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Dis Editorial

Megan A. Conway, Ph.D.

RDS Managing Editor

You would have thought it was enough that I have blindness on the eyes and deafness on the ears. Not to mention the creaking in my joints – what a pain. But now I've got "Dis".

It seems that Dis is always coming up. I am on my way to work, riding the number 6 bus and praying that I get off at the right stop, because Dis Van, called the "Handivan" in Honolulu I kid you not, takes me half way around the island just to go eight blocks. I flash Dis card at the driver, who tells me that I no longer get a free ride the way I did a year ago because the government is cracking down on Dis population. But I get half off the "normal" fare, so Dis counts for something.

I'm at work and the first thing that pops up on my screen is Dis news flash, "Funding cut for Dis program but Dis is nothing to worry about." I can't believe Dis, but Dis day is just starting. The next email is about Dis memo that I have to submit to our fiscal department so that I don't have to pay the difference in airfare between the flight I've booked for Dis business trip on Hawaiian Airlines, and the "lowest available fare" that happens to be \$13.56 cheaper. I booked the Hawaiian Airlines flight because it's the only transpacific airline where the bulkhead actually allows room for Dis Dog and my legs (ask me later about Dis time I stood up for the full 5 hour trip between San Francisco and Honolulu). So Dis only stands to reason. But when I explained Dis to fiscal I got glazed eyes until I specifically mentioned Dis as a "special accommodation" and then I got happy looks and lots of emails about multiple memos.

I have Dis meeting in the afternoon. I've learned Dis lesson for the day, so I blast off a reminder email regarding the "special accommodation request" that I made several days ago for the meeting because of the blindness on the eyes and deafness on the ears. Only before I did not call it a "special accommodation request" but I was assured that Dis is no problem. When I arrive at the meeting Dis request has been completely ignored and they say, "Why didn't you tell us about Dis?" I say, "I've been making Dis request for Dis organization for the past 3, 795 meetings that I've attended. How can you be surprised by Dis?" And they say, "Dis is not our fault. Dis is your fault."

So I get mad and I go home. I can't take Dis any more. What is Dis, anyway? I calm myself. Dis is real. Dis is you, but Dis is not you. Dis is mostly everybody else.

Dis is my day. Dis is my life.

RESEARCH ARTICLES

Teacher Educators' Varied Definitions of Learning Disabilities

Rachael Gabriel, Ph.D., University of Connecticut

Jessica Lester, Ph.D., Washington State University

Abstract: Research continues to demonstrate that the ways in which current federal and working definitions of “learning disability” (LD) are troubling for researchers, teachers, parents and students. We are therefore interested in how teacher educators present the dilemmas associated with learning disabilities to their students, and the discursive repertoires (Wetherell, 1998) that they deploy while discussing learning disabilities. We orient to the idea of learning disabilities as a troubled construct, with people deploying multiple, polarized metaphors and themes when attempting to make sense of the meaning and “realness” of an LD. Since teachers’ knowledge, skills, and mindsets prior to teaching have an impact on their actions and orientations as teachers (Brownlee, 2001, 2004; Brownlee, Purdie, & Boulton-Lewis, 2001), we argue it is paramount to investigate teachers’ first exposure to complex constructs such as learning disabilities, attending to ways in which it is described and made relevant in talk. As such, we present the findings from a qualitative study, situated within a critical discursive psychology framework (Wetherell, 1998), focused on the ways in which teacher educators who were responsible for formally introducing preservice teachers to the construct of LD discussed and defined learning disabilities.

Key Words: discourse analysis, learning disability, teacher education

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

Introduction

Research continues to demonstrate that the ways in which current United States federal and working definitions of “learning disability” (LD) are troubling for researchers, teachers, parents and students (Kavale, Spaulding, & Beam, 2009). In this paper, we focus on how teacher educators present the dilemmas associated with learning disabilities to their students, and the discursive repertoires (Wetherell, 1998) they deploy when discussing learning disabilities. The findings we present here show that learning disabilities are consistently presented as problematic, yet the problem is not always situated with the definition itself, but instead as being intrinsic to the individual labeled LD. This perhaps suggests that preservice teachers may not always be invited to interrogate or think critically about the ways in which learning disabilities are characterized and what this might mean for their work. Survey-based research estimates that between four and 16% of students currently enrolled in public schools have been diagnosed with a LD (CDC, 2005; LDA, 2010), and national trends towards inclusion of students with special needs in mainstream classes make it more likely than ever that teachers will have students with LD labels in their classes. The ways in which LD is presented in pre-service teaching settings is thus an important area for inquiry.

Although some scholars (e.g., Corker & French, 1999; Corker & Shakespeare, 2002; Sleeter, 1987), as well as disability rights activists (Charlton, 1998), have placed increasing emphasis upon the socially constructed and contested nature of disabilities such as learning disabilities, little work has specifically attended to the ways in which learning disabilities are constructed and “made real” through talk. Researchers often either define disability in terms of a medical condition or disease in which the source of disability lies within the child, or as a socially or interactionally constructed phenomenon that is located between an individual and their environment, though definitions may fall anywhere along the spectrum between these two. Further, researchers have long been troubled by the federal definition of learning disabilities, both because of the overreliance upon intelligence testing and the definition’s lack of specificity (Mehan, Hertwick, & Miehls, 1986).

Positioning the Study

We orient to the idea of learning disabilities as a troubled construct, and argue that people deploy multiple, polarized metaphors and themes when attempting to make sense of the meaning and “realness” of learning disabilities. Since teachers’ knowledge and mindsets prior to teaching likely influence their actions and orientations as teachers (Brownlee, 2001, 2004; Brownlee, Purdie, & Boulton-Lewis, 2001), we argue it is paramount to investigate teachers’ “official” exposure to complex constructs such as learning disabilities, attending to ways in which LD is described and made relevant in talk. As such, we present the findings from a qualitative study, situated within a critical discursive psychology framework (Wetherell, 1998), which focused on the ways in which teacher educators who were responsible for formally introducing preservice teachers to the construct of LD discussed and defined learning disabilities. The research question which guided our work was: How do teacher educators work up and define learning disabilities?

Prior to explicating our analytic approach, we begin with a brief review of the literature on the varied definitions and contradicting constructions of LD. Then, we provide an overview of our study’s theoretical and methodological framework, pointing to the philosophical assumptions that shaped our work. Next, we discuss the findings, presenting the ways in which the participants managed and, at times, contradicted the official and culturally familiar ways of talking about learning disabilities. Finally, we offer suggestions based on our findings for, what we argue, might be a more productive presentation of the notion of learning disabilities.

Literature Review

In this project, we attended to the ways in which the language used to describe learning disabilities provides resources for pre-service teachers to construct their understanding of this complex construct. Thus, in reviewing the literature focused on learning disabilities, we specifically attended to the ways in which the *official* (aka privileged) notions and culturally familiar ways of constructing learning disabilities were being deployed. We noted that there was generally minimal discussion and attention given to the “actual” ways in which teacher educators talked about the contingent and controversial nature of learning disabilities. In fact, the majority of the literature focused on learning disabilities and teacher education, begins with the basic assumption that the construct of LD represents a “real,” non-contestable category.

Some researchers have oriented to the notion of learning disabilities as problematic, putting into question the belief that an LD is a biological truth. Mehan, Hertwick, and Miehls (1986) claimed that the medical model is implicit in the language of public law 94-142, the initial special education legislation within the United States. They suggested that “the medical model is a conceptual tool that has been used in medical research to understand and combat pathological conditions in the organism. It assumes that symptoms are caused by some biological condition” (p. 70). They argued that “when mental states are equated with physical states, educational handicaps become equated with diseases” (p. 71). They therefore offered a different explanation for differences in school performance that involved the expectancy theory and labeling theory, situating both within a social constructivist perspective. This alternative construction casts learning disabilities as a social construct, not a biological truth, locating the disability within the interaction between a student and the educational environment. Sternberg and Grigorenko (1999) also subscribed to this second set of explanations. They wrote that a “LD is neither purely biological nor purely social, but refers to an interaction between the two factors” (p. ix).

When describing the history of learning disabilities, Sternberg and Grigorenko (1999) explained that a group of parent advocates took on the phrase, “learning disabled” from a local psychologist as they gathered to construct a social-advocacy agenda in support of their struggling children (see Danforth, 2009, for a complete history of learning disabilities). In her seminal article, Sleeter (1987) offered a careful critique of the social and political conditions that made the birth of learning disabilities possible.

Shannon and Edmondson (2010) argued that the medical discourse evoked in the language of the federal definition renders some people powerful (i.e., those who do the diagnosing and labeling) and others powerless (i.e., those receiving the labels). Kavale and Forness (2000), on the other hand, wrote that the federal definition of LD was not substantial enough to be effectively operationalized. Working within a medical discourse, they argue that a LD is currently best described as a rule-out disorder. It does not carry a set of “symptoms,” but is the label used when symptoms exist without a recognizable cause. For this reason, the definition does not describe the construct, but defines its boundaries based on what it *is not*, instead of what it *is*.

The diagnostic criteria in the federal definition have long been a bone of contention among researchers for a range of social, financial, and political reasons. In 2002, Steubing et al. performed a meta-analysis of 46 studies of the validity of the IQ-Discrepancy model for identifying learning disabilities specific to reading challenges. They found little evidence to support the use of IQ testing in the available literature. Similarly, a number of researchers have argued against the use of a discrepancy model and of IQ testing as part of the definition and diagnosis of reading related learning disabilities (e.g., Sternberg & Grigorenko, 1999), as they question the test’s reliability and validity, especially for students who may struggle with culturally-biased literacy and language-based tasks.

This brief review of the literature on the definitions of learning disabilities demonstrates the polarized repertoires upon which teacher educators and preservice teachers might draw upon when describing and enacting LD labels. Learning disabilities can be understood as anything along a spectrum from a social construction to a biological disease (Thomas, 2004). Even researchers who agree on the source of an LD (social or biological) have actively contested the

federal definition because of its lack of specificity, its reliance on IQ tests for diagnostic criteria, and its failure to evolve along with recent legislation and the introduction of alternative models like Response to Intervention (Zirkel & Thomas, 2010). Teacher educators therefore face a challenge as they prepare teachers to understand, identify and explain learning disabilities. There is no single, clear answer supported in the research for what a LD is, how to identify it, or what it means for instruction or expectations. As we found in this study, teacher educators navigate the troubled nature of this construct in different ways. We argue that their choices have consequences, creating and/or limiting the official discourse upon which pre-service teachers draw when constructing their professional understanding of learning disabilities.

Theoretical/Methodological Framework

We broadly situated this project within discourse theory and more specifically discursive psychology. Discursive psychology offers both a theory and method of discourse analysis, borrowing heavily from conversation analysis and ethnomethodology to investigate how psychological constructs are constructed and made relevant through everyday talk. Discursive psychology is often applied to naturalistic data, but may also be applied within interview settings in which the researcher orients to the interview itself as a collaborative conversation in which meaning is both situated and co-constructed (Reynolds, 2008). Discursive psychology attends to how “‘psychology’ and ‘reality’ are produced, dealt with and made relevant by participants in and through interaction” (Hepburn & Wiggins, 2005, p. 595). Within the discursive psychology framework, researchers view language as the medium for action by which specific versions of the world are constructed and made relevant. It does not assume that language is the expression of or proxy for inner thinking, and therefore does not attempt to infer what someone *really* means, but rather attends to the ways in which they use language to construct meaning in interaction.

More particularly, in this project we drew upon a critical discursive psychology framework (Wetherell, 1998), as we focused on interpretative repertoires. Like Cherrington and Breheny (2005), we viewed taking a discursive approach as “a theoretical position (locatable as poststructuralist, social constructionist, orientated to process and concerned with material conditions) as well as a declaration of methodology.” They explained further that discourse analysis can be used to interrogate dominant or hegemonic understandings based on taken for granted assumptions under which the “illusory idea of a unitary ‘thing’ often appears to present itself” (p. 92). To analyze the ways in which language was being used to construct professors’ definitions of LD, we identified, described, and evaluated (Howarth, 2000) the interpretative repertoires that were deployed within the teacher educators’ discursive practices. According to Reynolds and Wetherell (2003), “Interpretative repertoires consist of ‘what everyone knows’ about a topic. Indeed the collectively shared social consensus behind a repertoire is often so established and familiar that only a fragment of the argumentative chain needs to be formulated in talk to form an adequate basis for the participants to jointly recognize the version of the world that is developing” (p. 495). They add that, “Since different repertoires construct different versions of people and events depending on the rhetorical demands of the immediate context, ideological dilemmas...arise as people argue and puzzle over the competing threads and work the inconsistencies between them” (p. 495). For us, it was therefore important to identify the interpretative repertoires made relevant by professors in their talk about learning disabilities in

order to analyze some of the materials from which pre-service teachers may construct their own definitions.

Data Sources

In that we desired to interview teacher educators from those universities recognized for producing the highest number of certified teachers, we first created a list of the 15 largest teacher preparation programs across a state in the southeast region of the United States. Our list was generated by locating a public document that listed the number of teacher candidates from each university who passed national teacher exams (Praxis series) in 2009. After identifying the 15 largest programs, we contacted the relevant department chairs and secretaries to request the contact information of professors/teacher educators involved in teaching and/or coordinating the development of special education methods courses designed for preservice teachers. We emailed invitations to possible participants, with a total of seven teacher educators agreeing to participate in 15 to 20-minute phone interviews. We followed a semi-structured interview protocol (Appendix B), with six of the seven interviews being conducted by one of the researchers. All of the phone interviews were digitally recorded, and later transcribed by one of the researchers. Unfortunately, for one of the interviews, the digital recorder failed. For that particular interview, we wrote a descriptive synopsis of the interchange immediately following the interview, taking note of places of similarity and dissimilarity in relation to the entire data set.

For the discourse analyst, the sample size is dictated by the research question, with “the success of a study...not in the least bit dependent on sample size” (Potter & Wetherell, 1987, p. 161). Thus, we oriented to the participants’ language as the data source. As such, the number of participants in this study did not determine the ways in which we pursued our analysis and engaged in theorizing. We viewed each interview as a bank of language data to be analyzed, rather than as a single unit of data. We took, then, the participant’s talk—each utterance, each turn, each discursive feature—as the unit of analysis, working to understand the talk in nuanced and layered ways.

Data Analysis

Within the discursive psychology framework, the first layer of analysis begins with the listening and re-listening to the audiorecordings, familiarizing ourselves with the ways in which the talk of the participants was used to work up certain definitions of learning disabilities. Next, one of the researchers transcribed the entire data set. According to Potter and Wetherell (1987), transcription is understood as “a constructive and conventional activity,” and is positioned as a critical component of the analysis process (p. 166). Thus, during the transcription phase of the analysis, a transcription of each recording was constructed, with the understanding that this process was an essential component of our analysis process. Following the transcription of the recordings, we identified those segments focused specifically on defining learning disabilities. We focused on the extracts from the interviews that contained participants’ responses to the following interview question: “How would you answer the question if a student asked you what is a learning disability?” We selected to do a more thorough transcription of these segments, applying a transcription system (See Appendix A) developed by conversation analyst, Gail Jefferson (2004), that allowed for a level of detail far beyond the text of the transcriptions (See Appendix C). This allowed for conversational details (e.g., pauses, prosody, gaps, intonation,

etc.) to be represented in an alternate form to sound. We then transitioned to reading all of the transcripts independently in their entirety several times, continually re-listening to the audios, as we searched for and identified patterns and varied ways of talking about learning disabilities.

Over the course of six months, we met weekly to discuss themes within and across definitions of LD in terms of the possibilities they present for students to construct their own definitions. We worked to describe the ways of talking about learning disabilities by noticing what participants made relevant, what they referred to as a source or authority, and which other sources or definitions were challenged or resisted in their responses. We therefore took their construction of LD as both a statement of what “counts” in the definition of or as a source for a definition, as well as what does not count. We oriented to participants’ definitions as repertoires or material preservice teachers might draw upon as they construct their own definitions. We discussed what ideas were present, allowed for, privileged or denied in the construction of LD provided by each professor, organizing the noted patterns into four types of responses/definitions. Throughout the research process, we acknowledged the limitations of not having access to the related course materials and classroom interactions, and, that like all research, our understandings were “partial and positional” (Noblit, Flores, & Murillo, 2004, p. 22).

We offer several, amongst many, explanations of the ways in which teacher educators talk about learning disabilities, pointing to how talk may work to shape and re-shape how preservice teachers understand LD as a fluid and socially agreed upon construct in education settings. We begin by presenting the range of professor responses to the question, “How would you answer the question ‘what is a learning disability?’” Through our analysis, we identified several patterns across the data, naming such patterns particular types of professor responses (see Table 1).

