

Table of Contents

Legacies: Burning Books A-Foot in Heaven?	p. 3
Steven E. Brown, University of Hawai'i, USA	
Research Articles	
Social Entrepreneurs and NGOs for People with Mental Disabilities in Post-Communist Europe: Implications for International Policy	p. 7
Daniel Holland, The Neurobehavior Center of Minnesota, USA	
Vive la Révolution	p. 25
Essya M. Nabbali, Simon Fraser University, Vancouver, Canada	
From Dialogue to Bakhtin's Dialogue: A Critical Review in Learning Disability Research	p. 31
Waseem Mazher, Columbia University, New York, USA	
Jong-Gu Kang, Daegu University, South Korea	
The Uses and Implications of the Term "Retarded" on YouTube	p. 47
Brandy Johanson-Sebera & Julia Wilkins, St. Cloud State University, Minnesota, USA	
Book and Media Reviews	
Doctors of Deception: What They Don't Want You to Know about Shock Treatment	p. 62
Reviewed by Laura K. Corlew	
Disability and Diversity: A Sociological Approach	p. 63
Reviewed by Marjorie McGee	

Disability Studies Dissertation Abstracts **p. 65**

RDS Information **p. 69**

RDS Subscription Form **p. 71**

Legacies: Burning Books A-Foot in Heaven?

**By Steven E. Brown, Ph.D.
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In the early 1990s, on a panel at a Society for Disability Studies annual meeting and trying to model in some way the AIDS quilt, I shared a few names and a couple of stories of friends who had passed on. Afterwards, people shared some of their own names and stories. That led to the writing of “Martyrs,” a poem that begins:

The following have drawn their last breath,
They’ve been courted by death
Many gave their lives to the cause
Their passing should give us pause
Many gave all their hearts had to give
So the rest of us might live (Brown, lines 1-7)

Interspersed between stanzas are names. In 2010, too many names have been added to this poem, which now lists more than 100 people. Others continue to send names and some of these, along with “Martyrs” can be found at www.instituteondisabilityculture.org.

The *Review of Disability Studies (RDS)* began amidst life passages when Founding Editor, David Pfeiffer, passed on suddenly prior to publication of the journal’s first issue. In Volume III, Issue 4, we published an “In Memoriam” to RDS Distinguished Fellows Frank Bowe and Rolf Bergfors. In the current issue, we pay tribute to one of the giants of disability studies and acknowledge others who have impacted disability studies, Disability Culture, and our lives.

One morning in early August 2010, I received an email asking if I had heard about Paul Longmore’s passing. I had not and I had difficulty accepting the news without confirmation. Beginning a web search I could find no indication of Paul’s death. But when signing onto Facebook I read rumors, which Paul’s sister later confirmed. Paul had passed on the previous night.

Paul left a lasting legacy, including understanding and writing about how disability issues affected history (*The New Disability History*) and how he, as a scholar-activist, also impacted history (*Why I Burned My Book*). Not long before his death, Paul learned, and enthusiastically shared, the news that he had been awarded a prestigious Switzer Fellowship to write an American history college textbook about disability.

Like many of us in our 50s and 60s (he was 64 at the time of his passing), he came to disability rights activities because of discrimination. These activities led him to disability studies. A scholar of American history, Paul’s book on George Washington—the book he burned in a successful protest against the Social Security Administration’s recording royalties as income which threatened his benefits—remains highly regarded.

At the time of his passing, Paul was Director of San Francisco State University’s Institute on Disability as well as a professor of American history. Losing a friend is always difficult; losing a friend and colleague who is also a giant in his field is even harder. At one of Paul’s final public appearances—a

Disability Pride event celebrating the 20th anniversary of the signing of the Americans with Disabilities Act in San Jose, California, in July 2010—Paul said:

“Great leaders do not create great movements. Great movements give rise to great leaders.... No movement can exist without in this case millions of ordinary men and women asserting themselves to demand dignity and their rights. So that’s what our movement is all about. That’s our past. That’s our present. That’s our future” (Feingold, 2010).

Paul will be missed, but his was not the only huge loss of 2010. Cartoonist, humorist, musician, and writer John Callahan also moved on during this year. Author of numerous cartoons depicting disability with an eye toward moving people’s boundaries, Callahan’s autobiography, *Don’t Worry: He Won’t Get Far on Foot* (1990) remains a classic look into the life of becoming disabled and adapting to it. I never met Callahan, but his work impacted my Disability Culture perspectives and I read everything of his I could find. In the early days of presenting about Disability Culture I often passed his cartoons around the room and waited for a myriad of reactions, from laughter to “Oh, that’s gross.” Callahan constantly challenged our assumptions.

Too many others have left the planet this year to describe each in detail, but also missed will be disability rights activist and one of the founders of the oldest, ongoing Disability Pride Parades (in Chicago), Barb Bechdol; playwright and editor, Paul Kahn; writer and artist, Robert Mauro; photographer Tom Lee; musician and elder statesman William Loughborough; and activist Barbara Knowlen.

Two deaths—more personal and local—of this year include Tom Carter, a colleague from El Paso, who directed an independent living center there at the same time I directed one in Norman, Oklahoma and Mitch Stuart in Honolulu. Mitch was a person with a developmental disability who served on some Center on Disability Studies committees. He was also a recruiter for the Self-Advocacy Advisory Council. A perfect job for Mitch, whose booming voice and enthusiasm were hallmarks of his presence.

After writing and submitting this piece, we learned of the passing of another giant of the disability rights movement, Paul Miller, a former *RDS* Distinguished Fellow, who relinquished that title when he went to work in the Obama administration. Paul also worked in the Clinton administration, where he was instrumental in hiring persons with disabilities to work in Washington, D. C. An attorney and an advocate, Paul lived in Seattle, Washington, where he was Henry M. Jackson Professor of Law at the University of Washington and director of its disability studies program.

Each of these individuals in some way bettered others and the cause of disability rights. While they have moved on, we who remain have plenty left to do. “Martyrs” concludes:

These tales we tell have begun
Songs and poems and stories in all their glories
These tales we tell have begun
I don’t believe an ending will ever come. (lines 86-90)

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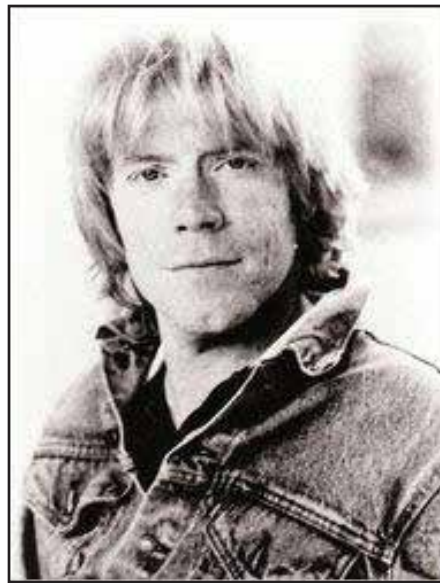
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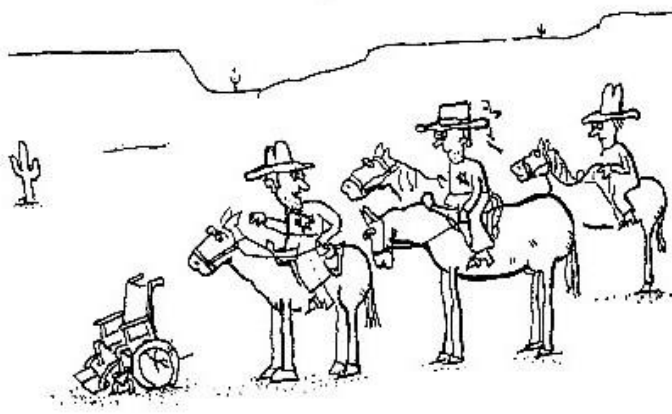
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Callahan ©19
"Don't worry, he won't get far on foot!"

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Social Entrepreneurs and NGOs for People with Mental Disabilities in Post-Communist Europe: Implications for International Policy

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Research Articles

Abstract: Disability activists and disability nongovernmental organization (NGO) leaders in post-communist Central Europe have been among the most instrumental force for promoting disability rights and community-based living initiatives in their formerly communist countries. During an on-going period of massive economic and political transition, these disability activists and NGO leaders managed to take advantage of emerging civil society freedoms and have established innovative models for the promotion of disability issues throughout the post-communist region. Of particular note are those initiatives that have addressed the needs of people with mental disabilities. The use of the term “mental disabilities” in this article refers to a diverse group of people who share the common experience of institutionalization due to perceived differences in emotion, perception, and/or cognition and who have faced longstanding barriers to community living in communist and post-communist Europe. The following article describes the national and historical contexts for people with mental disabilities in the Visegrad Four countries of Central Europe: Slovakia, the Czech Republic, Hungary, and Poland. It then highlights a number of innovative disability NGOs that are promoting human rights and community living for people with mental disabilities in each country. Implications for international collaboration with disability NGOs, and the importance of international disability policies, are discussed.

Key Words: Postcommunist; Disability NGO; Social Entrepreneur; Disability Policy

Editor’s Note: This article was anonymously peer reviewed.

Introduction

The Convention on the Rights of Persons with Disabilities and its Optional Protocol (United Nations, 2006) were adopted by the United Nations General Assembly in December 2006, and opened for signature in March 2007. Disability nongovernmental organizations (NGOs) were critical participants at this UN convention (Secretariat of the African Decade of Persons with Disabilities, 2007), and the final text of the convention emphasizes the importance of NGOs for promoting the involvement of people with disabilities in civic and public life across national contexts (United Nations, 2006). Previous initiatives focusing on international disability issues, such as the United States’ National Council on Disability (NCD) 2003 report, also called for greater attention to disability NGOs and the promotion of new ones as an important element in foreign policy and international development (NCD, 2003). The United States Agency for International Assistance (USAID) has indicated that the support of disability NGOs is consistent with the agency’s goal of strengthening civil society (USAID, 2003). Despite this apparent appreciation for disability NGOs and their role in international policy, however, little has been published about what these NGOs look like across different national and geopolitical contexts, what their priorities are within these contexts, or what makes some of them distinctive. The purpose here is to focus on the relevance of NGOs that are addressing mental disability issues in a specific geopolitical region of the world, post-communist Central Europe. The goal is to bring attention to the history and context within which these disability NGOs are functioning, and then

provide brief profiles of a number of NGOs in each of four countries so that concrete examples can be made apparent. The hope is that such a contribution to the literature will help provide a portrait of the current landscape for NGOs serving people with mental disabilities in this part of the world.

Source of the NGO Profiles

The profiles of disability NGOs offered here were gathered as part of a larger field study on disability issues in post-communist Europe. That larger research effort involved interviews with 17 key informant disability activists and NGO leaders in the Central European region. These key informants were selected according to criterion sampling. Criteria consisted of the following:

- 1) Informants must have been a founder or leader of a disability NGO;
- 2) Informants must have been perceived as a key figure by at least two experts outside their own NGO;
- 3) The NGO that the informant represented must have a presence in the literature, forums, or general discourse in the disability community; and
- 4) The informant had to be native to the Central and Eastern European region (i.e. not American, British, Scandinavian, etc.).

A number of different studies were drawn from the information gained from these key informant interviews with NGO leaders (i.e., Holland, 2008). The profiles provided here reflect a subgroup of the NGOs included in this larger field study. This subgroup was chosen for inclusion here for two reasons: a) they represented a good illustration of a variety of disability NGOs active in the region in terms of mission and priorities and b) they were engaged in some kind

of particularly innovative effort with regards to disability issues.

The Focus on Mental Disabilities

This article focuses specifically on NGOs addressing the needs of people with mental disabilities in the four post-communist Central European countries of Slovakia, Hungary, Czech Republic, and Poland. This focus has been chosen for three reasons: (1) people with mental disabilities in post-communist Central Europe have consistently faced restrictive and entrenched policies of institutionalization (Jenkins et al., 2001), (2) people with mental disabilities are frequently the least well represented group in human rights discussions (Mental Disability Rights International, 1997; Gostin & Gable, 2004) and the least well represented group among disability rights and disability studies initiatives (Scott-Hill, 2002; Chappell, 1998; Parmenter, 2001; Beresford, 2000), and (3) there have been some particularly innovative and successful social entrepreneurial efforts specifically aimed at promoting rights and community-based services for people with mental disabilities in post-communist countries that might now serve as models for replication and scaling-up.

The institutions of post-communist Central Europe tend to house people with psychiatric and intellectual disabilities in many of the same settings (Rosenthal et al., 1997; Tobis, 2001), which therefore, makes a generic term like “mental disability” a useful descriptor for those who have faced similar experiences within the health and social welfare systems of these countries. Furthermore, the initiatives aimed at promoting disability rights and community-based services profiled below are focused on assisting individuals with psychiatric and/or intellectual disabilities, warranting a general term to describe this group of citizens. It is the shared experience of people with “mental disabilities,” and the need for innovative programs to promote services for them that is most relevant here.

A Brief History of the Visegrad Four Partnership

The four post-communist countries that are the focus of this profile constitute what is known as the Visegrad Four. The Visegrad group of Poland, Hungary, and Czechoslovakia was established in 1991 by the respective leaders of the three post-communist nations in order to mutually facilitate their integration into NATO and the European Union. Two years later, in 1993, Czechoslovakia separated into the two independent nations of the Czech and Slovak Republics, resulting in a total of four sovereign nations in the Visegrad partnership. This geopolitical partnership suddenly became known as the “Visegrad Four.” The term “Visegrad” comes from the name of the town in Hungary where this geopolitical agreement was initially made.

Unlike some of their more resistant post-communist neighbors to the East, such as Russia and Belarus, the post-communist Visegrad Four countries have generally been perceived as eager to “rejoin” Western Europe since the dissolution of the Iron Curtain in 1989 (Gerner, 1999). This eagerness has been attributed to the longstanding alliance these countries have felt with regards to Western European democracies (Rupnik, 2002). The Czech writer Milan Kundera, for example, portrayed Central Europe as culturally tied to Western Europe, and historically, an unwilling victim “kidnapped” by the Soviet East (Kundera, 1984). It is also true, however, that other intellectuals, such as the Polish exile and poet, Czeslaw Milosz, cautioned against too sweeping of a characterization of the whole of Central Europe, and suggested that cultural and religious differences between some of the Central European countries had different implications for their respective contributions to a common Europe (Subrt & Dolezal, 2004). This message has been emphasized by other contemporary Central European figures and scholars (i.e. Nodia, 1996; White, 2003) who also warn against a homogenous view of the region—a view that would understate the troubling persis-

tence of regional and ethnic tensions within and among some of the post-communist Central European nations (Karklins, 2000; Vermeersch, 2002; Frankland, 2004). These regional and ethnic differences, however, do not negate the similarity of very general developmental trajectories that are occurring across these four post-communist countries which prove useful when evaluating them according to mental disability issues and the specific grassroots responses to these issues, as is the aim here.

Possibly most relevant when considering disability rights specifically, the Visegrad Four countries were perceived by many of their native intellectuals (i.e., Vaclav Havel in the Czech Republic, Gyorgy Konrad in Hungary, and Adam Michnik in Poland) as sharing value for a civil society (Gerner, 1999) even, or especially, during a time when civil society freedoms were suppressed under communism. The current shortage of civic volunteerism in the post-communist region notwithstanding (Howard, 2003), this anti-authoritarian ideological support for civil society activism united intellectuals and many citizens in these countries along certain democratic values. It is this history of democracy development and activism that does indeed have relevance now for the disability rights movement, as well as for other human rights movements, occurring within these Visegrad Four countries. The history of simmering dissent during the authoritarian period has given rise to a contemporary civil society movement with substantial momentum, if insubstantial resources.

