



# **Dyslexia as Disability**

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## Dyslexia as Disability

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on

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#### **Abstract**

These three qualitative studies describe and analyze how and when young dyslexic people manage disability labels in talk. The theoretical framework informing this study includes post-structuralist approaches to analyzing talk about disability (Tremain, 2002, 2006; Goodley, 2011) and on-going debates about using discourses to model the relationship between impairment, disability and culture inside and outside social model of disability (Hughes & Paterson, 1997; Corker, 1998; Allan, 1999; Shakespeare, 2000; Corker & Shakespeare, 2002; Grue, 2011) and resistance against ableism generally (Gabel & Peters, 2004). The research design involved semi-structured interviews of twenty-six students with dyslexia (Seidman, 2006) who attended a specialized high school and a review of three documentary films. The three articles detail different approaches to the same phenomenon of navigating and describing dyslexia.

The first article engages a primary analysis of how new discourses of the gifted dyslexic brain include persisting notions of a broken brain using Foucauldian discourse analysis (FDA) in educational documentary film. The second study reframes existing studies of conceptual metaphor among dyslexics moving discussion beyond dyslexia as a barrier to a dynamic range of metaphors including dyslexia as a journey, puzzle and even as existence. Contemporary studies of conceptual metaphor and disability continue to reveal how disabled students navigate the differences between impairment and disability. The third article relates long-standing theories of learning differences to the lack of claiming disability among dyslexic students. By exploring passing as able-bodied as a phenomenon, I theorize how schools, even specialized settings, as ableist institutions oppress, silence and foreclose the possibilities of group identity. This research contributes to discursive approaches to understanding dyslexia as disability and connects disabled identities in talk to work with dyslexic students in schools. Suggestions for future research include understanding neurodiversity movements in relationship to learning disabilities, continuing to examine conceptual metaphor use among dyslexics to build out a typology and the political and economic roots of the discourses of learning differently.

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## **Disability Studies in Education**

To understand disabled students, scholars typically consult educational and special education research. Yet special education and educational research has a long history of pathologizing students with disabilities by disproportionately seeking normalization, cures, and interventions. Critiques of special education research emerged in the late 1980's as an outgrowth of disability studies scholarship. At that time little special education research focused on the lives, experiences and cultures of disabled students.

In 1999, a group of critical disability studies scholars at a conference for The Association for Severely Handicapped (TASH) asked a series of questions of the body of research being done under the name of special education: "Why should a person with a disability or a teacher, or a parent care what the academics say in their research and writings? Why should you care about the seemingly distant and esoteric writings in research journals and university textbooks? What is happening in these words that make a difference?" (Connor, Valle & Hale, 2015, pg. 3). While not intentionally anti-intellectual, these questions brought attention to what had been overlooked by research: the disabled *person*. Restating the questions makes apparent how quickly research on special education had become distant from whom it served and from the types of knowledge valued by families and disabled students.

These concerns remain true today. Disability studies in education takes a more advocacy-oriented approach to including students in every aspect of education and makes an effort to distance itself from deficit-based ways of conceiving of disability or approaches that minimize the full humanity of

disabled people. Disability studies perspectives informed how we practice inclusive education, critical pedagogy, and educational leadership. They have helped secure full inclusion of disabled students and the future of inclusive education nationally and globally.

Disabled people, parents of disabled children, special education teachers and disability advocates turned activists populate the field and contribute their perspectives. The field while rather young has produced influential anthologies (e.g. Danforth & Gabel, 2008; Gabel, 2005; Gabel & Danforth, 2008; Kanter & Ferri, 2013), an annual conference through the American Educational Research Association (AERA), a host of journal articles, at least one monograph series, dedicated journals and increasingly connects parents, practitioners, and disabled people through advocacy groups locally, nationally, and internationally.

## **Models of Disability**

While disability studies as a small subfield within larger disciplines and fields is incredibly varied and diverse, there are some useful generalizations. This section aims to define some of the common terms and models referenced in the field. Disability studies has been shaped by at least three traditions emerging from the United Kingdom, the United States and Scandinavia which theorize disability in entirely different ways. According to Jan Grue (2015), a sociologist of disability, the following simplifications mostly hold true for each international tradition:

- 1. US Disability Studies conceptualizes disabled people as an ethnic-cultural minority.
- 2. UK Disability Studies conceptualizes disabled people as an oppressed class.

3. Scandinavian Disability Studies conceptualizes disabled people as the beneficiaries of welfare state programs and interventions (pg. 30).

Each of these propositions does not necessarily eliminate the possibility of overlap across them. After all, ethnic minorities are frequently oppressed classes. In addition, the same society may have sectors where one model is more prevalent than another or at least invoked more frequently. Even in the United States there are plenty of political discussions of who should receive disability benefits, how much and for how long. National Public Radio even documented this debate in an episode called "Trends with Benefits" of their popular broadcast *This American Life* (Glass, 2013). Yet the lens of economics too infrequently informs cultural approaches to disability in the United States.

Research aimed at modeling disability seeks to explain how disabled people interact dynamically with a variety of cultural, economic, social and political forces. Each model addresses the power and the resulting agency for disabled people associated with these dimensions differently and requires different assumptions to be applied. Much of the now four decade long debate surrounding the models focuses on how institutions, individuals and nations continue to privilege any model over the social model in an effort to understand ableism. Less frequently scholars have defined the interactions across models. This section introduces the most discussed models so that they can be refined through discursive approaches and deeper elaboration in future chapters. The models are not a complete list of all possible models but the ones most frequently discussed in available research: medical, social, charity, and gap models.

