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From the Editor's Desk: Subscription Sponsorship Program

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Research Articles

Social Change and the Disability Rights Movement in Taiwan 1981-2002

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Abstract: This paper provides a historical overview of the disability rights movement in Taiwan from 1981 to 2002. It shows the major events in Taiwanese disability history, legislation, and development of disability rights

organizations, with a focus on two influential advocacy associations: the Parents' Association for Persons with Intellectual Disabilities (PAPID) and the League of Enabling Associations (LEAs). It also demonstrates that the disability movement has developed in concert with Taiwan's democratic transition.

Key Words: disability rights, social movement, democratization

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*** Author's Note - Several Chinese Mandarin romanization systems are used in Taiwan. This paper follows the Hanyu Pinyin system. For particular names of organizations and for culturally specific languages, I include the traditional Chinese characters. For specific Taiwanese authors' names, this paper follows the romanization system used by the particular author (for more detail on romanization of Chinese Mandarin in Taiwan see <http://www.gio.gov.tw/taiwan-website/5-gp/yearbook/2001/appendix8.htm>).

"Disability is everywhere in history, once you begin looking for it, but conspicuously absent in the histories we write" (Baynton, 2001, p. 52).

Introduction

Taiwan has been known for its "economic miracle," "third wave democracy" and as an example of the new "Asian welfare paradigm." Nevertheless, people with disabilities are the hidden minority in Asian society. They are "hidden" because of the absence of an environment that enables them to become visible in public. They

are a hidden “minority” because people do not even consider them a minority. Social prejudices deny them basic rights as citizens. Physical barriers such as lack of access to public facilities “disable” them from sharing a “normal” social life in the community. People with disabilities usually are excluded from social life or even incarcerated in institutions. Their rights as citizens to be educated, to vote and to live in an accessible community are usually denied. The emergence and development of the disability rights movement has accompanied Taiwan’s democratic transition over the past 25 years. This paper provides a historical overview of the major events in disability history, disability legislation, and disability rights organizations, with a focus on two influential advocacy associations: the Parents’ Association for Persons with Intellectual Disabilities (中 民 智障者家 盟, Zhong-hua-min-guo Zhi-zhang-zhe-jia-zhang Xie-hui, PAPID) and the League of Enabling Associations (障 盟, Can-zhang-lian-meng, LEAs¹).

Few studies have been done on the history of disability in Taiwan. This research therefore integrates secondary resources and interviews in order to reconstruct the history of the Taiwanese disability rights movement. The narrative I provide is a partial history, constructed on the basis of diverse sources and some interviews that I conducted in 2003. I used United Daily News Index to trace all newspaper articles related to disability rights from the 1980s to 2002. I also collected newsletters and magazines from various disability rights advocacy organizations. Other printed materials include autobiographies of disability rights activists, journal articles written in Mandarin, governmental reports and reports from NGOs. In addition, I interviewed 38 disability rights activists from various related NGOs, selected through snow-ball sampling from the list obtained from PAPID. The small number of selective interviews has a limited representational value, but the interviews are used mainly to provide personal views to supplement information drawn from secondary materials.

I start with a general introduction to disability issues in Taiwan. In the main body of this paper, I divide the history of the disability rights movement into three time periods: (1) The emergence of the movement (1981-1987); (2) The Alliance and Institutionalization of the Disability Rights Social Movement Organizations (1988-1992), and (3) Engaging in public policies (1993 to 2002)² (Ma, 1995; Hsieh 1997; and Hsiao & Sun 2000).

The Language, Philosophy, and History of Disability Prior to 1980

Few historical studies focus on social perceptions of disability and attitudes toward disabled people in East Asian countries. Emma Stone (1999) analyzed Chinese writings and showed that the general term referring to people with disabilities is 殘廢, can-fei. This is a combination of two characters: “can” means “disability” and “fei” means “useless and worthless.” In other words, people with disabilities are linguistically marked as useless and worthless. After the 1980s people in China started to use “疾,” can-ji, to replace can-fei. “Ji” means illness. The meaning changed from defining people with disabilities as useless to defining disability as a medical condition (Stone, 1996, p. 136).

The semiotic transition in language took a different trajectory in contemporary Taiwan. In 1980 障 can-zhang, (disabled and impaired) was used in the first disability-related law, the Can-zhang Welfare Law. A 1997 revision of this law renamed can-zhang to 身心障者, shen-xin zhang-ai zhe, people with mental and physical disabilities, or zhang-ai zhe, people with disabilities. It adapted the “people first language” of international disability rights advocacy to add “zhe,” people. After years of disability rights advocacy, can-fei (disabled and useless) is seldom used in everyday life anymore. Can-zhang and zhang-ai zhe are now used interchangeably in Taiwan.

Defining disabled people as useless can also be found in Confucian philosophy. In *Li Chi (Book of Rites)* Li Yun, Section One, it suggests that in the ideal society, the Grand Union, (Da-Tong Shi-Jie) is realized:

“When the Grand course was pursued, a public and common spirit ruled all under the sky; they chose men of talents, virtue, and ability; their words were sincere, and what they cultivated was harmony... They showed kindness and compassion to widows, orphans, childless men, and those who were disabled by disease, so that they were all sufficiently maintained. Males had their proper work, and females had their homes” (Li Chi, Li Yun Section 1, p. 365, translated by Legge 1967).

In this ideal society (Grand Union), men work according to their abilities, women stay at home doing housework and the marginalized groups (widows, orphans and people with disabilities) are taken care of. It also presumes, however, that people with disabilities are not capable of taking care of themselves, and need to be “maintained” by others.

This discourse from *Li Chi* is constantly quoted in the Taiwanese disability rights movement in two different ways. First, it is used as a symbol of the cultural tradition that it is the government’s responsibility to take care of people with disabilities (Chiu, 1998). Second, Liu (1982) argues that it is also a charity paradigm. Traditional Chinese culture sees people with disabilities as useless and needing to be taken care of by society, and does not see that people with disabilities are capable of making a living by themselves. Liu argues that we have to show society that people with disabilities are not useless and are capable of working (1982, pp. 209-210).

Before the 1980s, people with disabilities received limited governmental support. The ideology of public policy assumed that families and good-will non-profit organizations (NPOs)

were responsible for caring for and supporting people with disabilities. The government would intervene only when “their family cannot take care of them.”³ Before 1981, institutions for people with disabilities were mostly private organizations, primarily in Northern Taiwan. The quality of service in these private institutions varied and some of them were questionable (Ma, 1995). As revealed by *Humanity Magazine* in 1986, the living condition in some of the poorly managed institutions could easily be identified as inhumane; the residents might be chained, and there were no public health facilities or any professional support (Yu, 1986). Needless to say, proper education and rehabilitation programs were not available.

The existence of these unregulated institutions from the 1970s to the 1980s was a result of rapid social changes in Taiwan over the preceding forty years. The family structure, which had played a primary care role for people with disabilities, changed rapidly during the process of industrialization. The nuclear family gradually replaced the traditional extended family structure. More and more mothers entered the job market and could no longer play the caretaker’s role for children with disabilities. As a result, private institutions, disregarding the quality of their service, emerged to meet the demand in the caretaker market (Sun, 2003).

In short, the lack of an enabling public infrastructure was a general phenomenon before the 1980s. Disability was mostly considered as a private issue. Since the 1980s, the disability rights movement emerged to seek recognition and to demand public support for people with disabilities.

The Emergence of the Disability Rights Movement (1981-1987)

The United Nations proclaimed the “Declaration of the Rights of Disabled Persons” in 1975 and started to reframe disability issues as a human rights issue. In response to this new

international trend regarding disability rights, the Taiwanese government passed the “Handicap Welfare Law” in 1981, which claimed to provide for the needs of people with disabilities and to protect their rights as equal citizens. Chiu (1998) points out that although individual rights are granted in the Constitution, the rights of citizens with disabilities were first written into law in 1981. This “Handicap” Welfare Law did not, however, bring the realization of disability rights. It included no regulations and no concrete policies. In other words, it is a “handicapped”⁴ law, referring to the fact that the law was not capable of doing anything. Although the first disability-related law did not function, the disability rights movement emerged in the early 1980s and turned a new page in the history of the struggle for disability rights in Taiwan.

The Professional Disability Non-Profit Organizations

In the history of Taiwan’s disability rights movement, the involvement of Christian church organizations and disability related professionals played an important role, not only by providing services, but also by introducing progressive ideas to disability rights issues. For example, the Yu-Ren Developmental Center was founded in 1972⁵ in Taipei and the Ren-Ai Developmental center was founded in 1975⁶ in Hsin-chu. Both were sponsored by Catholic Church organizations. Several other associations also were founded in the early 1980s. For example, the Sunshine Social Welfare Foundation was founded on December 18, 1981 as the first non-profit social welfare organization to support facial injury and burn victims in Taiwan.⁷ The First Children’s Developmental Center was founded in 1981 by several special education professionals to provide education to children with intellectual disabilities.

Liu Hsia (1942-2003)⁸ could be considered the pioneer of self-advocacy of disabled people in Taiwan. Liu developed rheumatoid arthritis during the sixth grade of elementary

school. She discontinued her formal education and educated herself at home. She started to publish articles in 1961 and published her first book, “The Song of Life,” (Sheng-zhi-gel) in 1977. The book was well-received and she became a well-known “wheelchair writer.” In 1982, she and a group of Christians co-founded the Eden Social Welfare Foundation to help improve the overall condition of people with disabilities.⁹ The organization aimed to provide social service and spread the gospel.

According to Liu, the discrimination she experienced when she was young motivated her to found an organization to promote the rights of disabled people. She was denied entry to a public exhibition on “Economic Success” in Taiwan in 1971. The excuse from the organizer was not lack of accessibility, but that “there are important people visiting, it does not look good if there are ‘handicapped’ people around” (Liu, 2004, pp. 205-206). At that moment, she realized that the organizer not only discriminated against her as an individual, but against people with disabilities in general. She had to speak for disabled people. She stated, “At that time, I knew that [to speak out] is God’s calling and it is my obligation and mission” (Liu, 2004, p. 206).

The first priority of Eden is to provide job training for people with various disabilities. Liu argued that people with disabilities can work; it is just that Taiwanese society does not educate them thus excluding them from the workforce. “We (Eden Foundation) have to empower disabled people to work, and show society that people with disabilities are capable of working and can be independent from others” (Liu, 2004). Liu passed away in 2003. Eden has become the most prominent non-profit organization providing support for disabled people and continuously advocating disability rights in Taiwan.

The first attempt to establish a national association to improve the quality of care was

made by Father Brendan O'Connell¹⁰ (Ma, 1995). Father Brendan has a sister with Down syndrome and his parents are founding members of the ARC (Association for Retarded Citizens) in the United States. In the mid-1970s he came to Taiwan and saw the quality of care in private institutions as a problem. He recalls that “many institutions only provide a space for people with disabilities to stay and do not educate them. Those children need to be educated” (personal communication, August 6, 2003). Thus, the Association for “Mental Retardation” (智 智 Qi-zhi xie-hui, AMR) was founded in 1983 and aimed to promote the quality and professionalism of the institutions.

During this period, the public and the government had a limited understanding of disability rights and the needs of people with disabilities. Even the establishment of a private special education center faced multiple obstacles. Tsao Ai-lan, one of the founders of the First Children Development Center (FCDC), recalls:

“First, the regulation of a special education school or institution makes it impossible to found a private special education school. As a result, we decided to start with a special education daycare center registered as a ‘training center.’ Second, the resources are limited and the demand is huge. We first found a basement with no windows and hired three or four social workers. There was quickly a long waiting list” (personal communication, July 30, 2003).

Besides the lack of financial resources and the strict governmental regulations, Tsao also points out that resistance from the community was one

of the most difficult challenges. The “Feng-Qiao New Village” incident illustrates the existing social prejudice against disabled people.

Feng-Qiao Incident and Community Segregation

The Feng-Qiao incident is a case of community violence against a daycare center for children with intellectual disabilities. The incident started in 1982 when the FCDC decided to move to a larger facility in Feng-Qiao village, a residential community, because of the high demand for professional special education. However, when the residents of Feng-Qiao New Village realized that their new neighbor would be a daycare training center for children with developmental disabilities, strong resistance emerged from the residents’ association. The protest and negotiation lasted several months. The reactions from the community’s residents included disturbing the construction work, not allowing FCDC staff to enter the community, destroying the center’s facilities and even threatening the lives of the FCDC’s staff. Besides questioning the FCDC’s legal status, residents argued that children with intellectual disabilities would “destroy the community’s living environment” and “affect the normal development of children in the community” (Where is Home for Disabled Children, 1983, p. 3).

In response to the community’s strong resistance, seven parents’ representatives brought a petition with more than 500 signatures to the President, Chiang Ching-Kuo, and asked the government to protect the rights and well-being of their children and to address the needs of children with intellectual disabilities (Where is Home for Disabled Children, 1983, p. 3). It was the first documented parents’ collective public action for disability rights in Taiwan.

The violent reaction and the discriminatory language used against children with disabilities, as well as the parents’ political action, attracted media attention and the involvement of politicians. The incidents were widely reported in the

media, including television stations and newspapers. The media exposure resulted in strong public sympathy and support. As a result, the Social Welfare Office of Taipei City stepped in and several well-known city council members got involved in the negotiation process. Finally, with strong public support and the intervention of government officials, FCDC moved into Feng-Qiao New Village on June 24, 1983.

The impact of the Feng-Qiao incident is significant in the disability rights movement in Taiwan. First, it drew public attention to the rights of children with disabilities, including the right to be educated and the right to be included in the community. Second, seminars and public forums addressing disability rights issues were held. Many NPOs such as the Sunshine Foundation, the FCDC and the Eden Foundation began to work together and organize public forums and workshops to discuss disability issues and to advocate for a non-discriminating environment (I am a Human Being, Please Respect Me, 1983, p. 7). In this process many new concepts were introduced to families with disabled members and to the public. Third, an unexpected result, recalled by Tsao, was the large amount of donations that went to FCDC, which resolved its major financial problem. Finally, the incident also reveals the lack of infrastructure and legal framework for persons with disabilities. The parents' petition became the first ever documented political action for disability rights and prompted the disability rights movement to promote disability legislation and welfare. It is also the first successful case of attempts to overcome the segregation of disabled people in Taiwan.

From Service to Advocacy: The Emergence of Parents' Associations and Disability Legislation

As in the early stages of the disability rights movement in the United States, parents' involvement plays an important role in Taiwan. According to Luo (1993), the first parents' attempt to organize for children with intellectual

disabilities started in the early 1960s. The Taipei Association for "Mental Retardation" (Taipei qi-zhi xie-jin-hui) was founded in 1963. This association sponsored the Yang-Ming Adult Care Center for "Mentally Retarded" People in 1974. However, it was a service-oriented organization whose aim was neither advocacy activities nor grassroots movements (Luo, 1993, p. 153).

Some special education institutions also encouraged parents' involvement. Father Brendan points out that he learned that parents' involvement is usually an important part of any organization from the experience of the ARC. He encouraged parents' participation in AMR in the early 1980s. Similar parents' associations were also formed in different special public schools, although advocating for disability rights was not their primary concern. Parents' voices for the rights of people with disabilities had not yet been heard in the public sphere before the Feng-Qiao incident, even though they were already active in other ways.

The Feng-Qiao incident marked a turning point allowing parents to organize themselves for disability rights and to politicize disability rights issues. Tsao Ai-Lan suggests:

"After the Feng-Qiao incident, parents from the middle or southern parts of Taiwan came to us and wished they could send their children here for professional training. We (FCDC) kept expanding our program in order to accommodate these huge demands. However, we could never help all the children with intellectual disabilities in Taiwan. At some point, I realized that we needed a national system to support those children. In order to achieve this goal, social movement would be

the necessary means. Thus, I started to organize parents into special education institutions for political action” (personal communication, July 30, 2003).

With the support of special education professionals and parent leaders, the Parents’ Committee was founded under FCDC. They quickly connected with other parents’ organizations, which already existed in some institutions, for instance, Yu-ren. In 1984 parent leaders such as Wang Guang-Xu and Zong Jin-yi organized several parents’ associations with a total of 500 parents with disabled children¹¹ and started a petition to revise the Special Education Law.

At that time the special education law allowed disabled children either to go to public school or to be educated at home. In practice, this meant that the state did not need to grant the right of education to children with disabilities. As a consequence of the insufficient infrastructure, the option “to be educated at home” just made most children with disabilities stay at home and deprived them of any chance to go to public school. Generally, the law excluded most children with disabilities from public school (Ma, 1995). The law was revised right after the petition was presented.

Under Martial law, civic organizations were under rigid governmental control. In the process of organizing for collective action, the parents faced various difficulties from the state. The first application to register as a non-profit organization was rejected by the government, because new organizations were not allowed to be established if a similar organization had existed before the revision of the Civic Organization (Ren-min tuan-ti) Law in 1989. The existence of the Association for “Mental Retardation” became an excuse for the government to hinder parents’ efforts to organize themselves. However, the parents found a way to work with the system. They participated in the AMR as individual members

and organized a parents’ committee under AMR in 1986. AMR thus became an institutional foundation for the parents to further expand their grassroots movement.

The state’s control over civil society can also be illustrated by showing its attempt to discourage individual organizers from participating in the movement. Zong Jin-yi, the founder of Hsin-lu, recalls, “Since I worked in the public service sector, I was warned of the potential consequence of losing my job. I was also told that they could make special arrangements for my child if I withdraw from the parents’ organization” (personal communication, August 13, 2003). Nevertheless, these obstacles did not prevent parents from organizing themselves in a gradually liberalizing political environment.

In 1987, as a result of a series of protests and media attention, the Taiwan Provincial government organized a public forum for parents of children with intellectual disabilities. Parents from different areas of Taiwan were invited. After the public forum, those parents decided to publish a newsletter, “心路Hsin-Lu,”¹² in 1987 under the AMR. The newsletter aimed to (a) communicate progressive concepts, (b) deliver the voices of the parents (to the government), and (c) work for the rights and welfare of people with disabilities. Following the lifting of martial law in 1987 and the revision of the civic organization law, the parents finally founded their own organization, registered as the non-profit civic organization “Hsin-lu Cultural and Education Foundation,” by the end of that year.

During the process of forming a civic organization, a confrontation between the state and the civic organization became unavoidable. There was a huge gap between the state’s rationale for, and parents’ perception of, citizens’ rights. The contestation of state regulations and contemporary ideas of citizens’ rights can be illustrated by the parents’ meeting with governmental officials. In their petition to the Department of Education in 1987, when parents of

disabled children complained about the lack of educational resources for disabled children and demanded more governmental support, the government official, Deputy Young, replied, "According to the Constitution, if children did not go to school, their parents should be punished." Wu—a mother of a disabled child—immediately threw the question to Young, "Would you please count how many of our children do not go to school? We are willing to be punished, if you can find a school for our children." After this question, most parents there raised their hands. Young was shocked and speechless (Hsin-lu, 1997, p. 52).

This encounter sums up the situation. The state did not recognize the lack of infrastructure for disabled children. The parents began to demand the educational rights of citizens. It also signifies a transition era when citizens' organizations began to use rights language to confront government officials.

