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## RDS EDITORIAL

### A Note from the Mouse Who Wanted to Be the Farmer's Wife

Megan A. Conway, Ph.D.  
RDS Managing Editor

*“Three blind mice...see how they run...they all ran after the farmer's wife, who cut off their tails with a carving knife...”*

See what happens when a blind mouse challenges the farmer's wife? Obviously this little nursery rhyme has been through more literary and sociopolitical analysis than anyone has time to contemplate, but I think it is a rather fitting analogy for where people with disabilities are at in the barnyard of education. It's just fine if we are skulking in the corner nibbling on bits of leftover grain, but the minute we come out to play with the humans, BAM.

As a deaf-blind person who received her doctorate in Special Education from an esteemed university, I have to admit that I do have some biases when it comes to the topic of Special Education and educators in general. When I went into education, I wanted to make a difference for others like me and blah, blah, blah. I thought it was weird that I was the only one with a disability in my doctoral cohort—no, make that my entire doctoral program. People with disabilities must just not be interested in education? Or perhaps they did not “qualify”? Anyway, it soon became apparent that most of the special education professors and doctoral students I was working with did not know what they were talking about. Okay, so I am not being fair. I did learn a lot about how to count (and the deep meaning of) the number of times someone does “repetitive head banging behavior.” However, when I tried to turn the topic to something that I saw as meaningful, such as, “Why the heck won't you guys facilitate my participation in this class by using my assistive listening device,” I was met with eye rolling and that look of non-gimp solidarity: “Oh here she goes again.”

Over a decade later, here I go again. There are about 50 faculty at our research center, a unit of the college of education focused on disability. Of those faculty, three (including me) are known to me to have a disability. I know that others may have a hidden disability I am unaware of, so please put your hands down. However, the fact remains that, in a program dedicated to “promoting diverse abilities across the lifespan,” only 6% of us openly exhibit such “diverse abilities” (saving a full description of my diverse abilities for another time, wink, wink).

Being a noble and worthy academic, I decided that I needed to pull apart these unscholarly little biases by doing some online research. It is easy to find statistics on children with disabilities in special education, since from day one they are identified, branded with the scarlet “S” and put to work. Here's what I found.

Some fast facts from the National Center for Education Statistics:

- 13% of all children enrolled in public schools receive special education services.
- 38% of these have “learning disabilities”

([http://nces.ed.gov/programs/digest/d10/tables/dt10\\_045.asp?referrer=list](http://nces.ed.gov/programs/digest/d10/tables/dt10_045.asp?referrer=list))

- 15% of all special education students, and 48% of those with an intellectual disability, spend more than 60% of their time outside a “regular” classroom.
- 21% spend “from 21-60%” of their time outside the regular classroom.
- 48% spend “less than 21%” of their time outside the regular classroom.

(<http://nces.ed.gov/fastfacts/display.asp?id=59>)

I thought this was a strange way to present statistics on inclusion, “The percent of students with disabilities who spend between a low percent and a high percent not in a regular classroom.” And are lunch and recess considered “time in the regular classroom” (I’ll bet they are). These numbers don’t really tell us very much, so I have interpreted these statistics for the layperson in a less optimistic fashion:

- Almost half of all students with intellectual disabilities spend over half their time in a segregated setting.
- Nearly one quarter of all special education students spend half their time in a segregated setting.
- Only half of all special education students spend less than a quarter of their time in the regular classroom.
- Five percent of all public school students have been diagnosed with a “specific learning disability.”

I was pleased to find out that the Department of Education still views Special Education as a privilege (privileges are cool)!

“Special education services through the Individuals with Disabilities Education Act (IDEA) are available only for eligible children and youth. Eligible children and youth are those identified by a team of professionals as having a disability that adversely affects academic performance and as being in need of special education and related services.”

([http://nces.ed.gov/programs/coe/indicator\\_cwd.asp](http://nces.ed.gov/programs/coe/indicator_cwd.asp))

Oh dear. I found that I was having a hard time putting my biases to bed. Let’s just say I was only seeing what I wanted to see. I decided to investigate how many teachers and postsecondary faculty there are with a disability. So I did a Google search and came up with...not much. Apparently there is some difficulty in identifying anyone past the age of 18 who has a disability because of “confidentiality” concerns. Funny how when you are in primary and secondary school you are supposed to wear your disability like a badge of shame (or courage) but when you turn 18 you are best advised to hide it. JAN does address the question of educators who have disabilities, without actually giving us a real answer (the statistics are a bit of a leap of faith, sorry JAN):

“Question: How many educators with disabilities are working today?”

Answer: According to the Bureau of Labor Statistics, nearly four million educators, specifically teachers, working in preschool to secondary settings were employed in the United States in 2006. In addition, there were close to 1.7 million professionals who taught in post-secondary settings, ranging from four year colleges and universities to technology and culinary schools in that same year (Bureau of Labor Statistics, 2009). If disabilities affect one-fifth of all Americans (Census Bureau, 2008), then close to 1.1 million educators, from preschool teachers to post-secondary professors and instructors, could be in need of job accommodations.”  
(<https://askjan.org/media/educators.html>)

Twenty percent of teachers and higher education faculty are disabled? Where are these people? Not on my block, baby. The fact is, we have no idea how many teachers or professors have a disability, but we can speculate that they are highly underrepresented. No, I don't have any data to back this up. But I have about as much real data as the government, apparently. So we'll go with my personal experience – 6%. If 20% of the population has a disability, and 6% of educators have a disability, where does that leave us? In the corner of the barnyard, nursing our wounded tails.

## FORUM

### Forum Guest Editors' Introduction: Disability Studies in Education "At Work"

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**Abstract:** This introductory article serves as the springboard for a greater discussion of the question: *How applicable are the ideas of Disability Studies in Education to educational policy and the practice of teaching?* As guest editors of the special forum of RDS, we illustrate how DSE continues to inform educational theory, research, policy, and practice. First, we chronicle the rapid growth of DSE over the past decade. Second, as educators of teachers, we raise three topics to contemplate further for our field: (1) improving the relationship between science and ethics, (2) better connecting knowledge, beliefs, and values to practice, and (3) determining the position of DSE scholars within the field of special education. Third, we briefly highlight the four featured articles from Belgium, New Zealand, Scotland, and the USA that constitute this special forum. Finally, we urge the field of education to be more critical of special education practices and continue to be receptive toward DSE.

**Key Words:** disability studies, education, practice

#### Introduction

It is with great pleasure that we introduce this special forum on Disability Studies in Education (DSE), a discipline that has grown exponentially over the last decade. DSE began when a group of critical special educators united in their desire to reframe disability sought to counter limited and oppressive understandings of disability promulgated within traditional special education research and pedagogy (Baglieri, Valle, Connor, & Gallagher, 2011). Their contention stemmed from the foundational knowledge of special education being deeply entrenched in science, medicine, and psychology, all of which positioned disability as a deficit, disorder, dysfunction, abnormality, or aberration. Rejection by these scholars of special education's monopoly on the concepts of *disability and education* drew them to the interdisciplinary field of Disability Studies, in which social, cultural, and historical interpretations are used to define disability primarily as a phenomenon determined by culture and context. From this grass-roots movement initiated by a small number of scholars, DSE has come to offer radically different ways of conceptualizing disability within theory, research, practice, and policy (Gabel, 2005; Gabel & Danforth, 2006; Ferguson & Ferguson, 2000; Gallagher, Heshusius, Iano, & Skrtic, 2004; Ware, 2004).

In the pivotal year of 2000, the establishment of both the DSE Special Interest Group (SIG) within the American Educational Research Association (AERA) and the inaugural annual DSE conference hosted by National Louis University provided "official" recognition and space for scholars to engage in a dialogue about disability issues. Over time, these venues grew to attract and nurture a variety of established and emerging scholars who offered alternative perspectives of disability that were all outside of the proverbial (special education) box. After several years of debate and a year-long online discussion among these groups, the tenets of DSE were formulated and published to provide a clear definition of principles to guide scholarship

within the newly founded sub-discipline of DSE (Connor, Gabel, Gallagher, & Morton, 2008).

In addition to these developments, scholars writing within DSE guest edited special editions of journals, published numerous articles in “mainstream” education publications, engaged the field of special education within traditional journals, generated texts within DSE book series, contributed to anthologies of multiculturalism, established disability issues within the larger domain of social justice scholarship, and called attention to ableism within organizational structures. As outlined above, the trajectory of DSE as an emerging discipline reflects increasing numbers of like-minded scholars around the globe contributing to a growing body of knowledge. Although DSE tenets remain outside mainstream special education literature for the most part, the rising incidence of DSE critique in special education literature as well as recent appropriation (and somewhat frequent misuse) of the term “disability studies” by special educators validates its presence as a *tangible* counter-narrative to traditional framing of disability. As a result of the scholarship generated in the last decade, DSE can rightfully claim status as a legitimate (albeit often contested) academic discipline. However, despite these significant accomplishments, there still exists the lingering question of some critics: *How applicable are the ideas of DSE to educational policy and the practice of teaching?* In other words, what does DSE look like “at work” and “in action”?

Taking up this question, we became interested in contemplating how DSE is used throughout K-adult classrooms, curriculum, educational institutions, and teacher education programs in the USA and around the world. In doing so, we seek to be realistic about DSE’s influence yet still cultivate optimism about the possibilities it offers. Given our professional role within traditional teacher preparation programs, we seek to highlight ways that DSE scholars who work within institutionalized dominant discourses of disability are able to infuse their pedagogy with ideas from DSE. Such scholars disrupt typically unquestioned practices within general and special education to respectfully challenge the status quo. We believe the work of DSE scholars, informed by an interdisciplinary humanities-based core of Disability Studies *applied* to educational issues, expands our knowledge about disability and “difference” within education—countering a range of harmful practices, from the entrenched pseudo-scientific foundations of special education that dominate its research agenda to the current zeitgeist of student standardization through “evidence-based practices.”

This special edition of RDS explores ways in which DSE continues to grow in practical ways, illustrating how it has influenced educational theory, research, policy, and practice. Each of the authors featured within the international forum bring a unique *application* of DSE to their work from within the global contexts of New Zealand, the United States, Belgium, and Scotland. Collectively, the articles illuminate the power of DSE to affect change within various connected domains of education, exemplifying academic activism and providing evidence of DSE “at work.” Together, they also raise further issues to consider in relation to teacher ethics, values and beliefs, and resistance to enculturation into dominant discourses of disability and education. Before introducing the four articles featured, we pause to share some of thoughts triggered by their authors.

Must Science and Ethics Remain Strange Bedfellows?

We three co-editors recently were asked to participate on a panel about DSE for a graduate school of education. The audience was comprised of doctoral students and professors from various disciplines within education. Each panelist spoke about the growth of DSE over the last decade and its particular impact upon his or her work in special education. During the talk-back, the panel received the rather unsurprising question: “We get all that about DSE’s critique of special education, but what is *the solution*?” Within the current climate of evidence-based accountability, it is a hard-sell to suggest that the solution lies with asking ethical questions about the consequences of a singular commitment to science in the name of education, special or otherwise. Moreover, posing philosophical questions in the face of data-driven practice predictably evokes the usual disdain for ivory tower mentality. It appears then that DSE, having succeeded in establishing itself as an emerging discipline, faces the central challenge of securing a legitimate “seat at the table,” where ethical questions are considered as important as perspectives defined by science—and equally applicable to the educational setting.

For those DSE scholars who work within traditional teacher education programs, the decision to infuse DSE into pre-service and in-service curriculum is far more about ethics than academic freedom. In preparing teachers to enter the context of public schooling, it is from a moral standpoint that DSE proponents challenge what is considered “right and natural” about the current response to students with disabilities—for to fail to do so is to fail teacher candidates (and ultimately *their* students) at a fundamental level. From our collective perspective as teacher educators, the presentation of a DSE perspective validates what pre-service and in-service candidates already “know to be true” about what they see in schools, provides a frame for better understanding the current system of special education, and prepares them to work within the inherent complexities of public schooling.

If we encourage teacher candidates to think about disability as an aspect of human diversity rather than human pathology, it follows that such a philosophical framing will influence classroom practice in significantly different ways. After all, philosophy leads practice. This is not to dismiss the contribution of science (past or present) to the field of disability. It is science that provides a frame for identifying, categorizing, and comparing phenomena so that we can make sense of “what is.” But it is ethics that evokes responsibility and action for the *meanings* that we attach to “what is.” We would argue that it is at the *nexus* of science and ethics that solutions emerge. The inclusion of an ethical framing of disability has the potential to move the conversation beyond a (futile) pursuit for absoluteness toward a *process* informed by responsiveness, reflection, and collaboration. If scholars and educators ask different questions, different answers emerge—as evidenced by the work described in this special issue.

### How Can We Better Connect Knowledge, Beliefs, and Values to Practice?

As teacher educators working within large institutions that at times resemble teacher factories pumping pipelines of ready-made professionals into the American public school system, we are concerned about how teacher candidates become variously enculturated into the separate worlds of special and general education. In particular, those who enter special education become automatically immersed in laws, regulations, mandates, and practices that revolve around organization and compliance rather than teaching, learning, providing access, and accepting diversity. Introductory courses to special education and their attendant glossy textbooks (Brantlinger, 2006) create artificial representations of the realities most teachers face



in their daily lives, sugar coating a segregated system that traditional special education willfully chooses to downplay or ignore (Kauffman & Hallahan, 1995). However, refusal to sufficiently acknowledge the failures of special education does not make them go away.

For example, in comparison to the nondisabled peers, students and youth in the American special education system are likely to have high dropout rates (Thurlow, Sinclair, & Johnson, 2002), low graduation rates (Advocates for Children, 2005), a lengthier time completing school (U.S. Department of Education, 2005), underemployment or unemployment (Moxley & Finch, 2003), less likelihood of entering college and more chance of leaving prematurely (Gregg, 2007), and higher rates of incarceration (Children's Defense Fund, 2007). Within the existing system, students continue to experience segregation according to disability, with children of color and/or from linguistic minorities being overrepresented in subjective disability categories and more restrictive settings (Losen & Orfield, 2002).

The results of being placed within special education for working class, poor, racial and linguistic minorities in America point to the likelihood of difficult futures for children and youth being served. This harsh reality remains unacknowledged within the scholarly and educational field of traditional special education. In comparison, DSE acknowledges the “bleak” trajectory of many children and youth with disabilities in schools because it takes to task the social, historical, and cultural forces that shaped the structures of contemporary education systems. The DSE story of *who* is labeled disabled, *why* and *how*, is a very different narrative than told in typical *Intro. to Special Ed.* courses.

A great irony here is that individuals who gravitate to the profession of special education are desirous of working with children and youth who often, but not always, require teachers to think differently from an omnipresent but usually untroubled “norm.” However, special education's foundations staunchly adhere to deficit-based thinking, emphasizing disability as an intrinsic personal dysfunction (Anastasiou & Kauffman, 2011). It is, therefore, incumbent upon DSE to continue to describe disability in multiple ways, ways that privilege the experience and voices of those *defined as disabled* rather than the definers. In all disability-related courses, teacher candidates should be afforded the opportunity to rigorously examine their own beliefs and values, explaining why they think the way they do about disability, locating their sources of knowledge, determining whose interests are served—and consider the implications for their own practice. Introducing them to DSE and explaining *why* it evolved is imperative. Asking teacher candidates to connect the ideas of DSE to everyday classroom practices of teaching and learning for K-adult levels demonstrates its value (Valle & Connor, 2010). In sum, by explicitly connecting the dots between how sources of knowledge shape personal beliefs, personal beliefs shape professional values and, in turn, how professional values shape pedagogical practice, teachers can see their ability to create changes in education. This way, in their conscience, they can honestly answer the question about educating children and youth with disabilities: *Am I part of the solution—or part of the problem?*

Placed in Special Education, Where Do We Position Ourselves?

The theme of this special edition of RDS reflects a growing sense of urgency within DSE. Marginalized within the field of education, we can only achieve greater influence by demonstrating that we can apply our theoretical understandings and principles to meaningful

effect. We must show that we can influence practice in K-12 classrooms and beyond, have a voice in curriculum development, and influence education policy. This is a tall order. We are few in number, and we face seemingly insurmountable competition in the field of educating children with disabilities. Before the hegemony of special education, fortified by its institutional legitimacy, legal authority, and historical inertia, it can be difficult to see ourselves as players on that field and not mere theoretical dissidents.

So, how can we demonstrate the practical value of our scholarship? What can we do to make our mark and enact tangible change? The four articles presented here illuminate pathways that veer away from questions of competition or recognition. They emphasize transforming language, reframing questions, and raising consciousness, but in ways that have real potential for making concrete changes. We all have the ability, within our grasps, to follow their lead. Most of us are part of it, important parts of it. Many of us work as professors in special education teacher programs. We are integral parts of the operations that contribute to molding special education teachers and, as such, are actually in potentially powerful positions at a vital point in the production line.

