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## RESEARCH ARTICLES

### Validation and Affirmation of Disability and Deaf Culture: A Content Analysis of Introductory Textbooks to Special Education and Exceptionality

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**Abstract:** This paper reports the findings of a review and normative content analysis of 10 introductory textbooks to Special Education to assess the extent that disability culture, Deaf culture and related topics were addressed. A total of 5,481 pages of text were analyzed to determine the number of pages that addressed disability culture, Deaf culture and related topics, and the number of pages of text authored by deaf persons and people with disabilities. Results indicated that disability and Deaf culture were not identified or discussed in any chapter specifically addressing cultural diversity, Multicultural Education or bilingual education. Disability culture was discussed on three pages and the discussion of Deaf culture comprised less than two percent of the total pages reviewed. Discussion of the advocacy efforts of disabled and Deaf persons, the disability rights and independent living movements and the identification of disabled and Deaf leaders was very limited. It was concluded that representation of disability and Deaf culture and the perspectives and views of disabled and Deaf persons in the textbooks reviewed was minimal. Discussion and recommendations address the need to promote cultural competence with respect to disability and Deaf culture in the preparation of Special Education teachers, and the need to provide disabled and Deaf youth access to their communities, history and shared experience.

**Key Words:** Deaf culture, disability culture, textbooks

## Introduction

Students come to schools with substantial variance in experiences, backgrounds, language, abilities, and belief systems. In this context, education systems at all levels prefer to be known as valuing diversity, cultural pluralism (Rueda & Prieto, 1979) and cultural competence and proficiency (Cross, Bazron, Dennis, & Isaacs, 1989; Lindsey, Robbins & Terrell, 2003). The profound influence of culture on the learning and education of all students and the need for teachers to demonstrate cultural competency and proficiency has been well established in the literature (Banks & Banks, 2004; Edgar, Patton, & Day-Vines, 2002; Gay, 2003; Kalyanpur & Beth, 1999; Lynch & Hanson, 2004; Sleeter & Grant, 2002). To this end, the National Council for the Accreditation of Teacher Education (NCATE) approved Council for Exceptional Children (CEC) performance-based standards for the preparation and licensure of special educators, which address the need for special educators to be culturally competent and proficient (Council for Exceptional Children, 2003). A number of authors have called for expanded efforts in this area (Edgar et al., 2002; Foster & Iannaccone, 1994; Sorrells, Webb-Johnson, & Townsend, 2004).

Disability and Deaf culture, though not new to the disability and deaf communities, have recently emerged as subjects of scholarship and study in the area of disability studies. Irving Zola (1982) published one of the first chronicles of the disability experience presenting the possibility of a common and shared experience by persons with disabilities. David Pfeiffer and Andrea Schein both presented papers published in the proceedings of the 1984 Association on Handicapped Student Service Programs in Post-Secondary Education (AHSSPPE, now the Association on Higher Education and Disability, AHEAD) addressing the question "Is there a Culture of Disability?"

Brown (1994) completed and reported the findings of a study investigating the emergence and existence of a disability culture. This report includes a comprehensive description of the cultural foundations of the disability experience and definitions of disability culture adopted for the investigation reported in this study. Ingstad and Whyte (1995) edited a book addressing elements of disability culture that have become the focus of the emergent discipline of disability studies including disability and personhood, social organization and disability, social position and disability, analyzing processes, and historical transformations. Longmore (2003) noted the disability rights movement in America has moved into its second phase—developing a disability identity with the task of exploring and creating a disability culture. The notion of disability culture and disability as a phenomenon worthy of study and understanding has resulted in the emergence of disability studies as a focus of intensive discourse and inquiry (Albrecht, Seelman, & Bury, 2001; Barnes & Mercer, 2003; Linton, 1998).

Deaf culture has also been well addressed in the literature. Burch (2001, 2002) has traced the early origins of Deaf culture in America during the late 19<sup>th</sup> century to the second World War. Padden and Humphries (1988) presented one of the first descriptions of the origins and emergence of Deaf culture. The Deaf President NOW movement in 1988 galvanized the deaf community, advancing deaf pride and leading to the appointment of the first deaf president of Gallaudet University. Harlan Lane (1976) authored one of the first historical accounts of the deaf community. Other authors have written extensively on the evolution and characteristics of Deaf culture (e.g., Van Cleve & Crouch, 1989; Groce, 1985). In short, the contemporary professional literature addressing disability and Deaf culture has accumulated since the early 1980s. Numerous authors have validated and affirmed disability and deafness as a cultural phenomenon (Brown, 2002; Charlton, 1998; Hahn, 1997; Hallahan & Kauffman, 1994; Ing-

stad & Whyte, 1995; Jones, 2002; Lane, 1997; Linton, 1998; Longmore, 2003).

However, disability and Deaf culture appear to have received limited attention in the Special Education and Multicultural Education literature. Kirshbaum (2000) addressed the concept of disability culture and the integration of disability culture in early childhood Special Education. While some authors of texts in Special Education (e.g., Lynch & Hanson, 2004; Kalyanpur & Beth, 1999) have addressed ethnic and linguistic diversity and culture among families of children with disabilities, minimal attention appears to have been paid to issues related to disability and Deaf culture. This raises questions about the extent to which disability and Deaf culture are topics of interest to researchers of Special Education and Multicultural Education.

While it is understood that it is important for students completing teacher preparation programs to develop cultural competence with respect to ethnicity, race, gender, class and other diversity factors, it is generally assumed successful completion of teacher preparation programs in Special Education results in cultural competence with respect to disability and deafness. However, the extent that disability and Deaf culture are addressed as topics of importance in teacher preparation programs and specifically Special Education and Multicultural Education has not been systematically investigated or reported.

One approach is to conduct a normative content analysis (Neuendorf, 2002) of introductory textbooks to Special Education and Multicultural Education to measure the frequency of occurrence and the number of pages that discuss topics related to disability and Deaf culture. Kuhn (1996) suggested textbooks recount elementary and advanced concepts, accepted theory, achievements, applications, principles, and methodologies typically regarded as supplying the foundation for further practice for

the study of virtually any field including Special Education and Multicultural Education. Introductory textbooks are important because they provide a relatively comprehensive overview of the perspectives, concepts, philosophy, ideologies, theory, practice, and issues comprising the framework of a discipline such as Special Education. In short, introductory textbooks generally provide a broad representation of the core elements of a discipline and represent the current thinking of a majority of professionals and experts within a given field. A content analysis of textbooks in both Special Education and Multicultural Education may be helpful to determine the extent that topics related to disability and Deaf culture have been adequately addressed.

The remainder of this article describes a study involving a content analysis of introductory textbooks that addressed the following research questions:

1. To what extent are disability culture, Deaf culture and selected topics related to disability and Deaf culture addressed in introductory textbooks to Special Education and exceptionality?
2. To what extent are disability culture, Deaf culture and issues or topics related to disability and Deaf culture discussed in chapters specifically devoted to a discussion of cultural diversity, Multicultural Education, and bilingual Special Education?
3. To what extent are people with disabilities and deaf persons provided opportunities to represent and describe their own experiences as persons identified as members of a unique microculture, minority, and community?

The next section of this article describes the content analysis methodology used, including definitions employed, textbooks selected for review, search categories and strategies; data coding, reliability, and data analysis. The results section identifies the number of pages of text

devoted to a discussion of each of the search categories and the proportion of total text reviewed that comprised the number of pages discussing each search category. The results include a) the number of pages of text that discussed disabled or deaf persons as members of a diversity group; b) whether disability and Deaf Culture were addressed by chapters devoted exclusively to a discussion of cultural diversity, multicultural and bilingual Special Education; c) the extent to which text that addressed the diversity of Special Education personnel included the number of disabled or deaf persons employed as Special Education or related service professionals, and, d) the number of pages of text found to address each of the search categories. The summary section of the results describes the overall findings of the analysis. The results of the content analysis are depicted in Tables 5 and 6. Finally, the discussion section describes the implications of the results of the study and recommendations.

## **Methods**

A simple normative content analysis (Neuendorf, 2002) of 10 introductory textbooks to Special Education and exceptionality was conducted to measure the frequency with which introductory textbooks to Special Education and exceptionality addressed disability culture, Deaf culture and issues or topics related to disability and Deaf culture. Of interest was the number of pages that specific search terms and categories related to disability and Deaf culture appeared in the text. In addition, this study sought to identify the number of pages in each text that included material authored by disabled and deaf persons who may have discussed perspectives about disability and Deaf culture, their understandings of the disabled or Deaf community, and their own individual experience as a deaf or disabled person.

## **Definitions**

The first step to conducting the content analysis was to adopt definitions of “culture,” “disability culture” and “Deaf culture.” These

definitions were generated from a review of definitions reported in the disability studies and Multicultural Education literature to establish the basis for identifying and selecting search terms and categories related to disability and Deaf culture.

### Definitions of Culture

For the purpose of this study the following definitions taken from the Multicultural Education literature were adopted.

- (1) "...the values, traditions, social and political relationships, and worldview created, shared, and transformed by a group of people bound together by a common history, geographic location, language, social class, religion, or other shared identity" (Nieto, 2004, p. 146).
- (2) "...everything you believe and everything you do that enables you to identify with people like you and that distinguishes you from people who differ from you. Culture is about groupness. A culture is a group of people identified by their shared history, values, and patterns of behavior" (Lindsey et al., 2003, p. 41).

### Definitions of Disability Culture

Pfeiffer (2004) noted, "There is no single definition of disability culture, but rather there are definitions. These definitions, while being distinct, have overlapping concepts" (p. 14). For the purpose of this study disability culture was defined as follows:

- (1) "Disability culture is a critical conceptual framework in disability studies scholarship for discussing the shared aspects of our experience, and the language, customs, and artistic products that emerge from it" (Linton, 1998, p. 102).
- (2) "Disability culture presumes a sense of common identity and interests that unite disabled people and separate them from their nondisabled counterparts" (Barnes & Mercer, 2001, p. 522).

- (3) "People with disabilities have forged a group identity. We share a common history of oppression and a common bond of resilience. We generate art, music, literature, and other expressions of our lives, our culture, infused from our experience of disability. Most importantly, we are proud of ourselves as people with disabilities. We claim our disabilities with pride as part of our identity. We are who we are: we are people with disabilities" (Brown, 2002, p. 52).

### Definitions of Deaf Culture

For the purpose of this paper, the definition of Deaf Culture is comprised of descriptors presented by Padden and Humphries (1988) that include the following:

- (1) "...a particular group of deaf people who share a language—American Sign Language (ASL)...use it as a primary means of communication among themselves, and hold a set of beliefs about themselves and their connection to the larger society" (p. 2).
- (2) "Deaf people have accumulated a set of knowledge about themselves...have found ways to define and express themselves through rituals, tales, performances, and everyday social encounters. The richness of their sign language affords them the possibilities of insight, invention and irony...what sorts of symbols they surround themselves with, and how they think about their lives" (p. 11).

### Textbooks Selected for Review

Table 1 provides a profile of the 10 texts selected for review for this study. The texts selected were known by the author to be widely used in introductory courses to exceptionality and/or Special Education. In addition, authors of the texts are well published in the Special Education professional literature and acknowledged



experts in the field. Textbooks were identified and selected so at least half included a chapter devoted specifically to addressing cultural diversity, Multicultural Education, and bicultural education. As Table 1 indicates, two texts were first editions while the remaining were third editions or later. Six of the 10 textbooks included a chapter devoted specifically to addressing cultural diversity, Multicultural Education, and bicultural education while the remainder embedded the discussion of cultural diversity issues throughout the text. Finally, the latest edition of the textbook available at the time of this study was selected for review.

A total of 85 pages of introductory (INTRO) material and 5,396 of narrative (NAR) were reviewed for mention or discussion of each search term and category. The introduction (INTRO) included any pages devoted to a preface, forward, and acknowledgements. The narrative (NAR) included all pages devoted exclusively to a discussion of content information. Pages included in the narrative category also included chapter summaries, resources, learning activities, names of organizations, and websites. If a page included both references and narrative content it was included as a narrative page. For the purpose of this study, the pages classified as introduction and narrative were the pages selected for review and determining the presence of discussion addressing search categories and terms. The term “text” refers to all information presented on any page of the introduction and narrative including text, graphics, tables, charts, photos, diagrams and illustrations.

## **Procedures**

### **Search Terms and Categories**

A simple normative content analysis (Neuendorf, 2002) was conducted to determine the presence or absence of specific search terms and categories generated by the author judged to be related to disability and Deaf culture based on a review of the disability studies literature. Table 2 provides a listing and description of 24 search

categories and a complete listing of all search terms included in each category. A review of the disability studies literature addressing disability and Deaf culture leads to an inexhaustible list of potential topics that may be related directly or indirectly to a discussion of disability and/or Deaf culture. Some topics related to disability and Deaf culture may or may not be relevant to a discussion of Special Education in the context of the instruction of children with disabilities. Topics and search terms included were those frequently identified in Special Education texts judged to be related to a discussion of disability and or Deaf culture. The search terms and categories listed in Table 2 were ones most likely to be addressed or discussed in introductory Special Education textbooks, based on the experience of the author of this article, and were relevant to a discussion of disability studies and disability and/or Deaf culture. Some topics related to disability and Deaf culture were not included, such as “service animals” and “technology.” While both of these factors are significant contributors to disability and Deaf culture they are typically characterized as accommodations and strategies to facilitate instruction, learning, and independence by Special Education textbooks.

American Sign Language (ASL) and interpreters of sign language were included as a separate category related to Deaf culture. ASL, sign language and interpreters are foundational elements of Deaf culture and any discussion of Deaf culture must address ASL as the primary language of the Deaf community. However, ASL and sign language are also frequently discussed in Special Education texts as instructional strategies for communication and language development. References to ASL, sign language and interpreters were coded as ASL-Deaf culture if the discussion of ASL was addressed in a discussion of Deaf community, Deaf culture, and/or as a unique language of the Deaf community. Discussion of ASL limited solely to the education and instruction of deaf children for the purpose of developing communication and language with no reference to Deaf culture or the Deaf

community was coded as ASL-deaf/HI (i.e., deaf/hearing impairment). References to ASL and related search terms involving strategies to instruct students with disabilities other than hearing impairments were coded as ASL-Other. The focus of this study was identifying text specifically focused on developing a knowledge and understanding of disability and Deaf culture and potential implications for Special Education that included a discussion of ASL as the defining linguistic foundation of Deaf culture. Therefore, for the purpose of this study ASL-Other was dropped from the analysis resulting in a total of 23 search categories included for analysis.

### Search Strategies

The first step was a thorough examination and review of the subject index of each text to identify all subject index entries relevant to disability and Deaf culture.

Following the compilation of subject index entries, the introduction and narrative text were read and searched for each subject index entry included in the list with specific attention paid to the pages identified in the subject index. Since most subject indexes do not include a complete listing of the page numbers of every instance a topic or term occurs, or the most complete listing of all possible search terms or topics that might be relevant to disability and Deaf culture, subject index page numbers were only employed as a preliminary guide for the most obvious possibilities. Thus, an important step involved reading each text and attempting to identify pages on which search terms and categories listed in Table 2 may have been discussed but not identified in the subject index. In addition, the text was read to identify search terms and categories relevant to disability and Deaf culture not listed in the subject index.

The review of subject index entries and the text resulted in a comprehensive and continuously expanded listing of search terms and categories related to disability culture, disability studies, and Deaf culture. When search terms

and categories expanded, textbooks were subjected to several iterations of review and analysis to identify occurrences of search terms and categories included subsequent to the initial review of the text. This assured each text was reviewed and analyzed for the presence or absence of the complete list of all search terms and categories.

### Data Coding, Entry, and Analysis

As Table 2 indicates, a comprehensive listing of search terms was compiled and organized into 23 categories assigned a unique identification number. When a search term or category was found in the text the author kept records for each search category identification number and the starting and ending pages on which the term or category was discussed. The total number of pages containing any of the terms included in each of the search categories listed in Table 2 was calculated as a measure of the amount of text devoted to a discussion of disability and Deaf culture. The proportion of total pages of all text devoted to a discussion of each of the search categories listed in Table 2 was also calculated. All data was entered and analyzed using Microsoft® Excel 2000.

### Reliability

A research assistant with a master's degree in rehabilitation counseling was employed to conduct a reliability check for data entry and coding. The degree of agreement between the author and research assistant about whether text on specified pages of each textbook addressed search terms and categories was employed as the measure for assessing coding reliability. The research assistant was provided explicit training on the rules for identifying the occurrence of a search term or topic. She was also provided a complete listing of all search terms and categories (i.e., Table 2) and trained on methods for recording the occurrence of terms or categories in text.

The author provided the research assistant with 20 entries of pages of search terms and topics previously identified and coded to pilot the

reliability assessment. The pilot sample included a code for the textbook so she knew which textbook to review and starting and ending pages to review. She reviewed the pages specified and identified the occurrence, or nonoccurrence, of any of the search terms or categories addressed in the text on these pages. If the research assistant identified more than one search term or category she was instructed to select only one and record the assigned search category code. Several pages were included that did not address any search term or category. If she determined the text did not address a search term or category she recorded a code (i.e., 99) indicating no search term or category was addressed on pages she reviewed. Agreement was reached when both the author and research assistant recorded the same search category code for the same pages of text reviewed.

Upon completion of the pilot reliability assessment, the author and research assistant discussed and clarified areas of disagreement to clarify questions regarding search criteria and coding. The final reliability assessment was conducted on a total of 140 randomly selected observations while assuring all textbooks and search categories were represented. This represented about 10 percent of the observations included in the dataset. Krippendorff's alpha (Krippendorff, 2004) was computed as a measure of the level of agreement between raters. When raters agree perfectly, observed disagreement is zero and alpha is equal to one. When raters agree on the basis of chance results indicating an absence of reliability, alpha measures zero. Thus, for reliability,  $\alpha$ 's range is  $1 \geq \alpha \geq 0$ . For this study, Krippendorff's alpha was based on a 23 x 23 observed coincidence matrix corresponding to the 23 search category codes that might be assigned. Krippendorff's alpha was calculated to be .91, suggesting an extremely high degree of agreement and coding reliability. Of the 140 units assigned, disagreements were recorded for 12 data units.

## Results

A total of 5,481 pages of introductory and narrative material subjected to the review and analysis for this study. A total of 1,737 pages were identified as addressing one or more search categories. A total of 1,403 occurrences of the 23 search categories were recorded. Table 3 summarizes the search categories addressed by each textbook, including the number and percent of categories addressed by each book, and the number of books that included text addressing each search category.

### Chapters Addressing Cultural Diversity, Multicultural and Bilingual Special Education

Of the 10 textbooks reviewed, six textbooks included a chapter specifically devoted to a discussion of issues involving the education of children with disabilities who were considered culturally and/or ethno-linguistically diverse. These chapters addressed the needs and issues of children and families for whom English was a second language, children whose families may have immigrated to the US and children and families of color. Of interest for this study was whether disability or Deaf culture and related topics were included as topics for discussion in chapters targeting issues of cultural and ethno-linguistic diversity. The six chapters expressly about cultural and ethno-linguistic diversity comprised 208 pages. While the other four texts did not have a chapter devoted exclusively to a discussion of cultural and ethno-linguistic diversity these topics were addressed in the first chapter of each text and the discussion of cultural and ethno-linguistic diversity was embedded in the text that discussed various disability categories. The results described below are limited to the six texts with chapters dedicated exclusively to cultural and ethno-linguistic diversity.

### Categories of Cultural Diversity

Table 4 includes seven categories of cultural groups including ethnicity/race, language, gender, socioeconomic status (SES), disability, sexual orientation (GLBT), and religion. Of these

seven categories, ethnicity/race, language, and SES were addressed in all texts, including the six chapters in the books with chapters devoted to multicultural and bilingual aspects of Special Education. Ethnicity and language were the primary focus of the six texts that included chapters dealing with cultural diversity. Only one of the six texts (Heward, 2000) addressed gender differences and sexual orientation. However, it should be noted that all texts addressed gender differences with respect to various disability categories. In addition, Smith, et al. (2004) included a section dealing with sexual orientation in a chapter about students identified as at-risk and Hunt and Marshall (2002) addressed sexual orientation in a chapter about gifted students. Three of the six textbooks briefly discussed religious factors as a relevant topic in their discussion of cultural diversity.

#### **Acknowledging the Existence of a Disability and Deaf Culture**

Three textbooks acknowledged people with disabilities as members of a cultural group, minority, and/or microculture. Only one text discussed Deaf culture (Hallahan & Kauffman, 2003) in chapters devoted exclusively to multicultural and bilingual Special Education limited to two pages. None of the textbooks mentioned or acknowledged the existence of disability culture in chapters devoted to multicultural and bilingual Special Education or discussed any elements or details about Deaf culture.

Hallahan and Kauffman (2003) acknowledged the existence of Deaf culture in their chapter addressing multicultural and bilingual Special Education. A description of this culture was included in a separate chapter on hearing loss. These authors defined an exceptionality group as "...a group sharing a set of specific abilities or disabilities that are especially valued or that require special accommodation within a given microculture. Thus a person may be identified as exceptional in one ethnic group (or other microculture defined by gender, social class, religion, etc.) but not in another (p. 90)." Similarly,

Colarusso and O'Rourke (2004) and Heward (2000) identified deaf and disabled persons as members of unique cultural groups. Hallahan and Kauffman (2003) included a discussion of people with disabilities as a minority in a separate chapter addressing trends and issues in Special Education.

#### **Diversity of Special Education Personnel**

Only two textbooks addressed the diversity of Special Education teaching personnel in chapters addressing cultural diversity. This discussion was limited solely to the representation of personnel with respect to ethnicity in all texts. The absence of racial diversity among both general and Special Education teachers was noted by Gargiulo (2003) and Smith (2004). Representation of disabled and deaf persons among Special Education personnel was not addressed by any text reviewed. Two textbooks suggested adults with disabilities might contribute to the education of children with disabilities. Smith (2004, p. 91) recommended that adults with disabilities should be included on staff to provide role models for young children. Turnbull et al. (2002, p. 428) suggested students with disabilities may benefit from adult mentors with disabilities. Although all of the textbooks reviewed suggested schools or teachers partner with parents, no textbook suggested teachers and parents consider partnering with adult members of disability or deaf communities.

#### **Nondiscriminatory Evaluation, Overrepresentation and Underrepresentation**

Table 4 indicates nondiscriminatory assessment and evaluation and ethnic overrepresentation and underrepresentation of students with disabilities in various disability categories received the lion's share of attention in chapters devoted to multicultural and bilingual Special Education. All textbooks addressed both topics.

In chapters addressing cultural diversity, several authors included recommendations for tapping resources, promoting partnerships, and including activities involving creative arts from

different cultures and communities (e.g., Smith, 2004). However, neither the deaf nor disability communities were named or mentioned in any chapter addressing multicultural and bilingual education as a potential resource for personnel or as a cultural or pedagogical resource.

In short, no textbook reviewed addressed any distinctive characteristics, elements or features of disability or Deaf culture in their discussion of cultural diversity, multicultural and bilingual Special Education. All the texts reviewed focused primarily, if not exclusively, on ethnic and linguistic differences.

### **In Search of Disability and Deaf Culture in Special Education**

Results of the review and analysis of each of the 10 textbooks in the 23 search categories are organized into six broad categories including: 1) disability and Deaf culture; 2) empowerment; 3) cultural elements; 4) socio-political elements; 5) definitions and perspectives; 6) classification and labeling; and 7) authorship. The results below refer to Table 5 that depicts the number of pages on which search categories and terms were identified.

#### **Disability and Deaf Culture**

Table 5 summarizes the results of the review and analysis conducted to identify the number of pages and the portion of each text that mentioned or discussed ASL, Deaf culture, disability culture and disability anywhere. While Deaf culture was addressed in all the textbooks, this discussion appeared in chapters addressing students who are deaf and hard of hearing. Deaf culture was mentioned or discussed on a total of 78 pages comprising less than two percent of the total pages of text.

As a critical element of Deaf culture, a search was conducted for text addressing ASL and other forms of sign language. Table 5 indicates ASL was discussed by nine of the 10 textbooks as the language of the Deaf culture and community. ASL was addressed as a feature of Deaf culture

on 44 pages of text comprising less than one percent of the total pages of text reviewed and analyzed. However, it is important to note the 44 pages which ASL addressed with respect to Deaf culture comprised more than half of the total pages of text found to address Deaf culture. ASL was more frequently discussed as a strategy for communication and language development for youth with hearing impairments. Discussion of ASL limited to the education of deaf and hearing impaired students without reference to Deaf culture appeared on 66 pages.

While acknowledging and discussing features of Deaf culture, in a chapter addressing Multicultural Education and bilingual aspects of Special Education, Hallahan and Kauffman (2003) questioned the extent to which a culture has the right to perpetuate itself asking, "How should we respond to some members of the Deaf culture, for example, who reject the prevention of deafness or procedures and devices that enable deaf children to hear, preferring deafness to hearing and wishing to sustain the Deaf culture deliberately" (p. 90).

