Clinical Psychology with a dual specialty in Cognitive Psychology.

The "Really Disabled": Disability Hierarchy in John Hockenberry's *Moving Violations*

Rachel Stewart
University of California, Berkeley

Abstract: This paper explores a disability hierarchy present in John Hockenberry's memoir, *Moving Violations*. Disability hierarchies are understood as the idea that some impairments are positioned as "worse" or more severe than others, and thus more deserving of stigma. I will examine the different ways a disability hierarchy manifests itself throughout *Moving Violations* in Hockenberry's discussion of disabled people he has encountered. Finally, the problematic elements that arise from a disability hierarchy are discussed.

Key Words: disability hierarchy, autobiography, John Hockenberry

A common belief within both the non-disabled and disabled communities is the concept of a hierarchy of disability. Disability hierarchies position certain impairments as more or less disabling than others, with the idea that some impairments are "better" or less severe than others. The fact that many disabled people believe in a hierarchy of disability only perpetuates the social exclusion and stigma felt by all persons with disabilities. Disabled people might not know they discriminate against or degrade others with disabilities, but it still occurs, often in forms not easy to recognize. In his memoir, *Moving Violations* (1996), John Hockenberry continually comments about people who are "really disabled." Although some of his comments are tongue-in-cheek, many others seem to stem from a deep-rooted belief in a hierarchy of disability.

In describing his concept of the "really disabled," Hockenberry jokingly comments on what they require: "I require no leg bag. That's for the really disabled. I have no van with a wheelchair lift anymore. Those are for the really disabled, and thank God I'm not one of them. I need no motor on my wheelchair. Those are for the really disabled, and I am definitely not one of those" (p. 87). Hockenberry is clearly not being serious in this quote; he is merely commenting on his tendency to push away from being categorized as "really disabled." He wishes to be perceived as "normal" as possible, which he thinks is trying to be as non-disabled as possible. This is evident in many different ways throughout the text, including his wish to drive regular cars: "I had a pickup instead of a hospital 'Ironsides' lift van. It was a form of liberation" (p. 126). Although it is possible for Hockenberry to drive a regular car, many disabled people aren't able to drive without a "hospital 'Ironsides' lift van;" does this mean someone who drives a car that is in some way 'marked' by disability is less socially valuable?

Though Hockenberry may make blatant jokes about the hierarchy of disability, there is also an underlying, less recognizable hierarchy implied in the way he writes about different disabled people he has encountered. This hierarchy first appears when Hockenberry describes the people that were in a rehabilitation facility with him, following his own injury. He explains that Ron, a man with a traumatic brain injury, "constantly stared at the ceiling, drooled, and had periodic uncontrollable seizures. Ron never spoke and never argued. Ron laughed a lot. He was the floor psychologist's favorite, which seemed to say more about the psychologist than it did about Ron" (p. 30-31). First of all, Hockenberry portrays Ron in a very degrading manner, as someone without any real thoughts or opinions. Secondly, he seems to imply that Ron is not worthy of being anyone's "favorite" person because he was constantly drooling and staring at the ceiling. Certain disabilities are more likely to lead to bodily leakages, or unusual cognitive behaviors, and Hockenberry alludes to the

idea that these types of disabilities deserve less respect than other disabilities.

Another person in rehab with Hockenberry is Roger, a "high quad" (p. 31) who can only move his head and neck. He describes Roger in ways that are inhuman, such as "a doll from a horror movie" (p. 31) and a "bobbing head and motionless body" (p. 39). Hockenberry resorts to degrading words to explain his disabled "friends," illustrating his condescending attitude towards them. He also portrays Roger as someone who is quite helpless: "[Roger] was starved for volition. He told me that he used to steal cars for fun. Now he couldn't make a pencil roll off his tray table" (p. 32). Hockenberry places Roger under the severely disabled category, unable to do anything for himself. He even compares his impairment with Roger's, saying: "For Roger, paraplegia was about as serious a disability as an untied shoe" (p. 32).

One might hope that as a person with a disability, Hockenberry would try to present a balanced view of the disability experience. However, he actually projects the hostile attitudes of society towards disabled people onto those who are "more disabled" than he is – trying to distance himself from other disabled people. For instance, Hockenberry also compares himself with Saul, a "really disabled" (p. 220) radio DJ with Tourette's syndrome. He states: "I could imagine [saying, 'I want to squeeze your tits,' to your date] as a far more serious problem than wetting your pants on the first date, as I had done when I met my wife" (p. 223). Comparing disabilities in this way, however, only detracts from the need to recognize that different types of impairments provoke different social reactions. Hockenberry depicts his interview with Saul like a circus show: "Listening to Saul was quite an adventure...each time he exploded into a self-destructive obscene shout I would look at Flawn as if to say, 'That was a good one. Let's have a couple more like that'" (p. 222). In his entire description of Saul, Hockenberry treats him like one big joke, and a freak. Disability hierarchies often exist inside the disabled community, causing isolation, conflict, and insensitivity. This prevents the disabled community from coming together and working towards a common goal which benefits all disabled people: ridding society of the discrimination and stigma directed towards the disabled.

A disability hierarchy is further reinforced when Hockenberry describes intellectually disabled clients at the nursing home where he worked. He explains them as having "personality defects" (p. 122) and "personalities... obliterated through years of psychoactive drugs like Thorazine and Seconal and institutionalization" (p. 121). Although they may not be "normal" according to societal expectations, that doesn't mean that their personalities are non-existent or defective. At the nursing home, the job of the employees is "strict behavior modification" (p. 122) by "putting them in 'time out' if they weren't compliant" (p. 122). They were "under express orders not to give any of the clients attention that they hadn't earned through screwing screws or writing in workbooks" (p. 122). Although some of Hockenberry's commentary may be tongue-in-cheek, he fails to discuss serious problems of treating clients not like human beings, but as dogs needing to be trained. Such dehumanization actually reinforces many commonly held prejudices about disability.

Hockenberry talks about two clients in more detail, a couple of friends named Jeanie and Jeff. He first states they are "a well-rehearsed comedy sketch" (p. 127). He took them out one day for a trip to the ocean, and describes how passing motorists would stare at "Jeanie's blotto face and... Jeff's undersized head" (p. 128). Again, he uses degrading words and comments when describing them, belittling their uniqueness. Out for a stroll on the beach, the cops were called because people thought they were carrying out a suicide pact, and Hockenberry was mistaken for just another disabled person, instead of the person who was "in charge." He states that he was "humiliated" (p. 131) by the whole experience. A big reason why he describes Jeanie and Jeff in such a degrading way is to reinforce the difference in their types of disability (physical vs. mental), placing himself in an entirely different level on the hierarchy: higher up and thus less disabled. Through such examples, Hockenberry seems to endorse the view that physical disabilities are less "deserving" of stigma than intellectual or psychiatric disabilities.

Hockenberry also places himself as higher up on the disability hierarchy when he goes to visit his Uncle Charlie in a nursing home. When he first entered the nursing home, he thought to himself: "In this place, I was the normal one" (p. 347). Again, this only reflects his belief that people with developmental disabilities are much more disabled than he is, and compared with them, he isn't disabled at all. One could also conclude from this statement that people inside of nursing homes are abnormal. Either way, he fails to explain the problem of locking up disabled people in institutions away from the "normal" people. He goes on to describe his Uncle as "a little man in a wheelchair with a bib on being fed a mixture of green mush and brown mush... [whose] eyes were darting aimlessly around the room" (p. 347). Hockenberry also states that when he said good-bye to Charlie, "his face twisted into a scowl, his eyes darted up to the ceiling, and he turned away" (p. 353). These descriptions portray Charlie as a "little man" who doesn't understand what is going on around him. In actuality, Charlie may know exactly what is going on, but may have no way to communicate in "normal" ways. Also, Hockenberry continues the practice of dehumanization when he likens his visit with Charlie as visiting an animal in a cage: "I was another one of those people who showed up every few years to rattle his cage, or tap on his glass tank to get a rise out of him" (p. 348). Although Charlie may be locked up in an institution (and not by his own will, but as a result of his parents decision), he is certainly not an animal. It is this kind of dehumanization which has led to disabled people being put away in institutions where nondisabled society can largely ignore them and not have to deal with them.