Rather than struggle against special education, we can subvert from within. Most likely, we are already doing so. The most practical, realistic, and immediate way to make concrete contributions that embody the principles of DSE is to focus our efforts on influencing the hearts and minds of our university students. We can, through our students, contribute to changing the culture within special education. No matter how rigid the structures (laws, regulations, procedures), their enactment is an act of interpretation and subject to the dispositional characteristics of those who interpret them. The principle of “least restrictive environment” within the mandated Individuals with Disabilities Education Improvement Act has no fixed meaning. Its enactment is a matter of interpretation. Whether or not the special educator who enacts it works from a deficit perspective or a strengths-based model, he or she determines everything. The greater the number of special educators shaped by, and grounded in, DSE, the greater will be our impact on the current deficit-based culture of special education. It follows that, as these teachers influence other teachers and eventually become administrators, the principles, values, and understandings of DSE become further embedded, contributing to a gradual cultural transformation. Thus, the fruit of our efforts increases exponentially over time.

### Facing Forward

We realize the issues raised so far are highly political and deeply personal for scholars working within DSE. Many seek alternative programs to special education altogether, such as working in inclusive education and/or within general education. It is important to note that we do not assume to speak for all DSE scholars, but must also acknowledge the reality of many who work in special education departments that reflect varying degrees of interest in and receptivity toward DSE. The authors in this special edition serve as beacons within this conundrum, showing how they have managed to maintain their integrity by staying true to themselves, while using DSE toward influencing educational policy and practice. To whet the reader’s appetite, we take this opportunity to briefly introduce contributors a sample of the ideas shared.

### Four Examples of DSE “At Work”

In this age of accountability, it is a frequent lament among educators that policy reform is driven by elected and/or appointed officials who claim expertise outside of education and/or who understand the purpose of public education as a data-driven enterprise. This lament is most often accompanied by a sense of malaise about our capacity to do much to disrupt the hijacking of educational direction except learn to live within it. In *Difference in Policy and Politics: Dialogues in Confidence*, Julie Allan offers us a model for productive dialogical exchange with politicians and policymakers based upon the work of a recent Council of Europe Project concerning teacher competencies for socio-cultural diversity. In her role as Expert Adviser to the Council of Europe, Allan, a noted DSE scholar, recounts the process by which she presented an *ethical* approach to competencies to the Ministers.

Allan's engagement with top-level stakeholders reflects how the introduction of a DSE perspective on difference frames new questions that yield different answers. Relying upon key ideas from DSE (and informed by the work of philosophers Derrida and Levinas), Allan was able to explain how the application of standards to diversity results in "the management of, rather than engagement with, difference" and why a competence framework rooted in ethics requires teachers to do more than perform discrete skills within diversity-related standards. The Ministers were encouraged to consider Derrida's notion of *aporia* (i.e., the belief that the act of keeping two seemingly contradictory questions open leads us closer to justice than the pursuit of absolutes) and to apply Levinas' 'framework of ethics' to teacher competence for diversity. Such a dialogue opened space for the ethical framework of competences to be presented not as a solution to the *problem* of diversity, but rather as a framework within which a teacher's *responsibility* with diversity—and with the Other—is its own solution.

Next, in *Using DSE to "Notice, Recognize and Respond" to Tools of Exclusion and Opportunities for Inclusion in New Zealand*, Missy Morton shares progress in advocating for humanizing processes utilized to track and project the learning of children identified as disabled. In the first part of her paper, Morton discusses the contributions of deficit perspectives and individual assessment to New Zealand's history of excluding children with disabilities from public education until 1989. In the next section, she describes her participation in a state curriculum assessment project that reflects the principles of DSE in broadening the scope of assessment from focusing on individual deficits and the educational structures and practices that disable children to one that encompasses individual strengths. The project she describes is informed by the principles of narrative assessment, applying phenomenological and interpretivist approaches. Morton demonstrates how such assessments enable teachers to 'notice, recognize, and respond' to children's competencies. She notes how the act of listening to students' stories has a transformative effect on teachers' perspectives and practices. By focusing on actions and relationships, narrative assessment allows teachers to see student learning in a wider context, beyond static and narrow measures of individual performance. It encourages teachers to be reflective, cognizant of their role in constructing student (in)competencies.

With Morton's input, The New Zealand Ministry of Education project developed formative assessment tools (curriculum exemplars), designed to assess authentic student work. Informed by the principles of narrative assessment, the exemplars facilitated the assessment of key competencies. This approach to assessment contributed to broadening teacher perspectives, fostering student identities as learners, and improving relationships with families by providing them with stories that focused on the children's learning rather than stressing inabilities. In her

final section, Morton stresses the importance of continued vigilance against policies that encourage individualizing assessment practices. The recent adoption of IEPs in New Zealand risks narrowing the focus of assessment and curriculum to the individual, to the exclusion of contextual considerations. Also, in New Zealand, as in the USA, results of individual assessment with reference to national standards are being employed to enforce the accountability of teachers and schools.

Moving from policy in practice to classroom practice, Nirmala Erevelles' "*What... [Thought] Cannot Bear to Know: Crippin' the Limits of 'Thinkability'*" takes the reader inside a class she teaches in leadership for nurse educators. She describes their discomfort and disequilibrium when the course content and her teaching style destabilizes security in their own knowledge, along with their belief in a tidy, predictable, scientifically-determined world. Erevelles reveals the administrators' own professional socialization into authority-based practices tied to positivist claims of evidence-based practice, and requests that they become open to different ways of knowing. In brief, she asks them to simultaneously consider *knowledge of bodies* and *bodies of knowledge* in relation to each other and the nursing curriculum.

Using humanities-based texts and guided by the work of several queer theorists, Erevelles troubles the limits of thinkability within nursing, a profession based upon interactions with bodies and minds that frequently "do not fit the mold." Rather than capturing precise, clinical answers that negate personal consciousness and involvement, she steers students to ponder what can be known through contemplating competing and contradictory "truths" via open-ended explorations of a particular issue or theme. In contrasting the clinical with the carnal, students come to see their initial view of cripp and/or queer bodies as "distorted images of the norm," ultimately shifting to view them as manifestations of humanity in their own right. Throughout this process of contrasting knowledge(s), nurse educators become aware of how the physical and cultural characteristics of patients have political implications, representing the imbalance of power and knowledge between "professional" expert and "patient," similar to teacher and student or teacher and parent.

In many ways, Erevelles' pedagogy that focuses on limits, ignorance, and "reading" (of knowledge) practices within the traditional academic field of nursing symbolizes the position of many scholars in DSE and the students they teach. However, rather than viewing the use of Disability Studies as a risk that could cause potential dilemmas when not "sticking to the script" of "appropriate" professional knowledge, she chooses to see it as an opportunity, a way of showing people how they can, and should, be open to crossing what are, in essence, artificial boundaries. Propelled by the desire to bring people closer together in understanding one another, Erevelles uses Disability Studies and DSE to convey the power of one instructor in one classroom.

Finally, in *Supporting Graduate Students toward "A Pedagogy of Hope": Resisting and Redefining Traditional Notions of Disability*, Geert Van Hove and colleagues at Ghent University, Belgium describe their process for enculturating graduate students into a DSE perspective within an educational context that is increasingly focused upon "instrumental rationality." Moreover, Belgium's strong reliance upon segregated placements for students with disabilities significantly promotes the notion of "disability as pathology" and segregation as "right and natural." In the face of such cultural adherence to traditional notions of disability, this

graduate program relies upon DSE tenets and the application of philosophical ideas (e.g., Paulo Friere, Gilles Deleuze) to challenge students to rethink disability as an opportunity for ethical response and action.

Van Hove and colleagues provide a working model for “what DSE looks like” within the university curriculum. They describe teaching “a pedagogy of hope” (a definitive nod to the work of Freire) in which problems, solutions, and roles are defined differently. Much like Allan’s model, Van Howe and colleagues reframe disability not as a problem but as an opportunity for dialogical action and reflection. The authors contend that such opportunities occur within the moment-to-moment interactions between teachers and students. To illustrate, the authors relate five key incidents that occurred with graduate students as examples of teachable moments that facilitate intellectual growth—and as such provide us with examples of moving conversations beyond pursuit for singular solutions and toward a *process* informed by responsiveness, reflection, and collaboration. Here we see how the study of disability becomes a fundamental social project with a human rights discourse at its heart.

### Conclusion

These four articles exemplify DSE in action, each contributing to our knowledge of how DSE “works” in practice. We are grateful to these scholars for sharing creative ways in which they have utilized DSE for the benefit of educating politicians, educators, children and adults with disabilities, and their families. We challenge special and general educators, guided by the tenets of DSE, to rethink how they “do business.” In doing so, we believe they will recognize the importance of an interdisciplinary knowledge base that sustains and improves inclusive education, cultivates critical thinking within all educators, and promotes active participation in a social-justice approach to disability. By moving in this direction, we have far more to gain than to lose.

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Difference in Policy and Politics: Dialogues in Confidence  
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**Abstract:** This paper reports on a process of engagement with administrators and Government Ministers in dialogue about diversity that was informed by Disability Studies in Education, a discipline that critiques existing ways of thinking about disability, actively promotes more positive constructions and representations of disabled people's lives and challenges conventional or traditional notions of normalcy. It took place within a project, initiated by Council of Europe, *Policies and practices for socio-cultural diversity* and involved the development of a framework of teacher competences for socio-cultural diversity. The paper charts the process of developing the framework and reports the dialogue that took place. The Ministers and administrators were encouraged to view teaching as a dialogue and to recognise teachers' competence in responding to diversity, following Levinas (1969; 1996), a philosopher who addresses questions of ethics, as a continuing responsibility of teachers to their students.

**Key Words:** disability studies, education, diversity

### Introduction

This paper reports on the engagement of politicians and policymakers in dialogue about difference and identities that was informed by Disability Studies in Education. This discipline critiques existing ways of thinking about disability, actively promotes more positive constructions and representations of disabled people's lives and challenges conventional or traditional notions of normalcy. The dialogue took place within a Council of Europe Project, *Policies and practices for socio-cultural diversity*, and involved top level stakeholders, including education Ministers and administrators of Education across Europe (Council of Europe, 2008a & b; 2009; 2010a & b). Key ideas from Disability Studies in Education (principally informed by the work of Derrida, 1992a & b; 1993, and Levinas, 1969) were infused within the dialogues with the Ministers and administrators. These ideas involved Derrida's notion of aporia, a double contradictory imperative, as an alternative way of thinking about policy questions and Levinas's ethics, used to reframe teaching as a more explicit relationship of continuous obligation towards and responsibility for students. The ideas were used as strategies for interrupting the hegemony of difference as deficit, whilst working within a familiar (and possibly obligatory) context of teacher competences. The engagement with these ideas and strategies, and the administrators and politicians' responses to them, are recounted in this paper. The outcomes suggest an openness and receptiveness to rethinking difference and identities and a recognition of the importance of assisting student teachers in becoming confident in responding to difference, rather than training them to manage difference competently. The relative success of the dialogues provides great optimism for the capacity for Disability Studies in Education to support and direct dialogue with administrators and politicians in positive and productive ways.

The Council of Europe *White Paper on Intercultural Dialogue: "Living Together as Equals in Dignity"* (2008b), whilst underlining the common responsibility among us all for fostering intercultural dialogue, identifies educators at all levels as playing an "essential role" (p.

32). This role places obligations on teachers to promote tolerance and understanding among diverse populations and to challenge negative attitudes. Yet, as the social capital theorist Robert Putnam (2007) has argued, diversity produces fear and leads people to disconnect from one another. He contends that diversity is a threat to democracy, citing evidence that in areas of high levels of ethnic diversity, people desist from associating with others and “hunker down—that is, to pull in like a turtle” (2007, p. 149). For beginning teachers, diversity produces significant fear and they see themselves as needing to acquire highly specific and narrow skills in order to address the perceived deficits among their pupils and manage diversity in their classrooms (Allan, 2008; Gallagher, 2010; Rizvi, 2009). Many of the textbooks on special education available to beginning teachers reinforce such expectations (Brantlinger, 2006; Sleeter, 1987). The segmented way of presenting particular ‘conditions’ within the texts and the absence of any regard for the intersections of disability with class, race, gender, sexuality or any other aspect of diversity inevitably limits student teachers’ understanding and sense of capability (Connor, 2006; Lewis & Armstrong, 2011). The realities presented in the special education textbooks bear little resemblance to the children whom the student teachers encounter and the certainty that they command makes them irresponsible (Allan & Slee, 2008; Brantlinger, 2006). The World Report on Disability (WHO, 2011), in reporting the problems of poor health, low educational achievements, and high rates of poverty faced by disabled people, identifies a lack of teacher capacity to teach inclusively as a key factor that contributes to these deficits.

A narrow view of teaching as involving the management of diversity is unlikely to enable teachers to foster intercultural dialogue and could lead to discrimination and exclusion (Oliver, 1996). The White Paper’s authors, acknowledging the impossibility of prescribing dialogue across cultures and ethnicities in law, offer the White Paper as an “open invitation” (p. 5) to engage in “open debate about the future organisation of society” (p. 5). The framework of competences for teachers that was developed within the Council of Europe project, with its emphasis on values and teacher capacities to respond to diversity, rather than on discrete skills, was a positive response to this invitation. The framework also provides a response to the enjoiner, issued by Lewis and Armstrong (2011), to:

“...Accept the responsibility to help the field progress from mere documentation and description of the problem of disability disparities toward the research outcome of developing, identifying, and promoting strategies that will begin to effectively address, and eventually ameliorate these challenges.” (p. 4)

The Council of Europe project represents a response to the White Paper’s invitation that is interpreted, following Levinas (1969), as an ethical responsibility. The project and the subsequent dialogues with Ministers and administrators were ethical, through their focus on the teacher’s relationship with their students, and responsible, through the emphasis on strengthening and intensifying that relationship. The status of being both ethical and responsible represents an important departure from approaches to teacher education for diversity that are concerned merely with helping teachers to manage difference.

The *Policies and practices for socio-cultural diversity* project commenced in 2006 and was co-coordinated by the Council of Europe’s Head of the Division of Citizenship, Human Rights and Diversity and Secretary to the Steering Committee for Education, within the



Directorate of Education and Languages, Villano Qriazi, and chaired by Anne-Lise Arneson, from Norway. Researchers from Scotland (author), Austria, Bulgaria, Estonia Cyprus, Greece and France participated. The project was undertaken in three phases and began with a survey of teacher education programmes within Europe, examining how well all aspects of diversity were covered. Phase 2 developed an analysis of concepts, principles and challenges for teacher education for diversity and the project concluded, in Phase 3, with the establishment of a framework of competences for diversity. The framework was taken on the road to a series of national consultation tables, held in Austria, Bulgaria, Cyprus and Estonia and involving member state officials, government officers, teacher educators, managers, researchers, principals, teachers and students. Following discussion in each of these consultation tables, the framework of competences was revised and refined.

The survey, carried out in Phase 1, found that in many parts of Europe initial teacher education did not adequately prepare beginning teachers to cope with the diversity which they met in their classrooms (Council of Europe, 2008a). In analysing the concepts, principles, and challenges for teacher education the project participants identified a number of problems which made the development of effective teacher education for diversity a complex task (Council of Europe, 2008a). One key issue was the increasing complexity and diversity of European societies and the limited, partial and outdated understandings of these societies, the needs and issues of particular groups within them, and the appropriate educational responses (OECD, 2005; Rizvi, 2009). A second issue concerned structural causes of inequalities and exclusion, including inadequate educational policies and legal frameworks. These were understood as being important in underlining responsibilities and obligations towards building diverse democratic societies but may themselves produce inequalities and exclusion or place constraints on the development of diversity within countries. Participants recognized that if these structural barriers were not addressed by member states, too much of a burden would be placed upon teacher education to support beginning teachers in responding effectively to diversity. The capacity of teacher education institutions to develop teacher competences was identified as a problem: the survey of teacher education institutions found that the experience and expertise of the teacher educators themselves was limited and there was a lack of relevant institutional policies.

Whilst these issues clearly made the task of improving teacher education in relation to diversity a significant challenge, the project team viewed it as one that could be taken up. There was an expectation, from within the Council of Europe, that the response to the challenge would take the form of the establishment of teacher competences for diversity, which could “serve as a common denominator” (Council of Europe, 2009, p. 12). The project team viewed competences, and governments’ and organizations’ attraction to them as part of a complex “governance turn” (Ball 2009, p. 537; Ozga, 2009), catching teachers and teacher educators in a web of accountability which emphasises proving rather than improving (Ball, 2000). We envisaged scope for reframing and reorienting competences. This was undertaken in relation to ethics and is discussed below.

### Becoming Competent, Becoming Ethical

The origins of the term competence can be seen in the Greek notion of *arete*, meaning excellence, in the sense of being the best, and the Latin term *virtus*, a kind of moral excellence. It

can be attributed to individuals, social groups or institutions, and the words “competence,” “competency” or the plural form “competencies” are often used interchangeably. The term has a large variety of meanings, and it can be captured by the terms “ability,” “aptitude,” “capability,” “effectiveness” and “skill” (Weinert, 2001). Competence can be attributed to individuals, social groups or institutions possessing or acquiring attributes that enable them to meet demands presented by the external environment (Weinert, 2001). However, the notion of competence and its plural, “competences,” have, in recent years, been replaced by the narrower version of “competency,” or the plural form “competencies,” denoting discrete skills and activities which individuals can perform.