In sum, if a social movement is defined as collective actions to promote social changes, the disability rights movement emerged in Taiwan from the early 1980s to 1987. During this period, Christian organizations and disability-related professionals not only provided services and funding but also espoused progressive ideas about the rights of people with disabilities. Parents began to advocate for their disabled children's rights. The state discouraged the interconnection of social organizations and the self-organization of citizens' advocacy groups under martial law.

The Alliance and Institutionalization of the Disability Rights Social Movement Organizations (1988-1992)

It is generally agreed that the mid-1980s was a critical transition period in Taiwan's political history. The first opposition party—the Democratic Progressive Party (DPP)—was formed in 1986 under the risk of a government crack-

down. The end of martial law in 1987 signified a new era in Taiwan's political history. Street protests were common - this period saw more than 2,000 street demonstrations, which stirred the deceptively placid surface of Taiwanese society. It was called the "suddenly awakened civil society" because social forces and societal dissatisfactions suddenly burst out after forty years of Martial law (Hsiao, 1996).

People with disabilities were not silent during this period. They founded disability rights organizations and organized demonstrations, not only for education, but also for work, for equal political rights and for an environment without discrimination. An umbrella organization, the League of Enabling Associations (LEAs), was founded in 1990. The national parents' association was also founded in 1992 to cooperate with different parents' groups and to promote disability-related research and legislation.

The League of Enabling Associations

Since the democratic transition in 1987, new demands and challenges have emerged in disability rights legislation and public policy. If the Feng-Qiao Incident triggered social concerns about the well-being of people with disabilities before 1987, the "patriot lottery"¹³ incident in 1987 further contested the social understanding of the rights of people with disabilities, in particular in the workplace. The incident also engendered the alliance of people with various disabilities, the founding of the League of Enabling Associations.

The patriot lottery was a government-sponsored lottery that aimed to increase the government's revenue. Interestingly, a significant number of lottery shops were run by people with disabilities. In the social context in which special education had only begun to get public attention and discrimination in the workplace was taken for granted, selling lottery tickets was one of the few job choices for people with disabilities. In the mid-1980s the gambling, da-jia-le (everyone is happy), associated with the patriot

lottery was extremely popular. The gang-related activities associated with the gambling and the moral concerns about gambling from government officials led the government to consider ending the 40-year governmental lottery. From 1987 on, public debate over the patriot lottery triggered a series of petitions and protests. The lottery's termination was announced suddenly on January 19, 1988 and made many people, including large numbers of disabled people who made a living from the patriot lottery, jobless overnight.

In response to this crisis the disabled people who lost their jobs after the incident contacted the Eden foundation to ask for help. The Eden foundation organized a series of petitions and public hearings. The Eden foundation saw this transition not only as a challenge but also as an opportunity to establish a support net for persons with disabilities. Eden held a national meeting on December 23, 1987 and invited governmental officials, social welfare experts, representatives from related foundations such as the Sunshine Foundation and the Dao-Hang Foundation, as well as persons with disabilities who had lost their jobs because of the new policy. The meeting addressed the right of people with disabilities to work in order to make a living, and made policy recommendations such as enacting special training programs, removing educational barriers and creating a special employment quota for people with disabilities.

The patriot lottery officially ended in January of 1988. Eden and 40 other disability-related associations organized the first ever disability rights street demonstration with about 500 demonstrators on January 19, 1988. The demonstration showed that the government had not kept its promise to protect disabled people and should revise the "Handicap" Welfare law to protect the right of disabled people to work. As Liu (2004) recalled, "The number of demonstrators was not really big, but the demonstration by disabled people such as persons in wheelchairs, with crutches, with visual impairment, etc., at-

tracted public attention." This event quickly garnered media attention, which helped to gain public recognition of welfare and job security issues.

After this demonstration, disability activists brought up other disability rights-related issues such as accessibility to public facilities and public transportation, restrictions on college entrance examinations and employment discrimination. Several petitions, demonstrations and public hearings emerged from 1987 to 1990 all of which primarily targeted the revision of the "Handicap" Welfare Law to address various disability rights issues (Chen, 1992). On April 27th, 1988, 18 disability welfare civic organizations petitioned the Ministry of Education to lift the restriction that excluded people with disabilities from taking college entrance examinations. On April 11th, 1989, during a petition to the Legislative Yuan, Zhang Zhi-Xiong, a demonstrator with a disability, attempted suicide to demonstrate against the hardship disabled people must endure to live independently. Fortunately, he did not succeed, but the act intensified media attention and public awareness (Chiu, 1998). Following the demonstration and public support, the government held a National "Handicap" Welfare meeting involving various civic organizations in order to revise the "Handicap" Welfare Law. Finally, the revision of the "Handicap" Law was passed on January 12th, 1990.

During this process of collective action and negotiation with the government, many promises were made, but little progress was actually achieved. Several laws were passed, but government officials were reluctant to implement them. Disability rights organizations realized that in order to continuously negotiate with the government, they needed an umbrella association to coordinate various issues. Different disability welfare NPOs began to create an alliance. Led by Liu Hsia, from the Eden foundation, the committee for the revision of "Handicap" Law was founded on March 14th, 1989. The com-

mittee led to the establishment of the League of Enabling Associations in 1990. Around 70 disability related civic organizations participated in the league.

The goal of the LEAs was to coordinate different disabled welfare groups to “advocate for disability rights and promote the welfare of people with disabilities.”¹⁴ The LEAs targeted legislation reforms and also used different strategies to increase public awareness. It became the most influential civic organization for disability rights in Taiwan.

Once the LEAs was founded, it began to consider nominating its own candidate to the Legislative Yuan. During the search for qualified candidates to represent people with disabilities, LEAs suddenly found out that Liu Hsia, the well-known “wheelchair writer,” was not qualified to participate in the election because she did not have a high school diploma. Liu Hsia was the founder of the Eden foundation and the winner of the National Literature Award. She did not complete her high school education simply because of her disability and the lack of a support system in school. This requirement actually took away the political right to be elected since many disabled people were rejected from public school and therefore could not finish an “official” education. As a result, they quickly decided to nominate Liu to run for the Legislative Yuan Election and use the “Elect Wheelchair Writer into Legislative Yuan” event to further highlight the unjust legal system and social barriers people with disabilities face.

Liu’s nomination to run for the legislature did not pass because of the conservative political environment and slow legal reform procedures. Nevertheless, this “incident” demonstrated a lot about the discriminative legal environment for people with disabilities. This incident also shifted the disability rights movement’s focus from special education to work, and from there to political rights and participation in elections.

Several legislative actions, such as the revision of the “Handicap” Welfare Law in 1990 and the revision of the Child Welfare Law in 1993, followed this event. One of the major achievements of the revision of the “Handicap” Welfare Law in 1990 was a disability employment quota of one percent for the private sector and two percent for the public sector. Chiu (1998) points out that this is the first instance of institutional protection of employment for people with disabilities in Taiwan.

Increasing awareness of disability rights issues also created a paradigm shift in public discourse. With the effort of advocacy NPOs, newspaper narratives began to reframe disability issues from a citizens’ rights perspective, as opposed to a charity perspective. The idea came into public discourse that “the disability itself is not a social problem, but rather the lack of public support for disabled people.” For example, an editorial of the United Daily said:

“[People with disabilities] might lose their body part, but their work ability might not be affected. They do not necessarily need pity, but they need social concern. It is the responsibility of the society to give them a reasonable and just living environment and entitled welfare benefit. If the government can hire disabled people and allow disabled people to take national examinations, it will encourage the private sectors to hire disabled people. If the government can expand their protection for disabled people in different private sectors, it will open more markets for disabled people. If the private sector can provide job opportunities, disabled people will be less likely to be

discriminated against. If we have the public facilities for people with disabilities, it will be much easier for them to go out” (Jobs for the Disabled People, 1988, p 16).

The founding of LEAs opened a new era in which disability related civic organizations worked together to promote legislative reform. It continuously played an advocacy role for people with disabilities and became an important component of the social welfare movement in Taiwan.

Building a National Civic Organization: The National Public Forum Tours and Local Parents Organizations

The lifting of Martial law in 1987 and the following revision of the Assembly Law opened a new era of civic engagement in Taiwan society, not only in street demonstrations but also in grassroots movements. Before the establishment of the Hsin-Lu foundation in 1987, there were only two regional parents’ organizations for persons with intellectual disabilities, one in Tai-Chung city and the other in Kaohsiung city. Both organizations were supported and led by professionals from the disability field. Following the founding of Hsin-Lu, parents’ influence gradually expanded in different socio-political spheres.

First, many parents joined the AMR and sat on its board of directors. Zong, the founder of the Hsin-Lu, was elected as the chairperson of the board of directors in 1989. The active participation of parents in AMR changed the organization’s dynamics. Parents were eager to advocate for their children’s right to education and to promote legislative reform. Most parents did not, however, have professional backgrounds strong enough to continue the AMR’s organizational goal—to promote professionalism in Taiwan’s system for persons with disabilities. In addition, some professionals in the health field felt that they should keep their distance from

politically controversial issues and focus instead on good-will, devotion and professionalism. This difference between parents and professionals soon resulted in the split of the AMR. A group of professionals split from the AMR and founded the Professional Association for “Mental Retardation” (PAMR) in 1989 (Luo, 1993).

Second, with the financial support of the Red-Cross, Hsin-Lu and AMR organized a public forum series in every city and county and conducted a survey on the needs of people with intellectual disabilities. This project aimed not only to estimate the size of the population, but also to support parent advocacy groups in different regions. To organize the public forums, organizers utilized different local resources, mostly pre-existing parents’ organizations, institutions for people with intellectual disabilities or government agents. After the public forum, parents and professionals from Hsin-Lu and AMR encouraged the participants to organize self-advocacy parents’ groups in each region.

This project was accomplished by May of 1990. Overall, 9,000 parents were invited and nearly 1,000 parents participated in the forum. Ten parent-led organizations (including Hsin-Lu) were established before the public forum series. Twenty-one parent-led organizations (including two national organizations and 90 local organizations) were founded after the project. Organizations for diverse intellectual disabilities were also founded, for instance the Down Syndrome Association and the Association for Autism.

In April of 1990, led by professionals, many parents from Hsin-Lu and local parents’ organizations visited the Parents’ Association in Japan. This well-organized parents’ association and its role in advocacy and service opened the eyes of Taiwanese parents. Some members of the organizations immediately decided to form a national parents’ association after this trip. Despite some political controversy and disagreement over the role of the parents’ organization, the Parents’

Association for Persons with Intellectual Disabilities (PAPID) was officially founded in 1992 with the support of the Hsin-Lu foundation and financial support from the International Women's Association. A functional differentiation between PAPID and Hsin-Lu was made. The PAPID positioned itself as a national advocacy membership association, aiming to voice for parents, to research welfare policy, to lobby for legislation and to play the role of check and balance in the government. The Hsin-Lu foundation became mainly a service oriented non-profit organization.

The history of PAPID shows that the involvement of professionals played an important role in organizing parents during the early stages of establishing a social movement. International organizations such as the Red Cross and the International Women's Association provided financial support for the further development of the parents' organizations. The state had been repressive earlier under martial law. However, the parents' advocacy movement found a way to survive and develop through good-will foundations. In the process of democratic transition, the state also tried to incorporate social demands, and organized the national meetings. The national forum for parents ended up helping the civic organizations to expand their landscape. As a result, PAPID has become one of the most influential member-based civic organizations in Taiwan, and has contributed to the formation of a welfare state.

Engaging in Public Policies (1993-2002)

In 1992, the first general election for the Legislative Yuan was held in Taiwan signifying the end of the authoritarian regime. Parliamentary democracy was realized in Taiwan. On the societal level many social movements which emerged from the democratic transition period, 1987-1989, gradually institutionalized and transformed their organizational strategies or goals from street protest to either service-ori-

ented NPOs or advocacy and research-oriented organizations (Hsiao, 1999, 2003; Ku, 1999, 2003). The outcomes of the institutionalization of each social movement varied. Some movements gradually disappeared, while others continuously grew and expanded their influence in different spheres. In the disability rights movement, LEAs and PAPID continuously played a significant role in public policy-making and in empowering civil society.

One of the achievements of the disability rights movement has been the significant increase in the government's budget for disability welfare. Before 1989, the social welfare budget included a social security budget for government employees such as military personnel, government officials and teachers in public schools. The budget for the social welfare of disabled people was almost nonexistent. Only after a series of petitions and public forums held by the LEAs and other organizations since 1989 did the government reform social welfare policy. Since then, the social welfare budget has become independent of the social security budget and, at the same time, the budgets of social security and social welfare for disabled people have increased (Hsieh, 1997). The government's total spending on disability welfare increased from 2,372,870 NT dollars in 1991 to 16,795,208 in 2002 (Ministry of Interior & Eden Foundation, 2002).

Achievement can be seen also in the increase in the number of individuals registered for disability status. In 1991, 204,158 citizens (0.99% of the total population) were registered as people with disabilities. In 2002, the number of disabled individuals registered by the government's system was 790,312, which consisted of 3.52% of the total population. The categories of disability also increased (Ministry of Interior and Eden Foundation, 2002). On one hand, this shows that people with disabilities gradually obtained recognition from the state. On the other hand, people with disabilities also gradually came out of confinement in search of public recognition.

At the organizational level the achievements of LEAs and PAPID from 1992 to 2003 are multi-dimensional, including, (a) deepening of the grassroots movement, (b) organizing social protest, (c) cooperating with other social welfare SMOs, (d) serving on the governmental advisory committee for policy making and new legislation, (e) supervising human rights violations, and (f) advocating disability rights with new agendas. At the grassroots level, PAPID continuously supported the development of local parents' organizations by providing educational training and by sharing organizational experiences. Hsiao and Sun (2000) point out that compared to other social welfare movements, PAPID is one of the few movements that continually developed after the democratic transition in Taiwan.

The LEAs also grew continuously and expanded their influences. LEAs' group numbers increased from around 70 associations to 230 associations, including PAPID, in 2002. Not only did the number of participants increase, but new issues were constantly raised. The PAPID and LEAs worked hand-in-hand on many major issues in the disability rights movement and continually played an important role in legislating, supervising and promoting public policy.

First, to promote the welfare state, the PAPID and LEAs worked with other social welfare SMOs and NPOs to promote social justice and social welfare issues. For example, they were members of the "Alliance of Social Legislation Movements," which aimed to advocate for national social security and social welfare in 1995, and the "Saving National Health Care System Alliance," which protested against the privatization of the national health care system in 1999.

Second, as representatives of the civil society, PAPID and LEAs continued their efforts to monitor the government's policy implementations. Several protests were organized by LEAs and PAPID to promote disability legislation and policy changes, including blocking the National

Education Meeting in 1994 and demonstrating for a larger special education budget and against the neglect of special education on the agenda. In 2002, PAPID and LEAs organized the "Against Backwardness, for Surviving" demonstration attended by approximately 3,000 demonstrators. The demonstration was a protest against the government cutting the budget for people with disabilities and was one of the largest street protests since 1992.

Third, besides advocating for the rights of people with disabilities, LEAs and PAPID played an advisory role in legislation and participated in related government advisory committees. The most important legislation was the revision of the "Handicap" Welfare Law. It was replaced by the "Disability Protection Law" (the Act for Rights Protection for Disabled People) in 1997, in which government's role was reframed from a passive-reactive one to an active-enabling paradigm. Under the new legal framework, public policy must accommodate the needs of people with disabilities and must mandate that persons with disabilities be able to enjoy equal rights as citizens.

In addition, LEAs and PAPID also watched for human rights violations and social discrimination. For example, in 1994 the PAPID uncovered mistreatment of people with intellectual disabilities in the military. Because of the lack of social understanding and legal protection for persons with disabilities, persons with intellectual disabilities such as autism were still conscripted into military service. As a result, they were usually abused, jailed or even listed as missing from their military service. In 2000, LEAs and PAPID investigated the inhuman living condition of the "Zhong-Sheng" (生) Institution, where people with disabilities were chained, or put into iron cages, and developed health conditions such as skin disease and malnutrition (Xie & Liu, United News, 2000, May 16).

New agendas were constantly raised by LEAs and PAPID. PAPID advocated for inclu-

sive education, de-institutionalization, community home (group home) projects and support for NPOs in their work with the government on planning and running community homes. In sum, from 1992-2002, the LEAs and PAPID worked with the state and against the state. They played a leading role in the disability rights movement and channeled the communication between state and society in Taiwan.

Conclusion

The disability rights movement has developed in Taiwan since the 1980s. The commitments of foreign missionaries and foreign-trained professionals played an important role in raising awareness about disability issues and initiating grassroots advocacy activities in their early stages. The charity-oriented NPOs not only provided services for disabled people in the early years when disability rights were not recognized by the state, they also provided the space to facilitate the disability rights movement. Parents' involvement has pushed the agenda into public policies since the mid-1980s. The end of martial law further opened up political space for disability rights advocacy in the late 1980s. Finally, the founding of the League of Enabling Associations in the 1990s and the Parents' Association for Intellectual Disabilities in 1992 signified a new era, when disability rights advocacy organizations work with the state for legislation reform, and at the same time continuously hold the state accountable and monitor human rights violations.

The Taiwanese disability rights movement started by bringing people with intellectual disabilities out from confined private institutions and homes into community-oriented service. However, although the spirit of community-oriented service has been written into law, the road to implementation at the community level remains long. Democratic transition might enable disability rights activists to promote progressive legislation, but the government might not be

willing to put the law into practice under the challenge of economic globalization in post-authoritarian Taiwan.

The awareness of educational rights and equal opportunities for employment has been addressed by advocacy organizations. It is still questionable how they are perceived in mainstream Taiwanese society. In addition, although self-advocacy groups have been active in the movement, the advocacy of professionals and parents for the disabled people has played a much more important, even leading, role. More participation by self-advocacy groups is needed to progress even further. Recently, one self-advocacy group of people with intellectual disabilities has formed, but there is a lot of room to improve in order to achieve the goal of "nothing about us, without us."

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development of social welfare organization (1989-1993) and further development (after 1993). Based on the studies of framing disability rights, Hsieh (1997) also divided the movement's development into similar time periods without specifying particular years. This study's focus is on changes in the political environment and the development of the disability rights movement.

³ Children Welfare Law in 1973 cited from Ma (1995).

⁴ The "handicapped" Handicap welfare law has been used widely in disability rights advocacy documents.

⁵ <http://www.lib.pu.edu.tw/catholicism/una/una.htm>

⁶ <http://www.st-joseph.org.tw/devenlop.html>

⁷ Sunshine foundation: http://www.sunshine.org.tw/news_view.asp?news_type=1&id=81

⁸ Liu passed away in 2003. Her autobiography was published in 2004.

⁹ <http://www.eden.org.tw/>

¹⁰ Father Brendan's Chinese name is Gan Hwei-jung. He started his service in Taiwan in 1963, received a masters degree in special education in the US in 1975 and came back to be the director of the St. Raphael Opportunities Center in Tainan city from 1976 to 1992. He is also the founder of the De-Lan Developmental Center in 1988 and the *Bethlehem Foundation* in 1995 in Tainan County.