The Persistence of Total Institutions in the Visegrad Four Countries

The institutionalization of people with mental disabilities is obviously not a practice unique to communism, post-communism, or Central Europe. Institutionalization was the dominant reaction to people with mental disabilities in most parts of the Western world from the 19th century until as recently as the 1960s and 1970s

(Fabrega, 1991), when a slow process of change occurred in some regions as the result of a growing, if uneven, emphasis on human and civil rights for people with disabilities. The resultant shift in many Western countries was, in varying degrees, towards community-based rehabilitation and independent living for people with mental disabilities, with a gradual reduction in the numbers of people confined to, what Erving Goffman (1961) famously termed, “total institutions.”¹

But, the de-institutionalization movement experienced in the West did not occur at the same time for communist Europe. There are a number of complex reasons why a particularly massive infrastructure of institutions and asylums was implemented in Central Europe during the communist period, and why this infrastructure persists today in varying forms across the Visegrad Four countries. The most significant reason is that economic progress in the post-communist countries has been given greater priority than social policy in most cases (Sinecka, 2009), resulting in a visible growth in market capitalism that is not matched by evolution in social policies, such as minority rights. Rapid privatization and a diminishing role of the state has resulted in a lack of attention to certain state supported social services that bear little or no potential for private sector financial success (Fajth, 2000; Deacon, 2000). So, while impressive economic and political progress has taken place in the region, many of the transitioning countries of post-communist Europe, including the Visegrad Four countries, currently maintain institutional settings for people with mental disabilities that are unacceptable according to international standards (Human Rights Watch, 1998; Disability Rights Advocates, 2001; Mental Disability Advocacy Centre, 2007). Indeed, Disability Rights Advocates (2001), an NGO based in the U.S. and Hungary, has stated that, “No country in [post-Communist] Central Europe has major institutions for the disabled which can be regarded as fully acceptable under contemporary standards” (p. 6).

The Cultural and Political History of Institutionalization under Communism

The reasons for developing, and then maintaining, the institutional infrastructure for people with mental disabilities in many of the communist countries were politically, economically, and socially motivated. Politically, mental disability presented a bit of a quandary for Stalinist ideology and its derivatives. To the extent that most personal and social “problems,” including mental disability, were presumed rooted in the vicissitudes of capitalism (UNICEF, 1997), the persistence of people with mental disabilities within a communist system presented an awkward challenge to this presumption. Furthermore, the uniform emphasis by the state on clearly circumscribed work roles was problematic for those families who had a child with a disability, since care in the home often compromised availability for participation in collective work settings. Placement of children in institutional care was deemed efficient and humane, if not by the parents and children involved, then by the abstract ideology governing the populace (Iarskia-Smirnova, 1999).

Compounding this political momentum was a general cultural development that infiltrated even the communist bloc. People with mental disabilities were sometimes considered a chronic embarrassment to Victorian era Central European communities, given what was then the emerging theory of “Degeneration,” which posited that people with mental disabilities contributed to social and genetic decay in kin and communities over time, and were a mark of weakness within a family (i.e., Morel, 1857). This theory was later propounded by the eugenics movement in the United States (Black, 2004).

As is well known, the problem of institutionalization was carried to its functional extreme in the Central European countries under the Nazi regime, when thousands of people with

mental disabilities in institutions were eliminated through systematic killing (Haug & Rossler, 1999). The typical Central European citizen may have found the Nazi response to disability grotesque and aberrant, but the well intended state-sponsored responses that eventually followed this pogrom were still misguided, since they continued to emphasize segregation and institutionalization as a means of appropriate care. The result in communist Europe was an entrenched and powerful ideological, sociopolitical, and economic push towards the continued institutionalization of people with mental disabilities, often occurring in early childhood and continuing for life (Tobis, 2001).

Even for children with disabilities, who were not committed to total institutions in communist Central Europe, segregated educational environments were imposed, resulting in another form of invisibility, stigma, and compromised opportunities. As noted in a fact-finding report for UNICEF conducted in 1999 by Mental Disability Rights International (MDRI):

“During [the first half of the 20th century], educational philosophy insisted on a State where as many children as possible could be brought up to standards that were predicated on ‘normal’ development. This tradition still prevails today in Russia and much of Central and Eastern Europe. ... Thus, instead of making schools accessible to children with disabilities, the child is excluded from school until he or she can be ‘corrected.’ In practice, some children will never conform to an inflexible ‘norm’ and will remain in separate, segregated schools her or his entire life” (p. 10).

One must be careful not to confuse popular Western anti-communist propaganda of the period with the complex reality of what was occurring in communist Europe, whether regarding the treatment of people with mental disabilities or otherwise. Nevertheless, it can be suggested that the communist-era emphasis on collective

organization over individualization, and the ideological position that the state could substitute for the family in certain ways (UNICEF, 1997), contributed to the belief in the advantages of institutionalization, both for the family and the individual with a disability. While this belief has since been challenged by disability activists in post-communist Europe, the attendant institutional infrastructure that originally stemmed from this belief has not changed much despite dramatic economic and political transitions in the Visegrad Four countries (Harangozo, Dome, & Kristof, 2005; Brunwasser, 2009). Mental disability and the perceived need for segregation remain conflated in post-communist educational and medical paradigms (MDRI, 1997; Mental Disability Advocacy Centre, 2007). This perceived need for segregation continues to justify the need for total institutions for those individuals assumed to have severe mental disabilities. The inertia of state agencies and institutional bureaucracies also serve to sustain this institutional system (Orlwska, 1991; Siska, 2006; Brunwasser, 2009). The result is a massive number of children and adults who will continue to be confined to institutions, even for long periods of time, if no contemporary interventions to promote de-institutionalization are aggressively pursued. Such interventions will depend on international policy like the UN Convention on the Rights of Persons with Disabilities, domestic legislation such as employment and housing protection, and civil society organizations such as disability NGOs.

The current era is one in which disability has gained tremendous visibility and import as an international human rights issue. International policy like the UN Convention will help to spur domestic legislation “from above,” while grassroots NGO activism will continue to demand progress and offer alternatives “from below.” Unfortunately, reports of what is occurring at this grassroots level are much less plentiful than those detailing the actions of large and powerful international bodies like the UN. What follows, therefore, are examples of some of the

grassroots NGOs that are executing innovative and necessary efforts within the Visegrad countries “from below,” since profiles of efforts being made at this ground level of activism remain few in number, but are indeed sorely needed, if a comprehensive and inclusive portrait of progress in disability issues is to be had.

The Role of Non-Governmental Organizations (NGOs)

NGOs are best conceived of as a subcategory within the elaborate and layered network of relationships and groups termed “civil society.” Civil society can be described, in the broadest sense, as a realm of social and collective interactions that are distinct from both the state and the market (Kaldor, 2003). The concept of civil society has had particular historical significance in Central and Eastern Europe, where it came to represent the pursuit of free association and collective action in the context of authoritarian states (Myant, 2005). Initially, the forms of civil society that were promulgated by Central and Eastern European activists were not NGOs, of course, since such nongovernmental entities were not permitted in most of the communist bloc. However, alternative, informal organizations, many focused on grassroots resistance, existed in a political underground particularly during the twilight years of communism in the Visegrad countries (Havel, 1990; 1991).

From the underground activists led by figures such as Václav Havel, to the Solidarity movement in Poland, self-organized groups led the charge for democratic transition in the Visegrad countries. Since the 1989 dissolution of communism throughout Central and Eastern Europe, self-organized groups in the form of NGOs have continued to be among the most important vehicles for change in Central and Eastern Europe. NGOs specifically addressing disability issues too, have been a crucial form and method of collective action in the post-communist countries, and currently bear a great

deal of significance for disability issues throughout the region.

While attention to the experiences and goals of disability NGOs have been recognized as essential to understanding disability issues across various world regions and national contexts (United Nations, 2003; Jenkins, Klein, & Parker, 2005), few sources exist in the disability studies or disability policy literature that offer specific examples of these disability NGOs or a sense of sociopolitical context within which they must function. The review and profiles offered here aimed to address this void by offering a contextual background and some specific examples of disability NGOs in the Visegrad countries. The intent here is that such information could prove useful to international agencies, funding sources, disability groups, or individual activists in other parts of the world with an interest in supporting or collaborating with disability NGOs in the post-communist region.

NGOs Promoting De-Institutionalization and Independent Living

The role of NGOs in the provision of services and advocacy for people with disabilities has long been crucial in democratic contexts. The rapid growth of such entities in the post-communist countries speaks to the urgent need for such organizations, both in terms of service provision (such as vocational training or special schools) and human rights advocacy. Many of the disability NGOs in the Visegrad countries are accomplishing a great deal with very few resources. It becomes essential then, to make the efforts and goals of these NGOs better known, since an increased visibility and understanding of these efforts is necessary in order to advocate for their sustenance. What follows are brief profiles of some notable disability NGOs in each of the Visegrad countries. These NGOs were selected either because they represent a particularly innovative approach to promoting disability

rights and independent living, or because they are addressing a critical need largely ignored by the agencies of the state. Most of these NGOs do not stand alone in their mission or goals. There are dozens of other examples that could have been selected to accomplish the portrait offered here. The author, however, is most familiar with the particular examples below as a result of doing work in the region. This selection of profiles therefore, serves as a convenient collection of innovative disability NGOs aimed at demonstrating what such organizations are achieving in the post-communist Visegrad countries.

Slovakia

A small group of disability activists and regional government agencies have forged a number of highly innovative efforts to promote de-institutionalization and independent living in Slovakia (Holland, 2003). These efforts have been successful despite daunting resource shortages experienced by most of these NGOs. What follows are specific examples of innovation as pursued by one NGO and one partnership arrangement between a regional government agency and disability NGO, a partnership that has created one of Slovakia's most progressive social care homes. Both examples highlight some of the ongoing efforts at reform in disability policy and services that have succeeded in Slovakia.

The Alliance for People with Disabilities

One of the most innovative disability NGOs in Slovakia has been the Alliance for People with Disabilities (The Alliance), led by Dr. Maria Orgonasova. The Alliance functions as an umbrella organization, serving to bring together approximately 35 local and smaller disability groups scattered throughout the country in order to optimize the groups' common interests by increasing their impact through greater collective size. While a number of umbrella organizations exist in Slovakia, The Alliance has been particularly distinctive in its focus on lobbying for policy and legislative change. Many of the disability NGOs in Slovakia, as in other parts

of post-communist Europe, continue to focus on service provision rather than policy activism. This service provision is imperative, but it often occurs at the neglect of broader social change through evolving disability policy. The Alliance has worked to address this void. Dr. Orgonasova has sought advisory roles to the Slovak Parliament and, most notably, devised a strategy which involved recruiting highly talented individuals with disabilities and preparing them to run for seats on the Slovak Parliament, thereby integrating the parliament with members who would promote disability issues as a priority (Holland, 2003).

The Kompa Social Care Home

One notable advancement in service provision in Slovakia has been the Kompa social care home in Banska Bystrica, a medium sized city in central Slovakia. The Kompa constitutes a partnership between the regional social welfare agency and an NGO in Banska Bystrica. It is funded by the regional government, so it is a state operated facility, but the regional agency directors have entered into a partnership with an NGO called ANNWIN. The NGO helps to foster a community-based living model for the home, and initiates collaborative relationships between Kompa and organizations independent from the regional government agency. Kompa is a residential program for children with developmental disabilities in which most of the children reside from Monday through Friday. Children participate in the educational program during the day, stay in the program's dormitory during weeknights, and return to their families on weekends. The reasons for this partial residential arrangement is that services for children with severe disabilities are still not available in many of the rural areas of Slovakia, so a centralized, partially residential service model continues to prevail. Unlike many social care homes in Slovakia, however, the Kompa home is not "invisible," located in some remote and isolated area. Instead, it is located on the center square of the city. Children are integrated into the community, if

not yet in integrated schools, through activities with the general population of the town. The dormitory is spacious and rooms, while shared, are not over-crowded, unlike many of the institutional settings in Slovakia. The children of Kompa, while not yet fully integrated into Slovak life, nevertheless promote the visibility of disability in Banska Bystrica through their active presence in the community. This, in itself, is progress, both for the children of Kompa and the larger nondisabled population of the town. Until decentralization of services is completed in Slovakia, with community-based programs and inclusive schools available throughout the country, centers like Kompa could constitute an intermediate option.

Poland

Poland has a long history of innovation and activism at the grassroots level, both under communism and since its fall (Linz & Stepan, 1996). Polish society has also tended to respond to disability somewhat differently than the other Visegrad countries. For example, during the communist period, there was less political, social, and economic pressure in Poland to place children with disabilities in institutional settings, and a greater tendency to care for them in the home (Mrugalska, personal communication, November 7, 2006). Custodial institutions for people with mental disabilities still existed, but this institutional infrastructure was not as pervasive or as inescapable as those in many of the other Central and Eastern European countries. Still, educational, social, and vocational services for people with mental disabilities were severely lacking in Poland, and the response to this void has been dramatic since 1989, with the accelerating growth of service-based disability organizations that existed in very quiet and modest forms under communism, as well as the establishment of new NGOs with innovative and creative missions and methods.

Polish Association for People with Mental Handicap

The Polish Association for People with Mental Handicap (The Association) was founded in 1963 and represents one of the first nationwide parents' movements in the communist block. The Association was initiated in order to address the complete exclusion of children with developmental disabilities from educational, recreational, and vocational development. During communism, The Association focused on developing its own programs to provide assistance to children with developmental disabilities, establishing special schools and recreational programs throughout different regions of the country. In the early years of its development, The Association was also focused on providing community-based support to parents in order to foster more comprehensive care in the home, and later established group homes for adults with developmental disabilities to live in the community (Mrugalska, personal communication, November 7, 2006). In 1976, it was among the first organizations in Poland to implement early intervention programs for children with developmental disabilities. Under communism, The Association operated as one arm of a larger quasi state-run social welfare organization. In 1991, The Association was able to establish itself as an independent NGO.

The Association's history as the first parents' organization in Poland to promote the greater integration of children with developmental disabilities into community life lends it a prominent status now in the contemporary disability NGO community. Many of The Association's current goals are quite similar to those of the organization during communist times: educational opportunities, recreational activities, and parental support in the community. The difference now is that The Association is able to operate with much greater freedom and is able to increase the sophistication of the programs it designs and offers. It has also been able to increasingly focus on individuals with more severe

disabilities, given that some of the programs it established in the past for individuals with less severe developmental disabilities have been adopted and funded by the state. The Association still provides segregated schools for children with severe disabilities. But, it is the position of The Association that children with the most severe disabilities cannot be educated at the regular state-owned schools since these are not prepared to respond to their specific needs. The Association, therefore, operates education and rehabilitation centers that provide comprehensive medical, psychological, and educational services for individuals aged 3 to 24. This segregated schooling is endemic throughout the Visegrad countries, and likely represents an interim situation following which integrated educational settings will eventually be phased in. Nevertheless, in the meantime, The Association is managing to provide some of the most progressive and comprehensive educational environments, albeit segregated, for children with the most severe mental disabilities in Poland.

The Association represents an interesting and valuable example of a disability organization that survived the transition from communist to post-communist society. The NGO appears to have done this by maintaining a certain cooperative, if somewhat tense, relationship with the state government even as that state government underwent a massive transformation. At no time did The Association seem to accuse or challenge the government, whether communist or post-communist, with regards to disability rights or even with regards to lack of services. Instead, The Association set out to fill a critical void by providing services the state did not provide, later transferring some of these services to state agencies and moving on to develop new or more sophisticated ones. The Association functioned as a sort of incubator for disability support services and, once these incubator projects were established and proven, used them to convince the state of their necessity.

Grodzki Theater

The Grodzki Theater is an NGO founded in 1999 and dedicated to the promotion of the arts and arts education for children and adults in the rural southern provinces of Poland. The common themes underlying the Grodzki Theater programs are the use of creative and performing arts to promote vocational, social, and life skills, and gearing the programs to serve a diverse collection of populations deemed “socially excluded,” including those with mental disabilities. These themes are broad enough, and the populations constituting “the socially excluded” are numerous enough, that the program gains the advantage of having broad relevance to multiple funding sources. The triumph of the Grodzki Theater appears to be the NGO’s ability to provide a broad array of programs serving a very diverse population without losing its primary focus, which is the promotion of inclusion through artistic involvement. The NGO, therefore, uses participation in the arts as its core rehabilitative function, pervasive across programs and groups served.

The Grodzki Theater is an NGO focused on service provision (as opposed to human rights promotion), which is the most common mission for disability NGOs in the Visegrad countries. But, the Grodzki Theater is clearly accomplishing its service mission through what are atypical methods. This melding of the arts and community-based rehabilitation represents a notable innovation among disability NGOs in the Visegrad countries, and has the potential to demonstrate to the broader disability NGO community in the region how service provision can be diversified and enriched in innovative ways.

Hungary

Hungary could be said to possess some of the most progressive disability NGOs in the Visegrad countries, though up to now, the existence and implementation of disability rights legislation has not been significantly more advanced in

Hungary than in the other Visegrad countries. Hungary has been the first among the Visegrad countries to sign and ratify the UN Convention on the Rights of Persons with Disabilities, as well as the Optional Protocol, so Hungary may now be taking the lead among the Visegrad countries with regards to the promotion of disability rights. Hungary has the distinct problem, however, of having the majority of its most active disability NGOs located in the capital city of Budapest, while the other Visegrad countries have a less severe geographic concentration of disability organizations in one location. As a result, Budapest represents a center of remarkable disability NGOs that serve much of post-communist Europe, but it also represents a relatively concentrated oasis of activism within its own country.