#### **Medical Model**

Medical models of disability tend to be traced to the invention of the concept of disability itself, yet persist inside and outside of the medical profession. A common misunderstanding about the medical model is that it is equated to the entire field of medicine and frequently education and psychology. Instead the medical model, if it is indeed a model, relies on medicalization, the process of reducing a person to a problem that needs treatment (Cameron, 2008; Gabel, 2005; Goodley, 2011). Medical models also employ scientific categorization and jargon that does not translate into lived experience: making distinctions difficult for even the disabled person to detect. Too often medicalized language used to describe disabled people goes unquestioned, becomes a label and prevents a holistic analysis of experience.

What else constitutes medical models of disability remains underexplored in both theoretical and empirical research on disability (Grue, 2011; Grue 2015). Medical models typically maintain coherence by privileging individuals over groups and reduce agency by seeing the person with the disability as being acted upon (i.e. the patient) rather than an actor (Thomas, 2007). Currently no scholars or activists are advocating for the role of the medical model in raising consciousness or empowering people with disabilities. Disability studies scholars can use the medical model as a scapegoat and a label, in and of itself, provided to express the frustration and pain of living under difficult and intolerant conditions for disabled people. This approach – at least historically – has failed to recognize the power of receiving a diagnosis in creating a disabled identity especially among people with non-physical disabilities.

#### **Social Model**

The social model contrasts with the medical model: pathology is replaced with solidarity and a spacious approach to what is considered normal replaces simplistic notions of aberrance or deficit. Dan Goodley (2011), a leading disability studies scholar, outlines these competing perspectives by modifying Olkin and Pledger's (2003) summary of eleven shifts in position by the American Psychology Association (APA). As can be seen in Table 1, the social model of disability advanced by disabled people's movements shifted psychology to consider how disability is constructed by normative expectations.

**Table 1:** Psychologies of Disability as reproduced in Goodley (2011, pg. 89)

09)		
Paradigm 1: Traditional (Medical)	Paradigm 2: New (Social)	
1) Is based on a medical model of	Is based on a social model or the	
disability	new paradigm of disability	
2) Is pathology oriented	Shifts to a systemic and societal	
1 0,	perspective	
3) Views differences due to disability	Takes a lifespan approach	
(impairment) as deficits or		
developmental aberrations		
4) Is usually cross-sectional	Uses concept of response to	
•	disability as a fluid process	
5) Sees people with disabilities	Promotes health and resilience	
(impairments) and their families as at		
high risk for difficulties		
6) Focuses predominantly on	Values disability history and	
intrapsychic, personal characteristics	culture as well as interpersonal	
or intrapersonal variables	relationships	
7) Research on disabled people –	Research with disabled people –	
which is more likely to be done in	incorporates those being	
inpatient or treatment settings	researched into the research	
	process	
8) Uses concepts like 'adjustment' or	Sees the major problems of	
'adaptation' to disability	disability as social, political,	
	economic, and legal	
9) Uses norms based on non-	Is grounded in the belief that	
disabled/able-bodied individuals for	those with impairments have been	
comparison	denied their civil rights	
10) Is about, but rarely by, disabled	Is usually not just about, but by,	
people	disabled people	
11) Perpetuates 'we-they' approach	Seeks remedies in public policy,	

legislation, and systemic programmatic changes

The listing above is rich and too detailed to explain fully here. A few examples from above are worth addressing. The social model as described in points 7 and 10 promote research that involves disabled people throughout the process and potentially as researchers themselves. This replaces the continued practice of researching disabled people heavily, and taking time from their lives without granting space for disabled people.

Disability advocates describe ableism as a norm that informs the life of institutions and people who inhabit or move through them. Tom Hehir (2002), professor of education, writes that ableism "results in societal attitudes that uncritically assert that it is better for people to walk than roll, speak than sign, read print than read Braille, spell independently than use a spell-check, and hang out with non-disabled students as opposed to other disabled students" (pg. 7). When ability is assumed, taken for granted, and barriers to access remain unexamined or unable to be questioned, researchers refer to this as ablenormativity.

To understand how disability and ableism function in society, the social model of disability separates the notion of impairment and disability. According to the first congress of Disabled People International (DPI, 1982) as cited in Goodley (2011), impairment is "the functional limitation within the individual caused by physical, mental, or sensory impairment"; disability "is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers" (113). Impairment is tied to biology and disability to cultural reality. While widely used, this

distinction has produced a lively debate about the ontological differences between impairment and disability and some have argued that they are mutually constituted (Tremain, 2002). Wendell (2013) borrowing from Crow (1996) argues that a social constructionist approach to disability and impairment is not impossible and requires researchers to consider how impairment impacts "how people experience, live with and think about their own impairments." Within this approach there is a possibility of uncovering how impairment is a *valuable* difference.

Much scholarly debate exists on the relative salience of the distinction between disability and impairment in the social model of disability and the experiences of people with disabilities (Hughes & Paterson, 1997; Corker, 1998; Allan, 1999; Shakespeare, 2000; Corker & Shakespeare, 2002). Very little of this debate, however, has examined the stories and the words of people with disabilities themselves to interpret the meanings of disability and impairment (Tremain, 2002).