¹¹ The parents represent different kinds of disabilities. The core members are from FCDC.

¹² Hsin-lu could be directly translated as "the road of the heart," i.e., an emotional experience (of the parents) or life journey. According to the first edition of Hsin-lu, it has two meanings: first, it refers to the life journey of the parents; second, it refers to the parents who are finding a path to communicate with their intellectually disabled children.

¹³ Patriot lottery refers to the idea of contributing to the government's revenue though lottery.

¹⁴ <http://www.enable.org.tw/about/about.asp>

Endnotes

¹ Can-zhang literally means "Handicap" in Mandarin, but the association uses LEAs its English name.

² Based on studies of the development of institutional support for persons with disabilities and the development of parents' organizations, Ma (1995) divides the development of parents' associations into four periods: the pre-development period (1949-1980), the emergence of parents' organizations (1981-1987), the alliance and institutionalization of parents' organizations (1988-1992) and further development of parents' organizations, and organizational transition (1992-1995). Based on the studies of social welfare movements' leaders, Hsiao and Sun (2000) divide the development of social welfare movements into three periods: promoting social welfare (before 1988), the

Inclusive Education in the United States and Internationally: Challenges and Response

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Abstract: Achieving inclusion of children with disabilities in general education remains a challenge. This article discusses United States and international legal developments and relates educational inclusion to controversies within the disability studies movement. It considers questions that have been raised about integrated education and concludes that inclusion should remain the goal, but that more attention must be devoted to making educational inclusion work.

Key Words: special education, disability studies, inclusion

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Historically, children with disabilities have been excluded from education and, when allowed into school, kept in separate settings where the expectations are low and the quality of services lower. Political action culminating in statutory change corrected that condition, so that in many societies children with disabilities now make their way through the schoolhouse door and receive some basic level of educational services. But achieving the goal of full inclusion in classes with nondisabled peers remains a challenge, and some writers have raised questions about whether overcoming that challenge is a worthwhile enterprise. In this article, I discuss the challenges and the questions, concluding that integration should remain the goal, but that more attention should be devoted to the mechanisms that will make the goal a desirable one. The article begins with a brief history of inclusion in American special education law, then takes up some legal sources from outside

the United States. It continues with a discussion of educational inclusion in relation to ideas developed by the international disability studies movement. It considers criticisms of the educational effectiveness of inclusive education, then discusses some possible solutions for the problems raised concerning inclusive education.

A Brief History of Inclusion in United States Special Education Law

Laying the Foundations for Inclusion

Two court decisions from the 1970s form the foundation of federal special education law in the United States. In *PARC v. Pennsylvania* (1972) and *Mills v. Board of Education of the District of Columbia* (1972), the class action plaintiffs asserted that by failing to provide educational services that met their needs, the defendants violated the due process and equal protection clauses of the Fourteenth Amendment to the United States Constitution. The *PARC* class consisted of children with mental retardation who had been excluded from public school. The court approved entry of a consent decree requiring, among other things, the placement of each child with mental retardation "in a free, public program of education and training appropriate to the child's capacity" (p. 285). The decree provided that:

“. . . [P]lacement in a regular public school class is preferable to placement in a special public school class and placement in a special public school class is preferable to placement in any other type of program of education and training" (p. 307).

The fundamental educational policy supporting mainstreamed placement to the greatest extent possible reflected current best educational practices, but also had antecedents in judicial activity in other contexts. The activists who brought the initial cases asserting a con-

stitutional right to education for children with disabilities had also worked on or were familiar with the contemporaneous litigation concerning conditions in institutions for persons with intellectual disabilities and mental illness. One of the most prominent claims the advocates asserted in those cases was that persons with mental disabilities should not be separated from the outside world unnecessarily. Courts ultimately recognized the principle that persons could not be involuntarily civilly committed unless dangerous to themselves or others, with the Supreme Court declaring, “[T]here is no constitutional basis for confining persons [with mental illness] involuntarily if they are dangerous to no one and can live in freedom... Mere public intolerance or animosity cannot constitutionally justify the deprivation of a person’s physical liberty” (O’Connor v. Donaldson, 1975, pp. 575-76). Over time, courts adopted the idea that among restrictive settings, the least restrictive is to be preferred (Youngberg v. Romeo, 1982).

These ideas resonated in policy-making bodies other than courts. When federal administrative agencies drafted regulations implementing section 504 of the Rehabilitation Act (which bars discrimination against persons with disabilities in federally assisted activities) (2006, originally passed 1973) and title II of the Americans with Disabilities Act (which bars discrimination against persons with disabilities in state and local government services, programs and activities) (2006, originally passed 1990), they included provisions forbidding separate services to persons with disabilities unless necessary to provide services that are as effective as those provided others (Section 504 Regulations, § 32.4(b)(1)(iv), 2006; ADA Regulations, § 35.130(b)(1)(iv), 2006). They also imposed the requirement that the state or local government administer services in the most integrated setting appropriate to the needs of qualified persons with disabilities (Section 504 Regulations, § 32.4(d); ADA Regulations, § 35.130(d)). This latter provision of the ADA regulations radiated its influence back to the Supreme Court by furnishing the grounds

for the holding in *Olmstead v. L.C.* (1999) that states must provide community based treatment for persons with mental disabilities when such a placement is appropriate, the individual does not oppose the placement, and the placement can reasonably be accommodated.

The litigants and judges in *PARC* and other special education cases also drew on the history of the racial desegregation campaign in the United States. The challenge to Jim Crow schooling went on for more than a generation before the Supreme Court recognized in *Brown v. Board of Education* that “[s]eparate educational facilities are inherently unequal” (1954, p. 495). *Mills*, a case similar to *PARC* filed by a broad class of children with disabilities excluded from the District of Columbia schools, quoted *Brown* at length, and relied as well on race discrimination cases specific to the District of Columbia (pp. 874-75). The comparison is obvious between the racial separation that existed between white and African American schoolchildren and the diversion of children with disabilities into separate locations in which expectations for their success diminish and opportunities for greater learning vanish. Distinctive treatment of those with disabilities and those without confers the same sort of stigma associated with separation of the races into inferior and dominant groups (Goffman, 1963, p. 4).

The Education for All Handicapped Children Act of 1975, the federal law that followed the *PARC* and *Mills* cases and required American states and school districts to provide all children with disabilities a free, appropriate public education, established that to the maximum extent appropriate, children with disabilities must be educated with children who are not disabled. Special classes, separate schooling, or other removal of children from the regular educational environment is to occur only when the nature or severity of the disability is such that education in regular classes cannot be achieved satisfactorily with the use of supplementary aids and services (Education for All Handicapped Children

Act of 1975, now Individuals with Disabilities Education Act (IDEA), 2006, § 1412(a)(5)(A)). The preference for inclusive placement was based on strong policy recommendations from professionals involved in the education of children with disabilities (Sheffler, 1981). IDEA nevertheless permits, and has always permitted, highly restrictive placements. In the earliest appellate and Supreme Court decisions under the law, several cases required school districts to pay for placements in residential schools or other children-with-disabilities-only settings that the parents contended their children needed in order to learn (e.g., *Burlington Sch. Comm. v. Dep't of Educ.*, 1985).

Presumption in Favor of Integration

Judicial decisions from the early years of the federal special education law established that the statutory provision and the regulations enacted to enforce it create a presumption in favor of least restrictive, more integrated placements. *Roncker v. Walter* (1983) vacated and remanded a lower court decision that placed a child with severe mental retardation in a county school that had no children other than those with retardation. The appellate decision found that the lower court had ignored the “strong congressional preference in favor of mainstreaming” (p. 1063). The appellate court stressed: “The perception that a segregated institution is academically superior for an handicapped child may reflect no more than a basic disagreement with the mainstreaming concept” (p. 1063). The court recognized that the child had not made progress when previously schooled in an integrated setting, but the crucial question was what services would be provided there. The court said that in order to comply with the congressional mandate, the lower court would have to “determine whether the services which make [a segregated] placement superior could be feasibly provided in a non-segregated setting” (p. 1063). If they can, the integrated placement must be provided.

Some other courts were less adamant in upholding the integration obligation. *Daniel R.R.*

v. State Board of Education (1989) affirmed a decision that kept a child with developmental disabilities in a separate classroom, relying on school district claims that the child could not satisfactorily be educated in a regular education setting. The court, nevertheless, treated integration as the presumptive choice: “Congress preferred education in the regular educational environment.” In applying that presumption, “First, we ask whether education in the regular classroom, with the use of supplemental aids and services, can be achieved satisfactorily for a given child. . . If it cannot and the school intends to . . . remove the child from regular education, we ask, second, whether the school has mainstreamed the child to the maximum extent appropriate” (p. 1048). Other cases approving highly restrictive placements also nodded to the integration presumption, although they ruled that integration was overcome by other considerations under the specific circumstances present (e.g., *DeVries v. Fairfax County Sch. Bd.*, 1989).

In the 1990s, two prominent cases appeared that not only applied the presumption in favor of integration in a rigorous way, but also took seriously the importance of delivering services that would enable the child to succeed in the mainstream. In *Sacramento Unified School District v. Rachel H.* (1994), the court upheld a lower court decision requiring a school district to place a child with severe mental retardation in a second grade regular education classroom. The court of appeals said that disputes over integration should be evaluated by considering (a) the educational benefits of full-time placement in a regular education class, (b) the non-academic benefits of integrated placement, (c) any effect of having the child with a disability in the mainstream class on the teacher and other members of the class, and (d) extraordinary costs of mainstreaming the child. The court relied on the lower court’s evidentiary findings that the child was making progress on her individual educational goals, even though she was not learning the same material as her classmates, and that she

gained non-academic benefits in terms of self-confidence as well as social and communication skills. The presence of an aide solved any problems with potential absorption of disproportionate time from the teacher's other activities, and the cost was not insurmountable.

Oberti v. Board of Education (1993) involved an eight-year-old child with Down's Syndrome; the school district wanted to exclude him from a regular classroom and place him in a special education class. The court of appeals affirmed a lower court decision in favor of the child's parents, who contended that the child could be educated in his regular education classroom if he were provided adequate support services. In the mainstream class, the child had displayed behavior problems including tantrums and aggression towards classmates. The behavior gradually abated after placement in a self-contained class for children with multiple disabilities. Experts testified that if the child received special support such as a behavior modification plan and instructional modifications, he could learn in a regular education class, and that the experience would assist him in working and communicating with children who were not disabled. The modifications to the curriculum would include parallel instruction, where the child would work separately within the classroom on activity similar to, but at a lower level than, the work of his classmates; some separate resource room instruction would also be provided. Speech and language therapy could be provided most effectively within the regular class environment.

The court identified an "apparent tension within the Act between the strong preference for mainstreaming . . . and the requirement that schools provide individualized programs tailored to the specific needs of each disabled child," but said that the tension could be resolved by the school's provision of supplemental aids and services to enable the child to be educated for a majority of the time in a regular classroom while still addressing unique educational needs (p. 1214). Adopting the multi-fac-

tor test from *Daniel R.R.*, the court found the efforts of the school to accommodate the child in the mainstream to have been insufficient. It further found that the benefits of placement in a regular education classroom were great, if the curriculum were properly adapted, and it concluded that adequate supportive services would minimize the likelihood of a significantly disruptive effect on the classroom.

Supplementary Services

Not all cases have taken the inclusion requirement as seriously as *Rachel H.* or *Oberti*, particularly in the insistence on schools' making mainstreaming work by adding supplementary services. Cases continue to appear in which the courts find the presumption in favor of integrated settings overcome by considerations of educational appropriateness, despite arguments that the goals are not incompatible if adequate supported services are provided (e.g., *Beth B. v. Van Clay*, 2002; *Sch. Dist. v. Z.S.* 2002).

Nevertheless, as *Rachel H.* and *Oberti* indicate, much of the debate over the application of the least restrictive setting mandate in the United States has shifted from a for-it or against-it clash to a discussion of what must be done to make it work. Cases thus tend to turn on the question of which related services the school needs to supply, at what level of intensity. Accordingly, one may conclude that the statutory language requiring "that removal from the regular educational environment occurs only when . . . education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily" is not just a prohibition on unnecessary separate schooling but a positive entitlement to the supplementary aids and services needed to make mainstream education work (Weber, 2001).

The role of trained, committed teachers and aides delivering specialized services has emerged as a major issue. In a recent case, a federal court of appeals found that a child's segregated educational program was inconsistent with the law

because the school had developed it without the participation of a general education teacher who could provide insights into how to adapt general education to meet the child's needs (*M.L. v. Fed. Way Sch. Dist.*, 2005). Another court of appeals rejected a school district's proposal for a less integrated placement for a young child with autism when the child was succeeding in a private general-education preschool chosen by her parents, in which she had the assistance of an aide and an intensive applied behavioral analysis program delivered primarily at home (*L.B. v. Nebo Sch. Dist.*, 2004).

Discipline

The courts have recognized that what makes inclusion work is not just personnel and specialized instruction, but also modification of policies. In particular, if children are to learn in the mainstream setting without facing constant suspension or other penalties for conduct related to their disabilities, schools have to modify their disciplinary policies. Early cases permit children's exclusion from ordinary school settings for behavior that is alarming to the intolerant, but of itself no impediment to anyone's learning, such as uncontrollable drooling and facial contortions (e.g., *Beattie v. Board of Education*, 1919). The *Mills* case illustrated the effect of these practices in 1972: One of the named plaintiffs, a child with a brain injury, was excluded from school because he wandered around the classroom. Two other plaintiffs, whose disabilities were not specified, missed several years of schooling after exclusion from third or fourth grade for having "behavior problem[s]" (p. 878). The court issued a decree forbidding the school system from suspending a child from the schools for disciplinary reasons for any period in excess of two days without affording a hearing and without providing for the child's education during the period of the suspension.

Disciplinary decisions continue to be a source of exclusion from mainstream educational settings, although current law affirms the obligation not to discipline for behavior related

to the child's disability, affords procedural protections, and forbids total cessation of services (IDEA, § 1415(k)). The most recent amendments to the special education law permit exclusion of children from their ordinary placements if they possess weapons or drugs in school or inflict great bodily injury, even if the behavior is related to their disability, but the exclusion is time-limited and other misbehavior related to disability is to be treated as a basis for improved services, not long-term exclusion.

Policies other than disciplinary ones may also present obstacles to realizing the simultaneous goals of effective learning and integration. The *L.B.* case cited above in connection with personnel and curricular issues is of particular significance because it overturns the tyranny of the six-to-seven hour school day and forces the school system to provide a program that takes place largely after school hours, so the child may attend integrated classes when school is in session. Some American courts have enforced the law to promote integration by requiring changes in teacher certification processes to eliminate inflexible instructional groupings and facilitate more inclusive classes (e.g., *Corey H. v. Bd. of Educ.*, 1998; see also *Reid L. v. Ill. State Bd. of Educ.*, 2002).

An additional step to facilitate educational success in mainstreamed education is aggressive action by schools to prevent harassment of children with disabilities and to stop it when it occurs. Courts have upheld claims for damages relief against schools and individuals under the Americans with Disabilities Act and the common law duty not to inflict emotional distress when teachers have responded to the placement of children with disabilities in mainstream settings by harassing the children or encouraging their peers to do so (e.g., *Baird v. Rose*, 1999). Nevertheless, there are numerous obstacles to suits of this type, and an increase in enforcement activity would facilitate inclusive education (Weber, 2002). As long as 25 years ago, a court affirmed that the likelihood of encoun-

tering hostile attitudes is not a justification for separate schooling, but rather a basis for ordering enhanced support for the child (*Campbell v. Talladega County Board of Education*, 1981).

IDEA Amendments

The most recent amendment to the federal special education law, called the Individuals with Disabilities Education Improvement Act of 2004, has potential to promote integration of children with disabilities in general education. The new law allows up to 15% of federal special education money to be used for early intervening services for children who have not formally been found to have a disability (IDEA, § 1413(f)). This innovation blurs the distinction between children designated as children with disabilities and other children, and accordingly may diminish the stigma that currently follows from labels of specific disabling conditions (Garda, 2004, p. 443). The new law also enhances coordination with the No Child Left Behind initiative, which establishes that a school may become in need of improvement or corrective action if any of various subgroups of its students, including students with disabilities, fails to make adequate progress towards meeting state grade-level achievement standards (Strengthening and Improvement of Elementary and Secondary Schools Act, § 6311(b)(2)(C)(v)(II)(cc)). The amended special education law provides that students with disabilities must be fully included in district-wide achievement measures, and that the assessments will count in determining the need for improvement or corrective action. These innovations may encourage school administrators to take the same responsibility for special education students that they take for students in general education, and to devote resources to bringing the achievement of special education students up to grade level. The focus on achievement may be expected to facilitate students' integration in mainstream education, as administrators realize that the overwhelming number of students with disabilities can succeed in mainstream instruc-

tion at grade level if provided adequate accommodations and supplemental services.

Some Approaches from Outside the United States

Canada

In Canada, the Supreme Court's decision in *Eaton v. Brant County Board of Education* (1997) denied the request of parents to keep their child in an integrated school setting. The child, a 12-year-old with cerebral palsy, lacked the ability to communicate through speech or sign language; she also had mobility limits. The Ontario Special Education Tribunal ruled that the child should be educated in a segregated special education classroom, and the Supreme Court found no violation of the equality rights guaranteed by the Canadian Charter of Rights and Freedom. The Supreme Court applied a best-interests-of-the-child standard. Justice Sopinka stated: "In some cases special education is a necessary adaptation of the mainstream world which enables some disabled pupils access to the learning environment they need in order to have an equal opportunity in education" (par. 69). The decision refused to adopt a presumption in favor of integrated schooling, though it acknowledged that "integration should be recognized as the norm of general application because of the benefits it provides..." (p. 69).

The *Eaton* decision appears incomplete because it does not discuss in any detail the role of specialized services in making mainstream education work. Separate placements may well be superior to integrated settings when there are no curricular modifications or support services in the integrated placement. But if a best-interests standard is to be applied meaningfully, the options should be supplemented to include something other than either inclusion with no modifications or completely separate education. Approaches taken in other industrialized societies may not be any more hospitable to inclusion than that found in the *Eaton* decision. There-

sia Degener and Gerard Quinn (2002, part 1.C.3.a.(ii)) describe a 1996 decision by the German Federal Constitutional Court rejecting the claim of a girl using a wheelchair for mobility for access to a regular school. The court ruled that the exclusion did not violate constitutional anti-discrimination provisions.

The United Nations

International Convention on the Rights of Persons with Disabilities

The United Nations General Assembly just passed the International Convention on the Rights of Persons with Disabilities (Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, 2007). Article 24 deals with education. The text declares that the States Parties recognize the right of all persons with disabilities to education, and that States Parties shall ensure an inclusive education system directed to the development of the child's personality, talents, and creativity, as well as the child's mental and physical abilities, to their fullest potential. With specific regard to inclusion, the text provides that States Parties must ensure that "Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability" (Art. 24, § 2(a)), also that "Persons with disabilities can access an inclusive, quality, and free primary education and secondary education on an equal basis with others in the communities in which they live" (§ 2(b)). The text further requires States Parties to give persons with disabilities "the support required, within the general education system, to facilitate their effective education."