The disability hierarchy is also seen in Hockenberry's phrasing and the way he lists things. This is evident in his description of his encounter with disabled skiers. He starts listing the different types of amputees, ending with: "Then there were the hot dogs, the armless torsos on legs whose balance was adjusted with a move of the head or shoulder. At the top of the heap were the leg amputes who skied solo on a single limb" (p. 219). Hockenberry lists the different amputees first de-

scribing the least disadvantaged, those with one prosthetic leg and one muscular leg, then to the "top of the heap" more disabled skiers, the "hot dogs" and those skiing with just one leg. This technique of listing from less disabled to more disabled is also seen when Hockenberry describes the different clinical names for the people he was in rehab with: "I was a para. There were the quads and hemis (hemiplegic), or CP's (cerebral palsy), BS's (brain stem strokes), or CVA's. Ron was a TBI, which meant traumatic brain injury" (p. 30). The author's impairment is listed first, as the least disabled, with the last being Ron's, the TBI who is "really disabled". One of the greatest achievements of the disability movement, and disability studies, has been to explore both the commonalities and differences which exist among people with disabilities – not to determine who is deserving of the most respect, but to examine how processes of stigma and disrespect create hierarchies of shame and privilege that injure all disabled people. The most problematic element of Hockenberry's writing is that he does not promote a message of universal dignity and respect. It is precisely the idea that there are some people who are "really disabled" and others who are not, which leads to social hierarchies between disabled people. Through this discourse, some disabilities become acceptable, while others remain highly stigmatized and are subject to social exclusion. Unfortunately, this argument also seems to imply that people who are "really disabled" somehow deserve the lack of rights and disrespect which they receive. After all, they are "really disabled" and therefore it may be impossible for them to have social inclusion. This message is antithetical to the foundational principles of the disability movement. Dividing people with disabilities according to who is "really disabled" and who is "not really disabled" also diverts attention from the stigma, prejudice and inaccessible resources that we all share in common. Whether the barriers are attitudinal or physical, the disability movement has challenged practices of social exclusion by promoting alternative messages of inclusion based on respect for diversity. When Hockenberry flippantly and disrespectfully describes the bodily habits of other people with disabilities, he is unfortunately promoting messages that run contrary to the entire

spirit of the disability movement. Although this is an autobiography, and Hockenberry is entitled to his opinion in his autobiography, many people are reading it and getting a certain message. This message is harmful and hurtful to many disabled people. All in all, the basic goals of the disability movement will be very hard to achieve unless disabled people themselves treat each other with more respect and equality. This will involve challenging hierarchies of disability both within and outside the disability community.

Rachel Stewart is an undergraduate in the Psychology department at the University of California at Berkeley. She is currently working on her honors thesis, examining different social influences on the quality of life of people with Spinal Muscular Atrophy.

Speaking for Myself: Reflections on "Passing" and Labels, 2002

Ruthie-Marie Beckwith, Ph.D.

Abstract: Poverty is viewed as one of the major contributors to stigma in this personal essay on labeling and its impact on people's humanity. Mental illness, a disability with no visibly apparent indicators, is particularly explored from the author's own experience in searching for recovery. Working toward empowerment for oneself and others is presented as a solution to overcoming cultural barriers.

Key Words: Stigma, Mental Health, Recovery

The Opryland Direct Action Prose Poem, 1993

Sitting in the minimum secure facility with fifty women—all of whom have disabilities. We have been arrested for standing in the driveway. Doesn't seem all that much like civil disobedience but it qualifies for criminal trespassing. "Anne" tells her story to a woman next to her. Both in wheelchairs, they share their histories. "Able-bodied" me eavesdrops— I am not included in their worldview now.

"Anne" tells the story of her brother threatening her with a gun when she screamed for help to get off the commode. As she described telling him to just

go ahead and shoot, I flashback to the front yard where my mother aimed a shotgun at my stepfather who was standing directly behind me. "Anne" and I were both in the way. She found a way to claim her personal power. I am transformed into a deer, my eyes locked on the gun, forever frozen in time.[1]

It's late at night and I'm up pondering how it is that I could possibly have something in common with Franklin D. Roosevelt, a national legend, highly regarded, and much revered figure in the world of disability. It's there though; just one tiny similarity except mine isn't taking a national debate to bring out into the open. He "passed" on being seen as a person who used a wheelchair and I, until very recently, "passed" on letting people outside of my closest friends and colleagues know I have mental health labels.

Thoughts and feelings about being labeled and being the labeler continue to abound. Characters on a recent television episode of the American TV show *CSI* (*Crime Scene Investigation*) even talked about the difference between having a visible disability and an invisible disability. A glorious new publication by *Self Advocates Becoming Empowered* [2](2002), <u>Sticks 'n' Stones</u>, gives voice to the feelings of the labeled people whose movement was launched on this very debate. Other segments of the disability rights movement insist on using a label as a way of proclaiming their identity and framing their own cultural experience. Some professionals and family members have never abandoned the old labels for the new nor accepted *People First* [3] language proscriptions while others disparage the whole enterprise. Still others condemn the whole *People First* language effort as language tyranny being carried out on by an out of control societal wave of mandating what's "politically correct."

In my life as an advocate during the last 20 years, I respected and carried out the mandate of the statement issued by some folks long ago in Oregon by *People First International*: "We believe labels hurt people..." You all know the yellow poster, "Label Jars, Not People"? In 1994, I testified under oath at a deposition that I couldn't and wouldn't label the people I worked for even though I had the creden-

tials that the attorney for the *Voice of the Retarded* thought were satisfactory to meet his demand to do so.

However, in all of the time that I campaigned actively against the process of labeling people, I was also campaigning heavily against the demons of a past that ended with a few more letters being added after my name: PTSD[4], DD-NOS[5], along with the words, depression, anxiety, and one which strikes terror into the heart of any good behaviorist, SIB[6]. At the same time, the campaign against those demons gave me "Other Professional and Volunteer Experiences" to add to my resume like, "Being an advocate on a locked in-patient unit for someone dumped into seclusion for 24 hours while you're an in-patient yourself" and "Criminal justice work on the inside while serving five days for DWD (Driving While Disassociated)".

For a number of reasons, I never brought these personal experiences to the table as examples when I worked as a "professional" advocate and sought to empower others to speak for themselves. I saw myself then as almost a tool that the people I served had at hand to open themselves up, connect with others, use as a guide and then springboard from as the leaders and owners of *their* movement. I, as the "advisor," was seen as at-one-with, but not "of" their movement. And, because I was cast in that role, I never felt like I was free to share/explore any other identity, as others who had disabilities but were leaders within the disability rights movement were able to do. Finally, as I continued to serve in the role of the "advisor," I couldn't help wondering, on a personal level, what life's little quirk had led me to blunder into being an organizer for and of a movement in which I would never feel comfortable disclosing who and how I came to be the person I am.

Going it Alone vs. Going it Together

Yesterday, here in Nashville, Bobby Silverstein was the wonderful keynote speaker at our annual State Independent Living Council Conference. He shared the admonishment that Justin Dart had given him regarding his role in the disability rights movement after he had stepped down from his work with the Senate Sub-committee on Disability Policy: Teach. Justin gave me a similar missive when I left *People First of Tennessee, Inc.*: Organize. Continue to organize but with a different focus. He told me to put my organizing expertise to use with people who have mental illness, confident I guess that I would somehow figure out how to get in the door.

Herein lies the heart of my midnight dilemma— Justin's missive and the very real fact that in reaching out to the mental health consumers' movement, I feel I have found a place where for the first time in my life I can truly be myself with all of my bumps, and warts, and scars hanging out there for all to see. At *Our Place*, our local mental health drop-in center, there was some initial confusion when I landed on their doorstep, but I was readily accepted into the fold. Acceptance is a heady thing. Of course, I was labeled "high functioning" because I "pass" so well and as such, given work to do. I grimaced at the "high functioning" remark and accepted the work.

At the time I appeared at *Our Place's* doorstep I was: supporting myself with consulting projects, a divorced single parent of three, facing breast surgery, and learning to accept that lightening can indeed strike a person more than once. I was also taking enough drugs to admirably hold my own in any pharmaceutical conversation with the other mental health consumers who struggled to be there on a daily basis. The work I was given and accepted was teaching consumer education (B.R.I.D.G.E.S.)[7] classes once a week. That, and the sense of real personal empowerment I felt at being a valued member of a consumer run organization, became one of the primary recovery vehicles that carried me back to the main road of the disability community's struggles.

So here I am facing the biggest irony and conundrum of my personal/professional life: the ticket into the mental health consumer (c/s/x/r)[8] movement means taking up the mantle of being a labeled person. I know I am not alone. I've spoken with friends who are struggling with the prospects of "crossing over," of "coming out," of "being yourself." We've talked about the constraints we've felt in the past and why we haven't done it until now. We've

talked about our "cognitive dissonance" with the whole labeling thing.

Another theme we've explored is how readily we're accepted by other mental health consumers as legitimate spokespersons in our own right on our word alone, but rejected as such by some of our fellow colleagues in the disability rights movements, some of whom we've worked with for over half our lives. We've talked about how we have worked so closely with people across the disability community and yet we cannot, in this community, find a home of our own. We've talked about how the plurality of our various roles we've played over the course of our "careers" seems to be denying us the opportunity to have what could be the most plausible role of all: serving as bridges between and among all of our various factions and fictions.

For me, what it seems to come down to is that because I have done such a good job of "passing," few accept I am eligible to bear the mantle of being a labeled person. It's true that I have not faced the public denigration and stigma of being forced to carry a mental illness label outside of trying to get in-patient services from recalcitrant insurance companies and avoid incarceration. My denigration and oppression was primarily private and I've spent many angry years and dollars dealing with that legacy. Yet, my current experience seems to tell me that this lack of public service as a publicly labeled person is somehow a key factor in the admission criteria.

The campaigns against my demons were shared only with closest friends and family until now. I, like FDR, had that choice. I'm grateful that I was able to keep my campaign private because it afforded me sorely needed and highly cherished energy, even though many perceive me to be a somewhat overactive-type person (another form of "passing"). The energy I was able to carefully garner was put to use in staying alive and developing the coping mechanisms I needed to fend off the demons, the side effects, the after effects, and the on-going fallout that physical, sexual, and emotional abuse leaves in its wake. Plainly put, I was able to divert the energy I gained from not having to fight the fallout that comes with being a publicly stigmatized and oppressed person in our society to helping to fight the oppression of others.