Definition Style	Sample Quote	Possibilities for Understanding	Implications
Complex/Contingent: Definition acknowledges and describes the complexity and contingency.	“This is a sort of a debate really you and I let them talk about it in the classrooms—what is “dyslexia” or far point copying problems, why can’t people reproduce what they see on paper or um you now is it a memory problem so we try to look at it from a lot of different ways.”	Offers opportunities to think/talk about the complexity of the definition.	LD is complex yet possible to discuss and explore its varied meanings.
Directive: A single definition is presented and supported by authoritative sources	“A learning disability is a valid construct supported with research and consensus of the learning disability roundtable that is characterized by intra-individual cognitive and intra-individual cognitive and academic variability.”	Offers opportunities to think and talk about an authoritative definition.	LD can be defined and understood by a single definition set by authorities (e.g., DSM-IV, federal government

			disability roundtable).
Misdirective: Definition presents a information that may lead to a misunderstanding.	“It prohibits them from performing in their academic classrooms. It hinders their learning.”	Does not offer access to a clear definition of the term.	There is a single definition, set by authorities (DSM-IV, federal government) of LD to be memorized.
Nondirective: Definition may be vague or tangential does not describe complexity or cite an authoritative definition.	“I would say it’s that these children can learn. I think the word disability on that gives a false impression. They may have to work around situations. And they may have to develop new skills in order to master the content.”	Does not offer opportunities to discuss the definition, but has access to one or more ways to talk about disabilities.	A specific definition is assumed not to be required or known.

Table 1. Definitions of Learning Disabilities.

Findings

We oriented to the response types in Table 1 in terms of the possibilities they presented to students, as well as the degree to which the complexity and the culturally contingent nature of learning disabilities was acknowledged (or not). Through the lens of our positionalities (Walkerdine, Lucey, & Melody, 2002), we considered whether space was created for further exploration and questioning within the presented definition (See “Implications” in **Table 1**).

Each of the participants used language in specific ways to construct learning disabilities as problematic, yet situated the problem in unique ways. For example, in **Extract 1 (See Appendix C)**, lines 3-4, the professor prefaces her definition with a confirmation: “I answer it by saying that a learning disability is (.) um a valid construct.” The emphasis on “is” works to create a contrast between the unnamed alternative. She makes this feature of her definition most relevant by emphasizing the contrast and placing it first (preferential order). This constructs LD

as problematic in that its definition is not agreed upon, while also constructing it as something that needs to be defended or clarified.

Extract 4 likewise begins by defending something essential in the definition. This particular professor starts after a 4-second pause with “I would say >it’s a::< < these children can le:earn.” She thus begins to answer the question the way it was asked “what would you say?/I would say” but then repairs, and reformulates her answer to include the information she found most pertinent. It is not what she would say to define it that is positioned as most important in this answer. Rather, it is a confirmation statement that children can learn, with “learn” being elongated and louder in volume than the other words in the sentence. It is as if she is responding to an unseen participant who argues that “these children” cannot learn. Thus, instead of providing the preferred response as she began to do (Sacks, Schegloff & Jefferson, 1974), one formulated in the way the question was asked, she repairs and reformulates her response by telling us what *not* to think.

We also noted that several participants construct the definition of a learning disability as something that is problematic for their students to understand. In **Extract 2** the professor begins her answer with what frustrates her about the way her students understand learning disabilities. “Well (3) I harp on my students all the time because they use LD you know generic term meaning any type of disability.” In **Extract 3** the professor also begins by pointing to the difficulty in understanding LD: “point blank (.) I would tell them that it (.2) is com:plex.” In **Extract 5** the professor mentions twice that she has to clarify certain aspects of the definition even for her graduate students, which either implies that the concept is extremely difficult to understand, or that graduate students are not very capable of understanding.

In **Extract 6**, the professor emphasizes her desire for students to understand and the difficulty of explaining it to them in a different way. She begins “I want to say you tell me” and then goes on to describe a critical thinking exercise she does with her students in order to explore the debate about whether or not learning disabilities are socially constructed. This works up a version of LD that requires critical thinking, but is both possible and important for students to debate, grapple with, and explain. She says that the concept of LD answers the question: “How do we explain students that have an average to above average IQ but still have difficulties learning?” She therefore constructs a version of LD that is meant to account for something otherwise inexplicable, instead of to label or define it. This provides a repertoire of ways of talking about LD in which its nature is open for debate and possibly imperfect.

One professor demonstrated that LD is a problematic construct because it is difficult to explain. She begins by working to deflect the question: “I begin by telling them there’s a variety of things a child could qualify to make them have a learning disability.” We were initially intrigued by this statement because it doesn’t make grammatical sense, but still works to open up the range of possibilities and lift the burden of explanation from the professor as if she is saying “it could be anything.” Even though they amount to the same thing, saying “it could be anything,” allows someone to maintain their position of expertise in a conversation in a way that “I don’t know” does not. One demonstrates that the construct is too large to define, and the other demonstrates that you are not able to define it. It does not, however, provide her students with any vocabulary or framework with which to begin talking or thinking about learning disabilities.

Her lack of specificity constructs LD as a non-issue, one that cannot be discussed because there is too much to it.

This professor goes on to construct learning disabilities as problematic for three other reasons: (1) they are not something you can see and they are not obvious (Extract 6, lines 7 and 10), (2) she cannot think of the words to define it and would need a textbook to do so (lines 22-24), and (3) even her graduate students do not understand it (lines 29-30). She was so unhappy with the definition she provided on the phone that within 15 minutes of the interview she emailed the interviewer a follow-up to her definition in which she referred to her textbook's definition of a LD and apologized for not having remembered it. This email implicitly defined learning disabilities as something that is not only hard to understand, but that exists in technical manuals and is to be memorized as received knowledge, not internalized or reinterpreted.

Discussion

Recognizing the contingent nature of a LD and the ongoing debates in the field, we were not necessarily looking for a professor who had a "correct" definition of an LD. We suggest, however, that some definitions leave more room for discussion and construction of knowledge and learning disabilities, while others either invite students to receive and memorize a single definition, or construct LD as something impossible to understand. We argue that professors who acknowledge the debate about the very definition of learning disabilities, such as the professor in Extract 6 who invited her students to participate in the debate, provide contrasts (what it *is/isn't*, what it *does/doesn't* do), promoting critical interrogation of the construct. We further suggest that those professors who positioned disability as internal (Extract 5) or placed blame on a student's failure to understand instead of on the construct's complexity (Extracts 2, 4, and 5), may not provide or model as many resources for talking about learning disabilities.

Building on research describing how preservice teachers' sense of efficacy and responsibility influences their assessment and instruction of students labeled as "struggling" learners (e.g. Scharlach, 2008), it is important for researchers and teacher educators to attend to the ways in which particular interpretative repertoires are deployed when talking about contingent, yet consequential disability labels. Our findings support our claim that there are more and less productive ways of talking about learning disabilities in educational settings, regardless of where professors fall on the spectrum of ways of understanding learning disabilities. We suggest that the ways by which teacher educators talk about learning disabilities both opens and limits how students discuss, envision, and understand disability labels.

We do not advocate a single definition of LD, but instead suggest the importance of making problematic all that works to position learning disabilities as a simplistic, biological truth. We argue that unlike professors who offered a single, authoritative definition or who provided a misleading definition, professors who were nondirective and made the complexity learning disabilities explicit provided more opportunity to discuss and debate with a wider array of interpretative resources available. Since there are consequences for the degree to which teachers understand and feel responsible for the education of students with LD labels, we suggest that the talk about learning disabilities in teacher preparation courses should acknowledge the complexity, allow for discussion, and provide multiple resources for understanding and discussing learning disabilities.

Rachael Gabriel is an Assistant Professor of Reading Education at the University of Connecticut. Her research interests include teacher preparation, development and evaluation with a specific interest in related education policy as well as reading instruction and instruction for struggling readers.

Jessica Nina Lester is an Assistant Professor of Educational Psychology at Washington State University. Her research interests include qualitative methodologies, critical notions of human learning and development, and the educational experiences of children with refugee status.

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Appendix A

Jeffersonian Transcription (Adapted from Jefferson, 2004)

Symbol	Example	Explanation
(0.6)	that (0.6) is odd?	Length of silence measured in tenths of a second.
(.)	right (.) okay	Micro-pause , less than two-tenths of a second.
:::I	:::I don't know	Colons indicate sound-stretching of the immediately prior sound. The number of rows indicates the length of prolonged sound.
_____	I <u>know</u> that	Underlining indicates speaker's emphasis or stress .
[T: [Well at's R: [I mean really	Left brackets indicate the point at which one speaker overlaps another's talk.
=	you know=I fine	Equal sign indicates that there is no hearable gap between the words.
WORD	about a MILLION	Capitals, except at beginnings, indicate a marked rise in volume compared to the surrounding talk.
> <	>I don't think<	Words in "greater than" then "less than" signs are delivered at a faster pace than the surrounding talk.
< >	<I don't think>	Words in "less than" then "greater than" signs are delivered at a slower pace than the surrounding talk.
()	What a () thing	Empty parentheses indicate inability to hear what was said.
(word)	What are you (doing)	Word in parentheses indicates the best possible hearing .

Appendix B

Interview Protocol

1. How do you describe the IEP process to your students?
2. How do you describe IDEA to your students?
3. What do you hope your students remember when they go to their first IEP meeting?
4. Have you ever been involved in a referral meeting?
5. If so, describe that experience OR If so, describe one of those meetings.
 - i. Do any stick out in your memory for specific reason?
6. What is your background/How did you come to being a special education teacher educator.
7. How long have you been teaching this course?
8. Did you work in a K-12 setting at some point in your career?
9. How do you describe RTI to your students?
10. How would you answer the question “what is a learning disability”?

Appendix C

Transcribed Extracts

Extract 1

1. Right. How would you answer the question if a student tasked you what is a learning disability.
2. ((laughs)). O::h I don't think we have time for that-um::
3. Ok
4. Um no um I um well um ↑I (.2) answer it by saying that a learning disability i:s (.) um (.2) a valid construct. Um supported with (.) um research and uh consensus of the learning disability roundtable
5. ... um (2) tha:t >uh is characterized by< <intra-individual cognitive and academic> variability↑
6. ... I:: would also add that <the most common type of learning disability is> uh dyslexia↑
7. Right
8. And uh discuss the pattern (.) uh that's evident uh <in individuals who have dyslexia.>
9. ... I would uh (2) at some point would you know share the the federal definition and note that <even though Rt↑I has uh been changing the way we look at learning disabilities> that t<he federal definition> hasn't changed. And that that's more THAT THAT is consistent with the um this con you know this idea of (.) intrA-individual variability
10. Yeah
11. and uh unexpected underachievement in certain areas.
12. ... Um I would tell them that the learning disability has (.) uh:: can be manifested in according to IDEA 04: reguLAtions actually <which came out in 06>
13. ... Um in 1 of 8 areas. >3 reading, 2 math, uh (/2) 3 language (2) areas.< So that's in a nutshell. How I would answer it.

Extract 2

1. And then my last question for you is how how would you answer the question if a student asked what is a learning disability?
2. (3) well (3) I harp on my students all the time because they use LD you know generic term meaning any type of disability.
3. Mmhm
4. And because we view learning disabilities in special education as a separate category with average IQ and discrepancy between functional ability and IQ level um then I try to stress that to my students that if we're talking about a learning disability we're talking about something that that relates to cognitive academic performance. If we're talking about a disability then that relates to vision and hearing and all the other disability areas

Extract 3

1. how would you answer the question if a student asked what is a learning disability?
2. Ok=I-i↑ (it) (.) <point blank> (.) I would tell them that it (.2) is com:plex
3. Uh huh
4. Um (.) I <tell them that it's a> specific learning disability. We take the >definition< <the [state name] state> definition
5. [Mmhm]
 - a. [And we] break (.) that up
6. Mm [hmm]

7. [And] I talk abo:ut um ha:ving (.) you know um (.2) a good child an average to above average IQ:
8. [Uh huh]
9. With a deficit in an area (.)
10. but its its broken up <we just finished that> in one of my classes and we spent about >two days on< it

Extract 4

1. Um how would you answer the question, from a student: what is a learning disability.
2. Um ((Audible breathe)) ((laughs)). I want to say you tell me uh
3. Hmhhh good.
4. Uh huh well I think you we I I haven't I have the critical↑↑thinking exercise in one cla- the general survey class I teach↑↑ which ASKS the question is learning dis is a learning disability a social construct?
5. Uh huh
6. Um (2) so (.) you know we talk about the 1960s a little bit. I talk about was this a white construct↑↑ or is there something in some students or how do we explain students that have an average to above average IQ but still have difficulties learning↑↑.

Extract 5

1. I see. Ok. Um how would you answer the question if a student asked you what is a learning disability.
2. (8min)
3. (4) I would say >it's a::< <these children can le:arn.> I think the word DISability on that gives a false imPRESSion. They may have to work (.) arou:nd situations.
4. Mmhmm
5. <And they may have to develop> new >skills< in order to: (.) master the content
6. uh huh
7. But I think (.2) that that's being a good student for ANYbody
8. Yeah
9. Um y-you get these uh these people that um (1) <didn't have to study in elementary school. (.) You know everything came easy.> Then in ↑↑middle school it gets a little ↑↑harder so they have to develop ↑↑study skills. Well (.) you get ↑↑some students that they go all the way through ↑↑high school and they just breeze through
10. Right
11. But they haven't developed the study >strategies<. Like if something is difficult with you ok how do you app↑↑roach that and how do you break it down into little pieces so that you can:: um make uh little accomplishments toward the goal:
12. Mmhmm
13. and those are good strategies for everybody to have.
14. Right right.
15. So, I mainly present it like tha::t because we we all have areas that we I I tell em SOONer or later everybody hits the wa:ll. It may in the ↑↑doctoral program. Maybe somebody doesn't hit the wall until their doctoral program
16. Uh huh

17. But there's always uh gonna be a challenge out there (2) that's not easy to overcome. and you may not find it early in your life but eventually you will. ((laughs)).

Extract 6

1. Um when your students ask and they may not because it sort is the actual topic of your course, but if a student asked what is a learning disability, what's your answer for that question?
2. U:m hu-h I: tell them there's a variety of things a child could qualify to make them have a learning disability.
3. Mmhmm
4. Um I also tell them that a learning disability is >not phys-< <a lot of times it's> not <somethin that's (.) you know> you can see. ↓
5. Mmhmm
6. Um children have a <learning disability and you have no idea they> have one (.) so it's not a disa <one of those disabilities that we talk about> (.) that is so obvious to everyone
7. yeah
8. That (.) it is actually (.2) <something the child is> struggling with.
9. So even though it's not something >physical< or <something we can> see, the child is really struggling (.) in that >area< and so (2.2)
10. we have to see we have to evaluate that child and say what is their <learning disability>and what is it.
11. I just it kinda it has a variety of things it can (.) qualify for lots of different disabilities.
12. Yeah yeah. What does it mean to have a learning disability?
13. (2) What does it mean to (.) t- have a learning disability? We::ll, hehe
14. Hmm((laughs))
15. Um:: well it means a dela:yed it um I mean I don't know if <I can I can't think of the exact words right this minute> um (.2) the definition of a learning disability. Well now you're making me (have) think of my textbook. ((laughs))
16. Oh no I'm sorry. I just you know in [terms-]
17. Well I
18. You know, yeah
19. <It it it so well it has it> prohibits them from performing in their academic classrooms. ↓ Um (.2) and it hinders that so because that's one thing that I have to emphasize <even to my graduate students> (2) >a child can< have a disability but if it >doesn't< prohibit them from: (.2) what is the word that we use. if it doesn't (.) <is it it has to> hinder their >learning.<
20. [Yeah]
21. [For] them to qualify.
22. Right sort of like with with psychological disorders it has to have an impact on normal functioning.
23. Right. And so they have to realize that even my even my <some of my graduate students say> like "well they have it" yeah <but if it doesn't> hinder their l- (.2) if it doesn't hinder their learning then they're not going to qualify (.2) and they're not going to receive services.
24. Right right.
25. So I emphasize it as that.
26. Mmhmm that makes sense.

Parental chronic illness: Current limitations and considerations for future research

J.W. (Bill) Anderson, PhD, CFLE, Illinois State University

Caitlin A. Huth, MS, RD, Eastern Illinois University

Susan A. Garcia, Western Governors University, Salt Lake City, Utah

Jennifer Swezey, MS, Advocate Lutheran Children's Hospital, Chicago, Illinois

Abstract: For the past fifty years, researchers investigating the impact of parental chronic illness or disability on the family have consistently noted the limited work in this area. Citations spanning several decades are included here to deliberately underscore this fact. The purpose of this article is to highlight this ongoing limitation, as well as a number of ongoing points of disagreement. To this end, issues of insufficient research, contested methodologies, assumptions of pathology, and the divided nature of existing research will be presented. Concerning the latter, for years, studies have appeared in two contradictory perspectives: those which view the families and children of chronically ill parents as at risk, and those who find these families and children developing normally despite profound, atypical stressors. These points seem mutually exclusive, but with current research it is difficult to determine how or where these distinctions occur.