There were alternate texts that were considered, including one that stated, "In those circumstances where the general education system cannot adequately meet the individual support

needs of persons with disabilities, States Parties shall ensure that effective individualized support measures are provided in environments which maximise academic and social development, consistent with the goal of full inclusion" (§ 2(d)).

The language chosen by the drafters of the convention suggests a decision not to accept any possibility that the general education system may fail to meet the needs of all children. The commitment is to provide inclusive education, and to provide supports to make inclusive education meet children's needs. The draft, however, also does not take a clear position on whether parents can choose programs for their children that are less inclusive than general education. The text forbids exclusion from general education and requires access to inclusive education, but it does not appear to bar States Parties from offering less inclusive options. Additional provisions call for facilitating the learning of Braille, sign language and other alternate forms of communication, as well as peer support and mentoring. The text requires "the promotion of the linguistic identity of the deaf community" and insists "that the education of persons, and in particular children, who are blind, deaf and deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development" (§ 3(a)-(c)).

On topics other than education, the convention draft adopts an approach strongly in favor of inclusion and against separation. Article 3 states that the fundamental principles of the convention embrace, "Full and effective participation and inclusion in society" (§ (c)). Discrimination is defined as exclusion and restriction of rights and freedoms, as well as failure to provide reasonable accommodation (Art. 2, par. 3). The draft affirms the right to live independently and be fully included in the community (Art. 19).

If the convention reaches widespread adoption, retains its current form, and is made enforceable, its effects on education will be quite uncertain. In *Eaton* and many United States and other countries' special education cases in which school systems insisting on separate schooling prevail, the parents wanted general education for their children, and demanded appropriate program modifications and extra services. If the convention were interpreted to require States Parties to honor parents' choices, the cases would be decided differently. But apart from imposing an obligation to provide support, the convention does not specify what school systems need to do in terms of enhanced services for children with disabilities in mainstream settings. If the specialized services that children need in order to succeed in inclusive placements are not available, parents may effectively be denied access to integrated schooling for their children. Similarly, if disciplinary policies are not modified and harassment stopped, parents' adaptive preferences are likely to be for separation. If the convention is interpreted in line with cases such as *Rachel H.* and *Oberti*, however, requiring schools to depart from standard operating procedure and greatly expand services and make policy modifications for children with disabilities in general education, the parents could make the choice for inclusive education. The requirement of "environments which maximize academic and social development" for children who are deaf, blind, and deaf-blind in section 3 of the education article may imply the possibility of separate educational settings for children with those disabilities. The desirability of those options is a subject of ongoing discussions in the disability rights movement generally.

The Salamanca Statement

The draft Convention builds on previous international efforts to shift policy towards inclusive education for children with disabilities. In 1994, representatives of 92 governments and 25 nongovernmental organizations adopted the Salamanca Statement on Principles, Policy

and Practice in Special Needs Education. The Statement declares that "those with special educational needs must have access to regular schools which should accommodate them with a child-centered pedagogy capable of meeting these needs" (p. vii). The statement thus recognizes both the importance of inclusion and the need for accommodations to make it successful. The statement also contains exceptions and limits, however. Governments are urged to adopt "the principle of inclusive education, enrolling all children in regular schools, unless there are compelling reasons for doing otherwise" (p. ix). Specifically, assignment to separate schools or special classes or sections within a school on a permanent basis is to take place "only in those infrequent cases where it is clearly demonstrated that education in regular classrooms is incapable of meeting a child's educational or social needs or when it is required for the welfare of the child or that of other children" (p. 12). In comparison to the draft convention, the statement gives more leeway for governments to deny inclusion on the basis of claimed educational goals.

With respect to separate education of children who are deaf or deaf-blind, the statement continues:

"The importance of sign language as the medium of communication among the deaf, for example, should be recognized and provision made to ensure that all deaf persons have access to education in their national sign language. Owing to the particular communication needs of deaf and deaf/blind persons, their education may be more suitably provided in special schools or special classes and units in mainstream schools" (p. 18).

This approach reflects ambivalence about separate schooling for persons who are deaf.

Integrated Education and the Disability Studies Movement

The early years of what became the disability studies movement were marked by attention to the social constructs that exclude persons with disabilities from mainstream society. The effort was integrationist and inclusionary (tenBroek & Matson, 1966). Timothy Cook (1991) accurately described the achievement in the United States of the Americans with Disabilities Act as the move to integration. The emphasis was on removing social, cultural, political, and physical barriers that prevented people with disabilities from participating in mainstream society. Leaders of the movement advanced various ideas: that the medicalizing of disability and consequent imposition of legal, attitudinal, and physical constraints marginalize persons with disabilities, effectively socially constructing disability (Linton, 1998, p. 35); that persons with disabilities are members of a minority group whose political and civil rights the majority refuses to recognize (tenBroek & Matson, 1966), and that economic and social structures devalue and exclude persons who do not meet an able bodied ideal (Hahn, 1997). Inclusion emerged as a priority for legal and social reform.

The commitment was not merely one of words. Inclusion lay at the heart of the goals of political and social activity towards disability rights. The Center for Independent Living at Berkeley promoted equal access to education, housing, and other social goods, and soon other organizations adopted the same objective (Scotch, 2001, p. 36). The striking achievement of the political efforts in the United States was the Americans with Disabilities Act and its mandate for integration of persons with disabilities in the mainstream of society. The 1975 Education for All Handicapped Children Act, with its qualified but resolute insistence on inclusive

education, was an earlier victory along the road to political reform.

More recently, a number of writers who are part of the disability studies movement have advanced criticism of non-nuanced efforts simply to inject persons with disabilities into previously exclusive settings. Assertion of the right to integration with persons without disabilities still leaves the person with disabilities the different one, the other (Johnson, 2003, p. 65). Thus it may reinforce the dominant, non-disabled norm (Minow, 1990, pp. 19-48). In education, laws prescribing inclusion without doing more exalt the prerogatives of special education experts and may cast students with disabilities into settings in which they will be token, low-ranking participants in social systems run by and for those who are not deemed to have disabilities (Cook & Slee, 1999).

These insights are less a challenge to the inclusion ideal than a criticism of how inclusion has frequently been realized in practice. If the non-disabled norm shifts because of integration of people with disabilities, or if the norm can be made to disappear altogether (Davis, 2002, p. 117), a truer inclusion occurs. Part of the problem is simply that of numbers. If larger numbers of persons with disabilities integrate into previous segregated settings, people without disabilities will display fewer reactions. Surprise wears thin over time. Another aspect of the problem is economics. In societies that value wealth, the typically lower economic status of persons with disabilities limits their integration on equal terms with persons who do not have disabling conditions. Lower economic status traces back, in turn, to the failure of the workplace to provide adaptations and the failure of social systems, particularly in the United States, to shoulder more of the medical and other costs currently imposed on people who live with a disability (Weber, 2000). Some writers who remain adamant on the integration ideal stress that society needs reforms directed towards placing larger numbers of persons with disabilities

into the mainstream of society and giving them more access to paying jobs, programs that cover extraordinary medical costs, and occasions for social and economic interaction on a plane of equality with others (Bagenstos, 2004).

With regard to inclusive education, the numbers and economics issues are not far from the surface, but the pervasive issue is the nature of the educational experience into which students with disabilities are integrated. Indeed, Professor Ruth Colker's (2006) recent critique of the integration presumption in American special education law stresses the failure of the general education system to adapt to the needs of children with disabilities and to change the prejudiced attitudes of mainstream teachers with respect to children with learning disabilities and other conditions. As American courts have come to realize, correcting the negative attitudes of teachers and the inflexible nature of conventional educational programming is necessary for integration to be successful.

In addition to the critiques of unadorned integrationism stand other criticisms of inclusion based on cultural integrity. One aspect of disability studies is to note, and to celebrate, disability culture. Prominent is the shared set of cultural connections that has developed around the use of sign language (Burch, 2002; Davidson, 2002). The recognition of that culture calls into question conventional inclusion practices. Inclusion may be a rationale for eliminating separate institutions that foster the use of sign. Ending those institutions challenges the continuity and growth of a linguistic minority's cultural tradition. Since these institutions typically constitute part of the educational establishment of the nations they serve, policies of educational inclusion may threaten the culture itself. In this way, dominant cultural institutions tend to drive out minority cultures and the institutions that would preserve them (Cover, 1983, p. 53).

Controversies About Educational Effectiveness

Numerous sources, some associated with the disability studies movement and some not, also criticize integration on the basis of educational effectiveness and related concerns about costs, disruption, and backlash. Ruth Colker (2006) argues that a presumption of a fully inclusive educational setting is not justified for children with a variety of disabling conditions. Colker compiles various sources of educational research, some of which demonstrate that teachers in mainstream settings are ill-trained to instruct students with mental retardation, and that mainstream classrooms have inadequate teacher-student ratios for the optimal education of students whose mental retardation is severe. She describes other sources as showing that mainstreamed students with learning disabilities make disappointing progress, although the sources do not make any rigorous comparison to students with learning disabilities in separate programs and some other sources cited indicate that gains in the two settings are comparable. She also demonstrates that students and teachers frequently impose stigma on students with disabilities, particularly those with learning disabilities and emotional or intellectual impairments. As Colker notes, other outsiders also experience ostracism and negative expectations when integrated with majority group members, notably African-American children suddenly placed in majority white schools.

That inclusion may be done badly is no news to people with disabilities. Similarly, anyone entering a social setting who is different is likely to be the target of stigma, particularly when the difference is manifested by the apparent failure to conform to established standards of learning or deportment (Goffman, 1963). Carefully designed interventions, such as joint work on academic and special interest projects, are needed to accomplish peer acceptance of students with learning disabilities in mainstream classrooms (Fox, 1989; see also Belkin, 2004). Not surprisingly, students with disabilities and teachers of-

ten feel more comfortable in segregated settings, particularly when the students are middle-school age or older (Gross, 2005). As noted above, the issue in contested cases in the United States has shifted from inclusion per se to the nature and quality of interventions. These interventions include teacher training, additional personnel, curricular and policy modifications, and effective action to halt harassment. A central insight of the disability studies movement is that attitudinal barriers are every bit as handicapping as physical ones. The idea is that the attitudes, not the disabilities, need fixing. Although clumsy inclusion initiatives will not improve attitudes (indeed, they will reinforce negative impressions), segregating children with disabilities eliminates any chance of progress towards that goal.

In the United States, the *Report of the President's Commission on Excellence in Special Education* (2002) stresses the importance of removing attitudinal barriers to the acceptance of children with disabilities in general education settings. One of the key findings states:

“Children placed in special education are general education children first. . . . [C]hildren with disabilities are often treated, not as children who are members of general education and whose special instructional needs can be met with scientifically based approaches, they are considered separately with unique costs—creating incentives for misidentification and academic isolation. . . .” (p. 6).

The Commission's prescriptions, such as adjusting financial incentives, encouraging early intervention, and enhancing teacher training, appear unlikely to be adequate by themselves to make inclusion work properly. Nevertheless, acceptance of the central insight that all children are the responsibility of the general education

system is logical as a first step in changing prevailing attitudes. Changes in policies and programs would then proceed from the premise that children with disabilities should achieve successful education in integrated settings.

Advocacy of integration is fueled in part by aspirations for a better future in the long run, even though there may be difficulties with reaching that ideal state. In other contexts, the law pursues integration even though lingering prejudice may result in hardship. In *Palmore v. Sidoti* (1984), the United States Supreme Court ruled that it is improper for a court to consider the social stigma that a child might feel remaining in the custody of a Caucasian mother who is living with an African American man after divorce from the child's father. Chief Justice Burger declared: “Private biases may be outside the reach of the law, but the law cannot, directly or indirectly, give them effect” (p. 433). The aspirational is never far from the descriptive. Even Colker, who elsewhere criticizes proponents of the inclusion presumption for relying on “moral, rather than empirical arguments” (p. 832) decides, apparently on a moral basis, not to consider any detrimental impact of inclusion or noninclusion on children without disabilities, “Because *all* children are entitled to an adequate and appropriate education in our society” (p. 793, note 12).

Some Possible Compromise Solutions

Is there room for compromise in the conflict between supporters and skeptics of integration? One possible compromise solution that has received some support, particularly with regard to matters of cultural preservation, is choice. Parents might be permitted to choose separate schooling, provided that integrated alternatives remain available. This approach has its attractions. Cultural institutions valued by persons with blindness or deafness can continue, but no one will be forced into them by the lack of anywhere else to go. Ultimately, however, choice presents its own problems. Few societies will be wealthy enough to provide intensive services in

both integrated and separate settings. Parents will be forced to make choices based on adaptive preferences. Moreover, if too few parents choose the separate options, the institutions will wither. The choice option is most realistic at the post-secondary level, where students are likely to be making their own decisions after exposure to the mainstream, and where relocation to a setting away from home may be part of the cultural norm for all students.

Even if choice is not the solution to the problem of preserving institutions that further disability culture, the nature of parental choice matters with respect to children's educational programs. When parents push for a more integrated program and the schools resist, it is unlikely that the parents are the ones in the grip of standard operating procedure. Conversely, when the school system proposes a more integrated setting and the parents resist, the parents may be harboring outdated attitudes, but the integration may in fact be deficient for lack of skilled personnel and quality services, curricular or disciplinary policy modifications, and protections against harassment. A classic work of procedural jurisprudence contends that what should determine the presumption for court cases should be which side is more probably correct in the run of litigated disputes (Cleary, 1959, p. 13). When parents fight for inclusion and schools resist, it is more likely than not that the schools are protecting their own interests, not those of the students.

A compromise solution to some of the questions about the educational effectiveness of integrated schooling might be found by attention to the temporary nature of many educational arrangements. There are two temporal dimensions that matter. First, separate schooling may be justified for part of the school day or for periods before the beginning or after the end of the school day. Individual tutoring in a resource room setting for a class period is an example. Individual activity for a small fraction of the day does not undermine a general program of main-

stream education. Some opponents of a presumption in favor of inclusion do not recognize this option. Colker, in particular, challenges inclusive approaches on the grounds that resource room services may be helpful for children with some disabling characteristics, when in fact the judicious use of resource room activities may be part of an otherwise highly inclusive program, as the *Oberti* court recognized.

In addition, temporal solutions may include full-day programs that are very intense and do not include interaction with children without disabilities for some period of time, if they are directed towards a dramatic improvement in the child's opportunities to participate in integrated education at an identifiable point in the near future. An example is autism treatment for preschool children, which may entail one-on-one behavioral training programs occupying most of the child's waking hours, with the goal of enabling the child to be integrated into general education kindergarten or first-grade programs with minimal supportive services. If this scenario is realistic for a particular child, the short-term separate schooling will promote long-term inclusion. The preferable option, however, is that endorsed by the *L.B.* court, which relates to the temporal dimension discussed in the previous paragraph: intensive, separate programs at home but integration in class during the school day.

Summary

Inclusive education in the United States and elsewhere is under challenge. The experience in the United States with legal efforts to compel schools to provide integration reflects an ambivalence that is present in similar enterprises elsewhere in the world. There is good reason for the ambivalence. The integration ideal remains central to the achievement of disability rights, but concerns over subordination and cultural identity also remain. Even the educational effectiveness of integrated schooling can some-

times be questioned. Nevertheless, the problem is not with the ideal of inclusive education, but with how it has been actualized. Support services, modifications of rules, and effective action against harassment are needed to make integrated education work. Efforts to obtain provision of services, modification of school rules, and prevention of harassment are central to achieving inclusion and meeting its challenges.

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Disability and Youth Suicide: A Focus Group Study of Disabled University Students

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Abstract: For young people thoughts of suicide are based on various social factors. The research literature in this area reveals that there are two important interrelated factors that correlate with suicide rates: being young and being disabled. This study was undertaken in order to explore possible reasons for this increased tendency for young disabled people to commit suicide. The study was carried out at a university in Turkey with a group of disabled students. All the members of the focus group had thoughts of suicide and felt that their disability played an important role in creating these thoughts. The basic premise of the research was that physical disability increases the young person's isolation and social loneliness and this can generate ideas of suicide in the young person's mind that may be acted upon.

Key Words: physical disability, suicide, social isolation

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Introduction

Suicide is a puzzle. The reasons human beings choose to end their lives remains a mystery, and it has been the subject of much research.

Some of the questions posed by researchers through the years have been, "How is suicide defined?" "Is it a crime or a sin?" "Is it an indicator of madness?" "Is it a part of the human condition from the past to the present?" "Why do people commit suicide?" "Why do young people think of committing suicide?" "How can suicide

be prevented?” “How can people be helped who are thinking of committing suicide and/or have attempted suicide?” and “What is the reaction of society towards suicide?” (Clemons, 1990, p.5). Many different branches of science have tried to find the answers to these questions by establishing relations between suicide and physical, psychological and social factors.

Suicide is a phenomenon influenced by social and cultural factors. It may change from one society to another and it may also reveal differences within the same society. For instance, the rate of suicide among young people aged 15-29 increased in Europe after the 1960s and this increase gained momentum particularly in the last two decades (Diekstra, 1992). In recent years, youth suicide has been accepted as a fundamental public health problem in the USA, ranking third as a cause of death for youth (Berman and Jobes, 1991). The ratio of suicides to the total number of deaths in Turkey was 2.36% in 1995, 3.11% in 1997 and 3.77% in 2001. The ratio of suicides among young people between the ages of 15-24 has increased in recent years although not significantly (34.24% in 1995, 35.17% in 1997 and 32.55% in 2001). The ratio of suicides among young people between the ages of 15-24 was 48.4% for young males and 51.6% for young females in 1995 (n=500), and 45.71%, and 54.28% in 1997 (n=700), 50.29%, and 49.70% respectively in 2001 (n=841). The main reason for suicides in Turkey is officially given as “illness” (SIS, 2001).

In Turkey, the suicide rate within general population was 2.36 % in the year 1995, 3.11 % in 1997 and 3.77 % in 2001. The rate of contribution by sex to the total number of suicides showed significant difference and fluctuation. The cases of male suicides constituted 62.12 %, 58.09 % and 93.06 % of the total case of suicides in respective years. A major contribution to these rates came from young people aged between 15-24. Their cases of suicides constituted 34.25 %, 35.18 % and 32.55 % of the total number of suicides in the country in the

respective years mentioned. Within the age category itself, the cases of male suicides constituted 48.40 %, 45.72 % and 50.28 % whereas the cases of female suicides constituted 51.60 %, 54.28 % and 49.72 % of the total cases of suicides in respective years. There were, however, significant differences again in the proportion of contribution made by each sex within this age category to the total number of the cases of suicides within each sex category: The cases of male suicides within this age category constituted 26.68 %, 27.68 % and 25.22 % of the total cases of male suicides in the country in respective years whereas the cases of female suicides constituted 46.66 %, 45.56 % and 46.09 % of the total number of the cases of female suicides in respective years.