My Own Big Picture of Our Real Division

As an advocate/c/s/x/r/whatever whose most visible work has been within the "developmental disabilities" community, I fret a great deal about the inequity of the separate and disparate support systems that continue to be promoted for us, by others, and amongst ourselves. Whenever I make the time I need to go to the mental health drop-in center to get "centered," I sit and wonder about a lot of things that usually have nothing to do with my own recovery. I've met a lot of wonderful people there and admire their resilience at dealing their own human needs and aspirations in a society that de-values and seems increasingly willing to toss some people away. I reflect on the amazing wisdom of having 50 or so mental health consumers control one aspect of their own destiny and recovery with the amount of money that would currently only cover the cost of keeping one person in Tennessee in a state-run ICF/MR for less than three months.

In my fretting, my stream of consciousness invariably bring me back to what I believe to be the most divisive element within the disability community even more so than things than like who/what system(s) are for and how they carry out their work; poverty. It is poverty that frequently decides who among us gets labeled. Poverty typically dictates where we will fall within our own disability caste system. It dictates whether someone will have the opportunity to speak for themselves and whether their wishes and decisions will be respected and honored. Finally, poverty factors into who will be anointed to speak for us and ultimately, whether they will choose to be accountable to us.

Most experts agree that poverty leaves its own lifelong stamp on ones soul that is hard to erase. Growing up with a single mother of seven children who was in denial about her own mental illness meant that I spent a lot of up close and personal time with poverty. I also spent some time voluntarily poor due to some good decisions as well as some bad.

Inasmuch as I've waded into a new personal era of being more personally "open and sharing," I've also spent some time talking with close friends and colleagues who shared the experience of poverty at one point or another in their lives. We acknowledge readily that we didn't transform ourselves into solid middle class citizens on our own. Along each step of our journey we had people who lent a hand, a dollar, a shoulder, and a real connection to reach out to. However, each of us acknowledges that we continue to look over our shoulders for reasons the experts don't typically describe or suspect. Many of us who were assisted in rising up out of poverty by others don't look over our shoulders for fear that poverty will again overtake us. We look over our shoulders for another reason entirely: a sense of social reciprocity.

The Challenge: Walking the Walk with No Roadmap

I find myself now walking a walk with no roadmap in hand. In reinventing myself and launching myself into another career cycle, I've decided that an integral part of who I am can no longer be left behind at the door. In the process, I am struggling to integrate what I've learned from moving toward healing myself to approaches that could be taken toward healing the way I do work in collaboration with others.

Burton Blatt, a man who was deservedly revered, warned us in 1981[9] about the "bureaucratization" of the values that we seek to promote and embrace in the work we do. His effort to sound the alarm about the impact of the advancing march of rules and regulations as an effort to keep people safe, and the programs that served them humane, was like most of the things Burt did—prophetic. Burt's prophecies have played out as he foresaw—rules and regulations were developed to codify such things as normalization, social role valorization, and mainstreaming, and continue to be developed for other "best practices" that have emerged since. Quality assurance efforts continue to try to get at and transform into a checklist those values that define how people with disabilities, families and many practitioners wanted people with disabilities to be treated. However, like

Burt predicted, they will never be a substitute for walking the walk.

I continue to steadfastly believe that it is down in the "roots" where the mystical seeds of social transformation are nurtured and planted. Moreover, I continue to believe that social movements are not an artifact of the "sixties." People have been joining together to change their social condition for thousands of years. Following the bubonic plague in the 13th century, the serfs who survived banded together to take advantage of the depleted labor force to become "freemen!" Unknowingly, they helped to create the map that led to the Renaissance and its legacy of our current euro-cultural context.

With no map in hand, it is very hard to find and get to places where the practice of social change itself is being transformed. It seems almost serendipitous when I encounter other people who are wandering around with no map in hand as well. I instantly want to install a sign-post and am easily distracted with the self-assumed responsibility of being a cartographer and reporter rather than letting myself just enjoy the landscape. Even so, I also find myself frequently slipping the old map out my pocket and wishing that a new print run rather than a major new expedition would serve to help us all move forward.

Like all who work at recovery, questions and situations that challenge my resolve to be different and do things differently lay around every corner. Our codified values and quality assurance checklists have not brought us collective equality, justice, or liberation. The sirens of our individualistic culture lure us to the rocks of separateness and isolation. The current ways of confronting the abuse(s) of power (personal and systemic) are rearticulated and reinforced as the only approach that those who are in need of confrontation can understand. I sit in my little home office and can't help wondering, "How do we know this to be true and what will we stand to both gain and lose if we try another way?"

Endnote and Invitation

Collective thought and action by a group of people who seek to transform the manner in which

their specific and unique needs and interests both serve and support society does require some form of an accepted identity, at least initially. This brings me back to the issues of labeling and "passing". Perhaps an additional mystical seed needs to be planted in the interest of transforming our organizational practice. Although the recognition and acceptance or rejection of one's own labeled identity used to be central to the beginning of the process of liberation, maybe on the new road map anyone who walks the walk of sharing his or her own personal authenticity has equal legitimacy.

A process based on respect, I think would be as good as any place to start. But more so, I believe we must build a collective process in which we all listen to one another and all voices that seek to help us restore and reclaim our humanity are welcome. In such a place, I might enter the room holding my new (or old) label sign but rapidly be able to place it on a bonfire built in celebration of our mutual gifts.

Writing this all down has given me a little more insight into my personal dilemma about accepting those labels and why I feel so enticed into doing so when I've spent a whole career fighting them. What I do know is that we all have to move past this categorization and classification thing somehow. New experts are bound to turn up to tell us how. But for now, I'm tired of "passing". I'm looking for a place to hold the coming out party to celebrate my differences. Maybe if FDR had had friends like the folks over at *Our Place,* he would have gotten into his chair and rolled right on over, in clear view of any and all to see.

Ruthie-Marie Beckwith, Ph.D. is a disability rights advocate who resides in Tennessee. She currently helps individuals and families create microboards, a single person provider based on the principles of self-determination.

Endnotes

[1] From Beckwith, R. (2003). *The Arlington poems: The struggle for the lives in a state-run institution.* Columbus: OH, Pudding House Publications.

[2] National self-advocacy organization

[3] People First language insists that the person be identified first and then, only if necessary, their disability.

[4] Post traumatic stress disorder

[5] Dissociative disorder, not otherwise specified

[6] Self-injurious behavior

[7] *Building recovery of individual dreams & goals through education & support, a consumer run education program on mental health recovery,* sponsored by the Tennessee Mental Health Association, the Tennessee Alliance for the Mentally Ill, and the Tennessee Department of Mental Health and Mental Retardation.

[8] Consumer/survivor/ex-patient/recovery

[9] Blatt, B. (1981). *In and out of mental retardation: Essays on educability, disability, and human policy.* Austin, TX: PRO-ED.

Disability Classics

The Thorn in Our Side

Rob Kocur

This article is reprinted with permission from the Nov./Dec. 1995 issue of *The Disability Rag* (www.raggededgemagazine.com).

Folks, I've always prided myself on my ability to be open-minded and peace loving and I've certainly done my best to get along with all members of minority groups. I have friends who are black, Jewish, and of course I have a girlfriend. These people have acclimated well into the mainstream of society. However, there is one group that, for some strange reason, seems content in remaining confrontational and militant with regard to all their mythical causes and demands. If you've ever met one of these people, you know who I'm talking about. It's the handicaps. I believe it was a foolish blunder on the part of the United States government to give these people the right to vote. It gave them the idea that they could compare themselves to real minority groups in terms of demanding equal treatment. It also opened a Pandora's Box of governmental handouts and concessions. Most recently, we have the ADA or the Affluent Disableds of America, which is what I call it. This piece of legislation is like an economic Smith & Wesson pointed right at America's head. When I think of how many more domed football stadiums could be built with the money we're frittering away on these crybabies, I just want to have Maalox pumped into me through an IV.

If you check governmental statistics, you'll discover that most businesses are struggling today and yet we all have to play the "accessibility game." To give you an idea of how silly this whole thing is, I personally own a small business and I guess there are about eight steps to get in the building. Someone explain to me why I should have to spend tens of thousands of dollars knocking out steps when the wheelchairs don't even shop at my store. Hell, they don't even come in to browse around. It's now the law though, and unless I do it, I risk losing my business, my home, and my car in a lawsuit.

I know who's to blame for a lot of this crap. It's Jerry Lewis and his little band of merrymen. By using him as a steppingstone, the disableds have managed to slip most of the politicians into their back pockets. I guess that's why so many of them walk funny. It's little wonder they're so brazen and hard to get along with. Believe me folks, I've tried. Back in my naïve days, I used to talk to them all the time. I was sensitive enough to know, however, that you can't just walk up to them and start badgering. What I always did was tell a few Helen Keller jokes before I asked them how they got that way.

In case any of you doubt my expertise on this subject, let me assure you that I know what I'm talking about. My father was in a wheelchair for about six months following a ski accident. Naturally, I took care of his mangled and repugnant looking body because he was my daddy and I loved him. You know, it's funny – now that he's a real person and back to paying taxes, you never hear him moan and groan about ramps and doorways or any of that other nonsense.