Key Words: family, chronic, illness

Some life events have little effect on people, other encounters leave longer lasting effects, and still others shift people into fundamentally changed life paths. The onset of a chronic illness or disability certainly holds the possibility of forcing decisions, adjustments, and futures never before considered (Murray, 2005). For all family members, the process of reconciling to this new life course can involve shock, denial, grief, panic, anger, guilt, and despair (Kuyper & Wester, 1998; Power & Dell Orto, 2004; Thorne, 1990). It is predicted that most Americans, as many as 80%, will experience a chronic illness or injury during their lifetime, either as a patient, family member, or friend (Gavaghan & Carroll, 2002; King et al., 2003). This group now consists of more than 54 million Americans (American Association on Health and Disability, 2009), along with their often overlooked families. With medical treatment advances and longer life-spans, this number will very likely increase (Lewis & Hammond, 1996; Morris & Edwards, 2006).

In this field of study—family functioning in the presence of parental disability or chronic illness—strikingly little research has been done. Even with several decades of ongoing but modest interest, studies involving the families of an individual with a chronic illness or disability remains markedly limited. Fewer still are studies that include the perceptions of multiple family members necessary to better understand the impact of disease or injury on parenting and family dynamics (Blank & Finlayson, 2007; Harris & Zakowski, 2003; Newman, 2002; Watson et al., 2006). Although noticeable research has been conducted on the effects of a child's chronic illness on the family and how adults with chronic illness react to their own disorder, much less is known about the effects of parental disability on the individual parenting role or on the larger family system if this role is modified (Pederson & Revenson, 2005; Peters & Esses, 1985). Certainly, the family experience of child illness and that of parental illness are not identical in coping strategies, shifts in traditional roles, or long-term consequences (Pederson & Revenson).

It is therefore essential to distinguish which member of the family actually has the disability or illness (Ferguson, 2001; Pederson & Revenson, 2005), as family may be modified when specific adult/parental roles are eliminated, expanded, or transferred to other family members. In this instance, family functioning is understood to be the carrying out of the family's day-to-day life, and adjusting individual roles, expectations, and control to accommodate, or failure to accommodate, to new situational demands. When considering a working relationship to parental chronic illness it is quite similar to the concept of family adaptability. Olsen, Russell, and Sprengkle (1984) defined this as the capacity of the family to change its existing power structure or hierarchy, roles, and relationship norms in response to new situational demands.

A Continuing Call for Research

Almost fifty years ago, Arnaud (1959) commented on a lack of systematic study of the influence a chronic parental illness might have on a child's development. Roughly twenty-five years later, McCubbin and Patterson (1983) continued to report that little work had been done concerning illness-related family stress. This deficit was consistently noted by their contemporaries specifically investigating parental disability or chronic illness and its possible impact on children and family relations (e.g., Buck & Hohmann, 1981; Peters & Esses, 1985).

With the passage of the Americans with Disabilities Act in 1990, the Disability Discrimination Acts in Australia in 1992 and in the United Kingdom in 1995, one would have expected greater research interest. Indeed, Hornby and Seligman (1991) described such an increased interest in the consequences of illness or disability within the family. However others, in apparent disagreement, simultaneously reported no increase in empirical research (e.g., Armsden & Lewis, 1993; Thorne, 1990). Roy (1990) concluded that with the available studies, it was simply not possible to determine the prevalence of physical, emotional, or psychiatric problems in children of parents with a chronic illness as compared to the general population. Furthermore, there was an evident lack of awareness among policy-makers of the fact that adults with disabilities are frequently also parents (Berkeley Planning Associates, 1997). The literature of the time described "a field of study in its infancy" (Armistead, Klein, & Forehand, 1995, p. 420) attempting to address a "rarely studied population" (Stuifbergen, 1990, p. 43). Over the next few years, a many others reported similar findings (e.g., Blackford, 1999; Ferguson, 2001; Mukherjee, Sloper, & Lewin, 2002; Newman, 2002; Sidell, 1997).

Little has changed, with Pederson and Revenson (2005) still describing a dearth of research on families coping with parental illness. Many more recent works have continued to acknowledge this essential need for research (e.g. Duvdevany, Buchbinder, & Yaacov, 2008; Kissil, Nino, Jacobs, Davey, & Tubbs, 2010; O'Connor, McCabe, & Firth, 2008; Sherman et al., 2007). It is no surprise then, despite the fact that the work reflects treatment and a disease experience from 50 years ago, that newer works (e.g. Diareme et al., 2006; De Judicibus & McCabe, 2004) continue to cite Arnaud (1959), offering further evidence of limited available research.

Studies have not only remained few, but have also left many necessary elements unexamined. Coates, Vietze, and Gray (1985) listed several factors that should be incorporated when considering the effect of a parent's illness on a child's development. These included:

socioeconomic status, ethnicity, size of the family, and the child's age and gender. Also necessary are multiple informants using well-standardized, norm-referenced assessment measures that are applicable across research studies (Champion & Roberts, 2001) and an improved awareness of prejudicial and negative stereotypes (Buck & Hohmann, 1981; Farber, 2000; Prilleltensky, 2004; Rehm & Catanzaro, 1998). Finally, a comparison group is viewed as often essential to interpreting data concerning these families (Helegson & Reynolds, 2002; Roy, 1990).

Missing a Familial Perspective

Illness in the family is a very complex experience and the illness effect on all concerned is critical to understanding the full impact on the family (Armistead, Klein, & Forehand, 1995; Gan & Schuller, 2002; Greer, 1985). Whether acute or chronic, illness is pervasive in its effect on the present and future dynamics of the person's family as a whole (Hornby & Seligman, 1991; Kissil et al., 2010; Reiss, 1986; Smith & Soliday, 2001). Stated simply, chronic illness happens to a family and not the individual alone.

Nevertheless, in 1984, Rustad reported a conventional bias in clinical research toward the person with the medical diagnosis and comparative inattention to the family. Greer (1985) concurred, and years later, Korneluk and Lee (1998) reported similarly. Children appear to be overlooked by those studying adult chronic illness and those researching childhood illness have little or no interest in adults (Champion & Roberts, 2001). Possibly as a result, children of a disabled parent have regularly been viewed "within a discourse of disability and not within a discourse of socialization" (Grue & Laerum, 2002, p. 679), with the child's perspective simply inferred (Kahle & Jones, 1999). Bentov (1999) described these children as being treated with *compassionate neglect*. Mothers with a chronic illness have similarly reported that some medical professionals were noticeably indifferent toward motherhood while those who recognized the parent role often failed to understand the implications of illness or disability (Thorne, 1990). Even though the possible reactions to chronic illness are many and difficult to predict (Sidell, 1997), studies have most often relied on a single informant or a single dyad for conclusions concerning family (Banks et al., 2001; Barlow, Cullen, Foster, Harrison, & Wade, 1999; Lewis & Hammond, 1996).

Barrett-Lennard (1981) wrote that knowing about others implies a perception and understanding of individual and unique qualities that comes from a position as "participant-observer" (p. 91). Family members of parents with a chronic illness could certainly be viewed as such participant-observers and therefore their inclusion in research is necessary. Although more than a few studies have used an "anemic perspective" to examine family functioning in chronic illness, fewer have sought perceptions of family phenomena related to parenting from multiple family members (Rehm & Catanzaro, 1998, p. 23). Understanding familial relationships is absolutely essential to any future understanding of chronic illness, and the perception and influence of all family members is vital.

Consistent Polarity in Research

Research methodology has also been a point of disagreement. Mukherjee et al. (2002) stated that little qualitative work had been done, explaining that most studies have utilized quantitative approach that has been “criticized for being methodologically unsound” (p. 479). Blank and Finlayson (2007) agreed, finding only one qualitative study relative to their work on caregiver burden and spousal chronic illness. Others, however, have described the opposite, seeing current literature as dominated by qualitative work in localized case studies (Romer, Barkman, Schulte-Markwort, Thomalla, & Riedesser, 2002). Later, Kahle and Jones (1999) concurred, citing the existence of very few empirically based studies to guide future work. Consequently, it is difficult to reach trustworthy conclusions concerning the influence of chronic illness on parenting because of the range of methods and goals in the existing literature (Rehm & Catanzaro, 1998). It also appears that the field has quite often studied variables without an interlinked theoretical model or comprehensive perspective (Armsden & Lewis, 1993; Champion & Roberts, 2001; Romer et al., 2002).

Some have also found the field to be divided with regard to findings: those who view children of parents with chronic illness as at-risk, and those who find these children developing normally despite profound atypical stressors. Over the years, many have linked parental disability to the occurrence of common behavioral patterns among non-disabled children (Arnaud, 1959; Barlow et al., 1999; Diareme et al., 2006). Several others have reported that these children have also exhibited higher levels of internalizing behavior, such as anxiety and depression (Compas et al., 1994; Osborn, 2007; Romer et al., 2002). However, contemporaries concluded that there was no difference in the levels of negative internalizing behaviors in the children of chronically ill parents (De Judicibus & McCabe, 2004; Harris & Zakowski, 2003). Certainly chronic illness has the potential to significantly alter the daily routine and future of the family. However, existing research has actually offered little unambiguous evidence of any detrimental effects on children's development originating from a parent's illness or disability (Kahle & Jones, 1999; Rehm & Catanzaro, 1998; Smith & Soliday, 2001).

A comparable diversity of opinion exists concerning the effect of parental illness on overall family functioning as well. In 1991, Hornby and Seligman wrote that chronic illness would very likely initiate an unwanted restructuring within the family and require individual role changes. Perhaps for the best of intentions some family members may then feel that their own personal concerns and comforts were less important than those of the family member with chronic illness. Such a process would very likely interfere with the normal and ongoing needs for autonomy, assurance, support, and comfort of all family members (Basra & Finlay, 2007; Cheung & Hocking, 2004) and leave many necessities unattended (Nichols, 1987; Patterson & Garwick, 1994). When rigidly organized around one parent's illness, family members risk no longer acknowledging the family system as a whole (Reiss, Steinglass, & Howe, 1993). In such a situation, with the aforementioned unwanted restructuring, multiple individual role shifts, and unattended necessities, the parent's illness can become what Reiss (1986) described as a *disembodied tyrant*, a too narrow and inflexible focus that diverts energy and attention from the family system.

Again in contrast, this very same ambiguity can become an impelling force towards a stronger orientation to live in the present and to reevaluate simpler experiences (Cheung & Hocking, 2004; National Institutes of Health, 1996). Although contrary to popular thought and

persistent stereotypes, relationships may actually strengthen with the realized threat of their potential loss (Alexander, Hwang, & Sipski, 2002; Segrin & Flora, 2005). Even a serious disability does not automatically rule out the continuation of an intact, interdependent, loving family, with the parent with a chronic illness being able to contribute in work and partake in play at a satisfying level (Mukherjee et al., 2002; Stuifbergen, 1990).

Supposition of Pathology

Some have suggested that the study of parenting with a disability has revolved around a search for negative outcomes (Alexander et al., 2002; Banks et al., 2001; Olsen & Clarke, 2003; Prilleltensky, 2004). In 1981, Buck and Hohmann recognized that many alarming predictions and assumptions had been made concerning the frightening repercussions of parental disability on family functioning and child development. Ten years later, Hornby and Seligman (1991) recorded a comparable overestimation of the negative impact, specifically on children. For example, Armsden and Lewis (1993), despite noting that existing research was limited, nevertheless assumed that changes in family functioning due to parental chronic illness clearly posed some danger to the psychological development of the child. Roy (1990) and White (1998) agreed, writing that common sense dictates that children of chronically ill parents *must* be more vulnerable, though also stating that the findings were inconclusive. Such vulnerability makes intuitive or superficial sense perhaps, but is nevertheless assumptive. Should that be the case in the face of inconclusive or opposing findings? Certainly not.

In 1990, Stuifbergen described a limited, but noticeable, core belief of pathology in families with a chronically ill parent that was supported only by much earlier research (e.g., Arnaud, 1959) and a common inference of negative effects on family functioning that was not supported by her study. At roughly the same time, Hornby and Seligman (1991) reported a trend in the relevant literature moving away from the common supposition of unavoidable pathology in families with members with a chronic illness, and moving toward identifying representative stressors, support resources, and coping strategies. Even so, disability has been routinely implied in research (Alexander et al., 2002) and untested assumptions of defectiveness concerning these families persist (Crawford, 2003; Kelley & Sikka, 1997). Although researchers have indeed challenged the field not to assume that negative effects are the standard, it seems possible, if not probable, that with the available “speculative literature” (Greer, 1985, p. 141) such “presumptions of deficiency” (Kelley & Sikka, p. 105) and “pathological assumptions” (Crawford, p. 68) will continue.

Additionally, and for quite some time, research has suggested that able-bodied health-care professionals and researchers might actually project their own expectations onto families with a disabled parent (Blechman & Delamater, 1993; Greer, 1985; Romano, 1984). Kahle and Jones (1999) stated matter-of-factly that researchers in this field have habitually found the problems for which they searched. Similar findings continue (Telford, Kralik, & Koch, 2006; Thorne et al., 2002). Consequently, Nichols' (1987) admonition against adopting a purely academic perspective that risks distancing the research from the present reality of family suffering, described as an especially disturbing attitudinal bias, remains too often unheeded. A more balanced research outlook which “joins the biological reality of living with a disability to an account of human agency and structure, set in time” is necessary (Blackford, 1999, p. 676).

Supposition of Commonality

Yet another problem in the field has been a focus on chronic illness in general instead of specific diagnoses (Champion & Roberts, 2001). Studies in chronic illness sometimes appear guilty of blending varied and seemingly unrelated diagnoses into samples of convenience. According to Kazak (1986, as cited by Padula, 1995), this overgeneralization of one illness or disability to another is among the most severe shortcomings in the field. Armistead et al. (1995) described such an approach as introducing an *artificial sameness* that can result in distorted conclusions. Diverse symptoms and trajectories require unique individual and family skills for successful coping and effective management (Coates et al., 1985; Crawford, 2003). For example, among those individuals with rheumatoid arthritis, hypertension, and multiple sclerosis, physiological adaptation varied, while psychological adaptation was found to be more similar (Pollock, Christian, & Sands, 1990).

In light of Buck and Hohmann's (1983) suggestion to measure parental illness and disability separately, it seems wise to examine individual conditions before judging commonalities. Armistead et al. (1995) suggested that future research should seek to determine if varied types of physical illnesses influence child development and functioning differently. They reported that no existing studies thoroughly compared children whose parents were experiencing different levels of a particular physical illness. Differences within families dealing with the same diagnosis should certainly be considered (Armistead et al.; Watson et al., 2006).

Conclusion

The literature concerning parental chronic illness and family functioning is limited in size but certainly not in findings. Indeed, it has an apparent tradition of being a visibly divided field, at odds in methodologies, findings, and implications. However, five decades of work has continually called for more deliberate, detailed studies of chronic illness in the family. Apparently all agree that research in this field is of critical importance.

This review has included much of what has been identified as important but often unacknowledged in many previous studies. First, there has been a need for more thorough demographic data concerning socioeconomic status, ethnicity, family size, child's age and gender, severity of any disability, parental education, employment status of the person with chronic illness, time since the diagnosis or onset, gender of the individual with chronic illness, and health status of the well-spouse. Such data becomes even more relevant when considering the absolute impossibility of having accurate baseline data before the onset of a disability or chronic illness (Nelson & White, 2002). Secondly, researchers have strongly stated that studies have too often involved a search for assumed pathology. Kelley and Sikka (1997) concluded that the use of measures that have a strong record of detecting unhealthy adaptation in specific areas of family functioning could help to avoid such biased, yet common, assumptions of deficiency. Third, many quantitative studies in the field could benefit greatly from the inclusion of a comparison group. With the aforementioned lack of baseline data, this would prove essential to interpreting data concerning these families.

A fourth shortcoming has been the focus on chronic illness in general, with much less work relative to a specific diagnosis. There is certainly value in examining parental chronic illness in a more general, or collective, sense (e.g. Lundwall, 2002), perhaps especially as it relates to stigma or stereotyping, social supports, public policy, parenting modifications, adaptation, and questions of gender. But, for reasons stated above (i.e., artificial sameness), careful awareness should be taken in following too general a path with varied diagnoses. Chronic illness can be visible or invisible, stable or progressive, treatable or untreatable, and debilitating to greatly varied degrees. Certainly, fewer studies exist that consider family functioning or parenting in the presence of a single illness, (e.g. multiple sclerosis, breast cancer, arthritis) with even more limited attention to within-group differences and/or similarities.

Fifth, many studies have inferred the absent child's perspective from parents, or the perspective of the person with chronic illness from the well-spouse, and so on. The contribution of future work in this field will be strengthened to the degree that it addresses these too often unacknowledged elements and consciously connects to, and builds on, the existing body of knowledge (Knafl & Gilliss, 2002).

With the variability in findings, future research must continue to question whether any single stressor, in this case parental illness, is the encompassing negative influence on family functioning that some have believed. Although it is more than 10 years of continuing research later, we strongly agree with Kahle and Jones, who in 1999 accurately concluded, "the available literature provides only *scant* information about a *few* factors that *may* influence the effects of parental chronic illness" (italics added, p. 396). Little has changed.

J.W. Anderson is Assistant Professor of Human Development and Family Resources at Illinois State University in Normal, Illinois. He holds a Ph.D. in Educational Psychology and an M.S. in Human development from the University of Alabama.

Caitlin A. Huth earned her MS in Nutrition and Dietetics at Eastern Illinois University in Charleston, Illinois.