Some sociological and anthropological studies have focused on “cultural differences” and “changes in social conditions” (when explaining different suicide rates between cultural groups). Other research carried out by social scientists such as Holinger, Offer and Zola (1988), and Hafner and Schmidtke (1987) explained differences in the numbers of suicides as dependent on the cultures of societies. Diekstra (1988), Lee (1978), Roy (1986), Brent, Perper and Goldstein (1988), and Shaffer (1974, 1988) attributed these differences to social factors such as broken families, problems at school, social relations and other important life events.

As suicide reveals differences between societies, it may also reveal differences regarding gender, age, occupation, level of education, and level of disability, even in the same society. For example, according to Clemons’ (1990) findings, the rate of suicide among black males in the USA is higher than that of black females, and the rate of suicide among police officers and soldiers is higher than other occupations.

Some studies have examined the relationship between suicide and age (Clemons, 1990; Diekstra, 1988; Durkheim, 1951; Hafner & Schmidtke, 1987; Haim, 1976; Holinger, Of-

fer and Zola, 1988; Jacobs, 1971; Lee, 1978; Miller, 1975; Shneidman, Farberow & Litman, 1970; Wenz, 1979). For example, Durkheim (1951) indicates that the rate of suicide increases with age. Shneidman, Farberow and Litman (1970) state that the tendency towards committing suicide is higher in young adults than in younger people. Haim (1976) claims that this tendency is at its highest level among young people between the ages of 15-20. In terms of the relationship between being young and committing suicide, a further factor drew the attention of some researchers, namely the situation of young people who are physically disabled. There has been research into suicide by young disabled people, although these studies are not high in number (Battin, Rhodes & Silvers, 1998; Coleman, 2000; Curran, 1987; McBride, Hazel & Siegel, 1997; Olafsen, 1983; Retterstol, 1993).

There has not been a sufficient number of studies on the relationship between disabled young people and the number of deaths by suicide in Turkey. But one sociological study is currently underway (*Being A Disabled Person in Turkey: Research On the Sociological Aspects of Problems Pertaining to Disability*, Burcu 2004-2006). Also, a Disability Survey in Turkey was carried out by The State Institute of Statistics (2002). As mentioned in this study, this survey aimed to alleviate gaps in information about disabled people. According to the findings of this study, total disability proportion in the overall population is 12.29%. The proportion of physically and mentally disabled people is 2.58% and the proportion of people with chronic illnesses is 9.70%. When the proportion of these disabilities is examined by age group, it is observed that disability increases with age. When examined by sex, it is observed that while the proportion of physically and mentally disabled people is higher in males, the proportion of people with chronic illnesses is higher in females. While the proportion of physically and mentally disabled people is higher in rural areas, the proportion of people having chronic illness is higher in urban areas (SIS, 2002). When the illiteracy rate

is examined by urban-rural, it is observed that while the illiteracy rate of physically and mentally disabled people in rural areas is 43.44%, this rate is 29.58% in urban areas. The illiteracy rate of physically and mentally disabled people is 28.14% for males and 48.01% for females (SIS, 2002, p.8-9). In the population of people with physical and mental disabilities, the labor force participation rate is 21.71%, and the population rate not in the labor force is 78.29% (SIS, 2002, p.14).

In our research, it is argued that being physically disabled has an effect on the tendency towards committing suicide. The main aim of the research is to investigate and discuss the relationship between being disabled, being young, and contemplating committing suicide. When developing thoughts of committing suicide, young people's social relationships with friends, family, school mates and acquaintances are of primary significance. On the one hand, young people need to develop stable social relationships and on the other hand, in this period of their life they have to face new social responsibilities. Likewise, disabled young people also desire to be involved in new social relationships. But their physical condition may be a deterring factor in creating and maintaining new relations. Disabled youth have the desire to have new friends, take individual responsibilities and use freewill in their actions, but their situation may create obstacles. In this context, their physical condition may turn them into a socially disabled person. A disabled young person may feel lonely, choose not to get involved in relationships with others or feel that others don't want to have a relationship with him/her. Consequently, disabled young people can lose the opportunity to maintain stable relationships with friends, family and acquaintances, leading to social isolation. On the basis that social loneliness and isolation reduce a willingness to carry on with life and reinforce the tendency to commit suicide, the main aim of this research is to investigate the relationship between being young, being disabled and the tendency in commit suicide. It is

hoped that research of this kind will contribute towards developing the knowledge base relating to disabled youth in Turkey and also contribute to the sociological discussion about the relationship between disability and suicide, which is not a frequently discussed topic in Turkey.

With this aim, a pilot study was carried out with young disabled students at a university in Turkey. Information concerning their life expectations and ideas about suicide were gathered in a focus group. In this study, the concept of suicide is treated in terms of different approaches, and the social reasons for youth suicide are discussed with regard to the relationship between suicide and age. The relationship between being physically disabled, being young and committing suicide is examined and explained in terms of an analysis of social isolation and social loneliness.

Theoretical Perspectives

Social Reasons for Young People's Suicides

Suicide is generally defined as an individual ending his or her life by his or her own hand. In law, suicide is killing oneself. It is a behavior by which an individual hurts himself (Shopsire, 1990, p.23).

The idea of suicide may include all thoughts related to committing suicide. Thinking of suicide also includes the premeditation–planning process. The application of this premeditation–planning process reveals the behavioral aspect of suicide.

When traditional and contemporary approaches to suicide are examined, it is seen that traditional sociological theories, in reaction to psychiatric theories, focus on statistics and emphasize the “social environment” as the fundamental and unique reason for suicide. Durkheim and Halbwachs are important representatives of these sociological theories (Haim, 1976).

Table I. Types of suicide (Haim 1976:11)

Single and mixed types	Characteristics	Secondary Variables
<i>Egoistic suicide</i>	indifference	melancholia, disappointment, scepticism
<i>Altruistic suicide</i>	energy of desires or emotions	mystic effort, courage
<i>Anomic suicide</i>	anger, hatred	intensive complaint about life, intensive complaint about individual
<i>Ego-Anomic suicide</i>	indifference+anger+hatred	indifference and agitation, boredom, imagination
<i>Anomic-Altruistic suicide</i>		agitation with a sudden anger
<i>Ego-Altruistic suicide</i>	indifference+intensive emotions	a slight melancholia as a result of patience

According to Durkheim, suicide is related to the level of the individual's unification with the goals of the group in which he lives. Durkheim sees suicide not only as an individual phenomenon but also as a collective one through the collective consciousness (Durkheim, 1951). The basic characteristics of six types of suicide determined by Durkheim are described in Table I. Durkheim attempted to explain and classify suicide in terms of the level of present social unification in a society or group.

Another traditional sociologist, Halbwachs, adds to Durkheim's discussion of level of loyalty to the social group by emphasizing the concept of life style. According to Halbwachs, increasing social confusion is one of the modern reasons for suicide (Haim, 1976).

Suicide has also been viewed from an interdisciplinary approach, for example, psychiatric, psychological and social factors are considered together in contemporary approaches. In contemporary sociological research, any analysis of the reasons for suicide takes into consideration the conjunction of individual, social structural and cultural factors. Contemporary sociological studies (Clemons, 1990; Coleman, 2000; Diekstra, 1988; Hafner & Schmidtke, 1987; Wenz, 1979) focus on the effects of ethnic and cultural factors under which the personality of an individual is formed, and on age, gender, physical features, marital status, and other factors that have roles in the development of personality.

Youth is accepted as the most dynamic period of human life. It is a period of transition between childhood to adulthood when an individual experiences biological, psychological and sociological changes (Burcu, 2003). These changes may sometimes create great difficulties for the individual to overcome. As Shopsire (1990) indicates, the problems that a young person faces during this period may be related his or her efforts to establish a relationship with the complex world in which s/he lives. Feelings of unhappiness, hopelessness, loneliness, and isola-

tion, the desire to draw attention to her/himself, identity crises, socio-economic conditions, stress at home, and peer group pressure may all lead to thoughts of suicide. Consequently, suicide is a critical social problem in many countries.

According to current research, the basic social reasons for youth suicide or thoughts of suicide can be separated into three parts:

1. *Family*—consisting of social factors such as the absence of one or both parents, difficult relations within the family, the fragmentation of the family, and marital status (Durkheim, 1951; Haim, 1976; Schrut, 1968).
2. *Young people's relationships with their peers and the opposite sex*—one of the important reasons leading to young people's suicide is their relationships with their friends, especially their relationships with the opposite sex (Hendin, 1990).
3. *Academic performance*—Research reveals that the rate of suicide among young students is higher than that of young people who are not students. Family and cultural pressure on the student to excel academically may push the young person to commit suicide (Ross, 1969; Seiden, 1966).

Suicide in Relation to Being Young and Disabled

Approximately 10% of the world population (Helander 1993), and 9-10% of the population in Turkey (Council of Disabled People [I], 1999) are disabled. In Turkey, a large proportion of disabled people are young. Being disabled is a concept often used to express limitations resulting from the loss of mental and/or bodily functions. A person who is disabled is usually defined as a person who can be rehabilitated but not totally treated (Whyte and Ingstad, 1995, pp.3-4). According to the International Classification of Impairments, Disabilities and Handi-

caps (ICIDH) being disabled means, “Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being” (ICIDH, 1980, p.28).

These definitions constitute a medical model of disability, where disability is conceptualized as an impairment that functionally limits the body and/or the mind. However, disability also refers to the disabling effect of prejudice, discrimination and social exclusion. The British Council of Disabled People has adopted the following definition: “Disability is the disadvantage or restriction of activity caused by a society which takes little or no account of people who have impairments and thus excludes them from mainstream activity. Therefore, disability, like racism or sexism, is a kind of discrimination and social oppression (Morris, 2001).” This approach is the social model of disability. Medically, disability is a physical or mental characteristic of the individual, but socially, people with physical or mental impairments are disabled by society. According to Morris (2001), social disability results from unequal access and negative attitudes. The bodily functions of many people with physical and mental impairments are influenced, and often compromised, by broader social and structural relations (Edwards and Imrie, 2003).

These two approaches, the social and the medical models of disability, form the main “views” in disability studies. The medical model is primarily concerned with an analysis of the body physically, propagating a medical orthodoxy that conceives of bodies as objects to be cared for through the application of medicine and rehabilitative techniques. Meanwhile, the social model seeks to understand disability as a socially-generated category and related series of experiences external to the body. Thus, disability is the body being transformed by “living in society,” where a person with an impairment is disabled through the attitudes and norms by

which society defines that person (Edwards & Imrie, 2003).

According to Taylor (1999), being disabled is related to the reactions of other people, and the social and cultural values that disabled people are faced with are important sociologically (Gannotti, et al., 2001; Gerhardt, 1989). In social and cultural terms, social reactions to disabled people and the results of these reactions are important for the disabled individual (Taylor, 1999; Whyte & Ingstad, 1995). Goffman (1963) states that disabled people are often labeled as “not worthy or valued in society,” “not respected,” “not given importance,” and “second class citizens.” The effect of these labels is that disabled people may refrain from participating in social groups and social activities. From this perspective, according to Goffman, disability is a barrier to participation in the society in which an individual lives (Murphy, 1995). The social and cultural values held by society in general create social disability. Here, deep sorrow and sadness created by social loss that a disabled person may face as a result of socio-cultural attitudes, rather than his physical disability, might form the basis of a disabled individual’s desire to die (Coleman, 2000).

Increases in social activities and the widening of the social arena are among the most fundamental features of the youth period. Taking these factors into consideration, it can be agreed that when studying the relationship between the incidence of suicide in young physically disabled people it is important to look at the extent to which the young person is socially isolated. According to studies on the relationship between physical disability and social isolation (Anderson, 1973; Anderson, et al. 1982; Brier & Demb, 1981; Morgan, 1972), disability increases social isolation for a young person. Generally, young people experience increased independence from their family and increased contact with their peers, and opportunities to explore their sexuality. For the disabled young person, the opportunities to satisfy these needs

may be difficult to achieve. In very early research carried out by Younghusband, et al. (1970), it was found that “potential isolation” and loneliness is intensified for a young disabled person. This problem is related to his/her social relations. Depending on their disability, the increase in a young person’s social isolation, as indicated by Anderson (1973), decreases the young person’s self-respect and thus weakens their ability to form and maintain social relations. This in turn contributes to problems with the development of social skills. This situation prevents the young person from unifying with the society in which they live and can cause them to assume a negative attitude to their own life and their future. All of these factors may contribute to the development in the young person of the idea of committing suicide. Barter, Swaback and Todd (1968), Jacobs (1971), Miller (1975), Lee (1978), Wenz (1979), and Husain and Vandiver (1984), stress social isolation as an explanation for young people’s suicide. They indicated that young people who contemplated committing suicide had no specific social groups in which to actively participate, and their participation in other social activities was minimal.

These studies reveal that the relationship between being young and thinking of suicide or committing suicide may be reinforced by disabling barriers, especially by an inability to resolve social problems which are further exacerbated by social loneliness caused by socio-cultural attitudes to disability.

In developing countries such as Turkey, physically disabled people come across many problems in their daily lives. The most significant problems for young people in Turkey today are education and employment. Accessing higher education and finding a job after a university education is a challenge for all young people. A disabled young person faces additional challenges, for example, mobility or the need for special equipment or medication. The challenge of going to university or finding a job may seem impossible to meet. In addition, the disabled

young person may be labeled as “poor,” “clumsy,” or “a second class person.” With all of these pressures, young disabled people may feel hopeless about their future, and they may start to feel alienated and their sense of ennui may grow. In this situation they may lose their motivation to resolve their problems and ultimately lose their desire to live.

Methods

This pilot study examined the relationship between being physically disabled, being young and committing suicide in the context of social isolation and social loneliness. The pilot study was carried out with young disabled students at a university in Turkey.

Participants

Nine physically disabled students participated in the study. University students who are disabled are thought to be very conscious of the difficulties of daily life for people with disabilities in Turkey and are aware of differences in their life experiences from non-disabled students. All of the participants of this study have had thoughts about suicide. The aim of the study was to explore their ideas rather than to judge them. False names are used in this paper to guard their identity.

In Turkey, according to data from ÖSYM (Student Selection and Placement Center), in 1999 there were a total of 374 disabled students enrolled in universities in Turkey. The overwhelming majority of these, 370 students, were physically (visually and mobility) disabled and the remaining four were included in the group consisting of other types of disabilities (ÖSYM, 1999).

There were 19 disabled students enrolled at the university, 10 at the campus that is the focus of this study and 9 at the other campus. There were two enrolled students who did not attend courses in their Departments.

The most important reason for choosing this sample group is that, being a disabled student in a developing country such as Turkey is challenging. It is very difficult for all young people to pass the university exam in Turkey. According to the data given by ÖSYM in 1999, of the total 1,007,707 who sat it only 414,315 total passed and only 374 of them were disabled. The sample group of this study is made up of students who were able to enter a department despite being physically disabled. It was thought that these students would have more focused ideas about the lives and problems they face and would be able to express these ideas and their attitude about suicide better than youth who are not enrolled in a university.

To understand the physically disabled student's ideas about suicide it is important to know the background of each member of the sample group. Long and detailed interviews with 9 students were made during the two years of the pilot study (1999-2001). From these interviews, it was clear that each of the young people in the study group had struggled to obtain an education and to go to a university. As Şenay expressed: "Despite my living conditions, I struggled to go to school and now I am at university."

As indicated above, this study only included the students at one campus. Those at the main campus of the university were not included in this study because of problems with transportation from the main campus to the other campus, especially in winter. Research involving disabled students at the main campus and at other universities will be carried out in the future.

Five of the participants in this research were female and four of them were male. They were between the ages of 18 and 21. Seven of them were born in rural settlements and two of them in urban settlements. Almost all of the participants spent most of their lives in cities. Their fathers worked either as farm workers or civil servants, and their mothers were housewives.

All of the participants believe in God. Six of them have three or more siblings and one of them has two siblings. Two of them are the only child in the family.

Data Collection

This study is descriptive, using qualitative data collection and analysis techniques. The data collection process was carried out between November, 1999 and May, 2001. Prior to the fieldwork, statistics and related literature were gathered and studied. Although there have been many sociological studies of disabled individuals internationally—including young people – very few studies of this group have been carried out in Turkey.

The data for this study was collected through one-on-one detailed interviews and focus groups. A semi-structured questionnaire was designed for the interviews with each participant. In these interviews, participants were asked questions about socio-demographic factors, their stories about their disabilities were recorded, and thoughts about suicide, how they evaluate life, and factors affecting their life were discussed.

In the focus groups, participants came together for a total of five times at two pre-determined places; in offices and seminar rooms of the Department in winter, in the campus gardens and cafe in spring. The main topics discussed in these meetings were the meaning of life, enjoying/not enjoying living and the reasons, and the effects being disabled has on negative feelings toward life. An information sheet, developed by Krueger (1994) was used during the interviews.

Techniques of Data Analysis

A qualitative analysis technique was used in the study. Collected data from notes, semi-structured forms and recorded interviews at meetings and focus groups were analyzed and reported. In the analysis of focus groups, Krueger's (1994) "descriptive summary" data evaluations were used.

These names were used for the participants in the meetings and focus groups:

Ceyda, Serdar, Adnan, Zerrin, Esin, Aydın, Fulya, Kadir, Şenay. The names are fabricated, to protect participants' identity.

At meetings and focus groups, the discussion categories were determined as, "Main Category= If and why physical disability can create thoughts of suicide in young persons." Sub-categories included:

1. How a young person thinks about the meaning of her/his life.
2. The problems that disability brings to their lives.
3. The young person feeling alone in themselves.
4. The young person seeing her/himself isolated and excluded from society.
5. The problem of a young person facing the reaction of society.
6. The situation where the young person is challenged by the problems.
7. The reasons why a young disabled person continues living.
8. Whether the young disabled person has a future plan.

By using these categories, "frequencies of words and sentences" were used to analyze topics that were important to the participants.

Results

A data set was formed from focus group and semi-structured interviews carried out with nine university students.