Let me tell ya something that really puts a bee in my bonnet. It's this whole handicapped parking nonsense. An incident that happened to me the other week will best express what I'm trying to say. My friend, Rusty, and I were heading up to the Fairmont Springs Mall to do a little shopping. When we got to the mall, it started raining cats and dogs. I didn't want us to get soaked, so I decided to pull right up close to the building. As I did, however, I noticed a drain'n'burden parked right in the spot I wanted to park in. He was just getting out of the

car because I noticed the wheelchair stuck between the car and the door. He was having a hard time because the chair kept hydroplaning away from him every time he tried to get in it. Rusty and I rolled our eyes and checked our watches. The next time we looked, we saw the man laying on the pavement with his chair several feet away. Apparently he had fallen. This made me mad, so I really laid on the horn. Finally, after about twenty minutes, I ran out into the pouring rain, looked down at him, and said, "Hey, Flash, how much longer is it gonna be?"

Don't get me wrong, folks, I'm no insensitive ogre. I don't have a problem with invalids having their own zones, but for heaven's sake, why do the spots have to be so close to the buildings? Why can't they be at the far end of the parking lots where they'll be clearly out of harm's way? See, that way the gimps would have plenty of time and space to fiddle around with all their crutches, canes, chairs, and all that other handicapped paraphernalia. The only exception would be blind drivers. I don't mind if they park their cars close to buildings. It sure beats the hell out of them wandering aimlessly around the parking lot like something out of "Night of the Living Dead."

I guess the thing that really burns my hide is this attitude of always wanting it both ways. The disableds want to be treated equally, yet insist on special treatment. I have a story that beautifully illustrates this point. It has to do with the time I was sitting in the lobby of the Holiday Inn reading the morning paper. As I glanced up, I saw a blind lady walking with her blind dog. As I looked at that beast, I couldn't believe a ritzy joint like this would allow such a practice. I wanted to walk up to her and remind her that the city pound was the in other direction, just in case she was lost.

Anyway, as the lady and her mutt left the hotel, I became increasingly disturbed. Suppose that wildebeest got loose somehow? I could just see him foaming at the mouth, attacking children in the gift shop and urinating all over the plastic ferns. At that moment, I decided there had to be some way to prove my point concerning the double standards and the potential dangers involved with these assistive beasts.

Suddenly it hit me. I ran out of the hotel and gave my friend Joey a call.

About an hour later, I walked back into the hotel. Luckily, there were a lot of people in the lobby, so I walking in wearing a pair of dark glasses leading everyone to believe I couldn't see. Right beside me was Snickles, my friend's pit bull. I held the leash tightly as I circled the lobby. I wanted to make sure no one suspected the truth, so I purposely kept bumping into furniture and twisting my head all around like Stevie Wonder. Then, at just the right moment, I let Snickles loose and watched in glee as he attacked several people, including a five-year-old girl. "Boy, does this ever prove my point," I thought.

The lady at the desk rushed over to me and started yelling. I just looked to the side and said real loudly, "Snickles, where are you?" People were screaming and running out of the lobby as the little pooch followed in hot pursuit. I pretended to realize that Snickles was gone and faked a panic. I climbed up on the sofa and waved my arms all around while forcing a good cry. Then, through my dark glasses, I saw a not-too-pleased hotel manager standing there with his arms crossed. Somehow, he knew I wasn't blind. He ordered me down off the couch and said he was calling the police. I later found out that Snickles had decided to ham it up a little and ended up chowing down on eleven different people. One of them was a resident of the Twin Rivers nursing home who had her left arm torn completely off. As I rode in the back of the police car, I became very upset. How could I have been so stupid as to come back to the hotel, wearing the same clothes, thus tipping my hand?

Folks, I could go on and on with countless examples of all the ways the cripples manage to work both sides of the street and get all sorts of special privileges, but I don't want to take the slightest chance of creating a perception that I'm some sort of stark raving lunatic. Instead, I would much rather present two different answers to the question: What can society do with this mutant army of welfare riff-raff? Well, let me begin by saying that since I only have two strategies, I'll simply refer to the second one as "the final solution."

The first strategy involves simply moving all crippled people to one central location, probably Montana, since it's real roomy up there and most of the state is wasteland anyway. Naturally, there are several advantages to such a plan. First of all, by giving the drains their own land, we get them out of our hair. For example, businesses, college campuses, and hotels would be liberated, free from their bondage and enslavement to potential ADA lawsuits. Folks, can you imagine how much cheaper and easier it would be for the government to give in to the disableds with regard to Montana, rather than having to overhaul the entire country? Under this plan, the money for "accessibility," sheltered workshops, bus lifts, and all those other pork barrel programs could be raised by having tourists come and visit the disableds. Each visitor would pay a five or ten dollar admission and he or she would get to observe and intermingle with these special people. There would be concession stands and games of chance which would present some real employment opportunities for the diseased, assuming of course that they wanted to work. Now, I don't know how big this "park" would be. That would have to be worked out with the Montana state government, but we could call it "The Rocky Mountain Convalescent Confinery." (I always hesitate to use the word "zoo" because I don't want those PC people writing me nasty letters.)

Another great benefit of this plan would be the fact that all these challenged people could breed to their heart's content with each other instead of puppy-dogging after normal people the way it is now. Actually, the whole disabled mating process could be one of the exhibitions at the park. A staff of normals would reside there permanently and tourists could watch in awe as the handicaps are turned over and repositioned as needed.

Probably the most important factor to consider, however, is that by limiting them to a designated area, the FBI, CIA, and all those other loyal watchdogs of the government would be able to monitor much more closely the activities of certain extremists. These hate mongers are often seen in Washington, D.C., chanting and yelling all manner of un-American phrases while moaning and groaning about "housing" and this law and that law. It's always troublesome to me to see these uprisings on the news, especially the way the police are so hesitant to use force to break them up. Boy, I'll tell ya, a lot's changed since Kent State. It's certainly true that since the disableds are never satisfied no matter what society does for them, and since many politicians and all lawyers adhere to their propaganda, they represent the most dangerous and subversive group we encounter today.

Now, although my plan is air-tight, in my heart of hearts I know that it probably will not be passed into law. The damaged goods are extremely bitter individuals who would be content only if they could cause trouble across the entire country instead of just Montana. They shamelessly make society the scapegoat for all their pent-up rage about not being whole. The proposal would invariably bog down in the Senate or wherever, while Jerry's crips busily worked to play one politician off the other.

Well, that beings me to my final solution. If you take a careful look at all the burdens in this country, one fact jumps right out at you. The handicaps are not like blacks, Jews, or women. They are what I refer to as a "manufactured minority," while the other groups are pure. Since outside forces such as diseases and alcohol related injuries caused this group, they certainly should not have the same rights as true minorities. They do, however – which is the reason for this plan. Why not simply have the government find cures for the conditions responsible for creating half-people? If they're all cured, they become one of us. It's akin to the way society tries to eliminate crime by legalizing drugs. I'll admit, there is one flaw with this plan: The disableds are extremely lazy and if the government normalizes them, they would have to go out and find jobs. Heaven forbid we should end the tomb-to-womb dependence on government handouts. The handicaps don't want to be cured because being different gives them "celebrity" status in the eyes of the government. Besides, if they were normal, no one would pity them anymore. Of course, one possible alternative to this problem is to simply have the government force them to be cured. Even if we would have to use federal troops, who cares? It's for the

good of society that these people undergo all manner of experimental surgery.

Well, I've briefly outlined my ideas about what we can do to solve the whole disability problem. I hope I've given each and every one of you food for thought. All of my state and local representatives will be getting a copy of this manuscript and I suggest all of you write letters, too. It's the only way we can ever make a change.

Rob Kocur is a writer and satirist residing in Erie, PA.

Book, Art and Film Reviews

Book Review

Title: *The Case Against Assisted Suicide: For the Right to End-of-Life Care*

Author: Edited by Kathleen Foley, M.D., & Herbert Hendin, M.D

Publisher: The John Hopkins University Press, 2002

Cost: $26.95 paperback

0-8018-7901-9

2004 392 pp.

$51.00 hardcover

0-8018-6792-4

2002 392 pp.

Reviewer: Christina Carty Bergholz

The Case Against Assisted Suicide is an edited volume addressing a highly controversial issue that is, and promises to remain, controversial for a long time. The book attempts to provide a comprehensive perspective on the case against physician assisted suicide and for the right to palliative care. Contributing authors represent a broad spectrum of stakeholders and include ethicists, lawyers, clinicians, and healthcare policy experts. The editors conclude that lack of education about palliative care, and limitations in a variety of health care resources, are at the heart of support for assisted suicide and euthanasia. This book is much needed and should be of interest to the public at large, due to the increasing numbers of people diagnosed with fatal diseases like cancers and AIDS, and the growing number of elderly people, as the baby boomers age.

The book is divided into four main sections, in addition to the introduction and conclusion. The sections are entitled *Autonomy, Compassion and Rational Suicide; Practice versus Theory; Reason to be Concerned;* and *A Better Way.* The first section consists of four chapters. From different perspectives, but from the common ground of medical ethics, the authors systematically address what may be consid-

ered the strongest arguments for legalizing assisted suicide - compassion for suffering patients, respect for patient's autonomy, and suicide as a constitutional right and a rational act on the part of the patient. The second section contains five chapters, each chapter using case examples of places where euthanasia and assisted suicide are legal, to empirically demonstrate and highlight the dangers of this practice. The next section consists of three chapters and includes a chapter by Diane Coleman, an attorney who is disabled, and a leading advocate against assisted suicide. This section focuses on the vulnerability of the disabled, elderly, depressed, and disenfranchised groups, in the face of the possibility of legalized assisted suicide and euthanasia, and addresses common arguments used to justify legalization. The final section consists of two chapters. This section, along with the conclusion, advocates better hospice care and improved palliative and psychiatric care as alternatives to legally sanctioned euthanasia and assisted suicide.