Susan A. Garcia is a Placement Specialist at Western Governor's University in Salt Lake City, Utah.

Jennifer Swezey, MS, is a Child Life Specialist at Advocate Lutheran General Hospital in Chicago, Illinois.

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Disability Studies and the Language of Mental Illness
Katie Aubrecht
University of Toronto &
Mount Saint Vincent University, Canada

Abstract: Much has been written about the dangers of mental illness, both by psychiatry as an empirical reality and by anti-psychiatry as a cultural category (Szasz, 1960). This paper considers how the language of mental illness, and more specifically, the discipline of psychiatry, structures how we relate to our everyday lives. I examine *how* the language of mental illness, and the psychiatric practices which have made this language possible, have conditioned the development of a disability studies community, culture and identity. This examination will involve a critical analysis of writing in the field of disability studies which illustrates the complex interconnections and interdependencies between self-identifying as a disabled person and rediscovering the aspects of oneself that have been stolen or stamped out by the imposition of a language of mental illness. This paper also aims to uncover some of the implicit assumptions about the nature of the relationship between language, culture, identity, and community.

Key Words: Disability Studies, language, community

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The language, similar to any skill or tool, becomes part of my bodily "I can." (Leder, 1990, p. 121)

The "New" Disability Studies and Its Methodological Approach

Maurice Merleau-Ponty (2008) writes in *The World of Perception*, "The contact I make with myself is always mediated by a particular culture, or at least by a language that we have received from without and which guides us in our self-knowledge" (p. 66). My lived experiences as someone whose body, mind, and senses bare the mark of the mental health system have led me to wonder whether simply avoiding the language of mental health and illness may in fact help to justify the marginalization, if not outright removal, of some people, bodies, and experiences from reflective consideration within conversations in disability studies. My being named mentally ill led me to view myself as a problem, my histories and experiences as deficient, defective, and the products of an unfortunate chain of events, and my perceptions as delusional. My being named this way also brought me to disability studies, which has in turn brought me to a more critical awareness of myself as an embodied being, and has helped me to realize that my experiences, histories and perceptions are both valid and valuable.

This paper turns on a central question, "What does it *do* theoretically to say that disability studies does not adequately address issues of mental difference?" In asking this question, I am

trying to make sense of my desire to make mental disability something that can be viewed as “just-as-visible” as physical disability. What is the theoretical work that is being done when it is said that disability studies does not adequately address issues of mental illness? Both my question and my response make use of interpretive methods in what Tanya Titchkosky has referred to as the “new” disability studies. According to Titchkosky (2000), it is important to note that,

“Whatever is deemed ‘new’ about Disability Studies is not attached to a concrete historical moment of birth, and is not due to a single transformative movement in time. Instead, the new appears to mark a movement, a movement from a seamless unified concept of disability to disjunctive and multiple conceptions of disability” (p. 213).

The “new” disability studies begins with the assumption that disability is, as Rosemarie Garland Thomson (1996) says in *Freakery: Cultural Spectacles of the Ordinary Body*, “always an interpretive occasion” (p. 1). Phenomenological methods play an important role in making the “disjunctive and multiple conceptions of disability” more explicit. According to Sara Ahmed, the significance of phenomenology is that, “Phenomenology asks us to be aware of the ‘what’ that is ‘around’” (2007, p. 151). Thus, what makes the new disability studies “new” is its use of phenomenologically-informed methods. In making use of interpretive methods, the new disability studies has become more conscious of itself as a form of political education.

Paulo Freire and Donaldo Macedo (1987) assert that a political education is not the kind of education that can happen overnight. Political education offers new ways of making life meaningful that celebrate, rather than dissect, the living significance of bodies (p. 33). Instead of merely *taking* time and effort, a political education requires new understandings of the ordinary ways we have of relating to the meaning of time and effort. A political education is not the kind of education that can be communicated in summaries and charts. Its relations refuse summarization, mechanical memorization, or memorialization (p. 34). Such an education is founded on the recognition that, “Mechanically memorizing the description of an object does not constitute knowing the object” (Freire & Macedo, 1987, p. 33). A political education rather involves an “a critical reading of reality, [...] critical perception, interpretation, and *rewriting* of what is read” (p. 36). In producing new shared understandings about how it is “human practice or work that transforms the world,” such an education is “counterhegemonic” (Freire & Macedo, 1987, p. 36). This is the kind of education that begins with the worlds we each inhabit, the worlds we live. It relies on our experiential knowledge of these worlds to develop new relations to the words that are our worlds meaning. It returns us to the worlds that first brought us to words, and the words that brought us to where we are today; the world re-invented and we re-born (Freire & Macedo, 1987). This is an education that makes time and gives effort to deliver. There is no guarantee how or when it will be received, or what will be made of it.

The interest in the formulation of a political education which I suggest underpins the “new” disability studies shares a certain affinity with psychiatric knowledge, insofar as both the new disability studies and psychiatry share an interest in childhood. The new disability studies asks students to think back to their first encounters with disability and the images and assumptions these encounters engendered. In re-establishing our connections with the words that first gave us disability we can occasion new points of contact with and in the world that makes

the phenomenal event of disability a reality. Thus making disability matter differently (Michalko, 2002); not as a problem, but a social and political project (Michalko, 2002; Mitchell & Snyder, 2006; Linton, 1998, 2007; Titchkosky, 2007). As Freire says:

“In the effort at recapturing distant childhood, trying to understand my act of reading the particular world in which I moved, permit me to say again, I re-created, re-lived in the text I was writing the experience I lived at a time when I did not yet read words. And something emerged which seems relevant to the general context of these reflections. I refer to my fear of ghosts. The presence of ghosts among us was a permanent topic of grown-up conversations in the time of my childhood... As I became familiar with my world, however, as I perceived and understood it better by *reading* it, my terrors diminished” (1983, p. 7).

Psychiatry, however, has a different way of relating to the child and childhood: as a means of objectifying disability as a negative value and locating it in the individual. As a practice, psychiatry recovers the terror. But, rather than reading terror as an expression of particular ways of relating to and in the world, psychiatry treats the appearance of terror as a sign or symptom of our separation from the world. Michel Foucault has written extensively on psychiatry and its role in the constitution of the individual through notions of mental illness (Foucault, 1973; Mills, 2008, p. 97). In *Psychiatric Power: Lectures at the Collège de France 1973-1974*, Foucault (2006) writes of how psychiatry orients to the child and childhood in terms of a means of expanding its domain, enlarging its resources and reproducing its authority. According to Foucault, “Childhood becomes the center, the target of psychiatric intervention indirectly, insofar as what one asks the mad adult is precisely, his childhood: let your childhood memories come, and through this you will be psychiatrized” (2006, p. 125). Rather than reading representations of childhood as an expression of our current relationships with the world, the psychological perspective orients us to our memories of our initial encounters with the world as a way to explain, and thus contain, the origins of our present difficulties.

Psychiatric practices have the effect of securing as the only valid perception the view that the present is itself a difficulty that must be overcome. At best, we can learn to tolerate – or live with – our difficulties in healthy ways. Learning to tolerate our difficulties involves identifying them as problems and engaging in practices that help us put these problems behind us. Our capacity to learn and teach tolerance of ourselves, others and the world is thus contingent on our capacity to uncover the true origins of the appearance of problems. Then we can commit to projects that we can expect will mitigate the likelihood of their re-appearance. In this context, disability is something that we can either learn to cope with or work to eradicate (Titchkosky & Aubrecht, 2009).

In treating childhood as no more than a question that can confirm or dispute the reality of one’s perception of self, others, and the world, psychiatry insulates and protects itself against any alternative or oppositional interpretations of disability. In relegating our relations to the languages we learned as children as proof of any and all present disadvantage, psychiatry teaches us with subtle precision that we are better off leaving childhood behind. Only in learning to forget our differences, and put our pasts behind us, can we secure our positions as normal, healthy individuals and communities. For psychiatry, the expressed desire to return to childhood,

to the *when* and *where* one first made contact with the words which have shaped how and what one can now do is akin to a declaration of madness (Foucault, 2006, p. 125).

Throughout this paper I use the phrase *disabled person* with deliberation. In contemporary politics, the phrase *person with a disability* is often championed as a progressive, socially-inclusive and politically viable way to display shared recognition of disability. However, as Titchkosky asserts in the article “Disability: A Rose by Any Other Name? ‘People-First’ Language in Canadian Society,”

“People-first language has been ubiquitous for many years now, and still the United Nations (1996) reports that disability is a worldwide ‘silent crisis’ leading to abysmal economic and social conditions for ‘people with disabilities.’ People-first language has not led to a greater understanding of disability and subsequent reduced levels of discrimination, nor to reduced levels of planned exclusions” (2001, p. 132).

What does this right way of relating to the wrongness of disability do to the way we conceptualize disability identities? If people-first language, “has not led to a greater understanding of disability and subsequent reduced levels of discrimination, nor to reduced levels of planned exclusions” (2001, p. 132), what has it led to? In the encounter with the cultural imperative to use people-first language we must pause to consider the potentially alienating effects of this way of describing one’s relationship to disability. Even as this version of disability identity validates personhood, the inclusion of the word “with” frames disability as an add-on requiring a supplemental claim to personhood. One which must be identified, reported, evaluated, and confirmed within a medical frame of reference in which disability is largely perceived as the result of personal or biological deficiency (Titchkosky, 2001, p. 129). Since one of the fundamental aims of this paper is to question the role of language in organizing social relations, my description of myself as a disabled person reflects an interest in reclaiming the living significance of disability in how I understand what it means to be recognized as a person *within* ablest social and cultural environments. In identifying as a *disabled person* and not as a *person with a disability*, I seek to “transgress” (p. 137) the normative demand to remove and distance myself from disability through use of the word “with.”

Understanding the importance of the act of engaging a notion of disability studies as political education, and shifting the attention from “people with disabilities” to the social and political contexts within which disability is made to appear as an individual problem of personal or biologically deficiency involves what Dorothy Smith (1999) has referred to as “writing the social.” According to Smith, “Writing the social profits from the dialogue between what we mean to say and what we discover we have said, and of course, the work of rewriting to embrace what we find we have said that is beyond or other than our intentions” (p. 9). The “discovery” so central to writing the social and embracing that which lies “beyond” our intentions necessarily involves the act of reading the social and more particularly, the social phenomenon of disability, differently (Titchkosky, 2007). I take as my starting point the relationship between disability studies and psychiatry as I have lived it as a disability studies student and someone whose identity has been conditioned by the language of mental illness. In the act of re-reading and rewriting this relationship we can discover new ways of relating to ourselves, the disability community and the new tradition of disability studies which our work is helping to realize.

Take, for instance, Rod Michalko's (1998) depiction of his relation to his discovery of blindness at nine years old and how it brought him to a notion of trust in *The Mystery of the Eye and the Shadow of Blindness*. Michalko describes how one day he lay crying on his bed after he overhears his mother and grandmother talking in "their first language" about how his grandmother could not see or hear well and soon would die. He realized that he could not see the blackboard at school for a few days now and had been hit in the cheek after losing sight of the line-drive, which led him to think that he too must be dying (p. 36). After that day, he says, he "spent the next few days testing my hearing to make sure that it was holding up" (p. 36). Michalko writes of his relation to this recollection:

"This is a story about going blind. This is my story. This is what I remember. This is a story of something gone wrong and a story of how wrongness is given life through the recognition that a life must be lived within the paradoxical awareness of the necessity and desire for life itself. It is the story of the necessity of diagnosis (what is wrong) and the desire for discovery (being wrong)" (1998, p. 37).

Michalko's story about going blind shows us how the practice of returning to and beginning with the lived experience of disability can provoke a rediscovery of oneself and the world which makes this self possible. In storying how blindness had become significant as "something gone wrong," Michalko depicts how a return to the language that gives life to blindness puts us in touch with how we value life and give life value. Rather than an object for psychiatric intervention, stories of a return to childhood in disability studies represent identity claims. They are stories of reclamation, and they are at the core of the disability studies community's strength; as a way to re-read the words that give our lives meaning in terms of "something gone wrong," reclamation stories offer new possibilities for resistance and rebellion.

It is in the spirit of resistance and rebellion, made possible by a practice of beginning with disability and privileging the disability experience that I have come to my question. My aim is not to fix disability studies. I do not aim to rehabilitate its body, nor do I hope to restore it to a more complete version of itself. To do so would be to invoke the significance of the new disability studies practice of beginning in-and-with the body (Michalko, 1998) in name only. On the contrary, I have come to my question by engaging in the very practice that I think makes the new disability studies what it is: new. That is, relevant: a living language of the present time.

In the remainder of this paper I trace out how I have come to think of the articulation of the experience of *something wrong* can serve as a reminder that there are always many more other ways of thinking and making sense of the worlds we live than we could ever hope to capture. Other ways of thinking which speak using words that read and write, as Smith says, "beyond or other than our intentions" (1999, p. 9).

Disability Studies and Psychiatric Survivors

In his article, "What Have Madness and Psychiatric System Survivors Got to Do with Disability and Disability Studies?" Peter Beresford (2000) asks an important question: "What have psychiatric system survivors, madness and distress got to do with disability, the disabled people's movement and, indeed, with disability studies and this journal, *Disability & Society*?" (p. 167). Beresford says that if thought differently, the very things that appear to be barriers to a

relationship between psychiatric survivors, people who have survived psychiatric diagnoses and treatments, and the disabled people's movement may actually provide for a common ground (p. 167). More specifically, Beresford understands impairment, a notion which he says once created a divide between psychiatric survivors and the disabled people's movement opening up new discussions in which we can "advance our understandings of each other, exchange our experience, knowledge and learning, and foster links, alliances and solidarity" (2000, p. 171). Beresford notices that despite progress made by the disabled people's movement, "The situation for psychiatric survivors, however, has unambiguously worsened" (p. 168). He is most troubled by what he perceives as the political perception of the failure of community care, and the trend towards "compulsion" coupled with a "renewed commitment to institutionalized provision" (p. 168).

According to Beresford, what little attention is paid to psychiatric survivors in disability studies has the effect of obscuring rather than enlivening the relations between disabled persons and psychiatric survivors. He also notes that while some disability studies scholars have worked to include a consideration of psychiatric survivors in their conversations, their ways of representing the mad, distressed or psychiatric survivor experience seem to "accept a medicalised individual model of 'mental illness,' where there would be little likelihood of them doing the same with impairment and disability" (Gabel, 1999, as cited in Beresford, 2000, p. 168). Ignoring questions that point to conflicts in the relationship between psychiatric survivors, madness, distress and disability will have serious consequences for both psychiatric survivors and people who have been disabled by society's inability to accommodate bodily, cognitive, emotional and sensorial difference. Beresford says this is not only because there are "significant overlaps between the two populations," but because "however, *we* as disabled people or psychiatric system survivors may think of ourselves, we are still lumped *together* within the same externally imposed definitions, administrative categories and statistics," and "we are both subject to discrimination and oppression" (original emphasis; 2000, p. 169). Here, Beresford raises an important point about one of the dominant ways we come into contact with disability identities – through the language and institutions of psychiatric knowledge.

Transient Interpretations and Identity Shifts

... our togetherness, our relations are always made on uncertain ground. Therefore, we are always caught between possibilities, always moving in the mysterious shadows of uncertainty. (McGuire & Michalko, 2011, p. 164)

In *Deaf Transitions: Images and Origins of Deaf Families, Deaf Communities and Deaf Identities*, Mairian Corker (1996) writes about her experience of finding herself in-between deaf and Deaf culture. Even though she was not born deaf, and British Sign Language (BSL) was not her first language, Corker nonetheless identified with the Deaf community. The Deaf community does not understand itself as a medical problem, but a culture with a language. Corker describes how needing an interpreter *and* being recognized as a hearing person by the Deaf world was a difficult situation to negotiate. Corker writes, "It can be very difficult to face oppression from both hearing and Deaf people, but it is more difficult and more painful to cope with when it comes from Deaf people" (1996, p. 165). There are many people within the disability community who do not necessarily appear disabled in the conventional sense of what is "normally" or immediately recognized as disability. Corker's words reminded me of occasions in my own life

when I had experienced and witnessed the refutation of a claim to a disability identity by other disabled persons. It is not always enough that people assert a disability identity; they do not have a secure place or a voice in disability studies until they can show that they have fully incorporated its language and practices.

The language of mental illness is a language made possible by psychiatric knowledge and practices. Psychiatric knowledge instructs us to interpret disability as a disadvantage suffered by individual persons to varying degrees depending on their distance from what Western culture has informed us is a normal healthy life (Foucault, 2003). Accepting the authority of this knowledge and using it as a standard against which realities can be said to be more or less true makes us complicit in the ongoing subjugation of already marginalized and oppressed peoples. Simi Linton asserts that in the disability studies community:

“The question of who ‘qualifies’ as disabled is as answerable or as confounding as questions about any identity status. One simple response might be that you are disabled if you say you are. Although that declaration won’t satisfy a worker’s compensation board, it has a certain *credibility* with the disabled community” (Added emphasis; Linton, 1998, p. 12).