#### **Minority Model**

In the United States after the passage of the Americans with Disabilities (ADA) act of 1990, disabled people have been commonly seen culturally as a minority group that requires civil rights. The movement from a minority that can be serviced can also be seen through European models, particularly the social model of disability, commonly referenced in the United Kingdom. The clearest definition of the minority model comes from the Stanford Dictionary of Philosophy: "the minority group model appears to favor measures to eliminate

or compensate for exclusionary practices and recognize their injustice" (Wasserman, Asch, Blustein, & Putnam, 2011).

The minority model much like the social model collapses individual experiences with disability under the banner of group membership. This presumes a cultural orientation where civil rights for disability emerges from shared struggle, a shared culture, and shared values. This involves disabled people experiencing exclusion from participation in the basic activities. The emphasis on group civil rights does produce limited opportunities for active engagement if the rights have been achieved and yet the social conditions for the group remain limiting. Some recent work in the field of social work blends the social model and the idea of "minority" rights to explain current movements to protect genetic diversity and the future of disability (O'Brien, 2011).

## **Charity Model**

The historical presence of charities dedicated to raising money to aid disabled people dates at least as far back as medieval Europe (Stiker, 1983). Yet the current associations with Charity models are not the same as the past. In the middle ages, disability was likely such a part of daily life that it would not have produced massive segregation, and in some cases even engendered group identity (Stiker, 1983). Within the twentieth century in the United States, charity models were widely criticized because they promote cures over concerns for general welfare and tended to be a means by which able-bodied people make a career out of using disabled people as props.

Historically there have been many organizations that have promoted cures over the general welfare of people with disabilities. Notably groups like

Jerry's Orphans, founded by Mike Ervin a former Jerry's kid in 1990, protested the Muscular Dystrophy Association's (MDA) annual telethon. They publicly denounced Jerry Lewis, the long-time host, as ableist because of his writings in newspapers where he described his preference for being dead rather than disabled. MDA had also been criticized for disproportionately promoting research for cures over the material needs of people with muscular dystrophy. Activists have levied similar criticisms against the Easter Seals and Autism Speaks<sup>TM</sup>.

### **Gap Model**

Jan Grue (2011) highlights the importance of the gap model through a discussion of Scandinavian legislation that guarantees everyone a basic standard of living. The gap model accounts for the fact that at any point "a proportion of the population at any given time will have either impairments or illnesses that place certain restrictions on their functional capabilities" (Grue, 2011, 540).

Because of its focus on government, it takes the role of fixing problems with awareness, access, medical intervention and discrimination from solely disabled people. Some parallels of the gap model in Scandinavia can be seen in the capabilities approach to welfare by Amartya Sen (1979) and elaborated for disabled people by Martha Nussbaum (2000). More work could be done to elaborate how the gap model differs, if it indeed does, from Nussbaum's capabilities approach.

#### **Subject Positions within Disability Models**

While discussions of disability models have captivated disability studies scholars for four decades, identification with impairment/disability remains

underexamined. How do identification patterns vary based on need, stigma, and access to disability culture, empowerment, and legal protection? To understand the dynamic and social nature of identity in the presence of multiple "models" or definitions of disability, it is worth articulating the possible identities for disabled people within models:

**Table 2:** Consolidated description of models and how they position disabled

people	Distinguishing	Identities for	Escare al ac
Model	Distinguishing Features	Identities for the Disabled Person	Examples
Medical	medicalization, pathologization,	Patient, "Cured" Person or Survivor	Institutionalization of disabled people
Social	empowerment, group membership	Activist, Beneficiary	British model from the 1980's to the present "embodied" model
Minority	group membership, group identity, cultural identification	Member of a minority, Activist	Disability as a protected class for anti-discrimination in ADA of 1990; (Cultural) Deafness
Charity	inspiration, exploitation of disabled people, elimination of disabled people	Poster Child, Object of Pity, Child	Easter Seals; Muscular Dystrophy Association; Autism Speaks <sup>TM</sup>
Gap	access to governmental resources	Beneficiary	Scandinavian welfare models, UN models of Human Development Indices

Table 2 quickly shows how certain models prescribe specific identities for disabled people. For example, the gap model gives little guidance on where disabled people are involved except to mention that they are beneficiaries. Is this lack of specificity an opportunity for all disabled people to participate in the political process or an oversight that may prevent access? Are there disabled activists in this model? The scant research does not provide clear answers.

Conversely are all disabled people meant to be activists in the social model? This

is certainly not how the social model has operated in the last few decades since most of the beneficiaries of access do not identify with their disability. All of these models presume a bit too much and perhaps not enough when examined at group and individual levels of identification.

Sociological research on disability identity and orientation that has already been conducted though has yet to be popularized, studying individuals in relationship to disability becomes easier to understand (Darling, 2013). In Darling's description of disability orientations, she defines three key features: identity, model, and role. While still relying on a binary model instead of the five models above, her theory situates the disabled person in his or her environment while also incorporating role and identity.



Figure 1 Darling's Model of Disability Orientations (Darling, 2013, pg. 85)

Darling's theory of disability orientations privileges pride, the social model and an activist orientation. As a theoretical exercise, the production of a clear set of categories allows for more empirical investigations. Here she also draws on the work of Swain and French (2000) and notes their affirmation model "views disability as a part of a positive social identity and rejects older models that view disabilities as personal tragedies" (Darling, 2013, pg. 90). It follows that this model would argue that disability then must be active and prideful.