This book is timely and important in the life and death debate that is of personal relevance to all of us. It is thoughtful and comprehensive in its critical examination of the arguments supporting assisted suicide, is intimately knowledgeable of the case supporting the legalization of assisted suicide, and does not dismiss these arguments lightly, which is one of the strong aspects of the book. Perhaps the strongest aspect of the book is that it does more than critique legally sanctioned assisted suicide, it also offers practical alternatives.

Book Review

Title: *Vulnerable Subjects: Ethics and Life Writing*

Author: G. Thomas Couser

Publisher: (Ithaca: Cornell, 2004).

Cost: Paperback - $19.95; Hardcover - $47.50

Paper, 2003 ISBN: 0-8014-8863-X $19.95s

Cloth, 2003 ISBN: 0-8014-4185-4 $47.50x

Reviewer: Steven Brown

In this fascinating book, G. Thomas Couser explores ethics through life writing. What I liked best are Couser's in-depth chapters exploring the work and life of Oliver Sacks, Michael Dorris's auto- and biographical book, *Broken Cord*, assisted suicide, and the Human Genome Project.

In the chapter about Michael Dorris and his adopted son, born with Fetal Alcohol Syndrome, Couser emphasizes the roles everyone around Adam, the pseudonym Dorris used for his son, assumes. While the book is ostensibly about Adam and Dorris, Couser demonstrates why some might read it as less about Adam than it is about everyone else around him. As an example, although Adam contributes to the book, his writings are placed in contexts dependent on his much more erudite parents (Dorris and Louise Erdrich). Having read *Broken Cord* a number of years ago, and liking it, did not lessen for me Couser's analysis, which I thought quite adept.

Even better was his analysis of Oliver Sacks and his place in life writing in relation to medicine, disability, autobiography, biography, and patient/doctor relationships. Sacks is himself an intriguing figure because he so easily seems to move out of the clinic (or office) and into the public arena. Couser is both critical and complimentary to Sacks and does a good job of explaining why he feels ambivalent about Sacks's role in modern life writing—and storytelling.

Couser's chapters on suicide and genetics explore information and analysis often missing in the heated debates in which many of us engage. He does an excellent job of showing why assisted suicide and its many parameters have much more to do with society and cultural values than "objective" medicine; and in his chapter on genetics he similarly explores how seemingly scientific data has much more to do with cultural values than one might at first expect.

Near the beginning of the book, Couser writes:

> "The potential harms of life writing are more akin to those of social research than to those of biomedicine; the former are not likely to cause physical injury or

death, as medical treatment too often does. But whether and how the representation of vulnerable subjects in life writing benefits them is also less clear than with medicine; hence, the need for ethical scrutiny" (20).

Clear to me in this reading is that no matter who we are, we are all potentially vulnerable subjects. The book would be an excellent addition to graduate seminars; it may be too sophisticated for most undergraduates. I highly recommend this book to anyone studying ethics, life writing, or any of the chapter subjects.

Correspondence

Disability in Chronic Fatigue Syndrome and Idiopathic Chronic Fatigue

Dear Sir/Madame,

I read the article by Carrico *et al.* [1], in which the authors concluded that individuals with chronic fatigue syndrome (CFS) and idiopathic chronic fatigue (ICF) as defined by Fukuda *et al.* [2] did not significantly differ in the level of self-reported functional impairment, with interest. However, three issues that may have influenced the outcome deserve more attention.

First, selection bias may have resulted in overestimation of the level of functional impairment in the ICF group. The ICF subjects were selected from a group of so-called 'CFS-like' participants, which means that they had reported at least four "minor" symptoms in their telephone interviews. Given that more symptoms should be associated with greater impairment, requiring a minimum number of symptoms implies the selection of more impaired individuals. Furthermore, since the ICF definition by Fukuda *et al.* [2] does not state that the absence of functional impairment is a reason to exclude a subject from an ICF qualification, the exclusion of the participant without functional impairment from the ICF group was not justified.

Second, the current CFS definition requires that chronic fatigue results "in substantial reduction in previous levels of occupational, educational, social or personal activities" [2]. Because subjects in the "mild" category of the present study were able to work full time and on some family responsibilities, one could argue that they were not substantially impaired in daily activities and, hence, should be qualified as ICF instead of CFS. With a 'mild' category consisting of zero CFS and 44 ICF individuals, the groups would have differed significantly ($Ç^2$ (2, N = 75) = 31.21, p<.001) in their functional impairment classifications. So the outcome strongly depends on the interpretation of the CFS definition and in particular, the interpretation of the word "sub-

stantial". It is worth noting that the original CFS definition by Holmes *et al.* [3] required fatigue that was "severe enough to reduce or impair average daily activity below 50% of the patient's premorbid activity level for a period of at least 6 months", thus individuals in the 'mild' category would certainly not meet those criteria for CFS.

Third, the authors found no significant difference when they compared the CFS and ICF groups using three functional impairment categories. If they had chosen to use just two categories, "mild" and "moderate/severe/very severe", then they would have found a significant difference between the groups ($Ç^2$ (1, N = 75) = 3.97, p<.05). Thus the outcome of the study strongly depends on the definition and the number of categories. It also depends on the selected statistical methods: a two sided Fisher exact test results in p>.05 for this example. It would be very interesting to see the results of tests that use continuous data instead of the rather arbitrary categories, e.g. Mann-Whitney U tests, for each of the three functional impairment measures that were assessed.

Although I welcome the authors' efforts to study disability in CFS and ICF, the effects of a slightly different interpretation of the definitions and the use of another functional impairment measure on the study outcome may have been overlooked. Especially when applied to representative community-based samples, studies that adequately address these issues can be very valuable to resolve some of the ambiguities that are seen nowadays in CFS research.

Bart Stouten

The Netherlands

References

Carrico, A. W., Jason, L. A., Torres-Harding, S. R., & Witter, E. A. (2004). Disability in chronic fatigue syndrome and idiopathic chronic fatigue. *Review of Disability Studies, 1*, 79-88.

Fukuda, K., Straus, S. E., Hickie, I., Sharpe, M. C., Dobbins, J. G., & Komaroff, A. (1994). The International Chronic Fatigue Syndrome Study Group. The chronic fatigue syndrome: A comprehensive approach to its definition and study. *Annals of Internal Medicine, 121*, 953-959.

Holmes, G. P., Kaplan, J. E., Gantz, N. M., Komaroff, A. L., Schonberger, L. B., Straus, S. E., et al. (1988). Chronic fatigue syndrome: A working case definition. *Annals of Internal Medicine, 108*, 387-389.

The Future of Medicaid

Arnold Birenbaum, Ph.D.
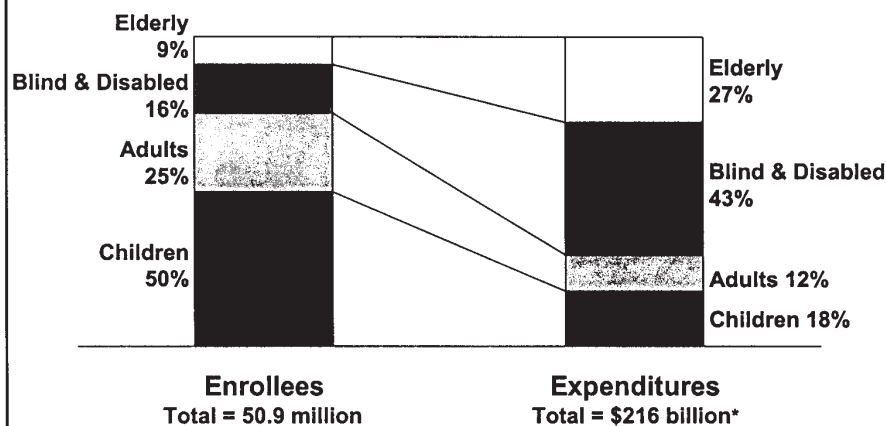Albert Einstein College of Medicine

Abstract: Medicaid, the US federal-state financed program that assists people to gain access to health services when they cannot afford them, is in peril. Some of the recently defeated proposals to change financing of the program, the shift to managed care, and massive state deficits all threaten to limit optional and Home- and Community-Based Waiver Services to people with long-term care requirements. This policy research paper will explore some current myths about Medicaid, what states are doing to reduce Medicaid expenditures, and propose 10 principles and observations that should shape a response from the disability community to efforts to shrink Medicaid.

Key Words: Medicaid, block grant, long-term care

Medicaid, the United States federal-state financed program that assists people to gain access to health services when they cannot afford them, has been in the news of late. Unfortunately the news is disquieting for people who count on this program for health care and rehabilitation services. In fact, when Medicaid is in the news, it is the equivalent of the Weather Channel coming to report on your hometown. You really don't want them to be there because TV coverage only arrives with a natural disaster. Perhaps something positive will come out of what we can characterize as a dust storm. But unlike weather forecasts, my predictions at the end of

Figure 5

Medicaid Enrollees and Expenditures by Enrollment Group, 2002

Enrollees
Total = 50.9 million

- Elderly 9%
- Blind & Disabled 16%
- Adults 25%
- Children 50%

Expenditures
Total = $216 billion*

- Elderly 27%
- Blind & Disabled 43%
- Adults 12%
- Children 18%

Expenditure distribution based on CBO data that includes only spending on services and excludes DSH, supplemental provider payments, vaccines for children, and administration.
SOURCE: Kaiser Commission estimates based on CBO and OMB data, 2003.