Table 5 also indicates three textbooks mentioned or discussed disability culture on three of the 5,471 pages addressing disability issues in 10 textbooks. Upon closer examination of these three pages it was clear that the entirety of each page was not devoted to a discussion of disability culture. The estimated cumulative proportion of total pages devoted to the discussion of disability culture was a single page for all 10 textbooks.

Gargiulo (2003) stressed the importance of recognizing "...the disability culture that surrounds physical disabilities" (p. 583). Citing Kirshbaum (2000), he concluded, "This disability culture emphasizes interdependence, empowerment, and respect for expertise and adaptations derived from personal disability experience. Students often benefit from meeting other people with similar disabilities for support, feedback, and discussions of disability cultural issues" (p.

583). Smith (2004) noted, “People with disabilities have also formed their own advocacy groups, becoming effectively organized during the 1980s and 1990s. The first phase was a quest for civil rights; the second phase is focusing on the development of a disability culture” (p. 19).

A total of 19 pages of text included some mention or discussion of disabled and deaf persons who have been considered by the disability and deaf communities as leaders of the disability rights movement. Below is a list of those named in each textbook who have contributed to the disability rights movement.

<b>Text</b>	<b>Leaders of the Disability Rights Movement Named in Textbooks</b>
Heward, 2000	Judith Heumann, Donald Cook, I. King Jordan, Bridgetta Bourne, Jerry Covell, Ed Roberts
Hunt & Marshall, 2002	I. King Jordan
Kirk et al., 2003	Deidre Davis, Joan Corsiglia, Karen Gaffney, Mary Lester
Smith, 2004	Ed Roberts, Justin Dart, I. King Jordan
Turnbull et al., 2002	Billy Golfus

Table 5 indicates that only one textbook (Smith, 2004) included any discussion of disability studies. She noted disability studies “... represents an interdisciplinary study of the history and culture of a group of people” (p. 23).

### **Empowerment**

This category includes the search topics of access, disability rights movement, disability rights leaders, and the independent living movement as search categories. Table 5 indicates access was addressed on 62 pages of the 10 texts reviewed. While some discussion of access addressed physical access, technology was frequently discussed as a means of accessing the curriculum, instruction and learning activities. Four textbooks discussed universal design including Hallahan and Kauffman (2003), Hardman et al. (2005), Smith (2004) and Turnbull et al. (2002).

Table 5 shows only four of the 10 textbooks reviewed discussed the disability rights movement, including Gargiulo (2003), Hallahan and Kauffman (2003), Smith (2004), and, Turnbull et al. (2002). A total of 13 pages included some mention or discussion of the disability rights movement.

From the list above I. King Jordan was the most frequently mentioned leader as a key figure of the Deaf President Now movement. Dr. Jordan’s name was identified in three of the 10 textbooks reviewed. Smith (2004) was the only author who acknowledged the contribution of leaders within the disability rights movement, specifically Ed Roberts and Justin Dart, to the passage of the Rehabilitation Act and the ADA. Only two textbooks mentioned the late Ed Roberts. Judith Heumann, a woman with a significant disability, who was appointed by President Clinton as the Assistant Secretary of the Office of Special Education and Rehabilitation Services overseeing all federal programs authorizing funding and provision of Special Education services, was mentioned in one (Heward, 2000) textbook. She was a leader in the advocacy and activism that led to implementation of rules and regulations related to the Rehabilitation Act of 1973. Justin Dart, also a person who had a significant disability and who was awarded the Medal of Freedom for his lifelong efforts to the disability rights movement and the passage of the ADA was mentioned in one textbook (Smith, 2004).

These findings are important since Ed Roberts, Judith Heumann, and Justin Dart, among others, are internationally recognized leaders in the disability community and the disability rights movement. In addition, they have been acknowledged for their contribution to the advancement of the civil rights and empowerment of all deaf and disabled persons, most notably their contributions to the passage of key legislation and rules and regulations including the Rehabilitation Act of 1973, the Individuals with Disabilities Education Act (IDEA), and the Americans with Disabilities Act (ADA). However, a number of disabled and deaf leaders who have been appointed by Presidents to key positions impacting policy and programs for youth and adults with disabilities were not identified, including Robert Davila, Evan Kemp, Paul G. Hearne, Kate Seelman, Bob Williams, and Marca Bristo to name a few. In addition, many other notable disabled and deaf leaders have contributed to the advancement of disability rights and disability and Deaf culture who were not discussed or named. In short, very little text included a discussion of the contributions by disabled and deaf persons to their own educational, social, political and economic status or advancement.

Only two of the ten textbooks mentioned the independent living movement (Gargiulo, 2003; Turnbull et al., 2002). This discussion was limited to two pages. It is important to note the independent living movement is a key element of disability culture since it involved one of the first organized efforts of persons with disabilities to advocate and empower themselves.

### **Cultural Contributions of Disability and Deaf Culture**

Of interest for this study was the extent authors of introductory textbooks to exceptionality and Special Education included cultural contributions such as artwork, poetry, stories, and music produced by disabled and deaf persons. This category also included a search for any discussion or mention of theater produc-

tions, radio shows and other cultural or sporting events or activities focused on the participation of deaf and disabled persons and the disability or deaf experience. In addition, these textbooks were reviewed to assess portrayal of deaf and disabled persons in film and media. Textbooks were also examined to identify whether there was any mention or discussion of publications authored or produced by deaf persons and persons with disabilities addressing issues of concern to these communities.

Table 5 includes the results of the review and analysis of textbooks for these search categories. Six textbooks included cultural contributions authored and produced by deaf and disabled persons comprising a total of 56 pages of text of which 47 pages (83%) were included in three texts (Gargiulo, 2003; Hallahan & Kauffman, 2003; Smith, 2004). The majority of the cultural contributions depicted paintings. Smith (2004) also included poetry, sculpture, sketches, and photography. Hallahan and Kauffman (2003) included a description of the National Theater of the Deaf and excerpts by Kathy Buckley, a deaf comedienne. Hunt and Marshall (2002) and Kirk et al. (2003) included poems by persons with a disability. Turnbull et al. (2002) described a book of photographs taken and compiled by a deaf person, Maggie Lee Sayre, about life growing up on a river in the South.

The portrayal of disabled and deaf persons in film and other media was addressed by four texts and comprised a total of 32 pages. This category included a listing and brief description of films that portrayed disabled and deaf persons. Of the 32 pages on which the portrayal of deaf and disabled persons were named or mentioned, 23 pages (72%) were addressed in a single text (Smith, 2004) and provided a brief summary of films portraying deaf and disabled persons and described ways persons with disabilities have been commonly depicted by the film industry. Gargiulo (2003) briefly discussed *Rain Man*, a film portraying a person with autism. Hallahan and Kauffman (2003) included several cartoon

strips addressing disability topics and mentioned the stereotyping and negative portrayal of disabled persons in the media. They also described a website that provides resources for deaf and disabled persons in the entertainment industry and the website for *On a Roll*. A radio talk show hosted by a person with a disability about disability issues which has evolved into *The Strength Coach*. Kirk et al. (2003) briefly mentioned *My Left Foot*, a film depicting a man with cerebral palsy. Turnbull et al. (2002) described the film, *How Billy Broke His Head and Other Tales of Wonder*, written and directed by Billy Golfus, a man who experienced a head injury, which provides an insider's look at the disability experience and the disability rights movement.

Five textbooks included information about publications, including online publications, devoted to issues of interest to the disability and deaf communities other than professional texts, journals, articles, and papers. Table 5 shows a total of 36 pages mentioned or discussed publications devoted to issues of interest to the disability and deaf communities other than professional material. Of the 36 pages on which such publications were mentioned, 20 pages (56%) were included in the text by Smith (2004) who listed a number of books authored by disabled and deaf persons in a section at the end of each chapter. Hallahan and Kauffman (2003) identified the website to the *Ragged Edge*, an online magazine devoted to disability issues and mentioned *Silent News* and *Deaf Life*, two magazines devoted to issues of concern to the deaf community. Hunt and Marshall (2002) also identified several publications authored by deaf persons and persons with disabilities about the disability and deaf experience. They also referred to *Ability Network Magazine*, a magazine devoted to disability issues. Turnbull et al. (2002) referenced a book by Temple Grandin, a woman with autism, and the compilation of photographs by Maggie Lee Sayre mentioned above. In most cases, while publications were named or referenced there was very little discussion, if any, of the content of these publications.

## Socio-Political Elements

This group included the search categories of advocacy, attitudes, discrimination, and legal issues. Table 5 indicates all except one of the 10 textbooks reviewed addressed advocacy and advocacy was addressed on 80 pages of text. Heward (2000) and Smith (2004) were responsible for the largest number of pages of text addressing advocacy. The results of additional analysis indicated that of the pages of text devoted to a discussion of advocacy only 12 pages addressed advocacy efforts and contributions of deaf or disabled persons. The remaining addressed advocacy activities of parents, professionals and organizations. While there are numerous advocacy organizations led by and for persons with disabilities only one textbook (Gargiulo, 2003) mentioned People First, a self-advocacy organization led by and for persons with intellectual disabilities. None of the textbooks mentioned ADAPT or named any independent living centers as advocacy organizations directed and led by disabled and Deaf persons on their own behalf.

Table 5 also includes the findings of a review of the 10 textbooks for any discussion of attitudes, discrimination and legal issues. Sixty pages of text addressed attitudes and 181 pages discussed issues of discrimination which was found to be the fourth most frequently addressed search category. Of the 23 search categories, legal issues was the most frequently addressed on 756 pages.

## Perspectives, Classification and Labeling

Table 5 shows the results from the review and analysis of the search categories that included historical and alternative perspectives, classification and the issues of labeling and language when referring to deaf and disabled persons. A total of 141 pages were devoted to the discussion of historical perspectives. Historical perspectives typically emphasized the origins and evolution of the field of Special Education. The historical treatment of deaf persons and persons with



disabilities received limited attention. Only two textbooks (Garaguiolo, 2003; Smith, 2004) referenced the work of Scheerenberger (1983, 1987), while one textbook (Hardman et al., 2005) referenced the work of Braddock and Parish (2001). None of the textbooks reviewed referenced the work by Joseph Shapiro in his book *No Pity* describing the contemporary history of the disability rights and independent living movements or any other such accounts.

The search category of alternative perspectives was an effort to identify whether texts and authors' perspectives of disability differed from a categorical or deficit-based orientation towards disability. Of specific interest was the extent that disability as a construct may have been discussed or examined and how it might have evolved as a social construct. Of the 10 textbooks reviewed, six offered some discussion of alternative perspectives, other than a deficit-based model, which might be of interest to the reader. A total of 21 pages of text included some discussion of alternative perspectives of disability. Of the 21 pages, Hardman et al. (2005) contributed 15 pages. The remaining were contributed by Garaguiolo (2003), Hunt et al. (2002), Smith (2004), Smith et al. (2004) and Turnbull et al. (2002). Hardman et al. (2005) briefly discussed a cultural view of disability arguing that normality is defined by societal views. He also described the medical model approach towards disability and in one sentence mentioned the impact of power relationships noting people with the greatest power within the culture can impose their criteria for normalcy on those who are less powerful. Hardman et al. (2005) also mentioned socio-cultural and eco-cultural factors that may influence perspectives about disability and described five approaches to the understanding and treatment of persons with emotional disabilities. Smith et al. (2004) addressed the need to understand cultural interpretations of disability. The social constructivist conceptualization of disability was presented by Hunt et al. (2002), Smith (2004) and Turnbull et al. (2002). The

discussion was limited to one or two paragraphs in each of the texts.

Classification was found to be the second most frequently addressed search category. This search category did not include discussion of the specific types and characteristics of disability but was limited to how disabilities were defined and classified. All 10 textbooks addressed classification issues on a total of 536 pages. The related search category of labeling and language was addressed by all of the textbooks on a total of 63 pages.

### Authorship

As indicated in the methods section, authorship was selected as a search category as a measure of the extent that deaf and disabled persons were consulted or invited to be participants in discussions that characterize who they are and their life experience. This category included quotes, excerpts, poems, and any material clearly authored by a person with a disability, parent, sibling, friend and a child of a deaf adult. Table 5 shows the number of pages on which material authored by such persons was identified. A total of 195 pages were found to have material with authorship attributed to a deaf person, a person with a disability, parent, sibling, friend and in one case a child of a deaf adult. As Table 5 indicates, a total of 96 pages of text included material for which authorship was attributed to a person with a disability or a deaf person while 94 pages were identified as having been authored by parents. Three texts included five pages of material authored by siblings, a close friend, and a child of a deaf adult. The 96 pages of text that included material authored by a deaf or disabled person represents about two percent of the total narrative portion of the 10 textbooks reviewed.

### Summary

Table 5 provides a summary of the proportion of introductory and narrative text (5,481 pages) that comprised the total pages on which elements of each search category were men-

tioned or discussed. As Table 5 shows, disabilities studies was only mentioned in one textbook comprising .02% of the total pages of introductory and narrative text reviewed while legal issues comprised almost 14% of the text reviewed. As reported previously, a total of 1,737 pages of text were found to have addressed one or more search categories comprising approximately 30% of the pages reviewed. However, as noted in Table 5, all search categories except for classification and legal issues comprised less than four percent of the introductory and narrative text. In addition, 10 of the 23 search categories comprised less than one percent of the introductory and narrative discussion of all 10 texts reviewed. The average proportion of the total introductory and narrative text comprising the 10 textbooks reviewed devoted to mentioning or discussing all 23 search categories was about two percent.

## Discussion

The purpose of this study was to review and analyze introductory textbooks to Special Education and exceptionality to assess the extent disability and Deaf culture were addressed. Evidence from this study suggests minimal attention has been paid to describing disability and Deaf culture and related topics in introductory textbooks to Special Education and exceptionality. Disability is clearly described and defined in terms of characteristics viewed as uniquely if not exclusively individualized. Definitions and classification of disability did not address characteristics of disability with respect to shared or collective experiences by deaf and disabled persons as communities. In addition, there was little evidence of efforts to define and describe characteristics of disability from the perspective of those who live with and experience disability and deafness. These findings extended to chapters devoted to a discussion of cultural diversity, Multicultural Education and bilingual Special Education. Neither disability nor Deaf culture were acknowledged or discussed in any of these chapters in any detail.

In addition, the textbooks selected for review were analyzed to determine the extent people with disabilities and deaf persons were provided opportunities to represent and describe their own experiences as persons identified as members of a unique microculture, minority, and community. While several textbooks included excerpts and quotes by deaf and disabled persons, the amount of text authorship that may be attributed to deaf or disabled persons comprised less than two percent of the introductory and narrative text. In short, deaf persons and disabled persons have been afforded very little opportunity to define, describe, narrate and discuss the disability or deaf experience from their own perspective in Special Education.

There are a number of implications that warrant consideration. As suggested earlier, introductory textbooks provide an overview of the foundation for the practice and study of any field. As such, they may be considered representative of the critical elements addressed by a discipline. The failure of introductory textbooks in Special Education and exceptionality to address disability and Deaf culture in any meaningful way, and the limited participation and representation of disabled and deaf persons in the discourse about who they are, and descriptions of their experience from their perspective, is very troubling for a number of reasons. First, the importance of training culturally competent and proficient teachers has been well established in the education literature, including Special Education. However, the findings of this study suggest Special Education has failed to adequately address disability and Deaf culture in any meaningful way. A consistent theme evident throughout the texts was a clear emphasis on the successful assimilation of students with disabilities in the dominant nondisabled society and culture. This would suggest that many teachers, while trained to deliver and implement Special Education services and practices, may actually have completed teacher preparation programs leading to teaching certification and graduate degrees with little or no understanding of what

it means to actually live with and experience a disability or deafness. That is to say, many Special Education teachers may have been trained to teach students with disabilities with little or no expectation for developing cultural competence and proficiency with respect to disability and/or Deaf culture. Unfortunately, there may be a widespread but false assumption that teachers are culturally competent with respect to disability and deafness solely as a result of having completed a teacher preparation program. Unfortunately, the findings of this study strongly suggest that while discourse about disability and Special Education are evident, the voices, narrative and discourse by disabled and deaf persons about their lives, experiences and culture is minimized and more frequently absent.

Another implication is that disability and deafness have been defined in Special Education exclusively in terms of undesirable anatomical, physiological and psychological characteristics that are uniquely individualistic. This narrow definition of disability steeped in biological determinism precludes the consideration and study of factors that may be collectively shared by large proportions of deaf and disabled persons, and emphasizes the cultural assimilation of disabled and Deaf persons into the nondisabled world. This dominant perspective evident in the textbooks reviewed limits a cultural understanding of disability that emerges from the shared and collective experiences, understandings and narratives. The result is a major gap in the knowledge and understanding of students preparing to be teachers of the disability and deaf experience from the perspectives of disabled and deaf persons. This may have serious impact on the development and implementation of research, policy, program development, and practice for the education of disabled and deaf youth. Clearly, there is a need to broaden the discussion of the characteristics and classification of disability in Special Education to include alternative perspectives of disability addressing the social, cultural, and linguistic constructions of disability and deafness, including an understanding of

socio-political factors that frame and define the personal and collective experience of disabled and deaf persons.

Related to the question of cultural competence and proficiency with respect to disability and Deaf culture is the question of the extent teachers and deaf and disabled persons themselves have epistemic access to the shared and collective experience of being disabled and/or deaf including access to their history, heritage and culture. Teachers who have no understanding of disability and/or Deaf culture may be deprived of knowledge, understandings, meanings and pedagogies that may facilitate both student success and failure. In addition, students themselves may have limited or no access to understandings of their individual experience within a cultural framework. The implications of repressing or limiting access to cultural understandings of disability and deafness for people with disabilities and deafness needs to be investigated. One possible reverberation currently being felt within the disability and deaf communities is the lack of understanding by deaf and disabled youth of their history, or knowledge of the work of many disability and deaf leaders, compounded by the aging and passing of older disability leaders. The result is a failure of many young persons reaching adulthood to understand the need to protect their civil liberties or contribute to the legacy, heritage, culture and opportunities they have been afforded as the result of the work of many older disabled and deaf adults. Promoting cultural competence with respect to disability and Deaf culture may offer unknown resources and opportunities for both teachers and students that, at a minimum, will lead to better understanding of the disability and deaf experience, and offer deaf and disabled students access to historical knowledge about other disabled and deaf persons who have made enormous contributions and sacrifices to advance the progress and status of persons with disabilities.

There are several limitations to this study. First, it cannot be concluded based on this study

alone that disability and Deaf culture are not addressed in other ways in teacher preparation programs, including other Special Education courses, Multicultural Education courses and fieldwork. Second this study involved a simple normative content analysis limited solely to an examination of the number of pages on which selected terms appeared as defined by the author considered representative of disability and Deaf culture. This was a subjective judgment, albeit supported by the disability studies literature. In addition, while the reliability coefficient was large warranting the conclusion that the identification and coding of specific search categories, terms, and topics was reliable, there is no doubt that a redefinition and reframing of the rules for identification may yield different results. This points to the need for substantial research to identify what may be considered to be the representative core elements of disability and Deaf culture. However, culture is ultimately a socially constructed perspective and subject to change over time as members of a group redefine who and what they are and the elements that define membership and identity (Cushner, McClelland & Safford, 2003).

This study did not address how much text should be devoted to such a discussion, in what context, and by whom. Are professionals without disabilities sufficiently qualified and informed to address disability and Deaf culture or characterize and describe the disability and deaf experience, the disability rights movement, and other features of disability and Deaf culture? To what extent is membership and participation in the disability and deaf communities a requisite for informing the discourse and narrative about disability and Deaf culture? To what extent should the discussion of disability and Deaf culture be limited to persons who are members of these communities and identify themselves as participants in these cultures? In short, how shall we identify authentic representatives of the disability and deaf experience and culture? These are important questions that cannot be addressed by the findings of this study.

Another limitation involves the recording of total pages in which search terms and categories were found. Recording that a search term was addressed on a single page implies that the entire page was devoted to a discussion of the topic. In reality, the discussion of search terms and categories was frequently limited to a single sentence or paragraph on many pages. Thus, the results presented in this study are a biased *overestimate* of the total pages of text devoted to the discussion of disability and Deaf culture and related topics. In short, far fewer pages of text were actually devoted to the discussion of search terms and categories included in Table 2 than are reported by this study.

### **Implications for Future Research**

Culture as a "...totality of socially transmitted behavior patterns, arts, beliefs, institutions, and all other products of human work and thought characteristic of a community or population" (Coon, 2000, p. 53) involves a process of intergenerational transmission. For many, if not most cultures, children learn about the elements of a culture from adult members of a community, typically within the family structure. While children may contribute to the elements of a culture, adults generally frame, structure, and communicate their culture through a complex process. Thus, children from many ethnic cultures acquire their cultural understandings, knowledge, behaviors, customs, preferences, beliefs, and artifacts from adult members of a community. This presents a dilemma for youth with disabilities. Typically, youth with disabilities are members of families where one or more members are adults without disabilities and have little or no understanding of disability, disability issues, and disability culture until they have child with a disability. The exception to this may be the children of deaf adults who themselves may be immersed in Deaf culture or parents who may be professionals in a field serving persons with disabilities. It is more likely that the transmission of disability culture occurs among adults with disabilities with little oppor-

tunity afforded for the transmission of cultural understanding to individuals who are not members of the community. Thus, research is needed to address the question of how "...group cohesion, culture and identity form when there is no intergenerational transmission of culture, as with most lesbian and gay, and disabled people" (Linton, 1998, p. 93).

Additional research is needed to examine the extent disability and Deaf culture and the discourse about disability and deafness by persons living with disabilities and deafness are actually addressed in teacher preparation coursework including Special Education and Multicultural Education courses. In addition, a review of textbooks addressing Multicultural Education text would be important to identify the number of articles and chapters that present a perspective about disability and deafness authored by persons with disabilities and who are deaf, and can speak to the disability and deaf culture as a shared, collective and true cultural perspective in contrast to a Special Education perspective. Authors of Special Education textbooks may have the authority and license to speak to the education of youth with disabilities, but the authority for speaking to a cultural experience must ultimately be deferred to the members of the community from which the culture emerges.

There is no question that the authors of the textbooks reviewed have made enormously important contributions to the education of youth with disabilities. However, the question raised by these findings is whether Special Education as a discipline, if adequately represented by these textbooks, has surpassed the lowest levels of cultural competence (i.e., cultural destructiveness, incapacity and blindness) as described by Cross et al. (1989) and Lindsey et al. (2003) with respect to disability and Deaf culture.

Additional research is needed to analyze the content of the discourse and pedagogy about disability with an emphasis on themes, meanings, semiotics, and inferences beyond the simple

enumeration of topics and pages reported in this study. While examples of this are emerging (e.g., Brantlinger, 2004; Smith, 2001) content analysis methodologies (Krippendorf, 2004; Neuendorf, 2002) may be extremely useful towards advancing a better understanding of what is both present and absent in the discussion about disability and deafness in Special Education and allied fields. Finally, schools and Special Education personnel must begin to explore the possibilities and benefits that might emerge from connecting deaf and disabled students to adult deaf and disabled communities and affording epistemic access to their history, heritage and culture and knowledge about the factors that structure and often define their personal and collective experiences as members of a unique culture.

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**Table 1**

Profile of textbooks selected for review.