Competence surfaced as a concept within teacher education in the early 1990s and has become firmly embedded within standards frameworks for the accreditation of teachers. However, these standards have been recognised as being problematic. Roy (2003) argues that they envelop the student teacher within rigid stratifications, which deny complex thinking and firmly entrench their novice and incompetent identities. They have been viewed as invalid indicators of good teaching (Smyth & Shacklock, 1998; Mahoney & Hextall, 2000) and as part of the “struggle over the teacher’s soul” (Ball, 2003, p. 217). When the standards have been applied to diversity, the effects have been sinister, pushing the new teacher towards the management of, rather than engagement with, difference. Teachers merely have to perform the diversity-related standards, without necessarily committing to the values associated with them. And since there has been little attempt to specify what effective engagement with diversity might look like, it is inevitable that scrutiny of these particular standards will be “light touch” compared with the attention given to those associated with the more visible aspects of teaching such as classroom management. Such a framing of competences is irresponsible because it makes few demands on beginning teachers to engage with the diversity in his or her classroom other than by problematising it and seeking to limit its impact. This problematising of diversity creates, as Critchley (1999) suggests, a forgetfulness of the Other and produces inequality and injustice.

The White Paper takes up competences as a necessity for promoting intercultural dialogue but suggests that these competences “are not automatically acquired: they need to be learned, practised and maintained throughout life” (Council of Europe, 2008b, p. 29). The paper identifies three key competence areas: democratic citizenship, language, and history. These are detailed as important areas of experience both in and out of school, but what is not made clear is the nature of teachers’ competence in order to facilitate these. However the warning against using history teaching as “an instrument of ideological manipulation, of propaganda or... for the promotion of intolerant and ultra-nationalistic, xenophobic, racist or anti-Semitic ideas” (p. 30) gives some indication of what teachers are expected *not* to do.

Disability Studies in Education opens up possibilities for thinking about – and rethinking – diversity that were taken up within the Council of Europe project, *Policies and Practices for Socio-cultural Diversity*. The contribution and potential of Disability Studies in Education, in spite of its relatively short existence, has been significant and extends beyond disability to all aspects of diversity as well as offering exciting prospects for intersectionality (Connor, 2006; Erevelles, 2006). Whilst there remains some debate about the precise nature of this field of scholarship, what is useful here is the delineation of what it *does*. First of all, Disability Studies

in Education offers critique of existing ways of thinking about disability, for example as a deficit or a medical condition. Second, it actively promotes more positive constructions and representations of disabled people's lives, often, as Connor (2006) points out, by reclaiming pre-existing knowledge that has either been silenced along with the voices of disabled people or left out of historical commentaries. Third it challenges conventional or traditional notions of normalcy by altering the space in which disabled people are represented and by subverting how this is done (Kuppers, 2003), actively altering the power relations and making a different kind of engagement possible. These achievements have been possible through strong argumentation (Sleeter, 1987; Valle and Connor, 2010, by the use of evidence from the previously subjugated voices of disabled people (Kliwer, 2006; Ware, 2001) and by engagement with a multiplicity of theoretical resources from the philosophers of difference (Allan, 2008; Kuppers, 2003; Tremain, 2008).

Levinas' framework of ethics (1969, 1999) has a particular value that was used to help to trouble the 'stuck places in our thinking about difference' (Ferri, 2006, p. 304). His ethics makes it possible to rethink the notion of teacher competence for diversity as a relationship of responsibility, directed at all students within the classroom. Such an ethics, constituting a reorientation to human subjectivity, stems from disappointment at the failure to be responsible for the Other, and at the forgetfulness of that Other, especially that Other who is different in some way, and aspires to "be able to face and face down the iniquities of the present" (Critchley 2007, p. 88). An ethics has as its core an absolute responsibility to the Other and the relationship is experienced, because of an inadequacy in the face of the Other, as asymmetrical (rather than as one of equals, which the White Paper advocates) and as not benign, but as a responsibility that "persecutes me with its sheer weight" (Critchley 2007, p. 59). This produces an absolute imperative towards the Other which is a "gratuitous and non-transferable responsibility, as if they were chosen and unique—and in which the other were absolutely other, i.e. . . . still incomparable and thus unique" (Levinas 1999, p. 170). The responsibility, according to Levinas, is inescapable:

"...To be a "self" is to be responsible before having done anything...I am not merely the origin of myself, but I am disturbed by the Other. Not judged by the Other, but condemned without being able to speak, persecuted." (Levinas, 1996, p. 94)

The responsibility to the Other is both "indeclinable" (Levinas, 1998, p. 134), so we cannot say "no" to it, and infinite:

"The idea of the infinite consists precisely and paradoxically in thinking more than what is thought while nevertheless conserving it in its excessive relation to thought. The idea of the infinite consists in grasping the ungraspable while nevertheless guaranteeing its status as ungraspable." (Levinas, 1969, p. 19)

The responsibility that one has to the Other operates at three levels: responding *to* the Other; responding *for oneself* to the Other and responding *for the other*, by substituting oneself for the other person in his or her responsibilities (Hutchens, 2004). And whilst these are heavy responsibilities, as Butler (2004) reminds us, being disturbed by the obligation of the Other is a vital part of what it is to be human: "Let's face it. We're undone by each other. And if not, we're

missing something” (p. 43). Biesta’s (2008) notion of “pedagogy with empty hands” (p. 198) is an extremely useful way of thinking about education from an ethical point of view. It requires teachers to approach students within their classroom without ready solutions or “tricks of the trade” (p. 208), derived from textbooks, research or elsewhere, and to ask “what do you think of it?” (p. 208). This notion of constant readiness is something of a departure from the idea of a teacher whose lessons, activities and outcomes are planned ahead and whose actions in class can be predicted. It does, however, appear more likely to enable teachers to respond to diversity in whatever shape or form it surfaces.

In considering the competences required by teachers for diverse democratic societies within the project, we posed the questions, ‘What do we want our teachers to understand? To be? To do?’ We suggested that teacher competence for diverse democratic societies could not reasonably be viewed as consisting of fixed amounts of knowledge, skills or behaviours to be acquired by teachers, but that it must be responsive to the changing nature of the society in which the teacher works and subject to the teacher’s continuous reflection and adaptation. This representation of the competent teacher in relation to diversity met with a positive response from the participants in the consultation tables, especially the teachers, teacher educators and students, and indeed one teacher from Estonia offered us an image of the teacher as gardener. This kind of teacher, she explained, had to be always ready and adaptive to the different demands of the various species in her classroom. She had to be prepared to provide different amounts of water, nourishment and protection to each individual and to recognise that they would flourish in different ways. Above all, the teacher had to love each one of her charges. The image of the teacher as gardener resonated well with the development of competences which were ethical and which principally concerned the relationship between the teacher and his or her learners.

The framework, in its final form, contains three clusters of competences. In the centre, and central, is *Communication and Relationships*. The competences within the clusters which flanked *Communication and Relationships*—*Knowledge and Understanding* and *Management and Teaching*—would, we argued, be of a second order to, and developed from, the acquisition of competences in, *Communication and Relationships*. Fundamentally, we argued, these competences were not finite skills that could be demonstrated, but required continuous development and review. Table 1 outlines the teacher competences for diversity.

<<Table 1 about here:>>

The framework was published in the third of the project’s reports (Council of Europe, 2010b) and is now in the public domain. The essence of the ethical approach informed some of the advice in support of the 23rd Council of Europe Ministerial Conference, *Teacher Education for a Sustainable Democratic Society*, which took place in June 2010 in Ljubljana, Slovenia. Ministers were invited to consider teacher competences alongside the status and conditions of teachers and partnership working. Acting in the role of Expert Adviser to the Council of Europe and taking responsibility for teacher competences, I conveyed the ethical approach to competences to the Ministers. Although it was not named it as such, Ministers were introduced to the notion of a continuous obligation by teachers to each child and to each new form of diversity as it presented within the classroom. The inappropriateness of a developing a fixed notion of skill for the purpose of managing difference was justified as unsustainable and the

Ministers were instead treated to the Estonian teacher's image of the teacher as gardener. The choice of language was important and was influenced by Solis and Connor's (2006) warning that much of the conversation within disability studies is inaccessible outside of academe. Although many of the Eastern European Ministers had a background in education, it was important not to assume this and it was a significant challenge to find words that provided solidity and reassurance within a familiar discourse of competences but which also conveyed a sense of openness and responsiveness to difference. Derrida's (1992a) notion of an aporia - a double contradictory imperative - was deployed as a strategy whereby Ministers were encouraged to understand that decisions were not necessarily resolvable or reducible to one single choice and indeed that it was the very process of keeping two apparently oppositional questions open that was at the heart of justice. Derrida (1992b) argues that it is the point at which decisions are made, when only one option is selected, that closure is created and injustice is produced:

“When the path is clear and given, when a certain knowledge opens up the way in advance, the decision is already made, it might as well be said that there is none to make; irresponsibly, and in good conscience, one simply applies or implements a program . . . It makes of action the applied consequence, the simple application of a knowledge or know how. It makes of ethics and politics a technology. No longer of the order of practical reason or decision, it begins to be irresponsible.” (pp. 41-45, original emphasis)

Questions were thus framed and presented to the Ministers as aporias, for example asking them to consider how, on the one hand, student teachers might learn to develop as autonomous professionals, and on the other hand learn to depend on others for support and collaboration; or how new teachers might work to maximise the achievement of students, with an eye on performance profiles and at the same time ensure that all students improve and that no student is excluded.

The Ministers were advised that although the challenge of developing competences for diverse democratic societies was both enormous and complex, there was clearly much that member states could do which was not dependent on vast amounts of resources, specialised technical knowledge or personnel, but which involved finding ways of simultaneously creating opportunities and removing barriers to dialogue and participation. Their response was one of recognition and desire and although such formal events can be more memorable for their ministerial platitudes than for their evidence of transformatory thought, there was a proliferation, in the dialogue with the Ministers, of a terminology of balance and of acting with two hands, “on the one hand . . . and on the other hand . . .” a frequent refrain. The subsequent declaration which the Ministers' signed up to expressed a significant commitment to, and responsibility for, the Other and an intent to remove barriers to intercultural dialogue:

“RECOGNISING that, in times of global economic crisis, European societies are facing many challenges such as increasing inequality and social exclusion, which threaten the fundamental principles of socially sustainable societies including equal opportunities and social justice.... CONSIDERING that all teachers and other education professionals are one of the essential pillars of the process of building sustainable democratic societies and need to develop the necessary transversal competences; these are interrelated knowledge, skills and attitudes enabling teachers

to model democratic and participatory processes based on respect for human rights, diversity and human dignity.” (Council of Europe, 2010a, pp. 2–3)

Beyond the formal language of the declaration, the Ministers can be seen highlighting the centrality of teachers as agents of intercultural dialogue and signaling the importance of teacher education in equipping teachers effectively and appropriately—enabling them to *be* democratic citizens in order to cultivate these values and attributes among their students. Ethics, even if they were just implied, had been invited along to the ministerial dialogue and appeared to have been a welcome guest.

### Conclusion: Infinitely Competent?

*[Ethics] being utopian does not prevent it from investing our everyday actions of generosity or goodwill towards the other: even the smallest and most commonplace gestures, such as saying “after you” as we sit at the dinner table or walk through a door, bear witness to the ethical. (Levinas, 1986, p. 32)*

Levinas invites us here to find ways of recognising the Other in the everyday and in the smallest of encounters. The Council of Europe’s invitation is on a larger scale and is concerned with the inequalities produced by an education system that insists that “everyone do better than everyone else” (McDermott, 1993, p. 274). The pathologising and naming of individual deficits within that system represents what Thomas (2008) calls a “closure on learning” (p. 7), which produces and reinforces disabled, ethnic, class and gendered identities as failures and, as Gillborn and Youdell (2000) have documented, there is a channeling (and rationing) of educational support away from these individuals and towards those most likely to benefit. Beginning teachers, through no fault of their own, lose sight of the Other or, worse still, become afraid of the diversity that the Other brings and are forced to think of diversity as a problem to be *managed* within the classroom.

The capacity of Disability Studies in Education to disrupt, trouble and subvert, through teaching and research has been ably demonstrated by Ferri (2006), Erevelles (2006) and Valle and Connor (2010) and many others. Here, the success, if I might claim such a thing, was evidenced by Ministers using the language of aporias to describe double responsibilities; calling for shifts in thinking, for example from needs to rights; an apparent willingness to experiment with difference; and undertakings to promote inter-cultural dialogue in Ministers’ own Member States. It was achieved by working from a Disability Studies in Education perspective, gently steering the administrators away from assumed knowledges about both students with diverse backgrounds and what their teachers need to manage them. Disability Studies in Education enabled a repositioning of diversity as interesting and as something for teachers – and indeed governments – to be curious about. This reorientation to difference as positive was experienced, not as disruptive, but as inviting and the notion of decisions being multiple and, in Derrida’s sense, aporetic, came as something as a relief to the Ministers and administrators. Furthermore Levinas’ ethics allowed for a rethinking of the relationship between teachers and students *as a dialogue*. The Ministers and administrators remained unaware of the way the pushing of their thinking had been informed by Disability Studies in Education and there was never any mention of either ethics or the aporia. Nevertheless, they became taken with the idea of teaching as a

dialogue and with how diversity, within such a dialogue, becomes a central and inevitable element and something that the teacher must be ready—and eager—to respond to.

Teacher education, in cultivating the beginning teacher's readiness, inevitably also has to take the form of a dialogue within which they can articulate anxieties and questions, rather than rehearse the dogma of tolerance. It was possible to introduce a Levinasian ethics into the process of establishing a framework of competences through a series of contingent elements. First, there was the Council of Europe and its commitment to dialogue beyond a rhetorical level. The Council of Europe's relative lack of power compared with the European Union is its strength, as it leaves it free to guide in a more ethical and responsible way. Villano Qriazi successfully managed the project as an intercultural dialogue, enabling it to develop along these ethical lines, whilst also having regard for the expectations of the Council of Europe and a detailed knowledge of how best to communicate complex ideas to policymakers and politicians. The researchers who participated in the project, whilst not all familiar with Levinas' ethics, brought a commitment to helping teachers towards greater recognition of, and confidence with, diversity. Thus, an ethical approach was possible, within the structure and ethos of the Council of Europe and through a dialogue that was itself intercultural and, above all, responsible.

The ethical framework of competences were presented as far from being a solution to the *problem* of diversity; rather, diversity itself, and teachers' relationship with it and with the Other, was its own solution. Re-presenting competences as ethical, using the recognisable language and structures of the competences themselves, appears to have engaged the policymakers and politicians, then redirected that engagement, in more responsible ways. It remains to be seen whether this particular competence framework will be *used* in the way we have intended, and as Levinas has suggested, to develop a teaching relationship in which the teacher, as well as the student, is taught. One might hope that it can provoke, among teachers and teacher educators, a dialogue that has responsibility at its heart.

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**Table 1:** Framework of teacher competences for diversity

Knowledge and understanding	Communication and relationships	Management and teaching
Competence 1 Knowledge and understanding of the political, legal and structural context of socio-cultural diversity	Competence 7 Initiating and sustaining positive communication with pupils, parents and colleagues from different socio-cultural backgrounds	Competence 13 Addressing socio-cultural diversity in curriculum and institutional development
Competence 2 Knowledge about international frameworks and understanding of the key principles that relate to socio-cultural diversity education	Competence 8 Recognising and responding to the communicative and cultural aspects of languages used in school	Competence 14 Establishing a participatory, inclusive and safe learning environment
Competence 3 Knowledge about different dimensions of diversity eg ethnicity, gender, special needs and understanding their implications in school settings	Competence 9 Creating open-mindedness and respect in the school community	Competence 15 Selecting and modifying teaching methods for the learning needs of pupils
Competence 4 Knowledge of the range of teaching approaches, methods and materials for responding to diversity	Competence 10 Motivating and stimulating all pupils to learn individually and in co-operation with others	Competence 16 Critically evaluating diversity within teaching materials, eg textbooks, videos, media
Competence 5 Skills of inquiry into different socio-cultural issues	Competence 11 Involving all parents in school activities and collective decision-making	Competence 17 Using a variety of approaches to culturally sensitive teaching and assessment
Competence 6 Reflection on one's own identity and engagement with diversity	Competence 12 Dealing with conflicts and violence to prevent marginalization and school failure	Competence 18 Systematic reflection on and evaluation of own practice and its impact on students

# Using DSE to 'Notice, Recognize and Respond' to Tools of Exclusion and Opportunities for Inclusion in New Zealand

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**Abstract:** In this paper, I describe three ways that Disability Studies in Education (DSE) informs our work on curriculum assessment in New Zealand. First, DSE provides a framework for interrogating practices of exclusion in education. Education has a (long) history of being unequally available to all students. Traditionally, in New Zealand as elsewhere, the role of assessment (and expert assessors) has been to decide which students get access to which types of education. Traditional forms of assessment focus on the individual. DSE suggests how this focus on the performance of individual has unintended negative consequences. Second, DSE suggests possibilities for inclusive education. When learning is understood as co-constructed, new approaches to assessment are needed. In this paper I describe a New Zealand project to support teachers to use *narrative assessment* as an approach that supports teachers to *notice, recognise and respond* to students' competences, with a developing understanding of learning as co-constructed. Narrative assessment supports teachers to get to know their students' interests and strengths and use these to support learning; to build relationships with their students and their students' families. I conclude by describing how DSE reminds us to be always vigilant to the pull of powerful normalizing discourses.