Sociological research has shown that initial thoughts of suicide can be turned into reality as the result of various social factors. The relationship between the factors of "being young"

and "being disabled" has been noted in research about suicide. In our study we found that three basic variables (youth, disability, and suicide) were linked. In particular, there was a need to determine whether the ideas about suicide that young disabled people develop affect their behavior. In this framework, the main topic of the focus group was being physically disabled, thoughts about suicide, and reasons for participating in the focus group. Responses to various sub-categories were analysed revealing important factors behind young disabled people's thoughts of suicide. All the members of the focus group had thoughts of suicide and they felt that their disability played an important part in creating these thoughts. For example, the group members Aydın, Serdar and Esin described the situation as follows:

"I think about suicide, this is a chaotic time, I haven't tried but I have thought about it."(Aydın)

"I have thought about suicide but I couldn't do it. From time to time I thought that life wasn't worth living." (Serdar)

"If my life was in my hands I could end it. From time to time I feel bad, I feel that I can't solve small problems."(Esin)

In our study, all the members of the focus group expressed that they want a social world in which they can take various responsibilities and can behave independently. However, disabled young people can face problems while they are creating their social world. Shopsyre (1990) explained that the young person tries to develop a relationship with the social world during the adolescent period. The young person wants to be independent, have a social life, play a role in life and also to take on responsibility. In this complex situation, physical appearance is important. As Taylor (1999) has pointed out, the social and cultural meaning attached by the

disabled person and society to physical disability turns physical disability into a social disability. As Goffman (1963) stated, what makes the person disabled is the meaning attached by others to his/her disability, because the person is what he/she is not “normally” expected to be. The focus group meeting provides support for this theory. For example:

“I come from a village. In my environment people are less educated, people always gossip and try to find out what other people are doing and making fun of people...sometimes I explain, sometimes I lie. When some kids ask me why are you talking like this I say I have lost my voice. Often I am so sad but I have to get on with this difficult life.”(Şenay)

“Some people are sympathetic, ‘Ah,’ they say but the young people make fun of me which is sad.”(Zerrin)

“When people laugh at me because of my disability this makes me think of suicide.”(Aydın)

“Generally human beings feel sympathetic. Maybe they are grateful that they do not have the problems that I have. When facing these people I feel very bad and from time to time I want to die. Its like to be normal is their choice and to be disabled is our choice...”(Esin)

“When my teachers behave negatively towards me I feel really fed up with life.”(Adnan)

“...About other people, my environment is important for

me but it is also important for me to feel important to other people, I don't like being alone.”(Ceyda)

“The most important problem is when society doesn't accept you, they don't see us as being like them, they want us to stay in our world.”(Kadir)

Goffman (1963) indicates that being set apart results in a weakening of social links. This situation results in the young person becoming socially isolated and leads some of them to think about suicide:

“To be alone affects me and I feel depressed...”(Zerrin)

“...In my private life my heart is empty. Sometimes I need to share situations with other people. A short telephone call can make you feel more comfortable.”(Adnan)

The point is made by Olafsen (1983), Retterstol (1993), Anderson (1973) and Fulthorpe (1974) that resolving problems is more difficult for the physically disabled young person and can cause them to think of suicide. Young people who are not disabled have problems, for example, to find work, to have a profession, to set up a family, to have a partner or lover for whom they worry about the future. For the disabled young person these problems are greater. In the focus group the comments on this situation were as follows:

“Personal relationships with the opposite sex are difficult when you are disabled, it makes me sad.”(Adnan)

“The work place, especially for the young disabled person, causes problems. Also, joining social activities makes me feel

unhappy.”(Kadir)

“Life is monotonous, boring. I want to play sports. I want a fast life but it cannot be, my disability is against me...I wanted to join a walking club. When I go they look at me, they don't listen to me, they say 'you can't do it,' and it makes me sad.”(Kadir)

On the other hand, there are factors which stop young people from committing suicide. These include particular beliefs such as religious beliefs that committing suicide is a sin. Family members want to see them happy and for them to continue living. In spite of life being hard they want to prove they can continue to live. In the focus group the young people expressed these sentiments as follows:

“I thought about suicide, I wanted to die but my belief stopped me, and I had to go on living.”(Şenay)

“My life is tied to various things: my family; I love my school; I want to find work [and] have children.”(Aydın)

“My target to have an independent life makes me want to keep on living.”(Şenay)

“My family's expectations keep me living [and] my belief stops me from committing suicide.”(Esin)

On the other hand, we found that although being young and disabled increases the possibility of thoughts about suicide, if young people are motivated and have goals, then they want to continue living. On this topic our group expressed goals such as to pursue education, to be married, to have children, to find work, and to have a profession.

“In the future my aim is to find a job, set up a family and have children.”(Esin)

“To finish school, do my masters, find a job and stay in Ankara.”(Fulya)

“My expectations are to have a good life, to get a doctorate in my branch, and if there is a possibility to have a happy life with less problems.”(Adnan)

“To finish school, do a masters, find work, get married...I am afraid to be alone.”(Ceyda)

Conclusion and Discussions

The foregoing analysis indicates that it is not the disability as a physical phenomenon per se but the social and cultural context in which both the disability and the disabled individual are constructed that constitute the hard core of the problem of disability and suicide in Turkey. What transforms the disabled individual's physical appearance and incapacity into disability is his/her self-perception and others' perception of his/her appearance and state as disabled. This in turn can foster both self and socially-imposed isolation, loneliness, helplessness and all the other negative feelings, thoughts, attitudes and ascriptions in establishing and maintaining efficient and balanced mutual social relations. The outcome of the process is the emergence of social disability in the sense of disabling barriers of prejudice, discrimination, social loneliness, and social exclusion, as Morris (2001) defines the term.

Many disabled young individuals in Turkey live in isolation from society. They may feel totally alone in life. These feelings present themselves as risk factors leading to suicidal feelings and behavior. Young people with disabilities want to be accepted by society so that their physical disabilities are recognized without be-

ing socially disabling. They want to be able to function: to live with their disability, to come to know their bodies, to accept what it can and cannot do, and to keep doing what they can do as long and as much as possible. They do not want to be dominated and labeled by other people, who they may depend on for help, and they do not want to feel ashamed (Siebers, 2001).

The results of the study also indicate that being disabled may motivate young persons to develop strong suicidal feelings and ideas in connection with the problems that may arise in their daily lives. These problems include or arise from barriers to completing their education, having an occupation, finding a job, earning income, being self-sufficient, marrying, being attractive to the opposite sex, establishing a family, having a child and the like. However, reinforcement or prevention of such negative feelings and ideas about their lives depends to a large extent on the relationships they have, especially with members of their family, peer-groups and other social circles that bear significance for them. In addition, having and maintaining their hopes to achieve their goals, and the emotional responsibility they have towards their family members, especially towards their mothers and their religious beliefs that suicide is a sin, often act as protective factors as well.

The very fact of being young, in addition to disability, is also an important issue as this period of human life poses other difficulties to be overcome. These other difficulties are concerned with youth unemployment, lack of educational facilities, problems of adaptation to a new social environment in the case of immigration, etc. These difficulties are of particular significance in Turkey, where the rate of unemployment is considerably high and the adaptation problems resulting from ongoing rural to urban migration is still very much noticeable.

It is important in this context to point out that the labeling of disabled individuals as “second class” by their social environment and society

at large, lack of meaningful contact between the disabled individual and their peers, lack of feelings of belongingness and a resulting lack of support from peers are also significant. These factors perpetuate other problems and lead to an inability to formulate convenient strategies towards solving these problems. As Goffman (1963) argues, disabled people can be labeled as discredited and this labeling gradually weakens the ties between them and the group to which they belong. This can lead to a state of loneliness and may even, as a reaction to this, lead to thinking of putting an end to the resulting misery and helplessness by taking their own lives. Living in a chronic state of isolation and loneliness, disabled young individuals may further withdraw from family, friends and others. They may feel that there is no one who they can talk to. At times, this isolation may become very acute, as revealed by participants in the study reporting that they lacked contact with others during their high school years.

These issues call for an understanding of the problems in the wider context of social, economic, cultural, legal and political conditions prevailing in Turkey. Conditions are not favorable for disabled individuals to construct their lives in a meaningful and productive way and take an active part in the wider society. For instance, laws do not secure equal rights for people with disabilities, and do not force society at large to create a physical and social environment in which people with disabilities can live their lives easily. Creation of such an environment requires putting conscious effort into promoting a positive image of disabled young people at all levels of society and enabling them to make as much economic and social contribution to society as other individuals do. To this end, schools should provide information about disability and professional services and facilities geared to the needs of disabled individuals. This will enable disabled youth to overcome their own obstacles and have equality of opportunities and conditions in order to be competitive with other individuals. Any kind of professional support given to disabled individuals should include not only imparting professional

knowledge about a particular physical disability, but also demonstrating a professional attitude that is sensitive enough to cater to other aspects and needs of the individual.

However, it is very noticeable in Turkey that many social and recreational activities do not take into account the special needs of disabled individuals. People do not seem to think that such individuals may want to take part in activities or benefit from the services provided. This lack of sensitivity and care extends itself even into social and recreational programs which are meant to be designed/organized specially for disabled individuals. This prevents people with disabilities from making effective use of such services and further reinforces their loneliness and helplessness. Efforts to decrease suicide in disabled youth at the societal level should be combined with assuming personal responsibility at the individual level as family members, friends, teachers, colleagues, etc. To this end families, teachers and other persons with whom disabled individuals have frequent contact should be instilled with information and understanding about how to approach disability and how to cope with its consequences. Uninformed care and protection only help to perpetuate or even aggravate problems rather than solving them.

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Hearing Impairment and Identity

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Abstract: This study examines the identity of persons with hearing impairments. Participants were solicited from a support group for persons with hearing impairments. An interview methodology was used to qualitatively explore communication and identity. Analysis of data revealed: persons with hearing impairments often minimize hearing loss until adulthood, use various compensatory communication strategies, work hard at receiving and processing information, and are often misunderstood by educators. Implications for researchers, educators and persons with hidden/invisible disabilities are discussed.

Key Words: communication, disclosure, identity.

Background

The number of persons included in the minority group "persons with disabilities" has been growing yearly in the United States (Braithwaite, 1990). Since enactment of the Americans with Disabilities Act (ADA) in 1990, a conceptual change in the notion of disability has taken place. "Disabled" is no longer defined only as persons with publicly visible manifestations of physical difference (Merrigan, 2000). The predominant medical model of disability is yielding to a social/civil rights model of disability (Pfeiffer, 2001). Yet metaphors, terms and models of disability are still created by the dominant "able" society to understand and explain disability on its own terms (Corbett, 1996; Matthews & Harrington, 2000).

Recently communication scholars focusing on the notion of disability have stressed identity management, accommodation, and disclo-

sure/privacy boundary management (Braithwaite, 1991; Merrigan, 2000). Interability communication has recently adopted cultural and co-cultural interpersonal theories to investigate issues of disability and communication. However, literature of medical practitioners and communication scholars has focused on readily identifiable physical disabilities and on issues of inclusion and acceptance of such persons in "normal" society. A dimension of disability not acknowledged until recently is the "hidden," or "invisible" disabilities. A common hidden/invisible disability is hearing impairment. In the case of hearing impairment there is no universally accepted standard definition of this widespread disability.

Research Questions

A person with a disability is aware of its stigmatizing effect from an early age. Often the individual attempts to render it unnoticeable to others in interpersonal communication contexts. At some point the disability may become more noticeable to others, and/or cause more significant difficulties for the communicator with the disability. This study seeks to understand and articulate the identity and communication strategies of persons with hearing impairments:

- RQ 1: What was the nature of the identity of persons with hearing impairments when the disability was "hidden"?
- RQ 2: How has the identity of the person with hearing impairments changed in the process of acknowledging it to other communicants?
- RQ 3: How has involvement with other persons with hearing impairments in a support group affected identity communication?

Method

Participants were solicited from a support group for persons with hearing impairments in the San Francisco Bay Area. Members of this group range in age from 21 to 72, evenly male/female. Their hearing loss may be congenital or adventitious, mild to severe. Six persons volunteered to be part of two focus groups lasting one to two hours. Their occupations are retired educator, psychologist, rehabilitation counselor, interior designer, attorney, and scientist. Four use hearing aids, three have cochlear implants. All refer to themselves as "hard of hearing" or "hearing impaired." The interviewer opened the discussion by relating his experience as a person with a hearing impairment, inviting others to share their experiences. A microphone was passed to whomever gestured a desire to speak. In a group of persons with hearing impairments, many rely on lip reading (speech reading) and prefer to concentrate on one person at a time. Free-flowing turn-taking ensured that all participants had maximum potential for hearing, being heard, and sharing experiences. An interview methodology was used in this study to qualitatively explore communication of identity by hearing impaired persons. Tape recordings of the focus group discussions were analyzed and categorized according to the research questions. Significant comments that elicited affirmative responses from other focus group members were selected to include in the Findings. An interpretive framework guided analysis to identify reoccurring response patterns and themes.

Findings

Living with Hearing Impairment

Often the participant's mild to moderate hearing loss was first noticed during elementary school screening tests. Taking cues from others during such tests to pretend that hearing was normal, and bluffing at other times, was common. Those diagnosed were referred to specialists, but professional help could be a hindrance

or misguidance. Audiologists recommended no hearing aid, powerful aids that worsened hearing, or didn't notice long term progressive loss. Physicians, audiologists, and specialists often had separate practices and didn't communicate. Poor treatment seemed to contribute to avoiding acknowledgment and significance of the hearing impairment.

In some cases, familial pressure demanded denial of an impairment. The lack of parental acknowledgment and support for the hearing impaired child encouraged ignoring the condition. For some parents imperfection was unacceptable, or the unfamiliarity of a disability rendered them helpless. It was easier to cope by ignoring or denying an unnoticeable disability. Other parents took the role of advocates, demanding that their impaired children be "mainstreamed." These parents advocated inclusion, hard work, and "overcoming" disadvantages. Participants reported that teachers rarely acknowledged their hearing impairment. Often it was ignored. Some related difficult experiences in early grades, feeling that teachers singled them out, ostracizing them unfairly. More often these hearing impaired students had to compensate in different ways: choosing optimal seating places, requesting notes, reading carefully, and becoming serious, attentive students. When they reached university studies, they had a repertoire of coping skills for varying situations and were able to function in educational settings without referring to their disability.

Three participants resumed studies after age thirty, receiving doctorates and professional licensing. Each reported that they advocated for themselves more than before, requesting accommodations in the form of note takers and assistive devices, and disclosing their hearing impairment to others, especially professors. They felt that they did well, despite hearing obstacles, since they worked extra hard and actively advocated for themselves. While some in the academic community were sympathetic and helpful, others shunned them or regarded the dis-

ability as insignificant. Teaching proved harder for hearing impaired participants. Paying close attention to students (in order to hear) lead them to be perceived as serious yet caring teachers. However, it proved stressful and exhausting to perform in front of an audience. As hearing deteriorated, some felt they could not control their classes, and the feeling of "missing something" in class became stronger.

Denial and Acknowledgment of Hearing Impairment

Often, traumatic childhood experiences associated with the first diagnosis and testing encouraged the participants to choose to "pass" as a person with normal hearing. They feared being found out, felt like outsiders, and experienced misunderstandings. When confronted, persons with hearing impairments chose to avoid people who might guess about a hearing "problem." Participants recognized that their personality and social image was affected by their hearing impairment. They might be perceived as quiet, thoughtful, insightful or working hard on a task. Unsure of what they heard, misinterpreting, or missing some things, they constantly needed to make decisions about whether to ignore it or ask again and somehow "spoil the moment."

There was incentive, and encouragement by others to compensate, hide, and ignore the disability. Participants developed communication strategies and coping skills at an early age. Speech therapy corrected pronunciation and speech reading provided communication cues. Personality quirks coupled with "bluffing" enabled some to get by in difficult communication situations. Initially labeled "different" because of out of the classroom speech therapy and speech reading training, they were eventually able to hide their hearing loss when aided by communication strategies or hidden hearing aids. They might have few difficulties in school, but never be sure what they missed. Unintended misunderstandings resulted in being regarded as inattentive, arrogant or stupid. "Passing" as normal

was stressful, as one participant put it, "... It was hiding, hiding, hiding."

When the person with a hearing impairment disclosed, it introduced the possibility of others identifying the person as the disability. Disclosing alleviated difficulties in noisy situations and work performance. It also improved perception and potential miscommunication, but, on the other hand, had the effect of labeling the person as the "hard of hearing person who does a great job." Disclosure of ones hearing impairment entailed risks. People attempted to be empathetic, but often misunderstanding and resentment were the result. Disclosing one's hearing loss did not make as much a difference as controlling a communication situation.

Sudden worsening of hearing necessitated a change in communication strategies. Having a new cochlear implant or hearing aid and adjusting to it lead to disclosing to coworkers and friends about dealing with worsened hearing. Yet at times these people said "you seem to be normal now," thinking the affected is "cured." In fact, participants said that hearing impairment was a communication disability that was highly situational, subtle in manifestations, involving a high degree of communication uncertainty. No formula fit all persons in every situation every time. Ever changing players and contexts in communication situations often caused these participants with hearing impairments to be stressed and exhausted.

Identifying with Other Persons with Hearing Impairments

Participants expressed a range of tolerance for different labels of hearing impairment. Some preferred hearing impaired, others prefer hard of hearing, but not deaf. Labels and misconceptions were "... someone else's problem...(but) deaf is a final condition...you spend a lifetime trying to avoid that with hearing aids, with the cochlear implant you have beaten deaf." Participants desired to be recognized for who they are, people who wish to be a part of the hearing

world but cannot do so completely. For some, balancing labels was difficult: "...I prefer hard of hearing. 'Disability' doesn't tell anyone what a person's needs are...people with hearing loss as being unique...for us at the heart of it is loneliness, isolation, depression or anger...over lack of communication," said one participant.

Persons with mild to moderate hearing impairments were often taught to compensate. They did not consider themselves "hard of hearing," and would not seek out those with similar conditions. Often participants felt isolated most of their lives, believing that no one else shared their experience: "... I didn't know anyone deaf or hard of hearing ...I wanted to disassociate myself from anyone having a hearing loss." Attempts to connect with other persons with hearing impairments were not always successful. Being involved with a support group for the hearing impaired offered a way to break out of the isolation and created a context of community. Said one member, "I'm no longer the lone ranger, no longer black in the middle of all white. I no longer stand out. I hear people talking about experiences that I've had, and I meet really nice people that I would have liked to meet anyway; and I have support."

Sometimes the personality difficulties a person with a hearing impairment experienced were not considered related to the disability. Because of lifelong "passing" and coping strategies, depression, anger, grieving and interpersonal communication difficulties were not connected to hearing impairment until the person became involved in a support group. The support group enabled some to affirm their multidimensional identity by meeting together to recognize one facet: hearing impairment identity. Making this connection created community for these people. "Feeling relaxed, these are people who understand...they know exactly who you are....we have this huge commonality... its community - our identity is different."

While there is similarity within the whole category of persons with hearing impairments, there is room for appreciating difference. For example, "One thing [that] comes out in the group is that people have different levels of functionality...[there] can be big differences even with the same experiences...social, family, work situations...loss manifests itself differently with others ...in a group we talk about it." The sharing of experiences carried effects beyond the group, to disclosure and self confidence in social situations. Outside the group, people felt they could move beyond the question of disclosing or not, to specific needs and finding ways of meeting them.

Conclusion

Hearing impairment is a disability that can be invisible or hidden. Persons with hidden or invisible disabilities are acutely aware of the social stigma of their disability. Not disclosing entails misunderstandings, isolation, and mental and physical stress. Communication difficulties may be situational, contextual or personal. This may foster a perception by hearing others of normal one moment and deficient another, as if by whim. Participants in this study desired inclusion in society, and have compensated in a variety of ways in order to be included. All participants experienced a liberation of identity by discovering and becoming involved in a support group for persons with hearing impairments. The shift in identity and forming of a community enabled participants to experience personal and social growth.