But are some disabled identities more easily claimed than others? Are there spaces and contexts where the claiming of disability accomplishes a less than ideal outcome? Moreover, is activism itself disabling by virtue of requiring time, energy and effort – resources that disabled people may not be able to give? The aligning of pride and shame to disability models and in sequence activist orientations suggests a complex set of typologies that may not all exist. For example, can a disabled person who subscribes to the medical model be passive and prideful? Certainly the case of pinkwashing in breast cancer activism/survivor circles provides a definitive yes. Darling's model relies on a fairly fixed notion of identity, model and role that I suspect does not hold true in conversation, social life, or identity.

For example, looking at what Darling calls role, one does not simply shift from a passive to active orientation developmentally and certainly not without ample exposure to activist thinking or advocacy organizations which presumes a specific governmentality. Charlton studied the development of activist orientations in his ethnography *Nothing About Us, Without Us* (2000) that explained how disabled people developed an empowered consciousness through contact with activist communities; the connection here is to Darling's conception of role. Charlton unlike Darling reveals, "the dilemma most people with disabilities throughout the world face is how to use their meager resources to attend to this condition" (2000, pp. 164). Charlton argues that developing an empowered consciousness is about making choices: who to fight and what issues matter, and to whom.

Still Darling's theorizing reveals one very simple fact: we do not know how vast groups of people with disabilities identify, situate themselves in relationship to models of disability and moreover, develop or have an activist stance. It is within this overarching framework that the studies included herein operate and ask questions about individuals in relationship to each other and to society as a whole.

## The Case for Dyslexia as Disability

Talking about disability instead of "disabilities" is a significant component of the social model. Under the broader category of disability, criticizing society's shortcomings becomes the goal of those with different impairments. By far the most common impairment in schools is that of being learning disabled. Despite the general growth of the field of disability studies in education, little research has focused on the contemporary experiences of dyslexic people specifically – partially because they have not historically identified with their impairment despite receiving accommodations in schools and being labeled with learning disability. Before elaborating this case as a liminal and instructive one for educational research, I take two positions on dyslexia as a disability.

First, the term *learning disability* is used in this thesis as a broader, categorical designation of a range of learning difficulties that includes dyslexia but is not solely defined by it. The use of the term *learning disability* varies across contexts and may or may not include dyslexic students. The studies cited here that use the term learning disabilities are inclusive of dyslexia, and studies where the sample does not clearly cite dyslexia have been excluded from review.

Second, as a rule, person-first language should be used when describing people with disabilities (APA, 2009) when in doubt, though preliminary research indicates that there is not a consensus in usage historically (Lynch, Thuli &

Groombridge, 1994), currently (Ladau, 2014), or across disability categories such as blindness (Vaughn, 1993), autism (Brown, 2011) and deafness (Folkins, 1992). This thesis differentiates itself from other research studies on dyslexia by only using identity-first language. It is worth noting that all the students interviewed in the studies detailed in subsequent chapters used dyslexia and dyslexic to refer to themselves and their identities.

By far the most important contribution to the scant research on dyslexia as a disability is Scot Danforth's *The Incomplete Child* (2009). It established a history of the emergence of the construct of learning disabled and shed insights into how it has been constructed by psychologists, neurologists and educators in different times and spaces and continues to be expanded and popularized today (Danforth, 2009). His investigations begin with learning science in early 20<sup>th</sup> century Germany including the work of Kurt Goldstein, its transmission across the Atlantic and to the United States in the work of Alfred Strauss at the Wayne School in the 1930's and 40's, and through to Newell Kephart's movement education in the 1950's and 1960's. He then connects this tradition to Samuel A. Kirk's foundational work from tutoring to research, which led to advances in psycholinguistic diagnoses and intervention and ultimately contributed to a proliferation of terms and labels – educational and neurological – that required additional research and revision by Donald Hammill in the late 1960's. Danforth's history stops short of the present but reveals clear implications: that learning disability as a concept has been constructed differently over time in research and education, and research on a disorder continues to struggle in informing pedagogy.

In schools, identification of dyslexia takes enormous resources and special training. Learning disabilities, and specifically dyslexia, are by far the most prevalent disability in school settings, with estimates ranging from 5-20% of all students affected (Moats & Dakin, 2008; Shaywitz, 2003). Previous research from a deficit-based perspective has defined dyslexia as learning or reading disability affecting speed and accuracy of word decoding, spelling and comprehension. Extensive efforts have been made to prevent reading difficulties in children with dyslexia as early as age five. These early intervention efforts are preferred to the more costly and less effective approach of waiting for students to show difficulties. This "wait-and-see" approach also has less of a chance of normalizing reading achievement due to the developmental nature of fluency delays (Torgesen, 2007). Dyslexia has shown to persist over the life course even after remediation efforts have ended (Shaywitz, Fletcher, Holahan, Shneider, Marchione & Stuebing, 1999) and has a genetic component suggesting dyslexia occurs in families and intervention could happen even earlier (Francks, MacPhie, Monaco, 2002). The current research agenda has continued to focus on early intervention efforts while adding the concerns of addressing special education needs in mainstream settings. None of this research adopts a disability studies perspective or reveals what could be learned about dyslexia or disability from that perspective.

Another reason dyslexic students may not have been studied through cultural methods may be because they are likely to be included in general educational settings and therefore their needs may not be seen as pressing. For researchers of inclusive education, why study a group that is largely included when other groups are less likely to be included? One reason why research

should invert this trend is because the treatment and problems of dyslexic students can provide powerful insights into how other disabled students are likely to be excluded or stigmatized even in inclusive settings.