The Mental Disability Advocacy Center

One of the most visible and successful disability NGOs in Hungary is the Mental Disability Advocacy Center in Budapest, a human rights NGO with a geopolitical focus that encompasses much of the post-communist region. The Mental Disability Advocacy Center (MDAC) is distinctive in its visible and vocal focus on mental disability as a human rights issue in the post-communist region. The NGO uses a combination of law and advocacy to advance the rights of people with actual or perceived mental disabilities in post-communist Europe and Central Asia. The strategies used by MDAC are sophisticated and multilayered. For example, MDAC works with individuals at a local level to document and challenge abuses in the national and international courts. At a policy level, MDAC has been engaged with the International Disability Caucus and the process that eventually resulted in the United Nations Convention on the Rights of Persons with Disabilities. In addition, MDAC has initiated the Guardianship Project in the post-communist region. The Guardianship Project addresses the various processes through which people with mental disabilities are adjudicated to lack com-

petence and are assigned guardianship, resulting in no sovereignty over their own lives.

MDAC has received support from the European Council, the Soros Foundation, and other government and foundation sources. Its emphasis on human rights, rather than service provision, has gained the NGO a good deal of influence and attention, in part because such a focus on mental disability as a human rights concern still remains unusual among most of the NGOs in the post-communist region. This important focus has likely enhanced its ability to gain international funding from such sources as the Sigrid Rausing Trust in the U.K., and may have hampered its ability to gain domestic government grants.

Members of the MDAC staff include Gabor Gombos, himself a survivor of the Hungarian mental health system, a former Ashoka Fellow, and one of the human rights pioneers spotlighted in Kerry Kennedy's (2004) book, *Speak Truth to Power*. MDAC has a significant presence not only among mental disability NGOs in the Visegrad countries, but also on the world stage, and its efforts appear to be gaining increasing recognition by the global disability community (i.e., Krosnar, 2006). As disability NGOs in the Visegrad countries begin to assume more of a human rights mission, and not only a service oriented one, MDAC will most likely emerge as one model to follow.

Hungarian Association for Persons with Intellectual Disability (ÉFOÉSZ)

The Hungarian Association for Persons with Intellectual Disability (ÉFOÉSZ) is an umbrella organization with the dual mission of community-based service provision and policy advocacy for people with intellectual disability in Hungary. This umbrella organization represents 50 member associations and has 25 local branches, representing approximately 22,000 citizens throughout Hungary. ÉFOÉSZ was founded 25 years ago, during the communist period by Piroska Gyene, whose son had a developmental

disability. It was because Gyene found herself having to navigate her son's early educational and community needs on her own that she pursued the establishment of an organization to support people with developmental disabilities and their families. What makes ÉFOÉSZ distinctive, however, is that it accomplishes both a service mission and an advocacy mission, blending grassroots community-based support with the promotion of improved policies for people with developmental disabilities in Hungary. This remains an unusual accomplishment in the post-communist region, where the vast majority of disability NGOs are service-based and do not pursue an advocacy role. Notably, however, the advocacy most often engaged in by ÉFOÉSZ is not the confrontational, rights-oriented approach of MDAC noted above. Advocacy efforts by ÉFOÉSZ most often consist of public education campaigns, as well as participation in Hungary's National Disability Affairs Council. This collaborative, more than confrontational, form of advocacy may represent the next wave of development for many of the service-oriented disability NGOs in the region, as they extend their foci to include activism, as well as service. If so, ÉFOÉSZ may present a hybrid model for the currently service-oriented NGOs to emulate over time.

Czech Republic

The majority of persons with mental disabilities in the Czech Republic are estimated to live in approximately 200 institutional settings spread throughout the country (Inclusion Europe, 2002). As with the other Visegrad countries, data regarding the nature of these individuals' disabilities, how many reside in which facilities, or even the precise number of facilities serving people with mental disabilities, are lacking. De-institutionalization has been slow to develop (Sinecka, 2009), in part, because legislative and financial support for community-based disability NGOs has been severely limited. Still, despite these challenges, a large number of innovative disability NGOs have succeeded in the

Czech Republic and are managing to change the nature and scope of services that promote independent living and community-based support, including caregiver education, supported employment opportunities, and advocacy for educational reform. As with the other Visegrad countries, it is in part the challenging socio-political context within which these disability NGOs have had to struggle that has contributed to their reputations as notably resourceful and resilient.

Autistik

Autistik was founded in Prague in 1994 by a group of parents of children with autism to address the perceived lack of national and professional attention to this developmental disability in the Czech Republic. Autistik represents a traditional, service-oriented NGO in many ways, focusing on the provision of supportive services such as vocational training and educational opportunities to people with autism, as well as therapeutic respites for families. The NGO might be said to adhere to an older model of disability organizations, in that it defines itself according to a specific diagnostic category, but in other ways, Autistik represents a disability NGO that is forging new paths in the post-communist region and resisting the confines of the service-oriented models of the past. For example, Autistik has been vocal regarding the inappropriate incarceration of people with autism and has challenged policies in the Czech justice system that the organization considers incompatible with the fair treatment of people whose disabilities contribute to unconventional behaviors. Likewise, Autistik has challenged unfair housing practices with regard to adults with autism who are seeking suitable apartments, at a time when many cities and towns in the Czech Republic are experiencing significant housing shortages. Such policy and legislative activism make Autistik one of the NGOs in the post-communist region that manages to balance both a traditional service-provision mission with rights-based activism, achieving a sort

of hybrid model among post-communist NGOs that typically adopt only one of these aims.

Centre for Mental Health Care Development

The Centre for Mental Health Care Development (The Centre) in Prague is distinctive in that it has an advocacy mission, but has adopted a largely collaborative method. The NGO was founded by mental health providers who possessed a mental health system reform agenda, thereby serving to promote change “from within.” The Centre has been instrumental in supporting community-based models of support and de-institutionalization in the Czech Republic, establishing pilot programs and conducting needs assessments. The Centre has successfully sought out and collaborated with different segments of the mental health sector, reaching clinicians, institution administrators, and government agency leaders at the ministerial, regional, and municipal levels in order to advocate for more rapid and pervasive transformation of the Czech mental health system. The mission of the organization is to help guide the Czech mental health system from one that over-relies on institutionalization to one primarily focused on community-based services. The Centre has crafted its mission and priorities according to the Principles for the Protection of Persons with Mental Illnesses and the Improvement of Mental Health Care adopted by a UN General Meeting No. 46/119 in December 1991, and thereby constitutes one of the few mental health NGOs in the Czech Republic to explicitly utilize this international instrument to shape its organizational purpose.

The Centre is one of the few disability NGOs in the post-communist region to assume responsibility for developing assessment and evaluation methods for mental health services. The development of such methods and the conduction of such research are critical if mental health service reform in the post-communist region is to be informed and driven by meaningful data. Indeed, the lack of data regarding mental

disability issues in the post-communist region, from little epidemiological information to a few thorough needs assessments, is an urgent concern. The Centre’s efforts to address this void and to begin producing reliable methods for data production are particularly distinctive.

Conclusion

There is clearly a great deal of development and evolution occurring among disability organizations in post-communist Europe. During this period of rapidly expanding civil society freedoms, however, there continues to be a lack of resource support for these disability groups. While the enhanced visibility of disability issues within the international community, such as the United Nations Convention on the Rights of Persons with Disabilities, will foster greater attention to disability rights and de-institutionalization, widespread progress will continue to take time. Both the deconstruction of the institutionalizing apparatus and the creation of community-based supports will involve a shift in values and behaviors among health and education professionals as well as government agencies. This shift will need to be massive within each of the Visegrad countries, and will require resources, personnel, and policies that are not currently in place. In the meantime, the growth and empowerment of disability NGOs like those profiled here will be essential, since it will be these grassroots efforts that will ultimately be scaled up into much broader initiatives over time.

Certain tension exists within the disability NGO community in the Visegrad countries, and this tension reflects the ideological differences frequently represented by two models of activism (Holland, 2008). One model of activism favors a service-oriented, community-based model in which the NGO provides much needed support directly to people with disabilities and their families. The Polish Association for People with Mental Handicap favors this model, as does the innovative partnership

struck between the NGO called ANNWIN and the regional social welfare agency for Central Slovakia, in their creation of the KOMPA social care home in Banska Bystrica. The other, less common, NGO model in the Visegrad countries favors a human rights advocacy approach. This approach challenges government agencies and official powers to do more to protect the sovereignty and freedoms of citizens who have disabilities. The Mental Disability Advocacy Centre in Budapest is an accomplished example of this model. A number of the human rights-oriented NGO leaders suggest that the service-oriented NGOs are providing essential supports, but they are supports that should be the responsibility of the government health and social welfare agencies. By providing such supports through the NGO sector, some of the conflict-based leaders argue, the service-oriented NGOs might inadvertently reduce the pressure on these government agencies to respond responsibly to their own citizens. Leaders from the service-oriented NGOs, on the other hand, frequently term the human rights NGOs as “too political,” and point out that in order to meet the urgent needs of people with disabilities and their families, NGOs must work cooperatively with government agencies and policymakers, not risk alienating them. Jan Pfeiffer, the Czech reform psychiatrist who has been advocating for the rights of people with mental disabilities for many years, is quoted as saying, “You can either be a bad German Shepherd who barks, or somebody who offers a helping hand. Both roles are important, but not compatible. You can’t bark at somebody, then sit down with him at a table” (Stojaspal, 2004). This statement captures much of the sentiment among the NGOs of the post-communist region. Human rights and direct service are often seen as two separate causes, so there is a perception that a choice between one or the other must be made by any NGO. That perceived dichotomous choice then results in the existence of two somewhat separate subcultures within the disability NGO community

in the region, and there is some minor tension between these two subcultures.

Yet, it remains important to note that there are a small number of examples of disability NGOs that contradict Pfeiffer’s dichotomous portrayal. Indeed, a handful of the disability NGOs in the Visegrad countries manage to balance both a human rights and direct service mission, adopting the seemingly contradictory roles of “the German Shepard that barks” and “the helping hand.” The Hungarian Association for Persons with Intellectual Disability and Autistik in the Czech Republic seem to have achieved this dual mission to varying degrees. Disability NGOs in post-communist Europe with such hybrid missions may serve a particularly important role in the future if they can come to bridge the two somewhat separate subcultures among the NGOs in the region, demonstrating how the two missions complement one another in effective, if sometimes awkward ways. In fact, the Centre for Mental Health Care Development, an NGO on which Jan Pfeiffer serves on the staff, is itself an excellent and elegant example of an organization that is managing to forge a new form of disability advocacy in the Visegrad countries. It is a form of advocacy that pushes for change by drawing even historically resistant stakeholders into the process through education, mutually beneficial demonstration projects, and broad based national and international support.

Both of the disability NGO subcultures in the Visegrad countries and each of the two types of missions these subcultures promote, human rights advocacy versus direct service provision, are essential to progress. A report on human rights and mental health in Hungary, compiled by the American NGO, Mental Disability Rights International (1997), notes that, “The history of mental health system reform in the United States and other countries demonstrates that there are dangers associated with legal reform not accompanied by a national commitment to plan and finance community services” (preface p. xx). Such dangers may not seem

imminent in the post-communist countries of Central Europe because so much of the emphasis of the disability NGO community is already on service provision rather than disability rights.

Yet, the mistakes made by the United States in its de-institutionalization process in the 1960s and 1970s could still be repeated in these transitioning countries if sweeping disability rights legislation is suddenly implemented without accompanying support for community-based services. This support may need to come from international sources as. As disability rights legislation is inevitably implemented in these countries, particularly now with the catalyst of the UN Convention on the Rights of Persons with Disabilities, measures will need to be taken to avoid the mistakes of the de-institutionalization process implemented in the United States, where a human and civil rights emphasis was not matched with the availability of community-based services, and people with mental disabilities were released from institutions often to fend for themselves. Ironically, as the United States continues to struggle, decades later, with the outcome of its own de-institutionalization effort, it may be well positioned to help other nations avoid the same problems through both international aid and the provision of a living model of how not to proceed. The avoidance of such mistakes, however, will require substantial engagement and investment from other EU and North American countries. Furthermore, a willingness to support the service-oriented NGOs, as well as the rights-oriented ones, will need to be paramount. Such support will ensure that de-institutionalization is met with community-based services and pragmatic support, and does not simply result in post-institutional homelessness and neglect.

The partnership among the Visegrad countries may also prove critical during this emerging era of disability issues in the post-communist region. Some have suggested that the Visegrad Four partnership is virtually irrelevant now that all of the member countries have reached their

original goals and have entered NATO and the EU ("From Visegrad," 2005). It may be, however, that one of the next waves of coordinated advancement to unite these four nations will be in the area of minority issues and human rights, which would retain the relevance of the Visegrad partnership under a new cause. Such an evolution in Visegrad partnership would make sense, since all four countries now face similar challenges in improving the rights of minority groups, including people with disabilities. For example, it has yet to be seen if Hungary's recent ratification of the United Nations Convention on the Rights of Persons with Disabilities and the Optional Protocol, will influence its Visegrad partners in any way, all of whom have, at the time this article was written, signed, but not yet ratified, the UN convention. Ideally, the furtherance of the Visegrad collaboration would make human rights efforts, like the large-scale de-institutionalization of people with mental disabilities and promotion of independent living alternatives, a shared priority in the four countries' coordinated march "back to Europe."

Regardless of the shape and purpose the Visegrad partnership now takes, what remains clear is that the disability NGOs of these nations will be essential to the continuing improvement of conditions, services, and rights throughout the post-communist region. What is essential at this time then, is greater attention to what these disability NGOs are accomplishing, what are their needs, and how international and informed crosscultural partnerships might assist some of them in not only surviving, but eventually scaling-up. The profiles and context presented here is one attempt to lend such attention to the disability NGOs of the post-communist region, with the intention of initiating more discourse in the disability policy literature regarding the crucial role of disability NGOs, not only in post-communist Europe, but in the global disability community at large.

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Endnotes

¹A “total institution” refers to an organization in which all aspects of a person’s life are subordinated to the rules, routines, and structures of the institution. A total institution often requires a loss of sovereignty over one’s own life, with deference to the authority of the organization and internal demands (Goffman, 1961).

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Vive la Révolution

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Research Articles

Abstract: Through the presentation of qualitative data, this verse reflects the author’s sincere effort to reconcile the divide between “town and gown,” all the while exploring the experiences and subsequent perceptions of activists within Mad Pride. In so doing, it creatively illustrates the broad dynamics and challenges that face those on the receiving end of the psychiatric system today.

Key Words: madness, activism, Mad Pride

Drawing on ethnographic and historical research undertaken between 2007 and 2009,¹ this verse traces – in a fanciful way – my uncertain and sinuous path to an “engaged sociology.” In so doing, it creatively illustrates the diversity and ethos of Mad Pride, an international coalition which buttresses events celebrating and demystifying what it means to be “mad.” It is intended to be sufficiently open-ended to stimulate curiosity, allow for imaginative interpretations, encourage Foucaultian problematization



“Long Live the Revolution, the Fourteenth of July”

Poster mounted in the shrubbery of the Centre for Addiction and Mental Health (CAMH) at the Second Annual Toronto Mad Pride Bed Push parade on Saturday, July 19, 2008.

Photo: Essya M. Nabbali

and invite further dialogue as a result. While the interview² snippets (cited in italics) are not quoted in full, and thus do not reflect the entirety of the participants' view, they have not been taken out of context. Moreover, I wish to make clear that such excerpts are used as a means of illuminating ideas so the portrayals of an "expectant mother," an "elderly bloke," a "babbling mental patient" and the likes, do not characterize the references whatsoever.

"choice, empowerment, self-determination" (Oaks)

I close my eyes...

July, 1789. Paris.

intoxicated with liberty and enthusiasm

the French masses storm La Bastille³

upheaval, insurgence, bloodshed

the first great triumph of the forces of anarchy⁴

freedom for all

"vive la revolution," I hear a man bellow

I open my eyes...

July, 2008. Toronto.