**Key Words:** curriculum, pedagogy, assessment

## Introduction

A key contribution of Disability Studies in Education has been to broaden our scope of investigation, to widen the lens, so to speak. Disability Studies in Education invites researchers, practitioners, and practitioner-researchers to step back from both 'special education'<sup>1</sup> and so-called 'regular education' practice-as-usual and to ask 'what else is going on here?' (Connor, Gabel, Gallagher & Morton 2008). This involves looking in different places as well as using different frameworks to make sense of what is seen. Attending to 'regular education' practices shifts the focus from the discursively produced deficits of *individual* students (and their families) to the daily, normative practices of education that simultaneously exclude while obfuscating practices of exclusion. In the first part of this paper I describe the ways traditional assessment practices focus on the individual. Models of assessment are embedded in understandings of teaching and learning. I show how this focus on the individual learner often has the effect, however unintended, of isolating and excluding disabled students and their families.

Disability Studies in Education can also suggest frameworks that allow us to recognize new possibilities for developing inclusive practices within 'regular education' practices (Gabel, 2005; Gallagher, 2004). Again, this involves both looking in different places and using different frameworks to 'notice, recognize and respond' to what is seen. The phrase 'notice, recognize and respond' comes from work on narrative assessment in New Zealand (Carr, 2001). In the second part of the paper I describe a project to develop exemplars of curriculum assessment that supported the introduction of the *New Zealand Curriculum* (Ministry of Education, 2007). The

*New Zealand Curriculum Exemplars for Learners with Special Education Needs* (Ministry of Education, 2009a) built on explicitly socio-cultural perspectives on teaching and learning that underpin large sections of the 2007 *New Zealand Curriculum*.

In the final section of the paper I describe some experiences in New Zealand that illustrate the value of Disability Studies in Education as a tool for monitoring development of policies and practices.

### Assessment and Exclusion

In this section, I illustrate how traditional practices of assessment have contributed to the exclusion of disabled children. Educational assessment of individuals has traditionally served a gatekeeping role, determining who would have access to scarce educational and other resources. Individual assessment using psychometric tools claimed to be able to determine which individuals, or groups of individuals, would most benefit from resources (Broadfoot, 2007; Gipps, 1994; James, 2006; Selden, 2000; Valle & Connor, 2010). Ironically, many children and young people in New Zealand were never assessed using these tools, as the tools themselves were highly verbal in nature. Because the tools were extremely verbal in nature, they were both inaccessible and biased. Despite never actually being formally assessed, many children and young people in New Zealand were ‘diagnosed’ as severely or profoundly mentally impaired – essentially by professionals just looking at the person. While it was not possible to formally administer these intelligence tests, children and young people were nevertheless given labels based on the tests, such as severely or profoundly mentally retarded. In New Zealand, as elsewhere, these labels led to a view of some groups of children as *ineducable*. In turn, this meant that they did not attend any kind of educational facility and they did not receive any kind of education. In New Zealand it was only with the change of the *Education Act* (1989) that *all* children were entitled to go to their local school (Millar & Morton, 2007; Wills, 2006; Wills & McLean, 2008). It still comes as a surprise to many New Zealanders to learn that there were groups of children legally excluded from school until 1989 (Millar & Morton, 2007).

In the subsequent twenty-plus years more and more disabled children and young people have been enrolled at their family’s local school. Exclusion on the grounds of disability is no longer legal but continues to be the experience of many students and their families (Gordon & Morton, 2008; Macartney & Morton, 2012; Wills, 2006). The role of individual assessment, both medical and educational assessment, continues to be implicated in exclusion (Macartney & Morton, 2011). Unlike many education systems, (e.g. US and UK) there is no diagnostic assessment for educational placement in New Zealand. There is however assessment for allocation of resources. These resources are not based on diagnostic category, but do require applicants to build a picture of need for support, painting a rather bleak picture of a student’s list of failures and weaknesses. Families find this disheartening, as do many teachers who prefer to build on their students’ interests and strengths (Morton & McMenamin, 2011).

By adopting a Disability Studies in Education framework, the experiences of exclusion may be understood from a socio-political model of disability. Two understandings are made possible. First, rather than assuming that all difficulties arise from particular differences inherent within an individual, it is now possible to see that the *processes* of identifying differences and allocating resources themselves contribute to, and justify, exclusion. That is, students’

differences are not a justification for exclusion. An important corollary for teaching and learning is that students' differences cannot be used as an explanation for why we haven't supported their presence, participation and belonging in local classrooms and the curriculum (Connor et al., 2008; Macartney & Morton, 2011; Morton & McMenamin, 2011). Drawing on an interpretivist understanding of the social construction of differences, and in particular disability, we can pay attention to the ways the meanings of differences are negotiated, shared, reified and resisted. Interpretivism can also attend to the ways meanings intersect, shape, and are shaped by, and within, discourses and hegemonic practices. In educational research, important contenders for attention are the socially constructed meanings of teaching, learning, pedagogy, curriculum and assessment.

Broadfoot notes that assessment models in education “work to shape the way people think about and practice education” (Broadfoot, 2007, p.24). It might be expected then that a model of *individual* assessment that is premised on expert knowledge used to diagnose and then prescribe teaching to remediate or ‘fix’ a disabled individual could shape the ways teachers think about and practice education in relation to that individual. Smith and Barr (2008) have described this as the “ideology of the individual” (p.405), common in many educators’ understandings and practices. Here the focus is on the development and learning of an individual; in response to the work, or instruction, of the individual teacher. All learning and development is expected to follow clearly defined trajectories that are universal and predictable. Context is largely irrelevant. Understandings of curriculum, teaching and learning are largely, if tacitly, based on an understanding of knowledge as fact, pedagogy an act of transfer from the individual expert teacher to the individual and inexperienced student. Smith and Barr (2008) further note that in this individualistic conceptualization, learning is understood as being “individual and affected by ability which is seen as fixed” (p.408). These are the views of learning that underpin traditional forms of educational measurement and assessment and that are rewarded in traditional measures of educational achievement (Gipps, 1994; Hipkins, 2007).

It is not surprising then that many so-called ‘regular classroom’ teachers believe they are unprepared for including students with disabilities in their classrooms. Paugh and Dudley-Marling (2011) describe how deficit thinking, the “unrelenting focus on what students cannot do” (p.820) impacts teachers’ sense of what they can accomplish. If we consider the views of teaching and learning described by Smith and Barr (2008) we might expect that, when teachers see “learning = being taught” then these teachers have difficulty seeing themselves as teachers when they do not view as learners some of the children and young people in their classrooms (Millar & Morton, 2007; Morton & McMenamin, 2011).

Disability Studies in Education is interested in moving beyond critical examination of past and current practices (Gabel, 2005; Gallagher, 2004; Valle & Connor, 2010). Gallagher (2004) enjoins Disability Studies in Education scholars to also consider the implications of social constructionist or interpretivist understandings for teaching and learning. As well as scholars in Disability Studies in Education, other educators and curriculum theorists have been considering these implications. In New Zealand, sociocultural understandings of curriculum, pedagogy and assessment have been a feature of *Te Whāriki*, the early childhood education curriculum, since 1996 (Ministry of Education, 1996) which states “Children learn through responsive and

reciprocal relationships with people, places, and things” (p.14). Margaret Carr has led this work in New Zealand (see, for example, Carr, 2001).

James (2006) has also challenged the focus on the individual as learner. Writing about the close connections between assessment, teaching and theories of learning she argues that new approaches to assessment need to pay attention to both social and individual learning *processes* as well as outcomes. James suggests that we might look to those disciplines (such as sociology, anthropology and social psychology) that explicitly focus on how people make sense of their world, and the interactive nature of their sense making. An earlier example of insights from sociology is found in Wansart’s (1995) article titled “Teaching as a way of knowing: Observing and responding to students’ abilities” and published in a special issue of *Remedial and Special Education*. Wansart opens his paper stating:

“Teacher research is about the knowledge created when teachers seek to discover the stories the students reveal about themselves as learners... Teacher researchers observe and describe the details of individual learners within the context of the classroom, the family and the community... Teacher researchers collect and combine their observations so that they may understand and interpret what students are telling them about their learning. Their primary purpose is to allow these *stories of ability* to change their teaching as they respond to their developing understanding of each student.” (pp.166-167)

Wansart is of course describing the tools of ethnography, participant observation with its rich description of context and conversations. He is also describing the aims of ethnography, to understand the perspectives of participants and the meanings they make of and give to their lives.

Wansart draws on the interpretive work of Ferguson, Ferguson and Taylor (1992), concluding with these authors that one purpose of telling stories, particularly the stories of traditionally disadvantaged groups, is to make a difference to how teachers see their work, with the explicit purpose of improving what happens in the classroom. Wansart notes that when teachers report their work about listening to students’ stories, they often tell transformative stories. Teachers’ stories of students’ learning – assessment that is reported to other teachers for example – can support or undermine students’ identities as learners. The impact of assessment on teaching and learning cannot be overstated. Hatherly and Richardson go so far as to claim “We can only transform curriculum and pedagogy by also transforming the way we assess learning” (Hatherly & Richardson, 2007, p.51).

In this section I have described some of the ways that Disability Studies in Education offers new approaches to interpreting disability and understanding exclusion. The understandings about disability as socially constructed, together with the implications of social construction for teaching, learning, curriculum and assessment, informed the development of the resources for curriculum assessment described in the next section. Where traditionally assessment has been of the individual, and *assessment of learning*, in the next section the focus turns to *assessment for learning*.

In 2006 to 2009 I was fortunate to lead a project (funded by the Ministry of Education) to research and develop the *New Zealand Curriculum Exemplars for Learners with Special Education Needs* (Ministry of Education, 2009a) and the accompanying resource *Narrative Assessment: A Guide for Teachers* (Ministry of Education, 2009b). The contract for the work stipulated the following outcomes:

- The scope of the *Guide* and the *Exemplars* is for *all* teachers, whose classes include students who, throughout most of their time at school, are working within Level One of the *New Zealand Curriculum*;
- Raise expectations for the group of students as active learners;
- Show that the *New Zealand Curriculum* is relevant for all students;
- Is focused on assessment of the Key Competencies within the context of the Learning Areas in *The New Zealand Curriculum*; and
- Illustrate an approach to assessment that could capture the complexity of learning that happens in the context of relationships (a socio-cultural perspective on teaching and learning).

The project team consisted of curriculum and assessment facilitators working in Education Plus, the teacher professional learning arm of the College of Education at the University of Canterbury. The curriculum and assessment facilitators were not special educators. Their areas of expertise included a deep knowledge of the *New Zealand Curriculum* and the principles and practices of assessment for learning, or formative assessment. These facilitators worked alongside 26 classroom teachers (the majority in ‘regular’ classrooms) to develop the curriculum exemplars. The facilitators and teachers met regularly over the two years of exemplar development to share readings that challenged traditional notions of disability, curriculum and assessment. The readings also provided support in developing a sociocultural framework to guide the development of the exemplars. In our regular meetings we shared, critiqued and workshopped the exemplars and the guide to narrative assessment. Morton and McMenamin (2011) provide a more detailed description of the project (the resources can be found online at [www.throughdifferenteyes.org.nz](http://www.throughdifferenteyes.org.nz)).

This project built on earlier work developing exemplars of curriculum assessment. The project also took advantage of new spaces and opportunities available in the *New Zealand Curriculum* (Ministry of Education, 2007) released during the course of the project. In the school sector, the *New Zealand Curriculum Exemplars* (Ministry of Education, 2003) were developed to support teachers to assess student learning against the levels of outcome in the seven subject areas of the *New Zealand Curriculum Framework* (Ministry of Education, 1993). The *Framework* was an outcomes or standards-based curriculum. On its assessment website (TKI), the Ministry of Education describes exemplars and their purpose:

“An exemplar is an authentic piece of student work, annotated to illustrate learning, achievement, and quality in relation to the levels in the national curriculum statement. The purpose is to highlight features that teachers need to watch for, collect information about, and act on to promote learning. Exemplars help to answer the question, ‘What is quality work?’”



In the early childhood education sector the curriculum, *Te Whāriki* (Ministry of Education, 1996) is organized around a constellation of interconnected learning dispositions. The name of the curriculum, *Te Whāriki*, translates roughly to a woven mat, and this is the visual metaphor to describe the relationships of the different aspects of the early childhood curriculum. The dispositions, or strands, of *Te Whāriki* are belonging, contributing, well-being, exploration and communication. Assessment of the dispositions is supported by a series of booklets and on-line resources, *Kei Tua o te Pae* (Ministry of Education, 2004-2009):

*“Kei Tua o te Pae explores and informs assessment practice in early childhood education. Everyday assessments from a range of early childhood settings have been selected as exemplars to explore important assessment and learning questions. They are not necessarily "exemplary" in the sense of being excellent or perfect, but rather they illustrate a wide range of learning experiences in a range of assessment formats. The exemplars strongly reflect the principles of Te Whāriki and sociocultural approaches to learning and teaching. The core framework of noticing, recognising, and responding is at the heart of effective assessment and quality teaching practice.”*

In these two excerpts we can see the Ministry of Education now uses the framework of “notice, recognize and respond” to describe the purposes of assessment in both the early childhood and school curriculum documents. In the school sector the framework is offered as “need to watch for, collect information about, and act on to promote learning” (2004-2009).

The introduction of the *New Zealand Curriculum* (Ministry of Education, 2007) included both traditional individualistic and sociocultural understandings of curriculum and pedagogy. The subject or learning areas were slightly expanded, but continue to be framed and presented in a matrix of (presumably) increasing levels of difficulty. Each curriculum area is presented as a relatively standalone subject. This new curriculum also introduced the *Key Competencies*. The five competencies are thinking, managing self, participating and contributing, using language symbols and texts and relating to others. The key competencies draw on knowledge, attitudes and values. They are both “a means to an end and a valued educational outcome.” The *New Zealand Curriculum* (Ministry of Education, p.12) describes how key competencies involve the learner in engaging personal goals, other people, community knowledge and values, cultural tools and the knowledge and skills found in learning areas. “People use these competencies to live, learn, work and contribute as active members of their communities” (Ministry of Education, p.12).

Hipkins (2007), writing about assessing these key competencies states, “New dimensions of learning are highlighted by the inclusion of the key competencies at the heart of the curriculum. These dimensions challenge some assumptions that are deeply embedded in traditional assessment practices” (p. 5):

- The knowledge, skill, or attitude being assessed is in a fixed state, what the test shows now is true forever.
- If the learning sampled in this one assessment is valid then the result is indicative of overall learning and ability in this area.

- Competency resides in individuals separately from the contexts in which they demonstrate it.
- Variations in an individual's assessment results that occur on different but related occasions are caused by measurement errors or poorly designed tasks.

In this project, we were particularly interested in approaches to assessment that focused on noticing students' competence. We built on the work of Carr and colleagues who developed the narrative approach to assessment (Carr, 2001; Cowie & Carr, 2009): "We take the view that learning and development, rather than being primarily about individual achievement, is distributed over, stretched across, people, places and things" (Cowie & Carr, 2009, p.105). We were interested in supporting teachers to pay attention to the contexts that supported students to show that they were competent; more importantly, teachers began to recognize that students were showing evidence of learning, and that learning could be directly linked to the subject areas of the *New Zealand Curriculum*.

We drew on the work of Carr and colleagues because we sought an approach to assessment that focused on looking for and reporting on the learning that students were able to show when given sufficient opportunities to demonstrate their competence. We sought an alternative to traditional forms of assessment that purported to show what children and young people should be doing at particular ages or class level "constructing children's learning and development as universal and children as passive recipients of knowledge" (Macartney & Morton, 2011). We chose to explore the narrative assessment approach because it focuses on actions and relationships. This approach enables the teacher to see the child and their learning in a wider context. The narrative assessment approach does not compare students to others, nor to standards. In this way narrative assessment values and fosters the students' progress and achievement at the same time recognizing that this progress is socially mediated and co-constructed.

The above characteristics of narrative assessment can be related to Wansart's (1995) description of the aims of teacher research: to capture stories of students' abilities. Like Wansart's work, narrative assessment draws on the traditions and principles of phenomenology and interpretivism – a search for understanding the ways that people (students and teachers) make sense of the world(s) they live and act in and upon. Qualitative researchers/participant observers need to be mindful of the ways their worldviews frame the questions they ask, what they see and hear when they observe and how they subsequently represent and construct people and places (Harrison, MacGibbon & Morton, 2001). Teachers using narrative assessment need to be similarly reflexive, paying equal attention to their role in creating and supporting teaching and learning opportunities, catching themselves in the act of seeing and constructing competence or incompetence.