With few dedicated research efforts aimed at uncovering the relationship or lack thereof between dyslexic students and disability – even when dyslexic students are disproportionately the beneficiaries of accommodations and modifications within the standard curriculum – dyslexia is perhaps best situated to reveal the liminal space that critical understandings of disability occupy in educational settings. This strand of research, since measures of identification and cultural sensitivity to disability are still emerging, still relies on qualitative inquiry (Darling, 2013). The lack of generalizability of qualitative research is a reason researchers avoid this work. Another is the persisting belief, despite decades of evidence to the contrary, that with the appropriate interventions and/or inclusive education practices, differences between dyslexic readers and their peers can be minimized or even erased. It cannot be denied that the results of intervention science have produced sizable changes and remarkable improvements in the quality of education for dyslexic people, but qualitative research can augment existing intervention efforts and efforts at inclusion by analyzing how dyslexic people understand their educational experiences.

Gaps in research cannot justify study by themselves. Why care about these potentially theoretical distinctions by understanding dyslexia as a cultural phenomenon? For example, understanding the labeling of dyslexic readers is of considerable value because it makes dyslexia a special case of the larger problem of how human categories do both a service and a disservice to their members. The category "dyslexic" encompasses great variation (Hammill, 1990) and within

this variation, the effects of embracing or, at least, accepting the category label and maintaining one's individual identity is still being investigated (Karande, Mahajan & Kulkarni, 2009; Nugent, 2008; Taylor, Hume & Welsh, 2009) with the result that more specific labels like *dyslexia* are perceived as more useful to students and teachers than labels like *learning disabled*.

In addition, researchers point out how current interventions for adolescents with dyslexia fail to "normalize" their reading trajectories (Torgesen, 2007) and that dyslexics are at greater risk than their non-disabled peers for depression (Alexander-Passe, 2006; Huntington & Bender, 2001), low academic self-concept (Burden, 2005; Elbaum & Vaughn, 2003), learned helplessness (Borkowski, Weyhing & Carr, 1988) and suicide (Huntington & Bender, 2001). It has been hypothesized that labeling and individual interpretations of that labeling affect many of these dimensions (Burden, 2005). To understand these associated risk factors as merely expressions of a reading deficit instead of the cultural and social forces disabling these young people in schools is to obscure critically important experiences.

Only a few examples of research exist where researchers interpret talk by dyslexic people: McNulty (2003) employed life story interviewing to relate early stigmatization in school to persisting life challenges, and Burden and Burdett (2007) used talk to examine self-concept and locus of control variables. Psychologists Robert Burden and Julia Burdett (2007) examined how forty young men with dyslexia used metaphors to explain their abilities and dyslexia. Burden and Burdett categorized the metaphors used into two groups: surmountable and insurmountable barriers. Dyslexia, in this case, is characterized only as a barrier whether it is something that can be overcome or not. Burden and Burdett relate

surmountable barriers to an internal locus of control, where the individuals themselves felt as if they could overcome them (e.g. dyslexia is a lock and I have the keys; dyslexia is a maze but I can find my way through it). The insurmountable barriers were usually more negative (e.g. dyslexia makes me feel like my head has knife through it; dyslexia is like a big, illegible book with Satan next to it). Though their study highlights differing understandings of dyslexia among young men with dyslexia – one adaptive and the other troublesome – it remains only one descriptive moment with only a moderately positive outlook, and with little or no context. The work of Burden and Burdett (2007) highlights the potentially troubling ways that dyslexic students describe their impairment. Without some contextual information it is difficult to ascertain the origins of the negative associations and their relationships to impairment and disability. We need a more systematic way of examining talk about disability and we need to understand how models of disability relate to other important categories like identity and agency.

Historically, as terms develop a negative connotation they are replaced with new terms that ultimately also develop negative connotations. Steven Pinker termed this the euphemism treadmill. So shifting terminology alone offers a temporary solution to a social problem, and may actually obfuscate the needs of people with disabilities by rendering the new term unintelligible to a range of scholars and advocates who understand it only in its previous form. Further it becomes even more difficult to construct histories, identities, and communities around shifting terminology. I eschew terms like learning difference or learning style because they risk hiding that schools are the primary context where people

with learning disabilities are *disabled* – in ways that *difference* and *style* trivialize (Danforth, 2009; McDermott & Varenne, 2010).

To understand dyslexia as a disability requires engaging with the history of shifting attitudes toward disability in the latter half of the twentieth century in the United States, the lessons learned from modeling disability, and contextualizing those models within the shifting educational discourses that influence practice and therefore available subjectivities in schools. The approaches and research outlined in the subsequent chapters aims to document these trends by dynamically examining cultural, individual and social trends through the analysis of dyslexic students talk about themselves.

### **How this Dissertation is Organized**

This dissertation explores the relationship between modeling disability and talk among a young group of dyslexic students. Each chapter highlights a critical component of the larger problem of theorizing dyslexia within existing disability models and reveals how dyslexics dynamically appeal to different discourses within and across models to accomplish different goals.

In Chapter 1, I discuss how discursive frameworks inform modeling disability. This involves defining discourse and other relevant terminology including positioning and metaphor. I then make an effort to document the studies of discourse and disability including general post-structuralist approaches to modeling disability especially the recent work of Jan Grue (2015). This leads into a discussion of a pilot study where I revealed the dynamic discursive moves among young dyslexics on YouTube™ including defining dyslexia as a gift, which prompted new research questions. I then discuss a new

study, built on previous findings, and its design, data collection, research questions, specific methods, and sample.