"vive la revolution," he shouts again

I look around

a jamboree of people

wearing all kinds of fucked up shit (Fabris)

a shirt reads "Nutter on Board"

a cape declares "Captain Crazy"

a hat reveres "Lithium Life"

purple pyjamas with moons

red thongs worn over slacks

jester crowns, masks and painted faces

just about anything that challenges the normative culture (Fabris)

it is beautiful

I want to clap but I don't

"choice, empowerment, self-determination" (Oaks), the horde repeats

the rhythmic beating of bongo drums

and people's cheers echo

“we need to get democracy hands-on” (Oaks), an expectant mother urges
 another revolution?
 a gentle voice murmurs *“satyagraha”*
 seemingly a more peaceful one
 I close my eyes once more...
 April, 1933. India.
 the outset of Ghandi’s *“fast unto death”*
 to restore communal amity
 suddenly, I am startled
 a young woman, probably in her early twenties
 with dishevelled hair, smudged make-up and smoking a cigarette
 grabs my hand, *“come, join us, make a statement”*
 she promptly cries, *“we’re here, we’re people like you and we have rights too”* (Briggs)
 noticing my puzzled expression, she explains
*“You don’t necessarily have to have seen a psychiatrist to be here.
 You don’t need to be on Zyprexa or Prozac.
 Perhaps, as a result of wealth or some semblance of togetherness
 or whatever else it is shrinks stay away from,
 you’ve managed to elude the system.
 Whatever it is, whatever your story,
 if you see the oppression,
 if you are or could be included in that oppression,
 celebrate Mad Pride!”* (Anonymous1)
 her friend earnestly elaborates, *“we need people to say ‘I’m proud of the fact that
 I’ve had experiences that could get me locked up”* (Fabris)
“but,” an elderly bloke interrupts, *“[you] do not have to identify explicitly”* (Reville)
 I look around again
 the mad, the oppressed, the ex-inmates of society
 asserting themselves
 demanding *inclusion and diversity* (Oaks)
harmony and respect (Bach)
 as well as *access and services* (Briggs)
 carrying signs such as *“Keep your labels off my mind”*⁵
 I snatch one which heralds *“stop loneliness once and for all!”* (Briggs)
“We need a voice for mental health consumers” (Oaks), some roar

others charge, “*The drugs and the electroshock and all that needs to go bye bye.*

[They’re] *completely screwing us all to hell!*” (Briggs)

a plethora of embodiments

multiple political struggles

intersecting oppressions

it’s complicated shit (Bach)

I sit next to the mental patient who’s babbling on “medication”

“*We recognize that there’s differences,*” he clarifies, “*and we’re trying to celebrate those differences and the ways we can reframe various experiences.*”

Mad Pride is providing the space to do that” (Bach)

so much for “babbling”

a moment of silence

to remember people who’ve been killed or who’ve died in mental hospitals (Oaks)

candles, flowers, speeches

In a way, it’s ‘Take Back the Night’ (Reville)

a campaigner then re-arouses the collective when she proclaims

“[Psychiatrists] tried to change us, tried to silence us

but we survived everything they threw at us!

That is something we should all be proud of”⁶

the rally starts to march

pushing a hospital bed, chased by a giant syringe

a father, clutching his child affectionately, informs me that we’re staging Britain’s “Great Escape Bed Push” as a means of drawing attention to the *flagrant abuse of power by the state* (Fabris) and the lack of humane alternatives in mental health services

over 100 people flock from CAMH to PARC⁷

frolicking, refreshments and a bbq await

‘It’s a big thing – free food – when you’re hungry’ (Anonymous2)

averts an activist dancing the characteristic “thorazine shuffle”⁸

upon arrival, the crowd chants

“Show me your Mad Pride.

I’ll show you my Mad Pride.

We’ll show the world Mad Pride!”

an impromptu piano recital from a member of the audience

laughter, chit chatting, togetherness

I casually probe the syndicate

in an effort to better understand this phenomenon

“Mad Pride, well, what you’re doing is you’re backing away from the original intent of the psychiatric liberation movement,” a bearded man grumbles, “you’re trying to put a soft shell on the movement and it’s not going to work because the issues are too intense. They’re too difficult for people to just come out and wrap up into [some public celebration]”⁹ (Fabris)

a woman draped in blue and gold sequence thwarts, *“I’m not worried that psychiatry is all of a sudden going to snap back and say ‘oh, okay, we’ll stop with the force. Yes, we’ll stop with the force.’ That’s not going to happen too soon, just look at the money”* (Fabris)

the circle pauses

I linger patiently for a riposte

“We’ve dealt with a lot of failure,” blurts the woman’s partner, hidden behind a Venetian feather mask, “so we’re not, maybe, the kind of political movement that sees winning as the only goal.

I think that winning has to come with people’s sense of self” (Fabris)

she continues, *“We don’t feel good about ourselves. People who live in the boarding homes, they don’t even have it together to go and talk to another human being. It’s pretty intense.*

You have to give people a sense that they’re okay, a sense of something worthy” (Anonymous2)

Indeed, *“It’s not about pride or dignity and all of that stuff,”* another bolsters,

“I mean I hear those words and I just go ‘yeah, yeah, whatever! What about safety, space?’

It’s more like, there are people who really do need to feel safe, just feel like they can live in their own bodies, and it’s that kind of stuff that I think [Mad Pride] has a lot to offer” (Fabris)

worthy of note

my attention turns to the adolescent addressing a journalist

“I feel that Mad Pride is really something much broader than any of this in the sense that human beings can embrace pride in being different, unique, creative, unusual and that’s what we mean by Mad Pride. It’s really ‘Human Pride.’ To be alive, to think, to be, to exist as a human being, as a living entity, it’s not normal. It’s a strange experience, inherently. In fact, science is finding in complexity theory that life exists on the edge between chaos and order, far from equilibrium. I think we’re always in that state, on the edge of chaos

in the sense that none of us have a grip on reality” (Oaks)

he bewilders and frustrates the reporter

“To put it more simply, Mad Pride is something that everybody can get involved in. It’s about having fun and being different. Everyone can celebrate that” (Oaks)

he smiles

the journalist smirks

I can’t help but giggle to myself

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The research upon which “Vive la Révolution” is based was conducted during her tenure as an M.A. student at York University, Ontario, Canada, under the remarkable (and much appreciated) tutelage of historian Geoffrey Reaume. Essya wishes to wholeheartedly thank Ryan Docherty, despite endings, for having been her muse and strength as she found her academic footing. She would also like to dedicate this poem to her beloved Nanny and two little munchkins, Lauren and Lexie Hood, whom may never read this, but if/when they do, will know that she is thinking of them, always.

Endnotes

- ¹ Nabbali, E. M. (2009). “A ‘Mad’ Critique of the Social Model of Disability,” *International Journal of Diversity in Organisations, Communities, and Nations*, 9 (4), 1-12.
- ² With artistic licence from Anonymous1 (self-styled “manically eccentric”), Anonymous2 (someone who has been “brutalized” by psychiatry), Jeremiah Bach (one of the central organizers of Mad Pride Toronto 2007 and 2008), Bonnie Briggs (ally), Erick Fabris (former psychiatric inpatient), David Oaks (director of MindFreedom International whose vision is for a non-violent revolution in the mental health system) and David Reville (psychiatric survivor). Approved over the months of October and November, 2008.
- ³ Mignet, F. A. (1885). *History of the French Revolution from 1789 to 1814*. London: George Bell and Sons.
- ⁴ Moreton-Macdonald, J. R. (1915). *A History of France*. New York: MacMillan.
- ⁵ Reaume, G. (1993). Psychiatric survivors hold Pride Day. *People’s Voice*, November issue, p.5.
- ⁶ Reaume, G. (1994). Psychiatric survivor festival. *People’s Voice*, June issue, p. 13.
- ⁷ Centre for Addiction and Mental Health (CAMH); Parkdale Activity and Recreation Centre (PARC)
- ⁸ A phrase referring to the stiff gait and involuntary muscle movements (especially around the mouth – often causing drooling – and in the arms and legs) resulting from tardive dyskinesia or the long-term use of neuroleptic drugs.
- ⁹ Fabris made this comment when discussing his earliest views on Mad Pride.

From Dialogue to Bakhtin's Dialogue: A Critical Review in Learning Disability Research

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Research Articles

Abstract: The purpose of this study was to understand the nature of dialogue used in peer-refereed research articles related to learning disabilities (LD) and instruction. We attempted to evaluate the quality of dialogue in these articles through a lens that Bakhtin and various disability studies scholars offer. In addition, we suggest that disability scholars' concepts and uses of dialogue provided a way for us to frame our Bakhtinian critique in the broader context of theorizing the social model of disability. From a critical review of these articles, we identified various limitations in ways that dialogue is used to conduct the studies and also in the ways that dialogue is represented by the authors. The studies often minimized the voices of the students labeled as LD. We offer many suggestions for how to present their voices in research and how to improve teaching through conceptualizing learning in a different, more sensitive way as informed by Bakhtin's notion of dialogue.

Key Words: learning disability, dialogue, Bakhtinian

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

Some authors in the field of special education, including Learning Disabilities (LD), have pointed out the need for researchers to engage in and report dialogue with students labeled as LD (Gallagher, Heshusius, Iano, & Skrtic, 2004; Reid, 1991; Reid & Button, 1995). Although there are several scholars who engage in dialogue with students labeled as LD, these students' voices are still hard to hear.

Gallagher (2003) proposes that academics should engage in discourse that considers the moral nature of positivist and other research. She urges researchers to have more dialogue with those participating in research to make "our research encounters human encounters" (p. 10). Including the voices of students labeled as LD is important because studies should eventually serve the interests of the students themselves. If researchers do not include the voices of students labeled as LD, it will be difficult to claim that current studies reflect the variegated considerations and interests of students so identified. Similarly, if researchers do not explore the dialogue between students labeled as LD and their teachers, it will be difficult to achieve a nuanced understanding of the human processes that occur between these two groups, because we might end up considering students from teachers' and researchers' perspectives.

In light of the contentious history of LD as a field, it is surprising that we have rarely heard the students labeled as LD through unstructured interviews, phenomenological studies, and thick descriptions (Reid & Button, 1995). Researchers seem afraid to get closer to students labeled as LD by talking to them informally, openly, and deeply. The problem is rooted and epistemological, and very likely related to a fear of subjectivity and emotions that stems from the writings of Descartes in the 17th century (see Boler, 1999; Dewey, 1929). As Moore, Beazley, and Maelzer (1998) show, researchers are often "afraid" of subjectivity. In this regard, Foucault might draw attention to the problem of science as discourse (Foucault, 1972; 1977). Neverthe-

less, some authors in the field of special education, including LD, have recently pointed out the need for researchers to engage in dialogue with students labeled as LD (e.g., Gallagher, Heshusius, Iano, & Skrtic, 2004; Reid, 1991; Reid & Button, 1995).

In order to include students' voices, it is necessary to explore how scholars discuss dialogue because they may approach it in various ways in connection with disabled people. For example, Thomas (1999) discusses the importance of dialogue through sharing narratives about pain in a disabled person's life. She mentions the importance of disabled people's right to express their humanity fully and subjectively. However, she also points out political aspects of dialogue, which concern language used to signify pain as it becomes oppressive to people who are different, as in "disabled." And unlike Thomas's inclination to call the body "impaired," Shuttleworth (2002) prefers to situate pain in a more discursively conscious body, a body that is vigilant about what it is called and aware of the implications of power that names capture, as in bodies called "different," "disabled," or "impaired." Through his concept of dialogue, Shuttleworth attempts to account for poststructural expressions of contradictory identities that give power to voice and action and help to debunk myths about what the disabled can and can not do.

As Thomas (1999) and Shuttleworth (2002) have their own interpretations of dialogue, articles related to dialogue concerning LD pose various problems in relation to understanding what sort of dialogue is used among the participants and how that dialogue is represented. Thus, it is useful to interpret dialogue related to LD from a lens that considers the play of power and perspective. Such analyses may help to understand how dialogue related to LD may be interpreted and very importantly, how dialogue can become more itself.

The Purpose of the Study and Research Questions

Mikhail Bakhtin was a Soviet philosopher and linguist who devoted much of his life to understanding the aesthetic function of dialogue and alterity (human differences) (Clark & Holquist, 1984). We attempt to connect Bakhtinian aims with the academic literature related to LD. We also make connections between disability studies scholarship and parts of the research literature concerning LD. We find disability studies scholarship germane to our efforts because such writings help us understand disabled people from a variety of sociopolitical perspectives.

In our article, we attempt to respond to two questions through a Bakhtinian/disability studies scholarship lens. We hope our answers spur more questions. Our research questions are the following:

- 1) What does a Bakhtinian/disability studies approach to dialogue tell us about the nature and functions of dialogue?
- 2) From such perspectives and understandings of the construct of dialogue, how can we critically re-imagine aspects of the studies we review in the field of LD to improve the quality of their dialogue?

Research Method

Since we wanted to understand the nature and functions of dialogue in the standard research literature connected with LD, we selected articles related to LD through an Educational Resources Information Center (ERIC) search with the following descriptors: "learning disabilities" and "dialogue." We found 20 refereed works noted in the ERIC search, and reviewed these works carefully. However, it was difficult for us to narrow the search concerning dialogue and LD to such a small number of articles. Therefore, we tried to find more articles. For example, when we found Englert and Mariage's

(1996) article and reviewed it, we found that these authors extensively discussed dialogue-related pedagogy in LD.

The constructivist oeuvre is rich in analyzing dialogue through the use of qualitative, but positivist methodologies (for a review see Swanson, Harris, & Graham, 2003). We thoroughly examined reference lists of seminal articles concerning constructivism and LD, as well as related works about strategy instruction and LD (for a review see Wong, 2004). We also came upon bodies of literature in LD involving the question of dialogue among researchers and teachers (the so called “research-practice divide”) (see Fuchs & Fuchs, 1998; Malouf & Schiller, 1995; Stanovich & Stanovich, 1997) and theoretical debates between critical theorists in LD and the dominant school of positivist psychology (see Reid & Valle, 2004; Walker et al., 1998).

After considering such bodies of literature related to several debates undertaken within fields related to LD in which dialogue is written about, we settled upon the constructivist perspective in which dialogue is talked about as a means for investigating various forms of situated learning. We decided to focus on 12 articles from mostly the constructivist perspective in the LD field to analyze further by using a Bakhtinian/disability scholarship theoretical lens. We felt these articles were appropriate for our needs because they helped us understand the role and limitations of dialogue, as currently conceptualized and represented in the research base. However, there is no question that these articles model a sliver of one type of explicitly-stated, dialogue-related research in the field of LD. We wanted to choose representative articles from the constructivist oeuvre to focus our analysis so that we could understand clearly the pedagogical and research implications of practicing and representing dialogue specifically in the context of learning situations involving students labeled as LD.

We settled upon 12 articles that we felt represented approaches, concerns, and research designs found in a range of other articles related mostly to constructivist pedagogy and LD. The authors of these 12 articles were Dudley-Marling (2004), Englert & Mariage (1996), Englert, Rozendal, & Mariage (1994), MacArthur (1998), Mariage (1995), Mariage (2001), Leshowitz, Jenkins, Heaton, & Bough (1993), Smith & Griffin (2002), Valle & Aponte (2002), Wong (1997), Wong, Butler, Ficzer, & Kuperis (1996), and Wong, Butler, Ficzer, Kuperis, Cordon, & Zelmer (1994).

When reviewing the 12 articles, we concentrate our critical attention on parts of the articles that lend themselves to a discussion of the representation and use of dialogue. In our writing, we do not summarize the articles that we reviewed, but instead provide some background in each case for the reader to understand our critique of the dialogical aspects. We analyze the dialogue involving students labeled as LD and their teachers from a Bakhtinian/disability studies perspective.

As far as picking disability studies scholars whom to reference in our discussions of conceptualizing dialogue, it was difficult to settle on how to approach the huge field of related writings. In particular, it was difficult to include some scholars as disability studies scholars because they may not consider themselves as such. Thus, we mostly chose authors who contributed books or articles related to disability studies such as “Handbook of Disability Studies” and “Disability Studies Quarterly.” We realize that our determination to this effect can be questioned because disability studies scholarship may include sociologists, linguists, and historians who write about issues such as poverty, alterity, and marginalization, but do not consider themselves specifically to be disability studies scholars.

A Bakhtinian Conception of Dialogue

We can understand dialogue in the context of the term *discourse*, which Bakhtin (1984) defines as “language in its concrete living totality, and not language as the specific object of linguistics” (Bakhtin, 1984, p. 181). Through his descriptions of the concept of the sign, Bakhtin emphasizes discourse and the word as living, changing, and forever becoming--never complete. Understanding meaning through signs involves less the act of recognizing a fixed quality or identity, and more recognizing novelty because each word is unique in its position relative to other words and uniquely real in time and place. Each word is a specifically located human production (Volosinov, 1986). Bakhtin provides a powerful lens to interpret disability-related literature as he emphasizes context and the concreteness of the dialogical event. Understanding contextual specificity is useful for understanding ways social forces construct the experience of being disabled.