There were a number of important outcomes from the project. The exemplars clearly show that narrative assessment was fostering students' identities as learners. Through making their learning visible and strengthening links to the curriculum, teachers had raised expectations for this group of students. Fostering students' identities as learners also fostered teachers' identities as learners:

“It also appeared that by using narrative assessment to reflect on student learning and teacher learning, the teachers began to facilitate different learning opportunities and provide students with support for new learning. We would suggest that these changes were facilitated by the nature of NZ revised curriculum which allows teachers to reframe and reinterpret what their students do, particularly when the key competencies are used as a lens through which to view student behaviours. The teachers in the project concurred that this perspective enabled them to give value to certain behaviours that they could now recognise as demonstrating achievement within the context of a learning area.” (Morton & McMenamin, 2011, p. 112)

The teachers on the project described the assessment as meaningful, providing them with valuable information to reflect on their teaching and to consider next steps for students’ learning. It supported building positive relationships with families through valuing families’ input (because learning also happens outside of the classroom and school) and providing families with stories that celebrated students’ learning. Narrative assessment challenged traditional relationships between teachers and students’ families. It supported more democratic relationships by seeking and respecting the voices of students and their families, as well as professionals.

#### Conclusion: We Need to Keep Noticing, Recognising and Responding

As Cowie and Carr (2009) have noted, assessments are a means by which competence and competent learners are constructed. They have for too long been primarily sites where incompetence has been constructed.

In our exemplars project, we started from the position that learning always occurs in social-political-cultural contexts. Educational transformation will not come about through focusing only on the learning of *individual* children. Our assessment practices need to also reflect these wider social-political-cultural contexts. Macartney and Morton (2011) outline a number of problems arising from focusing only on the individual, particularly the individual’s deficits that may in fact be a product of the individualised, decontextualised approaches to assessment: “Viewing a child’s ‘impairment/s’ or ‘deficits’ as the *defining influence* on their behaviour, participation and learning decontextualises learning and teaching and diverts attention from the multiple influences on a child within the socio-cultural environment” (Macartney & Morton, 2011, p.15). A result of this view is that any and all difficulties in teaching and learning are constructed as inherently residing within the learner. Teachers may not think to look more broadly at the student’s interactions with the people, places and things that provide the context for teaching and learning. The exemplars show the importance of context for noticing children’s learning. Teachers are part of this context, as are the opportunities they create for children to show their understanding and competence. Teachers’ frameworks for interpreting children’s actions also form part of the context.

In New Zealand, as elsewhere, we need to continue to be vigilant to the individualising practices of assessment embedded in policies that supposedly aim to support success for all learners. Within inclusive education policy, the adoption of the Individualised Education Plan (IEP) in New Zealand is a case in point. We have seen how some IEPs have become the default curriculum for some students, rather than a space for considering how well educators are doing to ensure students have access to and participate in the curriculum (Millar & Morton, 2007;

Mitchell, Morton & Hornby, 2010). Mitchell et al. noted that “IEPs suffer from having multiple purposes ascribed to them, the same IEP document frequently being expected to serve educational, legal, planning, accountability, placement, and resource allocation purposes” (Mitchell et al., 2010, p. 22). We were able to use our learning from the exemplars project to inform the development of the new IEP guidelines, emphasizing that all students learn with the *New Zealand Curriculum*, the collaborative element of planning including parents and students, and the importance of the quality of the relationship between teacher and student (Ministry of Education, 2011). The new guidelines are called *Collaboration for success: Individual education plans*. The guidelines compare what an IEP is and what it is not. For example:

“An IEP is a plan that brings together knowledge and contributions, from the student and those who best know them, about the student’s learning needs, aspirations, personality, and cultural background. An IEP is NOT a document prepared by professionals to be signed off by a student’s parents/caregivers.” (Ministry of Education, 2011, p.6)

In addition, the guidelines note “Team members might include: the student – who is at the heart of the IEP team, their parents/caregivers and members of their whānau, hapū, iwi, or other communities, school staff, including teachers, teacher aides, and school leaders; specialists” (p. 8). The guidelines clearly state that the *New Zealand Curriculum* is for all students. The IEP is one of the ways the school shows how it will adapt its teaching and learning programme to include the student, rather than require the student to fit the programme.

However, these are guidelines only. Guidelines, curricula, pedagogy and assessment are contested at the political level as well as at the school and classroom levels. Educational assessment of individuals has recently taken on a role in accountability in New Zealand, under the guise of National Standards. Primary (elementary) schools will be assessed and publicly reported for how well individual students are performing against national standards in literacy and numeracy. Two outcomes are likely: The focus of teaching becomes what is assessed in high stakes testing. The richness of curriculum becomes diminished under these conditions. Further, it may not be in schools’ interests to include those students who will not ‘show progress’ on the traditional measures of school performance. There is an ongoing need for using understandings from Disability Studies in Education to ‘notice, recognize and respond’ to assessment practices that promote exclusion.

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#### Endnotes

<sup>1</sup> By placing everyday expressions such as 'special education' and 'regular education' within single quotes I am signaling that the meanings of these expressions need to be problematised. In this paper I am attending to the ways understandings of curriculum, pedagogy and assessment are assumed to work within these settings.

“What...[thought] cannot bear to know”: Crippin’ the Limits of “Thinkability”

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**Abstract:** In this essay, I show how disability studies scholarship can challenge normative ways of thinking in higher educational contexts. I call this “crippin’ the limits of thinkability.” To make this argument, I draw on one pedagogical context, the course *Multicultural Education for Leadership Personnel*, offered to nurse educators enrolled in a doctoral degree in Instructional Leadership offered jointly through the College of Education and the College of Nursing in the university where I teach. In this course, through disability studies scholarship, students came to interrogate their own socialization into authority-based practices intimately tied to the positivist claims of evidence-based research. Thus, in this paper, I use queer theory and crip theory to describe three methods: the study of limits, the study of ignorance, and the study of reading practice (Britzman, 1998) to illustrate how disability studies scholarship enabled students to critically reflect on the *knowledge of bodies* and the *bodies of knowledge* manifested in nursing pedagogy and curriculum.

**Key Words:** disability studies, queer theory, transformative pedagogy

*To engage the limit of thought – where thought stops, what it cannot bear to know, what it must shut out to think as it does – allows consideration into the cultural conditions that, as Judith Butler writes, make bodies matter, not as sheer positivity, but as social historical relations, forms of citations that signify more than individuals or communities need or want.*

*Deborah Britzman, 1998, p. 216*

In contemporary educational practice in the U.S. in both K-12 and higher educational settings, instrumental rationality has become the reigning shibboleth of the times. Instrumental rationality is a form of thinking focused on pre-determined ends without any attention paid to social and political value of these ends. In both K-12 and higher educational settings, instrumental rationality is articulated through the enthusiastic touting of evidence-based practices that refuse to entertain any intellectual risks. Caught up in this mantra that requires a willful adherence to a future that is predictable, controllable, and replicable, proponents of instrumental rationality allow for very little (if any) space for boldly wandering outside the confines of the unexpected and engaging in the un-thinkable. Bolstered by high stakes testing and punitive accountability standards, proponents of instrumental rationality entertain a dogmatic embrace of an anti-intellectualism that requires the pursuit of only that which is easily observable, knowable, and especially thinkable in a facile celebration of a conventional intelligibility. Rejecting these accusations of anti-intellectualism, proponents of evidence-based educational practices argue that they are actually re-instating scientific rigor in educational research and practice. Gert Biesta (2007) describes this move as follows:

“Proponents of evidence-based education stress that it is about time that educational research starts to follow the pattern that has created ‘the kind of progressive, systematic improvement over time that has characterized successful parts of our economy and society throughout the twentieth century, in fields such as medicine, agriculture, transportation, and technology.’ ...They call for a culture ‘in which evidence is valued



over opinion' and argue that any approach to decision making that is not evidence-based is simply 'pre-scientific.'" (p. 3-4)

While I will not argue against the need for carefully conceptualized and thoughtfully researched pedagogical praxis, I am very skeptical about this casual dismissal of all that which does not neatly fit into very narrow and rigid depictions of what counts as acceptable evidence. For example, a few years ago, the mission statement in our College of Education was rewritten so as to omit the concept of "social justice." It was argued that "social justice" could not be included as one of the standards of pre-service education simply because it could not be measured. True, social justice is a much contested term, and hence clearly there can be no significant body of research that can say clearly without a shadow of doubt that the outcomes of social justice are both predictable and replicable. But, should there not be a space in almost every course in the teacher education curriculum where there is a sustained debate/discussion of the relationship of social justice (and its multiple/contested meanings) and the philosophical bases of pedagogy? This was something that the proponents of evidence-based research were adamantly against. Rather, arguing that the curriculum was already overloaded with courses that easily replicated the State's standards for effective education, the instrumental rationalists in the College of Education pointed out that it was "unthinkable" to spare any time at all in pursuing inquiries that would not lead to easily anticipated outcomes unhampered by the vagaries of context that they perceived as disruptive.

It is to those "unthinkable" spaces that I go to in this essay – spaces that are riddled with the discomfort and alienation often associated with radical possibilities that contemporary educational practice seems reluctant to explore. The title of my essay is derived from an essay by educational theorist Deborah Britzman (1998), *Is there a Queer Pedagogy? Or Stop thinking Straight!* In her essay, Britzman explores what happens "if queer theory is brought into tension with education in general and pedagogy in its specificity" (p. 213). Describing how the very notion of queer theory is seldom (officially) even thought of, and, if acknowledged, it is often conceived of as unthinkable in academic contexts, Britzman draws on a psychoanalytic framework to explore the relationship between "a thought and what it cannot think" (p. 211). Rejecting the construction of queer theory as the unthinkable discourse in the school curriculum, Britzman re-situates queer theory as the means to "rethink the very grounds of knowledge and pedagogy" (p. 211).

In this essay I argue that disability studies, just like queer theory, provides the disruptive means of troubling the limits of "thinkability" (or what we dare not think) in educational contexts. Disability studies scholarship throws the spotlight on disruptive bodies and disruptive minds. These subjects refuse the disciplinary pedagogical practices that require "docile bodies" to support the neoliberal vision for democratic education. This vision requires the management of levels of diversity that might impede efficient realization of measurable educational goals. Thus, even though educational contexts teem with diverse bodies and minds that are likely to disrupt this machine-like process, evidence-based pedagogical practices ignore this diversity or make concerted efforts to contain it. Hiding behind the façade of outcomes and standards, educational practices justify the segregation, disciplining, and even erasure of the existence of unruly, messy, unpredictable, and taboo bodies – bodies that are shaped by, and in turn, shape the social, political, and economic contexts which they inhabit (Erevelles, 2011).

Disability studies, on the other hand, revels in the celebration of those bodies that reject the dominant binary division of the world into able-bodied and disabled or normal and abnormal, by exposing these divisions as unnatural, hierarchical, and therefore oppressive (McRuer, 2006). Robert McRuer has conceptualized this radical disruption of normative belief systems as “crip theory.” According to McRuer, cripin’ is the subversive and disruptive act of “coming out” that rejects “compulsory able-bodiedness” and the disciplinary discourses it proliferates to celebrate the plethora of unruly possibilities for thinking about the body outside normative restrictions about what a body should be. Applying McRuer’s conceptualization of crip theory in educational contexts enables turning a “crip eye” (McRuer, 2006, p. 171) on the normalizing practices of education to shift the focus from test scores and normative standards to “bodies of knowledge” and “knowledge of bodies” that have historically been conceived of as “unthinkable” in contemporary educational practices (Britzman, 1998).

### Disrupting Bodies of Knowledge and Knowledge of Bodies

In this essay, I draw on McRuer’s conceptualization of Crip Theory to show how disability studies scholarship enables cripin’ the limits of thinkability in educational contexts. To make this argument, I will draw on one pedagogical context where I utilized disability studies scholarship to enable my students to explore what “thought cannot bear to know.” The course, AEL 667: *Multicultural Education for Leadership Personnel*, was offered to nurse educators enrolled in a doctoral degree in Instructional Leadership offered jointly through the College of Education and the College of Nursing at the University where I teach. In this course, students were nurse educators who held full-time positions in their fields of expertise. Unfortunately, however, their extensive professional experiences ensured their dedication to the practices of instrumental rationality and evidence-based research. The challenge in this course was the difficulty of encouraging students to interrogate their own socialization into authority-based practices intimately tied to the positivist claims of evidence-based research.

Much to their chagrin, my pedagogical strategies in the social foundations of education emphasize open-ended inquiry into the epistemological and ontological (what is accepted as knowledge and what is accepted as reality) roots of educational knowledge and pedagogical praxis. Thus, the course produced an intense culture shock in nurse educators exposed for the very first time to humanities-based scholarship with its open-ended injunctions to analyze competing and often contradictory truths. Disciplined as they were into following without question the dictates of “scientific” knowledge and located at the lower end of deeply entrenched professional hierarchies, my pedagogy that privileged the question rather than the answer was very disorienting to them. But, perhaps, more terrifying to them was that moment in the course when they found themselves brought face to face with disruptive bodies (disabled/queer) that refused to be neatly catalogued within already formulated bodies of knowledge such that they found themselves in a space “where thought stops, what it cannot bear to know, what it must shut out to think as it does...” (Britzman, 1998, p. 216).

The weekend we discussed queer/disabled bodies, my students (all 4 cohorts that I have taught in the past 4 years) seemed nonplussed when confronted with what disability scholars Patterson and Hughes (1997) have described as a “carnal sociology of the body.” Steeped in the phenomenological theory of Merleau-Ponty that grounds social knowledge in the experiencing and experienced body, disability studies scholars Paterson and Hughes (1999) argue that

impairment associated with disabled bodies is not an intra-corporeal phenomenon (within the body) but inter-corporeal (between bodies), such that the social meaning of one's impairment is not static but is, instead, always incomplete and transitory and always shaped and revealed "where the paths of ... various experiences intersect and engage each other like gears" (Merleau-Ponty, 1945/2002, p. 137). Here, knowledge of bodies is a social and not just a clinical event where all bodies are in a state of renewal and adjustment in changing physical and environmental contexts making bodies intensely aware, not just of their be-ing but also of their mutual becomings-in-the-world. Here, disability theorized as becoming-in-the-world, produces what Paterson and Hughes (1999) have called the "carnal information" of the disabled subject that imbues even the experience of impairment (e.g. pain) as the source of social and cultural meaning.

The readings that I had assigned for this section of the course were chosen to enable these nurse educators to extend their understanding of bodies outside the banality of clinical research. Though the readings did not include Patterson and Hughes' thought-provoking essay (an omission I intend to remedy this time), I had included other disability studies scholarship that included Audre Lorde's (1995) book *The Cancer Journals* and a short list of articles such as Parin Dossa's (2003), *The Body Remembers: A Migratory Tale of Social Suffering*; and Abby Wilkerson's (2002), *Disability, Sexual Radicalism, and Political Agency*. I was aware that the nurse educators in my class were not unfamiliar with phenomenology – a theoretical perspective that is often deployed in the nursing curriculum. However, it appeared that their phenomenological observations were employed in the creation of a database of clinical knowledge of bodies rather than exploring the subjectivities of lived experience replete with unanticipated meanings. More important, this "carnal" exploration of embodied knowledge has been frowned upon in clinical contexts wedded to the memorization of scientific fact and the efficient replication of scientific practice.

Even though they are constantly surrounded by vulnerable bodies, the nurse educators, many of whom who had worked in the field for more than 20 years, were taken aback by the bodily knowledges pervasive in the readings that now pushed their limits of "thinkability." However, this pushing of their limits was not a seamless occurrence. There was much resistance throughout the course in engaging in these issues. However, because of the limits of space, I am only highlighting the significant transformations that occurred in the course.

It seemed unthinkable that these disabled/queer bodies should produce such profound disruption in the matrix of their thinking especially because nurses are assumed to have a nuanced understanding of bodily difference that is intrinsic to intimate caring relationships. It soon became apparent that the limits of their "thinkability" were not a function of the paucity of encounters with disruptive bodies. Rather, they were a function of a peculiar form of invisibility. By invisibility I do not mean that the nurses did not see their patients as disabled/queer. Rather, their seeing was similar to Ralph Ellison's depiction of the racialized body in *Invisible Man*:

"I am invisible, understand, simply because people refuse to see me. Like the bodiless heads, you see sometimes in circus sideshows, it is as though I have been surrounded by mirrors of hard distorting glass. When they approach me they see only my surroundings, themselves, or figments of their imagination. Indeed, everything and anything except me." (p. 30)

Invisibility is dangerous because notwithstanding the presence of disabled/queer bodies, the dominant discourses that naturalize normativity see these bodies as nothing other than the distorted image of the norm. In nursing, in particular, where caring for all bodies is the central ethic of professional practice, the refusal to recognize the carnal possibilities for disruptive bodies in clinical contexts could prove extremely dangerous and oppressive. By “carnal possibilities”, I am referring to the other restorative aspects of embodiment (such as sexuality) that exceed the narrow clinical parameters of what is understood as “healing” or “cure.” For example, the nursing curriculum my students were exposed to acknowledged queer bodies mostly in the context of HIV/AIDS and disabled bodies mostly in clinical discussions of the ethics of death and dying. Thus, discarding the phenomenological sociology of carnal embodiment that was rife with emancipatory possibilities, the nursing curriculum seemed content to foreground queer/disabled bodies only when they were pathologized, policed, or made to disappear. Such practices support McRuer’s (2006) claim that visibility and invisibility are not after all fixed attributes that somehow permanently attach to any identity. Rather a political economy of visibility is deployed that only engages disruptive queer/disabled bodies when they are made (in)visible via pathology/policing/disappearance.