In Chapter 2, entitled The Broken Yet Gifted Brain: Dyslexic Subjectivity, the realm of dyslexia in cultural discourse is explored. In particular, media outlets and documentary film have normalized dyslexia as an expression of human neurodiversity while relying on problematic discourses of brain dysfunction to explain how dyslexic people see the world. The limits of the "broken brain" discourse are explored. So is the taking up of the discourse that dyslexia is gift by young people. Interviews with young dyslexic people reveal a much more complicated picture, however, where discourses of gifts and "broken brain" discourses explain how young dyslexic people can experience both failure in school and maintain hope for future success in a non-academic setting. The limits of these subjectivities in turn reveal the persistence of the American dream in shaping the expectations of education for middle class and elite students and the potentially damaging promises of gifts that may not exist.

In Chapter 3, previous qualitative research on dyslexia exploring the realm of cognitive metaphor has also been based almost exclusively on deficit-based approaches to dyslexia. A close reading of Burden and Burdett's work on cognitive metaphors of thirty young men with dyslexia illustrates how young people use metaphors of barriers and their relationship to those barriers (either failing to surmount or overcoming them) as the primary binary of metaphors employed by young dyslexic people. The sample of young people examined herein reveal new classifications including reframing the barrier as a journey metaphor and the use of a range of other metaphors among young dyslexic people previously undocumented in research studies.

Chapter 4 discusses the use of language to cover up disability – even in disabled-only educational spaces. An overview of the emergence of language of learning differences is connected to interviews with young people describing themselves as different. Through the application of positioning theory I illustrate how difference claims replace disabled-identity claims, thus distancing young dyslexics from others with disabilities and also from the minority model. Instead the young people present a disability as an inconsequential difference to cover the pain of transition, discrimination, and segregation in educational settings. This covering of disability has implications for documenting and modeling how disabled people manage difference in educational settings.

Mapping these four chapters topically, a new terrain where both how disabilities are discussed in relationship to identity but also how dyslexia is being reconfigured culturally emerges. Future directions for study are also offered making the connection between subjectivities within and across models and normalcy in the conclusion.

## **Chapter 1: A Discursive Approach to Disability**

Concerns with language, often dismissively termed political correctness, remain a central component of promoting awareness of disability in culture. Language binds the way that disabled people interact with culture and can foreclose the possibility of identifying with personal, social and political needs. Language changes in the last twenty years have replaced autism advocacy with recognizing neurodiversity, mental retardation with cognitive impairment, and dwarf with little person. All of these shifts have been efforts to connect to the humanity of disabled people. Words used to describe people as disabled like handicapped or any parsing of disability (i.e. dis/ability, (dis)ability, differently abled) are generally avoided in English speaking countries except for the most theoretical of discussions. The field of disability studies is marked by and has always been interested in how language interacts with culture.

Discourse analysis is a primary tool among social scientists for understanding how language interacts with culture. It is precisely by analyzing what Jan Grue (2015) terms the "amorphous" concept of disability from a variety of angles that a more refined conceptualization of disability emerges. To do that researchers in disability studies need to apply the lessons of discourse studies including models for understanding the relationships between the individual, social and cultural dimensions of language.

The goals of this chapter are fourfold. First I define and elaborate terminology including discourse, positions and metaphor to promote a clearer understanding of the methods used in this thesis. Second I highlight how studies of discourse have already helped redefine popular models of disability in culture

and in research. Third I relate the contents of a pilot study conducted prior to this thesis that led me to ask new and larger questions about how discourse can aid in modeling disability in educational settings. Lastly I detail my study design and sample used as data in the next three chapters.

## **Understanding Discourse and Relevant Terminology**

As a term *discourse* has come to be used in a range of philosophical, disciplinary and critical ways that can, despite efforts to maintain access, easily become jargon. The first goal of this chapter is to clarify the term to ease reader's understanding of future chapters. The term *discourse* emerged as a critique of literal interpretations of language. By studying discourse, researchers focus on what language *does* and not merely what it *is*. This shift from understanding language-as-descriptive to language-as-social action is an important one and has transformed the last forty years of qualitative research in the social sciences.

Discursive language is constructive and constitutive of social life (Wetherell, 2007). For example, let's assume I arrive at work late. As I walk in my supervisor says to me, "It's ten o'clock." I reply, "I was at the doctor." The supervisor then responds simply, "Ok." A range of complex assumptions is at play in this simple example. When the supervisor first speaks, he does not merely state the time. He indicates that I am late by reminding me of the time. I react by providing an excuse that he accepts. By mentioning a doctor's visit in this short conversational interaction I am providing an excuse that is likely to be accepted. I could have stated that I woke up late, which, perhaps, would have elicited a different reaction. While additional aspects may be communicated via intonation, emphasis, etc., this interaction reveals very quickly how talk

functions both at a literal level and a level of action through processes of questioning, excusing and validating the excuse.

Discourse is not simply language in action. People, often termed *subjects*, employ language to accomplish different goals. Discourses are comprised of examples of language in action spoken by participants in particular positions. Reciprocally, individuals' speech typically operates within existing discourses to achieve desired outcomes. When individuals choose what they are going to say and how they say it, they take up different positions. To delve into the above example further and examine its cultural content, I question the time itself: 10:00 o'clock. It is easy to assume that it is not 10:00PM because I contextualized the reply by saying it was from my supervisor who would most likely not be questioning my whereabouts or tardiness at a time when most working people would be home. Also 10:00 AM is significant because it signifies lateness in a traditional eight-hour workday stretching from 9:00 AM to 5:00 PM. In order for me to know that I need to provide an acceptable excuse I rely on a tacit acceptance of the value of the eight-hour workday and my supervisor's authority to determine acceptable excuses. These are both components of general discourses on work and authority where my position as employee gives me less agency and fewer choices than my supervisor who holds a different position. The supervisor may be able to excuse or hold me accountable.