Bakhtin also attempts to integrate visions of human culture (e.g., as depicted in works of literary art) according to values that capture cultural pluralism related to historicity and alterity. About pluralism, he mentions Dostoevsky's dialogues as “a plurality of independent and unmerged voices and consciousnesses” (Bakhtin, 1984, p. 6). Throughout Bakhtin's analyses of Dostoevsky's works, Bakhtin infuses his own voice and suggests a need for a sensitive approach to interpreting art, which he finds in Dostoevsky's literary works, to understand qualitative aspects of human worth, a Dostoevskyan and therefore, Bakhtinian vision. Such a vision suggests that rather than changing and dominating people as they are, great art supplies spaces for them to exist in an unfettered state, fully, and contrapuntally (to use a musical metaphor that Bakhtin also cites). Bakhtin emphasizes the need for multiplicity and recognition through dialogue.

In addition, Bakhtin (1984) notes, “There is always something that only he himself can reveal, in a free act of self-consciousness and discourse, something that does not submit to an externalizing second hand definition” (p. 58). In this sense, the Bakhtinian conception of the human being as ultimately and deeply subjective, as incomplete, as continually developing through talking and expressing, become compelling as we explore the articles considered as cultural products.

Disability Studies Scholars' Conceptions of Dialogue

Numerous disability studies scholars refer to the importance of dialogue but some also problematize speaking about disability (Corker & Shakespeare, 2002). For example, Allan (1999) points out various disability discourses (e.g., charity and corporate discourses) that define culture that engender real concerns about their libratory value for disabled people. She asks whether these discourses, as forms of pastoral coercion, are fundamentally good for disabled people. And on a microscopic scale, Goodley and Rapley (2002) show how dialogue with disabled students can be used to produce acquiescence on their part. Thus, these authors point out the treachery of dialogue for people with disabilities, especially when it favors the needs of the nondisabled. In the social model of disability, we often explore such macro and micro level plays of power to understand how disability is socially constructed (Linton, 1998).

Bakhtin is a master of qualitative analyses, as demonstrated by his critique of complex works of art and artists. The concept of dialogue is a useful tool to analyze cultural artifacts. We apply the concept of dialogue to see how various social interests are portrayed and allowed to communicate and question power or not through the practical and representative aspects of the research process. The point of using a Bakhtinian conception of dialogue is ultimately to open vistas in disability-related research that

permit greater communication among producers and consumers of research and in a broader sense, among purveyors of disability culture, which might be culture itself writ large. In this section, we point out ways scholars in disability studies tried to characterize and use dialogue in their work. By describing how disability scholars have characterized and used dialogue, we also situate our Bakhtinian critique of research artifacts within a disability studies framework.

Peters (2002) suggests that a key criterion for judging inclusion of disabled people is to ask to what extent the definition of culture used to define community and society allows disabled people access. With a limiting definition and, therefore, limited access, we can only engage in limited dialogue. Focused on education, Gallagher (2003) proposes that academics consider the cost of “mis”recognizing science as objective, which she points out often results in silencing other perspectives. She urges researchers to engage in dialogue with those participating in the research process to make “our research encounters human encounters” (Gallagher, 2003, p. 10). Moore, Beazley, and Maelzer (1998) suggest that researchers and the disabled populations they study should confront prejudices about disability by talking together and aiming to meet the needs of disabled people through research rather than simply finding out about them. In turn, Fleischer and Zames (2001) trace a history of legal struggles that show the importance of dialogue as political resistance. These authors describe the resistance of the Boston University LD students who rebutted the university administrator’s verdict instead of accepting it--that some students’ claims of having LD were spurious and opportunistic. Such dialogue helped instigate a countrywide movement to shape the Americans with Disabilities Act (ADA) in 1990.

In a more theoretical vein, Goodley and Rapley (2002) suggest the potential of disrupting the dichotomy between being with and without disability by problematizing dualisms between

dependence and independence. These authors suggest that poststructural conceptions of selfhood can reinterpret identity as a more expansive and situated subject. Such conceptions can help mitigate fears of interdependence in society. Disability studies scholars resist the threat of limiting dialogue among and with disabled people. They can help to counter the sometimes expedient reticence of those who resign themselves to fixities and unsung prejudices when conducting inquiry.

In addition to visions that encourage the celebration of human pluralism, some disability studies scholars emphasize the historicity of human knowledge and experience. Garland-Thomson (1999) states, for example, that “all terms resonate, of course, bearing long histories and summoning whole discourses” (p. 4). In writing this, she refers to words as objects, and as having historical contexts and impacts which make using them in dialogue political acts of historical significance. From a different register, Artiles (2003) critiques the scholarship of minority overrepresentation in high-incidence disability categories. He believes that instead of focusing on relatively static components of such students’ profiles such as dialect, language preference, and language style, scholars in special education should consider the full scope of the history of Latin America. Such inquiries can bring insights into the perseverance of students and their families within a context of historical adversity. Both Garland-Thomson and Artiles argue for more dialogue and a historically informed approach to the consideration of words we use to communicate and conduct inquiry.

Other disability studies scholars address the representational complexities of understanding experiences related to alterity. For example, Kudlick (2003) suggests that when disabled veterans returned from war, they often asserted leadership in garnering rights for disabled people. But, they did not readily associate with disabled people who were not victims of the war --that is, with those who were considered “naturally” or

congenitally disabled. Kudlick's point raises the specter of difficulties in representing alterity and the multiple qualifications needed to account for varieties of oppression. Moreover, Carrier (1986) points out the problem of the binary (culture versus nature) that permeates the conceptualization of LD as a construct throughout modern history. Carrier asks researchers to consider which pole they favor, nature or culture, in conceptualizing LD as an operational construct. He points out the suppressed assumptions of talking about LD throughout its history.

Furthermore, Shakespeare (1994) refers to the concept of liminality (i.e., belonging neither here, nor there) to explain nondisabled people's discomfort with disabilities. He believes that embedded in that discomfort is the fear of the animal other. Such theorizing of alterity is important to our understanding of dialogue because these theories relate to the problem of who has the power to speak and who can be spoken about in what ways. The kind of dialogue a person individually engages in influences the level and position that she is allowed to embody in society.

Coming from a poststructural perspective, Mitchell and Snyder (2000) analyze the privileges that society appropriates to its members through its discursive constructions. These authors state that language often strains and stretches to meet human conceptual barriers summed up in limits between normal and abnormal: disabled bodies posit and prosthetically stretch with the help of language to create meaning (e.g., the meaning of Captain Ahab's leg and the visage of the whale in Melville's *Moby Dick*). Mitchell and Snyder suggest the need to resist through analyzing and critiquing the way language becomes a prosthetic for oppressive meanings. Further, an area of contention among some scholars is the impact of language, both intended and not, that people use to convey emotions and describe them for theoretical purposes (see Shuttleworth, 2002).

In this and the previous section, we introduced Bakhtinian and disability studies scholars' perspectives on dialogue, and noted its importance in promoting awareness, change, and the understanding of the socially-constructed nature of disability. Bakhtin and disability studies-related scholarship can be used to analyze elements such as cultural specificity, historicity, power, and the representation of dialogue in disability-related research artifacts. We can use Bakhtin's concept of dialogue to closely examine how research is conducted with students labeled as LD, and how that inquiry is presented for consumption of other researchers. Such a critique can build bridges among communities of researchers by locating the critical analyses squarely within the field of disability studies scholarship, a field that continues to theoretically and politically grapple with dialogue as an important ingredient for liberation. Such a critique can also help to create grounds in the LD field for integrating new sensibilities into its fold. Hence, based on the perspectives offered from a Bakhtinian/disability studies theoretical lens we review how dialogue concerning LD has been addressed.

A Critique of Dialogue in the Research Articles

We discovered that the authors of the articles reviewed, tend to be monologic and prescriptive of the way dialogue should occur in classrooms. The authors often measure dialogue for its effectiveness in promoting understanding in students. Even when dialogue is presented for inspection by the reader, the presentation tends to shut out the world in which the dialogue occurred. Authors often fail to reveal the context, the inner feelings, and the power relations that were a part of the dialogue among the research participants. However, we also reviewed articles that achieve more of a Bakhtinian sense of dialogue among the participants in that they reveal the qualitative aspects of dialogue's functions in the classroom. Most of all, we found that authors often emphasize describing the process

of dialogue and highlight certain elements of it, which they synchronically isolate, but which prevent exploring meaning in a holistic sense of chronicling the effects of dialogue among participants. We first begin by reviewing Englert and Mariage's (1996) article about constructivist pedagogy.

Englert and Mariage's (1996) article is about the effectiveness of a sociocultural approach called the early literacy project (ELP) used to teach students labeled LD. The developers of the ELP put particular emphasis on the interactive element in learning, their theory being based on Vygotsky's work of the zone of proximal development (ZPD) (Englert & Mariage, 1996; Vygotsky, 1986). In the article, the excerpts of dialogue reflect the monologic viewpoint of the researchers who wish the readers to see that there are (a) conversations among students, (b) conversations among students on the researchers' desired topics, and (c) discernible patterns in the ownership of the conversations being slowly transferred from the teacher to students. The dialogue scripts never seem free of the dominance of the teachers' or the researchers' viewpoints. Englert and Mariage (1996) write, "The social interactions that unfold have the *flavor* of conversation [emphasis added]" (p. 158).

We think that the authors of the article might have made the conversations more dialogic if they first presented the students in their own words. This might require the inclusion of a narrative technique that takes into account and presents ethnographic information. However, no less important to the realization of a dialogue, we believe, might have the researchers consider curricular content and its meanings to the students. Like many other authors in psychology, the authors of the article seem to focus on process over content. For example, Englert and Mariage (1996) note, "An examination of the entire transcript from the lesson shows that students were acquiring many *skills* and *processes* related to writing [emphasis added]" (p. 164).

Bakhtin might say that it is not enough to confine presentations of dialogue to the realm of form. The presenters of dialogue must also write clearly about the effects of the content. To take the example of the student who "improved," readers may see the vision of the teachers dominating in terms of the student's text better meeting the guidelines of what the teachers consider good writing. This is an example of the monologue of the written text.

It seems that there is no discussion about the talk expressed in the student's writing. The authors' judgment on the student's text seems finalizing (i.e., the judgment does not consider the student's perception of his own writing in relation to the content of his life and his learning). We suggest that the researchers might arrange their study in such a way as to have the students talk about their own texts and researchers talk about the text with the student. From a Bakhtinian perspective, such reframing and contextualizing can make the content of the dialogue in the study more itself, that is, more dialogic.

Similarly, some articles concerning ELP (e.g., Englert, Raphael, & Mariage, 1994; Englert, Rozendal, & Mariage, 1994; Englert, Tarrant, Mariage, & Oser, 1995) imply similar limitations as those in Englert and Mariage's (1996) article. Among the articles on ELP, Englert, Rozendal, and Mariage's (1994) article about Adam is particularly interesting. The authors seem to give some time and space to the narration of how Adam improved his writing over the course of an academic year. It would seem, *prima facie*, that the article has more potential in achieving dialogicality since Adam, as a person, becomes better known through the study. However, we believe that the presentation of Adam too suffers from the monologism of the other articles.

For example, Englert, Rozendal, and Mariage (1994) write that, "In September [before the intervention], he [Adam] refused to gener-

ate any texts independently; in fact, he threw his chair across the room when he was asked to write" (p. 190). The authors go on to discuss details about Adam's writing in September. However, such a striking fact (i.e., a boy throwing a chair across the room) should not escape further commentary from Adam and the authors. We need more information about Adam that might help us understand his feelings in school. We need to hear from Adam why he reacted in such a way when asked to write. Adam's comments might then suggest his feelings about writing and schooling. We need Adam to talk retrospectively about the earlier incidence of his throwing a chair, so that we can gain a clearer sense of what writing has done for him and, more generally, how competent intensive instruction from others (e.g., the researchers and the teacher together) has helped him. Once again, the authors seem to miss an opportunity to allow the readers to get closer to Adam's discourse, which we can know to be reflected only through his own words.

Other articles address the role of dialogue in writing instruction; they too fall short of achieving dialogue in a Bakhtinian sense. One such article is about Morning Message (Mariage, 2001), which is a dialogue-based interactive writing session that involves the whole class guiding and sometimes directing a student seated in the front of the classroom with the teacher seated beside her or him as a scribe. The researchers focus on aspects of the teacher's verbal behavior that make her effective. The study is a linguistic analysis of the teacher's side of engagement in dialogue. For example, the authors write, "... The total number of [conversation] turns across the five events was divided by the number of lessons the student participated in to arrive at the average number of speaking turns per event. Participants were rank-ordered by the average rates of participation..." (Mariage, 2001, p. 177). Bakhtin might say that such a quantitatively driven study misses the artistic quality of human interactions and reduces such interactions to their most external facts through an

analysis of components of performance and not their holistic effect.

A Bakhtinian study might attempt to reveal the students' and the teacher's personalities and have them engage in classroom talk. In such a scenario, the authors might attempt to reveal contexts and meanings around such talks through thick narrative descriptions. The authors might point out how the classroom talks move to reflect the interpenetration of the participants' consciousnesses. Bakhtinian conversations might reflect without resolving or fusing people's differences in personality and perspectives how each approaches the topic of a conversation.

Our review of two other articles (Wong, 1997; Wong, Butler, Ficzer, & Kuperis, 1996) on teaching writing through genre-specific strategies (e.g., teaching the reportive essay, the opinion essay, and compare and contrast essay) may also imply a limited conception of dialogue. Wong and her colleagues seem to explain the role of dialogue in the students' pairing up and then collaborating through think-aloud and peer critiques. However, we think that both articles stress process over content, which makes the dialogue less from a Bakhtinian perspective.

To illustrate our point, in Wong's (1997) article she writes, "When adolescents with LD are the target subjects, one has the added problem of motivation. Invariably, when that occurs, the intervention researcher faces total cognitive shutdown in the adolescent with LD, and has the unenviable task of cajoling him to apply himself [sic]" (Wong, 1997, p. 156). Bakhtin might inquire dialogically about the conditions that lead to a loss of motivation among students instead of passing a verdict, as the author seems to, which finalizes the existence of problems as perhaps an implicit part of having LD. In this article, the authors suggest the parameters of boredom without revealing the specific curricular circumstances of content that lead to such a state for the student.

In contrast with Wong's (1997) study, Wong, Butler, Ficzer, and Kuperis (1996) examination of teaching writing through the genre of opinion essays seems quite a bit less dialogic. Even though the authors mention in the procedures section that the planning and the revision phase involved dialogue among paired students, the authors fail to represent and reveal the dialogue among the students. They exclude any samples of how the students talked and failed to achieve dialogue. The authors pose research questions to determine the effectiveness of the opinion essays and by default, end up forfeiting any reason to include samples of actual student dialogue --as such, an epistemological move might fall outside the purview of questions posed within a quantitative framework. When describing classroom dialogue during the study, the authors depict scenarios that imply monologism and not dialogism. For example, in the revision phase the authors note that they told the students in pairs that each would alternate between being a critic with her peer. The authors write:

"The student-critic's (student A's) role was to spot ambiguities in the partner's, student B's, opinion essay.... After this student critic (student A) had finished critiquing student B's opinion essay, the teacher-researcher would go through ambiguities that she had found in student B's essay and seek clarification on them" (Wong, Butler, Ficzer, & Kuperis, 1996, p. 203).

In the sequence of the editing described in the excerpt, the teacher's editing operates as the standard to which the students aspire as they peer edit. The student first tries her hand at critiquing and editing, and then the teacher implicitly fills in any gaps in the essay the student has not pointed out. Such a process constitutes a fairly stringent standard for considering the essay "adequate" and reflects the vision of the teacher. A student's role as a peer editor is constrained by the teacher's vision of what a good essay should be. In this sense, the authors

want that students' judgments should aspire to be more like the teacher's, which is the heart of monologism. Researchers might facilitate instruction so that students become aware that the comments they make on their peer's essays will not be judged on the basis of the authoritative voice of the teacher.