The introduction of disability studies’ scholarship to the nurse education curriculum, disrupted these habitual “ways of seeing” (Berger, 1990) forcing my students to recognize this tension between the clinical and the carnal. This was apparent in one of the responses posted on the discussion board attached to this course by a student, Lydia (a pseudonym) who wrote:

“The body to nurses is usually something we see as biological and scientific. When I catheterize a man it is just that... putting a catheter in a penis! I see nothing sexual or attractive about the process. That is how nurses view bodies, nothing special just another naked person.”

But this clinical objectivity could not hide their real discomfort about non-normal bodies. Thus, notwithstanding the centrality of care in the nursing curriculum, another student Leah observed that:

“Typically, nurses avoid patients with different bodies out of fear.... Because nurses feel uncomfortable with their fear of different bodies, they may ask to be assigned or reassigned to different patients. Still other nurses may only go into those patients’ rooms when it is absolutely necessary.... Generally, patients with different bodies feel ignored and isolated by the nursing staff, the people that they seek for care.”

Leah’s observation was one shared by several students - an uneasy reminder that even though they had extensive knowledge of bodies, even though caring was central to their work, and even though their practice relied on the infallibility of evidence-based research, this did not allow them much “room to maneuver in thinking the unthought” (Britzman, 1998, p. 216) in the nursing curriculum. Instead, disability studies scholarship transformed their understandings of diversity as objective physical/cultural characteristics into recognizing disability as a political encounter between different bodies. This transformation also brought to the forefront a critical self-awareness of their agitated silence, their bemused reluctance, and their silenced terror in these encounters with disruptive embodiment. Also, evident was the uncomfortable realization that pedagogy is more than just imparting information (evidence-based though it may be); more

than testing students on those facts (irrefutable as some of them may be); and more than hoping that students ace those standardized tests (the NCLEX for nursing certification). In this way, disability studies scholarship began to initiate possibilities for re-thinking the very grounds of knowledge and pedagogy in the nursing curriculum.

Many of the nurse educators teach in community colleges where they are forced to adhere to a pre-existent curriculum or face the threats of sanctions if they do not teach to the test. Thus, in class, they raised these rather desperate questions: If this (any disruptive issue) is not on the test, can we even teach it? If it is a skill that cannot be measured, should it even be on the curriculum? What if students complain that we are exceeding the limits of what is conceived of as the curriculum in nursing? What if we are uncomfortable with the issues that we raise? These questions foreground precisely what Britzman argues is the relationship between “a thought and what it cannot think.” Thus, in the next few sections of the paper, I will explore this relationship in the nurse curriculum using:

“...Queer Theory’s [and Crip Theory’s] insistence of three methods: the study of limits, the study of ignorance, the study of reading practices. Each method requires an impertinent performance: a struggle to think against the thought of one’s intellectual foundations, an interest in studying the skeleton of learning and teaching that haunt one’s responses, anxieties, and categorical imperatives and a persistent concern with whether pedagogy can allow for more room to maneuver in thinking the unthought of education.” (Britzman, 1998, pp. 215-216)

Hence, drawing on the course readings and students’ writings from the on-line discussion board, I will illustrate how disability studies scholarship enabled students to critically reflect on the *knowledge of bodies* and the *bodies of knowledge* manifested in nursing pedagogy and curriculum.

### Crippin’ the Limits

According to Britzman (1998) the study of limits foregrounds “unmarked criteria that work to dismiss as irrelevant or valorize as relevant a particular mode of thought, field of study, or insistence upon the real” (p. 216). The study of limits became a central theme in my course. To the predominantly southern Baptist, straight, female, nurse educators one of the limits that marked what “they could not bear to know” was the issue of sexuality in clinical contexts. Comfortable only around clinical discussions of sexuality in the context of disease or in the mechanics of care, their introduction to the erotic queer/disabled body in Abby Wilkerson’s (2002) article was initially disturbing to them. Wilkerson (2002) argues that issues of sexuality are markedly erased in in medical contexts unless they manifest themselves in contexts of control. At all other times, Wilkerson points out, medical personnel experience what Cindy Patton describes as “erotophobia” that she defines as follows:

“...[E]rotophobia...[is] ‘the terrifying, irrational reaction to the erotic which makes individuals and society vulnerable to psychological and social control in cultures where pleasure is strictly categorized and regulated’.... Erotophobia (like homophobia) involves not only explicit declarations of pathology, but also other practices and attitudes that

more subtly reflect cultural taboos against sexual practices, desires, and identities.” (p. 40)

Reading Wilkerson’s essay began to make visible to these students their own terror of the carnal sociology of non-normative bodies. Thus, for example, one nurse educator Mary Jean wrote:

“Wilkerson (2002) argues that erotophobia is a means of ‘creating and maintaining social hierarchies’ and ‘oppressing marginalized groups.’ In medicine, for example, healthcare workers often do not address sexuality with marginalized patients....Even discussions about racism, sexism, homosexuality, desire, classism, and ageism [are] considered taboo in our culture. Trying to discuss these issues with patients and students are difficult and often are avoided.”

In exploring why these fears exist especially around disabled bodies, Sandra, another student wrote:

“...[P]athologized bodies represent social upheaval and chaos...It is really our underlying fear that feeds biases towards disabled people. Fear is borne out of lack of understanding, lack of familiarity and that subtle horror we all have that it could be us. This horror or fear really should make us more willing to see their lives through their eyes not ours. Unfortunately it doesn't.... As the ‘caring’ profession you would think we would be at the forefront of listening to these patients and advocating for them. However we have often been guilty of treating them like children, not capable of having the same desires or feelings that all adults have.”

As the quotes above indicate, it became increasingly apparent that erotic queer/disabled bodies forced these nurses to the very limits of their thinking. Needing a way to think outside these limits, I shared with the nurse educators the poet, essayist, and activist Eli Clare’s (2001) more embodied description of his disabled body:

“I want to write about the body, not as a metaphor, symbol, or representation, but simply as the body. To write about my body, our bodies in all their messy complicated realities. I want words shaped by my slurring tongue, shaky hands, almost steady breath; words shaped by the fact that I am a walkie – someone for whom a flight of stairs without an accompanying elevator poses no problem – and by the reality that many people I encounter in my daily life assume I am ‘mentally retarded.’” (p. 369)

Clare’s exhortation that the body is more than its clinical symptoms enabled the nurse educators to recognize how the limits in the nurse curriculum simultaneously also produced limits in nursing praxis and called into question the key tenets of caring work. Thus, Juanita, a nurse educator explained:

“[N]urses claim to espouse the holistic approach in nursing by considering all aspects of a person's life that impact their health.... [N]urses reinforce and promulgate taboos about sexuality, especially in disabled patients. Nurses leave out one of the basic needs from Maslow's hierarchy....sexuality.... Denying the disabled their sexuality is the same as

refusing to grant them equal status as a person. It is another form of injustice and an expression of structural violence towards a marginalized group.”

Juanita’s reflection foregrounds Britzman’s argument that the notion of limits requires the presence of those considered unfit, unworthy, those who are dismissed. In shifting from clinical knowledges to a carnal sociology, the nurse educators embraced a more expansive conceptualization of care that required a radical re-thinking of the nursing curriculum.

### Crippin’ Ignorance

Britzman (1998) argues that the study of limits does not necessary explain why and how queer (and crip) discourses foreground “the margins between claims of truth and the claims of textuality [a space where] all discursive structures are formed” (p. 221). The example that Britzman (1998) uses in her essay is Cindy Patton’s discussion of how AIDS education represents a disjunction between the facts of viral transmission and the fashioning of safer sexual practices. This disjunction problematically produces sexual identities that are either guilty or innocent, yet, at the same time, supports a sex education pedagogy that claims that no one is safe. Britzman (1998) argues that, in such contradictory contexts, pedagogy, itself, becomes “the production of knowledge, ignorance, and subjects who presume to know” (p. 224).

Audre Lorde’s (1995) *The Cancer Journals* was an effective text situated in opposition to this form of willful ignorance. In this book, Lorde resists her normalization into straight white femininity after her diagnosis of breast cancer and the mastectomy that followed. Many of the nurse educators had worked with post-operative breast cancer patients and not until reading this book had they ever questioned whether the immediate implantation of prosthetic breast options soon after surgery was necessary and/or safe. Moreover, in almost every class, I encountered at least one nurse educator who had undergone a mastectomy. Here, Lorde’s critique enabled a thoughtful reconsideration of normative medical practice because it foregrounded again “the margins between claims of truth and claims of textuality.” As Jenny, a nurse educator, wrote:

“This ...injustice is demonstrated in Audre Lorde's experiences with mastectomy as a black lesbian. The lady that comes in to discuss prosthetic breast options comes in with the presumption that [Lorde's] hope and desire is to look "just as good as you were before because you can look exactly the same" and goes on to describe her own heterosexual viewpoints on how she does everything (sexually) that she did pre-mastectomy. She never considers the possibility that [Lorde] is anything but heterosexual invoking a sense of shame in [Lorde] and keeping her silent. This causes an injustice by denying [Lorde] the opportunity to discuss her own unique concerns.”

Reading Lorde foregrounded for the students “how the disjunction between what the normal subject-presumed-to-know and the deviant subject obligated-to-confess [becomes] discursively produced” (Britzman, 1998; p. 22) Lorde’s description of the hostility raged against her for being “one-breasted” and refusing to conform to the normative image of “breast cancer survivor” foregrounded for them how identity is forged in the interactions between bodies. In other words, these nurse education students through their thoughtful reading of Lorde’s text realized how their own perceptions of normativity were forced on their patients in ways that they

now perceived were oppressive. Thinking this through, another student Susan wrote this in response to Lorde's text:

“In Lorde's readings, she felt that she was forced to wear the prosthesis in order to not be different. This choice made her different. The loss of her breast made her body different as well. Lorde was telling us that it seemed that other women had a harder time with her choice of not wearing the prosthesis. As a nurse, we need to pay attention to this difference. Lorde's difference may not be a personal feeling of difference (self), but the feeling of this difference comes from us (others)...As nurses we need to be aware of these intersections.”

Reading bodies as interacting with each other within inter-subjective contexts also opened up a space for nurse educators to questions aspects of their knowledge base that seemed sacrosanct earlier. Thus, Jameela, a nurse educator writes:

“As nurses we come to accept a patient's disease process as detrimental and something that we must "cure" them of or return them to a 'normal' state. It is the definition of normal that I fear is most misleading and confusing for nurses. What is normal? Who defines 'normal' and why do we as nurses constantly strive to return the patient to their 'normal' state?... When a patient makes a choice not to go along with the "normal" sequence of events, such as Lorde did by not wearing a breast prosthesis, does that affect our ability to care for them as a person...? Do we know how to accept that an individual may choose to be 'abnormal'?”

### Crippin' Reading Practices

The third method that Britzman foregrounds in her essay is the study of reading practices. Here Britzman (1998) calls for a critical self -reflection of how one reads, paying close attention to practice of engaging with the other while “reading” the social. In doing so, she calls for a practice that “provokes a theory of reading” (p. 225), that is unafraid of the risk to self when thinking at the limits. This mode of reading was alien to the nurse educators for whom reading implied a transparent straightforward relationship between reader and text. Parin Dossa's (2003) article, *The Body Remembers* challenged this linear relationship. In this article, Dossa presents a narrative anchored in the suffering body of an Iranian immigrant woman living in Canada such that as researcher, Dossa could no longer remain detached but felt compelled to become a vulnerable and witnessing observer in order to bridge the gap between silence and speech. Dossa's essay had an impact on the nurse educators because it provoked a theory of reading that foregrounded the body as a source of language and meaning – especially the “suffering” body. As another student, Reena wrote:

“Dossa argues that ‘silence, the marker of human agency may be recognized as language.’ The silent language of bodily symptoms allowed Zahra to relate her suffering in the only way she could. Marginalized and oppressed groups have used silence and storytelling to voice their pain, which is against the dominant culture's version of the story. For example, Japanese women after the bombing of Hiroshima relayed their suffering through words of motherhood: worrying about ability to produce children and voicing concern about the conditions of children produced. Nurses have to learn this



silent language of symptoms to truly give patient holistic care. For, as Dossa noted, if one looks at the body and its symptoms, a story of structural oppression may appear.”

The most exciting aspect of this reading practice was that nurse educators who formerly conceived of pedagogy as lectures and tests now began to recognize students as embodied subjects in the classroom. Thus, Tabitha, another student wrote:

“...I think we can use this same listening in nursing education as we learn to read students' silence in order to hear what they are really saying. As educators we may interact with students undergoing the silence which lends itself to the 3 performative acts which Dossa spoke about: retrieval of voice, testimonial speaking, and deployment of words. Firstly, a gender minority or disabled student regains their voice after the empowerment which nursing school brings. Secondly, this student represents other voices within the newly gained voice they achieved. Lastly, they establish their own ‘moral authority’ with their words or their own place within the subordinate group in nursing school. As educators, we must listen not only to their voices but also their silence, which is a story in itself. All the students we encounter have stories to tell but as Dossa states ‘silence does not rule out speech.’”

Similarly, in direct opposition to the clinical context of evidence-based research practices, the nurse educators were open to exploring the possibilities of the role of vulnerable observer in the research process. For example, Sara wrote:

“In regards to research within nursing education, Northway emphasizes how “the position a researcher takes is not fixed but is an on-going process of self-critique and self-appraisal.” We must look within our own suffering and reflect in order to promote honesty within our research as nurse educators. We must listen to our inner self to promote reflexivity. I like the idea of a journal during ANY nursing research in order to reflect on our own inner critical thoughts. Also, the dialoguing which is required within our journal to ensure we ‘debrief’ with another regarding our ‘silence’ of thoughts is so very vital in research.”

### Crippin’ Care

In this essay I have highlighted how disability studies scholarship challenges the hegemony of instrumental rationality in nurse education and practice as described earlier in this essay. In my course I realized that the nurse educators seemed to be stuck between a rock and a hard place – between the impersonal objectivity of clinical research/practice and the intimacy of caring relationships. Attempts to efficiently negotiate this dichotomy required that nurse practitioners support a disciplined and controlled existence within the limits of normative thought. The introduction of disability studies proved to be disruptive causing students to rebel against these limits, to reject the ignorance of centering the normal subject –presumed-to-know and to re-think the reading practices that reproduce dichotomies of normal/abnormal. These disruptive reading practices also disrupted imagined notions of caring that these nurse educators had long held dear. They now argued that it was not enough for nursing praxis to just care. Authentic caring praxis necessitates that one confronts the limits of one’s ignorance and venture into spaces where diverse bodies are enabled to forge relations that are disruptive of the norm. In

short, the radical possibilities inherent in cripin' care are possible only if we can refuse the "cultural insistence to put back into place the boundaries at all cost that education is obliged to exceed" (Britzman, 1998, p. 212).

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## Supporting Graduate Students toward “A Pedagogy of Hope”: Resisting and Redefining Traditional Notions of Disability

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**Abstract:** This article describes the process by which faculty at Ghent University enculturate graduate students into a Disability Studies in Education (DSE) perspective within a culture that actively supports segregation of students with disabilities. Our curriculum centers around “a pedagogy of hope”—a way of thinking and working in which problems, solutions, and roles are defined differently from the traditional models of disability. To illustrate this work, we present five key incidents (real-life vignettes) that have occurred within the day-to-day interactions with the students and analyze the significance of these incidents in regard to student growth. We conclude with a discussion of ten basic elements of DSE that are central to research, teaching, and action.

**Key Words:** disability studies, education, inclusion

### Introduction

At Ghent University in Belgium, the faculty of Educational Sciences exposes graduate students<sup>1</sup> to concepts, research evidence, and examples of good practice as established within the field of Disability Studies in Education (DSE). Promoting a DSE perspective might be considered radical in a country with a public educational system that excludes students with disabilities—as evidenced in Belgium’s *nine* different types of special schools for those students. Moreover, *The World Report on Disability* (2011) indicates that Belgium sends more children with special needs to special schools than any other country in Europe. Thus, the Educational Sciences program prepares students to work within contexts (e.g., special schools or traditional service delivery models) where colleagues may have an intense link with the individual/medical model of disability (Van Hove et al., 2008).

Our process for enculturating students into a DSE perspective can be considered a work in progress. Resistance to change from an old-fashioned special education expert position to a human rights perspective seems to be the central challenge. Extra emphasis is given to helping our students make this shift because we live in a European region where thinking about education has become increasingly focused upon “instrumental rationality.” For example, we observe ongoing and proliferating discussions about student and teacher “competencies.” The function of higher education appears to be as the provider of intellectual capital for the knowledge economy (Allen, Ramaekers, & Van Der Velden, 2005), and students are increasingly seen as future employees for the labour market.

In this article, we rely upon the method of key incidents (Emerson, 2004) to illustrate *how* we encourage “a pedagogy of hope” (Freire, 2004) in resisting and redefining traditional notions of disability. Emerson (2004) defines key incidents as rich descriptions of people and interactions as they exist and unfold in their native habitats. To illustrate our process at the university, we describe five key incidents (represented as vignettes within text boxes) that

occurred during our interactions with students and analyze their significance to student growth.