Authors	Textbook Sections						Total
	<i>Ed</i>	Intro	Narr	Gloss & App	Ref	Index	
1. Colarusso & O'Rourke (2004)	1	2	498	9	39	8	556
2. Gargiulo (2003)	1	7	572	29	40	18	666
3. Hallahan & Kauffman (2003)	9	10	511	11	40	26	598
4. Hardman, Drew, & Egan (2005)	8	7	548	0	33	25	613
5. Heward (2000)	6	12	632	13	65	22	744
6. Hunt & Marshall (2002)	3	6	521	11	30	18	586
7. Kirk, Gallagher, & Anastasiow (2003)	10	13	534	5	28	26	606
8. Smith (2004)	5	12	477	12	45	27	573
9. Smith, Polloway, Patton, & Dowdy (2003)	4	7	508	10	26	26	577
10. Turnbull, Turnbull, Shank, Smith, & Leal (2002)	3	9	595	8	32	35	679
Total	50	85	5396	108	378	231	6,198

Table 2

Search categories and a description of search terms and constructs

Search Category	Description of Search Terms and Topics
Access	<p><i>Access, accessibility, mobility, web access, Bobby approved, wheelchairs, universal design</i>; text addressing access to physical environment, information technology, curriculum, instruction, and learning activities.</p>
Advocacy	<p><i>Advocates, advocacy, self-advocacy</i>; text that discussed personal advocacy activities, skills and efforts for obtaining services and opportunities. Did not include text addressing disability rights movement or legal advocacy which were treated as separate categories. Also did not include self-determination, unless an explicit reference to <i>self-advocacy</i> was discussed as an element of self-determination.</p>
Alternative Perspectives	<p>Alternative perspectives about how disability as a concept and construct has emerged. This search category was focused on identifying any discussion of political, sociological, linguistic, anthropological, philosophical, and ideological perspectives of disability as an alternative to a categorical deficit-based perspective. Of specific interest was the extent that disability might be addressed as a <i>socially constructed</i> phenomenon. This category included text that presented alternative and competing perspectives of how disability may be defined, treated, and/or conceptualized.</p>
ASL – deaf/HI ASL – Deaf Culture ASL - Other	<p>Included the search terms <i>American Sign Language (ASL), finger spelling, gestural language, interpreters, manual communication, manual sign language, manually coded English, pidgin sign language, sign language, and total communication</i>. This category was subdivided into three subcategories including deaf/HI that included references to the use of ASL or other forms of communication with persons who were deaf or hearing impaired without any discussion of Deaf culture or the Deaf community; ASL - Deaf Culture that included any discussion of ASL as a language unique to the Deaf community and Deaf Culture; and ASL – Other that discussed the use of ASL and other forms of manual communication with persons who were not deaf or hearing impaired. The latter category was not included for analysis in this study.</p>

Search Category	Description of Search Terms and Topics
Attitudes	<i>Attitudes, beliefs, stereotypes, assumptions, expectations</i> and <i>acceptance</i> by nondisabled persons about deaf and disabled persons. This category did not include attitudes, beliefs or ideologies about inclusion.
Authorship – PWD Authorship – Parents Authorship - Other	Text or material authored by persons with disabilities; parents of children with disabilities; siblings/friends of persons with disabilities, and children of deaf adults including excerpts and quotes.
Classification	Text addressing <i>classification</i> and <i>definitions of disability</i> . Did not include text addressing types and characteristics of disability.
Cultural Contributions	Included descriptions and depictions of artwork, paintings, sketches, poetry, songs, sculpture, stories, music, theater productions, led, produced or authored by persons with disabilities.
Deaf Culture	<i>Deaf activism, deaf club, deaf culture, deaf pride, Deaf community, Deaf President NOW, Gallaudet, I. King Jordan, bilingual-bicultural</i> , and any text addressing the response by members of the Deaf community to cochlear implants. This search category did not include discussion of ASL or interpreters (See ASL category above).

Search Category	Description of Search Terms and Topics
Disability Culture	<p><i>Disability culture, disability identity, and disability community.</i> This search category did not include identifying people with disabilities as a minority group. This category included any text that discussed people with disabilities as members of a community with a unique and definable culture including but not limited to a collective identity and shared experiences, beliefs, and other key features that may define a culture.</p>
Disability Rights Leaders	<p>Persons with disabilities who are known leaders in the disability rights movement including, but not limited to Ed Roberts, Justin Dart, Judith Heumann, Wade Blank, Nancy Ward, Tia Nelis, etc. Does not include persons who are famous and may be identified as having a disability. Persons identified must have contributed to the advancement of the rights of persons with disabilities.</p>
Disability Rights Movement	<p>Search terms included <i>disability rights, disability rights movement, disability activists, and disability activism.</i></p>
Disability Studies	<p>Limited solely to the term <i>Disability Studies.</i></p>
Discrimination	<p>Search terms included <i>ableism, discrimination, handicappism, prejudice, stigma, oppression, repression, eugenics, sterilization, extermination, institutionalization and nondiscriminatory assessment or evaluation.</i> This search category was limited to a discussion of societal responses to disability that result in unfair, unequal or unjust treatment.</p>

Search Category	Description of Search Terms and Topics
Film/Media	Search terms included any discussion of the way in which disabled and deaf persons are portrayed in films and in the media. Also includes any film that was named or included at the end of a chapter that portrays persons with disabilities or deaf persons.
Historical Perspectives	Text addressing the historical treatment of disabled or deaf persons, the origins and evolution of Special Education, and specific disability areas.
ILM	Search term was limited to the explicit use of the terms <i>independent living movement</i> and <i>independent living centers</i> . This category did not include discussion of skills related to independent living. This category was limited to a discussion of the movement that resulted in the organization of independent living centers funded by the Rehabilitation Act.
Labeling & Language	Search terms included <i>labeling</i> , the use of language and discussing or writing about persons with disabilities including <i>People First</i> language. This category did not include classification or type and characteristics of disability.
Legal Issues	Search terms included <i>legislation, litigation, due process, court decisions, federal rules/regulations, IDEA, ADA, Rehabilitation Act, and Section 504</i> . This search category included any federal or state law and any reference to legislative, court actions, or statutory provisions including rules and regulations.

Search Category

Description of Search Terms and Topics

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Publications

Magazines (printed and electronic) that address issues of interest to the disability and Deaf community (e.g., *New Mobility*, *Disability Rag*, *Mouth*, *MAINSTREAM*) excluding professional literature and products focused on Special Education and Rehabilitation. Also included books that may have been listed authored by persons with disabilities about various disability topics, excluding Special Education and Rehabilitation textbooks and materials. Materials authored by persons with disabilities addressing areas related to the field of Disability Studies were included.

**Table 3**  
Search Categories Addressed by Each Textbook

Search Category	Textbook										Books	Total Pages
	1	2	3	4	5	6	7	8	9	10		
Access	•	•	•	•	•	•	•	•	•	•	10	62
Advocacy		•	•	•	•	•	•	•	•	•	9	81
Alternative Perspectives		•		•		•		•	•	•	6	35
ASL – Deaf		•	•	•	•	•	•	•	•	•	10	44
Culture		•	•	•	•	•	•	•	•	•	10	66
ASL – deaf/HI	•	•	•	•	•	•	•	•	•	•	10	66
Attitudes	•	•	•	•	•	•	•	•	•	•	10	58
Authorship – Other				•	•		•				3	5
Authorship - Parents		•	•	•	•	•	•	•	•	•	9	94
Authorship - PWD		•	•	•	•	•	•	•	•	•	9	96
Classification	•	•	•	•	•	•	•	•	•	•	10	519
Cultural Contributions		•	•			•	•	•		•	6	56
Deaf Culture	•	•	•	•	•	•	•	•	•	•	10	78
Disability Culture		•	•					•			3	3
Disability Rights Leaders				•	•	•	•	•		•	6	22
Disability Rights Movement		•	•					•		•	4	11
Disability Studies								•			1	1
Discrimination		•	•	•	•	•	•	•	•	•	9	181
Film/Media		•	•				•	•		•	5	32
Historical Perspectives	•	•	•	•	•	•	•	•	•	•	10	141
Independent Living Movement		•								•	2	2
Labeling & Language	•	•	•	•	•	•	•	•	•	•	10	63
Legal Issues	•	•	•	•	•	•	•	•	•	•	10	754
Publications			•	•		•					3	36
<i>Total</i>	8	19	18	17	15	17	17	20	14	19		
Percent of Total												
Search Categories (n = 23)	36.36	86.36	81.82	77.27	68.18	77.27	77.27	90.91	63.64	86.36		



**Table 4**

Topics addressed by chapters addressing cultural diversity, multicultural and bilingual education

Search Category	Textbook										Total
	1	2	3	4	5	6	7	8	9	10	
Chapter on Cultural Diversity, MCE or BLE		✓	✓	✓	✓	✓			✓		6
No. Pages of Chapter		32	53	23	27	33			40		208
1. Disability (as a group of persons)											0
2. Disability culture											0
3. Deaf culture			✓								1
4. Gender					✓						1
5. GLBT					✓						1
6. Diversity of Special Ed personnel		✓						✓			2
7. PWD identified as members of a culturally diverse group or microculture		✓	✓		✓						3
8. Religion				✓	✓	✓					3
9. Ethnicity/Race		✓	✓	✓	✓	✓		✓			6
10. Language		✓	✓	✓	✓	✓		✓			6
11. Nondiscriminatory assessment/evaluation		✓	✓	✓	✓	✓		✓			6
12. Over/Under representation of PWD		✓	✓	✓	✓	✓		✓			6
13. SES		✓	✓	✓	✓	✓		✓			6

**Table 5**

Number of pages on which search terms and topics were found for each textbook and percent of total pages reviewed.

Search Category	Textbook										Total Pages	% TPR
	1	2	3	4	5	6	7	8	9	10		
Disability and Deaf Culture												
Deaf Culture	1	6	17	5	11	11	11	8	1	7	78	1.42
Disability Culture	0	1	1	0	0	0	0	1	0	0	3	0.05
Disability Studies	0	0	0	0	0	0	0	1	0	0	1	0.02
ASL – deaf/HI	1	1	8	8	6	10	14	8	1	9	66	1.20
ASL – Deaf Culture	0	6	9	5	2	4	5	7	1	5	44	0.80
Empowerment												
Access	10	3	4	15	1	4	4	10	4	7	62	1.13
Disability Rights Movement	0	3	3	0	0	0	0	6	0	1	13	0.24
Disability Rights Leaders	0	0	0	0	6	1	6	5	0	1	19	0.35
ILM	0	1	0	0	0	0	0	0	0	1	2	0.04
Cultural Contributions by Disabled and Deaf Persons												
Cultural Contributions	0	17	13	0	0	1	2	17	0	7	57	1.04
Film/Media	0	3	3	0	0	0	1	24	0	2	33	0.60
Publications	0	0	2	7	0	5	0	20	0	2	36	0.66
Socio-Political Factors												
Advocacy	0	4	8	9	12	8	6	17	7	9	80	1.46
Attitudes	1	1	5	7	3	9	1	13	18	2	60	1.09
Discrimination	0	25	19	26	24	4	4	28	8	43	181	3.30
Legal Issues	63	102	48	85	67	56	62	78	73	122	756	13.79
Perspectives: Historical, Alternative, Classification, Labeling & Language												
Historical Perspectives	7	34	11	19	10	5	10	33	4	8	141	2.57
Alternative Perspectives	0	1	0	15	0	1	0	2	1	1	21	0.38
Classification	45	58	43	61	59	51	79	57	35	48	536	9.78
Labeling & Language	2	3	5	7	24	5	1	2	3	11	63	1.15
Authorship												
Authorship – PWD	0	5	18	9	13	12	10	10	1	18	96	1.75
Authorship – Parent	0	31	2	7	9	9	10	1	1	24	94	1.72
Authorship – Other	0	0	0	2	1	0	2	0	0	0	5	0.09

# Social and Economic Stress Related to the HIV/AIDS Epidemic in Botswana

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**Abstract:** The paper describes the consequences of HIV/AIDS in Botswana; the country with the highest HIV prevalence rate in Africa. In addition to frequently experienced trauma due to sickness and death, many households experience rising health expenditures and a sharp deterioration of incomes. High levels of morbidity and mortality among workers result in depressed returns on investment, reduced productivity and increased expenditure on training and replacement of workers. As the health care system finds it increasingly difficult to cope, home-based care provides an inadequate solution since the home infrastructure of many households is inadequate for proper care of seriously ill patients. The stigma associated with AIDS often isolates fragile households and provides an environment in which abuse of infected individuals and of orphans whose parents have died of AIDS is not uncommon. The quality of education also

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suffers, resulting in an ill prepared skilled manpower, with adverse consequences for social, economic, and political development as well as for good future governance of the country.

**Key Words:** Botswana, AIDS, stress

## Introduction

HIV has spread very quickly throughout Botswana since the first reported AIDS case in 1985, resulting in the country having the highest prevalence rate in Africa. The epidemic has been attributed to multiple causes, including an economic structure that has promoted long-term separation of husbands and wives, insufficient attention to AIDS prevention education in the late 1980s, and a good network of highways that facilitates travel and internal migration and rapid spread of HIV (United Nations Development Program, UNDP, 2000). The national median HIV prevalence among 15-49 year olds increased from 18 percent in 1992 to 36 percent in 2000 (Khan, 2001). The results of the year 2000 sero-prevalence regional survey indicate an HIV prevalence rate ranging from 30.4 percent in Molepoloe (Kweneng East District) to 50.3 percent in the town of Selebi Phikwe, with a median prevalence of 38.5 percent (National AIDS Coordinating Agency, 2000). This means a large proportion of households will lose at least one member due to AIDS. Current HIV prevalence rates imply increasingly difficult conditions for households with rising expenditures when household incomes are falling. High prevalence rates also imply frequently experienced trauma due to the sickness and death of family members.

As a result of the HIV/AIDS epidemic in Botswana, more than three decades of successful human and economic development are being reduced and reversed. Life expectancy has been estimated to drop from its peak of 67 years to 29 years by the year 2010 and a third of the adult population is expected to be dead by 2010 (UNDP, 2000). Although the population is estimated to continue to grow, the average annual

rate of growth will be 0.9 percent, with AIDS, as opposed to 2.8 percent, without AIDS, and the population will be 29 percent less than what it would have been by 2021 (Botswana Institute for Development Policy Analysis, 2001).

**Table 1:** The Percentage of the Population 15-49 years old who are HIV positive in Selected African Countries

Botswana	36
Swaziland	25
Zimbabwe	25
Lesotho	24
South Africa	22
Zambia	20
Namibia	20
Malawi	16
Kenya	14
Central Africa Republic	14
Mozambique	13

Source: Botswana National Commission on AIDS, 2002 Annual Report, Gaborone, Botswana

This article attempts to articulate the psychological, social and economic consequences of the HIV and AIDS epidemic in Botswana. The authors combine knowledge gained from interviews, committee meetings, seminars, conferences, and research literature to contribute to an understanding of the implications of HIV and AIDS for individuals, households and national development.

### **Economic Implications of HIV and AIDS**

An increase in morbidity due to HIV and AIDS will weaken and kill able-bodied working

persons who support countless dependent children, elderly parents, and grandparents. It will result in early retirement of infected persons due to ill health and stigmatisation and early retirement of uninfected family members who devote time to looking after their infected relatives. It will result in increased household expenditures on health, increased debt to finance rising health costs, and to finance the cost of funerals of relatives who die of HIV and AIDS. It will also result in reduced household labour and reduced educational and employment opportunities for children from affected households. Productivity in all areas of the economy, especially agriculture, will be depressed (United Nations Development Programme, 2000).

The illness and death of a household breadwinner will result in a sharp deterioration of household income, savings, and assets, which will then reduce the quantity and quality of household food supplies, leading to poor nutrition and ill health. Estimates indicate a drop of 13 percent in per-capita household income for the poorest quarter of households as well as significantly higher income dependency ratios, with every income earner in the poorest category supporting an extra four or more dependents as a result of HIV and AIDS (United Nations Development Programme, 2000). The high HIV prevalence rate is associated with a high rate of poverty, whereby about 47 percent of the population live below the poverty datum line (United Nations Development Programme, 2000). It is also associated with a highly skewed income and cattle ownership (a major source of family wealth) distributions, with the wealthiest one percent of the population owning roughly 25 percent of the herd, while 71 percent of farming households own only eight percent of the herd (United Nations Development Programme, 2000). Without effective intervention, the epidemic will increase the extent of poverty and human suffering and weaken the government's capacity to deliver essential services and sustain human development. This may result in

disturbances to the hitherto tranquil and peaceful political landscape.

### **Psychological Impact on the Infected and Affected Persons**

When they first hear of their diagnosis, people with HIV are frightened by the prospect of sickness and death. Denial is often the first line of response after confirmation of HIV positive status. The person usually does not believe he or she could be infected. For some time he or she may pretend that nothing has happened and continue to live a lifestyle that includes unprotected sex, which puts others at risk of infection. After some time, however, people eventually accept their predicament and may begin to blame themselves for their HIV status. At times there is transference of blame to the person they believe may have passed on the virus to them (Badisang, 1996).

While going through the stage of blaming others, the person may adopt an attitude that he/she does not want to die alone and may deliberately spread the virus to unsuspecting others. This often manifests itself in reckless sexual behaviour. Some infected persons resort to alcohol and drug abuse and in some instances ultimately commit suicide. Some people find comfort in religious commitment and faith in the God who loves them unconditionally and non-judgementally. Other coping strategies include accepting one's condition and attempting to live positively. This includes positive thinking, good nutrition, and practicing relaxation techniques (Fako & Linn, 2003).

Knowledge that one is HIV positive or is faced with an incurable illness such as AIDS brings about a feeling of being unlucky or careless. It also brings about anger, guilt, anxiety, confusion, despair and hopelessness in the absence of a cure. Those infected worry about the idea of facing their own mortality and about the implications of their condition for family and friends. They lose self-esteem, sense of worth and dignity, and suffer perceived and actual so-

cial isolation. The infected may also experience both rational and irrational fears, mostly because of what they do not know or understand. This includes fears of stigma associated with HIV, fear of abandonment, and loss of health, income, friendships, sexuality, home life, and work (Fako, 2005).

When people learn they are infected with a deadly virus they are likely to go through some degree of psychological shock and experience feelings of anger, fatigue, anxiety, guilt, and depression. These feelings do not occur in predictable stages or intensity. Some people are overwhelmed by several or all these feelings at once. Depression in persons diagnosed HIV positive may be mild or severe. Mild depression basically runs its course within a few days and often resolves itself without intervention. When depression lasts too long it tends to overwhelm the individual, who may show signs of alienation, deep apathy, profound hopelessness and chronic lethargy as they begin to think of their privacy, intimacy, and independence. The trauma experienced by the patient is often shared by, or in some way affects, relatives and significant others. The main source of trauma is the fact that there is still no cure for AIDS. This trauma is reinforced when traditional medicines fail to eliminate the virus. There are numerous instances where persons with HIV have relied solely on traditional cures. This has resulted in depletion of already limited family resources, more rapid progression of illness than if available drugs had been used, and further sexual exposure of family members to HIV because the infected persons, at least for a while, believed they were cured (Jack, 1999).

HIV/AIDS remains a stigmatised condition in Botswana. Persons with HIV disability are viewed differently than individuals with other disabilities because they are presumed to be responsible for their condition. Stigmatisation leads to victimisation, blame and discrimination. It reinforces and reproduces social divisions, increases misery and supports the spread of disease as resources essential to preventing infection are

displaced (United Nations Programme for HIV/AIDS, 2000). Infected persons carry a stigma, a mark or token of social disapproval, shame, infamy, disgrace and condemnation, which leads to exclusion, ostracism and isolation. Stigma is a condition that interferes with normal social interaction and social relationships; causes people to react with dislike or disgust; is blamed on the individual affected; is not alterable; and is perceived as likely to contaminate others physically, socially, or morally (United Nations Programme for HIV/AIDS, 2000). Although HIV transmission is largely heterosexual in Botswana, homosexuals and sex workers, who are generally rejected and their existence sometimes denied, continue to be blamed for HIV transmission through what is perceived as their “deviant” or reckless sexual behaviour. In general, people infected with HIV are stigmatised because:

1. HIV and AIDS are life threatening.
2. People are afraid of contracting HIV.
3. AIDS is associated with behaviours already stigmatised in many societies.
4. HIV infection is often, although not always, blamed on irresponsible behaviours and lifestyle.
5. Religious and moral beliefs associate HIV/AIDS with sin, immoral behaviour, promiscuity, “deviant sex,” homosexuality, drug use, and prostitution; all of which are said to deserve punishment from God (Scrambler and Jacoby, 1994; United Nations Programme For HIV/AIDS, 2000).

Although concealable early in its course, later stages of HIV infection and AIDS are rarely hidden from others. AIDS physically disables and disfigures. It produces aesthetically unpleasant results that interfere with normal social interaction. Because the course of AIDS is degenerative and not alterable, it poses risks to others, and

frequently reinforces dominant ideologies concerning good and bad with respect to sex and illness, and regarding the extent of exclusion and inclusion of those infected (Fako et al., 2003).

Because stigma marginalizes, excludes and reduces a person with an undesired difference to the status of a social outcast who is devalued, tainted, despised, and rejected, it can prevent individuals from engaging in positive actions to access health care or participate in studies designed to find a solution. It can also lead to the continued spread of HIV/AIDS due to infected persons concealing or denying their HIV status, thereby putting their partners at risk. Denial and secrecy are a direct response to panic and fear of discrimination resulting in some HIV infected persons refusing to inform others, avoiding medical advice or treatment, and postponing sharing the devastating news to family and friends (United Nations Programme on HIV/AIDS, 2000).

Rejection by friends, co-workers and family is not uncommon. Rejection may manifest itself by others not wanting to share utensils, equipment, and furniture with the infected. Sometimes it may lead to serious discrimination and/or physical abuse of the infected. There is an example of a child who was physically abused by her father and brother for “bringing shame to the family by revealing her HIV status” (World Health Organisation, 2000).

Children whose parents are infected with HIV, or have died from AIDS, are often discriminated against, shunned, and even abused. Sometimes they are denied the privilege of playing with other children or expelled from school. Some guardians and orphans are reluctant to register with the AIDS orphanage programme from fear of being stigmatised. Infected mothers eligible for retroviral drugs to prevent Mother to Child Transmission (MTCT) in Botswana tend to prefer to keep their status secret for fear of stigmatisation, discrimination and physical violence. Families are reluctant to inform health au-

thorities and trained voluntary caregivers about their patients and attempt to keep the HIV infection a family affair. They attempt to shield infected members by keeping them within the household as a way of managing stigmatisation and reducing its spread within the wider community. This often means early withdrawal of the infected from the labour force. There are cases of patients neglected by their families because the affected family does not want to be part of the label and stigma associated with HIV infection (United Nations AIDS, 1999).

### **Stress Associated with Caring for Clients with HIV and AIDS**

As the HIV/AIDS epidemic spreads, it overwhelms the capacity of health services, health workers, social workers, and non-professional caregivers. The patient becomes progressively more dependent and an increasing burden to those who help to feed, wash and respond to their calls, including at night. Becoming a caregiver changes one's lifestyle and predisposes one to considerable stress (Fako & Linn, 2003).

In areas badly affected by HIV and AIDS, many who work as counselors, nurses or trained Community Volunteers, are also caring for someone at home who has AIDS (United Nations Programme on HIV/AIDS, 2000). While at work, they are constantly worried about the patient they have left at home, and are under constant stress from fear of being infected both at home and at work. After working throughout the night changing clothes for the patient and answering their calls, caregivers go to work too tired to function effectively and may run the risk of infection due to fatigue-related carelessness. The burden is borne predominantly by women and girls who provide care as part of their nurturing role. The low status of women results in there being little or no discussion within the family about the personal sacrifices that caregiving will demand on women.

The following psychological, behavioural and physical signs and symptoms of stress among

AIDS caregivers have been identified (United Nations Programme on HIV/AIDS, 2000):

1. Loss of interest in and commitment to work, as manifested by loss of punctuality and neglect of duties;
2. Feelings of inadequacy;
3. Helplessness and guilt;
4. Loss of confidence and self-esteem;
5. A tendency to withdraw from clients and from colleagues;
6. Loss of sensitivity in dealing with clients;
7. Loss of quality in performance of work;
8. Irritability;
9. Tearfulness;
10. Loss of concentration;
11. Sleeplessness;
12. Excessive fatigue;
13. Depression; and
14. Bowel disturbance.

Much of the stress experienced by carers is due to the fact that AIDS is an incurable disease that causes great suffering. Knowledge that the goal of healing cannot be accomplished for any patient leaves the caregiver as helpless as the patient who is facing certain death. Due to oppressive workloads and over-involvement with patients and their families, there is often no time to mourn the death of one patient since the caregiver has to attend to the immediate needs of the next terminally ill patient. The caregiver soon discovers that HIV/AIDS carries a stigma for both the infected and uninfected caregivers. The caregiver is viewed as having AIDS and is rejected and sometimes isolated. As a result, caregivers experience depression, loss of self-esteem, low job satisfaction, loss of concern for others,

a sense of guilt in the midst of helplessness, irritability, excessive fatigue, restlessness, irrational mood swings, negative attitudes towards work and difficulty getting along with others (Ministry of Health, 2003).

### **AIDS Orphans and Changes in the Structure of Families**

One of the significant social and economic consequences of the HIV/AIDS epidemic is the soaring numbers of orphaned children faced with the grim reality of not having a mother or father. Some children have absolutely no adult relative who can care for them. The exact number of orphans is difficult to specify due to different age limits used for the classification of young people as orphans. For purposes of government policy and action in Botswana, an orphan is a child below the age of 18 years who has lost one (single parent) or two (married couple) biological or adoptive parents (Ministry of Local Government Lands and Housing, 1999). Although this definition excludes many school-going dependent children above 18 years of age, thereby underestimating the number of children whose lives are severely affected by the loss of parents due to HIV/AIDS, the trends in numbers of orphans are clearly on the increase.

Dingake (2000) noted that by the end of 1997 around 4 percent of children under the age of 15 years in Botswana had been orphaned as a result of HIV/AIDS. It has been estimated that the number of AIDS orphans below the age of 15 years will increase to 65,000 by the year 2000 (Ministry of Local Government Lands and Housing, 1999). The rapid assessment of the situation of orphans in Botswana conducted in Francistown, Kanye, Mahalapye, Maun, Mochudi, Masunga, Molepolole, Serowe, Tutume, and Palapye, identified and registered 4,496 orphans in 52 days (Ministry of Health, 1998). As many as 1,346 had dropped out of school permanently for various reasons including fear of rejection, isolation and stigmatisation, lack of uniforms, ill health, and/or to provide care

to their younger sisters and brothers. More girls than boys had dropped out of school to give care to other orphans. Many of the girls were secondary school students about to sit for their examinations in Forms Two and Five (Ministry of Health, 1998).