KAISER COMMISSION ON
Medicaid and the Uninsured

For those who need an update, Medicaid today provides long-term care and health care coverage for more than 50 million people, among them, 12 million elderly and persons with disabilities, including 6 million Medicare beneficiaries (dually eligible) who rely on Medicaid for long-term care, prescription drugs, and help with Medicare cost-sharing. It also supplies inexpensive health insurance for 38 million people in low-income families, covering one out of every four children in the USA. Therefore, the expensive and the inexpensive are supported in this safety net.

this essay require that we become proactive to control damage.

The refinancing of Medicaid is one of the things that the Bush administration has sought. It, along with the privatization of services, and state fiscal woes, may produce the perfect storm. The new is not always better than the old. Change is not always the friend of vulnerable people, and in this instance, it can be downright disruptive when it comes to accessing services. Because they are not well organized, people with Medicaid coverage do not have political clout, even though more people are covered by Medicaid than Medicare (e.g., the public insurance program for almost all people over the age of sixty-five and some people with disabilities). New Bush administration proposals and ongoing practices could be particularly harsh for people with disabilities. The current fiscal crisis of the states—brought about by the bursting of the technology stock bubble—has made the future of Medicaid even more uncertain. Those who follow the state of the states closely, such as the Kaiser Commission on Medicaid and the Uninsured, are seeking to determine the impact of state fiscal conditions on health coverage in all 50 states. Kaiser's presentation on September 22nd, 2003, was covered widely by health policy specialists in the print media.

This paper will first address recent Medicaid block grant proposals, then the trends in Medicaid managed care, and finally, how state deficits have resulted in measures attempting to rein in the costs of Medicaid. The paper will also try to dispel some myths about Medicaid as a massive burden on the federal government and state governments as well. Finally, the paper will draw out some principles and predictions from Medicaid, privatization trends and state efforts to reduce spending.

Block Granting

First, on February 3, 2003, Tommy Thompson, Secretary of the U.S. Department of Health and Human Services (HHS) and the former governor of Wisconsin, made a bold proposal: allow states to generate any waivers they wish, without prior federal approval. Funding for Medicaid would be split into two pots—acute and long-term care. On February 20, the HHS Secretary sought the approval of the National Governors Association for this plan, one that would give states options in how they spend their proposed block grants. The former Wisconsin governor compared these reforms to Temporary Assistance to Needy Families legislation (TANF). It is important that we think about how his proposal will

impact children with special health care needs and adults with disabilities.

Determining the intended and unintended consequences of major health care reforms is a central task in any responsible health policy analysis. Even proposals to extend coverage do not always understand what Medicaid does. For example, Ted Halstead, president of the New America Foundation, in an Op-Ed piece in the *New York Times* (1/30/03, p. A27), called for guaranteed universal coverage, which, he claims, will eliminate the need for a separate Medicaid system for the very poor. Halstead was well intentioned but misinformed. Medicaid is more than a safety net for poor people; it is a complex program that is extremely valuable for those who have long-term health and social support needs.

Medicaid has to be handled with care. Many of the services it pays for are special. It's the health care and social support system of such fictitious Americans as grandma Bessie in the nursing home, uncle Bill, a person with a history of mental illness who lives in a half-way house, and cousin May, a child with severe chronic illness and a developmental disability. These homey examples are not meant to make the reader reach for a box of tissues, but to point out how Medicaid has evolved into a mix of health, social, and psychoeducational programs, each tailored to a specific client population.

Medicaid, from its start, has offered states the choice of furnishing an impressive range of optional services to clients. It has also subscribed to definitions of medical necessity that are far broader than those found in commercial insurance policies. Optional services and definitions of medical necessity complement each other; they encourage medical providers to prescribe speech, physical, and occupational therapies, even when cure or recovery are not possible.

The Social Security Act, which authorizes the Medicare and Medicaid programs, allows the Secretary of the Department of HHS to waive the Department's rules and regulations, permitting states to make applications to innovate. Waivers are especially important in encouraging children and adults with serious chronic illnesses and/or disabilities to

lead normal lives, including living in the community and with family. Consider the Katie Beckett Waiver program, conceived when Julie Beckett, the mother of a three-and-a-half year old with viral encephalitis, discovered that Medicaid would pay thousands of dollars to support her daughter Katie in a hospital, but would not pay for medical services and equipment, e.g., a portable respirator, that would allow Katie to live at home. Katie was eligible for Medical Assistance because the family had spent most of their assets to pay for her extraordinary medical bills. The state of Iowa would not pay Katie's bill, a smaller expense than hospital care, if she returned home, so Julie petitioned President Ronald Reagan to waive the Medicaid rules to permit Katie (and 300,000 others) to have home care and remain with her family (Roberts and Considine, 1997: 164).

Established in 1981 by the HSS Secretary, the "Katie Beckett Waiver," as it became known, is an override on Department regulations. It permits states to use Medicaid funds to assist children with special health care needs to avoid hospitalization and be with their families at home.

The story continues to validate the idea that consumers can be the best advocates. Julie Beckett not only made Medicaid more flexible, she later founded a voluntary association, Family Voices, made up of parents just like herself. In 1998-1999, a national survey (*Policy Brief*, 2003) was conducted by Brandeis University and Family Voices, with funding by the David and Lucille Packard Foundation. In this study, 2,220 families of children with special health care needs reported that their satisfaction with care and services paid for by Medicaid was greater than the care paid for by private insurance.

Thus, Medicaid plays an essential role in assisting families of children with special health care needs. This impact goes far beyond keeping American children healthy. Children who have access to skilled and experienced specialists, physical, occupational, and speech therapy, and other optional services miss fewer school days and are less subject to hospitalization. Cognitive and social development is encouraged by opportunities to be in school and be with the family of orientation.

Putting a human face on health care does not stop with children. The Home and Community Based Waiver Program (HCBW), made law as a part of the Omnibus Budget Reconciliation Act of 1981 (PL 97-35, section 2176, 1981), was created as a way to contain increasing costs of institutional care paid out of federal revenues. The funding authority for this program came from amendments to the Social Security Act, wherein states could receive Medicaid matching funds to provide home and community-based services to individuals who otherwise would receive care in a nursing home. What is truly unique about this program was the authorization to states to pay for clinically appropriate non-medical services, including care coordination, habilitation services (i.e., occupational, physical, and speech therapies), homemaker services, personal care, and adult day care.

The original purpose of the HCBW Program was to dampen the demand for institutional care by making other, more affordable community-based services available to low-income individuals with chronic disabilities and illnesses. Under the HCBW, the U.S. Department of Health and Human Services allows states to finance community services through Medicaid for people with developmental disabilities who would otherwise be in Intermediate Care Facilities (ICF/MR). By 1995, all 50 states were participating in the HCBW.

The HCBW initially accounted for only a small percentage of total expenditure on community services in the United States, but it grew rapidly during the 1980s, making it, by 1994, the largest source of federal funds for community services. The program establishes individualized service options and family supports, administered by the state mental retardation and developmental disabilities agency, through direct payments to service providers. Included among these services are habilitation services, respite care, family counseling, equipment to promote adaptation or safety, architectural adaptation of the home, in-home training, education, behavior management, and recreational services.

In my opinion, optional services and waiver programs represent the impressive flexibility already built in Medicaid. The Bush administration sought to throw states facing substantial deficits a lifeline without having to appropriate additional funds to assist them. At the National Governor's Conference on February 24, 2003, President Bush told the disappointed of both parties that no further assistance for their enormous deficits were going to be fueled by the federal treasury. Moreover, this new move toward state autonomy will only lead down the path of allowing states to avoid being out of compliance with their established obligations when they start restricting access to optional services and waiver programs. No longer will state departments of health be able to identify an appropriate benefit for a patient population with expensive medical bills or long-term intervention requirements, including cost-saving care coordination services, and "Medicaiding" difficult problems. This safety valve encourages providers to do the necessary interventions for the medically needy and the disabled. Moreover, experimentation will be less frequent under block granting of funds because states won't receive additional federal funds for attempting innovations. While the block grant would be front-end generous, it becomes less so over the years, making the states more cost-driven than before. In sum, cost-driven approaches to health care make the primary goal of the agency that administers the state Medicaid program to restrict spending to within the limits of the block grant, thereby disincentivizing state planners to create new programs.