In disability studies, just saying you are disabled has “credibility.” If this is so, what provides for the question orienting this paper? Perhaps it is not just *that* we say we are disabled, but that we say it in a *certain way*. What specific practices, what dialects, shape how a claim to disability is received and received as having just been said? Leaving such questions unasked, we risk negating the significance of the social and political processes that organize our relations to ourselves and one another. “Person-first language” has provided a powerful mode of articulation, the use of which displays knowledge of how relationships to disability identities ought to be expressed. I do not want to dismiss the significance of this form of identification as it is lived and experienced by some people. However, person-first language is a way of knowing disability that has been challenged by disability scholars and activists (Titchkosky, 2001; on the grounds that it locates disability in individual people. In placing people first, disability becomes a problem that individual people have. The power of person-first language lies in its capacity to transcend embodied difference. According to Titchkosky, “Separating the person from his or her disability is the aim of people-first language, an aim that does not acknowledge that the social consequence is the alienation of persons from a political understanding of disability” (2001, p. 133). The suggestion that this one way of articulating disability identity is the one and only correct form of address guide us away from questions concerning the societal and environmental barriers to equal access and full participation which *disable* people. What discussions and debates about the appropriate way to describe and, therefore, define disability identity can teach us, is that it is vitally important to think about the social and political contexts in which language is used. They serve as a reminder, not only of the highly contested nature of disability identity, but the importance of paying attention to the power of language in organizing perceptions of disability.

The language of mental illness provides a means of collecting experiences which exceed the unified structure of Western culture’s overtly medicalized way of perceiving and making sense of the world. In *Disability, Self, and Society* (2003), Titchkosky describes an experience of being caught up in this language and how it created barriers to self-understanding. Not yet diagnosed with dyslexia, she had come to believe that she had “a kind of mental illness”:

“Since about the age of thirteen, I went to garage sales and bought every introductory psychology textbook I could find, and I spent many weekends in a downtown public library also looking for a definition of my problem. I was searching for a name, which I never found, for my symptoms. What I conceived as mental illness took shape in strange ways: at times, I would have a terrible anxiety, hear a voice that said, ‘You can’t do that,’ and begin to imagine a garbage-dumping ground standing between me and the visible world, especially the world of print” (2003, p. 33).

Reading Titchkosky’s account, a number of questions arise: What provides for the immediacy with which we turn to psychology for a way to account for the problem and secure its solution? How is it that when we experience difficulty we know that we can and must educate ourselves in psychology; to the point where, like Linton, we aspire to become its teachers? What provides for the desire to stand out against, or stand over and above, the garbage-dumping grounds that stand in our way and keep us at a distance from the “visible world”? In her narrative Titchkosky opens a space for questioning how the requirements of the visible world are made visible. Is all that disability is, anything that is totally visible or invisible? Is disability only either in our way of belonging to normate culture or our only way out? Corker writes:

“If disability is indeed ‘*any* departure from an unstated physical and functional norm,’ binary thought leads us to the conclusion that disability is the transient yet ever-present embodiment of dis-value – a category of ‘other’ designated as a dumping ground for anything that cannot be valued” (2001, p. 47).

In “We Were Never Identified,” McRuer (2006) asks what we, as disability studies scholars and activists, are to make of those of us who never make it to diagnosis and discovery, or to those of us whose arrival we have not anticipated. Asking this question disrupts a common practice in the language and culture of disability studies. It draws attention to the need to think about what established assumptions and accepted practices condition the cultural resonance of a disability story that starts with madness and ends with a name. A story that starts with the kind of thinking which can be perceived by the thinker as out of order and ends in a legitimization of this thinking that takes the form of a qualified disability. The question, however, also limits our inquiry by relegating the ways we have of thinking about madness to unfinished beginnings or premature endings, both of which are represented as so horrifying, it would have been preferable to never have been born. Such thinking is embodied in Lynn Manning’s (2003) story of his re-birth in *Weights*:

“I slowly become aware that something’s not right. There’s this nebulous fog of colors swirling before my eyes. Whenever someone enters the room, a reddish silhouette appears amidst a fog, and more people enter, more silhouettes appear. No matter what the people in the room are doing, these silhouettes stand stark still. If I lie back in bed, they remain before my eyes. If I squeeze my eyes shut, the apparitions are still visible. It’s not until the last person leaves the room that they slowly dissolve into the fog. I’m both fascinated and terrified by these visions, but I don’t tell a soul about them. After the surgery comes the medicine. Alone in my hospital room and cruising on painkillers, I discover that I can manipulate the colors on my mental canvas. I quickly progress from childlike finger paintings and primary

colors to near photographic renderings of places and faces. It's a pleasurable distraction, but is this blindness? Or madness?"

In *Weights*, Manning describes how "something akin to joy surges through me" when the doctor tells him that he is blind. He says the doctor asks him if he understands what he has just heard. Manning responds, "I understand. I'm blind, I'll probably be blind the rest of my life. As long as I'm not doing it to myself I think I can handle it." Here, Manning illustrates his knowledge that to be mad is a fate worse than blindness. This, even though, as he informs the audience earlier in the performance, he is a firm believer in "Murphy's Law" and as an adolescent he tried to imagine the worst thing that could happen to him and decided that would be blindness. Manning shares that after he decided blindness would be the worst thing that could happen to him, he secretly prepared for blindness. He did this by walking around with his eyes closed.

And then he is blind. After learning he was blinded by a gunshot wound to the head, Manning says he could "handle" blindness over madness. He had, after all, prepared for blindness. But he was not prepared for madness. However, he also says that prior to what he describes as the "medical verdict" of blindness, he seemed more ready to believe that the experiences he was having were the result of "madness." In his performance, he shares his familiarity with the language of mental illness. He even knew the symptoms, which for him appeared with the awareness that *something's not right*. After a while, he starts to manipulate his newly present sensibilities, orienting to them as a pleasurable distraction. But, for whom is madness, or blindness, a pleasurable distraction? From what perspective is such a statement based – the actual experience of living in and with the difference that disability makes, or what Hannah Arendt refers to as "the experience of the thinking ego" (1978, p. 33)?

As students, teachers, researchers, artists and activists in disability studies, we have a collective responsibility to recognize that we have inherited some of the established traditions of our community and culture from ableist assumptions about how people are supposed to look, think and feel. In our examinations of how disabled people have been constituted as a marginalized and excluded group, let us also ask what power and privileges the field of disability studies has gained as a result of its intimate relationship with psychiatric knowledge and practice. As things "stand," we are proceeding as though the experience of madness, while providing for new understandings and revaluations of disability, is best understood as a tool for pinpointing the reflective origins (Canguilhem, 1991) of normative able-bodied culture.

The use of the word "stand" is important, for it tells us something about how we have positioned ourselves, in an upright position, sanctioned and supported by the authority of a psychiatric worldview which treats our thoughts and ideas of the world as always potentially separable from the experiences the world gives us and the words we've used to make the world. Ahmed writes, "Bodies stand out when they are out of place" (Ahmed, 2007, p. 159). What, then, is providing for the persistent reappearance and disappearance of the language of mental illness in personal narratives of being given disability as a name? Does this apparent "disappearing act" point to a need to rethink my relation to this paper's question? Does it signal that the *real* issue in the call for more adequate representations of the lived experience of mental illness is a matter of proper placement? Is the body of knowledge that is represented in the

language of mental illness *out of place* in disability studies? How do these questions both reinforce and disrupt conventional understandings of disability?

Making the Language of Mental Illness “Worldly”

The medical diagnosis provides a name that can direct people to the disability community, but there is a fundamental difference between residing in a community and being fluent in its culture. Medicalized and psychiatrized understandings of disability secure a position for disabled persons within the community, but they do so primarily from a nondisabled perspective, and within an institutional framework that has its historical origins in the devaluation of corporeal difference.

“Naming the figure of the normate is one conceptual strategy that will allow us to press our analysis beyond the simple dichotomies of male/female, white/black, straight/gay, or able-bodied/disabled so that we can examine the subtle interrelations among social identities that are anchored to physical differences” (Garland Thomson, 1997, p. 8).

In the above passage, Garland Thomson offers an interesting counter to McRuer (2006). Rather than treating our not having been named as a deficiency or a loss, perhaps we need to rethink our relations to being named and naming, and name the namer in an effort to make visible both theirs and our advantage. Such a move represents what Titchkosky (2008) has referred to as a “politics of wonder.” This offers a new perspective from which we can reflect on how we have been positioned without normate culture. Here, I use the word “without” in two ways: as an expression of being outside of normate culture, and as though we do not have our own normate culture, like a “dump” for whatever it is that normate culture is *not* (Titchkosky, 2008). No longer are we objects that have been named, left unnamed or treated as forgotten, but social beings who can name, and who have named our worlds in ways that resist any easy explanation, summary or diagram, using our first languages. As Freire (1983) tells us, our first languages are the languages we create in our initial encounters with the world we had yet to experience through the word, before we learned to separate our words from worlds and ourselves from both. My question brings me to why we need social theory and social theory that is grounded in a self-reflective, phenomenological approach. Thinking of mental illness as a name that can either be adequate or inadequate, right or wrong, and a claim whose legitimacy can be measured by its distance from dominant cultural conceptions of disability secures disabled people in preconceived notions of disability. It teaches us that the disability we live with is all in our heads. It teaches us that, as alluded to by Manning (2003), unless we claim disability as a name, unless we can qualify our claim, and unless we can relegate our experience of disability to one of disadvantage, we will never escape the question: are we just doing it to ourselves?

In *The History of Disability* (1999), Henri Jacques Stiker writes, “But the fear I fear is an ancestral one, for in the end it is the fear of fault. Somewhere in me there lies a culpability, and I am made to feel it acutely” (1999, p. 4). What do the questions, “Am I just doing it to myself?” or “Are we just doing it to ourselves?” speak to, politically? Are they just a representation of a delusional personal culpability, and the consequences of the dominance of the medical model? Could such questions also be read as the site of a struggle to negotiate the meaning of collective

responsibility in a world that values individualism? Rather than a symptom of the hegemony of medicalised thinking, could such questions be a space for re-politicization?

In *Responsibility and Judgment*, Hannah Arendt writes that collective responsibility is always political (2003, p. 149). However, Arendt says that there are two conditions which have to be present for collective responsibility:

“I must be held responsible for something I have not done, and the reason for my responsibility must be my membership in a group (a collective) which no voluntary act of mine can dissolve, that is, a membership which is utterly unlike a business partnership which I can dissolve at will” (Arendt, 2003, p. 149).

The culpability Stiker (1999) writes of, and the constant anxiety that finds form in the question, “Am I doing it to myself?” have been read as further proof of the existence of an individual, medicalised model of thinking. This model describes disability as a personal tragedy that is imposed on disabled people by able-bodied perspectives in neoliberal societies. These expressions, which tend to appear in the presence of a disjuncture (Pollner, 1975), could also be read as attempts to make sense of our membership in a group which as Arendt says, “no voluntary act can dissolve” (Arendt, 2003, p. 149). In recognizing that we have learned in Western culture to orient to the question, “Am I doing it to myself?” as a symptom of mental disorder, we can begin to trouble the usual ways we have of representing our sensibility of disability.

This question could also be read as an expression of a personal recognition of membership in a community, and of oneself as a participant in this community’s realization - an individual embodiment of collective responsibility. Answering the question, “Am I just doing this to myself?” in a definitive way separates disabled people from their capacity to participate in discussions about mental illness. It also reinforces the belief that as disabled rather than mentally ill people, or ordinary people who happen to have disabilities, they do not have the authority to comment. As Goffman says in *Asylums*,

“To have one’s behavior defined as involuntary, non-responsible, and non-culpable may be helpful in some cases, but this none the less involves a technical schema, not a social one, and ideally ought to disqualify the patient for any participation in the service relation even while qualifying him as an object of service” (1961, p. 364).

To re-turn to the question orienting this paper, perhaps what is at issue cannot be reduced to an observation that the disability community discriminates against psychiatric survivors, consumers, and mad people. Perhaps it is rather the systematic separation of disabled people from their capacity to speak back to the presence of the language of mental illness in their own lives, a process facilitated by psychiatric knowledge and practice. Do not worry. You are disabled, not crazy. The doctor tells Manning he is blind, and he can live with that. He can manage that. But madness, well, only the experts can manage *that*.

Reclamation stories provide a politically significant way to reunite disabled people with their capacity to speak back to language. This is because reclamation stories draw on a commonsense of the body to speak their relationships with the world. Such stories provide a clue

as to how we understand our positions in the world as given to us by the world. That each story reveals a perceived barrier, whether in the form of another language, “strange silhouettes of red” (Manning, 2003), or psychology textbooks (Titchkosky, 2003), tells the reader something about how this position is being negotiated by the one who recounts the story. That is, as a relationship to the limits our culture gives us knowledge of. For, as Hans-George Gadamer (1996) writes in *The Enigma of Health: The Art of Healing in a Scientific Age*, “... there are limits to what we can do, limits which are taught to us by illness and death” (p. ix).

Representations of mental illness thus teach us about how Western culture understands itself and recognizes and relates to its limits. As I have tried to show, the question, “Am I doing it to myself?” reflects the value of individualism in Western cultural knowledge. More importantly, it reveals its underlying anxiety: as long as we are doing it to ourselves, there is something we can do about it. At the very least, we can learn to control our environments and manage situations, mitigating the effects of stress. In this context, in the visibility of the assumption that we can do anything if we put our minds to it, there is a growing recognition that the definition of the problem and its solution are given to us by environments. What should be of concern to us is that in contemporary times these environments are becoming more and more institutionalized.

Titchkosky says, “The point is not that stories change, but that people change in the telling and retelling of stories” (2003, p. 36). Manning’s depiction represents a self-reflective relation to the cultural worlds he moves through. This, even as it represents culture’s demand to leave the difficulties that bind body-world-self behind and accept in their place a new name and with it a new life. In our day-to-day lives, we are often told that we have no time, or that there is no use and no point in asking what assumptions and inversions made this new life possible. We are encouraged to overcome difficulties and welcome the advances and improvements which will allow us to do so. Even if the new understandings they give us are the result of dissecting dead bodies, or walking around with our eyes shut. Manning explicitly names his name, giving it a life. He does so not once but twice: “Is this blindness or is it madness?” Given a choice between blindness and madness, Manning says he is relieved to be able to choose blindness, but only after this name has been conferred on him—only once madness is no longer a choice. The doctor tells him he is blind. The reality of the experience of madness disappears, and with that, sweet relief. The doctor’s diagnosis confirms it; whatever *it* is that is happening to him, he is not doing it to himself.

We in the disability community are not all the same and our lived experiences are irreducible. What unites the disability community is not our distance from the norm. It is rather what Michalko refers to as our shared “recognition that a life must be lived within the paradoxical awareness of the necessity and desire for life itself” (1998, p. 37). This recognition meets Arendt’s conditions for collective responsibility. In making us aware that we need and desire life, the paradoxical awareness that comes with being recognized as *something wrong* in need of diagnosis and discovery, or a problem in need of a solution, places us in a group which no voluntary act can dissolve. The assumption of formal equality within the movement is both problematic, and downright dangerous. Saying people who are experienced and experience themselves through the language of “mental illness” are invisible in disability studies communicates a sense that in the present moment *we are just a thought*. It suggests that our perspectives and personal experiences of issues of mental illness are lacking in reality. This way

of approaching how the field of disability studies represents issues of mental illness justifies, welcomes and encourages the demand to intervene and the authority of psychiatric knowledge. We therefore have to think about how we as disabled persons and disability studies scholars and activists are implicated in the reproduction of the authority of psychiatric knowledge. The present task concerns how together we can take collective responsibility for the way the disability studies community recognizes and responds to its relations with psychiatric knowledge.

Katie Aubrecht is a Ph.D. Candidate in Sociology and Equity Studies in Education at the Ontario Institute for Studies in Education, University of Toronto, and Research Coordinator at the Nova Scotia Centre on Aging, Mount Saint Vincent University, Halifax, Nova Scotia. Using a critical disability studies perspective, her teaching and research questions the role of psychiatric knowledge in the reproduction of power relations.

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Education of Children with Disabilities as Constructed within a Russian Newspaper for Teachers

Maria Oreshkina, Ph.D., University of Scranton
Jessica Lester, Ph.D., Washington State University
Sharon Judge, Ph.D., Old Dominion University

Abstract: This study explored the ways in which the varied meanings of the education of children with disabilities were discursively constructed in a Russian newspaper for teachers, the *Teacher's Gazette*. We identified three articles addressing issues related to children with disabilities. Based on our analysis, we identified the use of two broad discourses: special education as separate and special education as inclusive. In our discussion of the findings, we point to the importance of giving voice to children with disabilities and engaging with children with disabilities and their families in constructing new imaginings of what education might be.