Although orphans have been a part of society since time immemorial, and were adequately cared for within the extended family system, the traditional means of caring for orphans have become insufficient to cope with the growing numbers of additional orphans and dependents due to HIV/AIDS. The social and economic impact of orphanhood is just beginning to emerge. As able-bodied household income earners die of AIDS, the family safety net has been overstretched and significantly weakened, leaving an unprecedented strain on the family. The death of economically active members of households means that young adults leave the unfinished job of raising, socialising, educating, and setting an example for their own children. They also leave behind a growing number of their aging parents who tend to be very old, unemployed, dependent and often helpless. In many cases, orphans left in these circumstances are forced to become caregivers for their aged grandparents. Further, orphans are less likely to complete their schooling or to secure employment. They are at risk for becoming a permanently marginal social and economic group (Fako et al., 2005).

### **Conclusion**

HIV and AIDS are devastating conditions that have imposed, and will continue to impose in the foreseeable future, a significant and potentially crippling burden on the peoples, economies and health care systems of African countries. It has emerged as an uncontrolled worldwide public health emergency as well as a human and economic disaster exacting a devastating toll on the health, economic and social fabric of many communities worldwide. The social impact of HIV/AIDS is far-reaching and can be felt by individuals, families, and com-



**Table 2:** Distribution of Orphans by Sex and Study Sites

District	Population	Orphans		
		Male	Female	Total
Francistown	652,000	295	242	537
Kanye	314,000	315	271	586
Mahalapye	281,000	356	328	684
Masunga	not available	114	139	286
Maun	268,000	232	194	448
Mochudi	255,000	117	115	232
Molepolole	369,000	161	186	347
Serowe	303,000	293	343	636
Tutume	101,000	226	220	446
Palapye	173,000	181	168	349
		2,290	2,206	4,496

Source: Ministry of Health. 1998:13

munities. HIV and AIDS will result in frequent trauma and grief associated with caring for a patient who wastes away very slowly and eventually dies. While volunteers and health workers may drop out if HIV-related stress becomes too great, those at home are more likely to be isolated with their problems, without easy access to anyone who can help them find solutions or relief.

Although vaccine candidates have been tested since 1987, vaccine development for HIV has not been and will not be an easy process. The complexities of HIV as a virus and AIDS as a disease have made successful vaccine development a formidable task. Finding an effective and safe vaccine and protecting the population from HIV infection and its long-term consequences remain urgent goals of the global community, which will only be realized with substantial increases in funding from the donor nations.

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## **Bypassing the Perils of Victimisation: A Suggested Future Pathway for Disability Studies**

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**Abstract:** Current trends in Disability Studies hint at an overemphasis on the social model. Much description and analysis has been devoted to the dimensions of stigmatisation—how and why people with a disability are a disadvantaged social minority. While this is important, it can exacerbate victimisation in political and personal domains. This article scrutinises victimisation in disability thought and suggests ways to bypass the perils of victimisation. The article focuses on psychosocial implications of disability and, above all, suggests prescriptive measures—something rarely mentioned in disability thought.

**Key Words:** Disability Studies, Social Model, Reflexive Sociology

### **Introduction**

There is a dearth of knowledge in disability studies. This intellectual void concerns maximising psychosocial potential of people with a disability. At present we have a sound and comprehensive understanding of social dynamics and structures prohibiting access to society. The social model has enabled this through extensive epistemological description and analysis. It has shown how and why ableism is prevalent. But little academic investigation has been allocated to how people with a disability can maximise their potential in a personal domain. As a theoretical critique, this paper attempts to show why this is so. Additionally, it suggests prescriptive measures by advocating epistemological innovation in Disability Studies - psychosocial potential maximisation. The article is divided into three

parts; description, analysis and prescription. It begins as a sociological study - to describe and analyse - then funnels into micro-sociological thought - the prescriptive element.

### **Description: Stigmatisation, the Glass Sphere and Victimisation**

Feminist Ann Morrison coined the term the “glass ceiling” in 1987. She identified the glass ceiling as the invisible barrier preventing women and people from minority groups from attaining exclusive management jobs in commercial organizations (Code, 2000). In feminist thought, the concept also refers to a point or rung in the organization’s hierarchy where women cannot go further. It is an artificial social barrier created by the historical premise that males are more competent and deserving of status than are females. Men with the same qualifications and abilities or less are given preference over women on the basis of their gender. The glass, a transparent barrier, is metaphorical. Women can see beyond but are prevented entry by the glass ceiling.

People with a disability face a similar situation. The “glass sphere” is a figurative representation whereby a person with a disability can see through the surrounding glass and others can see the person inside the sphere (Jacobs, 2003). Untouchable and unreachable by others, the outside world is inaccessible to the person within. This sphere is by no means an illusion and has two defining themes. The first is the stranger-to-stranger dynamic that is a common characteristic of traditional relationships whereby people act in “roles” ascribed to them (Giddens, 1996; Kopp, 1971). Traditional communities, which still exist and function worldwide, are mechanical solidarities whereby the power of the state and/or religion are paramount and function best with the stringent allocation and conditional interplay of roles. There is a tendency to denounce, or even eradicate, individual autonomy. Pressure toward conformity is another inherent human trait (Giddens, 1996). Human character is deemed unalterable and fixed, and

certainly not something that can be improved or maximized (Seligman, 1994). In these social circumstances, the person with a disability has little choice but to “be disabled” for the non-disabled person (or who Ervin Goffman [1963] often refers to as “we normals”) and thinking and interaction is dictated by stigma. Martin Seligman (1994) believes the evolution from the entrenched belief in the unchangability of human nature towards its opposite of human autonomy is relatively recent. Self-identity has become a psychological rather than a social construction whereby people assume roles that are simply inherited or predetermined by status (Giddens, 1996). This concept of identity generates a politic where the self, and increasingly the body also, operate as a reflexive project. To determine the health of ones lifestyle, a “person’s identity has in large part to be discovered, constructed and actively sustained” (Giddens, 1996, p. 82; Jacobs, 2002, p. 63). This implies people have control over their destiny and presumes a close tie between individual autonomy and lifestyle. The second major influence on the glass sphere is more complex and relates to individual autonomy. Since the glass sphere caused by their disability separates them, the person is in many ways exempt from responsibility for personal well being, which is a natural condition of everyday living that generates psychosocial competence (Csikszentmihalyi, 1992; Namka, 1989). This will be explored later in this article.

The glass sphere is perhaps a more debilitating condition than the glass ceiling. At least with the ceiling there is interaction and “touching” with others beneath it. Nevertheless, the glass sphere is of particular relevance to disability. The glass is hardened by the outside incurrance of stigmatisation and can be perpetuated by the victimisation of the person within. Little or nothing is done and the person remains fixed in the glass sphere. Goffman (1997, p. 205) explains:

“By definition ... we [*sic*] believe a person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his [*sic*] life chances. We construct a stigma-theory, an ideology to explain his inferiority and account for the danger he represents, sometimes rationalising an animosity based on other differences...”

Goffman identifies three contributors responsible for the existence of the glass sphere. Firstly, the person with a disability is deemed subhuman, even animal-like; secondly, the process of stigmatisation is often a subconscious rather than conscious act on the part of “normals”, and finally, deviance is often legitimized.

Stigmatisation, however, is not exclusively an externally imposed phenomenon. Through shame and guilt, the disabled person is often forced into the stranger versus stranger social dynamic. Shame, stated Goffman (1997, p. 206), arises “from the individual’s perception of one of his [*sic*] own attributes as being a defiling thing to possess, and one he can readily see himself as not possessing.” For the disabled person it could be the perceived advantages of being able bodied. Guilt originates in the realisation that we or, more specifically, our behaviour is deviant and/or transgresses the bounds of social norms – something that is apt to cause anxiety. Anthony Giddens (1996, p. 68) claimed that this may also derive “from a failure to live up to expectations of the ego-ideal.” This goes beyond simply wishing to “lose” ones disability to having the ability to function with greater ease in social circles. Nevertheless, the notions of shame and guilt hint at the internally driven socio-cognitive processes that harden the glass sphere. These phenomena lead us to victimisation.

### **Victimisation**

The term “victimisation” is commonly known as the context where a person or group is victimized because they are socially disad-

vantaged. This paper views victimisation as a mindset. Usually, stigmatisation precedes victimisation because stigmatisation is largely a macro-sociological concept and victimisation is primarily micro-sociological. Although two separate theoretical entities, both stigmatisation and victimisation operate through an oppressor/oppressed binary. Stigmatisation is the creation of a social victim through labels, stereotypes and discrimination. Victimisation is self-generated, whether in a personal or group domain. This circumstance is primarily the acceptance of stigma by a social victim who manipulates their inferior social status for perceived gain. This manipulation may perpetrate socially unaccepted behaviour and an endless cycle of desperation—a situation for which victims often blame others or society because they are seldom accountable for their actions (Kopp, 1971). The serious problem is that the victim remains a stranger to a stranger by choice. They sidestep genuine interaction or feelings for ready-made responses (Jacobs, 2002). Sheldon Kopp (1971, p. 117) said this can be “accomplished through threat, flattery or pathetic appeal” – forms of emotional blackmail or bribery. The denial of personal accountability can reinforce traditional perceptions of the disabled as incapable of making life choices and as “dependent, passive, helpless, and childlike because that is what is expected of them” (Coleman, 1997, p. 224). Thus, alienation is not necessarily a one-way process where a person feels expelled because of their disability. Exclusion, then, is not simply the result of stigmatisation.

Goffman (1963) stated that stigmatised or social victims tend to be fixated on their perceived weaknesses. This is the “hook” upon which the person has hung all their inadequacies, dissatisfaction, procrastination and unpleasant duties. It appears in the manufacturing of excuses to exculpate one from everyday chores and responsibilities. The hook becomes a dependency, or a psychic addiction, that provides refuge from the competition of everyday life and social accountability (Goffman, 1963). Thus, victimisation derives from a species of obsessive-compulsive

behaviour—a driving uncontrolled motivational force. Obsessiveness is noted in the unwillingness to stop the negative thought processes or voicing of the same problems that have no answers (Namka, 1989). Compulsiveness is apparent in the urge to get others to play reciprocal roles (Kopp, 1971). Generated by self-pity, this desperate game requires securing a supporting response. The result is never losing but, equally, never winning—a vicious cycle that produces psychic stagnation and disillusionment (Kopp, 1971; Jacobs, 2002). Kopp (1971) suggested the preservation of various character defenses is due to the avoidance of genuine relationships with others. Additionally, victimisation exists on the presumption that all misfortunes in one's life are a result of "fate" and that little, if nothing, can be done to remedy a low quality of life (Goffman, 1963). His/her identity changes little for it is distilled at an infantile level of psychosocial development—a point prompted by the Dalai Lama (1999, p. 181) who stated that if everyone continually treated us as infantile the result would be a person "with the mental and emotional development of veal" for it is "the very struggle of life that makes us who we are."

Victimisation, however, is not always overt manipulation of others. It may be an existence caused by resignation or overwhelming helplessness caused by too many punishments or rejections and too few rewards for toil. This may be caused by a dire lack of assistance that enables a person to maximise their psychosocial potential—something encountered by Anthony Hogan (2001) in his study of psychosocial skills for deafened adults. He interviewed 58 deaf people for his doctorate thesis and their stories emphasised the need "to move beyond deafness rather than seeking to get over it" (Hogan, 2001, p. xiv). "Seeking to get over it" intonates short-term remedies or patch up jobs. "Moving beyond" disability implies a permanent proposition with proactive lifestyle strategies. To move beyond disability as a social construct alone, it is necessary to understand psychosocial dynamics—in particular the cognitive element of victimisation.

Nevertheless, the key principle remains—the individual denies themselves opportunities to develop psychosocial competencies.

The seeds of victimisation are usually planted during times of adversity. They appear in the following examples of common mistakes in thinking paraphrased from the works of behavioural therapists Bob Montgomery and Lynette Evans (1989). These have purposefully been placed in the context of disability.

### **Common Mistakes in Thinking**

#### **Overgeneralising**

Overgeneralising involves making concrete conclusions on the basis of random incidents. You are telling yourself that individual events are "proof" of the overall picture: "He/she rejected me because of my disability and that means everyone else thinks the same."

#### **Black and White Thinking**

Black and white thinking involves seeing things as polar opposites, this or that but never in-between. A friendship must be very good, or it is very bad. No shades of grey. Read: "People must accept my disability or else they are discriminatory."

#### **"Who Needs Evidence?"**

This mode of thinking includes making and acting on a conclusion without any real evidence: "I am a lonely person because of my disability and everyone is scared of me. That's why my future is bleak." How is this possible when you have not asked everybody, or even do have some friends?

#### **Looking at the World through Deep Blue Glasses**

This mode of thinking entails focusing steadfastly on perceived weaknesses and magnifying beyond all proportion mistakes, failures and problems. It also involves ignoring or belittling personal strengths, successes, happy times and achievements. This, for instance, may mean

focusing on the negative aspects of a disability without paying heed to the competencies and abilities one has to best the disability.

### Imagining the Worst

Imagining the worst means anticipating the worst possible outcome for any event. The fear is so exaggerated that it is realistically improbable, if not impossible, for the dreaded event to manifest itself. And sometimes it eventuates in self-fulfilling prophesy. Read: “I am disabled and many people with a disability are unemployed. That means I’ll be unemployed for the rest of my life.”

### Taking Things Personally

Taking things personally includes blaming yourself for everything despite only being partly or not at all responsible. Taking things personally can also mean assuming every mistake is immediately detected and disapproved by others, and everything in this universe is immediately connected with you. It defies the logic that most people are too self-involved even to notice what you are saying or doing. Having a disability can also make one too self-conscious. This self-imposed reservation can impose dire restrictions on the ability to maximise psychosocial potential. It can cut the bud of potential friendships, prevent one from trying new experiences, taking risks to develop new competencies – all of which are stimulants of personal growth.

How does a social victim think? “Common Mistakes in Thinking” were examples of *how* people with a disability can think. The following, “Negative Thought Processes” are socio-cognitive processes devised from Montgomery & Evans’ (1989) *Ten Popular Irrational Beliefs*. They are examples of *what* people with a disability can commonly think. This cognitive element shows how the metaphor of the glass sphere can be generated from within.

### Ten Negative Thought Processes

1. I must be loved, at least appreciated or approved by each significant person I

meet. This can stem from the common thought: “I have to prove that I am not a disabled person.”

2. Since disability is often synonymous with failure, I should be completely competent, be flawless and achieve with every opportunity. Otherwise I am worthless, useless.
3. Some people are discriminatory, immoral, depraved or evil. They must be punished for this. This is particularly true of those who patronise me and wish ill on people with a disability.
4. I will never be normal and I’ve had enough. My life is helpless and hopeless because I have a disability.
5. Unhappiness, including mine, is the result of society’s wrongs against people with a disability. Society is to blame for my plight, not me.
6. I should worry a great deal about dangerous, unpleasant or frightening things. Social wrongs always need to be righted.
7. My life is extremely hard because I have a disability. This means I am entitled to allay difficult or unpleasant tasks or problems rather than to address them. Ignore the problem and it will go away. Better safe than sorry. No one will notice and it is okay because I have a disability.
8. I have to have that stronger person in my life. I am one half of a whole, otherwise I am not a complete person. That is why having a partner makes me feel normal and not disabled.
9. I cannot do anything right because I have a disability. My history is riddled with mistakes and misfortune because I

am not normal. This is the reason why I have my problem(s) now.

10. I ought to ease the suffering of others. If I do not I am a bad person.

These negative thoughts are rife with “I must,” “I ought to,” “I have to,” and “I should”. Thus we can feel the obsessive-compulsive nature of the social victim’s thought processes. We can sense the anxiety evident in victimisation--the result of self-defeating cognitive processes. Stigmatisation has nothing to do with it, nor has a physical, sensory or intellectual “abnormality” for that matter. Imperatives and absolutes are disabling thought processes. They cripple able bodied “normals” and disabled people alike. Whilst these thoughts were made in the context of an individual’s perceptions of the world, the concept of disability can transcend to the group realm.

### **Analysis: How Victimisation Can Manifest in Disability Studies**

The macro sociological or political activist approach of appealing to one or many social establishments that oppress people with disabilities can be counterproductive. Political activism, stated Tom Shakespeare (1997, p. 31) “is a very powerful rhetoric device for demanding social change,” because “it identifies society as the main problem for disabled people, but it says little about the experiences of disabled people” - explicitly, psychosocial experiences. Consequently, the disabled can remain exiled as a ghettoised social minority who are “considered as a separate political and social constituency” never operating on par with others (Shakespeare, 1997, p. 31).

Disability Studies has defined disability as a social construct. It shows how people with a disability transgress overarching social norms, values and beliefs. It has also generated many positive changes that have influenced policy making and perceptions in society at large. Thus, Disability Studies shares similarities with Femi-

nism, Gay and Lesbian suffrage and Indigenous studies. Kinship is shared in the social model. The following randomly selected quotes reflect a sentiment Disability Studies has inherited from other civil rights movements:

“The disablement lies in the construction of society, not in the physical condition of the individual” (Brisenden, 1998, p. 24).

“We are disabled by the lack of social and personal support. We are all disabled by society’s barriers” (Cooper, 1997, p. 39).

“Disabled people are disabled not by the fact of their impairment, but by disabling prejudice and discrimination” (Cooper, 1997, p. 39).

Society is the problem, not me. There is a lot of truth in the statement that society “makes” a disabled person (Scott, 1969). But how much of this social phenomenon is externally imposed or internally driven? Barriers do exist, so too does discrimination and prejudice. But comments like these cast the blame onto society and can detach the individual from stigmatisation processes. They miss the crucial importance that self determinism has to play in garnering social acceptance. How? Proactive measures required for psychosocial potential maximisation--what the individual can do to negate the forces of stigmatisation and avoid the perils of victimisation - are neglected.

The political activist impulse, in an extreme form, can mirror fundamentalist ethos apparent in other civil rights movements who use the social model. The works of Andrea Dworkin, Susan Brownmiller and Catherine McKinnon are the feminist equivalent (Paglia, 1995). Disability Studies has the potential to become a safe haven for victims to share and air personal grievances in the guise of political activism. The result could be similar to the current crisis of victimisation experienced by feminism--a concern voiced by non-conformist feminists such as Eva Cox, Helen Garner, Christine Hoff Sommers,



Camille Paglia, Katie Roiphe, and Elizabeth Wurtzel. Also, we can be drawn into what feminist Eva Cox (1996, p. 80) called a “competing victim syndrome.”

Mark Deal’s (2003) article *Disabled People’s Attitudes to Other Impairment Groups* does not specifically address the notion of competing victims. But he does speak of a hierarchy of impairments. He devotes much of the article to the perceptions of able bodied adults and children of people with disabilities, before analysing the views of people with disabilities on the same subject. He shows the exclusion of a person with dyslexia from a support group for people with disabilities and uses this notion as a thesis that can be generalised across the spectrum of disability activism. Certain disabilities have more status than others, more privilege. Individuals with these disabilities are deemed to have greater ownership of disability. There is also an unwritten rule that the greater the person’s ability to assimilate into mainstream society, or the more invisible their disability, the less equal they are amongst others with a more “abnormal” disability. Hence, a person with dyslexia is less an equal than a person in a wheelchair. The anti-assimilation politics of Deaf culture is another example of political activism causing adverse affects. It is why deaf individuals, who pursue, attain and sustain relationships with hearing peers are deemed to be “uncritically” embracing a lifestyle that betrays their deafness (Lane, 1993, p. 7). Identity politics framed in this manner can exclude valuable human resources—people who can help us move beyond the traditional perception of disability as an ontologically intolerable experience.

As suggested, the social model tends to be overly concerned with how social factors “create” a disabled person. There is a limit to how much social barriers can be deconstructed using the social model of disability. Disability, like race or gender, is not wholly the product of external or structural influences. Wheelchair friendly buildings may allow physical access for

a person using a wheelchair, but the psychosocial dynamics can remain largely unaltered. The person can still be an inhabitant of a glass sphere, be socially scared and psychologically impaired. As Daniel Johns (2003) sang, “All the bridges in the world won’t save you if there is no other side to cross to.” “Building bridges” or pathways, which is the product of deconstructing structural barriers and the true value of the social model, is crucial. But true integration, assimilation with the mainstream, breaking out of the glass sphere, requires competence with psychosocial skills in a personal domain. Where the social model of disability places the onus on society this new way of thinking imposes responsibility on the individual. This aptitude determines the extent and quality of relationships with the “Other”—those known as “normals.” Surprisingly, few disability activists have taken advantage of the proactive micro-sociological thought at our disposal - namely the works of cognitive behavioural theorists. Nor has there been a comprehensively devised intellectual framework that assists people with a disability in becoming ontologically-secure, self-actualising agents.

### **Disabled Heroes**

Some disability theorists view psychosocial potential maximisation as problematic. They claim that the “process of adaptation” is expected of people with impairments in order to become as “normal” as possible. This pressure can be overwhelming, if not more disabling. Additionally, those who perceivably “overcome” or “eradicate” their disability are sanctified and viewed as exemplars, whereas the perceived majority who do not achieve or aspire to this idealised perception of disability are deemed lazy, pathetic and antisocial. Susan Wendell (1997, p. 271) refers to the sanctified exemplars as “disabled heroes”: “people with visible disabilities who receive public attention because they accomplish things that are unusual even for the able-bodied.” Lennard Davis (1995, p. 10) supports this claim that the majority see the disabled as individuals without abilities, social function or status, and those who

“perform successfully” somehow lose their disability. The manufacturing of “disabled heroes” creates a “feel good” factor that is comforting to the able-bodied and fuels the myth that “science will eradicate the disabled body” (Davis, 1995, p. 40). This is often perpetuated by tabloid newspapers and television citing the “miracle of medical science” for “cures.” An example is the media’s portrayal of people who have successfully received a cochlear implant. Those content with their deafness, and I am one, are deemed abnormal because they have not adhered to the ableist conception of eradicating their disability via a perceived medical marvel. Hence, sanctified disabled heroes can serve to increase “the ‘otherness’ of the majority of disabled people” (Wendell, 1997, p. 271). It is worth remembering that the disabled hero often has social, financial or physical resources that are unusual for most people with disabilities. Abraham Maslow would argue that their basic needs have been gratified because it is precisely these support systems that have enabled them to maximize their psychosocial potential. But disabled heroes should not be dismissed on the basis of their being perceived exceptions to the rule.

Criticisms by Wendell, Davis and the like are constructed by assistance of the epistemological prism that is the social model. Whilst directed at ableist media practices, aforementioned citations by each author intonate cynicism towards “disabled heroes.” This attitude can come at cost. It evokes the question: “Is it wrong for people with disabilities to maximize their psychosocial potential?” More damning still is shunning a wealth of knowledge these people can possess to negate stigmatisation and avoid the perils of victimisation. How do they do it? This is a question the social model of disability is ill-equipped to answer. Why? The telescope is on overarching macro-sociological structure. A microscope, micro-sociological investigation, is required to see how people with disabilities maximize their psychosocial potential.

Psychosocial potential maximisation could be interpreted as “becoming as normal as possible.” This is a mistake. Although there is an element of normalisation, this proposed epistemology is devoid of sinister ableist notions of repairing a broken body, of denying one’s disability. Where the medical model of disability is one-dimensional, psychosocial potential maximisation is multi-faceted. It involves knowing, developing and mastering as many social and psychosocial competencies as one’s potential can permit. Put simply, the imperative is to purposefully seek out and continue a lifestyle that is healthy for both body and soul. This is as close as one can be to being happy (Csikszentmihalyi, 1992). Thus, normalisation is incidental and not the paramount goal. Normalisation, which comes through actively sustained and maintained interdependence, is a by-product among many.

Disability Studies has a responsibility to learn personal characteristics and lifestyle practices that increase the likelihood of living a rewarding life with all kinds of disabilities. By thinking outside the social model, taking a micro-sociological approach, “disabled heroes” may show us that living with a disability is manageable. Disability is not purely the product of ableism and can be deconstructed on a personal level. Disseminating and utilising this micro-sociological knowledge is no different than sportspeople learning and executing specialized skills to best their ability in a chosen sport. Psychosocial potential maximisation embraces all social spheres in a person’s life and contributes to personal well being. Finally, investigation into proactive lifestyle skills learned from “disabled heroes” is not just for academic benefit. People whose lives are impacted by disability, ordinary citizens with a disability and their significant able bodied others, have an insatiable demand to have their needs met on a personal and interpersonal level. This brings us to the next section.