In addition to writing skills, some authors address reading instruction through a comprehension strategy known as POSSE (an acronym for predict, organize, search, summarize, and evaluate) to help students labeled as LD read better (e.g., Englert, Rozendal, & Mariage, 1994; Mariage, 1995). Mariage's (1995) article seems to compare verbal performances of high with low-gaining student teachers. The author seems to analyze the transcripts of dialogue through POSSE to discover patterns of differences that the two categories of teachers demonstrate. The author states that high-gaining teachers more often used such techniques as teacher initiation statements, teacher evaluative statements, and teacher scaffolding statements.

As in the other study we reviewed by the same author, in another article Mariage (2001) seems to single out external features of the high-gaining teacher's speech that may have "caused" the superior academic results of students. The author does not present the students' dialogue, but instead lists the frequency counts of the teacher's speech during POSSE and also tallies the teachers' statements isolated from their dialogical context in which not only teachers, but also students spoke in class.

Bakhtin might question Mariage's extraction of the teacher's words from their embedded streams of conversation. It is as if a linguist has uprooted for inspection the teachers' words from their organic context. From the author's presentation of the teachers' bits of speech grouped into high and low-performing categories, readers can no more than speculate about what happened during the dialogue. From a Bakhtinian context, without including the students' words,

the author fails to present even the rudiments of dialogue in the article. Conversations are multisided events that cannot be artificially fragmented and homogenized of their sociopolitical contexts without losing their meanings in the classroom.

MacArthur's (1998) article is further testimony to the problem of being somewhat oblivious about the talk around interventions in the classroom. He writes about the effects of a computer program that allows students labeled as LD to use speech synthesis to write legibly in student-teacher dialogue journals. MacArthur uses a multiple-baseline alternating design to study whether moving students from traditional writing exercises (i.e., writing on the word processor) to a word processing program equipped with assistive technology increases legibility or the ability of the reader to make sense of what the student has written.

We point out that the author seems to be wholly devoted to the process of how he arrived at the results of his study. The article indicates very little about the content of the dialogue, except in one place where the author writes about the students' difficulties with finding something to write about, "... Students wrote to the teacher [in the dialogue journal]. If they had trouble thinking of what to write or if they wrote fewer than three sentences, they were prompted to write more using standard prompts suggesting that they answer the teacher's question, ask a question, or tell something that they did in class or at home" (MacArthur, 1998, p. 156).

We would like to know what the students thought about the writing assignment and not just what they thought as reflected in the author's summary found in the "Social Validity" section. In addition, we would like to hear from the students on an ongoing basis, so that their thoughts do not fossilize and become silent through time. We would like to see another layer of information regarding student commentary on the assignment and counter-com-

mentary from teachers. We would especially like to hear what the students have to say about the purposefulness of the assignment, what parts of it they find meaningful and relevant, and in what ways. Also, we wish to hear students talking about the content of what they are writing, which can add to our understanding of the meaning of dialogue between each student and the teacher. When the researcher talks mostly about the process of inquiry in a limiting way and neglects to write about the talk around content, that is, about the dialogic experiences of the participants, Bakhtin might suggest that such a way of writing research ignores, diminishes, and finalizes dialogicality, an inherent part of conducting research.

Our examination of two articles by two groups of authors (Leshowitz, Jenkins, Heaton, & Bough, 1993; Wong, Butler, Ficzer, Kuperis, Cordon, & Zelmer, 1994) further implies the problem of dialogue without representation. Wong, Butler, Ficzer, Kuperis, Cordon, and Zelmer (1994) conduct a positivist study about dyadic interactions among students labeled as LD. They do not discuss how the dialogue functioned in these dyads. Similarly, Leshowitz, Jenkins, Heaton, and Bough (1993) do not discuss how dialogue between a teacher and students labeled as LD leads to superior results in critical thinking. Both groups of authors present statistical results to indicate the efficacy of dialogue for instructing labeled students, but they fail to discuss through a contextually sensitive analysis how the dialogue functioned in their studies.

We think that these authors pay scant attention to representation as a vehicle for communicating qualitative aspects of human interaction. Both groups of researchers might arrange their studies so as to allow the students not only to speak, but also to be heard by readers. The researchers might also present samples of talk and counter-talk between students and teachers to further dialogize their study and improve the ability of the reader to hear the students' discourses. For example, Dudley-Marling (2004)

explicitly illustrates samples of talk and counter-talk between teachers and students. He shows how two teachers use a different pattern of talk with their students. The talk between the first teacher and a student labeled as LD is not as interactive as the second teacher and her students. Moreover, Dudley-Marling notes about the first teacher, "... In this nearly dysfunctional interaction between Regis and Mrs. Stroh, while maintaining the assumption that there is something wrong with Regis..." (p. 486). The pattern of talk between the second teacher and her students with academic difficulties is very different from the first case. When the second teacher talks with a few students with language difficulties, she provides them with plenty of chances to talk and take positions, and justify points that help them engage actively.

Regarding the second sample of talk, Dudley-Marling notes that, "In particular, rather than positioning himself as someone on the lookout for deficits in need of remediation, the teacher established himself as an interested listener..." (p. 488). As these two samples of talk illustrate students' interactions with teachers, the talk presented between teachers and students labeled as LD helps readers understand the spirit or the holistic tone of the participants' discourses. But on this score, the authors could provide more narratively-construed details to help us vividly see and hear the contexts in which these conversations took place in their respective classrooms.

Smith and Griffin (2002) conduct a study about teaching incarcerated juvenile delinquents labeled as LD. The authors visit a prison to teach juvenile offenders how to engage properly in dialogue. In the treatment section of the study, the authors (researchers and language-speech pathologists) seat the adolescents around a table and monitor and prompt them to find out how they talk on given topics. Raters score the adolescent's conversational skills through such criteria as appropriate transitions, responsiveness, and feedback events. We believe that such conversation trainings may reflect the interests of

researchers more than those of the adolescents labeled as LD who are jailed. Researchers seem to make no attempt to represent the dialogue that occurred during these sessions. Nor do they provide any context for understanding the people they research.

The authors do not tell readers about the participants' social class and ethnic backgrounds beyond the teenagers' psychometric profiles, ages, and genders (all males). The authors fail to mention and explicate the implications of the teenagers' racial and socioeconomic backgrounds. The study fails to develop any sense of historicity, a sense of community from which the teenagers came. The subjects of research seem to cease to exist. The study takes on a distinctive feel of Pygmalion. The researchers seem to want to teach the teenagers the "art" of talking, which may be quite removed from the context of the society from which the children came, a society steeped in poverty and violence that affects the lives of inmates throughout their lives.

Finally, we review Valle and Aponte's (2002) article that does well a lot of what we point out as weaknesses of the other articles. Valle and Aponte (2002) present a narrative about the dialogue between the mother of a student labeled as LD and the special services professionals she meets in the school concerning the needs of her child. Through the structure of the article Aponte, the mother, emerges as a person with a particular accent and position in the world that she articulates through her own words. What we feel can be improved in the article, however, has to do with the professionals that Valle and Aponte address in their article. Bakhtin might say that we need to hear from the professionals too about what Valle and Aponte are thinking and saying. To heighten the ongoing nature of talk and the creative aspect of seeking knowledge, we think that adding another layer of cross-talk between professionals and the parent and the researcher might enrich the insights the study has to offer and at the same time, make the findings less finalized, less abrupt.

Theorizing Dialogue from the Learning Disability to the Learning Person: Points of Further Dialogue

In his book *Rabelais and His World*, Bakhtin (1968) finds in the writings of Rabelais, the novelist, signs of a fundamental shift from a vertical world of relatively fixed hierarchies to a horizontal plane, where carnivals functioned to dissolve the power differences into a commonly shared event cleansed with uncrownings, unmaskings, profanations, and laughter. Thus, Bakhtin traces a basic change in people's thinking informed by a newfound sense of bodily and mental freedom in the time of European Renaissance. In describing this historical shift, Bakhtin (1968) writes:

“[S]uch concepts as becoming, the existence of many seeds and of many possibilities, the freedom of choice, leads man toward the horizontal line of time and of historic becoming. Let us stress that the body of man reunites in itself all the elements and kingdoms of nature, both the plants and animals. Man, properly speaking, is not something completed and finished, but open, uncompleted” (p. 364).

If there had been a relative suspension of hierarchies during Renaissance, then, as Davis (1997) points out, belief in hierarchies crept back into being in the enlightenment age that followed the period of the renaissance. Foucault (1970; 1972) argues that we have perhaps never left the enlightenment age, as apparent in ways we obey the call of and at the same time, avoid confronting and critiquing science.

Eskin (2000) writes that of all the other theorists of dialogue, Bakhtin is the only one who emphasizes the function of authorship and the central role of art in dialogue. Bakhtin's notion of the importance of art in accounting for and understanding human experience may be considered antithetical to the impulses of enlightenment science. He imagines a truly different world order in which every person harmonizes

with everyone else based on differences and not similarities. In such a transformed world, we listen to students labeled as LD and indeed to all students, unhindered and let students speak more freely. This is in juxtaposition to the often stringent world we live in, where, as Dudley-Marling and Dipppo (1995) demonstrate, differentiated instructions that schools provide to students labeled as LD often reveal a concern for sameness, streamlining, and seldom, for differences. This is an oppressive, authoritative discourse of the “regular,” nondisabled child in school.

In such a transformed world, we might treat each student as an individual through supporting classroom practices in which teachers arrange broad plotlines through dialogue with students, so that students speak and reveal their emerging points of view; classroom practices in which the teacher is unafraid to debate with and question students and to challenge them (without imposing of course), and be challenged by them. In such a world, we might see classrooms where the teacher is unafraid to hear them (i.e., each disabled person in the classroom) over and above a fear of the unknown. For each person labeled as LD is unknown. What we know of each student he must tell us.

Michalko (2002) tells a story about his meeting with a blind girl named Jenny and her trainer named Cheryl. In the story, Michalko brings up a striking point that we think has potential for explicating the implications of limitations we came to realize that exist in the articles we examined. Michalko writes that from the outside of a person's inner life, we can never really understand what the person is thinking or feeling. We might add that from the outside, we cannot understand what a student labeled as LD knows or feels inside her or himself. As a sensitive observer, Michalko understands this basic point - the impossibility of crossing the boundary into Jenny's world. However, Cheryl, Jenny's trainer, is less wary about the implications of imposing her own sense of the world upon

Jenny. She would like to support Jenny in the world, to help her.

We observed a similar emphasis in our articles, placed on supporting students labeled as LD. From our review of the articles we came to believe that researchers need to dedicate more time and resources to have students engage in dialogue and through it, allow for the emergence of their unique thoughts and feelings, their discourses, which can help them learn and perhaps even more importantly, help them figure out the implications of learning for their own lives.

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The Uses and Implications of the Term “Retarded” on YouTube

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Abstract: In this article, we provide a historical glimpse into the changing use of terminology for people with intellectual disabilities. In order to determine how the word retarded is currently used in popular culture in the United States, we analyzed one hundred randomly selected YouTube videos with the word retarded in the title. Five themes emerged: (a) the traditional use of the term retarded, (b) the use of retarded in humorous context, (c) the use of retarded to insult or criticize, (d) the term retarded as a substitute for other words, and (e) the slang use of retarded in a hip hop context. The coexistence of these multiple definitions is an unprecedented situation in the history of disability terminology. While advocates in the US are pushing for abandonment of the “R” word, establishing rules about language use is clearly a simplistic solution to a complex problem.

Key Words: retarded, disability terminology, YouTube.

Editor’s Note: This article was anonymously peer reviewed.

Introduction

The US federal government has used the term *mental retardation* as a special education classification since the passage of The Education for All Handicapped Children Act of 1975. However, many school districts and professional organizations in the United States no longer use the term. For example, The Arc, the primary parent and family advocacy organization for people with intellectual disabilities, no longer uses the term mental retardation because it “was offensive to many people” (The Arc, 2004). Instead, in their mission statement, The Arc uses the terms *children and adults with cognitive, intellectual, and developmental disabilities*. The

American Association for Intellectual and Developmental Disabilities (AAIDD), the primary professional organization in the field, uses the term *developmental and intellectual disabilities* (Prabhala, 2007).

Currently, many people use the word *retarded* in a derogatory manner (Walsh, 2002). The meaning and context of retarded has changed over time and is now used in everyday language to imply a person is “foolish or socially inept” (The American Heritage Dictionary, 2006). More recently, this term is being used in a variety of ways on the Internet video-sharing site, YouTube. YouTube specializes in brief videos created and submitted by users and reports 10 hours of video footage uploaded every minute (Sarno, 2008).

In light of these situations, there are two research questions that guided this study (a) How has use of the term *retarded* changed over time?, and (b) How is the term *retarded* used on YouTube? For consistency purposes, the term *intellectual disability* will be used in this paper in place of the more controversial mental retardation.

A Brief Chronological History of Mental Retardation Terminology

Prior to 1700

Although historical accounts of individuals with disabilities date back to ancient civilizations (Berkson, 2006; Patton Beirne-Smith, & Payne, 1990), *idiocy* is one of the oldest disability terms and its use can be traced to the 13th century. While the word idiot is now used as demeaning slang, the origin of the Greek word *idiotus* simply meant “a person who does not take part in public life” (Patton, Beirne-Smith, & Payne,

1990, p. 36). This characterization indicates the beginning of labeling for individuals with intellectual disabilities.

1700 to 1900

During this period of time, the notion in Europe was that all people were created equal and, therefore, even those who had disabilities should be given rights (Patton, Beirne-Smith, & Payne, 1990). The individualized educational approach of French physician Jean-Marc Itard revolutionized the treatment of individuals with developmental disabilities. The belief in the equality of all people spread to the United States, and in 1855 Samuel Gridley Howe founded the Massachusetts School for Idiots and Feeble-Minded Youth in Boston (Verstraete, 2005).

The term *feeble-minded* began to replace the term *idiot* during the 19th century (Noll & Trent, 2004; Walsh, 2002). In 1876, the Association of Medical Officers of American Institutions for Idiotic and Feeble-minded Persons was formed as the first professional organization in the disability field (Reynolds, 2006). By 1892, almost every state in the United States had at least one residential training school for individuals with intellectual disabilities (Minnesota Department of Education [MDE], 2004). Viewing Performances

1900 to 1940

Throughout this time period in the U.S., individuals with intellectual disabilities began to be perceived as a burden and menace to society. Residential training schools were converted into warehouse-type institutions. Concurrent with the institutionalization movement, eugenics was advocated as a means of controlling these individuals who were blamed for many of the social problems of the day (Elks, 2004; Noll & Trent, 2004; Patton, Beirne-Smith, & Payne, 1990). Professionals in the medical field desired a way of categorizing individuals who were labeled feeble-minded and consequently, created the subcategories: *moron*, *imbecile*, and *idiot* (Noll & Trent, 2004; Walsh, 2002). Henry H. God-

dard, an American intelligence researcher in the early 20th century, coined the term *moron* to refer to individuals who would now, in the United States, be classified as mildly mentally retarded (Greenspan 2006; Smith & Smallwood, 2007). The term *imbecile* was used to refer to individuals with moderate intellectual disabilities and *idiot* was used to describe those who had severe intellectual disabilities (Noll & Trent, 2004).

1940 to 1975

During the 1940s, conditions and treatment in institutions in the U.S. came under public scrutiny (Noll & Trent, 2004). Terminology also began shifting during this time to encompass the term *mental deficiency* (Greenspan, 2006; Noll & Trent, 2004; Walsh, 2002). The name for the professional organization in the field was changed from the American Association for the Study of the Feeble-minded, a title it gained in 1906, to the American Association for Mental Deficiency (AAMD). According to Greenspan (2006), the term *mental deficiency* was used until the early 1960s.

As this term began to acquire negative connotations over time, there was a push among disability advocates to use the label *mental retardation* (Walsh, 2002). Acceptance and empathy began to replace society's previous feelings of fear and disdain. In the United States, parents of individuals with disabilities became advocates for their children and began to organize. A notable result of this was the beginning of the National Association for Retarded Children, the primary advocacy group for parents (MDE, 2004; Noll & Trent, 2004).

According to Hewett and Forness, this parental and professional advocacy, combined with federal, state, and private funding, provided great impetus to the field in the U.S. (as cited in Noll & Trent, 2004). From the 1960s through the early 1980s, individuals with intellectual disabilities were classified by the level of care they required using the educational subcategories of *educable mentally retarded (EMR)*,

trainable mentally retarded (TMR), and *custodial* (Beirne-Smith, Ittenbach, & Patton, 2002; MDE, 2004). These categories reflected societal attitudes favoring services for individuals with intellectual disabilities, regardless of the severity of their disability.