Key Words: inclusion, Russia, special education

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Historically, the education of children with disabilities¹ in Soviet Russia has been predominantly segregated. Children with relatively severe, low incidence disabilities have often experienced significant alienation from society (Dimenstein & Larikova, 2000). Further, even children with less severe and pervasive disabilities have frequently received education in specialized preschools and schools, most often within boarding schools (Malofeev, 1998; Oreshkina, 2009). Children with severe and multiple disabilities have usually been placed in closed institutions under the supervision of the Department of Social Welfare, with many of them receiving no education at all. In the past, individuals with disabilities, including children of school age, were essentially invisible within the society at large. During the 1980's, Russian handicap activist Fefelow, exiled for his position abroad, succinctly captured this situation in Soviet Russia in the title of his book, which reads *There are No Handicapped in the USSR*² (as cited in Grigorenko, 1998).

The education of children with disabilities in post-Soviet Russia began to change in the early 1990's. Russia adopted several international policies that supported the rights of children with disabilities, including *The Salamanca Statement and Framework for Action* (UNESCO, 1994). Newly adopted state documents also expressed Russia's commitment to integration and inclusion. As a result, more children began to attend programs and schools where they freely interacted with their non-disabled peers. A recent overview of special education policies and practices revealed different approaches to making the system more inclusive (Oreshkina, 2009). According to the representatives of the formal special education system (Malofeev & Shmatko, 2008), the amount of time children with disabilities spend with their peers should be determined by the "severity" of their disability, with special education services being provided in a pull out manner. Another approach, promoted by non-governmental organizations, supports the ideas of inclusive schools (Perspektiva, 2009). Others suggest that a variety of settings should be created whereby students with disabilities can receive quality education of their parents' choosing (Dimenstein & Larikova, 2000; Smolin, 2006). These varied approaches are reflected in the variety of educational settings available. Despite increasing numbers of schools offering

inclusive education, many children with disabilities continue to be placed in self-contained classrooms or are minimally integrated with their non-disabled peers.

After decades of being muted and dismissed, a national dialogue regarding the education of children with disabilities has been taken up by educators and society at large. In an attempt to explore this evolving dialogue, our study aimed to examine the ways in which the education of children with disabilities was represented in a Russian newspaper for teachers, *Uchitel'skaya Gazeta* (*Teacher's Gazette*). Considered a reputable publication within the Russian community, *Teachers' Gazette* has been published since 1924, with an electronic version published since 1995. Approximately 95,000 copies of each issue are distributed across Russia. The central focus of the publication includes education, education-related laws, and the social protection of children and adolescents.

The study of newspapers offers one means by which to explore the varied ways in which society talks about disabilities. Kellner (1995) pointed out the power of the media culture in shaping “the prevalent view of the world and deepest values” and defining “what is considered good or bad, positive or negative, moral or evil” (p. 1). Oliver (1990) noted that historically, people with disabilities as represented in films, newspapers, and novels have been constructed as “more than or less than human, rarely as ordinary people doing ordinary things” and are often portrayed “either as pathetic victims of some appalling tragedy or as superheroes trying to overcome a tremendous burden” (p. 61). He further noted that many of these cultural images have not resulted in an understanding of “the actual experience of disability” (p. 62), and at times have worked to perpetuate prejudices. Recognizing the power of mass media in constructing and mediating understanding of given phenomena, we decided to explore the representation of children with disabilities in a publication for teachers, those individuals closely engaged in everyday educational practices.

We focused our analysis on the most recent articles of *Teachers' Gazette* (2009), which, in our view, offered current examples of the conversation around children with disabilities. Within this qualitative study, we drew upon methods of discourse analysis (Wetherell, 1998; Wood & Kroger, 2000), treating articles as discourse. The following research questions framed our inquiry: (1) What meanings are constructed in newspaper publications which discuss the education of children with disabilities? and (2) How is the discourse within such publications used to construct these varied meanings?

Theoretical Framework

In our project, we took a social-relational (Thomas, 2004) perspective on disability. This perspective holds the view that disability is constructed in the relationship between the individual and the environment. This position, however, does not deny the fact that impairments, not disabilities, are *real* and do have consequences for the individual in his/her everyday life (Osteen, 2008). Thus, as we carried out this project, we were informed by the work of disability studies scholars (Finkelstein, 2000; Oliver, 1990, 1992; Thomas, 1999, 2004), which served to support our presumption that disabilities are not knowable as objective truth. Instead, we assumed that disability is only known as it is interpreted and constructed. This understanding aligned closely with the underlying assumptions of our study's analytical framework: (1) we are all active producers of social realities and (2) these social realities are continually being

constructed and re-constructed through discursive practices. Following the principles of discourse analysis (Potter, 2004), we understand discourse as action-oriented, situated, and constructed, moving away from a view of discourse as representative of static, internal thoughts. The action-oriented nature of discourse led us to focus on what the discourse was doing within each newspaper text. In other words, what meanings did the discourse construct? The situatedness of discourse implies that phenomena are always bound up and embedded within a given context (Potter, 2005). Finally, discourse is both constructed and constructive, being made up of actual words, rhetorical devices, idioms, metaphors, and so on that work to construct and stabilize certain versions of the world (Potter, 2004).

Methodology

Data Sources and Collection

One of the researchers (Maria) searched the 52 issues of *Teachers' Gazette* published in 2009. Despite 2009 being named "The Year of Equal Opportunities" in Moscow, we identified only three articles that addressed issues related to children and individuals with disabilities. We viewed the absence of extant writing around inclusive education and/or children with disability labels as significant, interpreting this as indicative of the low priority given to this issue within the educational community. We decided to use all three articles for the analysis for several reasons. First, we decided to focus on articles within the newspaper written specifically for teachers. Second, in that we choose the discourse itself as an object of the study, the number of analyzed articles did not limit our study.

Data Analysis

We viewed our analysis as an interpretive and iterative process, and our interpretations as emergent. The first step in our analysis involved reading and translating the articles. The first author (Maria), who is a fluent speaker of English and Russian, read the articles out loud, translating them into English for the second author (Jessica), who typed the translated articles. Throughout the translation process, we stopped to discuss and record idiomatic expressions and metaphors, and took notes of the implicit and explicit meanings of the texts in relation to the larger socio-political and cultural-historical contexts. To ensure the fidelity of the translated text to the original text, the first two authors were particularly attentive to word choices made in the translation processes. Following Temple and Young (2004), we acknowledge that translation involves meaning construction. Unfortunately, we did not have access to another native Russian speaker who was capable of confirming the translation; therefore, our interpretation of meanings constructed in the publications was based on only one version of the translated text.

As we did this intensive reading and translation, we developed a thick, rich description of each publication. Analyzing each article line-by-line, we then compared within and across the texts, identifying patterns of meanings, word choices, text structures, authors, and the relationship of the texts to the larger contexts. Further, we considered what was not being discussed by the authors, as well as other ways in which the authors could have constructed their accounts. We also took into consideration the stated purpose of each article, attending to the genre in which it was written. Upon the completion of the analysis, the initial findings were sent to the third author (Sharon) who read the text in English to ensure that the initial interpretations

were plausible and to indicate whether further clarifications were needed. The communication between the authors continued until we reached consensus regarding the findings.

Within this process of interpretation, we viewed both the researchers and the journalists of the researched articles as active producers of knowledge (Potter & Wetherell, 1987). We recognized the importance of explicating our positionalities (Aretxaga, 1997; Noblit, Flores, & Murillo, 2004; Pillow, 2003; Tillman, 2002) and acknowledging that the ways in which we chose to represent our findings have consequences (Hall, 1997). We did not attempt to generalize our findings to the larger society and we acknowledge that our interpretation is one of many possible interpretations. We recognize that in the broader conversation about special education in Russia, there are likely perspectives that work to disrupt and complicate the patterns we noted in our study. As such, we invite the active role of the reader in re-interpreting our descriptions.

Findings and Discussion

In this section, we present a detailed analysis of the three articles, illustrating the varied meanings of educating children with disabilities, and how the discourse is used to construct varied meanings. The three articles were written in different genres which reflected the different purposes that the authors pursued in their writings. These differences in genres influenced the way in which we wrote up our findings. We present the articles in chronological order, beginning with the title of each and followed by the abstract in its entirety.

Issue #9, "Fluffy fairy tales for little people: A diagnosis is not a reason to give up joy"
(Muravieva, 2009)

The first article, constructed as a narrative account, discusses recent practices within a boarding school for children with developmental delays. The journalist narrates the experiences of the school, and includes some quotes from the school principal and teachers. The abstract is as follows:

“The student is laughing and hiding her face in her hands—being bashful. ‘Why are you hiding?’ The principal moves next to her and puts her arm around her. ‘Look at these pictures.’ There are puzzles in front of her on the desk that she will have to put together. Why is she laughing? Either she really is bashful or it is the sunny weather which is not so typical for February or it is the end of the school day or it is her grandmother who came to pick her up; and indeed there are so many reasons for children to laugh. ‘Sonechka [diminutive term] has autism,’ says a special educator and the principal, Galina V., of a boarding school for children with developmental delays. ‘She started writing recently on her own, with her own hand.’”

The article has eight paragraphs, each communicating a distinctive meaning. The first paragraph introduces the reader to the history of a particular special education institution, as well as the school’s goal to raise “full-fledged members of society.” The principal is quoted as saying:

“During our history, our students graduated from community colleges and with professions they became full-fledged members of society. Now, our goal is to

continue this tradition so that in our difficult society our graduates can work and make a living (make money for bread) and not to walk on the road (beggars).”

In the above quote, the reference to “our history” seems to legitimate the practices of the institution as being valid and effective. These institutionalized practices, situated within the traditions of special education, appear to position individuals with disabilities as being in need of “service” in order to decrease their chances of becoming peripheral members of society (aka beggars).

The second paragraph describes the current changes resulting from the restructuring of the school. This restructuring is constructed as positive, as it improved the school’s ability to provide more services to its students and some of their families. Further, the words of the principal also make explicit the school’s close alliance with the local psychiatric hospital. For us, this stated alliance is particularly important, as it reinforces the consistent emphasis upon expertise, while also points to the new practice³ of bringing educational services to students in psychiatric institutions. This alliance is also noteworthy considering the historical and cultural emphasis upon the medical model of disability which views disability as a pathology in need of being cured (Davis, 1995; Waltz, 2005).

Within the third paragraph, the journalist constructs children with disabilities as the same as their peers. She states:

“Children here are the same as in regular schools—curious, ready to laugh, eager with the first invitation or even a hint to tell you that ‘my skis slide and are very uncomfortable to wear,’ ‘we had nice soup for lunch,’ ‘we liked our excursion very much.’”

The journalist’s use of the phrase, “children here are the same as in regular schools,” seems to presume that the readers view children attending special schools as being different. The journalist constructs an alternative view of children with disabilities by using the historical values of Russian education to normalize their life experiences: emphasis on fitness (“my skis”), good nutrition (“nice soup for lunch”), and raising a well-rounded individual (“liked our excursion”).

The fourth paragraph tells the story of a student, Serezha, described by his teacher as follows:

“Serezha is our best shop student...In summer he works for a local businessman who makes furniture. He [local businessman] had fired all the alcoholics and hired Serezha instead.”

Within the paragraph, the journalist describes Serezha’s future as being “cloudless,” grounding this conclusion in her claim that one day Serezha will become “a wonderful carpenter or tile layer.” Implicit within this description of Serezha is an assumption that by giving a trade to a student with a disability, society and perhaps more particularly, the experts, create a “cloudless” future for the student. We noted that Serezha’s story and his “success” were depicted solely by the journalist and his teacher, with the reader never meeting Serezha and learning of his life story.

Moving from the individual, the fifth paragraph focuses upon disability within the family. The paragraph begins with the words of the school principal who states:

“In fact we have children from different families.... Of course, we have children from single parent households and at-risk families. But in fact, developmental delay is a tragedy which doesn't choose the family. For example, we have a child from a family of university professors.”

For us, on the one hand, the principal constructs disability as being typical for “single parent and at-risk families” by introducing the second sentence with the words “of course.” On the other hand, she describes disability as being a “tragedy” that may even “choose” a family of intellectuals. The journalist concludes that the graduates of the boarding school can continue their education in community colleges and “even higher education institutions,” “if they develop normally.” In this paragraph, the reader is presented with a particular version of normalcy where everyone is assumed to continue their education upon completion of secondary school.

Within paragraph six, the definition of family is expanded, with the journalist describing the boarding school as “a big family where everybody knows everybody.” Furthermore, the principal is presented as the expert who has worked in the school for 36 years. The description of the institution as a family legitimizes the institution's capacity to fulfill the role of the family.

Paragraph seven locates the institution's needs within the larger political and economic contexts. In the previous paragraph, the reader learns that the school received 3.4 million rubles from the president's fund and that resources from private donors are also available. Yet despite these new resources, “the story is the same” as in the 90's—the school must go door-to-door requesting for money. Here, we noted the principal's reference to the 90's, a particularly difficult time for the Russian economy and society in general.

The final paragraph highlights that, despite the economic problems, life within the boarding school results in success for its students. The notion of success is re-introduced with further elaboration; it is described as the students' ability “to sew, needlepoint, do carpentry, garden, write, speak, think, in other words to live.” More importantly, the description of the environment of the boarding school works to challenge the assumption that life in boarding schools is limited. The journalist does this by describing the school as a place where “on the clean children's bed one can find fluffy fairy tale characters, and the children who walk out of the boarding school are not invalids⁴ needing medical and social help but are children who have a full life ahead of them.” From our perspective, the last paragraph ultimately works to encapsulate the overall meaning of the article: special education boarding schools are “special” places that produce success for their students.

In many ways, this article is written as a “success story,” with the institution's experts turning a story of “tragedy” into one of hope and success. The untold story is of the individual students and their families, which is reinforced by the fact that the “success story” is told by a journalist and expert teachers. Never does the reader hear from a student or family member, as the historic emphasis on the role of the expert pervades. Ultimately, educational practices are situated in the tradition of segregated special education, thus legitimizing this practice.

Issue #28, "The year of equal opportunities: Capital standard for all of Russia"
(Larionova, 2009)

This particular article, constructed as a factual account, describes a bill on the education of children with disabilities developed in the city of Moscow. The head of the Education Department of Moscow, the author of the article, presents the salient points of the bill. In contrast to the previous article, the speaker does not draw upon personal narratives; instead, she uses statistical evidence and legal discourse to validate her claims. The abstract was as follows:

“For a long time children with disabilities had an opportunity to study only in special schools. It seems that they have always had a right for education, but they couldn’t use that right because the whole system didn’t offer opportunities for that. There was no legislation which would support education of children with disabilities in regular schools. This gap is supposed/needs to be filled with a bill developed by Moscow Department of Education. According to the deputies of State Duma⁵, these documents will serve as a model for all other parts of the country, and possibly will push authorities to pass a federal law. So what does the Moscow Department of Education have to offer? The head of the department talks about that.”

With Moscow presented as the center of expertise and policy development, the abstract communicates the idea that the bill will be disseminated throughout Russia. However, the potential of dissemination is never re-affirmed in the article, leaving the reader wondering if it will occur.

The head of the Education Department of Moscow chooses to present the bill article-by-article, working to educate the audience on students’ rights and the technicalities of the bill’s implementation. As we attended to the description of the bill, we noted contradictions between the stated commitment to education for all and actual implementation policies. For example, the bill purportedly guarantees “education in any state, educational institution in any form,” yet the required condition to realize this right is “to act upon the recommendation of the psycho-medical-pedagogical committee.” Another guideline outlines the expected ratio of children with disabilities to their peers in inclusive classrooms, with no more than “10% of all students within a particular institution, and no more than 3 children of a particular type of disability” allowed in “the same class.” And finally, students are “guaranteed” psycho-educational-pedagogical supports; however, such services are only available in regular schools if there are more than six children with disabilities enrolled. Otherwise, the children and their families must turn to special education schools for services. Therefore, these guidelines work to counter not only the noted right to receive education in *any* school, but also the bill’s purported intent to increase the numbers of children studying in inclusive settings. The author’s final account of the bill situates its prospects for passage and implementation in the larger socio-political and economic context. Due to a shortage of federal and city funding, the review and vote on the bill has been postponed. Nevertheless, some parts of the bill are already being implemented.

Issue #30, "Inclusive education: Equals among equals/how the problems of education of children with disabilities are being solved" (Molodtzova, 2009)

The third article appears as the leading article, with the journalist presenting the experiential accounts of five individuals (referred to hereafter as “speakers”) who participate in developing new practices and policies for individuals with disabilities. The article was written against the backdrop of “The Year of Equal Opportunities,” a Moscow initiative designed to promote inclusive practices. The abstract was as follows:

“In the 90’s the *Teacher’s Gazette* published a special issue on education of children with disabilities. At that time we talked about something that didn’t exist, yet according to our deep convictions it should have existed—inclusive education, which allows the integration of children invalids in the environment of their peers. The year of 2009 became in Moscow ‘The Year of Equal Opportunities’ as well as the year of making evident many problems of inclusive education.”

The first speaker, a school principal, describes the advancement of inclusive education in her school and school district. She indicates that 13 children with disabilities attend her school. However, she also notes that “the more children we enroll... the more problems we encounter.” Such obstacles include the lack of legislation, unclear role of psycho-medical-pedagogical committees, and lack of funding. The speaker emphasizes that only when such issues are addressed can children with disabilities become “equals among equals, not on paper or mere words, but in real life.”