Do we dare risk further deterioration of our health care system by downsizing or eliminating an extremely important set of services and programs? Maintaining adequate funding of Medicaid, two-thirds of which goes to pay for optional services, is especially important for vulnerable populations.
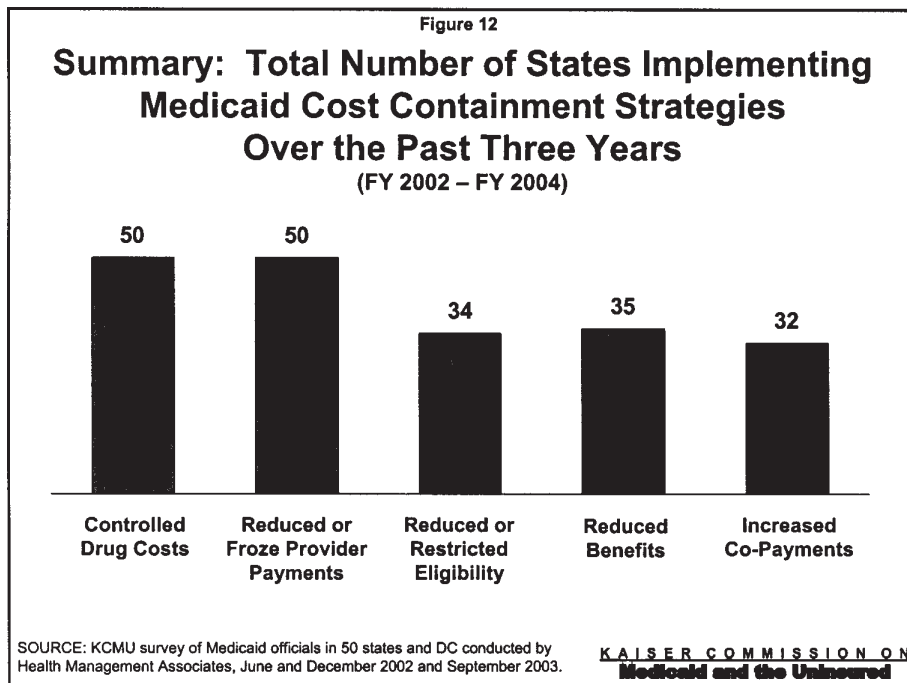
Managed Care

A second way Medicaid has made the news is on the front page of the business section of the *New York Times* (February 19th, 2003: B1). Medical business reporter Milt Freudenheim, on February 19th, found a trend toward privatization of Medicaid services via for-profit managed care companies. These companies, with the encouragement of the Bush

administration, have skimmed off the most frequent types of Medicaid recipients: healthy children and their mothers, clients who need very little in the way of services.

An additional problem has emerged with regard to Medicaid managed care plans. In New York State, plans have recently reported a turnover of almost half their members over the course of a year, usually through involuntary disenrollment, when eligibility is lost. Absent, under these conditions, are the advantages of managed care, prevention and early detection through regular contact with a primary care provider (Perez-Pena, 2003).

The trend toward enrollment in managed care plans for Medicaid recipients does not mean that the quality of care is improved, despite the achievement of cost containment via per-person-per-month, or capitated payments, to managed care plans. Because many managed care plans serve both Medicaid funded and commercially insured beneficiaries some comparisons are possible. To what extent is the quality of care (QOC) the same for both populations? The September 17th 2003 issue of JAMA contained an article on the quality of care for children in commercial and Medicaid managed care (Thompson, et al., 2003). Analyses restricted to data from plans reporting both commercial and Medicaid results for children were performed in a national study. In so doing, potential variations between plans on corporate philosophy, structures, management strategies, and types of delivery network were controlled. Using data from the Health Plan Employer Data and Information Set (HEDIS), the authors found that clinical quality (immunizations rates), access (visit levels) and procedures (myringotomies) were less frequent in Medicaid managed care than in commercial managed care patients.

What happens to children with disabilities in managed care plans? Using less rigorously drawn samples, but with 58% of the children covered by Medicaid, in a national survey, investigators found that parents reported that more than a third of the children with autism, over a fifth with mental retardation, and more than a fifth with other disorders had problems accessing needed care from specialty physicians. Referrals were not always available from primary care physicians and locating specialists with the appropriate experience were some of the difficulties cited by parents (Krauss, Gulley, Sciegaj, and Wells, 2003).

While an intriguing question, it is not known to what extent children served by Medicaid managed care organizations (MCOs) are receiving better or worse care than Medicaid children not enrolled in MCOs. Nor do we know if more vulnerable children are better served. More sophisticated measures for quality introduced recently for children with special health care needs will furnish a more in-depth look at Medicaid managed care in comparison with commercial plans. Impressionistic evidence suggests that managed care plans recycle the expensive child with special health care needs back into fee-for-service Medicaid. The "carve-out" for

Figure 12

Summary: Total Number of States Implementing Medicaid Cost Containment Strategies Over the Past Three Years
(FY 2002 – FY 2004)

Controlled Drug Costs	Reduced or Froze Provider Payments	Reduced or Restricted Eligibility	Reduced Benefits	Increased Co-Payments
50	50	34	35	32

SOURCE: KCMU survey of Medicaid officials in 50 states and DC conducted by Health Management Associates, June and December 2002 and September 2003.

KAISER COMMISSION ON Medicaid and the Uninsured

different categories of special needs children makes managed care plans avoid risks to their bottom line.

Managed care companies supply preventive health services to the relatively low-cost population of healthy children and their parents and avoid elderly and disabled Medicaid recipients, most extensive users of services. Profit making depends on selection and avoiding adverse risks. Once in Medicaid managed care plans, those who are seriously ill are sometimes denied authorization for services, or, when they receive services, their providers find that it is tough to get paid by the plans.

What is hidden from view by the move toward privatization is the skewed distributions of expenditures in Medicaid. Most of the costs of Medicaid go to pay for long-term care services for people with disabilities, the elderly, and those with serious chronic illnesses. Many of these procedures are found in the optional services section of this public insurance program, which states may pay for or decline to support.

This trend toward privatization brings us back to the block grant approach, or what was being peddled in 2003 by Thomas Scully, then Administrator for the CMS, as the "alternative global financing option." The public may believe that using for-profit managed care plans is the way to save the state money. This is a way of creating cost-driven thinking. It is another way to divide Medicaid recipients into low cost and expensive groups. Do we need to further divide the Medicaid service system and the populations that it serves? A cost-driven health-care payment system will lead to denials of access for the categorically needy or those receiving Temporary Assistance to Needy Families (TANF) and the medically needy (i.e., people with medical expenses that overrun their assets and incomes). Some providers, particularly hospitals and academic medical centers, are already unwilling to contract with Medicaid managed care plans that refuse to pay or delay payment for several months

The Fiscal Crisis of the States

All of these changes, proposed or ongoing, today rest on a shaky platform of state debt. The states address the issue of loss of tax revenue by cutting capitation payments to managed care plans and providers in the fee-for-service parts of Medicaid or limiting eligibility to the poorest part of the population. Under-funding will produce penalties for consumers as providers leave plans. Moreover, patients may seek more accommodating plans or will follow their doctors to other plans. This kind of "churning" has consequences. It will mean that the combined service advantages of managed care (i.e., intensive care coordination) and Medicaid (i.e., removal of the financial barriers to access to care) will be unrealized. They will be eclipsed by the need for consumers to learn about new rules and regulations, once again, of the new managed care plan; or the providers will be compelled to make new assessments of what patients require in the way of care.

Current Myths About Medicaid

If the real estate game is all about three things: location, location, location, attitudes toward Medicaid is all about perception, perception, perception. There are three myths that make Medicaid a target in future budget cuts.

1. Medicaid spending is out of control.

According to the Kaiser Commission on Medicaid and the Uninsured, Medicaid spending growth declined for the first time in seven years. In 2003 it dropped to 9.3 percent and is lower than the national average for growth in health care spending of 12 percent.

2. State fiscal crises are the result of increased spending for Medicaid over the past seven years.

The sudden falloff in tax revenues has played a larger role in this current fiscal crisis than increases in Medicaid spending. The fall off in state revenues is 7.4 percent compared to 3.5 and 3 percent respectively in the recessions of 1990-91 and 1980-82. Capital gains income would have to double to return to the tax revenues of just two years ago. The drop in revenue collection is 61.8 billion while the growth in Medicaid spending is $6.9 billion. States would be in even worse shape today without the $20

billion added to federal assistance to states, which went largely for Medicaid.

3. The increase in Medicaid spending is due to rapid enrollment of large numbers of unemployed and their children becoming eligible for Medicaid.

Sixty percent of the growth of Medicaid spending over the last two years is related to the elderly and disabled, particularly for acute care services and including prescription drugs. More attention could be paid by providers to secondary prevention, a cost-offsetting intervention which should work with chronically ill individuals and people with disabilities. A takeover of prescription costs from the states for the dually eligible by a new prescription benefit in Medicare, which may be a long time coming, would be helpful. We are all living longer, including persons with disabilities, and this means, over a lifetime, more maintenance medications, visits to doctors, and hospitalizations.

What Are States Doing to Reduce Medicaid Expenditures?

There are four ways of doing this: 1. Increase the income eligibility requirements, 2. Freeze or reduce payments to providers, 3. Limit benefits, or 4. Require that Medicaid recipients share some of the costs through co-payments for prescriptions or visits to providers. A survey of all 50 states and the District of Columbia tracks current and future efforts to relieve some of the fiscal pressures.

Despite federal contributions, ranging from 50% to 75% of the cost to a state, Medicaid has become the second largest item in state budgets, following educational expenditures. This situation could lead to the pitting of health care vs. education advocates for the shrinking tax dollars.

Moreover, of late, counties and cities that are required by state law to share Medicaid costs are also complaining about the added burden of Medicaid costs. They are also seeking ways to limit access to services, especially nursing home care (Saeed and Wallace, 2003).