## Significant Others and Researchers who are an Outsider

Each and every person with a disability has significant others in their lives. As David Wright (1993, p. 5) stated about his deafness:

*“About deafness I know everything and nothing. Everything, if forty years firsthand experience is to count. Nothing, when I realise the little I have to do with the converse aspects of deafness – the other half of the dialogue. Of that side my wife knows more than I.”*

Disability Studies, as Jill Humphrey (2000) argued, is at a dire risk of alienating a vital resource - significant others in the lives of people with a disability. These people include partners, family members, peers, professionals and assistants who are a supporting cast in the lives of people with a disability. Disability is an extremely personalised experience. But our experience is shared, our loved ones and peers can have an affinity with disability that far exceeds our own. Our voice is not the only voice. The experience of disability is holistic, not just individualistic.

A parent of a child with cerebral palsy, providing they care and love their child, has an intimate and expert understanding of that specific disability. They have experienced the unique psychosocial processes that have occurred since the birth of their child. This knowledge is often undervalued. It is certainly under-utilised. Subsequently, future generations of parents with children who have cerebral palsy will endure the same cumbersome, painstaking process. This learning process, often a lonely one that need not be so isolating, is wrought with trial and error. One crucial problem is that the legacy of knowledge experienced by previous generations of parents is lost. There are two reasons, which can be linked to the social model. Firstly, the experience of parents who have a child with a disability is deemed less important than the experience of the disabled person. The same ideology applies to the experiences of significant

others. Secondly, the psychosocial dynamics of disability have been placed a distant second to the social model in academic inquiry. Undermining psychosocial dynamics indirectly undervalues and excludes the experience and skills of significant others, able-bodied researchers and “disabled heroes”.

Believing “the other half of the dialogue” of disability is vicarious at best is a fallacy (Wright, 1993, p. 5). The partner of a woman who has actively chosen a life as a non-signing deaf person in mainstream society has a specialised perception of the psychosocial dynamics specific to that phenomenon. She/he is emotionally equipped to nurture the ontological security of her/his cherished friend and lover. That intimate experience, as Wright insinuated, is not vicarious but equal with the person who has a disability. Significant others are not strangers looking in from the outside but insiders operating from within. Exclusion of able-bodied people from disability discourse for the sake of identity preservation can be counterproductive (Humphrey, 2000). Ignoring significant others, their voices and vision, defeats the purpose of understanding disability as a whole—in particular the specialised knowledge and skills of psychosocial potential maximisation that significant others can offer.

The same can be said of the able-bodied researcher. Providing their minds are stimulated, their hearts are keen and their work is meaningful, what is the problem? Yet it is naive to assume a researcher coming from another civil rights headspace can immediately slot into the disability mode of thought. A gay able-bodied researcher may have an intimate understanding of societal pressures that come with being a same sex lover. But that experience alone is not enough to adequately understand disability. I have equal credibility writing about feminist issues, as I am a white heterosexual male who has had a profound hearing impairment since the age of five. People researching disability need to have lived with a person with a disability, to have been a significant other in a person’s life.

Overreliance on the social model of disability can inadvertently package its practitioners and believers as disabled. Embracing reactive identity politics can engender navel gazing questions like, “Can a fat woman call herself disabled?” Charlotte Cooper (1997) provided a strong argument that justifies the importance of differentiating what constitutes disability. But disability need not be limited to a physical, sensory or intellectual “abnormality.” The concept of disability transcends to the emotional or psychic domain—something that is outside the square of the social model.

### **Beyond the Social Model and Post Structuralism: Epistemological Innovation**

“Rarely,” wrote Fiona Campbell (2001, p. 1), “is the matter of ontology considered a paramount concern in unpacking the ways in which a ‘disabled person’ is produced.” Ontology concerns the psychosocial dynamics in a person’s life and how they manage these dynamics. Often, people with a disability are assumed to be in an irreparable “static” emotional state. Furthermore, Campbell (2001, p. 2) states that disability “is assumed to be ontologically intolerable” and certainly not an autonomous experience. We know living with a disability need not be an ontologically intolerable experience. But, as Campbell stated, little investigation has been made into how we can master what is presumed to be an ontologically intolerable experience. We are yet to devise a comprehensive socio-cognitive processing approach in Disability Studies—to go beyond the social model as it were. That does not imply the social model is redundant. The proposed approach absorbs the social model whilst advocating and executing a psychosocial potential maximisation epistemology in Disability Studies. The social model could provide a foundation upon which a micro-sociological model can be built.

The reason why ontology has been rarely considered in disability thought could be be-

cause there has been too much description and analysis; too little prescription. Analysis and description serve mainly to provide the dimensions of stigmatisation. This is vital, but it says little about the self-generated elements of victimisation and psychosocial potential maximisation. Academically, the over-reliance on description and analysis may suggest the social model is a restricted epistemology in a disability context. Part of the problem is a strict adherence to Post Structuralist and Interpretivist thought. Post Structuralism describes an overarching belief that scientific rationality is increasingly becoming ineffective and anachronistic (Denzin & Lincoln, 1998). It connotes the replacement of empiricist thought and practice with an increased emphasis on a plurality of viewpoints (Jary & Jary, 1991). Post Structuralism is social analysis that attempts to unearth dynamics beneath surface appearances. It strives to conceptualise deeper, more “real” social structures and power dynamics (Giroux, 2001). Interpretivism, which is primarily qualitative research, entails a researchers’ involvement with the researched. It empowers by connecting people otherwise not connected. The research is interactive, inclusive, dialogic and democratically esteemed rather than hierarchical, separative and categorically validated (Ferguson, Ferguson & Taylor, 1992, p. 296). Interpretivism has given voice to people with a disability, has shown that the reality of disability is distinct from the medical model and ableist conceptions of disability. Where Post Structuralism has demonstrated social structural implications, Interpretivism has provided previously unacknowledged personalised insights. Post Structuralism is the parent epistemology of Interpretivism. In context, this helps explain that Post Structuralism is perhaps more prevalent in Disability Studies than Interpretivism.

While Post Structuralism and Interpretivism have achieved a richer understanding of disability, both are still locked in describing and analysing. Interpretivist investigation in Disability Studies is yet to comprehensively explore the vital concept of ontology and how this influ-

ences the lives of those experiencing a disability. Active participation consists of two parts to a whole. The environment is one half and the internal thought processes are the other. Prescriptive measures for psychosocial potential maximisation are required to by-pass victimisation and negate the forces of stigmatisation. This connotes equipping people with a disability and/or their significant others with emotional tools to live an ontologically productive lifestyle relative to the restrictions of disability. Interpretivism has the potential to help us understand these micro-sociological lifestyle practices. Increased focus and understanding on how people with a disability utilise their socio-cognitive skills can accelerate the deconstruction of traditional modes of disability, especially if this knowledge is disseminated, shared and practiced. Qualitative research also has the power to include the voices of significant others in disability research. Prescription is the action component of theory—a critical concept not fully utilised let alone understood in Disability Studies.

### **Prescription: Psychosocial Potential Maximisation**

Questioning traditional modes of thought has been the first step towards detraditionalising disability. This is a sociological perspective. Actively deconstructing disabling environments on an individual level is another step. This is a psychosocial perspective. By seeing society as the sole problem we can perceive ourselves as members of an oppressed minority and not as autonomous social agents. How we think affects how we behave. How we behave determines the quality of our lives (Harvey, 1998). These are the two core concepts of cognitive behavioural therapy. Successful implementation of prescriptive measures requires incorporating cognitive behavioural theory into Disability Studies. Detailed analysis regarding the social integration of people with a disability is too comprehensive to address in this article. However, key issues could be (a) realistic expectations, (b) assertiveness training, and (c) pre-preparedness.

In short, expectations relate partly to identifying situations in which the individual is more likely to maximise social interaction. Expectations also involve challenging “what you think” or “how you think”—the Belief System which will be explained shortly. Assertiveness training involves developing confidence and competence in skills that enable a person to actively and independently operate in social situations. Pre-preparedness is training in identifying possible threats and preparing oneself to deal with these social situations beforehand. These are examples of psychosocial skill training. Mastering these skills leads to psychosocial potential maximisation and a better quality of life for people with and without a disability.

Humanist psychologist Abraham Maslow is renowned for his theory of self-actualisation. Self-actualising individuals are self-sufficient people who maximize their psychosocial potential in a diverse and perpetual manner. Maslow’s works cannot be condensed in one quote, but the following identifies self-actualising traits as:

*“... Self-decision, self-government, being an active, responsible, self-disciplined, deciding agent rather than a pawn or helplessly ‘determined’ by others ... [Self-actualising people] make up their own minds, come to their own decisions, are self-starters, are responsible for themselves and their own destinies” (Maslow, 1970, p. 161).*

Social destiny has direct links with psychologist Julian Rotter’s (1972) notion of Locus of Control. People who believe their fate is determined by outside forces/chances have *external locus of control*—a core component of victimisation. Those with *internal locus of control* believe and demonstrate their destinies are in their control. Where people with internal locus of control consciously and autonomously maximise their psychosocial potential, those with external locus of control have not developed or utilised skills necessary to determine their quality of life—they are, and behave like, a pawn helplessly deter-

mined by others or the mythical unseen hand of fate. Numerous studies have shown “internals achieve more in school, act more independently, and feel less depressed than do externals” (Myers, 1995, p. 489). As determined by Maslow and Rotter, self-actualising individuals execute internal locus of control in their everyday dealings with the world. From this, a transition can be made into how victimisation can be bypassed via prescriptive measures for psychosocial potential maximisation. This entails changing “how you think” and “what you think.”

Some people by nature appear to be successful at everything they do. Maybe they are competent with managing their thought processes, and are better able to utilize internal locus of control. The following thought maps show the mechanics of what Coleman alludes to as socio-cognitive processing. They are an elaboration of themes in Davis, Esheiman & McKay’s (1982) *The Relaxation & Stress Reduction Workbook*.

A > C

“A” equals the Activating event and “C” equals the emotional Consequence/s. Simplistic thinking sees A directly causing C – outside events causing internal monologue and feelings (Bourne, 1990). This thinking is reactive, not proactive. It also suggests the presence of an external as opposed to an internal locus of control. “She said this about me, and that means I am a loser” – activating event and emotional consequence. The negative thoughts create negative consequences. What cognitive behavioural therapists do is look at the “B” – the person’s Belief system – in between “A” and “C.”

A > B > C

The Belief system is how you view the issue at hand. “Society is to blame, not me” is a Belief. The Ten Irrational Thought Processes are Beliefs, so too are the Ten Rational Thought Processes. It is the interpretation of the Activating event that determines the Consequence/s. A does not

cause C, B causes C – beliefs cause emotional reactions (Davis, Esheiman & McKay, 1982). The role of cognitive behavioural therapists is to challenge these negative Beliefs and change them into positive Beliefs. Following the A-B-C logic, proactive Beliefs ensure positive outcomes or emotional Consequences. A thought such as, “My life is miserable because I am stigmatised,” is likely to create negative Consequences. A proactive self-actualising person is able to identify these reactive thought processes, challenge them and act upon them (Bourne, 1990). They think, “My disability is only part of who I am, but I can be friends with a diverse range of people.” Thus, they are likely to create positive Consequences for themselves. Application of this to a diverse range of events may see general practices of proactive coping strategies. In all, this approach is likely to increase a person’s quality of life.

The following Ten Rational Thought Processes derive from Montgomery & Evans (1989), and are rational responses to the Ten Negative Thought Processes. Again, they are placed in the context of disabilities.

### Ten Rational Thought Processes

1. I have a need to be loved, liked or appreciated by some people in my life. This will not always happen. I will feel lonely and disheartened because of it. But, I can cope with these emotions. My disability need not be an obstacle to this. I can make constructive steps to pursue and maintain better relationships.
2. I want to succeed. Risk taking is never without occasional failures or periods of ill fortune, even for people without a disability. I will feel bad when this happens. But I can cope and persevere by trying better next time.
3. The world never has been and never will be a fair place, especially for

disadvantaged minorities like people with a disability. Some people have done and do bad things. Upsetting myself will not change it.

4. My expectations will not always be met, but this is manageable. I can usually take constructive steps to ensure my expectations are met. But, if I cannot, exaggerating my disappointment makes things worse.
5. Factors outside my control can influence my problem(s). Prejudice and discrimination towards myself and others with a disability are real. But my present thoughts and actions can worsen the problem(s). I can control these.
6. There is a time to think about the future, but too much worry can make me unhappy. This is especially true when my disability can affect my aspirations. However, I can prepare for possible threats/problems that may or may not be directly related to my disability. That is the best anyone can do.
7. Adversity can be difficult and particularly unique because I have a disability. But I can cope with these times. Avoiding problems just gives me longer to worry about them and makes me stressed. Issues will remain.
8. Support from others when I want it is good. But eliciting pity or sympathy is destructive and offers no potential for personal growth. The person I need to rely on the most is myself.
9. Having a disability can cause troubling experiences and past events may cause current problems. But my thoughts and actions can keep them 'alive' and I have control of these.

10. It is disheartening to see others in trouble. But I cannot help them when I make myself miserable. I can manage feeling sad, and sometimes I can constructively help them.

These thoughts are proactive, not reactive. Instead of going straight from A to C, you stop at B before going to C (Davis, Esheiman & McKay, 1982). The Belief system determines the thoughts, actions and emotional consequences of a person - their ontology. It is not what happens to me but how I view it. My Belief system determines the nature of my emotional Consequences. From a disability perspective, people with a disability can actively deconstruct what it means to be disabled through positive thought processes. This is proactive, not reactive. Destiny or fate is internally as opposed to externally driven. Thus, social structures - the Post Structuralist approach to disability - have little or no part to play. Enacting positive thought processes creates constructive pathways to happiness, i.e. psychosocial potential maximisation. Social destiny is personally, as opposed to socially, determined. Hence, in an epistemological context, there is a fundamental shift from external factors to internal influences determining quality of life for people with a disability. This is the defining difference between the epistemologies of Post Structuralism and Reflexive Sociology. The latter refers to the works of Beck and Giddens (Beck, Giddens & Lash, 1997). Reflexive sociology connotes social relations that are not fixed and macro and micro-sociological realms that are mutually influential. Each shapes the other. Thus, there is the prevalent theme of individualisation - a contemporary sociological phenomenon whereby individuals increasingly "cannot rest content with an identity that is simply handed down, inherited, or built on traditional status" (Giddens, 1996, p. 192). Since the onus is on individuals, their thought processes - how they view the world and deal with it - takes on even greater importance. Hence, there is a need for Reflexive Sociology to supersede Post Struc-

turalism as the principle research paradigm in Disability Studies.

Developed competency with the Ten Rational Thought Processes also has close ties with Jane Loevinger's (1976) "tolerance of ambiguity," which incorporates the willingness and capacity to entertain numerous perspectives of reality, not simply one's own viewpoint. Accordingly, such a person is better able to acclimate to various circumstances. They are adept in converting "entropy into a consistent flow of experience," which is not simply turning sadness into happiness, for instance, but the ability to competently manage adversity (Giddens, 1996, p. 192). They are able to go from A to C via B. Their flexible Belief system enables them to tolerate ambiguity. Conversely, a person displaying intolerance of ambiguity appears rigid in their thinking and, thus, has difficulty in managing potential threats to their worldview. Typically, they are emotionally "locked," inflexible and are usually practitioners of the Ten Negative Thought Processes. They are stuck in an A equals C mindset. Unfortunately, intolerance of ambiguity appears commonly in studies of people who are deaf—a point made by Marschark & Spencer (2003, p. 178) who report that people who are deaf "demonstrate reduced mastery" of the conditions required for psychosocial potential maximisation "and thus are at risk for a number of adverse outcomes" - being prey to stigmatisation and victimisation. Psychosocial incompetence is not exclusively linked to deafness, but to people with all kinds of disabilities. Indirectly linking deafness with psychosocial potential maximisation are Greenberg & Kusché's (1993) definitions of outcomes and processes required for social-emotional competence:

- Good communication skills;
- Ability to think independently;
- Aptitude for self-control and self-direction;

- Understanding the needs, feelings and motivations of others and oneself;
- Flexibility in adapting to the requirements of individual situations, and the ability to manage multiple perspectives in any given situation;
- Capacity to rely on others and be reliable;
- Appreciating and understanding the values of both one's own and other cultures; and lastly;
- Utilising these skilled behaviours to achieve socially approved goals and to maintain healthy relationships of varying degrees of intimacy.

A review of this list shows high compatibility with Maslow's definition of self-actualising people, and a strong inclination towards internal as opposed to external locus of control. They concern life politics that are not so much "of life chances, but of lifestyle" (Giddens, 1996, p. 14). The term "life chances" intonates passive resignation to fate; "lifestyle" connotes proactive control of destiny. Thus, in a disability mindset, the self is not simply the traditional perception of disability as a physical, sensory or intellectual "abnormality." The self is reflexively determined (Giddens, 1996). Otherwise, such a person may be an inhabitant of a glass sphere and have the psychic mettle of veal.

## Conclusion

Social emotional competence is vital to ensuring that individuals maximise their social, psychological, vocational and academic potential. Conceptualising stigma, as the social model effectively does, is only half the journey towards people with a disability "freeing" themselves from disabling experiences. It is a critical part nonetheless. Stigmatising social structures and practices need to be understood. There is no disputing this. But disability is not purely the



result of social structures alone. Ableism is not totalitarian. Identity is not fixed. Emancipatory disability politics by-passing the perils of victimisation views the self as a social agent who is able to reflexively challenge stigmatisation, to turn adversity into a rewarding flow of experiences. It is not what happens to you but the way you view it.

Can the fat woman call herself disabled? If she sees herself as a victim and behaves like one she has every right to call herself disabled. She will be a social victim confined to a glass sphere whose barrier is externally and internally hardened. But if she reflexively challenges the externally imposed stigmas that come with societal pressures, if her self worth is internally validated through proactive lifestyle pursuits, then there is a likelihood that she is a self-actualising individual. Her glass sphere will have melted into a latex body wrap that enables her to touch and be touched by others (Jacobs, 2003). Being fat in a fat-hating culture is disabling for two reasons. The first is the external impositions and the second is the internal processes. Negative thought processes can exaggerate the externally imposed stigmas beyond their actual worth. This can create an ontologically intolerable experience that has little or nothing to do with physical, sensory or intellectual “abnormalities.” It is not the actual condition that is causing the disability, but rather the disabling thoughts. In effect, many people with a disability have an additional disability largely unseen—a social disability. It is common to see stigmas as a blueprint for ones own past, present and future. Yet, according to Maslow, one prominent characteristic of self actualising people is that they refuse to be handicapped by negative social perceptions of who they are as a person. With emotional intelligence they de-traditionalize what it means to be fat, or disabled, in a personal and political domain.

The contemporary psychosocial approach to understanding disability goes beyond the social model. Without it, we will continue to show how people with a disability are a ghettoised

social minority. We will never fully understand disabling socio-cognitive processes. We will never know the prescriptive courses of action on a personal level that we need to infiltrate into mainstream society, to maximise our psychosocial potential. The benefit of this emancipatory interpersonal politics is that it is applicable to all kinds of disabilities. Originally used to “free the minds” of “normals,” socio-cognitive therapy puts people with a disability on an equal plane with others. The disablement does not lie totally in the construction of society. Lack of social and personal support is not exclusive to society’s barriers. Disabling prejudice and discrimination is not just the result of a physical, sensory or intellectual “abnormality.” Inclusion is mutually generated.

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# **“If They Could See Me Now!”: College Students Reflect on Their Experiences as Special Education Students in the K-12 System\***

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**Abstract:** The current study examined the experiences of six students with learning disabilities in a four-year public, liberal arts college and discusses the meaning they attributed to their previous identification as special education students while in the K-12 system. Data was gathered through a semi-structured interview, questionnaire, and a sentence stem structure. A qualitative approach was used and results were analyzed using principles of content analysis. Themes emerging as noteworthy were: (a) the effect on relationships with peers, (b) lack of developmental knowledge by school support staff, (c) family support, and (d) the challenges of upholding expectations.

**Keywords:** special education, expectations, meaning-making

\*This article is dedicated to the memory of Willa Peterson, former Director of Expanding Horizons for eight years and of Disability Services for three at Fitchburg State College. Her spirit, compassion, and tenaciousness inspired all who knew her.

## **Rationale**

This article was inspired by students from Kellner’s Behavioral Sciences classes and from Freden’s outpatient psychotherapy practice.

Over the years, several of Kellner’s students mentioned the lack of expectations placed on them as a result of being labeled “special education students.” One, who refused special education services in tenth grade, despite protests from her teachers and guidance counselor, said, “If I had stayed in special education, I’d be working in Burger King now. No one expected me to go to college. I wouldn’t be here at all.” At the time, she was a senior graduating with honors and completing an internship in school counseling. Freden has heard several parents of students in special education programs note their children did much better in school when more was expected of them. One set of parents removed their teenager when the school recommended that he go to a trade school to “work with his hands.” He is now working in an architectural firm designing multimillion-dollar homes.

The purpose of this study was to understand the experiences of a small group of students in a four-year New England state-funded college and the meaning they attributed to their previous identification as special needs students, including implicit messages regarding what they were expected to accomplish in school, and beyond.

## **Review of the Literature**

### **Philosophical Foundations of Stigmatization**

Triano (2000) traces the stigmatization of disabilities back to eighteenth century France when separate public schools were established for deaf (1760) and blind (1784) students (p. 2). Segregated education for those with disabilities was founded on a medical model that was soon extended to people with mental retardation. The Connecticut Asylum for the Education and Instruction of Deaf and Dumb Persons, the first American school to specialize in educating students with disabilities, opened in 1816. The Elementary Education (Blind and Deaf Children) Act of 1883 charged British schools with educating blind and deaf children, and in 1899 the Elementary Education (Defective and Epileptic)

Act extended this responsibility to children with physical disabilities. Children were classified into eight categories of “physical defect” to receive services and be placed in special schools underscoring the belief they could not benefit from “normal” public school instruction. Triano (2000, p. 4) noted that attitudes still prevail that children with disabilities cannot learn in regular classrooms, stating that the Individuals with Disabilities Education Act (IDEA) “... require[s] medical categorization for eligibility purposes and attribute[s] the educational problems experienced by children with disabilities to the child’s disability and not to the failure of the regular education system.” Friedman (1997) argued the helping professions historically disempowered people by labeling them and defining their experiences for them. He recommends the helper and helpee co-construct the meaning of the helpee’s experience from a strength-based model, rather than having that experience defined solely by the professional.

While medical classification allowed parents and educators to advocate for children, it also placed the onus of the problem on the individual child rather than within the educational system. To provide the rationale for services, the Individualized Educational Plan (IEP), the backbone of special education instruction, has been primarily-deficit focused, often minimizing a student’s strengths. Anzul, Evans, King and Tellier-Robinson (2001, p. 236) observe “... Special education students are viewed more in terms of their specific weakness rather than their total personalities, talents, interests, or the ways in which they function in other settings.” There is growing acknowledgment that students with learning disabilities may also be “gifted” and possess exceptional talent or abilities in at least one academic area (Dole, 2000).

Fortunately, many educators now also focus on the strengths of children with disabilities as well as their challenges. Students are encouraged to be active participants in their own education as they mature, for instance, the 1997 Amend-

ments to IDEA helped facilitate this empowerment by switching responsibility from parents to students when they reach the age of majority and by emphasizing the importance of post-secondary transition planning (Council for Learning, 2004).

With this emphasis on student responsibility and an understanding of the capabilities of students with disabilities, an increasing number of students with disabilities are entering post-secondary education. The percentage of students with disabilities graduating from high school has clearly increased; however, figures vary from 30.5% (National Institute for Literacy, 2004), to 80% (Patwell & Herzog, 2000, p. 1) for the year 1998. Statistics on the percentage of full-time college freshmen with disabilities in 1998 vary from 9.8% (Council for Learning, 2004) to 34.3% (George Washington University, 2004, p. 13). Determining the percentage of students with disabilities who go on to post-secondary education is complicated by such factors as reporting criteria (self-report versus school-based diagnosis) and definitions of various disabilities.

### **Reactions of Family, Peers, and Professionals to Students with Learning Disabilities**

When families first receive a diagnosis of an illness or a disability that impacts learning, many parents initially feel guilt and sadness over “lost” dreams for their child’s future (Austin, 2000). Children who are faced with stressful life experiences need the influence of protective factors, such as parents, to counterbalance negative events (Werner, 1993). Intending to provide help and support, some parents take responsibility and decision making away from their children with learning disabilities, thus disempowering them further (Mitchell, 1998). When families received six ninety-minute school-based trainings, developed by the Illinois Service Resource Center and the Academic Development Institute, focusing on improving their understanding of special education and how to navigate the system, parents were better able to support their

children in special education and work with school personnel (Stevenson, 2003).

Educational professionals may disempower students with learning disabilities when they “try too hard” to help them. Skrtic and Sailor (1996) note schools are not organized around the premise that students are capable of self-determination. When teachers work from a model where they are the experts and it is assumed students cannot articulate their own educational needs, neither students with learning disabilities nor students without learning disabilities are encouraged to view themselves as active participants in their own education. On a practical level, Patwell and Herzog (2000) note special education students are often given too much “informal” assistance. For example, when teachers allow extra time to complete work not specified in IEPs, students are less likely to develop the self-management skills necessary to negotiate larger and more demanding college systems.