This study, while rich in depth, was limited in scope due to the small, specific sample. Participants were well educated, articulate professionals representing a narrow generational part of the population. Although some inferences to other hidden/invisible disability groups may be made, this study only begins to examine the identity and communication issues of persons with hearing impairments. A larger study

with a broader representative sampling of persons with hearing impairments should be conducted. Although a survey instrument was used in this study, the small number of respondents provided little conclusive data for triangulation. Future research should qualitatively explore the dimensions of living with hidden/invisible disabilities from the perspective of persons with other hidden disabilities. Deep insight into their unique perspectives can be gained by bringing participants together in a focus group interview approach. Hidden/invisible disabilities have a subtle yet profound effect in an educational setting on the person, the educator and fellow students. With the expanding population of older persons living longer, there is a need to understand issues of those with hearing impairments. By understanding their perspectives, educators and helping professionals will be better equipped in imparting knowledge and treatments that are respectful and well received.

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Essays

Assistive Technology Supports for Self Determination and Community Inclusion

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Abstract: A description of media techniques that “give voice” to people with disabilities to engage in assistive technology problem solving, including video collages, interviews, walk-about and “how to” demonstrations. Ethical considerations related to publication and dissemination are addressed.

Key Words: assistive technology, digital storytelling, creative problem solving

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

The “Tech Act”: An Invitation to Come to Hawai'i

In 1988 the U.S. Congress authorized the “Technology-Related Assistance for Individuals with Disabilities Act,” otherwise known as *The Tech Act*. This legislation was a forerunner to the *Americans with Disabilities Act*, giving voice to the growing civil rights movement within the disability community. The Tech Act was reauthorized and amended in 1994 and again in 1998 when it was renamed the *Assistive Technology Act*.

The intent of the *Tech Act* was to raise awareness and “pave the way” for widespread dissemination of technologies believed to hold the promise of “leveling the playing fields” in our schools, homes, work places and communities, for persons with disabilities and their families. The *Tech Act* also affirmed the federal role in promoting assistive technology devices and services for all American citizens. It recognized the considerable barriers to technology acceptance and adoption, including lack of access to informa-

tion, assessment, training, customization, maintenance and repair. The *Tech Act* represented a leap of faith that a truly inclusive society could be constructed with the appropriate application of technology tools (Alliance, for, Technology, & Access, 2002). The *Tech Act* came to Hawai'i in 1992, as did this author.

In summer 1992, I was invited by the Hawai'i University Affiliated Program for Persons with Developmental Disabilities (now called the “University of Hawai'i's Center on Disability Studies”) to become Hawai'i's *Assistive Technology Outreach Trainer* for this new *Tech Act*. My job was to deliver assistive technology “awareness” and “training” to any audiences in Hawai'i who should request them, including the production of community television programs to be aired through our local public television network.

This essay describes this writer's story of service and discovery, with the intention of promoting creative partnerships among professionals and persons with disabilities and their families, to attain self-determination and community inclusion in the Hawaiian islands utilizing *assistive technologies (A.T.)*, or what we came to call *technologies for voice* (Skouge, 1993).

Consumer Driven and Consumer Focused Supports

The language of the *Tech Act* was challenging and perhaps unsettling for those of us with traditional training in special education or rehabilitation. The *Tech Act* called for “consumer driven” and “consumer focused” initiatives and supports – notions which were somewhat contrary to the “medical” and “expert” models espoused in the professional literature (Alliance et al., 2002).

I read the Congressional Record in its entirety regarding the debates and ultimate passage of the *Tech Act*, moved by the testimony of families and individuals with disabilities sharing

anger and frustration, hopes and dreams that assistive technologies could transform their quality of life. For the first time in American history, augmentative communication users spoke out in the U.S. Congress. Steven Hawking was becoming a household name.

“Leveling the playing field” was the phrase that stuck with me. Filled with enthusiasm and trepidation, armed with a fist full of airline coupons, I struck out on a great inter-island adventure, speaking with any community group that would invite me.

What is A.T.?

What is “assistive technology”? This was an important first question. Unlike rehabilitation engineering, or physical therapy, or special education, this new field did not fit into traditional textbooks or professional domains. A.T. was (and is) required by law to be “considered” in the development of individualized service plans, including *Individualized Family Service Plans* (IFSPs), *Individualized Education Plans* (IEPs), and *Individualized Work Rehabilitation Plans* (IWRPs) (Alliance et al., 2002). But, who was to do the “considering” and how was this “consideration” to be accomplished? The law defined *assistive technology* as any technology that supported a person with a disability to function more independently at home, in school, community and work place. The definition was expansive.

At one of my first talks on Maui, I tried brainstorming with the audience about the meaning of A.T. A well-traveled gentleman of the Pacific noted that eye glasses and hearing aids were lacking on many of the islands. “Perhaps we should begin there,” he suggested. “What about electric can openers,” “television remote controls” and “baby alarms” suggested others. Every suggestion sounded reasonable. The list grew. The need for a working definition become increasingly evident.

The *Tech Act* defined *assistive technology* in terms of “devices” and “services.” Devices were to be understood as *tools to improve human functioning*. In Hawai‘i we began calling them tools for life. *Devices* were described as ranging from “low tech” to “medium tech” to “high tech.” *Tools for life* could be home-made, “off the shelf” or custom built. Services included a broad range of supports such as assessment, funding, training, maintenance, advocacy, and even systems change (Alliance et al., 2002).

The conventional wisdom was to consider the lower technologies first, moving to the higher technologies only as needed. This wisdom had a certain appeal in terms of cost savings, not to mention training, repair and upgrade. It also presented risks. Would a letter board and a typewriter really substitute for an electronic “talker”? Would a “mouth stick” substitute for a head mouse or voice dictation on computer? We learned early on that money affects many decisions, sometimes at the detriment of respect and empowerment.

The law made it clear that assistive technology included *more than devices* (Alliance et al., 2002). It became abundantly clear that just knowing about a device (perhaps seeing it on television, or reading about it in a catalog or magazine) or even acquiring one, rarely prepares the user to integrate it successfully into daily life. Technologies may alter how we look, how we fit into groups, perhaps even our sense of who we are. No wonder it is difficult to predict in advance how they will work out. Many technologies require training. Many involve the support and acceptance of family or teachers or employers. Technologies cost money. They break. They disappoint. They are abandoned. In fact, for every successfully adopted technology, it is now recognized that there are many in disrepair, in closets, symbolizing disappointment and failure.

One thing became certain, assistive technology was to be understood and explored in

terms of individuals with disabilities and their families, as they lived and functioned within the daily contexts of their lives. Assistive technologies are not “things.” They represent a process of partnership, risk taking, becoming and empowerment (Alliance et al., 2002).

Halona Farden, a wheelchair user, who was to become a role model for many of us, closed his front door by tying a dog leash to the knob, so as he passed over the threshold he could grab and pull. “Assistive technology is creativity,” Halona explained. We began working from that premise.

Broken Promises

Within several months of my arrival in Hawai‘i, I had acquired wonderful films from the U.S. mainland, depicting all manner of persons utilizing technologies for joy and independence – blind children riding tandem bikes with sighted partners, paraplegic skiers using sit-skis, and youth with cerebral palsy using electronic talkers for communication and switches to control toys and the environment. Many of these films were being produced and shared by the *Tech Act* projects across the United States, as part of a growing realization that people needed to visualize possibilities.

“Seeing is believing,” I thought, as I stowed a 30-pound video projector as carry-on baggage with Aloha Air. I also equipped myself with a few devices of my own, including an Alpha Talker, an Intellikeys Keyboard, and a laptop computer with voice synthesis and picture symbols (*Board-Maker*, *Intellitalk* and *Speaking Dynamically*). Aloha Airlines gave me a waiver to exceed their carry-on limit, agreeing with me that my bags were too breakable for check-in and my mission too important to abort. I flew with them weekly, appreciating their aloha spirit.

One evening I gave a talk to a parent group in Kona, on the Big Island of Hawai‘i. Although I had no first-hand experience with augmenta-

tive communication, I had acquired a film produced by the American Speech and Hearing Association, depicting kids in the most awesome wheelchairs imaginable (little fork-lift trucks) - communicating, even singing, through their electronic talkers. After presenting the movie, I demonstrated how to record voices on my Alpha Talker, passing the device around for the parents to touch.

Several parents began to speak tearfully about the lack of services on their island for their children – tears were mixed with outrage. I stood alone in front of 25 “consumers” feeling powerless and hurt. We were not celebrating technology. We were expressing broken promises and pain.

One mother invited me to return to Kona the following week to spend a school day with Allen, her son with Down syndrome who did not speak. She wondered if I might spend a day with him, observing how things were going at school, to see if I thought an augmentative communication device might be helpful. Ignorant of what I might be getting into, I agreed. The family would host me at their home. They would make all arrangements with the school administration. All I had to do was arrive at the airport. It seemed easy enough. (Perhaps this is what the *Tech Act* meant by being *consumer responsive*).

A week later, on a Monday morning, I arrived at the school promptly at the start of the school day, parking my rental car close to a building marked “office.” My intent was to spend the day observing Allen’s communication strategies and opportunities, to make positive suggestions to the family and his teachers. This intention was not to be realized.

I was greeted in the parking lot by a grim-faced school principal who gestured me into his office. “I know why you are here,” he intoned in a cold voice after I was seated. “You are here to cost me band uniforms and athletic equipment.

Technology costs money and you are here to sell technology.” I was frightened.

It proved to be a long and fruitless day, marred by cold receptions and hurt feelings. That evening on my plane ride home I realized that “leveling the playing field” would not be as simple as showing movies and demonstrating devices. I needed a team and a voice that was stronger than my own – a circle of support, perhaps, anchored in persons with disabilities who could join me in the story telling.

“Perhaps we could do video vignettes,” I wondered aloud, “Profiles of people. Nothing to embarrass – local folks, talking story” (to use the local vernacular). I closed my eyes and rested my head against the cold window, listening to the jet engine hum from the wing just outside in the darkness. We’d be touching down on O’ahu soon. I’d make it home, video projector and all, by bedtime. Exhausted.

The Touchdown

Hawai’i’s *Tech Act* project had a 12-member advisory board, with a majority of the membership representing persons with disabilities (as mandated by the law). The board had been formed several months before my arrival, so I was the new kid on the block – a project director still in his “honeymoon” period.

It was at our October meeting (I had arrived in July) that I made my proposal that we produce video vignettes of local people utilizing assistive technologies.

“I will use my camcorder to do the recording, and I can do all the editing myself. We will share the videos on televised forums, in which the person with a disability and his or her ‘circle of support’ (family, professionals and friends) talk about it and discuss its implications with the community.” My proposal was met with considerable doubt among the board members. Some feared that the production costs would be high. Others suggested that “local people”

would either be too shy to be video taped, or so critical of the “system” as to be embarrassing. Dr. Richard Radtke, a professor of marine biology with quadriplegia, quietly interrupted the negativity getting everyone’s attention by inviting me to meet him at the University of Hawai’i pool the following day to film him swimming. I accepted the invitation without hesitation. The board meeting adjourned moments later, with the understanding that we would meet again two weeks hence to revisit the topic.

The next day, promptly at 2:00, I was standing waist deep in the U.H. Olympic swimming pool, with my VHS camcorder on my shoulder, filming Richard, his attendant, his wife Judith and his son David, as they laughed and played in blue water. As Richard floated, his attendant systematically rotated, first, Richard’s head, back and forth, then his arms, one at a time, around and around, and then each leg through what Richard called “range-of-motion” exercises. All the while, 8-year-old David laughed and splashed and played with Judith. Although totally paralyzed from below his neck, Dr. Radtke floated weightlessly. My camera lingered on every movement, including the hydraulic lift that lowered and raised this huge man into and out of the water and the wheelchair van that carried the family home.

That night I “edited” my video tape from camera to VCR. I didn’t know how to create titles. I didn’t know how to record narration or add music. All I knew was how to selectively dub the “good stuff” onto a new tape by pausing and un-pausing the VCR as my camera played. What I knew was enough. The story would more than compensate for my technical ineptitude.

The advisory board met soon thereafter, as agreed. Dr. Radtke was in attendance, as was his wife. We started the meeting by playing the video on a large television monitor, pausing it every minute or so to talk, reflect and enjoy. The blue colors of the water were vibrant. The hydrau-

lic lift was awesome to behold. Laughter and joy filled the meeting room. Richard was dried and dressed. He was secured in his van, and the family departed, with Judith at the wheel.

When the tape was done, we talked about accessible transportation, access to recreation, the importance of attendant care, and the value of aquatics in people's lives, and Richard's near single-handed struggle to persuade the U.H. athletic department to install the lift.

Everyone on the board was animated. We all "got it." We could tell local stories, and we didn't need to embarrass anyone. Video vignettes could serve as spring boards for learning and sharing. It did not have to break our budget. It was so "local" – to watch and talk story!

The swimming pool episode marked the first of hundreds of video "pieces" that we have produced, all sharing snippets of people's lives, proudly and sometimes shyly sharing one tool or invention or adaptation or accommodation (Skouge & Ratliffe, 2003; Skouge, Ratliffe, Callan, & Roberts, 2001; Skouge, Ratliffe, & Uesugi, 1994 - 1998). It marked the beginning of several hundred hours of programming for Hawai'i community television. We had stumbled onto a formula that worked. We scuba dived and sky dived and mouth painted. We cruised parks in powered wheelchairs, accessed beaches in balloon-tired beach chairs, sang songs and ordered "local food" using augmentative communication devices. We cooked with blind chefs, danced with the Deaf community, and explored myriad ways to access toys and computers, appliances and musical instruments. It was within this "crucible of story telling" that we learned that people want to speak for themselves, sharing their stories of life in the community.

Dare to Dream: Extending Digital Storytelling to Consumer Problem-Solving

By the end of our first two years our circle had grown to include perhaps 100 persons with disabilities and their families, in partnership with physical and occupational therapists, rehabilitation engineers, speech therapists, special educators, social workers, volunteer videographers, and a host of creative, handy people (many of whom were retired engineers). We had gotten the message that *assistive technology* required a circle of friends, engaged in creative problem solving. Assistive technology was creativity. It was human beings reinventing themselves and their world (Alliance et al., 2002; Skouge, 1997).

It was at this point that we began working with the *Hawai'i Centers for Independent Living*, developing an assistive technology self-assessment tool entitled *Dare to Dream*. The project extended our video techniques to individual consumers and their families engaging in assistive technology problem solving, focusing on 5 steps:

I WALK WITH OTHERS

- meeting role models on video

I CELEBRATE MY LIFE (profiling assets, strengths and resources)

- video mapping the people, contexts, activities and routines of daily life

I ENVISION MY FUTURE (clarifying values, hopes and dreams)

- video self-modeling: visualizing one's own participation and inclusion

I CREATE A PLAN

- identifying needs and challenges
- identifying partners

- identifying assistive technologies

I GIVE BACK TO COMMUNITY

(acquiring a public voice; becoming an agent for social change)

- sharing my story in multimedia

The *Dare to Dream* self-assessment tool was developed in partnership with more than 50 families in Hawai'i, living on Kaua'i, O'ahu, Maui, Lana'i and the Big Island. It extended and systematized many of the visual and "talk story" components that played well on our television programming. This time, however, the purpose was not for dissemination on community television, but to empower people within their personal and local communities to own the process of self-determination (Skouge, 1997). In the following sections, I describe some of the techniques we employed.

Video Collages: Visions and Dreams

This activity is most often conducted in small groups, either with focus groups of people with disabilities or with circles of support. Team members are provided poster paper, marking pens, scissors, tape or glue, and a stack of magazines rich in illustrations. The first step, quite simply, is to produce a collage of hand drawn pictures and magazine clip art illustrating an agreed upon theme from the person's life.

Themes are positive in tone, focusing on hopes, dreams and visions for the future as related to independent living, mobility, communication, education, recreation, employment, friendship, community service, lifelong learning or the like. The collage is to contain a title and a tapestry of pictures and text captions. It takes perhaps an hour to complete the activity.

The second step is the presentation of the poster to a video camera. Typically, one or two team members hold the poster by its edges as a designated speaker stands or sits to one side, pointing in turn to each of the collage elements,

while describing, reading and elaborating. As the speaker points and talks, the designated camera operator records each of the picture elements in close-up.

The resulting video product consists of a narrated, thematic "slide show" with each of the picture elements magnified to the size of the screen. Both the paper poster and the video recording become gifts to the person about whom the hopes and dreams are expressed. As possible and appropriate, the person with a disability is the speaker.

As simple as this activity may be, it can be powerfully moving, perhaps especially for adults for whom picture making is an activity long-forgotten from childhood. Many people have stopped dreaming about their futures, choosing instead to live in the present "state of stuck."

Recorded Interviews: Profiles of Accomplishment

An important component of our *assistive technology* problem solving consists of structured interviews. These interviews are often conducted "one-on-one" in the family home (living room, kitchen, patio). The interviews are "formal" in the sense they follow a protocol of questions, encouraging open-ended dialogue. Interviews are typically one hour in duration. They are audio recorded. Interviews are "strengths based" rather than "problem based." The goal is to "profile" the individual in terms of his or her unique history, beauty, strengths and to do so in their own words and voice. For people who cannot speak for themselves, we convene a "circle of support" to facilitate communication.

The interview focuses upon values, strengths, interests, likes, aptitudes, skills, gifts, hopes and dreams. The theme of the interview has *absolutely nothing to do with disability*, but with sharing a great day. Preparing a meal with friends. Describing beauty in nature. Giving a gift.

Overcoming an obstacle. Feeling pride. Helping someone. Something to love.

We focus the conversation onto *details or events* that can be *visualized*. “Describe helping someone?” “Describe a meal you would prepare to make a party for friends?” We listen and show genuine interest. This is not a “counseling” interview; nor is it an effort to gain a client “history” which professionals might be expected to write in case studies or reports. Rather, it is a process of breaking the pattern of focusing on deficits, helplessness, dependence, loss and disability, which so often become the focus of professional-client relationships. It is an effort to “break through the wall” – to dare to imagine and dream. When the interview concludes, we leave the recording with the client that she might reflect on her own words (Skouge, 1997).

Video Walkabouts: Mapping, Photographing and “Talking Story”

We produce visual maps of daily routines and activities, beginning with getting up in the morning, preparing for the day, leaving the house, experiencing school or work, recreating in community, and life at home (including chores, meals and leisure). It is easy for people to talk about routines. Routines present a structure for conversation. We listen. We ask questions. We try our very best to visualize the details of the routines of the day.

As we “map” we are attentive to physical and social contexts or “environments.” These, too, are easy for people to visualize and talk about: at home it is the kitchen, the living room, the bedroom, the bathroom, the yard; at school it may be the bus, the playground, activities in the classroom, lunchroom, recess, and so forth.

Typically, we conduct a “walk through,” visiting each of the contexts with the family, seeking to get a first-hand visual orientation. After this *walk through*, we take a digital camera and retrace the steps, taking pictures of elements of

each scene. We take pictures of details representing both “successes” and “challenges” – the ramp neighbors built out of good will; pliers that have become indispensable in the kitchen to open bottles; stairs in need of a railing; the fire extinguisher out of reach to the wheelchair use; the telephone too difficult to dial. These *little things* bear further scrutiny.