The second speaker, a chairperson for the Association of Young Invalids, states that his institution of higher learning has become more open to students with disabilities. Yet, due to the lack of funding and legal foundations for alternative forms of education, such as online learning, those students who go on medical leave are still minimally supported.

The third speaker, a parent of a child with a disability and special educator in a boarding school, shares her firsthand experiences. She first describes how she encountered the “tragedy” of having a child “bound to a wheelchair,” as she put it. As a result of minimal support, her son did not have access to preschool. The rest of her account communicates the hope that she associates with a new Moscow-based bill (the bill discussed in the previous article). She believes that with the passing of the bill, parents “will not feel as unprotected as we did when we were faced with a tragedy,” and schools will have access to badly needed resources.

The fourth speaker, the director of a resource center for families of children with Down syndrome⁶ shares innovative practices for such children, describing how the center provides teacher support in education of these students. Similar to the previous accounts, this speaker reiterates the need for legalizing inclusive practices.

The article concludes with the words of the Deputy Chairperson of the Committee of Education of the State Duma who talks about “the violation of the rights of children with disabilities” in many regions of the country. “On the one hand, parents are denied access to schools. On the other hand, [there are cases of] enforced integration...when in order to save money special schools are being dissolved, and children are transferred to regular schools without the necessary support.” The speaker suggests a comprehensive approach to inclusion which will provide full and equal access to all forms of education.

We interpret the intent of this article to offer diverse perspectives of five individuals who, through sharing personal experiences, become positioned as experts. The sequence of the five accounts is similar: all five of them start by discussing the benefits of inclusive education, followed by the need for legal and financial support. In contrast to the first article we analyzed, which legitimizes education in boarding schools, these five accounts promote inclusive education through personal experiences.

Conclusion

The intent of this study was to explore how discourse is used to construct various meanings of the education of children with disabilities in Russia. Across the three publications in the *Teachers' Gazette*, we noted two broad discourses—*special education as separate* and *special education as inclusive*. The discourse of *special education as separate* was grounded in the tradition of segregated education and was prominent in the first article. This discourse privileges expert knowledge and locates this knowledge in institutionalized spaces. The discourse of *special education as inclusive* introduces the idea of equitable educational rights and was noted in the second and third articles. These two broad discourses were produced against a larger socio-political context and, in our opinion, reflect the current condition of educating children with disabilities in Russia. The discourse of *special education as separate* supports the approach of educating children with disabilities in special education settings. The discourse of *special education as inclusive* reflects the growing awareness of the rights of children with disabilities to receive education alongside their peers in regular education settings. Despite the fact that these two discourses are associated with different approaches to educating children with disabilities, two similarities stood out: (1) the role of experts in shaping the education of children with disabilities and (2) the view of the context as restrictive to the development of special education and inclusion. Therefore, we suggest it is not only the commitment to the idea of inclusion that matters, but also how it is taken up, negotiated, and deployed within a local context is critical.

Our findings indicate that the discourse of *special education as inclusive* produces and maintains the authority of expert knowledge, positioning children with disabilities and their families as passive receivers of “services.” While our goal is not to generalize, and we apply our analysis only to the publications we analyzed, the broader disability studies literature has also noted and examined the existence of unequal relationships between individuals with disabilities and service providers (Tremain, 2005). Broderick and Ne’eman (2008) suggested that individuals with disabilities typically remain the “off-stage character” (p. 471) in conversations about their lives and educational hopes. We propose that this was indeed the case in our study, with no individual children with disabilities or their parents being included, apart from one parent who was legitimized in this context as an expert by virtue of her vocation rather than her parenting experience. We ask then: Who benefits when *only* the “experts” or “non-labeled” individuals are allowed and/or encouraged to speak?

Viewing people as active producers of their realities, we attended to how the context was constructed within the texts. We noted that the authors of the articles described their context as restrictive. The lack of appropriate legislation and funding were repeatedly mentioned as impediments to promoting inclusion. While these challenges are real, we also recognize that constructing the context as limiting, may constrain the social imagining of developing a more

inclusive approach to the education of children with disabilities. Following Fairclough (1993), we orient to the “constitutive/constructive effects of discourse” (p. 4) as a tool to shape and shift the ways in which people with disabilities and their environment are constructed. Instead of a discourse that privileges the voices of experts and depicts the context as limited, we argue for discursive practices that are built around the experiences of individuals with disabilities and create new public imaginings of education. Through such a discourse, children with disabilities and their families may develop a sense of agency and empowerment. Media sources, such as newspapers, offer one such venue for the production of new and varied ways of talking about and imagining how the education of children with disabilities might be.

Maria J. Oreshkina is an Assistant Professor in the Department of Education, University of Scranton, Scranton, USA. Her research interests include exploration of special education and inclusionary practices in Russia and internationally.

Jessica Nina Lester is an Assistant Professor of Educational Psychology at Washington State University. One of her lines of research includes the social, cultural, and historical understandings of disabilities and inclusive pedagogies.

Sharon Judge is the Associate Dean of the Darden College of Education, Old Dominion University. She has published numerous articles, chapters, and a book in the areas of assistive technology, professional development, and children with special needs. She was a U.S. Fulbright Scholar at Moscow State Pedagogical University in Moscow, Russia in 2001.

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End notes

¹ Even though we chose to use person-first language, we recognize that the words we chose are not without contradiction and consequence.

² Fefelow's text, *There are No Handicapped in the USSR*, was originally translated into English in 1986. "Handicapped" was the translator's word of choice.

- ³ Educational services were not available to residents of psychiatric hospitals during Soviet times.
- ⁴ The term “invalids” or “children invalids” is used within the newspaper publications. It is important to note that within the Russian language, “invalids” or “children invalids” is a word/phrase used to refer to children with severe disabilities.
- ⁵ The State Duma is a lower chamber of the Russian parliament.
- ⁶ In the past, parents of children with Down syndrome were advised to give up their newborn children to the state.

Conceptualizing the “Dis” of Our Abilities: A Heuristic Phenomenology
Jamie Buffington-Adams, M.Ed.
Indiana University

Abstract: Social conceptions of disabilities rely on a positivist construction of a singular common normalcy which allows for the other-ing and subsequent devaluing of individuals who fall outside of that norm. Such devaluing and marginalization begins with and is evidenced in the very label *disability* and continues down a linguistically slippery slope of *deviance* and *abnormalities* until those being labeled as disabled can easily be conceived of as less than fully human. Nowhere, perhaps, is this phenomenon more poignantly played out than in schools, the very places that, ironically, purport to leave no child behind.

Guided by the voice of a character living with cerebral palsy and through the auspices of a heuristic phenomenology, I describe how my students and I, as individuals labeled with disabilities, experience, understand, and negotiate our differences within the confines of an education system rife with the pressures of standardization. In doing so, I shed light on the ways in which standardization dehumanizes individuals with differences, and I attempt to recapture my students’ full humanity.

Key Words: curriculum, phenomenology, standardization

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

“In the eyes of the world I’m a total retardate ... a *real* retard. Real in the same way that total means *total*. As in *total retard*.... They think it’s because my brain doesn’t work. They don’t know that is only partially true” (Trueman, 2000, 4-5).

Shawn McDaniels, quoted here, is the character stricken with cerebral palsy whose story constitutes Terry Trueman’s (2000) incisive book for young adults titled *Stuck in Neutral*. Like Shawn, I frequently battle misconceptions—telephone operators who believe the call has been disconnected, museum security to whom I appear to be disregarding explicit instructions, and that one ineludible student who on the first day of school asks (often with a mischievous glimmer in his or her eye), “So you can’t hear *anything*?” I can hardly blame any of them. Time spent in audiologists’ waiting rooms has familiarized me with the common conception of individuals with hearing loss. Having neither silver hair nor pervasively slurred speech, I simply do not fit the mould. Rather than believing I fail to live up to expectations, I prefer to conceive of myself as defying them. As my first audiologist commented shortly before informing me that testing had indicated a 35% binaural hearing loss, “I have no clue how you made it this far in school. In fact, I’m not sure how you even learned to read.”

Oddly enough, my interest in teaching students with disabilities arose long before I learned of my hearing loss, something which would have qualified me for special services. Now, the scenario reads something like a bad joke: what happens when you put a “deaf” teacher in a special ed. classroom? My humble response remains: amazing things.

Using Shawn's fictive yet candidly authentic voice as a guide, this paper explores how social conceptions of disabilities allow for the marginalization and dehumanizing of individuals who fall outside of the norm, and how my students and I, as individuals labeled with disabilities, experience, understand, and negotiate our differences within the confines of an education system rife with the pressures of standardization. In doing so, I explain how a paradigm shift from *curriculum as standardized criteria* to *curriculum as individual lived experience* allows my students and I to recapture our full humanity.

Social (Mis)conceptions of (Dis)abilities

"We are different! I call my classmates retards because that's the word people use when they look at us. Retard means 'slow,' but it's also a word used for a whole class of human beings who are only slow because normal people try to make everybody do things in the same ways and at the same pace. We retards are retards only because normal people call us that" (Trueman, 2000, 42).

Linguistically speaking, the very terms *disability* and *disabled* necessitate positively construed opposites (Smith, 2006). These *able/disabled* and *ability/disability* polarities expose the ways in which notions of disability are socially constructed and rely upon a singular, positivist normalcy against which individuals are measured allowing for the other-ing and subsequent devaluing of those who negate the norm (Linton, 1998; Gallagher, 2006). Failing to subsist as an approximate match to society's conception of normalcy one is said to deviate from the norm. If one deviates from the norm then it is no linguistic leap to branding one a deviant, and inclusion among humanity and access to the full experience of being human starts to slip from one's grasp (Becker, 1963). It begins with the forced passivity of being disabled, in which one becomes the direct object rather than the agent of action, and continues through the discussion of one's abnormalities until one is inevitably placed away from the rest of society, on the margins of the human experience.

Nowhere, perhaps, is this phenomenon more poignantly played out than in schools, the very places intended to leave no child behind (Bejoian & Reid, 2005). In a standardized and norm-referenced era, it is no small wonder that many students already identified by schools as disabled, as falling outside of the norm, struggle not only academically but also personally with passing the test—after all, failing to do so carries stringent consequences in the various forms of remediation. Defined as the correction of a fault or deficiency, remediation enacted encompasses those means through which students' passive role is reinforced and marginalization is achieved as identified students are frequently removed from the general population, forced or coerced to participate in ways that limit personal choice, and further inhibited both academically and personally through banal, mechanistic curriculum. Subjected, limited, and mechanically trained, humanity slips away.

What's in a Name (or a Label)?

"It probably sounds like I think I'm better than the other retards. Maybe I sound cruel to talk about us the way I do. Well, I absolutely don't think I'm better. I don't think there's some kind of retard ranking, with me on top and all the little stupids below me. I use the word 'retard' the way I use any word or words: dolphin, racehorse, sandwich, sidewalk,

and apple.... Words just stand for the things they are and for what people mean them to stand for” (Trueman, 2000, 41).

As an educator both living and teaching on the margins, I am simultaneously fiercely protective and highly demanding of “my kids.” A particular colleague of mine is especially gifted in bringing out this strange duality. While commenting on what he perceived as rigorous and equitable practice in my self-contained classroom, he continually referred to my kids as “’tards,” his pet name for identified students. Complimented and insulted simultaneously, I fired back that: yes, indeed, we all did rather well together—that is, for a bunch of ’tards at least. Recognizing the choice to include myself under the umbrella of his moniker, my colleague quickly replied that he had not been applying the term to me. My disability, he explained, did not count.

Just as it is faulty to assume that someone identified as having a reading disability will perform poorly in mathematics or that someone with poor vision is completely blind, assuming that all identified disabilities or differences are the same is absurd. Oswald and Coutinho (2007), in advocating for a perspective of individual differences within special education, refer to the currently recognized exceptionalities as “practical kinds,” categories which recognize fundamental differences between groups of similar disabilities (p. 7). This notion of practical kinds, of variation within the realm of disabilities, opens the door to those who, like my colleague, would rank our differences along continuums of visibility, severity, and impact.

For me, it raises many questions, chiefly: what does it mean to experience disability? As I reflect upon the daily lived experience of my classroom as well as of each individual who shares this space, I must admit that no amount of cupping their hands over their ears will allow my students to fully comprehend how my world sounds. Likewise, try as I might, I recognize my inability to understand in their totality the effects of Duchenne’s muscular dystrophy, the practically paralyzing fear of expressive language disabilities, or the anxiety of autism. Perhaps, I have often thought, the extreme variance precludes a common experiential thread (Linton, 1998; Oliver, 1998). Yet, although I cannot experience and comprehend, I am able to empathize. Hence, I am led to believe that, unique as we are, we share more than the space of my self-contained classroom to which my students were relegated in the context of these standardized times (Solis & Connor, 2006). What does it mean to experience disability in this curricular context? In search of an answer, I turn to the experts—my students and myself.

A Sense of Place and Participants

“Although we’re located at Shoreline High School, we’re not really a part of it” (Trueman, 2000, 40).

My school is a part of a large, urban district known for its extreme poverty and transience. It is also, unsurprisingly, known for low passing rates on the state’s required exams for graduation. Narrowly conceived graduation requirements require all students to earn 40 credits (1 per semester in each course) and pass a battery of end-of-course assessments. Those unable to pass the tests must still earn the 40 credits, maintain a C average and 95% attendance rate, demonstrate effort through enrollment in additional remediation classes and summer school, prove commensurate competence through the auspices of a graduation portfolio, and continue to

repeatedly take the state-required tests which they have not yet passed. Those students unable to pass or to meet the laundry list of alternative criteria for graduation are counted by the state as drop-outs.

In response to state pressure to improve the district's overall test scores, the current superintendent instituted district-wide curricula and pacing guides as well as additional testing in the form of benchmarks which are administered at least three times a year. Although attaching high-stakes such as promotion to these assessments has been recommended, such mandates have not yet been made.

The school in which I teach houses approximately a thousand students in grades 5 through 12. Nearly 25% of those students enrolled have been identified as having a disability and needing special education services. As magnet programs have grown and faded throughout the district, the running joke amongst staff at my school is that we house the special ed. magnet. The school, which reopened in 2000 serving only grades 6 through 8, has been confronted with the many challenges of transitioning into a middle and high school combination. Amongst the many decisions to be made as a new grade level was necessarily added each year was how to handle self-contained classes at the high school level or whether a fully inclusive model should be utilized. Fears from both special education and general education staff over the difficulties they foresaw in including students with special needs as well as an underlying belief in the limited capacity of students in special education led the staff as a whole to choose to continue offering self-contained classes in nearly every core subject course throughout the middle and high school grades. Consequently, the rigor of modified special education curricula and the awarding of credit for self-contained classes have been topics of frequent debate.

As the school transitioned into a high school format, I too transitioned from an eighth grade inclusion teacher for all subjects to a high school self-contained English teacher. Because of my transition and the variety of high school grade levels I have taught, this is the third year I have spent in the classroom with many of my students who are now juniors. Due to the junior and senior English program I proposed several years ago, this also marks the second year I have spent with many of my seniors. To date, although several students' most recent scores came close, no one enrolled in my class has passed the required exam in English. Thus, my students will almost exclusively rely upon graduation waivers to obtain their diplomas, a fact of which they are well aware.

Thus, my class, which due to the constraints of construction has met in a temporary conference room in the school's media center for the last year and a half, has become a place where the work holds real-world value. Every piece of writing and every project in which we engage shares the common goal of proving each student's individual competency as a counter-narrative to their failure to meet the standards of testing. Initially dumbfounded and run ragged by the number of questions students posed about credits, GPAs, attendance rates and progress towards demonstrating standards-based criteria, I have since downloaded the many forms, instructions, rules, and regulations instituted by the state. Thus, conferencing with students about their portfolio work usually entails conferencing about their progress in meeting the additional criteria as well, and it is with a true sense of pride and accomplishment that most of my seniors close the cover of their portfolio one final time before submitting it to the school's principal. I would like to think that these accomplishments are impressive. However, "amazing"

is a term reserved for the daily witness I bear to the ways in which my students and I experience, understand, and negotiate our differences.

Methods

From the group of juniors and seniors with whom I work, I selected six students to invite to participate in this phenomenological study. In choosing students, I attempted to represent variations in gender, race, and exceptionality in order to ensure that phenomena and experiences distilled from the data would stem from the experience of disability rather than other demographics. I then began the process of obtaining parent consent and student assent to participate.

Procedure

Students participating in the study were asked to engage in individual interviews of which I made audio-recordings to ensure accuracy in quoting responses. The prepared interview protocol focused on: student response to the school setting, student knowledge of and response to personal disability, student perceptions of school relationships, and variations in student perceptions and response between home and school. Interviews were conducted in the privacy of my classroom outside of school hours, and I explicitly explained my desire to record the interview session to each student. Because of the rich history which I have shared with this particular group of students, I also reference my personal observations of classroom behaviors or occurrences.

In addition to student data, I include my own reflections upon the ways in which my disability pronounces its presence in daily life and specific memories of interactions in which my disability played an integral role (Patton, 2002).