### Educational Practices Linked to a Pedagogy of Hope

Freire (2004) describes *hope* as follows:

“Hope is necessary but is not enough. Hope is an ontological need; it demands an anchoring in practice. As an ontological need, hope needs practice in order to become historical concreteness. One of the tasks of the progressive educator, through a serious, correct political analysis, is to unveil opportunities for hope, no matter what the obstacles may be.” (pp. 2-3)

We describe the pedagogy of hope for our educational practices (Van Hove et al., 2008) as a way of thinking and working in which:

- *Problems are defined differently.* No longer are the impairments of the children we work with seen as the main problem or obstacle. Instead, within a process of “conscientization” (Freire, 2000), students learn to see and analyze obstacles in attitudes, school culture, the training of experts, and discriminatory practices.
- *Solutions are defined differently.* We introduce students to the idea that we do not need detached and objective professionals with standard solutions. Instead, we expect students to strive toward becoming *companions*, who support solutions that are built via dialogical action and reflection.
- *Roles are defined differently.* Children with labels and their families are no longer docile acceptors of “what is there” (Freire, 2004). Instead, problems are perceived as challenges to overcome. Students are challenged to act as allies with children, parents, and teachers to concretize the ultimate dream of children with labels and their parents: to participate in society.

#### Key Incident One

Problematization: Students live in a culture that initiates and socializes them to become experts for “the Others.”

*We recently received the correspondence below from one of our students in the Educational Sciences program.*

...Yesterday I got information about my practice period concerning the topic of “inclusive education.” I am asked to give support to a boy who will not attend school any more from September on. His support team has prepared an alternative program for him. They asked me to give support on Mondays when he will go to work in a farm for old horses. They expect me to help him when he is taking care for the horses. I don’t want to be too critical but...I don’t think what they have asked me to do can be seen as “real inclusive education.”

I really want to learn new things in my practice period and I already got the opportunity to guide children within “hippotherapy” while I was working in a psychiatric hospital for

children. So I'm writing you this mail to check if this new task can be seen as a valuable project.

To understand this student's perspective, we turn to a Foucauldian discourse analysis (Arribas-Ayllon & Walkerdine, 2008) to help us identify specific discursive techniques within the communication, such as:

- *(Subject) positions.* "Positioning" refers to communicative strategies used to assign the self or others to positions. It is a speaker's moral and personal attributes that shape how "what is said" may be understood (Wells, 2011).
- *Technologies of power and self.* These technologies can be seen as methods used by people to have an impact on how they will be perceived by others and themselves.

It is worth noting that this student is a Belgian citizen in a country where children are raised with "regimes of truth" such as: special children are better off in special schools; adults with disabilities live together in residential facilities; and citizens should feel a kind of pity for persons with disabilities. In light of these "truth(s)," our students typically are initiated and socialized to become "experts." From an expert position, people act as if they know what the (one and only) norm is. We see this student as running the risk to colonize (Pfeiffer, 2001) the life of the boy in question by making comparisons that can be described as "(only) understandable from an empirical-analytical perspective" (Skrtic, 1995; Gabel and Peters, 2004)—i.e., working with horses from a job coaching perspective is compared (incorrectly) to hippotherapy. Being outside the classroom (because this student is brought into a practice period experience) is seen as incompatible with inclusive education. Our student appears to be trapped by the idea that there is only one standard situation, forgetting that a lot of youngsters *without* impairments also have periods of practice within their curriculum.

### Key Incident Two

Problematization: Students may struggle to understand disability within a human rights perspective.

*We take you to a class discussion within one of our courses: "Diversity and Inclusion in Pedagogical Settings." Let's listen to a discussion in a student group within our course while they are asked to position themselves personally in relation to phenomena, such as diversity, disability, inclusion/exclusion.*

Student 1: ...from my perspective inclusion has to do with parents who do not accept the handicap of their children...

Student 2: ...don't you feel ashamed to take this position?

Student 3: ...PRESUME WE FOLLOW STUDENT 1's POINT OF VIEW. THIS WOULD MEAN THAT I AM NOT ALLOWED TO FOLLOW THIS COURSE ... AND FOR ME FOLLOWING THIS COURSE IS ESSENTIAL BECAUSE I WANT TO GET ENOUGH

BACKGROUND TO CRITICISE INCLUSION FOR DEAF STUDENTS WHO USE SIGN LANGUAGE. INCLUSION AS IT IS ORGANISED NOW WILL KILL OUR DEAF CULTURE. DEAF CHILDREN AND YOUNGSTERS WILL GET ISOLATED WITHIN SCHOOLS THAT ARE DEFINITELY ORGANISED AS PLACES FOR HEARING PERSONS....<sup>2</sup>

This key incident shows that some of our students still live with the idea that the ultimate alternative - bringing children/persons with disabilities into a parallel system of special schools and special services is the one and only solution. So from this perspective, parents and children who do not follow this path and make a choice for inclusive education are seen as not accepting the burden of the “handicap” of their family member (Ferguson, 2001).

Even the International Classification of Functioning, Disability and Health (not known in disability studies circles as a particularly progressive instrument) tries to put the notions of health and disability in a new light. It mainstreams the experience of disability and recognizes it as a universal human experience. Furthermore, ICF takes into account the social aspects of disability and does not see disability only as a medical or biological dysfunction. By including contextual factors (in which environmental factors are listed), ICF recognizes the impact of the environment upon a person's functioning.

In this light, participation becomes a crucial and central concept and a human right – as stated in the UN-Convention on the Rights of Persons with Disabilities as ratified by Belgium in July 2009. Instead of thinking about exclusion and parallel systems, this human rights perspective forces our students to think about support systems for full participation and reasonable accommodations. If we return to the key incident, we see that some students persist in giving time and energy to old discussions while losing track with interesting new challenges like: how do we preserve the Deaf Culture when we promote inclusive education?

### Key Incident Three

Problematization: How do we place central issues like personal position and perspectives on the agenda?

*Join us in a conversation with a student that occurred after we invited parents to the classroom to talk about their decision to choose inclusive education...*

...one of the students asked if she could ask a question in private (she was upset, I could see tears in her eyes.) “My parents chose years ago to bring my brother with a disability to a special school. Does the discussion we have here in this course prove that my parents made the wrong decision? How do I talk with my mother (who is very interested in what we learn here at the university) about inclusion? I don’t want her to feel guilty....

This key incident can be analyzed from different perspectives. On the one hand, it shows that each topic we study is (also) understood through our life stories. Although our students are following courses and training sessions, the way their parents and their family dealt with

challenges in the past stays as a very important frame of reference. On the other hand, we know that siblings of persons with disabilities often see themselves (and have made explicit or implicit promises to their parents about it) as the next generation of care givers for their brother or sister (Vanhoutteghem & Van Hove, 2012). Universities that conceive of themselves as houses full of science and objectivity must learn to deal with very personal stories that students bring into the courses.

#### Key Incident Four

Problematization: How can we encourage students to cross borders?

*Consider this example of crossing borders...*

Martin is a young man with a label of developmental delay. His parents brought him from kindergarten to a regular school believing in the talents of their son and in the power of bringing children of the same neighborhood together in the same school. Martin is now in his last years of secondary school and listens very carefully to stories in the press. He heard that the Government makes a promise to send more students abroad to enjoy international experiences. In the professional training center where he is enrolled, not many opportunities seem to exist to enjoy such an international experience.... But in coalition between his parents and one of our teaching staff members a great idea was born. Martin shared an information moment for our university students who were thinking about having a practice period abroad. He got the opportunity to present himself and his dreams. He asked if he could join one of our students (for a short period) while they went abroad and presented himself as a man who could cook great meals.... Some weeks later Martin had “a deal”: one of our students travelling to Manchester for a semester there will be Martin’s guide and roommate.

Within our university classrooms, *students are deliberately challenged* within co-teaching moments we organize with parents (from the Parents for Inclusion movement) and with self-advocates (from Our New Future). With these first actions, we hope to be able to challenge dominant assumptions and positions. In these lectures and workshops with the so-called clients of the care and school system, students are asked to work toward crossing borders. We start from the assumption that individuals have to admit that there *are* barriers that divide them, but they can also learn that these barriers can be crossed to work together in promoting social change.

#### Key Incident Five

Problematization: How can we help students develop a critical eye for representations of people with disabilities?

*Aren’t we all students first? Here we provide opportunities for duos to work together.*

Last year, a group of students was asked to build portraits (Lawrence-Lightfoot & Hoffman Davis, 1997) of students with special needs studying in higher education institutions. They were asked to build a dialogue with a colleague who needed reasonable accommodations to

study in a university or university college. In each duo, they had to negotiate which medium (e.g. film, poster, slide show, storytelling) was preferred. They learned that their work would be used by the Expert Center on Studying with Special Needs in Higher Education. They were asked to discuss with their colleague how he/she preferred to be represented. Some of them were taken to the social networks in which their colleagues were active.

We introduced portraiture exercises to confront our students with the way representations of persons with disabilities are constructed. Within their lives, our students are permanently confronted with media representations of race, class, gender, ethnicity, sexuality, and disability. While building a portrait together with someone with a label, students' everyday representations are questioned, criticized and eventually rejected. Within the process of building a portrait together we hope our students learn to balance their experiences with the lived experiences of their colleagues with a disability.

### From Problematization to a Frame of Reference for Practice

We have learned through the years that *it is necessary to work with students starting from a stable and clear frame of reference*. Therefore we combine the theoretical basics of Disability Studies in Education as articulated in the book series of Danforth and Gabel (e.g. Connor, 2008; Danforth, 2009; Danforth and Gabel, 2006; Gabel, 2005; Gabel and Danforth, 2008; Smith, 2010; Valente, 2011) with the early ideas of Giroux (1983; 1988; 1990; 1992) and the work of Demetrian (2001). Before going to practice in the field and while they are doing their practica<sup>3</sup> our students attend lectures and study basic texts from the field of Disability Studies (Van Hove, 2009). We call attention to the following basic elements of Disability Studies that can be seen as central in research, teaching, and action:

#### 1. Participation is essential.

For persons with disabilities, it is not enough to be present. Participation is more than presence. We should think about belonging and about active involvement in whatever is going on (Biklen, 1992). Disability Studies invites us to become careful and active listeners (Rinaldi, 2005) to what people with disabilities want and how they want to participate. It makes us think about ways we can/should support people with disabilities to enhance their participation and opportunities to participate. Following the adoption of the UNESCO Salamanca Statement and Framework for Action on Special Needs Education (1994), inclusion and participation are seen as essential to human dignity and to the enjoyment and exercise of strategies that seek to bring about a genuine equalization of opportunity. In addition we are interested in the barriers to participation for people with disabilities.

#### 2. Disability Studies turns around talents, dreams, and desires of people with labels.

For years, we focused solely on what people with disabilities are “not good at” and what they are not *allowed* to do. Professionals have traditionally behaved like managerial ticking boxes (Parton & O’Byrne, 2000). It is a challenge for our students not to fall into this trap. We want to explore *explicitly* talents, dreams, desires and plans. We need to handle any questions that need negotiations with other people closely involved. How can we understand who the child



and his/her potentiality actually is? How can we support this child and his/her parents and family on their journey?

3. With Disability Studies, we join the human rights discourse.

The UN Convention on the rights of persons with disabilities ratified by Belgium in 2009 is an important guide for the way we support and encourage people. We are not in the position to say what is “reachable” (Barton and Oliver, 1997). Inclusive education and living are part of a human rights approach to social relations and conditions. The intentions and values involved relate to a vision of the whole society of which education is a part. Issues of social justice, equity and choice are central to the demands for inclusive education. Inclusive education is concerned with the well-being of all pupils, and schools should be welcoming institutions.

4. Persons with disabilities have their own voices and their stories must come first.

A crucial feature of disabled people has been the extent to which their voices have been excluded. Overcoming disabling barriers will include listening to the voice of disabled people and their organizations, especially as they struggle for choice, rights and participation (Clough & Barton, 1995). The voices of family members (or of other persons close to persons with disabilities) cannot be regarded as a substitute for the voices of people with disabilities themselves. The person with disabilities always comes first, is listened to, is offered opportunities for communication, and is not excluded because of traditional ways of thinking e.g., “he is looking for attention,” or “she does not understand very well what is happening.”)

5. Families, natural networks, and actions in society should come first.

Disability Studies recognizes the important role that family members play in the lives of many persons with disabilities. Scholarship in this area includes research into the views and experiences of family members. Embedding the individual in a web of relationships ensures greater opportunities for shared identity formation with multiple social partners (Ferguson, 2003). Murray and Penman (1996) are very clear in what they think about segregated and so-called specialized systems: for us the concept of segregation is completely unjustifiable – it is morally offensive – and contradicts any notion of civil liberties and human rights. Whoever it is done to, wherever it appears, the discrimination is damaging for our children, for our families, and for our communities. We do not want our children to be sent to segregated schools and any other form of segregated provision. We do not want our children and families to be damaged in this way. Our communities should not be impoverished by the loss of our children.

6. People with a professional role must recognize their position and give it a place in their relationships with others.

We do not believe in professional attitude that is based on objectivity and detachment, people have to take each other’s expertise and experiences seriously. To us, modest relations (Goodley & Van Hove, 2005) are the central motive. Assumptions about normality and the reproduction of structural differences are disclosed and mirrored in these modest relationships. In view of this choice and following Paulo Freire, we cannot stay (in research and practice) neutral. This leads to communal activism and resistance in order to further a longed for social change (Freire, 2004). It is a living engagement; it applies to resources of our creative imagination in an

attempt which is as much to disclose something about ourselves as it is to disclose something about them. It is an engagement that tries to find a way of being open to them and a way of learning from them and which, having tried once, will return and try again renewing, renewing, renewing (Campbell, as cited in Davis, 1998). In this perspective our pedagogical work becomes a combination of a political act, a creative act, and an act of knowing (Gadotti, 1998).

7. We believe in the strengths of reflective practitioners.

Reflective practice is an approach to practice that involves: (i) asking questions to get beneath the surface of the situations we encounter to ensure that we have more than a superficial grasp (Murray & Kujundzic, 2005), and (ii) takes account of wider social and political processes that disadvantage marginalized groups of people and reinforce patterns of discrimination and oppression (Mullaly, 2002). A person who constructively queries critical situations, organizations, and structures, begins to see and work toward creating a better world for all citizens.

8. Disability Studies is not afraid of contradictions.

Dilemmas are revealed as fundamentally born out of a culture that produces more than one possible ideal world. Social beings are confronted by and deal with dilemmatic situations as a condition of their humanity (Billig et al., 1988). It must be possible to think about and to search for various entrances within the same challenge. Pedagogues are not plumbers who immediately need to solve the problem. Complexity is the norm and we have to take different options into account.

9. It is important to consider disability from a historical and comparative perspective.

We must ask how were phenomena that we know now constructed in the past? How do people who live in different cultures tackle phenomena we live with? From such analyses, much can be learned. The field of (special) education is full of histories that define and classify individuals according to specific concepts and along specific lines. These not only mark the individual development of those who are subjected to these procedures but also open up possibilities for them to become agents of their own realities.

10. Disability Studies goes hand in hand with action.

We cannot be bystanders with our hands in our pockets and wait. We have to act together with people with disabilities and their families.

### Conclusion

Our DSE curriculum offers students *short confrontations with practice situations* while being coached by one of our staff members. These experiences are designed to bring students to the idea that schools and care organizations can be viewed as political and cultural sites as well as institutions of instruction or care. Students are asked to build experiences from the perspective that we cannot ignore difference. Difference in a Deleuzian perspective (Davies & Gannon, 2009) can become a productive force—accepting difference on the one hand and finding ways to articulate shared goals and values on the other hand. Empowerment means more than self-

confirmation. It also refers to the process by which students are able to interrogate and selectively appropriate those aspects of the dominant culture that will provide them with the basis for defining and transforming, rather than merely serving the wider social order.

In the final year of the Masters trajectory, some students follow a disability studies path concerning their practice period (one semester) and for their master thesis project. In the spirit of Giroux, we encourage our students to align their practice period and their research project with like-minded social workers, community activists, parent groups, and others across disciplines and roles for the purpose of working toward the vision of a transformed society and reasonable accommodations. Students really need these allies to work with/through tensions of power, knowledge, and ethics as they play themselves out in the institutions of schooling and other social arenas.

Within this one semester practice period, we bring students together in little communities of practice (Wenger, 1998). With coaching and support from one of our staff members, we motivate them to learn from each other. We also want them to discover that the same processes of power, of labeling, of ignoring the voice of certain people, of bringing standard solutions to very personal questions can be observed and challenged in different settings and to different groups.

We hope that at the end of the day our students become reflective practitioners. We would like to see them as transformative intellectuals linking their academic work with an emancipatory vision. Seen from this perspective, critical reflection and action become part of a fundamental social project that is embedded in a human rights discourse. The responsibility of the transformative intellectual is to create oppositional public spheres to challenge the hegemonization of dominant institutions with their discourses and practices. We encourage them to participate in the creation of oppositional counter-spaces that challenge any totalizing influence of institutions.