On yet a subsequent visit, we display the pictures either on a computer screen or living room television, encouraging the family to celebrate accomplishments and think about needed accommodations. We always ask the family for permission to show the pictures of their successes and “lessons learned” with others. They almost always agree (Skouge, 1997; Skouge, Ratliffe, & Guinan, 2001).

Showing and Telling: Video “How To’s”

During our initial years when we produced materials for community television, we learned people enjoyed showing, telling and demonstrating their skills, accomplishments and handiwork. We are all teachers at heart. It does not really matter whether we are 5 years old or 80 years young, there are things that give us great pride in showing and telling. Over the years we have produced many hundreds of simple “show and tells,” usually keeping them to 5-7 minutes in duration.

For example, Jamie is a medically fragile youth who receives his education at home. He teaches us how to use a favorite piece of software. Michael is quadriplegic from muscular dystrophy. He shows us how to grow herbs in the raised garden beds in his backyard. Artis is blind. She invites us into her kitchen to make spaghetti and salad. A family of a child with severe physical disabilities takes us swimming with the boogie board they’ve adapted for their son. A father shows us how to adapt a battery toy with switches.

Our video techniques are simple. We shoot with one video camera “up close and personal.” We do not use a microphone, nor any special lighting. Sometimes we shoot *over the shoulder* to get close-up shots of people working with their hands. We ask people to talk about what they are doing, as they are able. In recent years, with more technological sophistication, we pour the video onto our computers, add a title, credits and background music and “burn” to DVD (Skouge, 2004; Skouge & Boisvert, 2004).

Many videos are shown only to the family of the person with a disability. Sometimes, however, we incorporate them into our teaching at the university or share them at conferences and meetings. They function to give people with disabilities a voice; and to put us as professionals into a partnership. We always ask if we might share the videos with outsiders, and the families almost always say “yes.” These videos, by the way, are enthusiastically received within the disability community. People are proud to serve as role models for others; and eager to learn from one another’s experiences. This may especially be true here in Hawai‘i, where people in the local community know one another.

Occasionally our videos are shown in client-centered planning meetings. They provide clients the opportunity to show and say “first hand” what they can do. It is one thing to report to a committee that an individual can take the bus and work at a grocery. It is quite another to produce a music video depicting the same. Pictures are worth a thousand words.

Considerations for Professionals-in-Training

Assistive Technology is not a linear process of assessing and locating devices and services. It is instead a process of engagement and encounter. It is recognizing that human beings are both “social animals” and “tool users.” We engage the world through extensions of ourselves as we live and thrive in community. We are programmed

to be included in the construction of our world. Nothing less works.

As professionals we are in a position to value these tools and apply them in our work. This requires commitment, however, since media and multimedia are still mostly seen as the tools of “others,” rather than ours. We are taught to maintain “professional distance” from clients, to write reports and present case studies.

The values and tools described in this article lend themselves to new possibilities, in which professionals engage in partnerships with persons with disabilities and families to create and share stories of discovery, experience and becoming. This represents a shift in thinking: Our mission becomes one of supporting persons with disabilities to find their own voices.

None of us can accomplish this alone. It requires vision, re-training, equipment and commitment. Old paradigms of “teacher-student” or “counselor-client” relations must give in to notions of role transcendence, shared ownership, collaboration and teamwork.

Imagine our *tool kits* to include cameras, voice recorders and multimedia computers. Imagine “stories” rather than “case studies,” and our partners to include the very people about whom the stories tell.

Creating Virtual Communities: Creative Possibilities and Significant Risks

Technology means “change.” Nothing stays the same. Opportunities widen. The digital revolution provides increasing opportunities for community building and sharing, transcending the obstacles of “time and place.” Digital information can now be disseminated almost instantaneously wherever the high speed Internet is in place, including text, picture, sound, movie and “real time” imaging. The opportunities to interface people in creative dialogue are limited only by our imaginations.

With this opportunity, however, comes our responsibility to council and protect the privacy and confidentiality of the people with whom we partner. For those of us who work for “professional” agencies, it is likely that procedures and legal protections are in place, requiring “informed consent” from people to permit information sharing. These legal protections are important, but *they may not be sufficient*.

The implications of the digital revolution are new and largely unimagined by us all. For example, the power to broadcast video information over the Internet that is recorded in our living rooms calls for serious consideration. We say and do things differently in the privacy of our homes than in public arenas (even when cameras are recording), little realizing that an audience of “strangers” may see us completely out of context. As professionals, it is essential that we develop and practice techniques to fully inform consumers of the possibilities, the risks and realities of such digital communications, including safeguards to review, delete and edit digital information before dissemination.

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Reviews

Title: *Crip Theory: Cultural Signs of Queerness and Disability*

Author: Robert McRuer

Publisher: New York University Press, 2006

Cloth, ISBN: 081475712X, 299 pages

Paper, ISBN: 0814757138

Cost: Cloth \$70.00 USD, Paper \$22.00 USD

Reviewer: Carrie Griffin Basas, J.D.

Robert McRuer's latest contribution to the fields of disability and queer studies is *Crip Theory: Cultural Signs of Queerness and Disability*. In this series of related essays, he allies disability and queer theory by situating them in relation to the dominant paradigms of "heteronormativity" and "compulsory able-bodiedness." Normativity's obsession with bodies that sense, move or experience pleasure differently manifests itself in the perpetual pursuit of fixing queer and disabled bodies.

"Homosexuality and disability clearly share a pathologized past," opens McRuer. (p. 1) Contemporary American culture is a place where able-bodiedness and heterosexuality "masquerade as a non-identity, as the natural order of things" (p. 1). Economic and socio-political changes have slowly transformed ideas about the visibility and invisibility of queer and disabled individuals. McRuer is concerned with how oppression is produced within the mainstream, and uses the lenses of able-bodiedness and heterosexuality to show the ways in which "normal" is but a construct of its own.

Through disability and queer theories, new identities, bodies and positions can be invented or challenged. McRuer links these emerging bodies of theory and practice with feminist, cultural, minority and film studies. In doing so, he demonstrates the place that queer and disability studies can have at the center of scholarly and

cultural inquiries, disturbing notions of what is mainstream or desirable.

McRuer is not only concerned with how disability and queer theories inform other fields, but also how they sharpen and expand one another. Discourses about rehabilitation, pathology and “coming out” mark both areas of study. The demands placed upon people with queer or crip bodies are to become docile, in a Foucauldian sense (pp. 20, 22). To submit to “rehabilitative logics” is to allow “normal” others to “govern, in complex ways, who we can be” (p. 116).

Disturbing normative values is McRuer’s central pursuit. He sees queer and disability studies as capable of subverting the powers of composure and control. A refrain of the disability rights movement is that eventually, everyone will experience disability. McRuer encourages that insight, but suggests, “If we live long enough, we will all become normates” (p. 198). He urges scholars and activists of disability and queer studies to participate in crafting their futures and evaluating their histories.

Crip Theory is insightful and compelling. At times, the chapters seem meandering and dense, but McRuer brings the reader back to his thematic arguments and always delights. Interestingly enough, his chapter on college composition classes being hijacked by a “corporate model of efficiency” supports a less orderly, structured approach, in the name of disability and queerness (p. 148). Each chapter can be read alone, but is more satisfying in the collective. Scholars and students of humanities, social sciences and other disciplines will find a chapter or two that resonates with them, if not the entire book.

Carrie Griffin Basas is an attorney, nonprofit consultant and educator. She received her J.D. degree from Harvard Law School and her B.A. with honors from Swarthmore College. She received the Paul Hearne Award in disability rights leadership from the American Association of People with Disabilities. She is an adjunct

professor in the MBA Program, Saint Joseph’s College of Maine.

Title: *Bodies in Commotion: Disability and Performance*

Editors: Carrie Sandahl and Philip Auslander

Publisher: University of Michigan Press, 2005

Cloth, ISBN: 0-472-09891, 352 pp.

Paper, ISBN: 0-472-06891-1

Cost: Cloth \$75.00 USD, Paper \$26.95 USD

Reviewer: Carrie Griffin Basas, J.D.

Carrie Sandahl and Philip Auslander’s collection, *Bodies in Commotion: Disability and Performance*, moves forward to fill a space between disability and performance studies. Disability causes a commotion in public realms. Its presence is often considered “out of the ordinary, separate from the everyday, a cause for pause and consideration” (p. 2). As the editors note, “commotion” can mean more than disruption or disturbance; it can also mean moving together.

Highlighting five major themes within performance and disability studies—taxonomy; disability/deaf aesthetics, audiences and the public sphere; rehabilitating the medical model; performing disability in daily life; and reading disability in dramatic literature, this collection moves the reader through terrains that are varied and interesting, foreign and familiar. This book is not just for theatre, literature or performance scholars, just as it is not only for disability studies scholars. With contributing authors such as Brenda Jo Brueggeman, Owen Smith and Marcy Epstein, *Bodies in Commotion* finds ways of sparking the imagination of newcomers to either field, as well as accomplished theorists in both.

The contributors to *Bodies* explore how disability is performed, knowingly and intentionally, such as on stage or in a film. However, they go beyond carefully constructed embodiments

of disability to examine ways in which people with disabilities are pushed to public center stage in even the most mundane of encounters—such as riding the bus or attending class. It is on this ubiquitous stage that disability becomes more accessibly performative—available for all to behold or deconstruct. “Performance studies and disability studies have been . . . revising what it means to have a body and what it means to be alive” (p. 325). The fields bring together lived experience, subjectivity, and an “ethics of embodiment” (*Ibid.*) to ask such questions as: How should disability be performed? What is the role of one’s personal experience of disability in an acting role that calls for “neutrality,” or a lack of disability? Can students learn from intentional performances, even when they are not aware that they are an audience, such as in the case of invisible theatre? To each of these questions, the answers presented are critical and nuanced.

People with disabilities occupy an interesting space—as the objects of stares, yet not at the centers of most images about daily life. David Mitchell and Sharon Snyder have described this phenomenon as the “double bind of fascination/repulsion with physical difference” (p. 303). The essays in *Bodies* analyze the stereotypes and scripts that limit people with disabilities, while at the same time, try to expand cultural images and metaphors. In many of the cases described in the book, such as in the technology-rich choreography of Cathy Weiss or the dynamic storytelling of Time Slips, “alternative subjectivities” are proposed, “ones that do not attempt to be understood as the equivalent of able-bodied norms, but instead pose a challenge—to expand our cultural understandings of the body” (p. 102). Furthermore, in discussions of people’s theatre, cyborgs, and Australian men’s wheelchair sports, the contributors discuss alternative platforms for embodying self and disability.

Bodies in Commotion creates new spaces for the performance of identity, disability and community, while at the same time, highlights how simple acts of daily living can be performances

in themselves. This volume is an exciting collaboration between disciplines. Future areas of inquiry might include the performance of non-disabled roles amidst groups or communities of people with disabilities, and the performance of disability by “pretenders” and “wannabes.”

Title: *Human Oddities: Stories*

Author: Noria Jablonski

Publisher: Shoemaker and Hoard, 2005

ISBN: 1-59376-084-1

ISBN: 978-1-59376-084-7

Cost: Paper \$15.00 USD

Reviewer: Steven E. Brown

As the title says, this is an odd short story collection. I imagine people unfamiliar with the world of disability might find these stories fascinating. They include characters ranging from separated Siamese twins to an alcoholic drag queen to an obese, apparently cognitively disabled man. On the other hand, I found these tales disturbing: relentless stories of alienation, pain, disillusion, and life’s losers.

The book is divided into two sections. The first is a series of three stories all of which are connected through one character who has experienced disasters ranging from bursting a stomach staple from laughing too hard to losing (literally) a sibling because she was confused by an adult’s appearance.

The second, and longer, section has six stories. Some of these stories are lengthier, some characters find a measure of redemption, and the alienation is not all related to disability issues. One of the happier stories in the book is also the shortest one and has as its protagonist a wheelchair user. This particular character may be the most “normal” one in the book.

Jablonski’s writing is skilled, but for my taste too focused on life’s tragedies. I like complex

fiction, but my own thinking is that complexity would include both pessimism and optimism, not just the glass-half-full outlook that dominates most of these stories.

Title: *The Disability Pendulum: The First Decade of the Americans with Disabilities Act*

Author: Ruth Colker

Publisher: New York University Press, 2005

ISBN: 0814716458, 280 pages

Cost: \$45.00 USD

Reviewer: Katharina Heyer

Fifteen years ago a bipartisan Congress passed the Americans with Disabilities Act (ADA), the nation's premier law affecting the lives of millions of Americans with disabilities. The ADA firmly lodges disability into a civil rights paradigm and offers comprehensive protection against a wide variety of disability-based discrimination. It is only fitting that one of the nation's premier scholars of the ADA, law professor Ruth Colker, has now written a comprehensive – and accessible – analysis of the statute.

Colker reminds us of the high hopes fueling the passage of the law: "as a package, the ADA contains marvelous language. It provides comprehensive protection from the moment one is born or becomes a person with a disability and might need access to public services to the time when one might enter the workforce or seek to use a forum for public entertainment" (p. 21). During the first decade of the ADA's treatment in the courts, however, these high hopes have given way to what many observers have termed a backlash. Colker was one of the first to document the ways that the ADA has been interpreted narrowly in the courts, resulting in overwhelmingly pro-defendant outcomes, primarily in employment discrimination cases. In *The Disability Pendulum*, Colker expands her empirical study to the ADA's three main titles: employ-

ment, public services, and privately owned public accommodations. She carefully explains the reasons for the judicial hostility towards enforcing the Act and offers insightful and practical suggestions on how and where to amend the Act to ensure that the true Congressional intent is reflected in the ADA's enforcement.

This book will find a wide readership in graduate and undergraduate courses that examine disability as a legal, political, or social issue. It carefully illustrates the landmark cases litigated under each of the three titles, allowing readers not trained in disability law to understand both the legal principles as well as the powerful personal stories at work in these cases. Colker then expands her analysis to larger constitutional issues regarding the relationship of an increasingly conservative Supreme Court, Congress, and the States. Finally, Colker offers the first comprehensive legislative history of the ADA's enactment, illustrating how, among others, homophobia and powerful business interests led to a "fragile compromise."

In the end, the image of a backlash is simplistic. The ADA continues to have a "transformative effect on American life," (p. 21) and as such has served as a model of disability rights legislation for the rest of the world. While the first decade of the ADA's enforcement may have been disappointing, Colker's book tells the story of a "swinging pendulum" (p. xiv) in which broad pro-defendant decisions are followed by occasional, albeit much narrower, victories for plaintiffs. It is now time for the pendulum to swing back to the center.

Katharina Heyer is Assistant Professor of Political Science, Law, and Disability Studies, University of Hawai'i.

Title: *Handbook of Inclusive Education for Educators, Administrators, and Planners: Within Walls, Without Boundaries*

Editors: Madhumita Puri and George Abraham

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Reviewer: Christine Su

The *Handbook of Inclusive Education for Educators, Administrators, and Planners: Within Walls, Without Boundaries*, is a noteworthy addition to the growing library of materials on inclusion of persons with disabilities in the educational process. While the *Handbook's* target audience is educators and administrators in India, most of the discussions and recommendations are general enough to appeal to an international readership. Its contributors include special educators, psychologists, attorneys, and governmental officials, all of whom are involved with disability and education in one way or another.

Divided into three large units, the *Handbook* begins with a brief description of the Universal Declaration of Human Rights adopted by the United Nations General Assembly in 1948, and the Declaration on the Rights of Disabled Persons, adopted in 1975. Above all, the authors assert, education is a human rights issue, and persons with disabilities should not be excluded from universal human rights initiatives, regardless of nationality or state residence. Thus, from the beginning of the text, the global significance of education for persons with disabilities, and in particular, inclusive education of persons with disabilities, is emphasized. The authors do discuss national programs, such as the provisions of specific sections of India's Persons with Disabilities Act (1995), but this adds to rather than detracts from the readers' connection to the authors, as many of the struggles and successes within India are likely similar to those in the

readers' home countries, and make for interesting comparisons.

The second unit of the *Handbook*, "Innovations in Implementation," is the most useful part of the work. This section describes in detail approaches to inclusive education for persons with hearing impairment, vision impairment, orthopedic impairment, learning disabilities, cerebral palsy, intellectual impairment, and autism. Each of these is addressed separately, beginning with discussions of what inclusion means for children with each type of disability in school settings. For children with hearing impairment, for example, inclusion means that "children must have full and uninhibited language and communication access to all facets of the program and personnel" (p. 49). The authors offer suggestions for instruction, classroom support, coping with conflict, assignments, and other classroom elements, as well as suggestions for administrators in addressing parental concerns, handling peer issues, and so forth, at both individual and systematic levels.

Each chapter provides guidelines for optimum learning environments, including both the physical environment (e.g., managing reverberation for hearing impaired students, or installing warning blocks in front of entrances, staircases, sinks, etc. for students with vision impairment) and the social environment (e.g., ensuring that teachers do not assume that persons with disabilities are necessarily incapable of making decisions about their learning needs, or teaching other students about a student with a hearing impairment's different concept of personal space). Interspersed throughout each chapter are vignettes detailing tangible methods that have helped actual students with disabilities to thrive in their classrooms. While some of these methods are culturally-connected—such as the use of yoga *asanas* (postures) to help a student with attention deficit hyperactivity disorder and other cognitive impairments—they are certainly not confined to persons who live in that culture. Many are broadly, if not universally, applicable.

The *Handbook* is best suited for teachers and other educators who work with students with disabilities. Some of the chapters in this section end with a series of fact sheets, which encapsulate indicators/characteristics of the impairment and strategies for teaching students with various disabilities. These fact sheets could easily be used as handouts for training sessions.

The third and final unit, “The Way Forward,” returns to suggestions for modifications and amendments in law and policy to facilitate inclusive education. While the target audience here is policymakers in India, the suggestions are general enough for an international readership. Included in the appendices are a glossary of terms, and a series of frequently asked questions, which could serve as an excellent resource for discussion groups. (One example from this section is as follows: “Are advocates of inclusion primarily concerned with socialization? Are academics being sacrificed?” (p. 259). The subsequent discussion emphasizes the interconnectedness of social, emotional, and academic development). Finally, the unit concludes with a model of a “real school,” a school where “LEARNING is for ALL” (p. 252). The model reiterates that inclusive schooling should be viewed as a continuous process that involves extensive planning, goal-setting, implementation of ideas, and program review by a team which includes policymakers, administrators, educators, family members, social workers, and others.

The *Handbook* is a worthwhile read for all who have an interest in inclusive education. While somewhat expensive, it is full of excellent suggestions, and moreover, many of the concepts pertaining to students with disabilities are also relevant for students of color and other students who have been marginalized in the education process. The editors note that “special schools continue to have a definite role and responsibility in the inclusive scheme,” but stress that inclusivity in the mainstream education system is a “logical step forward in the evolution of education of persons with disability” (p. 246). The

inclusive process can be summed up by the final sentence of the text: “It is only fair!” (p. 254).

Christine Su, Ph.D., is an independent researcher living in Honolulu. Her research interests include physical and mental disability in post-conflict societies, particularly in Southeast Asia.

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