Experiences in the classroom can reinforce feelings of stigmatization and marginalization. Baglieri and Knopf (2004) found efforts to accommodate students with learning disabilities results in special education students receiving instruction that is different and separate, and often less challenging, from that of the general curriculum. They observed that, “[S]uch ineffective instructional practices confirm the understanding of students with learning dis/abilities as less able. As such, even ‘included’ students labeled as having learning disabilities (LD) continue to be excluded, not by classroom location but by the instructional discourses that circulate the school” (p. 526). Bruck (1986, p. 365) observed, “[D]ifferential patterns of teacher-child interactions may shape the learning disabled child’s self-perception, and they may also serve as models for peers to react to learning-disabled children.” Social difficulties may be magnified if the child with a learning disability is placed in a special class (Bruck, 1986). In-depth interviews with people with learning disabilities who dropped out of high school revealed that for

these students “personal opinions were neither sought nor valued in the school setting” (Lichtenstein, 1993, p. 8).

The experiences of children with learning disabilities are often shaped by gender-related societal expectations (Goldberg & Herman, 1993). When girls have trouble reading or writing, skills often believed easier for girls, parents and teachers may be more critical of their lack of success, and these students may internalize a sense of failure. In an elementary school founded on an “open concept” model designed to minimize stigmatization of special education children, girls as young as first to third graders were viewed less positively by peers and more often socially rejected than boys with learning disabilities (Scranton & Ryckman, 1979).

### **Impact of Special Education Designation on Self-Concept**

Students with learning disabilities who receive special education services sometimes attribute academic success to “easy work” (such as completing a worksheet rather than writing a book report) and blame their failures on a lack of help. Implicit is a sense they cannot do the work alone or that it must be easy and meaningless. Conversely, Palladino, Poli, Masi, and Marcheschi (2000) found students without disabilities more often attribute success or failure to effort and individual characteristics.

Academic problems are often compounded by social problems for students with learning disabilities. For example, 43% of a sample of 11-14 year-olds with learning disabilities met criteria for clinical depression in contrast to none in a control group without learning disabilities (Palladino et al., 2000, p. 145). From a meta-analysis of studies on the social and emotional adjustment of children with learning disabilities, Bruck (1986) found the social and emotional behaviors which often differentiate children with learning disabilities from children without learning disabilities are also found among children with other disabilities, those with emo-

tional disturbances or epilepsy, and among low achievers. She concluded it is the stigma of labeling or academic failure rather than the disability itself that results in emotional difficulties for many children. Galvin and Hons (2003, p. 149) suggested it is not the actual impairment, but the “social construction of disability as an inferior status” that results in feelings of marginalization for the student.

### **Successful Students with Learning Disabilities**

Students with learning disabilities who have achieved some success, whether it be by maintaining good grades or by keeping up with non-special education classmates, have a better sense of control over their environment than less successful students. Successful students with learning disabilities often pride themselves on strengths developed through their efforts to cope. Gerber and Reiff (1991) conducted in-depth interviews with 71 adults diagnosed with learning disabilities as children. A successful sub-group emerged, with personally satisfying careers, highly motivated educational attainments, and an acceptance and understanding of their learning disabilities. They reframed their disabilities as having some positive attributes (fostering coping strategies, learning to identify goals, and seeking mentors and support systems).

Students with learning disabilities who are successful in life tended to seek support from their families, and if unavailable, found support and mentors in teachers, school personnel, and friends (Greenbaum, Graham, & Scales, 1995; Spekman, Goldberg, & Herman, 1992; Werner, 1989). In interviews with high school seniors with learning disabilities, Werner (1993, p. 30) found many credited elders or peers with having helped boost their self-esteem, but “considered interventions by counselors, mental health professionals, and special educators of ‘little help’ to them.” Perhaps the lack of helpfulness the students attributed to their professional helpers reflected a healthy desire to use their own voices rather than accept the opinions of the “expert” professionals. Foucault (1983) criticized help-

ing professions for their attempts to gain knowledge, leading to a disempowering relationship with the “subject” who is not invited into a discourse on his or her own experiences.

In a study of fifty young adults with learning disabilities, Spekman et al. (1992, p. 167) found the 58% who achieved both successful employment and interpersonal relationships “seemed to compartmentalize their learning disability and saw it as only one aspect of their identity rather than defining themselves entirely by it.” Greenbaum et al. (1995) found 37% of college students with learning disabilities credited their own tenacity and hard work for their success. Sometimes anger and determination to prove others’ low assessments of them wrong motivated them to succeed. The desire to attend college was the strongest indicator a student would continue onto college (Farrell, Jr., Sapp, Johnson, & Pollard, 1994), suggesting that when students with learning disabilities felt empowered and responsible to facilitate their own success, they were more likely to do so.

### **Research Questions**

This study was founded on the premise that learning disabilities are “both socially produced and culturally constructed” (Priestly, 2003, p. 1). We sought to understand how six students with learning disabilities in a four-year public New England institution perceived their experiences as special education students while in the K-12 system and the dynamic process through which their self-concepts developed as they interacted with the world. In particular, we asked the following: (a) What meanings do college students attribute to their previous experiences as special education students? (b) Do students believe their status as special education recipients impacted the expectations that others had of them? Did it change the expectations they had of themselves? (c) What supports and stressors do students with learning disabilities experience specific to their special education participa-

tion, and (d) Did students make a shift from a deficit-based model of self, as implied in the Individualized Educational Plan (IEP), to a model based on competency? If so, how do they recall this process?

## Methodology

### Measures

Qualitative measures are well suited to investigating the meaning people ascribe to their experiences. McLeod (1996, p. 177) commented: "People may be silenced because they are not 'authorized' to tell their own story. They are prevented, by whatever means, from being the 'author' of the stories they tell about self." Our intention was to make our participants the authors of their own stories. Evans (1998) noted when students were allowed to talk about their experiences openly in loosely structured interviews, points of view emerged that the researcher did not anticipate. Since this study was based on learning the students' points of view, such a nonreductionist methodology was well suited.

Kellner introduced the study at a Disabilities Services Ice Cream Social; three students signed up on the spot. Two participants referred friends, and another was referred by the College Tutoring Center. Each participant signed an informed consent form, chose a pseudonym (or was assigned one if preferred), and provided basic demographic information (type of learning disability, age at identification, type of placement, other diagnoses if applicable). Each participant completed three instruments. First they completed a questionnaire, consisting of eight items, which asked participants to respond to statements about their special education experiences on a scale of 1-5 (1 = *much better*; 2 = *better*; 3 = *about the same*; 4 = *worse*; 5 = *much worse*). Next, participants completed a sentence stems exercise, which asked them to complete sentences soliciting reflections on their experiences with special education. Finally they took part in an audio-taped interview, which was

semi-structured so we would not constrain the content through our omission of important issues: Each participant was asked at the conclusion of the interview if there was anything to add we had not asked. The first interviewee mentioned feeling "left out" during the IEP process, so we added a question about the IEP process to subsequent interviews (see Appendix A).

### Data Coding and Analysis

After transcription, Kellner coded the interview statements in categories of themes following the principles of content analysis methodology (Lincoln & Guba, 1985), and then Freden did an inquiry audit of the raw data to determine if the study was undertaken in a careful and systematic manner and if the first researcher's analysis and constructions made sense (Lincoln & Guba, 1985). The QSR N6 computer program was used to aid in the data analysis.

The initial coding yielded sixteen categories. Based on the inquiry audit, and noting similarities in content, categories were grouped more broadly into the following nine items:

- Stigmatization
- Goals
- Significant Others and Resources
- Advocacy
- Hidden Advantages
- Stressors and Coping Mechanisms
- Self-Reflection
- Diagnosis and School's Response
- Recommendations

Three overarching themes emerged across all three instruments: personal narratives, supports and stressors, and treatment by others (how they perceived others responding to them as a result of their special education status). By noting these three overarching themes, the researchers



could look for similarities and/or contradictions among each participant's responses. This technique, known as triangulation (Lincoln & Guba, 1985), serves as a cross-reference through which to substantiate impressions and pick up inconsistencies.

Table 1 shows how the questions were coded into the three themes. Note that due to the wording of the questions, the scale was reversed on questions three through eight so the meaning would be consistent with the first two themes. Since the questionnaire was based on a scale of one to five, the researchers decided to code the interviews and the sentence completions on a similar scale, with higher ratings as those perceived as more favorable, as follows: 5 = *a completely progressive narrative in which the individual only tells stories of moving forward*;<sup>1</sup> 4 = *an essentially progressive stance but includes some negative circumstances or reactions*; 3 = *neutral*; 2 = *a primarily regressive narrative but with some sense of movement*; and 1 = *a totally regressive narrative*. Freden and Kellner independently assigned ratings to the interviews and the sentence completions, and then discussed them until they reached agreement on a final rating (see Table 2 for the coding of the sentence completions). Although ratings of sentence completions and interviews admittedly included some subjectivity, we devised this system to allow us to look at the three instruments to determine if data was consistent enough across the instruments to indicate it was valid.

### Program Participants

All six participants were enrolled in a four-year New England public College, which served as a selection criterion. All achieved some degree of academic success. Five participants were female and one was male. They ranged in age from 19-27, with a mean of 21.7 and modes of 19 and 22. Two were freshmen, one a sophomore, one a junior, one a senior, and one a graduate student. Two previously attended community colleges, and two transferred from other four-year colleges. The mean grade level for initial diagnoses

of LD was third grade, with modes of Kindergarten, fourth and sixth grades. In the aggregate total (participants could check off multiple categories), three reported disabilities in mathematics, two reported learning disabilities in written language, two reported reading disabilities, one reported auditory processing difficulties, and three reported other disabilities (1 blindness as a primary disability and memorization difficulties secondarily, 1 non-verbal learning disability, and 1 unspecified). None reported receiving services for confounding factors such as attention or mental health issues (see Table 3).

At the time of the most intensive services in Special Education, two were placed in a full-time resource room, one in a part-time resource room, and the remaining three received special help in the classroom. They all had IEPs through twelfth grade, and continued to receive minimal services in college through Disabilities Services or the Academic Success Center on campus, but only when they requested them.

## Results

### Triangulation of Data

In looking at the data, it must be remembered that the interviews elicited more subtle and complicated responses than the other two instruments. Some participants left items blank on the sentence completions. This complicated the scoring of completions. The sentence completions coded as "others" pulled information on how they thought teachers and parents perceived them. The questionnaire included items relating to treatment by teachers, parents, and peers. Finally, the interview also included information on parents, teachers, peers, as well as other school personnel and other significant people in the participants' lives. By looking at data for individual participants, rather than as a group, some variation among scores reflected the complexity of their experiences, and distinctions between the benefits of services versus difficulties with peers (see Table 4).

**Table 1**  
Coding of Questionnaire

Theme	Question
Narrative/Supports	If I had not received SPED services, I believe my academic performance now would be...
Narrative/Supports	If I had not received SPED services, I believe my selection of career options would be...
Narrative	Participation in SPED services made my attitude toward school
Others	Because of my involvement with SPED services, my parent(s) viewed my options for the future as...
Others	At least one of my teachers told me that SPED services would make my options for the future...
Others	When my friends became aware that I received SPED services, their opinions of me were...
Narrative/Supports	I believe my academic performance in high school was ___ as a result of receiving SPED services.
Others	As a SPED student, I thought my teachers believed my prospects for the future to be compared to non-SPED classmates.

**Table 2**  
Coding of Sentence Completions

Theme	Sentence Stem
Supports/Narrative	The thing I found most useful about the services I received was...
Narrative	If I had not received special education services I would not be able to...
Supports	The thing that was least helpful about the services I received for me was...
Others	My parents believed the services I received...
Supports/Others	I think my teachers viewed me as...
Supports	I considered stopping special education services because___, but then continued with them because...
Narrative	When I think of my life now, if I had not participated in the services that were offered to me, I would...
Narrative	When I think of my life now, the special education services have allowed me to...

### Individual Student Responses

During the interview, Autumn maintained she would have done just as well without special education services, and that the stigmatization was very difficult for her. Her responses on the questionnaire were consistent with not want-

ing to acknowledge any benefits of the added help. The high score for “others” on the sentence completion was consistent with her assertion that others saw her as “perfectly fine” while the low interview score reflected the irritation she felt with school personnel.

**Table 3**  
Study Participants

Name*	Age	Grade Diagnosis	Type of Disability	Most Extensive Services
Autumn	22	4 <sup>th</sup>	Math, other (unspecified)	Full-time resource room
Caroline	21	K	Written language, reading, math, auditory processing	Full-time resource room
Donna	19	4 <sup>th</sup>	Non-verbal learning	Part-time resource room
Kayla	22	K	Written language, math, Cerebral Palsy	Special help in classroom
Luke	19	6 <sup>th</sup>	Reading, memorization	Special help in classroom
Suzanna	27	6 <sup>th</sup>	Blindness, memorization	Special help in classroom

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\*Each student picked a pseudonym.

Caroline left two items on the sentence completion blank (one for supports and one coded supports/others) which compromised the coding. Caroline had positive responses about services during the interview and on the questionnaire, responding that services she received made a substantial difference in her life.

Donna's low scores on the interview may relate to the delay she experienced in receiving services; her teacher refused an evaluation calling her "lazy." Her seventh grade special education teacher had a dramatic impact on her

skill development as well as her confidence. Few people, except her parents, encouraged her or supported her. Nevertheless, Donna graciously acknowledged the help she received, and this is reflected in the slightly higher scores on the questionnaire.

Luke's high scores in the interview and the sentence completions reflected his determination to make the most of life's experiences. This theme emerged more strongly in interviews and sentence completions than it did on the questionnaire with set selections. While Luke clearly

**Table 4**  
Triangulation of Data: Scoring of Responses

Participant/Theme	Interview	Sentences	Questionnaire	Variance
Autumn:				
Narratives	2.0	3.5	3.00	1.5
Supports	3.0	4.0	3.00	1.0
Others	2.0	5.0	3.00	3.0
Caroline:				
Narratives	4.5	5.0	4.75	.5
Supports	4.0	3.0	4.67	1.67
Others	4.0	3.0	3.50	1.0
Donna:				
Narratives	2.5	5.0	3.75	2.50
Supports	2.0	5.0	3.33	3.00
Others	2.5	3.5	3.25	1.00
Luke:				
Narratives	4.0	5.0	3.50	1.50
Supports	4.0	3.0	3.67	1.00
Others	3.5	4.0	3.50	.50
Kayla:				
Narratives	4.0	5.0	3.75	1.25
Supports	4.0	2.0	3.33	2.00
Others	4.0	3.0	3.75	1.00
Suzanna:				
Narratives	4.0	5.0	4.25	1.00
Supports	4.0	3.0	4.33	1.33
Others	4.0	4.0	4.00	0.00

found some services helpful and his school-based liaison (paraprofessional advocate and service coordinator) indispensable, he also felt the stigma of special education status. The variation in his scores may be a function of the depth of experiences he discussed.

Kayla's experiences were basically positive, as her scores for "narratives" and "others" reflected, except for ongoing struggles with her high school teaching aide. The major discrepancy in her scores for "supports" resulted from the fact Kayla only completed one item on the sentence completion which she answered negatively. The scores on the other two instruments reflected

a more global assessment of her sense of supports.

Suzanna did not complete one sentence for the "supports" category; this may account for the fact that this score is the lowest of all. Otherwise, Suzanna's scores were all heavily on the positive side indicating a consistency in the data. Reasons for Suzanna skipping the "supports" category were unknown.

#### **Meanings Attributed to Special Education Status**

Four participants expressed feelings of stigma related to receiving special education services, including "not being normal" or "being different," being singled out, and shame. All re-

called peers either shying away from them, teasing them or ostracizing them. The special attention, particularly when pulled out of classes or lunch, had social consequences. Autumn recalls: “It was just so embarrassing, ‘cause I was trying to be as normal as I could be. And I just didn’t want to be associated with it [special education] if I didn’t have to be, you know.” Luke found the hardest part of receiving special education services was “...they made you different. They put you apart from everyone else.”

Four respondents tried to distance themselves from the special education identification. Luke ensured that his teachers knew him as a student before he introduced his special needs:

“If you don’t tell them [teachers] right away, and you just participate in class, and you come tell them the truth about how you sometimes need some thing sometimes, with either extra time with tests or just better explanations of the material, because you just didn’t process it all. Um, and because you didn’t come out right away, they never noticed. They just thought you were a regular student, had regular grades.”

It was important to Autumn that her special education classes seemed like normal classes: “But it was like a regular class too. We had tests. We had to do this, we had to do that. We had projects... I’ll take it with people who are part of special ed, but they’re still treating the class like it’s a normal class.”

### **Impact on Expectations**

Autumn and Caroline believed less was expected of them than their non-special education peers; the other four felt they were usually “treated like any other student.” While Caroline believed the decreased expectations negatively impacted her readiness for college, Autumn appreciated the slightly less demanding curriculum because it allowed her to excel. Donna, on the other hand, remembered her teachers pushed her to do more: “I think they wanted me to come up to them and tell them when I had a

problem.” Kayla usually felt that she was viewed as capable, except by one teacher who negatively pre-judged her on the first day of class when she entered with an aide. Luke believed that since he held high expectations for himself, the school followed suit: “I think I was the one who didn’t expect any less of me... If I asked for it, they would give it to me [less work]. I didn’t want that.”

Suzanna believed her teachers’ low expectations were not based on her special education status, but on the fact that none of her older siblings graduated from high school. However, the school’s delay in acquiring adaptive technology for her blindness prohibited her from participating in such activities as science labs, and she fell behind. Thanks to her mother’s advocacy, Suzanna obtained the adaptive technology (AT) in high school. Even with AT supports, she needed to do extra work to catch up for time lost before she used AT.

The participants had varying experiences with the IEP process. Only Autumn felt included and listened to in the process. Suzanna recalls: “... They would talk about me like I wasn’t in the room.” Both she and Donna let their parents do the advocating. Not wanting to miss classes, Luke chose not to attend. Kayla did not find it important to go to the IEP meetings when old enough to attend because she no longer needed many services.

At some time in their educational careers, each participant became motivated to attend college, with or without school support. Caroline always wanted to be a teacher, but her high school guidance counselor discouraged her from applying to college. Autumn received mixed messages: “... They said, ‘Your grades are really good and you can go to college and do this, do this, do this. But I can’t tell you a college which you can go to, that will be able to accommodate you.’ And I was like, ‘Uh?’” Only Kayla and Suzanna found their guidance counselors helpful in the college search process. Kayla appreciated

the counselor's advice to attend a community college and felt it prepared her for a four-year school, but found the reduction in services in college difficult because no one told her she would have to pay for an aide herself. She was terrified and furious when she was told. Luke believes he would not be at college if it were not for his special education liaison. He remembers that she and his parents were "...talking about college all the time."

The desire to prove others' low expectations of them wrong was a powerful motivator. Kayla recalls with pride: "You know, it was just downers and everything from the day I was born. It was like, 'She's not gonna walk, she's not gonna talk, she's only gonna...'. And I keep proving everybody wrong!" When Suzanna's doctor told her to stay home in sixth grade, she "tried it" but returned to school with increased enthusiasm for learning. She decided to attend college in her junior year when her Braille teacher took her around to various colleges. Shortly after receiving her eye prosthetic, she began college despite her doctor's recommendation to take a year off to adjust.

### **Stressors, Supports and Coping Mechanisms**

Participants identified several stressors associated with receiving special education services including: wanting to be like everyone else (n = 3); receiving unwanted, and in their eyes unneeded, assistance (n = 3); academic worries (n = 2); and struggling to receive needed services (n = 2). Two participants experienced stress when the schools delayed providing services. Donna's mother noticed difficulties before her teachers and insisted on testing, but the school refused since her teacher said she was "lazy." Suzanna's mother researched and presented programming options to the school, and then placed the school in a position in which they had to comply to meet IDEA requirements.

Academic difficulties caused severe stress for Donna and Caroline, especially when younger and less able to handle frustration. Donna would

"give up and cry," and although grateful for her mother's help with schoolwork, found "...not being able to do it myself was really hard." At school, however, she remained positive: "... I was such a nice kid, I was really sweet; all the teachers loved me. And then at home I was really mean and I didn't... like I was mad and angry at my parents." Caroline's experience was similar: "When I was younger, I gave up. I didn't really realize I would be able to be successful when I was younger." When interviewed, Kayla was struggling with the required college math course. She articulated the struggle with self-blame that many with disabilities feel: "There's no reason for me to put myself down. There's nothing I'm doing wrong. It's not because I'm not trying. I have to make myself realize it's not worth putting myself down for it."

Sometimes services themselves caused stress. Autumn perceived school personnel as "breathing down her back." She criticized the school for not re-evaluating the necessity of services for each student: "They just babied me because they were used to babying everyone." Kayla's elementary school aides presented invaluable techniques to help her understand material, but by high school she felt "annoyed" that her aide "just followed her around." One middle-aged aide, suffering from a back problem, frequently directed anger or frustration at Kayla, once calling her a "bad little girl" for not cleaning out her backpack. While the services Luke received as a freshman provided skills necessary to succeed in high school, they became "babysitting" afterwards. He sometimes made himself "look busy" so teachers and aides would leave him alone.

Responses coded as "stigmatization" overlapped those coded as "peers" considerably: 20% (Kayla), 36% (Luke), 58% (Donna) and 72% (Autumn). Only Caroline and Suzanna did not connect peers with feelings of stigma. But Caroline does recall that when placed in the resource room "...My friends started teasing. They noticed that I wasn't in their classroom and they stopped hanging out with me." When

pulled out of class, Donna remembered her fellow students were “very mean” to her. Half of the participants reported peers teased them for having an easier workload or for needing additional assistance. Luke hesitated to ask for additional time on tests, as required by his IEP, because “...if I did ask for it, the eyes would be looking at me.” To avoid teasing, he told friends he was going to study period when in fact he was going to the Resource Room. Not surprisingly, peers became more important during adolescence. Three participants recalled feeling like “outcasts” in middle/high school. Suzanna felt she was missing out: “...My fellow classmates were going, were learning a lot more than me. Um... and then they got their [drivers] licenses.” Three participants found their initial disability diagnosis to be the most difficult time in terms of stigma. The five females distinguished peers from “true friends,” who were not affected by their special education status.

All found ways to cope with frustration. Autumn “brushed it off.” Caroline and Donna relied on their strengths and used strategies learned in class to help with academics. Three participants learned to pace themselves and established helpful routines. Caroline found one-on-one and small group instruction helpful. When frustrated, she would “sit down and spend a minute or two in order to calm down.” For Suzanna, finding humor in silly situations really helped, and travel with the Camps for the Blind also alleviated stress. When all else failed, she threw alarm clocks across her bedroom. Luke chose not to focus on his disability: “I’d rather not be dwelling in my... my Special Ed.”

Four participants found school personnel provided both support and stress; Donna only recalled positive interactions while Autumn recalled primarily negative ones. Although Caroline felt unsupported by her elementary school teachers, her high school guidance counselor and the school psychologist, and her seventh grade special education teacher taught her strategies to be successful. Suzanna felt supported by most

of her teachers, including those for Braille and mobility, her advocate, and her high school vice principal and guidance counselor. One “very supportive” paraprofessional helped Kayla get involved with television, a dream of hers. Kayla’s friendships with “parental figures” gave her a different perspective on life than just spending time with peers.

Luke found most teachers supportive, except those “... near retirement, [who] kind of find it a drag to have a special needs student in their class. Thinking that they need so much more than everyone else and it’s just going to slow their class down.” His drama teacher mediated for him with such teachers: “He talked to the teachers about what a good person I was. ‘Would you mind red-carding him in because he really won’t slow your class down; he won’t be a problem.’” Overall, positive relationships were spoken of in extremely glowing terms, negative interactions were often recalled with anger, annoyance or sadness.

Family also played a key role for all participants. Three credited their mothers as a major reason for their current academic success. Parents helped advocate for services and managed teasing or jealous siblings who resented the additional attention the special needs child received. Luke stated his parents believed his services were “phenomenal.” Most parents were pleased with services once implemented. Only Autumn reported her father thought she did not need services since she was doing “perfectly fine” and viewed the professionals involved as “a bunch of quacks.” Autumn convinced him to allow her to continue her IEP because she found the testing accommodations helpful and because, “It’s nice to know if I want something, it’s there.” Sometimes parents were “too supportive,” as Kayla’s father was when he did simple tasks for her. Once, she spilled a glass of water and as her father began to clean it up, she asked, “How am I supposed to be independent, if you’re not letting me clean up water off the floor?”

## Personal Narratives

Learning to self-advocate was a turning point for all female participants. Suzanna recalls an IEP meeting in which "...one teacher asked, 'Suzanna, what do you want?' And I started talking, and I haven't stopped telling them what I want...." Suzanna believes she would not be successful now, despite her abilities, if she had not learned how to self-advocate from her mother and two junior high school teachers. Autumn and Kayla both noted the importance of being able to reject services. Kayla reflected: "... Things that might be right, even necessary, at one time in your life, but now... may not be. May even be annoying, or a problem at another time in your life." Luke felt empowered when his teachers would "... think past it [special education] and forgot how I'm on it," as well as through extra-curricular activities such as music, drama and volleyball.