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#### Endnotes

<sup>1</sup>Our students get a Master Diploma in Educational Sciences. In the future most of them will work as team coaches within institutions and services (such as special schools, services for early intervention, services for supported living or supported employment). Some will give direct support to children or adults with a label, e.g., through projects of inclusive education or personal budgets.

<sup>2</sup>This quote from a Deaf student is written down as it was translated through a sign interpreter for the hearing students

<sup>3</sup>Within their 5-year training period, our students have to observe basic pedagogical practices in their third year of Bachelors in schools, (special) services for children with disabilities for one month. They co-coach pedagogical processes in their last year of Masters training for 6 months.

## **BOOK AND MEDIA REVIEWS**

### **Book Review**

**Title:** *Arts, Culture, and Blindness: A Study of Blind Students in the Visual Arts*

**Author:** Simon Hayhoe

**Publisher:** New York: Teneo Press, 2008

**ISBN:** 978-1-934844-07-6

**Soft Cover:** \$30.00, 193 pages

**Reviewer:** Katherine Reid

The visual arts has the power to build confidence, molding a creator's worldview and perceptions of his or herself. Simon Hayhoe supports this theory in his extensive study on blind students involved with the visual arts. The students in this study vary in age, gender, causes of blindness, and self-confidence levels; however, Hayhoe suggests that the self-confidence instilled in these students by peers and mentors correlates to how successful their artistic and academic careers will be. The visual arts and self-confidence are a symbiotic relationship, exemplified by many of the students interviewed or observed in this study.

Hayhoe's study explores one of the most powerful myths in modern society: the myth that blind people are incapable of understanding and creating visual arts and how it relates to theories about self-worth and confidence of blind people. More specifically, Dr. Hayhoe's hypothesis is that "attitudes towards students who are blind in the visual arts radically changed after they were integrated into mainstream schools, making students more educated and thus more willing to undertake new arts" (p. 5), yet attitudes that yielded negative experiences affected students' behavior in the classroom as well. He supports this hypothesis by addressing two questions throughout this book. Hayhoe concludes with the questions "can attitudes towards blindness in art education merely be discussed in terms of a physical disability, or are they affected by social and cultural assumptions?" (p. 5) and "what does blindness stop people from doing in the visual arts?" (p. 5).

Hayhoe began his research in 1993 with a more anthropological perspective of research, observing students from Leicester and Bristol Universities in England. They were blind from birth or early childhood and had attended schools for the blind as children. Hayhoe tested his results using American educational psychologist Walter Doyle's theories on ambiguity and risk: the greater the ambiguities in the tasks given to inexperienced students, the less likely students were to try them as a result of their lack of self-esteem (1979, 1983). While Doyle's theories were observed in the classrooms, Hayhoe felt more information could explain the students' behaviors. In 1999, Hayhoe began to redesign his study to focus on students studying art at an advanced level since it would demand greater risks, for which the students may not have had experience. Hayhoe's study also considered a cultural approach to blindness. He reasoned the

study would be conducted from the perspective of society's attitudes to students' blindness and test the premise that their educational and social culture would affect their willingness to try tasks once they had entered the classroom. Students who were blind from birth or early childhood, as well as those who became blind later in life, were observed and interviewed in classroom settings.

The assumptions made about disability affect how people view others who are blind as well as how students who are blind are treated in art education. Hayhoe examined this social conception of disability and blindness in academic studies and characterized it into two perspectives: subjective disability, or what an individual can do or feels that he or she can do in a particular context, and objective disability, or what society tells a person what he or she can or cannot do given a particular context. Many societies define blindness as an objective disability, and blindness can be legally classified at different levels of severity, thus preventing people who are blind from most social tasks. A person is therefore judged according to a strict medical test at a particular point in time under certain conditions that prevents those who are blind from having a positive subjective view of their own capabilities based on their test results.

The most interesting aspect of the study is the experiences of the adult students compared to those of the young art students. The adult blind art students were interviewed and observed at Leicester and Bristol from 1993 to 1994. Both the Braille pianist and the sculptor who was afraid of clay shared similar experiences of being forced into music at a young age. The only visual arts allowed in their residential schools for the blind was basket weaving. It was not until later in life that met each other (and eventually married) but also found that the arts improved their confidence. Despite the fact that they had limited arts education and that teachers doubted their ability (taking the view of objective disability in regards to blindness), both the sculptor and pianist were eventually persuaded to pursue careers in the arts, but it took years to negate the negative influences of their past.

The younger art students who were blind had mainstream school experiences that greatly affected them later during their college years. The boy observed by Hayhoe felt psychologically excluded from many art tasks that his sighted peers had the opportunity to try, even though he was physically included in their classes. Hayhoe deduces that this “might have been a result of the lack of training on the part of his teachers[...]" (p.131.). The boy later avoided the same tasks required of him in college-level art classes at his mainstream school. However, if he were asked in one of those classes to try a completely new task for which he had no prior experience, he would. This drove him to find a subject he could excel in that bore no relation to those he had previously attempted and experienced negative experiences. Conversely, the female student who was also in a mainstream school did not have negative experiences and was presented with normal expectations that allowed her to take more risks when experimenting with new materials or methods. Hayhoe concludes this sense of experimentation became a trait she generated from within herself, from a sense of self-worth in her ability to create successful artworks, even when her assessments demanded a more cautious approach (p.133).

I recommend *Arts, Culture, and Blindness* to those interested in teaching students who are blind, especially in the visual arts field, art museum educators, and anyone interested in learning about blindness and the visual arts. Simon Hayhoe's thorough study was written in a



language accessible to anyone in any field of study and Hayhoe's clear, concise writing style and formatting of his chapters made this an enjoyable read, which supported his hypothesis. As quoted by Hayhoe in his introduction on page 4, John Steinbeck wrote in his book *Sweet Thursday*, "Looking back, you can usually find the moment of the birth of a new era, whereas when it happened, it was just one day hooked on to the tail of another..." This quote sums up how students who are blind find learning about visual arts from positive, encouraging teachers will be able to have self-confidence in their abilities in and out of the classroom.

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## Book Review

**Title:** *Surprised to be Standing: A Spiritual Journey*

**Author:** Steven E. Brown

**Publisher:** Honolulu, HI: Healing Light, 2011

**Paper:** ISBN: 13: 978-1456521691

**Cost:** \$19.95, 218 pages

**Reviewer:** Janine Bertram Kemp

With *Surprised to be Standing*, Steve Brown is turning over new ground in disability literature. Activists, academics, and advocates might do well to listen up, especially those looking to toss a little wellness or self care into their mix. Brown's book does not point the path for others. His is a deeply personal narrative. He is a writer of integrity and solid disability rights credentials who wades into arenas that could create controversy if his views are misconstrued.

The narrative is divided into three sections: pain, healing, and liberation. The section on pain greatly details the author's experience with Gaucher Disease (GD), which began for him at age 5. GD involved perpetual, excruciating pain and regular experiences with broken bones. Brown managed to work and gain advanced degrees when many might lie in bed and whine,

“Just shoot me.” The author is affected but yet not beaten down by intense pain. His accounts are matter of fact, no-pity-please: here is how it was and here is how I dealt with it.

At one point Brown notes that for some reason, during the times of body and mind-wrenching pain, he could eat only nuts. And he writes of nuts in poetic prose that made this reader laugh out loud:

“Nuts: cashews have a lovely curve...tender, undulating. Walnuts are like a saw, striated, just enough space for the tongue to lap the salt. Almonds are best whole, yet small. Did nuts feel pain when the nutcracker pierced their tough shells? Brazil nuts are odd – sometimes the flaxy taste one wants, other times, a waxy flavor to avoid. Peanuts, last eaten....” (p. 23)

Reading through seemingly unending descriptions of pain, broken bones and the insults perpetrated by representatives of the medical profession, I wondered how much Brown’s inner poetry led to his ability to metaphorically keep dancing.

Yet he had bleak thoughts, like most of us who ride the severe pain train. He describes a particularly desolate episode during the early 1970’s when he was attending Southern Illinois University:

“My body responded in a way I had never felt before. It was my worst bone crisis. ...All I could feel was pain...I cursed God. I cried. Suicide began to appeal. Not because I wanted to die, but to do something, anything to escape the pain” (p. 51).

GD weakened Brown’s body, and he began using crutches, a manual wheelchair, and then a power wheelchair. In the book’s first section, the physical aspects of GD are interwoven with matter-of-fact depictions of his life and politics as a student and early spiritual explorations. He becomes active in protesting the Vietnam War, but committed to his hero Gandhi’s principles, and drops back when groups move from non-violence to revolutionary resistance.

Noting his own early psychic abilities, Brown briefly affiliated with Quince, a practitioner who bases his mystical competence on power and fear, rather than knowledge and love. That being the one brush with “the dark side,” the book touches on a number of modalities, including channeling and *A Course in Miracles* that the author’s spiritual travels took him through.

The final portion of the first section “Pain” could almost be in the section on healing. It concerns Brown’s discovery of and joining with the disability rights movement, where with his wife Lillian, he founded the Institute of Disability Culture and, through work and insight, carved out a leading role for himself.

Many parts of Brown’s evolution as a disability rights leader will resonate with others, and some parts are uniquely his. “Overnight Radical,” one of the book’s chapters, tells Steve’s story of finishing graduate school without a job. He had already spent a year as a History Instructor at his university. His department chair called to say he had recommended Steve to a

Tulsa-based firm to write the history of the organization. The phone interview went swimmingly, but after the in-person interview, the company representative said they had changed their mind and would not hire Brown because of his disability. They thought someone on crutches could not possibly do the job. “I became radicalized overnight into a disability rights advocate” writes Brown (p.74). Indeed it is a common story for those seeking employment in the 1970’s and 1980’s.

Brown found his way into the independent living movement in Oklahoma, and his first experiences were lessons in the need for consumer, rather than service provider, control. He was part of a group that wrested control of a Center for Independent Living from a provider group run by non-disabled personnel. He became involved in the national disability rights movement and joined people with disabilities all over the country in working for the passage of the Americans with Disabilities Act. Brown moved from Oklahoma to the World Institute on Disability in Oakland, California. He married a co-worker, Lillian Gonzales Brown, whose work as a disability rights advocate is also well known. Together they founded the Institute on Disability Culture.

In his section about healing, Brown describes moving from using crutches to a manual and then a power wheelchair. And finally, after spiritual healing experiences, Brown moves back to walking again. This is a journey that could raise eyebrows among members of the disability community. Faith healers have discounted many of us with disabilities and spiritualists have viewed cure of our disability, be it physical, cognitive, or emotional, as necessary to recreate us as whole. In our community, “cure” is a dirty word:

“This tension between what any healer – traditional or alternative – offered and our quest to live as people with disabilities, struck at the core of our beliefs. We’d worked for decades to convince society those of us with disabilities lived meaningful, productive, and proud lives despite existing in a society filled with prejudice and discrimination based on disability. A core principle that we didn’t need to change, society did, informed all our thinking. Now this man Lil and I had brought to the conference claimed we didn’t need to hang on to our disabilities if we didn’t want to. How could we merge this kind of thought with being proud of who we were as people with disabilities?” (pp. 154-155)

Brown is not talking about a spiritual cure. He is not stating that a life walking is better than a life riding and he is in no way denying the depth of disability culture and its impact on his own experience. That said, one of my few criticisms of this book is that it would benefit from more exploration of this very point as well as the controversy that engenders the need for it. Few disability rights writers or leaders have had the courage to venture into spiritual realms that many criticize as “woo woo.” Given that the author does not appear to be out to convert readers and that spirituality is a personal, individualized path, it is best to leave skepticism at the door when reading this book.

The healing journey bridges numerous geographies. Brown and Gonzales Brown lived in Las Cruces, New Mexico, traveled to Germany, and moved to Hawai‘i, where they currently reside. In Germany, they met and formed ongoing relationships with two different healers, Otto (no last name cited) and Herwig Schoen, who played key parts in Brown’s odyssey. Otto was a

physical therapist and a practitioner of cranial-sacral therapy. Through Otto, Brown met a physician and his wife who used Pulsed Signal Therapy (PST) to treat pain. PST, which seems similar to an Alpha-Stim or TENS unit, uses electrical stimulation to “stimulate the body to rearrange cells to their original non-pain situations” (p. 140). Both Lillian and Steve had several treatments in Germany, which decreased pain enough to lead Brown to a watershed moment. “Lying on the table one day...I remarked, ‘I think I need to focus on healing. I’ve written and talked about pain enough’” (p. 141).

Brown met Schoen at Otto’s wedding and was introduced shortly thereafter to the very new Reconnective Therapy (RCT) that Schoen was developing. It was a life-changing modality for Brown. The therapy is based on the theory that there is a disconnect between our energetic and physical bodies that causes disease and dysfunction. Brown’s RCT experience led to a significant decrease in pain and bone breakage. It also led him to follow his inner wisdom, which kept sending him visions of himself running. Gradually, he reduced pain medication and finally slowed and stopped using a wheelchair. Over time, he became an RCT therapist.

Brown pulls together his stories in the Liberation section of the book. He uses some universal themes like internal focus and connectedness to other people and energies. The author was able to understand liberation through a quintessentially human experience: the deadline crunch. There is so much to do and so little time. Brown writes: “What does the work matter if I lose myself in the process? How can peace be made from this internal war?” (p. 191). The author stops, balances, reflects and can choose a path of love rather than fear. He sees liberation in his connections to others and the universe and usefulness in the universality of his particular story:

“While this book is my story, the patterns in it – pain, anger, accomplishment, isolation, victimization, disease, connection, healing, and others – aren’t unique to me. Mining my personal experiences is one way to channel and explore universal truths. But fascination with an individual life and becoming mired in its details is when we are most likely to neglect our connections to others, to forget to reach beyond ourselves” (p. 192).

The point is to move beyond individual experience and plum the greater universe.

Brown concludes with noting subtler energies and offering suggestions on paths that lead to them as well as one’s center. This book covers new ground and is a must read. It will prove especially fruitful for anyone who has the honesty and ability to put preconceived ideas and belief systems on hold.

**Janine Bertram Kemp** is President of the Disability Rights Center (DRC). Bertram Kemp, who has spinal disease and healed a psychiatric disability, is a writer who has worked for over twenty years in the cross-disability world – always with the optimistic goal of the full societal integration of people with disabilities. DRC distributes Tom Olin's disability history photos, completes oral histories, and gives presentations on the history of ADA, where the grassroots met power and triumphed. A member of ADAPT, she is committed to creating inclusive systems change. She lives in Zigzag, Oregon, where she has a spiritual and healing practice and may be contacted at [janinebk@mac.com](mailto:janinebk@mac.com).

## DISABILITY STUDIES DISSERTATION ABSTRACTS

### Disability Studies Dissertation Abstracts

**Editor's Note:** The information for this section of RDS is provided by Jonathon Erlen of the University of Pittsburgh. A full list of disability-related dissertation abstracts may be found at <http://www.hsls.pitt.edu/guides/histmed/dissertations/>

*Social experiences of adolescents with high functioning autism (HFA) and/or Asperger's syndrome (AS) – their perceptions and their views of their caregivers: An exploratory study*  
Kunz, Patricia A. Proquest Dissertations And Theses 2009. Section 0112, Part 0451 178 pages; [Ph.D. dissertation].United States – Illinois: Loyola University Chicago; 2009. Publication Number: AAT 3387416.

*Learning to listen: The voices of post-secondary deaf and hard of hearing learners*  
Martin, Deena Marlene. Proquest Dissertations And Theses 2009. Section 0351, Part 0525 199 pages; [Ph.D. dissertation].Canada: University of Alberta (Canada); 2009. Publication Number: AAT NR54062.

*Ukrainian hearing parents and their deaf children*  
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*Hispanic mothers' experiences of raising children with moderate to severe autism: A phenomenological study*  
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*Perforating tympanic walls: A second look at identity politics in relation to the 1988 and 2006 protests at Gallaudet University*  
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*An examination of Section 504 in practice: Dark days for student rights*  
Maydosz, Ann S.. Proquest Dissertations And Theses 2009. Section 0418, Part 0529 246 pages; [Ph.D. dissertation].United States -- Virginia: Old Dominion University; 2009. Publication Number: AAT 3393002.

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Anand, Shilpaa. Proquest Dissertations And Theses 2009. Section 0806, Part 0582 210 pages; [Ph.D. dissertation].United States -- Illinois: University of Illinois at Chicago, Health Sciences Center; 2009. Publication Number: AAT 3394318.

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*Spiritual community experiences of families of children with disabilities*

O'Hanlon, Elizabeth Ellen. Proquest Dissertations And Theses 2009. Section 0117, Part 0529 184 pages; [D.Ed. dissertation].United States -- Maryland: University of Maryland, College Park; 2009. Publication Number: AAT 3391287.

*The relationship between attendance at Muscular Dystrophy Association summer camp, attitude towards illness and level of anxiety*

Gant, Jamie Colleen. Proquest Dissertations And Theses 2009. Section 0664, Part 0384 121 pages; [Ph.D. dissertation].United States -- Oklahoma: Oklahoma State University; 2009. Publication Number: AAT 3390907.