Data Analysis

In analyzing this collection of data, I referred to Moustakas' (1994) modification of the Stevick-Colazzi-Keen method of analysis for phenomenological data. Before conducting student interviews, I wrote my own responses to the interview protocol and made note of experiences in which I specifically remembered being confronted with or becoming keenly aware of my own disability.

Once my personal reflections were complete, I proceeded to interview students, taking care to transcribe each recording within several days of conducting the actual interview. I then sought to identify significant statements in each student transcript. Looking across all of the significant statements as well as my own reflection, I clustered similar comments or responses thereby creating themes which, from the data available to me, appear to constitute the essence of our experience as individuals with disabilities.

Findings

Normalcy Interrupted

“Everything that was ever going to be,

Everything that was going to become,
Begins a slow unraveling” (Trueman, 2000, 31).

Kyra, a senior, responds, “I don’t,” when asked if she knows she is enrolled in special education, and then continues to explain, “I mean- I know, but if the teachers or nobody didn’t tell me, I wouldn’t know because - I mean- I feel that I learn like a regular student learns.” When asked how he knows he is enrolled in special education, George, another senior, responds with a hint of contempt, “Somebody told me,” and when asked if he knows why he was placed in special education, says rather quietly, “It wasn’t my fault.” “I didn’t know until I came here, and then they put me in smaller classes,” Dana, one of my juniors, recalls in responding to when she realized she was in special education. Molly, another junior, explains how she came to the realization that she had been diagnosed with a disability and placed in special education:

“Nobody ever explained it. In sixth grade they put me in for math and English and then in the seventh and eighth grade they had me in just for English.... Nobody explained it but I know why ... ‘cause I got dyslexia.... Yep. I have a learning disability.”

Essential to the experience of living with a disability is that moment in which your normalcy is interrupted by others who ultimately render you deviant, and in that moment, reality is rent in two. As evidence of your unique existence, your pre-existing reality continues for you to be normal, but now you must carry within you a second reality, in many ways as much your own but framed by another’s perspective. It is as though in being deprived of your abilities you gain a second pair of eyes with which you are forced to see yourself as the world perceives you. Although Du Bois (1903/1989) writes from his perspective as an African American, his notion of double consciousness also rings true for those living with disabilities: “It is a peculiar sensation, this double-consciousness, this sense of always looking at one’s self through the eyes of others, of measuring one’s soul by the tape of a world that looks on in amused contempt and pity” (p. 3).

Jekyll and Hyde Duality

“Most of the rest of the strangers surrounded me and talked about me as though I weren’t there, and for them I actually wasn’t. The me they talked about ... is not the real me, not even the me my family knows” (Trueman, 2000, 28-29).

George, who has muscular dystrophy and uses a wheelchair, alludes to a kind of home/school duality when discussing how he believes people view him. “Some of them [people at school] probably have problems with me. Yeah because sometimes they say things. They just keep asking me questions.” Home, meanwhile, is a place where George describes himself as feeling “normal” and “awesome.”

I met Dana when she was in the sixth grade, and she tagged along with an older sister to the middle school volleyball practice. Every day, every practice she came. She interacted with the other girls. She participated in all the drills and scrimmages. She followed every order I gave the team. But Dana never said a word the entire season.

Two years later, after I had moved into the high school coaching position, the new middle school coach cut Dana from the team. I questioned her rationale. “She doesn’t talk.” Without

needing to look up, I knew the shadow in my doorway the next morning belonged to Dana's older sister. "Can't you do something?" I invited Dana to practice with the high school team. If she responded to my invitation, I did not hear her, but she showed up for practice every day, all season.

Another two years later, I am late for my fourth period class. Dana has stopped me in the library, and she talked my ear off:

"At school, I'm quiet. I don't talk. People at school see that I get good grades and do my work all the time. That's all they care. At home, sometimes I'm crazy silly. I talk all the time and drive my sister nuts. If I don't know people well, I just don't talk."

For Dana, who has an expressive language and speech disability, the boundaries between selves is as real as the school's walls inside of which who she is does not matter so long as she conforms to the image of the ideal student. Although I am reluctant to speak for Dana because so many others already have, I offer her story here:

"I think I am ready for some harder classes, some inclusion classes, but I didn't tell them that in my case conference. Everyone else was talking – about how I am doing and what classes to put me in. And they stopped and asked me what I thought, but I didn't say anything. They already knew what they wanted to do. I didn't want to argue, and I wasn't sure they would listen to me" (paraphrase based on Dana's interview).

For some students with disabilities like Dana, playing the part of the good student might get them by, but it might also fail to get them an education.

While Dana's experience speaks to the reluctance to advocate for themselves which students with disabilities sometimes experience, Kyra relates how her attempts to ask questions in class often turn sour: "I can ask them a question, and they get smart like 'Didn't I just say?' You know, I'm just asking a question. You know, you don't have to answer if you don't want to." Yet for Kyra, home is a place where learning naturally takes place. "I know about the government – politicians and all that ... because, my daddy, he's into all that stuff, so I just sit around and listen to him talk and stuff."

Whether the difference manifests itself in the incessant questions some students with disabilities face, the questions some never find the voice to ask or in the impatient responses to the questions they pose, students with disabilities appear to inhabit two worlds, a public one in which they must perform and a private one in which, in George's words, they get to be "normal."

Challenge(d)

"When people first meet me, they usually do their Annie-Sullivan-meeting-Helen-Keller-in-The-Miracle-Worker routine.... For some reason people always speak real slowly and real loudly when they're introduced to me" (Trueman, 2000, 55).

"Some people be like readin' baby books and like that's not cool," Molly responds when asked why she feels some of her classes are boring. Several minutes after listing U.S. history among her toughest classes, Dana lists it again among the classes she looks forward to attending.

“It’s hard, but it’s interesting,” she offers. “Easy classes are boring – like geometry. It wasn’t easy when Ms. Dames was teaching it, and I liked it... Mr. Harkberg just hands out worksheets with easy problems, and now I don’t like going at all.”

Like Molly and Dana, I too often react with greater resistance to the stinging insult of low expectations than I do to the burning rigor of a difficult task. As marked as the difference between *disabled* and *unable* or *disability* and *inability*, what it means to be “challenged” can be perceived in vastly different ways. For the able individual, being challenged is immediately understood as being presented with a difficult task. However, for the individual with disabilities, being challenged is frequently equated with the presence of that disability. Consequently, the opportunity to encounter and engage in difficult tasks, the chance to be challenged, is often withheld.

No Difference When Everyone’s Different

“I hate the word ‘special’ when it’s applied to people. As in ‘he’s a very special person.’ Geez! Who isn’t!” (Trueman, 2000, 3)

When I ask if she believes she is different from other people, Molly’s eyebrow arches in a warning shot. Over the years, we have frequently engaged in playful verbal combat, and I have learned to watch the eyebrow, so I add in a mockingly serious voice, “Other than you’re cool and they’re not, of course.” She laughs, and then in a tone which clearly signals her opinion of the question as ridiculous, she sighs and lets out in a rush, “*Everybody* be different, Ms. B.” Yet, perhaps George said it best when he responded that he did not feel any different from other students at school and then added, “Everybody has problems with something.”

Exceptional Empathy

In January, the grandparent of one of my students who uses a wheelchair and whose motor skills are rapidly deteriorating in the late stages muscular dystrophy gave me the greatest compliment of my teaching career: “No one has ever tried to see the world from George’s perspective before. Thank you for that.”

Perhaps having one’s own normalcy interrupted changes one’s perceptions and understanding of the intricate interactions of daily life. Perhaps in negotiating one’s own duality one learns to recognize and respect others’ attempts to do the same. Perhaps the innate and immediate knowledge that everyone is different fosters patience and tolerance. Though the explanation eludes me, the common thread of my students’ humanity does not. It manifests itself daily in the creative systems they derive for communicating things which I cannot fully hear. It fills the silent void when a classmate struggles through a difficult reading passage. Three years of unzipping pencil cases, opening books to the correct page, fetching paper, and making sure George’s hood is up during fire drills and cold bus rides home have served as constant examples. The ways in which it is acceptable to have bad days, their collective test anxiety, the act of lending a helping hand with the things they know a classmate finds difficult, and the shared joy of a senior’s success speak volumes about what my students know, wisdom I cannot take the credit for imparting.

Conclusion

Left to their own devices, my students' curriculum is one of journeying towards better and more fully human versions of themselves, of *currere* (Pinar, 1994). There is a curriculum which without being standardized in no uncertain terms sets a standard (Hehir, 2005), not of language mechanics or vocabulary knowledge, but one of embracing humanity. From them we have much to learn. If we as educators continue to accept the narrowly defined and exclusionary standardized curricula of legislators, MBAs, and economists, we risk denying our differences, our individuality, and our opportunity for praxis. Eschewing a curriculum focused on producing and reproducing society's ideal norm requires us to stand naked in front of the proverbial mirror of perfection and admit the absurdity of standardization. It is only in shattering this socially constructed idea of normalcy that we can embark on a curricular journey which will honor our differences and experiences. Only then can we regain our humanity (Freire, 1970/2000; Pinar, 1994).

Until such a time, in the midst of this era of standardization which chooses to highlight our disabilities, my students' greatest ability goes unnoticed. Yet it is essential not only to the disabled experience but to the human experience, for what it has meant to collectively experience and negotiate our disabilities is to be deeply and honestly human in our foibles, flaws and follies, and to rise from the pieces of a normalcy the world has shattered only to approach that same world with eyes of empathy.

What happens when you put a "deaf" teacher in a special ed. classroom? In this case, I answer – amazing things.

Jamie Buffington-Adams has spent the majority of her ten years as a classroom teacher working with students enrolled in special education or otherwise labeled as "at-risk." She is a Ph.D. candidate at Indiana University.

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BOOK AND MEDIA REVIEWS

Book Review

Title: *The Stress of Combat, the Combat of Stress: Changing Strategies Towards Ex-Service Men and Women*

Author: Roy Brook

Publisher: Eastbourne, UK: Sussex Academic Press, 2010

Cost: Hard Cover, \$32.50; Soft Cover, \$24.95 from Amazon. 344 pages

ISBN: 978-1-84519-407-9

Reviewer: Katherine Li

The story takes place in Britain and is about Roy Brook, an ex-service member with 20 years of prior service whose mission it was to identify ex-service members who may not have been receiving their fully entitled military benefits. He began working at the Ex-service Mental Welfare Society, Combat in 1994 after answering an advertisement in a local newspaper. The Society was founded shortly after WWI to help servicemen and women recover from service-related physical and mental disabilities. According to Brook, “50,000 cases were handled in the first seventy years and there are 3,000 current cases” (pp. ix-x). Brook began his journey by interviewing patients at Tyrwhitt House, one of three short-stay houses in Britain. From there he covered one million miles reaching out to men and women who had served their country as military personnel or peace-keepers.

The book is organized chronologically so the reader is able to understand changing attitudes over time about combat stress; during the American Civil War (for example) it was viewed as cowardice and malingering. Since the Vietnam War, it has come to be called Post-traumatic Stress Disorder (PTSD). By retelling the many stories of the people he encountered along the way—from those who had loving spouses to help care for them to ones who had been abandoned—we discover Brook’s remarkable compassion. He strove to reach out to as many people as possible to ensure that those entitled to benefits were receiving them and to help those who were not getting them. Throughout his work he was cheerful and optimistic about the goodwill of the Ex-Services Mental Welfare Services, but was also saddened by some of the circumstances in which he finds some people living.

The target audience of this book is prior military service members who may be suffering silently from physical and/or mental injuries as a result of exposure to combat. In learning that they are not alone, it may encourage and embolden them to be proactive about pursuing service-related benefits. The way *The Stress of Combat, the Combat of Stress* adds to the existing knowledge—and its most important message—is that it highlights the importance of the role of the advocate. Ex-service members need to advocate for themselves or have an advocate who understands the War Disability Pension to be able to advocate on their behalf. While “demand for the Society’s services has risen by 53% over the past three years,” it is important to know that “the average time between a serviceman or woman being discharged and seeking the Society’s

help is 13 ½ years” (p. vii). The work is interesting because it reads like a Robin Hood-type of adventure.

I recommend this book be used as a textbook in Social Work, Psychology, Public Health, Education, Military Science, Disability Studies, and Sociology classes. It is also accessible to a general reading audience of family members and friends of military ex-service members who want to become more informed.

Katherine Li, Ph.D., College of Education, University of Hawai‘i at Mānoa. She may be contacted at katherineliphd@gmail.com

Book Review

Title: *Historicizing Fat in Anglo-American Culture*

Author: Edited by Elena Levy-Navarro

Publisher: Columbus, Ohio: The Ohio State University Press, 2010

ISBN: 0814211356

Hardcover: \$49.95, 254 pages

Reviewer: Anna Kirkland, University of Michigan

Elena Levy-Navarro’s *Historicizing Fat in American Culture* is an edited volume of ten essays plus Levy-Navarro’s introduction. I greatly enjoyed all the essays, but they vary widely in their accessibility to a non-expert in the field and in their topic and coverage, making it hard to imagine any single course in which this book could be assigned. None of the essays is situated within disability studies explicitly, though all frame fatness as a site of knowledge and power in ways that accord well with disability studies’ aims.

Six of the ten essays focus on the representation of the fat body in works of literature such as Shakespeare’s *Venus and Adonis* poem or on the fat bodies of famous writers such as Ben Jonson. The literary essays are written for an audience of graduate students or professors in the humanities. Of these, the most accessible to a broader audience is Zeynep Atayurt’s chapter on Piggy from *Lord of the Flies*, a widely read classic with an ill-fated fat character. These discussions are historical in the sense of seeing the past through fiction and poetry. Cookie Wooler’s essay on Lillian Russell is a culturally focused (as opposed to literary) chapter, and it offers a richly detailed treatment of the meaning of the popularity of Russell’s nearly 200 pound body and her decline as an icon of female beauty by 1920. From my perspective situated in the social sciences, Greta Rosenbrink’s essay about the early founding of the fat feminist movement in the 1970s and 1980s and Alex Evans’ piece on fat and class in contemporary Britain are exciting contributions. There has been a lot of writing about the early fat rights movement, but Rosenbrink’s contribution is the most detailed I have seen. This chapter could easily be

excerpted in an undergraduate syllabus in Women's Studies or LGBTQ studies and is written in quite readable prose.

The best features of this collection are its constant reminders that we ought not simply hearken back to a lost past when fat bodies were unstigmatized. We often hear that back when food was scarce, being fat was good and now that there is abundance, it is bad. Many of the essays show how the meanings of fat have changed across time and place while nonetheless showing how stigma has endured. The book achieves this subtle balance that has also been the hallmark of much of the best work in disability history. The pieces are so detailed and in some cases so different from each other, however, that the collection does not hang together very well. Because the price is relatively high and it is only available as a hardback book, it will probably be available mostly in libraries, and scholars will have to select out chapters most relevant for their work or courses. It would be very well worth the time to do so, however, since the pieces are of high quality and in some cases represent the best treatment of their topic in print.

Anna Kirkland, J.D., Ph.D., is Associate Professor of Women's Studies and Political Science at the University of Michigan. She is the author of *Fat Rights: Dilemmas of Difference and Personhood* (New York University Press, 2008) and is currently working on a second book on the vaccine injury compensation court and the autism litigation.

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/>

Physical disability and masculinity in mid-Victorian narrative

Bourrier, Karen Amy. Proquest Dissertations And Theses 2009. Section 0058, Part 0593 191 pages; [Ph.D. dissertation].United States -- New York: Cornell University; 2009. Publication Number: AAT 3376511.

Art education and disability studies perspectives on mental illness discourses

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Exploring postsecondary education disability service's standards: Alignment with disability studies

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The mission of the Center on Disability Studies (CDS), at the University of Hawai'i at Manoa, is to support the quality of life, community integration, and self-determination of all persons accomplished through training, service, research, demonstration, evaluation, and dissemination activities in Hawai'i, the Pacific Region, and the mainland United States.

The Center on Disability Studies is the umbrella for some 25 funded projects. It originated as the Hawai'i University Affiliated Program (UAP) funded by the Administration on Developmental Disabilities of the U.S. Department of Health and Human Services. It was established in 1988 as part of a network of over 60 UAP's in the United States. It is now a University Center for Excellence in Disability Education, Research, and Service.

Although core funding for the Center is provided by the Administration on Developmental Disabilities, other federal and state funds are provided by the Maternal and Child Health Bureau of the U.S. Department of Education, various other programs in the U.S. Department of Education, the University of Hawai'i, and the State Planning Council on Developmental Disabilities.

The activities of the Center for Disability Studies extend throughout the state of Hawai‘i, the mainland United States, and the Pacific region with funded projects in several initiative areas including intercultural relations and disability, mental health, special health needs, Pacific outreach, employment, and school and community inclusion.

The Center provides a structure and process to support and maintain internal professional development, collegiality, and cooperation, reflecting an organizational commitment to excellence. Center activities reflect a commitment to best practice and interdisciplinary cooperation within an academic, community, and family context. Activities are culturally sensitive and demonstrate honor and respect for individual differences in behavior, attitudes, beliefs, and interpersonal styles.