This reveals another critical dimension of cultural discourses. They both constrain and make available different actions as subjects moving through different positions invoke them. As subjects take up, reject and move between positions the nature and limits of the discourse can be revealed. I often think of this through the metaphor of the dance floor. Individuals can stand or move around

the dance floor and dance. Perhaps someone may even feel more comfortable dancing if they are in specific places on the dance floor. They would most certainly ham it up if they were placed in the spotlight. Individuals can dance outside of the dance floor, but it would not necessarily be understood, welcomed or celebrated in the same way. Therefore the dance floor is the discourse and the spaces people dance are positions and the dances they perform are the linguistic possibilities available to them. Dancing some place other than the dance floor involves creating new ways of understanding what it means to dance. What it is like being, acting or seeing as a particular subject in the discursive world is commonly referred to as *subjectivity*.

There are many more characteristics of cultural discourse that I have yet to cover but will prove relevant to its definition. Multiple discourses are often invoked or called on by the same subject. This can even happen linguistically in the same phrase, word or lexical unit. Discourses are frequently hybrids of other discourses (Gee, 2006). A common hybridized discourse is the voicing of textspeak: someone saying "lol" or "lolz" for example in the middle of a conversation. Discourses are also contextually bound which means that the same discourse may not be used in the same way in every circumstance or in different times historically.

Researchers have distinguished *discourses* at the level of conversational interaction from *Discourses* at the cultural level of analysis to map how analyzing each poses unique challenges (Gee, 2006). As the example of being late illustrated, however, interactions at the interpersonal level still require information from the personal and cultural levels of discourse (value of the workday, trust in authority). To treat them as completely independent may be fictive and may

even obfuscate the complex possibilities for choice, agency and subjectivity in the world. Nevertheless models and methods are needed to explain how individual choices in *discourses* relate to *Discourses*. This requires defining and elaborating on how culture shapes discourses and vice versa.

## A Theoretical Model for the Relationship Between Culture and Cultural Discourses

Personal, interpersonal and cultural understandings are all present in most texts. I employ the word text in the post-modern constructivist sense where everything is a text and therefore open to analysis (Rosenau, 1992). The word *text* is used by constructivists and post-modernists to emphasize how ideas, language, phenomena, histories and events are actively constructed by subjects in the world. To examine cultural processes thoroughly, researchers must consider all three components in each text. The model below [Figure 2] proposed by Helen Haste (2009) illustrates this interdependent relationship:

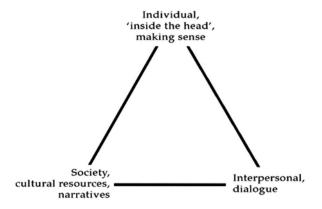


Figure 2: Haste's (2009) approach to understanding culture

This approach to analyzing culture (herein noted as narratives and cultural resources) acknowledges different inputs and outputs (each node being both) that reciprocally inform each other. Since there is no center to the triangle it is important to note that society is both informed by and shapes individual

understanding and dialogue. This remains an important precursor to understanding how discourses operate on multiple levels of analysis.

There are many discourses that operate at a cultural level and ultimately define culture itself. According to Stuart Hall (2007), "By discourse, Foucault meant 'a group of statements which provide a language for talking about – a way of representing knowledge about – a particular topic at a particular historical moment" (72). This then philosophically entails acknowledging that discourses bind the way that people make meaning from culture and each other. The example of a mountain is often invoked here. First, I cannot deny the material existence of the mountain. Second, I cannot talk, gesture, think or write about mountains without relying on discourse. Nothing has any meaning outside of discourse – even if it has a material reality. This has complex implications for the subject. Even an individual cannot be outside of discourse "because it must be subjected to discourse" (Hall, 2007, 79). Therefore the subject is *subjected to* the aims, power and construction of the discourse that it in turn, produces and reproduces.

Medical discourses for example have long determined what needs are personal and what needs are political. The power behind medical discourses even for disabled people is the primacy given to the language of medical institutions, practices and certifications that determine who gets how much support. The ongoing project of seeing patients as discrete units to be managed until cured also manages possibilities for social cohesion or group identity formation. Culture privileges medical language, classification and treatment often putting it in an unassailable position even when scientific evidence suggests that the classification or language may not be useful. Jan Grue (2015)

highlights this power dynamic by writing "medical language has been positioned as prior to knowledge about disability." That to even understand oneself as disabled, someone needs a diagnosis from a medical practitioner. But what if you are chronically ill?

In the recent past distinctions made between illness and disability have highlighted the differences between medical and social approaches to disability. Disability rights became the domain of the physically and sensorially disabled. Disability rights culture almost required the sublimation of pain and exhaustion for solidarity. Illness, even chronic illness, did not initially fit into this category of activist. Patricia de Wolfe (2002), in a thought provoking analysis blending personal and theoretical explorations of the divide between disability and illness, examined this debate by pointing out the major difference: disabled people culturally and politically are seen as having the right to place demands on institutions. People who are ill do not.