Understanding their disabilities helped the participants to take charge of their lives. Donna's parents answered her questions about her disability and helped her understand she was not "stupid," but just "learned differently." In college, Donna had additional testing and gained a clearer understanding of her disability; the new knowledge allowed her to self-advocate. During the interview, Luke demonstrated a good sense of his strengths and weaknesses. When asked how he developed this understanding, he remarked, "I really think it was the special education services, as much as I don't probably want to admit it."

Participants were motivated by parental expectations or by the success of older siblings. Caroline appreciated her mother's encouragement to pursue her goal to be a teacher. Donna was partially motivated by her parents' expectations for her and her brother. Kayla remembers her cousin confronted her about her future: "... She was like, 'Which resume do you think people will pick up?' ....She kind of pushed me along to realize what I am and who I can be." For Kayla, seeing her older sister graduate from

college was inspirational. Luke's older brother excelled academically, and he did not want to lag behind despite acknowledging they had different strengths.

Half of the participants found positive assets to their disabilities, much like Gerber and Reiff's (1991) successful group. Allowed by his IEP to choose his elementary school teachers, Luke remembers having "tons of great teachers." Suzanna believes her illness and accompanying disability brought her closer to her sister, and her two younger siblings developed an increased appreciation for those with disabilities through their interactions with her. Both Kayla and Suzanna treasured camp and travel experiences available to them because of their disabilities. When faced with the loss of her eyesight, Suzanna framed learning Braille as having the benefit of a second language.

Achieving success helped participants develop progressive narratives. Kayla's self-image changed from one of needing lots of help to that of an independent woman. She recalled seeing an old classmate while shopping: "...I think, some of them saw me as so dependent upon another person. Now it's like, 'What? You're in college doing what?'" Caroline's self-image changed drastically after seventh grade when "...a really good special ed teacher worked with me a lot – helped me explain things and got me started... I know before seventh grade, it was hard for me in school. But once that year came, it seemed like everything changed." For Autumn, receiving good grades motivated her to continue to do so. During the interviews, three participants prided themselves on their grades.

Having benefited from the support of individualized services, several participants are now considering careers helping others. Caroline hopes to be a special education teacher, Luke is considering technical education as well as other options, and Suzanna is training to be a mental health counselor. Suzanna notes, "I think that I should be spending time on other people, in-



stead of self-reflecting. So, focusing on the other people, other things I can do, other ways I can help, that's one of my coping skills that gets me through issues."

### **Participant Recommendations**

Based on their experiences with special education systems, the participants suggested the following to future students: keep minimal services while trying your best to do it on your own, set goals, learn to self advocate, ask questions, develop good study habits, and find people who will listen. They recommended schools hire only people who can actually do the job, and provide peer education on disabilities to help ease the social difficulties they endured. The participants' overall conclusions provided ample discussion points for students and service providers alike.

### **Discussion**

Although the participants generously offered their views, this was a Caucasian, mostly female, opportunistic sample from the Northeast. Only one possible gender difference emerged: the emphasis females placed on friends, often calling them "true friends" and distinguishing them from peers, versus the more moderate distinctions that Luke made. Since adolescent girls tend to focus on relationships more than boys of this age, this may account for the increased significance they attached to this distinction.

All participants sought and found supports from teachers, paraprofessionals, liaisons, other adults, and occasionally friends, as successful students with disabilities often do (Greenbaum et al., 1995; Spekman et al., 1992; Werner, 1989). Parents often provided a "protective factor" (Werner, 1993) through their advocacy for services, by helping their children gain an understanding of their difficulties, by assisting with schoolwork, and through intervening with teasing siblings. The participants reported they had similar views as their parents did about their services. This suggests how significant parents

are in shaping their children's perceptions of services.

Teachers may not view the full range of a special education student's emotional experience. Donna and Luke both understood the benefits of being liked by teachers. Donna only vented the depth of her frustration within the safety of her home. Although no participants recalled feeling depressed, Donna's anger may have been a mechanism for warding off depression. Three other interviewees recalled residual anger. Palladino et al. (2000) found depression in almost half of 11-14 year olds with learning disabilities. It is unclear whether these respondents chose not to focus on any feelings of childhood or adolescent depression, or simply did not experience depression relative to their disabilities.

Although all but one participant acknowledged the helpfulness of educational services, all experienced the "social construction of disability as an inferior status" (Galvin & Hons, 2003, p. 149). Four recalled the teasing and/or ostracism by peers that often accompany a special education designation (Bruck, 1986; Lichtenstein, 1993). Caroline and Donna's experiences were consistent with Bruck's (1986) finding that social difficulties may be magnified when a student is moved to a special class placement. Resilience to surviving feelings of being an outcast may separate college students with learning disabilities from those who do not attempt post-secondary education.

Autumn repeatedly mentioned teachers told her to "slow down" and she found everyone else "too slow." These vignettes, along with her fast-paced speech, are consistent with borderline attention and/or hyperactivity issues. Since all six respondents reported peer difficulties as special education students, and only one may have had borderline attention issues, this study does not support Bruck's (1986) suggestion that social difficulties may be a function of hyperactivity rather than the specific learning disability.

The participants embodied the profile of the successful college student as self-determined, working toward realistic goals, using problem-solving strategies, and choosing people and environments that support their learning (Council for Learning, 2004). This sample did not uphold findings that special education students attribute academic success to the easiness of the work and blame a lack of help as reason for their failures (Palladino et al., 2000). Only Autumn acknowledged the modified curriculum (i.e., Introduction to Chemistry rather than the standard high school Chemistry class) helped her excel. While Caroline did not mind the decreased expectations; she now believes it did not adequately prepare her for college. The others wanted and sought at least a “normal” curriculum, and Luke chose a college level math course. None blamed others for their difficulties. All prided themselves on accomplishments, past and present.

The participants displayed motivation, a realistic understanding of their disabilities (Bruck, 1987), and the persistence typical of successful college students with disabilities (Vogel et al., 1993). They viewed their learning disabilities as one part of their lives, not their whole identities (Spekman et al., 1992). Five of six viewed their own tenacity and hard work as responsible for their success. Proving others’ low assessments of them wrong was a strong motivator, similar to the findings of Farrell, et al. (1994).

Because only two participants found their guidance counselors helpful in the college search process, a question emerges as to whether guidance counselors have reduced expectations of special education students, as in Caroline’s case. Lack of adequate guidance staffing may result in counselors focusing more on higher performing students. Since all participants are now successful in college, guidance counselors may need to re-examine their advising of special education students. This trend may continue into college. Luke recalls during freshman orientation when he mentioned his goal of achieving a 3.3-3.5 GPA, he felt “almost laughed at” and was told

how difficult that would be. The two students who first attended two-year colleges found the extra support and smaller campuses helpful in preparing them for a four-year school. Guidance counselors should consider community colleges as “stepping stones” for students they may not otherwise encourage on to higher education.

Several mentioned they felt their aides “smothered” them while in high school; what once was supportive became “annoying,” to use Kayla’s word. No such criticisms emerged regarding teachers. One reason for this distinction may be that teachers study child and adolescent development and have at least been exposed to special education issues. Many paraprofessionals, however, have no such formal training. Training of paraprofessionals varies as some districts employ only certified teachers as aides, but others only require a high school diploma. The well-intentioned, nurturing aide may have difficulty setting age-appropriate expectations for adolescents. This suggests the importance of providing all special education personnel, particularly paraprofessionals, with a solid understanding of adolescent development and disability-related issues.

Several factors helped participants develop progressive narratives, including the ability to self-advocate, feelings of accomplishment after hard work, and the support of family, school personnel, or friends. Since self-advocacy seems a key to empowerment, it is recommended that schools make a concerted effort to include adolescents in the IEP process. Perhaps the ability to develop progressive narratives about their experiences and their potential for post-secondary advancement distinguishes special education students who go on to college from those who do not; it is suggested this be further researched.

College students with disabilities are in a unique position to reflect on their childhood experiences because many have gained the vocabulary to look at constructs such as gender roles, expectations and stereotypes. It is suggested

future research look at the commonalities and differences of how male and female college students recall their experiences as special education recipients along the lines of peer interaction and teacher expectations. In addition, further research on programs designed to aid peer acceptance of students of learning disabilities would be helpful in reducing the stigma students with disabilities experience. Finally, research in general on the academic and non-academic issues correlated with future student success will help guide decision making.

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#### (Footnotes)

<sup>1</sup> Gergen (1999) suggested that individuals develop personal narratives to understand themselves and make sense of their worlds. He described two rudimentary narrative structures: "progressive," in which the narrator creates a story of events leading up to success, and "regressive," in which the events lead to failure and/or loss. Many people include elements of both in their life stories. Transformation occurs when the individual can turn a regressive narrative into a progressive one.

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## Appendix A

### Semi-structured Interview Guide

You have had some success, you are in college and that is an accomplishment. And you deserve credit for that. Could you tell me a bit about how the special education services you received either helped you, or not, to get here.

What do you think your teachers expected of you? Did they ever talk to you about college, career, or other future goals?

How about your parents, did they talk to you about college, career, or future goals?

Did you think you parents and your teachers, guidance counselors, principals, etc. had common expectations for you?

What were your greatest sources of support while you were in special education?

What were the biggest stressors for you?

How did you handle the frustration? Did you ever get in trouble?

Are there ways that your challenges with learning disabilities helped you to develop particular coping skills?

How challenging do you think the SPED curriculum was compared to that in other classes?

How did your friends perceive the fact that you were getting special education services?

If you have siblings, what did they think about you receiving special education services?

Were you included in the IEP process? Could you tell me a bit about that process for you?

If you had to identify one thing, or person, responsible for your success now, what would it be?

What else do you think we should know to understand your experiences as previous special education students that we did not ask directly?

What other questions should we be asking you?

Thank you for your participation.

## ESSAYS

### Using Children's Literature to Cultivate Compassion for People with Differences

Anna Stewart

**Abstract:** A review of 20 children's picture books and novels featuring characters with disabilities. Through examining the literature, parents, teachers and students can learn about disabilities in a safe, informative and engaging way. Understanding is the first step to cultivating compassion for people with differences, thereby fostering tolerance and social change.

**Key Words:** children, literature, disabilities

#### Introduction

Grace looks like an average kid. She wears glasses and loves to tell jokes. She is also behind academically and has difficulty understanding social cues. Grace has learning disabilities and speech problems. She is in classrooms all over America.

Grace has been called names, which makes her mad. She has been left out of games, which makes her sad. She goes home and hugs her dog, which makes her feel better. In more ways than not, she is just like all the other kids, but Grace has different needs than many others.

Grace's teachers and peers do not know how to talk about her differences. She is embarrassed if they focus on her in class, so they do not say anything. Instead of making the situation better, their silence makes her feel that no one understands her, only adding to her social isolation.

What can they do?

Children's literature can help teachers, children and parents understand what life is like for children with disabilities. Reading a story about

children's differences is a safe and respectful way to talk about issues and concerns. Writing a poem, a story, or an essay about the feelings and concepts addressed in a book is a natural way for kids to process and express their reactions. This is true for *all* children.

Books written before the 1980s negatively portray children with disabilities. They are never in a typical school setting. Even in more recent books, such as *My Sister Annie* (1993), Annie is sent to a "special school" because she has Down's syndrome. In *Crazy Lady* (1993), Ronald, a young adult with mental retardation, is also sent to a separate school though he longs to be with all kinds of people. It is still very rare in children's literature to see a child with a cognitive disability or severe multiple disabilities in an inclusive school environment. Most books dealing with school issues feature kids with learning disabilities (*Hank Zipzer, Thank You Mr. Falker*) or Attention Deficit Disorders (*Joey Pigza, Eddie Enough!*). Kids with typical intelligence and physical disabilities such as hearing impairments, visual impairments or physical disabilities are seen in books in regular classrooms.

I chose the following books to illustrate how children's literature reflects societal norms and biases as they have evolved over time. In the last 26 years, since the Individuals with Disabilities Education Act (IDEA) was enacted, our society has moved from believing people with disabilities should be put in separate schools and institutions to "mainstreaming" kids or putting them in regular schools and classes, though not necessarily providing the free and appropriate education (FAPE) they have a legal right to obtain. Currently, there is a movement towards creating inclusive educational environments. Inclusive education is an approach to educating children with disabilities using research-based standards curriculum in a general education classroom. It is supported through the December, 2004, reauthorization of IDEA. Inclusion is a premise backed up by IDEA, and the Americans with Disabilities Act of 1990 that provides civil rights

protection to individuals with disabilities in all aspects of life, including employment and other public sector positions

Children are usually accepting of people with disabilities. Their natural acceptance makes it easier for schools to implement new curriculum incorporating all types of learning styles. Authors are writing books reflecting this needed change in public attitude. Nearly every classroom in America has a child with some kind of disability. If young children read books like these in preschool and kindergarten, perhaps the world would be as Charlie (*My Friend Isabelle*) says, "more fun with friends like Isabelle."

### **Illustrating Tolerance: Picture Books**

Picture books are uniquely suited to depict people with disabilities as more like everyday, average individuals. The use of engaging illustrations safely invites readers to look at people with disabilities and to see how they are equal members in society.

#### **Don't Call Me Special**

Pat Thomas's non-fiction book, *Don't Call Me Special*, is an overview for educators, kids and parents about kids who have disabilities. The book conveys information about disabilities, but not about children who have disabilities. Harker, the illustrator, presents simple pictures, uses normal colors and portrays kids in typical school situations. This illustrates the text and does not distract the reader from valuable information.

*Although the picture book medium is appropriate for kids under five, the content is not. It is possible that the kind of information presented could lead to name-calling behavior or cause others to be jealous of special equipment.*

#### **Different Just Like Me**

Author and illustrator Lori Mitchell offers a more complex picture book in *Different Just*

*Like Me*. Her daughter has vitiligo, a loss of skin pigment. Like most kids with differences, she is very much like her peers. She just happens to have white spots on her skin.

In the story, mother and daughter describe different people they meet on their daily outings. On Monday, they see two kids who are deaf using sign language. On Tuesday, they see people choosing different fruits and vegetables at the farmer's market. At Dad's office, a blind woman uses Braille to read the elevator buttons and an artist draws different kinds of chairs (the daughter also likes to draw). At the diner, the man next to them has the exact same lunch and in the restroom, a woman in a wheelchair and the daughter both wash their hands.

Mitchell's illustrations burst with detail and realism. The backgrounds are left as line drawings while the featured characters shine with color. Her intention is to ask readers to look carefully at each illustration and play a "Same and Different" game (other games and lesson plans can be found on her website at [www.differentjustlikeme.com](http://www.differentjustlikeme.com)).

Both Mitchell's daughter and the people in her story are those with physical differences; none have social, cognitive or behavioral differences. Given the author's art background, perhaps it was easier and more appealing for her to use visually recognizable disabilities.

Like Mitchell, Thomas also focuses on physical disabilities. It is much more difficult to portray kids with "invisible" disabilities (such as learning disabilities and autism spectrum disorders) using pictures. There is considerable need to teach understanding about those issues for readers at the picture book level. *My Friend Isabelle* addresses these issues for the youngest readers but for kids in first grade and above, more examples of invisible disabilities in their books are needed. Good examples of invisible disabilities can be found in *Ian's Walk* and *Moses Goes to a Concert*.

## My Friend Isabelle

In *My Friend Isabelle*, written by Eliza Woloson and illustrated by Bryan Gough, Woloson charmingly shows the tender friendship between her daughter Isabelle and Isabelle's friend Charlie. Like most friends, they enjoy each other's company. On their weekly play date they eat snacks, go to the park and play together. They are very much alike.

Though the same age, they are also different - one is fast, the other slow, one is tall, the other short. The biggest difference between them is that Isabelle has Down syndrome.

Woloson's book does a much better job both normalizing disability and making it personal for her readers. She never tells the reader that Isabelle has Down syndrome. Parents learn this fact from the back cover. The author gracefully shows that everyone is different and that differences are not impediments to forming friendships. Woloson's message is that differences are what make friendships interesting. From Charlie's perspective, and hopefully readers', Isabelle is not defined by Down syndrome—it is just part of who she is, along with being a good friend to Charlie.

A perfect example of using illustrations to teach tolerance, Gough's gentle illustrations complement Woloson's succinct text. Soft sweeps of color are given shape with pencil outlines giving both children a realistic and whimsical look. Though simple, there is movement and expression. This book does a beautiful job of showing the natural acceptance kids have for one another. It draws on common activities and realistically shows what a friendship between preschoolers looks like.

## Ian's Walk

In *Ian's Walk*, Ian's two big sisters decide to take Ian, who has autism, on a walk to the park. Their mother makes sure they feel it is a choice and not an obligation; they are the ones who want to take Ian for a walk to get an ice-cream



cone at the diner. Ian is not interested in ice cream or a soda. He sniffs the brick wall at the post office but will not smell the lilacs his sister shows him. Ian insists on eating his baggie of dry cereal one by one while his sisters urge him to get pizza. At the park, he flaps his hands and then, when the girls go get pizza for themselves, he wanders off.

The girls frantically ask everyone but no one has seen him. One sister closes her eyes and tries to think like Ian. When she hears the park bell ringing, she is sure it is him. Relieved to have found him, they are more tolerant of his different interests on the way home. The final line, when Ian gives his sister a slight smile, makes Ian seem like a typical child.

Author Laurie Lears provides a good introduction to classic autism. She portrays Ian as someone who has interests, tastes and desires—they are simply very different than most people's. His sisters also show a range of reactions to Ian - they are embarrassed by him, frustrated by him and also worried about him - but most of all, they accept him as their brother. This is a realistic picture of a family living with autism.

### **Moses Goes to a Concert**

In *Moses Goes to a Concert*, author Isaac Millman presents Moses, a boy who goes to a deaf school. It offers a delightful glimpse into the experience of being deaf and communicating with sign language and other senses.

Moses and his classmates go on a field trip to a concert of classical music. It is not where readers expect them to go - all the kids are deaf or hard-of-hearing. Moses's teacher hands each child a balloon. He asks them to hold them in their laps to feel the music. The percussionist, who is not wearing shoes, creates music they can feel. She is deaf too. Afterward, they go backstage to meet her and she tells them how even though she lost her hearing at age seven, she wanted to be a percussionist. She worked very hard to make her dream come true. That night,

Moses signs to his parents that though he knows he could be a doctor or an artist or a lawyer or a teacher, he wants to be a percussionist.

Millman's drawings do a fine job of illustrating the story. Each page has Moses signing a few key words, encouraging readers to try for themselves. Showing Moses and his friends enjoying a musical concert in an everyday way is a great way to see people with disabilities as more similar than different. We need more books like this one.

### **Thank You, Mr. Falker**

A few picture books for older kids show kids with challenges/disabilities in the school setting. Based on a true story, *Thank You, Mr. Falker* is the story of Trisha, a young, gifted artist, who could not read. It is torture for her to sit in class trying to sound out simple words or to solve simple math problems. The shapes just looked like squiggles to her. When her family moves to California, Trisha hopes for a fresh start but ends up having the same problems. The kids call her a dummy and laugh at her. Trisha becomes depressed and hides in the stairwell to avoid being teased on the playground.

Then, in fifth grade, Trisha gets a new teacher. Young and enthusiastic, Mr. Falker recognizes Trisha's problems. He acknowledges her pain and isolation and honors her cleverness at fooling so many teachers. He gives her the specific help she needs to learn to read.

This book's illustrations have edginess to them. The author uses lots of bold pen strokes and darker colors. They are not "childlike," but are definitely appropriate as the story is a serious one. Patricia Polacco realistically portrays her emotional struggle and the triumph of adapting to her disability. Without Mr. Falker, Trisha could have had a very different life. Instead, she took her talent at drawing and her new joy with words to become a prolific children's book writer. It is certainly an inspiring story.

## The Face at the Window

In many ways, we shun those with mental illnesses as much as those who have learning disabilities. Sometimes we can understand differences better when they are filtered through different lenses. In *The Face at the Window*, Regina Hanson describes Dora, a young girl in Jamaica. Dora's neighbor, Miss Nella, suffers from untreated mental illness and is seen as having magical powers.

Miss Nella is feared among the children; they believe if a child looks upon her face in the window, something terrible will happen. Though Dora's parents have told her that Miss Nella is sick, she believes her friends. After trying to steal Miss Nella's mangoes, she sees Miss Nella's face in the window. She runs home after her friends tease her and that night it starts to rain. When it doesn't let up for days, she believes it is because of her bad deed and she finally tells her parents what happened. They explain that Miss Nella is not an evil sorcerer, just an old woman whose mind plays tricks on her. As the three walk to Miss Nella's for Dora to apologize, she learns her parents had good memories of her and that Miss Nella knows who they are. Dora starts to see Miss Nella as a person and offers her a small gift.

Using rich and vibrant pastel illustrations, an authentic island setting and speech patterns that evoke the Jamaican culture, Hanson gives readers a unique view of mental illness. Through young Dora, whose own mind plays tricks on her, we see how rumors create separation and fear. When Dora faces her fears with the help of her attentive parents, she finds her own compassion. This is a lovely book on many levels - from how different cultures view mental illness, to how we can cultivate compassion by learning to look at our own faces in the window.

## The Seeing Stick

In *The Seeing Stick*, Jane Yolen, a master storyteller, tells a tale about a Chinese emperor's

blind daughter who everyone feels sorry for, including herself. Her father hopes that some day she will be able to see and sends word he will reward anyone who can restore her sight with a fortune in jewels. A blind old man, who lived far away, takes up his walking stick and whittling knife and goes to help the princess. He carves his journey with uncanny likeness on the stick and shows her how to "see" through her fingers. Happy that she is part of the world again, she tells the other blind children she meets that she learned to grow eyes on the tips of her fingers, just like the blind old man.

Children's picture books that portray kids with special needs in an inviting and accepting light are valuable tools for teaching kindness and compassion. These books each offer a piece of understanding. Some, such as *Moses Goes to a Concert* or *The Seeing Stick* illustrate a specific disability. It shows how being blind or deaf is part of who a person is but does not define them. Moses wants to be a percussionist in a symphony. The old man has an extraordinary ability to carve. In *The Face at the Window*, fears and myths around disability are dissolved when young Dora meets the woman with a mental illness and realizes she is part of their community, sharing history, skills and a mango tree. Woloson sums it up beautifully when writes in her notes to parents, "Through their friendship, Charlie and Isabelle are doing their small part in making the world a more tolerant place" (page 28).

## Differences in Common: Chapter Books

Several novels for children and young adults have kids with disabilities as the main characters. These books offer insight and information in an interesting and entertaining fashion.

## Stuck in Neutral

Some books are told from the view of the child with disabilities, such as the intense young adult novel *Stuck in Neutral*. Shawn McDaniel tells readers what it is like to live in a body he cannot control. He has a rich inner life, but he

cannot tell anyone about it due to his severe cerebral palsy.

What makes the story interesting is that Shawn's father thinks Shawn has a horrible, painful life and that it would be merciful to kill him. Shawn has no way to tell his father he is happy and wants to live even in the limited way he does. As his father gets closer to killing him, we see what it is like to be Shawn, brilliant inside, and totally crippled outside. It raises the issue of the quality of life for people with differences and asks readers to consider another way of viewing their lives.

### Sees Behind Trees

Easier chapter books, such as *Sees Behind Trees* also take readers into the mind of the hero – in this case a blind Indian boy living in sixteenth-century America. Michael Dorris's compelling story is about a boy named Walnut who learns to listen deeply to the forest and to "see" what cannot be seen. Dorris has a profound ability to enter an individual's body, mind and soul and show him as a real person with both challenges and gifts.

In this tribe, a boy becomes a man when he can accurately shoot an arrow. But Walnut cannot see the target. He cannot see the tops of trees or clouds or his people around a fire. However, his other senses are highly developed, and he can move through the forest by listening and feeling. The tribal elders understand his differences and see the gifts he does have and so he becomes Sees Behind Trees and embarks on a journey that tests his courage and his skills.

On this quest, a village elder continues to teach him to see without his eyes: "Your body will remember where it has been if you let it. It recalls what's familiar—but not as your mind does. With your mind you stand outside the world and look in. With your body you are inside already" (p. 52).

*Sees Behind Trees* starts by depending on the elder and through a terrifying ordeal, he learns

to depend on himself and the profound skills he has. His story, set in a seemingly much simpler era, is actually quite similar to several books set in present times. Joey Pigza and Hank Zipzer also learn that they have gifts because of their disabilities, not in spite of them.