Conclusion

Since its inception in 1966, Medicaid has worked as an acute care safety net for the categorically needy and taken on the characteristics of a wrap-around patchwork quilt for people with long-term care needs. It has evolved into 50 different state programs because the level of generosity of each program varies—the income cutoff levels, the extent to which optional services are offered, and the payment schedules for physicians, hospitals, and other providers—are different from state-to-state. It does not need to be fixed through block granting and creating more health plans. It needs a powerful infusion of funding to attract more quality providers and an environment that encourages the continuation of the availability of long-term care services to populations that depend on them. It may also require additional funds from the federal government to extend it to families with children with special health care needs, who cannot afford to purchase private health insurance, or who are regarded as adverse risks in the insurance marketplace. This new entitlement is already part of proposed omnibus federal legislation, the well-intentioned Family Opportunity Act (HR1811/S622), a law up for Congressional approval during the Summer of 2004, but unlikely to be signed into law.

In other words, Medicaid is more than a safety net for those who live in extreme poverty. It is a medical and social program that has grown incrementally according to need. Protecting Medicaid today is as important as protecting Medicare. Currently, it is in danger of being divided by block granting and privatization. So long as the United States fails to introduce universal coverage with appropriate benefits for children with special health care needs, the elderly, and people with disabilities, Medicaid represents federal and state creativity .

Here are some important principles, based on recent history, which can be used to create a support network for Medicaid:

1. Coalitions of consumers and providers are required to tell the story of Medicaid to the Congress and state legislatures. Medicaid, through case law, is an entitlement upheld

in numerous court decisions when administrative agencies have not been willing to approve services. Access to the courts means entitlement to a process rather than to specific services. This due process protection of rights has worked for people with disabilities.

2. Medicaid is the closest thing we have to a federal health entitlement in the U.S.A. The CMS, by law, can hold states accountable when they do not make payments sufficient to attract providers so that an acceptable service capacity is maintained.

3. Providers need to forcefully present the case that frozen rates or lower payments to providers will threaten a state's capacity to deliver vital services to the categorically and medically needy.

4. Capacity cannot be improved without federal support for recruitment, training and a living wage in areas of employment with critical shortages. Trends toward community housing in the least restrictive environment (Olmstead Decision) will be based on both the availability of housing and an adequate supply of personal care assistants (paid for by Medicaid). Both are critical to the success of these federal mandates. The Center for Medicare and Medicaid Services must insist that states have payment rates that can attract and retain personnel to carry out these tasks.

5. The state budget declines will continue until tax revenues improve. Advocacy groups need to have members who can head off the expected battle between funding Medicaid and funding education. Localities do not want to raise taxes to support education and are willing to pressure their elected officials to maintain or increase state aid for education. Parents of children with developmental disabilities and adults with disabilities are good at articulating that there should not be

an agonizing choice between access to a good education and access to good health care.

6. The volatility of tax revenues from capital gains should be taken into account when planning state budgets. Whatever spikes will come down again. Funding of programs should not be based on mandated spending of a proportion of the incoming tax revenues on education, as in California.

7. The parable of seven fat years and seven lean years can be instructive for state officials. The economic boom years will see a reduction of the Medicaid rolls as employment and benefits grow. Surpluses generated during those years can be put aside for spending in economic downturn years, when it can be predicted, that Medicaid spending will rise to biblical proportions.

8. We can anticipate from the increase in the number of people living in poverty, moving up to 12.1 percent in 2002 from 11.7 percent in 2001, that Medicaid enrollment will continue to increase (Associated Press, 2003).

9. Given these needs, federal subsidization of Medicaid beyond the $20 billion appropriated in 2003 would appear to be required if not inevitable to avoid the kind of public health disaster predicated on continued state fiscal woes.

Organizations such as the Association of University Centers on Disability (AUCD) should start working now to defend Medicaid rather than wait until governors and state legislatures begin their cuts in the next round of budget formation.

10. Do not let the anti-government ("let's shrink the beast"), pro-business public relations campaigns organized by small government advocates make you believe that less is more. There are some things that only the federal government or a federal-state partnership can create. These initiatives go well beyond national defense and fighting terrorism. Orwellian rhetoric about weapons of mass

destruction and phony linkages of Saddam Hussein to 9/11 only obscure the value of a healthy population.

Medicare and Medicaid are paradigms for universal support for and access to health care. Politically protected by virtue of the claim made by participants that they have paid for health care after 65 through payroll taxes, the concept of an exchange or social insurance lends Medicare powerful stability. Medicaid is also a bridge to universal access. The more people eligible, the more support for it. It is, perhaps, an on-ramp to the future. As Timothy Stoltzfus just wrote in his impressive new book, *Disentitlement? The Threats Facing Our Public Health-Care Programs and a Rights-Based Response*, "Only universal access undergirds the sense of solidarity necessary to sustain health-care entitlement in the long run."

Arnold Birenbaum, Ph.D. is the Associate Director of Rose F. Kennedy University Center for Excellence in Developmental Disabilities and Professor of Pediatrics at the Albert Einstein College of Medicine.

Correspondence regarding this manuscript should be sent to 1410 Pelham Parkway So., Bronx, NY 10461, TEL: (718) 430-8523.

This paper was presented at the annual meetings of the Association of University Centers on Disability, Bethesda, MD, November 11, 2003.

References

Associated Press. (2003, September 26). Number of people living in poverty in U.S. increases again. *New York Times*. Retrieved June 2nd, 2004 from http://www.nytimes.com/aponline/national/AP-Poverty.

Freudenheim, M. (2003, February 19). Some Concerns Thrive on Medicaid. *New York Times,* B1.

Halstead, T. (2003, January 30). To guarantee universal coverage, require it. *New York Times,* A27.

Just, T. S. (2003). *Disentitlement: The threats facing our public health-care programs and a rights-based response.* New York: Oxford University Press.

Krauss, M. W., Gulley, S., Sciegaj, M., & Wells, N. (2003). Access to specialty medical care for children with mental retardation, autism, and other special health care needs. *Mental Retardation, 41*, 329-339.

Perez-Pena, R. (2003, October 14). Report faults Medicaid managed care plan. *The New York Times*. Retrieved October 15th, 2003 from http://///www.nytimes.com

Public Law 97-35, section 2176. (1981). United States Codes.

Policy Brief. (2003). *The importance of public insurance/Medicaid coverage for children with special health care needs*. Retrieved October 30th, 2003 from www.familyvoices.org .

Roberts, B. S., & Considine, B. G. (1997). Public policy advocacy. In H. M. Wallace, R. F. Biehl, J. C. MacQueen, & J. A. Blackman (Eds.), *Mosby's resource guide to children with disabilities and chronic illness* (pp. 162-171). St. Louis, MO: Mosby-Year Book.

Saeed, K., & Wallace, J. (2003, November 2). Health care costs burden taxpayers. *The Journal News*, A14.

Thompson, J. W., Ryan, K. W., Pinidiya, S. D., & Bost, J. E. (2003). Quality of care of children in commercial and Medicaid managed care. *Journal of the American Medical Association, 290*, 1486-1493.

RDS Information
Information for Advertisers

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

Why Advertise With RDS?

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

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

Copy Requirements and Cost

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

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

Discounts:

10% discount for 3, 4 or 5 insertions

20% discount for 6 or more insertions

10% publishers discount

10% discount for first time advertisers

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

Copy Dates (subject to change)

RDS is published four times a year and runs approximately 100 pages.

Issue	Published	Date Copy Due
1	January	December 1 of the previous year
2	April	March 1
3	July	June 1
4	October	September 1

Terms And Conditions

1. All advertisements submitted are subject to editorial approval. We reserve the right to refuse or to remove advertisements at our discretion.

2. A confirmation of your order will be supplied upon acceptance.

3. We cannot make any guarantees as to publication dates. While we will make every effort to ensure that your advertisement will be published, the Review of Disability Studies may run ahead or behind schedule.

4. All advertisements are accepted on a space available basis. On rare occasions it may not be possible to accommodate a particular advertisement. Should this be the case, a refund or substitute issue will be offered.

5. No liability is accepted by the Center on Disability Studies or the University of Hawaii for the content of any advertisements or quality of any products, materials, or services advertised.

6. The Center on Disability Studies and the University of Hawaii do not accept any

liability for loss or damage arising from the use of any products or materials purchased as a result of advertisement publication.

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

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

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

About the Center On Disability Studies

The mission of the Center on Disability Studies (CDS), at the University of 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 Hawai'i, the Pacific Region, and the mainland United States.

The Center on Disability Studies is the umbrella for some 25 funded projects. It originated as the 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.

Submissions and Subscriptions

Information about submissions can be found on the inside cover of the journal. A subscription form is included at the back of the journal.

Review of Disability Studies Subscription Form

Please complete this form and mail with payment to the address below.

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

Name: _____

Address: _____

_____

_____

Email: _____

Phone: _____

Please Select:

__Personal $50.00 (personal check only)

__Libraries and Institutions $100.00 (check or purchase order)

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

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

Amount enclosed by check or purchase order $_____

Please make payable to RCUH 2144

Credit Card#_____ Exp. Date_____

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

__Braille

__CD-ROM   __Large Print

__Diskette   __Audio Cassette

Mail Form and payment to:

RCUH 2144

University of Hawaii at Manoa/CDS

1776 University Avenue, UA 4-6

Honolulu HI, 96822

Attention Subscriptions: Velina Sugiyama

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