1975 to Present

In 1975, The United States Congress passed The Education for All Handicapped Children Act (P.L. 94-142), which ensured that all children with disabilities were entitled to a free and appropriate public education in the least restrictive educational setting (Hallahan & Kauffman, 2006). In 1990, this law was reauthorized as the Individuals with Disabilities Education Act (IDEA), a name change that emphasized “person-first” language. However, the federal IDEA designation for students receiving educational services in this category was unchanged. Educators, researchers, clinicians, and other professionals in the United States continued to use the term mental retardation (Goode, 2002).

IDEA was reauthorized again in 1997 and 2004 with no changes to the federal category of mental retardation. Recently, advocacy groups in the U.S. have supported changes to federal and state educational categories to an alternative term such as *cognitive* or *intellectual disability* (Prabhala, 2007). In fact, terms other than mental retardation are now used by 25 states to classify students with intellectual disabilities. Forty-three states continue to use the federal definition or a slight derivation of it (Muller, Markowitz, & Srivastava, 2005).

There are many reasons for these seemingly never-ending changes to disability terminology, the main one being that the terms used to describe people with intellectual disabilities have consistently taken on demeaning connotations (Smith & Smallwood, 2007). Consider for example, the everyday use of the terms moron, imbecile, and idiot, terms which were once used to describe individuals with mild to severe intellectual disabilities. Their changed meanings in-

dicating that simply adopting new names to identify those individuals appears to be a short-term solution (Prabhala, 2007; Smith & Smallwood, 2007; Walsh, 2002).

The concept of an intellectual disability is highly fluid and subject to change. Students in U.S. schools are classified as mentally retarded based on how they score on tests such as the Wechsler Intelligence Scale for Children (WISC). Classification levels on these tests are arbitrarily set. At one time, the upper limit for classification was 85 (Heber, 1961), and in the following decade, it was 70 (Grossman, 1973; 1977). While this change led to a decrease in the number of individuals considered mentally retarded in the U.S., updated tests with new norm groups can create the reverse situation. If every state had switched from the WISC-R to the WISC-III when the latter was introduced in 1991, the number of individuals in the United States labeled mentally retarded would have doubled (Gladwell, 2007). Although it is important to recognize the socially constructed nature of the disability that gives rise to the mentally retarded label, the focus of this article is on the changing nature of the terminology used to describe those so classified.

The extant literature that explores the fundamental nature of the relationship between language and disabilities is limited in scope and reveals mixed findings. Little to no research has been conducted to determine the relationship between language and intellectual disabilities in new electronic-media domains such as YouTube. This research attempts to fill this gap.

Communication and YouTube

YouTube is available in 24 different countries in 6 continents, in addition to the worldwide version. Viewers can select the country content they would like to view, as well as the language for the website text (YouTube, 2010a). With 35 hours of video uploaded every minute (YouTube, 2010b) and 2 billion videos watched

per day (YouTube, 2010c), YouTube is the leading forum on the Internet through which people can share, watch, and comment on videos. People can share videos by uploading them from personal computers, mobile devices, or by recording directly on to the site (YouTube, 2010b). With the increased accessibility of the Internet and the many user-friendly options to share videos without needing electronic expertise (Sandoval, 2006), people are fulfilling their desires to have a voice. In fact, in 2008, YouTube was granted a Peabody Award and was described as a “Speakers’ Corner” that both embodies and promotes democracy (Peabody Awards, 2008).

Since being launched in February 2005, the uses and purposes of YouTube have expanded exponentially to include almost anything. People who become members of YouTube can have personal channels to which other viewers can subscribe. YouTube has progressed from allowing people their “15 minutes of fame” (Warhol, 1979) to creating overnight stars. As Palfrey and Gasser (2008) point out, these new forms of expression are unlike anything the world has seen before. A cooking series, “Show Me the Curry,” which was started by two stay-at-home moms, is now a channel with almost 19,000 subscribers. Academic scholars and professors have produced videos in order to share their lectures and explain new concepts in their fields (Young, 2008). Scientists from the University of California, San Francisco have joined YouTube in an effort to drive medical research (Driving Medical Research via YouTube, 2008). The US Internal Revenue Service has joined the YouTube community by creating four 30-second videos explaining the process of claiming tax rebates from the economic stimulus plan (Kutz, 2008). Video instruction of learning another language can easily be accessed by a simple YouTube search. It is even possible to watch video clips of television shows and music videos from previous decades.

It is difficult to find a societal topic that has not made an entry into the YouTube community. It seems as if everybody wants to be in on

this new form of electronic communication. In 2007, YouTube even started annual video award recognitions, a situation that created overnight stars. Tay Zonday won the 2007 YouTube Musician of the Year award and subsequently appeared in the US financial newspaper *The Wall Street Journal* and the entertainment-centered *PEOPLE Magazine*, as well as numerous shows on US television (Zonday, 2008). Because of his popularity on YouTube, Judson Laipply, creator of the all-time most viewed video on YouTube, Evolution of Dance, was invited on to Oprah, The Today Show, and the Ellen DeGeneres Show (Oprah After the Show with Mr. Evolution of Dance, 2008; Smith S., 2007). In 2006, an ordinary man in Hong Kong became front page news in that country after a video of him arguing with a passenger on a bus was uploaded to YouTube, and shortly afterwards became the most viewed video on YouTube (CNN.com International, 2006). Although these individuals’ newfound fame began on YouTube, it quickly filtered into mainstream popular culture. The simple and straightforward manner in which this process takes place demonstrates the growing influence and popularity of YouTube. The research described in this article explores how the rapid transmission of ideas through YouTube has affected the use of terms related to individuals with intellectual disabilities.

Method

Procedure

On November 6, 2007, the word retarded was entered into the YouTube search engine using the default “relevance” setting and 45,600 hits were returned. To reduce the sample, the list of returned videos was analyzed for selection features. An examination of the text associated with the videos revealed that after the first 400 videos, the word retarded did not consistently appear in the title. Many videos after this point contained the word in the author’s description or in the comments section written by viewers. Therefore, only the first 400 videos were retained

for the initial pool. To ensure that the videos had been viewed by a large number of people, only those videos that had been viewed a minimum of 1,000 times were retained. Videos were then removed from the sample if they had not been on YouTube for at least 3 months. These sorting criteria were established to produce a sample of videos containing the word retarded in the title that had been viewed with high frequency for an extended period of time.

This initial sort produced a sample of 222 videos. These videos were copied and pasted into a Microsoft Word document to create a numbered list of still video images containing the embedded hyperlinks, allowing for immediate access to the live videos on YouTube. An online random number generator was used to compile a list of 100 random numbers, which were then used to select videos from the list. This resulted in a final sample of 100 randomly selected YouTube videos.

Data Analysis

Using qualitative techniques, the researchers used consistent procedures to record information about each video and analyze the data. The YouTube website provided factual information about each video. Before watching each video, the following information was recorded on the front of a large note card: (a) the title of the video, (b) the summary written by the individual who posted the video, (c) the date the video was added to YouTube, and (d) the number of times the video had been viewed.

The videos were viewed multiple times by both researchers. Notes were taken and compared to reach consensus throughout the process. An emergent research design was used to code and categorize the videos. First, the researchers watched the videos to determine where the word retarded was used (e.g., title only, song lyrics, dialogue, printed text). These data indicated initial ways to categorize the videos. The researchers watched the videos again to determine the referent (e.g., other people, things/

objects, nonhuman characters, actions). The use and tone of the word (e.g., negative, neutral, positive) were then recorded along with the purpose of the word use (e.g., humor, criticism, education). The format of the video (e.g., live footage, animation, music performance) was also documented. Videos were watched as many times as was necessary to obtain this information. These initial categories were then recorded on the back of each video note card.

A review of these categories revealed four main video formats and these were each broken down into several subcategories. Further analysis of the data revealed three more relevant categories. These included: (a) whether individuals were aware of their being filmed for a YouTube video; (b) whether individuals were pretending to have, or actually had, an intellectual disability; and (c) whether text, music, or dialogue was added to existing footage. Videos were then viewed to determine the use of retarded in each of these contexts (e.g., people with disabilities who were unaware of being filmed, original animation using the word retarded in title/dialogue). Table 1 was then created with counts of the videos that fell into each category. Some overlap occurred in this section between altered animation, live footage, and music lyrics.

The researchers then began an ongoing process of grouping themes from the individual videos and categorizing these into common themes among all videos. Direct quotes from the videos and the synopsis added by the individuals who submitted the videos were used to verify and clarify identified themes and categories. The index cards were read and reread to determine recurrent uses of the word retarded. Five themes were identified. Again, the researchers conferred and reached agreement over the uses of the word retarded and the naming of themes. These themes are described in the following section.

Table 1. Video Format of Retarded

Use of word	Number (N = 100)
Live Footage	
People with disabilities - unaware of being filmed	2
People with disabilities - aware of being filmed	4
People without disabilities acting as if retarded	9
People without disabilities - word retarded used in title or verbally in video	30
Music Video	
Black Eyed Peas song, "Let's Get Retarded"	18
Original song with retarded in lyrics	9
Altered Animation	
Existing animation with dialogue containing word retarded dubbed over original	3
Existing animation with text containing word retarded added	10
Existing animation with music containing word retarded dubbed over original	10
Existing animation with alterations - word retarded used in title	6
Original Animation	
Animation and dialogue created - word retarded used in title and/or dialogue	9

Results

Overview

Table 1 shows the four main video formats in the YouTube videos, along with the way retarded was used and the number of videos in each category.

Almost half of the videos ($n = 46$) were classified as live footage. These videos included

footage of individuals who had disabilities, but did not appear to be aware of the fact that they were being filmed. There were also videos of people who had disabilities and appeared aware of the fact that they were being filmed, albeit not necessarily for a video that would be posted on YouTube. Of those individuals who did not have disabilities, some were performing the part of a person with an intellectual disability. In the majority of cases ($n = 30$), however, the word retarded was used in the title or verbally in the video.

A considerable number of the YouTube videos included music lyrics containing the word *retarded*. Of the 27 videos that fell into this category, 18 were based on the Black Eyed Peas song, "Let's Get Retarded." The videos that featured this song were presented in various formats including (a) animations with the song as a soundtrack, (b) videos of people dancing to the song, and (c) images or photo clips set to the song. The lyrics contained in the remaining videos ($n = 9$) were written by a variety of individuals with the only commonality being use of the term retarded.

Over one-third of the videos ($n = 38$) were animations. These videos were categorized according to how they were created: (a) existing animations from television shows or video games, (b) altered existing animations, or (c) original animations. The alterations of existing animations varied, but uniformly used the word retarded in the new creation.

Table 2 shows how the word retarded was used in the YouTube videos. Specifically, it shows the referent and whether the use was negative, positive, neutral, traditional, slang, or unidentified, along with the number of videos that fell into each category. Some of the videos fell into multiple categories.

A small portion ($n = 9$) of the videos contained the word retarded solely in the title. In some cases ($n = 3$), the word in the title was referring to the created video, but in the other

Table 2. Context of Retarded

Retarded referent	Number
Title only	9
Unidentified/arbitrary use	9
To refer to self	8
Negative use	2
Traditional use	6
To refer to others	25
Traditional use	3
Negative use	22
To refer to things/objects	10
Neutral/positive use	5
Negative use	5
To refer to nonhuman characters	16
Traditional use	2
Negative use	14
To refer to actions	7
Neutral use	2
Negative use	5
Song lyrics	27
Unidentified/arbitrary use	9
Slang use “get crazy,” “have fun”	18

Note: “Traditional use” refers to situations in which the word was used to describe a person/animated character with an intellectual disability.

instances, the word retarded did not seem to be referring to anything in particular. In one-third of the videos, the term retarded was used to refer to people. In 6 of 8 cases where an individual used the word as a self-description, the person actually had an intellectual disability. Such instances were considered to represent traditional use of the term. Ten videos used the term retarded to refer to objects or things, such as cars, Internet browsers, and the videos themselves. The authors of half of those videos (n = 5) used the term in a way that illustrated pride in their video creations. Such use was determined by the researchers to be a neutral or positive use of the word.

The word retarded was used to describe nonhuman characters in 16 videos. Nonhuman characters were typically animals or animated characters. In two of these cases, the nonhuman characters were actually portrayed as having an

intellectual disability. Seven of the 16 videos used the term retarded to refer to the actions of individuals in the videos.

Song lyrics formed the largest context for the use of retarded, accounting for 27 of the videos. The use of retarded in 18 of these cases referred to the slang use meaning to “have fun.” The remaining nine videos used the term retarded in an arbitrary way that was unidentifiable to the researchers.

Themes

Five themes emerged from the analysis of the term retarded in the YouTube videos: (a) the traditional use of term *retarded*, (b) the use of *retarded* in humorous context, (c) the use of *re-tarded* to insult or criticize, (d) the term *retarded* as substitute for other words, and (e) the slang use of *retarded* in hip hop context.

Traditional Use of Term Retarded

The term mentally retarded became an official special education classification in the US with the passage of P.L. 94-142 in 1975 (Hallahan & Kauffman, 2006). For the following two decades, the term was used in everyday language without much controversy. As the term came to take on negative connotations in popular culture, many advocacy organizations and state education departments saw the need to abandon the term and replace it with a new one. Use of the word retarded by people with intellectual disabilities in the YouTube videos indicated that despite official changes, these people continued to use the word in its traditional sense. This suggests that official changes to terminology do not necessarily change the way that people identify themselves, or if they do, there may be a time factor involved. This quote from an individual on YouTube illustrates this point:

“Asking me to see being called ‘retarded’ as an insult is asking me to choose a medical over a social category.... The word ‘retarded’ just means ‘slow.’ I don’t know what the big deal is about being thought

of as slow. By some standards I am slow, very slow. This does not mean that I think it's okay to use the word 'retarded' as a substitute for 'stupid'" (About Being Considered "Retarded," 2006).

In another example, Josh Perry, an individual with Down syndrome, who stars in the popular *Retarded Policeman* series, (each video has been viewed 1.5 to 2 million times) appears with his sister who states, "He is an actor," and "He is hilarious" (Perry, 2007). Josh and his sister acknowledge that Josh has Down syndrome and that he is an actor who wants to act for a living. It is implied that Josh understands his disability and is "using it" to his advantage to act in the *Retarded Policeman* series on YouTube. A search of the Internet Movie Database (IMDb) revealed that Josh Perry is represented by an agent in Los Angeles, California, and has appeared in cable television shows in parts that did not involve his disability. This situation indicates that Josh chooses to use the term retarded in its traditional sense and that he embraces this identity to perform certain roles and further his acting career.

Use of Retarded in Humorous Context

When the word retarded was used in a humorous manner in the YouTube videos, it appeared that the intent was not to be deliberately offensive. The word was being used in videos created for the purposes of entertainment. An example of this use was evident in the video, *Retarded Kids Show* (2006), in which puppets and actors in costume acted out a skit. While the word retarded was not used in the video, the implication through its use in the title and the accompanying content of the video was that the performance was intended to humor and entertain its audience.

The video *Cute and Retarded Animals* (2007) was constructed of images and clips of animals doing odd or silly things. Text added to this video stated, "cute first" and "now retarded," with the first clips showing animals doing

cute things, and the later clips showing animals doing silly or funny things. The overall purpose of this video was clearly to provide lighthearted entertainment. In another video, a young man was clearly having fun dancing in a humorous way (*Retarded White Kid Dancing*, 2007). The video was presumably created to entertain those who were recording it and subsequently those who viewed it on YouTube.

A question posted on *Yahoo! Answers* in July, 2009, asks "What's something retarded/fun to do?" This is an example of the word retarded being used in conjunction with the word fun. This appears to be a new use of the term retarded. The word has strayed from its traditional sense, but unlike the common understanding of the shifting use of the word, it is not explicitly negative or offensive.

Use of Retarded to Insult or Criticize

The term retarded is frequently used in everyday popular culture in the US to criticize or refer to a person or thing in a negative sense. Retarded used in this way puts a negative spin on the word to attribute supposed characteristics of a person with an intellectual disability to a person without such a disability. This was deemed to be the most malicious use of the term identified through this research. When the word retarded was used as an insult or to criticize a person, it was a deliberate and direct attempt to put that person down. This use of the word was evident in a YouTube video in which Tucker Carlson, MSNBC's senior campaign correspondent, compared Canadians to "your retarded cousin" (*Tucker Carlson Calls Canadians Retarded*, 2006). The word retarded was deliberately used to belittle and insult Canadians.