### Joey Pigza Loses Control

*Joey Pigza Loses Control* is a contemporary tale of a boy with Attention Deficit Disorder who takes medicine to control it. Joey spends the summer with his father, who is also hyper but medicates with beer and compulsions, and careens in and out of Joey's life. In one of his manic modes, his father flushes Joey's medicine down the toilet. Jack Gantos's writing changes as Joey loses control:

*So we each jumped [bungee-jumping] five more times and all the fear and falling and screaming wiped out every hyper feeling I had and when we got home I was exhausted and went directly to my room and threw myself onto my bed and it was as if I had fallen one more time, only straight down an endless black hole. (p. 139)*

Gantos makes the "problem" kid real and ordinary. Joey craves a relationship with his absent father and tries to please him. He wants to have friends, play baseball, love his Chihuahua, Pablo, and let his mom take care of him. He tries to please others, but without his medication, he only disappoints everyone. It is a powerful way to learn about an attention disorder through the eyes of a boy who is really just a regular kid.

### Hank Zipzer: The Mostly True Confessions of the World's Best Underachiever Series

Hank Zipzer, hero of the *Hank Zipzer: The Mostly True Confessions of the World's Best Underachievers* series, is a great kid with a big problem. Though he is a smart fourth-grader, it is very hard for him to read, write or do math. The school principal, who has a mole on his cheek in the shape of the Statue of Liberty, thinks he is a troublemaker. His teacher, in gray from head

to toe, thinks he does not try hard enough. His dad, a crossword puzzle nut, thinks he just needs to focus. No matter how hard he tries, he always seems to mess things up. Thank goodness Hank has two best friends and a grandfather who believes in him.

This series is available both in print and audio form. Superbly read by Winkler, kids who learn better by listening than by reading will laugh (and cry) as they identify with Hank. Each of the four stories in this series can be read alone. The first book is *Niagara Falls or Does It?* It is the first day of fourth grade and the gray teacher assigns a five-paragraph essay on what they did over the summer vacation. So many words and sentences make Hank's head swim. Before he has even written a word, he already feels like a failure. But Hank, like many kids with learning challenges, is gifted in other ways. He decides to build a working model of Niagara Falls.

Ashley (an Asian-American girl) and Frankie (an African-American boy), his two best buds, along with Robert, the boy-genius who tags along, help him make a model, complete with water gushing over the falls. Once again, his creative attempt to impress those that doubted him ends in a wet classroom, an outraged teacher and two weeks of detention. The detention turns out to be a blessing when the new music teacher recognizes Hank's "learning differences" and not only gets him help, but truly understands what he needs from the adults around him. Henry Winkler, whose affection for Hank is palpable in his readings, based these stories on his own life. Winkler went to school before there was much awareness about learning problems, so he did not get help for his dyslexia the way Hank does. Winkler offers a great service by showing Hank as a regular kid, who wants good friends, to do well in school and to be treated with respect and not scorn. It is important for kids and adults to see kids like Hank as a smart, creative and loyal friend, even if he has trouble reading. Hank deserves to be understood and included. Winkler, with lots of humor and heart, does a fabulous

job at making Hank a real success. The other books in the series follow a similar plot. Hank, ever the delightful adventurer, tries to make something better and ends up making a mess.

### My Sister Annie

Chapter book stories often take place in the school setting. For instance, *My Sister Annie*, by Bill Dodd, is told from the viewpoint of Charlie, an eleven-year-old boy in middle school and on his way to the league championship for his baseball team. While he yearns to be part of the cool group, he has to come to terms with what he wants his life to be like and what it is like living with his older sister Annie, who has Down's syndrome. Her child-like behavior embarrasses him. She cheerfully yells at him when he is on the pitcher's mound. She throws a tantrum in a restaurant and a boy he wants to like him sees the whole thing. He goes to Annie's special school's open house and sees the girl he wants to ask to the dance. Involved in his own embarrassment and anger, it doesn't occur to him that they are both at a "special school." Instead, he sees it as more proof that Annie is ruining his life.

He thinks he is the only person who has a sister with a disability. His parents just accept Annie and all her needs, so they expect Charlie to do so as well. Through the plots of the baseball championships and his wanting to be accepted by the cool middle-school boy's group, he finds comfort from unexpected places.

Written with realistic language and real-life emotions experienced by many kids who have a sibling with differences, Bill Dodd's book is an honest portrayal of what life can be like for a "typical" brother. His coach tells Charlie about his own brother, blinded as a baby:

*... When I was a kid, sometimes I wished my parents would put him in an institution. Then I'd hate myself for feeling that way. I'd feel guilty about it. Some choice, huh? Feel mad or bad or guilty. I loved my brother, and sometimes I hated him. You aren't the*

*first one to go through this, you know.*  
(p. 86)

### **Eddie Enough!**

A new style is for authors to write about disabilities from the perspective of the character who has them, rather than from the view of a family member.

An example is Eddie, the protagonist of *Eddie Enough!*, who narrates his own story. He takes readers through his day and tells what it is like to live in a hurry, forgetting along the way, bumping into people, spilling drinks and eagerly raising his hand in math. Just reading it is tiring!

Eddie is likable. Kids will surely laugh at his fumbblings until they get deeper into the story. Eddie shares how hard it is for him when he gets in trouble all the time, and always having the adults around him telling him to sit still and slow down and pay attention. He shares how hurtful his nickname is, and how angry he gets at the other kids for teasing him. It is not easy knowing Eddie, and it is clearly not easy being Eddie.

The school principal tells Eddie that he used to have similar problems in his life, so Eddie starts to trust him. After some testing, assessments, and a visit to the doctor, Eddie is put on medication, which makes him feel like Eddie Just Right.

Very readable, entertaining and realistic, *Eddie Enough* shows one way to help kids with ADHD. Although medication worked for Eddie, the author missed a chance to educate readers that it does not work for everyone.

### **The Gift of the Girl Who Couldn't Hear**

Earlier, the picture book, *Moses Goes to a Concert* was discussed. In that book, Moses goes to a school for deaf children and uses sign language to communicate. The chapter book, *The Gift of the Girl Who Couldn't Hear*, offers a different choice. The main character, a middle school

student, goes to a typical school and reads lips instead of using sign language. It is one of the rare books showing a child with disabilities being mainstreamed.

The narrator, Eliza, is in the middle of the awkward transition from girl to teen. She's moody, depressed, overeating and getting poor grades. The seventh grade tryouts for the musical *Annie* are coming up and though she has been waiting years to get the lead, she has no interest in doing the play. She feels fat, ugly and unmotivated.

Her best friend Lucy, who is deaf, decides she is going to try out for an orphan part and asks Eliza to help her learn to sing. Lucy cannot sing, even with Eliza gesturing the cadence and tempo of the song. And Eliza cannot believe she is going to go up on stage in front of everyone and attempt to sing. Lucy, an incredibly optimistic girl, signs Eliza up to audition and, of course, she gets the part of Annie. Lucy does not get an orphan part, but her courage to audition has earned new respect from other kids who sometimes made fun of her.

Lucy's parents insist that Lucy learn to communicate by reading lips. In the book, she does not know anyone else who is deaf. Though it is not discussed in the book, that choice is part of an ongoing debate. The deaf community is the largest sub-group of people with disabilities. Furthermore, the deaf community has its own culture as a result of having their own language, a shared system of beliefs, and similar values, customs and behaviors. Many deaf people do not agree with choosing not to be part of this community. With this in mind, it is refreshing to see her fully included without making it too rosy. Susan Shreve makes good use of dialogue and keeps the story engaging. It is a good middle-school book to talk about inclusion and how kids treat people with differences.

Lucy struggles as a deaf person in a hearing community. Her positive personality makes it work for her but others do not have the cogni-

tive abilities she has, and, as a result, did not go to typical schools. They, like Charlie's sister in *My Sister Annie*, Shawn, in *Stuck in Neutral* or Ronald, in *Crazy Lady!* struggle not only because of their disabilities but also because they often get little or no support.

### **Crazy Lady!**

In *Crazy Lady!*, Ronald is a boy with mental retardation. He goes to a "special school," never speaks, and lives with his alcoholic mother. She is the crazy lady the rest of the neighborhood kids poke fun at as she stumbles down the street in wild costumes ranting at everyone in her drunken state. But they are not the only family with problems. Vernon's mother has recently died and his illiterate father is barely keeping Vernon's large family afloat. Through the elderly lady who lives next door to Ronald, Vernon finds himself slowly drawn into Ronald's and his mother's world. Jane Leslie Conly shows all the characters' weaknesses. Vernon's siblings squabble and fight as they figure out how to live without their mother. Maxine, the crazy lady, cannot control her drinking even though it means she may lose Ronald, and Vernon struggles with his own anger and pain.

Conly makes the people of the neighborhood real and shows, not tells, readers how inclusion should work. The whole neighborhood learns how to be a friend to Ronald and realizes every family has their secrets and their struggles:

*"... Well, with Ronald I didn't really know him, so he made me nervous. But then we became friends. After that, I kept learning more and more about him—he's complicated, you know?" Vernon tells the special education teacher. She responds, "Yes, he feels deeply. It must be frustrating to have strong emotions and not be able to express them." (p. 167)*

Conly gives us a glimpse into the needs of kids and families with disabilities and shows us a way to help them. Vernon has to move through

his own fears and feeling uncomfortable in order to begin to see Ronald as a whole person. He learns about him by being with him. He notices what he is interested in even though Ronald can't tell him and then he acts upon his new knowledge such as the time he gets involved in Special Olympics. The elderly lady next door supports Vernon by tutoring him and in exchange, he plants a garden for her since she is no longer able to do physical work. Her physical infirmity is another kind of disability. Conly subtly reminds readers that many "typical" people will be dealing with their own disability someday. Another book, *Tiger's Fall*, deals with a child who becomes disabled due to an injury.

### **Tiger's Fall**

A strong book about an eleven-year old girl in Mexico who falls from a tree and breaks her back, *Tiger's Fall* is a powerful tale of how life does not always turn out the way you expect. Another author might have made Lupe consider her future deeply, but Molly Bang understands that is not how preteens think. Instead Lupe is at first in a daze, then grief-stricken when she finds herself in a self-sustaining community for "cripples" where others in wheelchairs carve wooden toys, meld metal parts of wheelchairs and take care of each other. Though readers know that she will find her path there, Bang makes the path believable. She makes us care about Lupe and her poor, worried family. Bang based the book on PROJIMO, a center for people with disabilities near Mazatlán.

Bang's book is also unusual in that it features disability in another country. She raises big questions—how do people with little money and limited services deal with disabilities such as paralysis? Bang does not weigh the tale down with the enormity of this question, however, she lets little Lupe, based on a real girl from the center, show us. Unlike many of the other books on this list, Lupe became disabled at 11. *Tiger's Fall* is a wonderful book that allows readers into the mind of someone who becomes disabled.

## A Corner of the Universe

It is hard to stay away from disability clichés. And though the protagonist in *A Corner of the Universe* is an engaging young girl who questions stereotypes, the adults around her never rise above them. Believable Hattie Owens lives in a small, middle America town with her parents in a boarding house. She is happier visiting and talking with the storekeepers than girls her own age. Her quiet summer is shaken up when her mother's twenty-one year old brother comes back to live with Hattie's grandparents, a formal, snobby, rich couple. The fact that Hattie has never been told she has an uncle reflects the ongoing shame and silence surrounding those with disabilities. Her uncle's parents had sent him to an institution and tried to pretend he didn't exist; his autism-spectrum disorder too unruly and disruptive for their way of life. Hattie and her uncle Adam become friends, though she feels like she has to take care of him. Her mother and grandmother do not explain why they never told her about him. He still seems like a burden to them and Hattie tries to understand. The story is well written and begins asking the reader difficult questions until, shockingly, Adam kills himself over an unrequited love. His suicide seems totally out of character and only leaves the reader disappointed. Hattie's coming-of-age realization comes out contrived. Hattie didn't need his death to know she had a unique place in her own life. Author Ann Martin could have "lifted the corners" without killing the messenger.

## The Curious Incident of the Dog in the Night-Time

Mark Haddon did a much better job portraying the silence and shame that well-meaning people have about disability. In this case, the parents kept secrets from their son who has autism. A 2003 release, *The Curious Incident of the Dog in the Night-Time* is high on the best-seller list. It features Christopher, a 15 year-old with a very different approach to life, who "writes" his story. It opens with him finding the neighbor's

dog killed with a garden fork in the middle of the night. When he decides to solve the case, we meet his teachers, neighbors, and other adults, but as is typical of kids like him, no other friends. Set in England, he attends a school for kids with disabilities. He lives with his father. He believes his mother has died. Christopher has Asperger's syndrome, an autistic spectrum syndrome that makes him self-aware but in great need for structure, routine and predictability in his life.

In his quest to solve the murder, Christopher has to move outside of his comfort zone and knock on neighbor's doors, have conversations and ultimately take a train to find his mother. Christopher goes off on all kinds of tangents in the story, such as explaining some of his quirks and habits. If he sees four yellow cars on the way to school, it becomes a Black Day. He will not eat yellow food and he dislikes novels because they are so full of lies. But these tangents give his tale texture and interest. Mark Haddon puts readers right into Christopher's unusual mind; bringing us back to the "plot" before the tangents become uncomfortable.

Like any rite-of passage story, Christopher does things outside of his realm of experience. By the end, he solves the murder case, finds his mother alive, and realizes he is capable of much more than he or anyone else thought. Though there are other books with characters like Christopher, they are not usually told in the first person. This book stands out. Through the carefully constructed portrayal of Christopher's mind, readers are likely to find connections, leading to understanding and, ultimately, compassion.

## Granny Torelli Makes Soup

One of the best books on accepting with our hearts and not necessarily our minds is *Granny Torelli Makes Soup*. In this excellent novel by Sharon Creech, twelve-year old Rosie and her buddy and next-door neighbor, Bailey, have known each other forever, but they are having a problem. Rosie's grandmother, Granny Torrelli, uses cooking, eating and storytelling to gently

guide the kids to understand each other's perspective.

Bailey joins them as they make homemade pasta, tomato sauce and spareribs. Granny Torrelli tells Rosie to guide Bailey's hands to mix the dough. Bailey is blind. His blindness has never interfered with his and Rosie's friendship, though she was devastated that he could not go to the same school as her. However, Bailey's blindness is at the heart of the problem between them. Rosie taught herself Braille so she could read Bailey's books with him and he got very angry. With Granny's help, she learns that Braille was one of the few things Bailey had that she did not. When she learned it, in a way, she took it away from him.

Other characters, like the new girl down the street who has a crush on Bailey, also challenge their friendship. At the end of the story, as everyone is gathered at the table for a big pasta party, Granny raises her glass to Rosie and Bailey for making the meal. Rosie, filled with the love of her family and friends, realizes she is stronger after weathering the storm with Bailey, still her pal, her buddy and her best friend. This is a delicious story, seasoned with complex characters, and filled with hope, love, and Granny's charming wisdom.

### Summary

There are still relatively few books available featuring characters with disabilities. Increasingly, more well-written and engaging stories are being published involving characters with disabilities. This is a good sign for the future as we define and adapt to a culture where disabilities are not just tolerated, but understood and accepted. As a society, we are welcoming more and more people with differences and viewing them as whole people with their own gifts to share. Fiction offers a way to develop our ability to create an inclusive society by giving readers a first-hand perspective on what it's like to have a disability.

Books can illustrate tolerance and acceptance. They can show that people have much in common with one another and everyone has something unique or "different" about them. Children with "invisible" disabilities such as Trisha in *Thank You Mr. Falker*, Hank in the *Hank Zipzer* series, Joey in the *Joey Pigza* series or Eddie in *Eddie Enough!* are often misunderstood by peers and the adults around them. Reading their stories allows children to learn about their challenges without focusing on a real child in their class.

Perhaps the most important point offered in all of these books is given in *Stuck in Neutral*. Through Shawn's personal story, the author asks readers to consider their own judgments about people with disabilities. He challenges readers, as do the authors of *Ian's Walk* and *The Curious Incident of the Dog in the Night-Time*, to consider what it might be like to be a person with a disability. Fiction allows readers to put themselves into the shoes of the characters and to see the world from their eyes, thereby cultivating compassion and tolerance and ultimately realizing their own differences.

**Anna Stewart**, B.A., is an accomplished reviewer, writer, teacher, advocate, and leader. A prolific writer and columnist, she has published more than 80 book reviews and over 200 articles, essays and columns. She is on the Boulder Valley School District Advisory Board for disabilities, works as a parent mentor, and edits a bi-monthly newsletter for parents who have children with disabilities.

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Eliza Woloson

Bryan Gough, illustrator

Woodbine House, 2003



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*Ian's Walk: A Story about Autism*

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Also *Joey Pigza Swallowed the Key* (2000) and

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*Hank Zipzer: The Mostly True Confessions of the World's Best Underachiever, Niagara Falls or Does It?, I Got a D in Salami, Day of the Iguana, The Zippity Zinger*

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*Tiger's Fall*

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Ann M. Martin

Scholastic Press, 2002

*The Curious Incident of the Dog in the Night-time*

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Doubleday, 2003

*Granny Torrelli Makes Soup*

Sharon Creech

Illustrator, Chris Raschka

Joanne Colter Books, 2003

## REVIEWS

### Book Review

**Title:** *My Friend Isabelle*

**Author:** Eliza Woloson

**Illustrator:** Bryan Gough.

**Publisher:** Woodbine House, 2003.

Cloth, ISBN: 1-890627-50-X, 28 pp.

**Cost:** \$14.95 USD

**Reviewer:** Rhonda S. Black

*My Friend Isabelle* is a delightful book for children ages two to six. The story is told from the perspective of Charlie, Isabelle's friend. Charlie talks about how he and Isabelle are different. Although they are the same age, Charlie is tall, Isabelle is short; Charlie runs fast, Isabelle takes her time; and Charlie knows lots of words, some of Isabelle's words are hard to understand. Charlie tells the reader that his mother says differences are what make the world great. Charlie then talks about how he and Isabelle play together every Friday. The focus shifts to their similarities, such as "we cry when one of us forgets to share," and they both like to slide by themselves without help when they go to the park.

Charlie concludes the story by stating life is more fun with friends like Isabelle. A one-page afterward explains that Isabelle is a child with Down syndrome. What is outstanding about this book is that the story line never mentions that Isabelle has a disability. This book is similar to *Where's Chimpy* (Rabe & Schmidt, 1991) which received much positive attention for creating a story about Misty looking for her lost stuffed chimpanzee. The story didn't mention that Misty had Down syndrome, although one could tell from the photographs. *My Friend*

*Isabelle* makes a similarly strong statement by portraying Isabelle as a child, not a child with a disability. The message in *My Friend Isabelle* is that **everyone** is different. Isabelle is a valuable child who is desirable as a friend.

A portion of the royalties of this book are donated to the National Down Syndrome Society. In addition, this book is currently a nominee for the 2004 Dolly Gray Children's Literature Award. See the following web site for further details. <http://www.geocities.com/marissa-johnstun/dollygrayaward.html>

**Rhonda S. Black** is an associate professor in the Department of Special Education at the University of Hawaii at Manoa.

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### Book Review

**Title:** *Nick's Gallery*

**Author:** Gill James

**Publisher:** Publish Britannica, London, 2004

Paper, ISBN: 1-4137-2186-9, 149 pages

**Cost:** \$16.99 USD

**Reviewer:** Steven E. Brown

James is a former schoolteacher who recently became disabled and turned her attention to writing. *Nick's Gallery* is a novel aimed toward younger readers. The protagonist of the story, Barney, is an overwhelmed, but conscientious teenager, struggling with the obvious decline

and imminent death of his best friend, Nick, who has Muscular Dystrophy. Nick is an angry, passionate young man, who wants to make the most of the time he has left. Barney tries to please Nick, his own parents, his swimming coach, bosses at a new job, his teachers, and a new girlfriend. He manages, barely, until the night he misses his friend's trip to the hospital and subsequent death.

We watch Barney alienate everyone around him as he tries to cope with the death of his friend and regain his own equilibrium. Most of his family and friends are understanding, but impatient, as Barney's grieving process takes longer than they want. Barney begins the road to returning to his own life when he discovers the joys and friendships that sailing can bring. This leads him full circle to forgiving himself and Nick for the way their paths parted.

This is an excellent book to explore feelings about death and disability. While I would have liked a little different, and perhaps deeper, look into Nick's life, the book is not about him, but Barney. As such, James does a good job in exploring the feelings of someone whose friend is deteriorating quickly. I would especially recommend this book for high school students.

**Steven E. Brown**, Ph.D., is an Assistant Professor at the Center on Disability Studies at the University of Hawai'i and an Editor of *RDS*.

### **Book Review**

**Title:** *I Can, Can You?*

**Author:** Marjorie W. Pitzer

**Publisher:** Woodbine House, Bethesda, MD, 2004

ISBN: 1-890627-57-7

**Cost:** \$10.95 USD

**Reviewer:** Taletha M. Derrington

*I Can, Can You?* is an attractive board book featuring colorful pictures of children with Down syndrome enjoying a variety of activities. The most appropriate audience is children with Down syndrome from birth through age four and the adults in their lives.

There are few board books for infants and toddlers that feature children with special needs in general, and Down syndrome in particular. The pictures are of real children, as opposed to animals or cartoon children found in many other beginning books, and the wording and scenes highlight these children's abilities. This book gives young children with Down syndrome the opportunity to look at other children who look like they do, and it gives new parents of a baby with Down syndrome hope for their child's potential. For early childhood professionals, the book is a needed literacy tool that may engage young children with Down syndrome more than the average picture book.

Each activity is presented in the form, "I Can, Can You"? The pictures portray these children's abilities and do not single them out as being different, although the back cover states these children have Down syndrome. Large print, simple sentences, and repetition make this a good book for beginning readers of any type. The large, sans serif lettering and simple style make the book accessible to older readers and caregivers with low vision, intellectual, and/or learning disabilities who might wish to share the book with a young child.

Although the book adds to the body of children's literature including children with special needs, the children are predominantly engaged in solitary activities, leading to a sense of separateness that counters the contemporary struggle for inclusion. The opportunity to see that children with Down syndrome can, and like to,

do the same things as other children, coupled with the phrases “I Can, Can You?” could foster appreciation and identification of typically developing children with their peers with special needs.

The back cover indicates this is the first edition; if there is another edition, the author might expand the appeal of this book to a wider audience by including pictures of typically developing children and adults interacting with children with Down syndrome. Despite these criticisms, the book is an interesting contribution to young children’s literature. The full list price is somewhat high compared to other board books, but better deals may be available at discount bookstores and online resources. Nonetheless, the focus of the book makes it worth the cost. I would recommend this book to parents of young children with Down syndrome and professionals who work with them. Teachers of integrated preschools and day care centers should also consider using the book to create more learning opportunities about the similarities and differences among all children.

**Taletha M. Derrington** obtained her B.S. in biology from the California Institute of Technology, and her M.A. in developmental psychology from the University of Hawai‘i at Manoa. She is currently working on her doctoral degree at the Heller School for Social Policy and Management at Brandeis University.

### Book Review

**Title:** *Early Communication Skills for Children with Down Syndrome*

**Author:** Libby Kumin

**Publisher:** Woodbine House, Baltimore, 2003

Paper, ISBN: 1-890627-27-5, 368 pp.

**Cost:** \$19.95 USD

**Reviewer:** Martha Guinan, MPH, Center on Disability Studies, University of Hawai‘i

*Early Communication Skills for Children with Down Syndrome*, is an indispensable guide about language acquisition for young children with Down syndrome. The author, Libby Kumin, is the nationally recognized authority on the subject.

This book is an updated, expanded edition of her earlier work, *Communication Skills in Children with Down Syndrome* (1994). She takes a practical approach providing understandable technical explanations and related activities to increase learning and language. She concentrates on the early ages where language makes the most impact, from birth to about ages 5 or 6. Dr. Kumin describes the stages of communication development and how physical characteristics common to Down syndrome affect acquisition of language and speech skills. She explains how the delayed progression of those skills can lead to frustration and other problems.

Leading readers through the results of a speech-language assessment, Dr. Kumin helps us understand the role of a speech language pathologist. To prepare the parent, she describes what to expect in communication skills development in school. A proponent of inclusion, she emphasizes the need for strong communication models and opportunities to practice communication skills. She describes school language demands such as the language of instruction, curriculum, testing and classroom routine and its effect. For example children with Down syndrome may have difficulty following long and complex verbal directions. By breaking the directions down, they can experience success in following classroom rules.

Through explanations and strategies to improve expressive communication skills, this book is an able assistant to the parent in alle-

viating the frustrations of a child who may not have intelligible speech until age two or later. Every parent of a child with Down syndrome can attest to their own, as well as their child's, frustration of others needing the parent to serve as interpreter.

*Early Communication Skills for Children with Down Syndrome* puts 23 years of research and experience in working with people with Down syndrome into an easily readable guidebook for parents and caregivers about characteristics unique to Down syndrome and their impact on language development. It is highly recommended as an informational resource by parents, caretakers, teachers, and anyone else charged with the responsibility of caring for a child with Down syndrome.

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March 13-15, 2006, Sheraton Waikiki,  
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The mission of the Center on Disability Studies (CDS), at the University of Hawaii at Manoa, is to support the quality of life, community integration, and self-determination of all persons accomplished through training, service, research,

demonstration, evaluation, and dissemination activities in 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.

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