Other examples of YouTube videos that used the word retarded to criticize or put down others were *Retarded Comedy Time* and *Retarded Moshpit*. In *Retarded Comedy Time* (2007), an individual without an intellectual disability was imitating a person with such a disability in a negative and demeaning way. The performer, a

small-time comedian, was acting in this way to elicit humor, but the actual outcome was overtly demeaning and insulting to individuals with intellectual disabilities. *Retarded Moshpit* (2007) featured individuals without visible disabilities dancing at a concert. The use of the word retarded in this case was being used negatively to insult the individuals by implying that they were not good dancers.

In another video, *Retarded YouTube Users* (2006), a compilation of photos and video clips presented depictions of people with disabilities along with offensive text. Where people without disabilities were shown, the implication was that they were retarded like the other individuals who were featured. In one case, the text that accompanied the image of a person without a visible disability read, “Not retarded, just very, very, creepy.” The images and text in this video were explicit in the negative attitude they expressed towards people with intellectual disabilities.

Term Retarded as a Substitute for Other Words

The word retarded is frequently used as a substitute for other words. It is a word that now “expresses disdain or stupidity, funny or simpleness” (Hoad, 2006). Through the analysis of YouTube videos, it was found that retarded was used in the ways mentioned by Hoad, in addition to some other uses, not all of which were negative. For example, there was a video in which the individual consecutively stated, “That was retarded...that was amazing” to describe an event (Steve Meade-Retarded Knock, 2007). In this situation, the individual was using the terms *retarded* and *amazing* synonymously.

In another video, *The Most Retarded Fergie Video U Will Ever See!* (2007), the creator had filmed her own “music video” using the music of Fergie’s song, Glamorous. Based on the fact that the individual who posted the video seemed to be proud of her creation, the word retarded in the video’s title indicated a positive use. In fact, the words “most retarded” in the title could easily be substituted for “best” without altering the

creator’s intent. In *How Retarded Can YOU Get to the 90s??* (2006), the individual featured in the video was reminiscing about, and lip synching to songs from the 1990s in a fun, theatrical way. The term retarded in this case could be substituted for the word “silly” in the title without changing the meaning.

The researchers classified the video *J Retarded Version* (2007) as an altered animation. The music lyrics and text in the video were in Chinese and the researchers were therefore unable to determine the exact use of the term retarded. Information about the user who posted the video to YouTube indicated that he was a 12-year old boy from Taiwan currently attending an Anglo-Chinese school in Singapore. It is significant that despite the fact that the video was made entirely in Chinese, the term retarded was still used in the title. This indicates that the substitution of the word retarded for other words is a phenomenon that has infiltrated English-speaking countries around the world.

Slang use of Retarded in a Hip Hop Context

The term retarded is used in hip hop slang and party vernacular to mean “have fun/go crazy.” Flexner (1975) described this type of word use as a counterword, a word meaning that has expanded to have wider applicability than that of the original referent (as cited in Moore, 2004). The word retarded and the expression “get retarded” with this particular meaning can be found online as early as 2003. In a web-based urban dictionary, the expression “get retarded” was defined by a user as, “To consume intoxicating alcohol or drugs to the point where you are incapable of verbally communicating past incoherent mumbles. Motor skills are also severely hampered thereby giving the overall impression of severe retardation--‘Let’s go out and get retarded tonight at the bar’” (Urban Dictionary, 2003a). Similarly, the word retarded was defined as, “The act of getting wasted on drink or drugs i.e., being in a retarded state. *Man I drank so much last night I was retarded, and let’s get re-*

tarded” (Urban Dictionary, 2003b). This was the same year that the Black Eyed Peas song, *Let’s Get Retarded* was released. Eighteen of the randomly selected YouTube videos analyzed were based on this hip hop song. The majority of those videos (n = 16) consisted of the unaltered Black Eyed Peas song dubbed on to new footage. The diverse nature of these homemade videos indicated that the slang use of the word retarded was not limited to hip hop artists. One video, for example showed young white men dancing to the song while skiing and snowboarding in the French-speaking resort of Ovronnaz, Switzerland (Los Kippos - Let’s Get Retarded, 2007).

In another YouTube video, the creator dubbed the Black Eyed Peas song onto video clips of LeBron James, a professional basketball player, making skillful shots (Lebron James-Let’s Get Retarded, 2006). This choice of song could be interpreted as representing James’ great basketball plays. In another instance, the video showed a live Black Eyed Peas performance in Germany (BEP Let’s Get Retarded, 2006). As a prelude to the song, *Let’s Get Retarded*, a member of the band declared to the crowd, “Everybody’s gonna get a little crazy right now, everybody’s gonna get a little loud right now.” These assertions substantiate the slang use of the word retarded to “get crazy” and “have fun” in a hip hop context.

Discussion

On March 2, 2008, it was reported that YouTube was about to reach 75 million videos, up from 70 million one month prior (Sarno, 2008). According to Bucholtz (2000), the rapid transmission of culture, and by extension language, is one of the most obvious consequences of new communication media. The changing use of language on YouTube, and YouTube’s ability to reach global audiences (such as skiers in Switzerland and school boys in Singapore) was apparent from our research.

Of the 100 videos analyzed, approximately half (n = 48) used the term retarded in a negative way. This use of the word reflects the way the word is used in mainstream U.S. society. Only 11 of the videos used the term in the traditional sense, meaning that the term was used to describe someone with an intellectual disability. Of the remaining videos (n = 41), the word was used in a neutral, positive, or sometimes unidentified way. Using retarded in a positive way is a new application of the word, which appears to have originated in the “club scene” (Urban Dictionary, 2003). While the term was originally adopted with negative connotations, “get retarded” referred to becoming intoxicated and “acting like a retarded person,” the term infused its way into this subculture and eventually came to simply mean “have fun” in a partying context. This transformation of the word followed the usual pattern that words take as they change over time, a pattern that can be illustrated through the current use of the word “lame,” which, although used for things considered substandard, no longer carries with it any suggestion of a physical disability. This situation raises the question of whether using the word retarded in a positive way can ever be innocuous. To date, all disability words that have taken on new meanings have maintained negative connotations: idiot, moron, dumb, and spastic (spaz) serve as pertinent examples; and disability words are frequently used in everyday language with negative associations, as in the expressions *blindsided*, *crippled by*, and *deaf ears*.

Conclusion

It is not known why the word retarded has also come to be used as a substitution for other words (e.g., silly, funny) without any particular positive or negative connotations. However, the many meanings associated with the word retarded demonstrate the fluidity of language and the particular fluidity of language on YouTube, an arena in which information and knowledge are created. This situation indicates that attempting

to create rules about language use may be a futile endeavor.

Many advocates are pushing to change the term mental retardation as a classification category and abandon the “R” word (Retarded) in everyday language in much the same way the “N” word (Nigger) has been abandoned (Felty & Felty, 2007). However, it is widely recognized that the connection between language and attitudes is complex and attitudes cannot be changed with such simple solutions. History indicates that simply changing a term such as retarded will not lead to positive attitudes toward people with intellectual disabilities. It is more likely that the word retarded will take on new meanings and the term that is adopted to replace it will in turn carry with it negative connotations. Walsh (2002) aptly stated:

“...The real question about individuals should not be what we are going to ‘call them’ in the future, but whether or not they will continue to be devalued because of certain personal characteristics associated with their development” (p. 72).

Despite education laws in the US mandating education for students with disabilities in the “least restrictive environment,” students with intellectual disabilities continue to be segregated in schools. The least restrictive environment is based on a continuum of settings and is therefore not synonymous with full inclusion; however, there are those who believe that categorical disability determination hinders the full inclusion of students with intellectual disabilities and their segregation could therefore be alleviated by moving federal and state legislation in noncategorical directions (Smith P., 2007).

Other advocates in the US Disability Pride movement have adopted a “disabilities are beautiful” position modeled after the US “Black is Beautiful” movement of the 1960s, and are striving to show society that disabilities are a natural part of life (Triano, 2003). However, many people with intellectual disabilities cannot easily

communicate their views (Taylor, 1996), which opens up the question of who should speak for them, particularly with regards to issues such as their empowerment through reappropriation of the term retarded.

While advocates in the US are working to create change around mainstream ideology, YouTube is expanding as a site of rapid cultural change. In 2008, a music video based on “familiar YouTube faces” was added to YouTube (Pork and Beans, 2008). According to YouTube’s Michele Flannery, after this video was posted, “[It shot] up to 500,000 hits in six hours” (Snider, 2008). Another video, *Evolution of Dance* (2006), has been viewed over 92 million times, making it the most viewed video on YouTube. These situations serve as pertinent examples of the influence of YouTube and the role it plays in cultural transmission.

The potential of YouTube videos to reach and influence masses of individuals around the world must be considered with regards to disability terminology. Language can now change more rapidly and spread more globally than at any previous point in history. Consider that with only verbal, print, and other traditional media outlets to transmit the word, it took six centuries for the term idiot to become negative to the point of being abandoned as a means of classifying individuals with intellectual disabilities (Patton, Beirne-Smith, & Payne, 1990; Walsh, 2002). The professional organization, The National Association for Retarded Children, was founded in 1953 and in 1992, the term retarded was removed from the organization’s title and it became simply The Arc (2008). In this case, it took almost 40 years for the term retarded to become negatively stigmatized and for the organization to reject its usage.

The rate of change in today’s society is rapid when compared to that of the past. Through new communication media such as YouTube, words continue to take on new meanings, and old and new uses now coexist in this online

world. YouTube reflects the language of mainstream society in the US, where traditional and negative uses of the term retarded are used; however, it also provides a forum for words to evolve in new ways and in turn, become integrated into mainstream society. Take, for example, the original Black Eyed Peas song, *Let's Get Retarded*, which was changed to *Let's Get it Started* under pressure from The Arc (Johnson, 2004). The Internet became the primary means for airing the song with the word retarded in the title and lyrics. Eighteen percent of the randomly selected YouTube videos analyzed in this study featured this song, a statistic that serves to further illustrate the astounding impact of YouTube culture.

Despite this historic trend, the current situation that now exists--multiple-meaning, coexisting uses of a disability word--is unprecedented and cannot be compared to the straightforward transformation of disability classification terms in the past. The YouTube culture in which the word *retarded* is being used and redefined is both osmotic and borderless. Only time will tell what the consequences will be for those for whom the term was originally intended.

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Book Review

Title: *Doctors of Deception: What They Don't Want You to Know about Shock Treatment*

Author: Linda Andre

Publisher: New Brunswick, NJ: Rutgers, 2009

Paper: ISBN: 978-0-8135-4441-0

Price: \$26.95, 336 pages

Reviewer: Laura K. Corlew

Linda Andre's book *Doctors of Deception* is an engaging journey through the modern day atrocity of electroconvulsive therapy (ECT), more commonly known as shock treatment. She is a self-described "accidental activist" (p. 165) who has spent the better part of the last three decades attempting to bring patient rights into the foreground of this industry, or rather more to the point, into this industry. The stigma surrounding mental illness in this country, along with the fear associated with people who have mental illness, has led to a system in which people can be forcibly committed and treated against their will (including receiving ECT). Equally unjust, patients who do consent to ECT are not first informed of the extensive cognitive and memory risks associated with the treatment. The absence of an adequate informed consent process is largely due to the dearth of research into the dangers of shock.

Doctors of Deception is a chronicle of the evolution of the shock industry, from its early ties to the eugenics movement and pre-World War II fascism, to the modern Public Relations (PR) machine that obscures the intertwining financial ties to the leading psychiatrist practitioners who support it as a "safe and effective" treatment. Claims of a "newer" and "safer" ECT are nothing more than empty labels assigned to an unchanged process. In fact, many of the industry claims about the "new" ECT are unsubstantiated or purposefully false. Andre painstakingly researches the sources of these claims.

The most shocking detail of this history is that the industry has never conducted human or animal trials to determine either the safety or effectiveness of the treatment. Andre implicates the creators and manufacturers of the machines, the practitioners who use them, the American Psychiatric Association, and the Food and Drug Administration all for failing to conduct these trials despite both opportunity and obligation. This failure to act would perhaps be understandable were it not for the fact that ECT causes cognitive damage and permanent memory loss, as patients have been explaining to industry members and politicians for decades. Unfortunately both the industry and the general public seem to believe that mental health patients are unreliable, and therefore unworthy of belief in or protection from the irreparable brain damage they have consistently and persistently claimed to sustain.

Andre tells her own story within this system. She tells of the devastating (and gradual) discoveries that five years of her life had been erased from her memory, that her cognitive processing abilities had been greatly damaged, and that ECT was the cause. She tells of the loss of her professional and personal memories, including the expert knowledge in published journal articles she does not remember writing, and the entirety of the depressive episode that supposedly warranted the administration of ECT. She tells of the months-long inability of her brain to form new memories after ECT, during which time she became an activist for patients' rights. She does not remember this early activism. Five years of her life are contained solely in the anecdotes of colleagues and loved ones.

Anyone who is interested in patients' rights, especially rights which are compromised due to the stigma of mental illness, ought to read *Doctors of Deception*. This thorough and well-researched history of the shock industry and the political and PR campaigns surrounding the industry is a fascinating, if horrifying, read.

Laura K. Corlew, MA, is pursuing her PhD in Cultural Community Psychology at the University of Hawai'i at Mānoa. She is a Project Assistant at the East-West Center with the Pacific Regional Integrated Science and Assessment program. She may be contacted at corlew@hawaii.edu.

Book Review

Title: *Disability and diversity: A sociological approach*

Authors: Mark Sherry

Publisher: NY: Nova Science Publishers, Inc., 2008

Paper: ISBN: 978-1-60456-914-8

Cost: \$89.10 from the publisher, 105 pages

Reviewer: Marjorie McGee

This introductory text is highly relevant to students and professionals in public health, sociology, and social work who aim to learn how disability intersects with race, ethnicity, gender, and socioeconomic status (SES) through a sociological lens. This book also challenges those in disability studies who may not be accustomed to looking at disability intersecting with other forms of diversity.

The first chapter provides an overview to those who may be new to thinking about disability. It includes such topics as problematizing disability, the medicalization of disability, disability identity, and people-first language. Sherry also discusses the relationship with geography and age in the context of disability. The idea of disability as a monolithic category is quickly dismantled, placing emphasis on varied lived experiences instead.

The next three chapters tackle the intersections of disability with ethnicity, gender, and socioeconomic status. Issues of power differentials are explored in these categories as they intersect with disability. Often disability is presented as

an association or consequence of the power imbalances and social stratification associated with these categories, for instance, the prevalence and distribution of disability among people of color, by gender and socio-economic status. Occasionally other intersections of diversity are woven in the chapter, such as race and gender in the chapter on disability and socioeconomic status.

The author summarizes the complex intersections nicely: “Everyone is simultaneously gendered, sexualized, racialized, and so on.” (p. 73). Sherry then explains any one chapter on one aspect of difference must “be read in conjunction with the other chapters, in order to get a more comprehensive picture of the overlapping—and sometime contradictory—ways in which inequality manifests itself in the health and wellness of people in the U.S.” (p. 73)

There are some limitations to this text. The placement of disability status as an “upstream” variable affecting education and employment opportunities, and thus socioeconomic status, could be more prominent in the discussion. However, if you want an introduction to the intersection of disability with socioeconomic status, race and/or ethnicity, and gender, this is an excellent text. Sherry’s chapter on “Disability and Ethnicity” begins with an explanation for his preference for the term ‘ethnicity,’ arguing race is a social construction. However it was disappointing that Sherry did not acknowledge how the race of a person “socially perceived” by dominant culture in the U.S. can result in different lived experiences, even among those sharing the same ethnic identity. For example, in the U.S. the lived experience as a white Latina versus a Latina who is not “socially perceived” to be white can be quite different. This omission of the differences between race and ethnicity (as social constructions) was puzzling, particularly as Sherry devotes a section in the chapter to address racism (and genomics), drawing from the works of Patricia Hill Collins, Eduardo Bonilla-Silva, and others.

Despite its limitations, this text is interesting and important, and the reader who is familiar with many of the issues in disability studies is cautioned not to skim. You may be surprised with the attention to issues not common in introductory texts, such as the gendered and racist discourse that seeks to separate disability from race or ethnicity, as well as issues of power relating to these intersections. It is short, brief and accessible. However, so short that \$89 for the thin hardback seems a very high price to pay, which may make it prohibitive to assign as a required text for students.

Marjorie McGee, M.S., L.P.C., is a doctoral student and instructor at the Graduate School of Social Work, Portland State University. She may be contacted at mcgee@pdx.edu

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Medicalizing edutainment: Enforcing disability in the teen body, 1970--2000

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