Patricia de Wolfe has Myalgic Encephalomyelitis (ME), which at times drains her completely of energy and limits the amount she can do with her muscles before they may fail her. For years she did not have problems accessing her university's information center until heavy doors were erected between the main library and the issue desk. She struggled with understanding how new barriers render a previously accessible resource inaccessible to her. It took her longer than one year after an initial complaint to get the doors pinned back magnetically. She had only encountered the possibility of receiving accommodations through her explorations of medical sociology and in particular disability rights activism but she learned very quickly that "the quality of life of someone like myself hangs by a thread and may be destroyed by a simple act of

stupidity; that an institution may devise an impressive equal opportunities code without . . . implementing it; · that the words 'disability' or 'disability rights' induce a recognizable reaction . . . a kind of dismayed gulp, followed by two steps backward" (deWolfe, 2002).

In deWolfe's case, her failure to identify with the disability rights movement beyond intellectual curiosity matched the disability rights movements either perceived or real distance from people with chronic illness. Issues that structured this largely discursive divide included "political efficacy; the problems with reconciling accommodations with one of a cure; and a Western cultural emphasis on the controllability of the body, which fosters a denial and stigmatization of frailty and suffering" (deWolfe 2002). Again it could have been argued that disabled people may not gain much more than pity by associating with the chronically ill politically or culturally – especially when so much of the disability rights movement was built on the rejection of pity (ie. Protests like "No Pity" and "Piss on Pity"). If people were only temporarily ill did that mean the disability itself could also be temporary?

Discussions surrounding cases like the one above ultimately led to the inclusion of many invisible disabilities, psychiatric disabilities, aging and chronic illnesses into disability rights movements across the country and the globe. The telling function of the medical discourse for bounding deWolfe's perceived agency reveals its power. Medical discourses in the past and in some cases the present have been responsible for everything from the legitimation of segregation and isolation of people with psychiatric disabilities in institutions and asylums and the justification of placing children with cognitive and developmental impairments in institutions or restrictive settings in schools.

Historical examples of this mismatch between illness and political access can be seen in the AIDS movements of the 1980's and early 1990's where the uniting force for change in medical and drug testing practices was a social discourse (gay identity).

Important in all of the cases above is the individual's sense of agency. Different approaches to discursive methods attribute more or less agency to subjects. Few methods elaborate how subjects can break outside of existing discourses by creating new ones. One such approach that specifically calls for the understanding and labeling of agency in the discursive world is Foucauldian Discourse Analysis (FDA).

## Foucauldian Discourse Analysis (FDA)

Willig's (2010) Foucauldian Discourse Analysis (FDA) emerged from groundbreaking research in psychology, such as *Changing the Subject* (Henriques, Hollway, Urwin, Venn & Walkerdine, 1984) and was influenced by Foucault's constructionist theory and notions of discourse. This early work cemented the importance of post-structuralist and feminist psychology and gave a new means by which scholars could understand the political aspects of culture. The goal of FDA is to connect the individual subjectivities possible within discourse to the discourses themselves. This is most often demonstrated through an analysis of multiple texts and through language as social action. Text here becomes shorthand for data. The six steps in FDA according to Willig (2010) are as follows:

- 1. Identify the *Discursive* Construction: what is being constructed in the texts?
- 2. Uncover the *Discourses, which* bound how the discursive construction is being addressed.

- 3. Examine how the differing constructions operate within the discursive context. To what end is something being constructed? This is the *Action Orientation*.
- 4. The subject positions referred to as *Positionings* reveal what positions are available within the discourses for individuals to be in.
- 5. These subject positions are not permanent but often moved through by the individuals with their talk. This often-dynamic movement is termed *Practice*.
- 6. The final step, *Subjectivity*, asks the analyst to think through the "ways of seeing the world" available to the subject in the different positions and through movement between positions referred to as practice phases. These can include emotions and common phrases as well as link to broader orientations.

Before undertaking FDA, it is important to thoroughly review the data. If not, the steps are much more iterative and it is common to go through at least the first two or three steps repeatedly to identify what is salient in the text, a process I followed in Chapter 2. A more accurate model would reflect this common repetition [1-2-3-(1-2-3)-4-5-6]. This allows for an EMIC approach to the discovery of the discursive construction and a refinement of the topic through a deep engagement with the data.

Foucauldian approaches to discourse are used in a variety of social scientific and humanistic inquiries and especially across educational research and disability research (Allen, 2008; Bjarnason, 2010; Bruin & Nevøy, 2014; Corker, 1998; Mclaughlin, Goodley, Clavering, & Fisher, 2008). FDA as articulated by Willig (2010) has a small but lively history of explicit application in the health sciences, feminist psychology and education. Zitz, Burns and Tacconelli (2014) and Kavoura, Ryba and Chroni (2015) in recent studies of transgender men and female judo athletes employed Willig's stepwise approach to FDA but largely reported discourses (step 2) and positionings (step 4). Foucauldian approaches to discourse appear more commonly under the larger

designation Critical Discourse Analysis (CDA), and sometimes under Critical Discourse Studies (CDS), a specific approach to CDA (Meyer & Wodak, 2010).

# **Elaborating on Subject Positions and Positioning**

The words subject position, position, and positioning appear across discursive methods and signify slightly different concepts and research traditions. I have previously defined and connected that to step four of FDA, which refers to both subject positions and positioning. Positioning theory models complex social, frequently dialogic interactions instead of relying on static understandings of social events (Harré & Slocum, 2003). Examining positions in discourse allows researchers to make inferences – not about the internal states of the participants – but how the discourses constrain the subjects and require specific sets of legible actions.

For example, in previous social psychological research on attitudes it has been frequently assumed that adolescent boys who say things like "That's so gay" as a means to express disgust, contempt or label something as stupid simply have a heterosexist attitude. Initial research on the topic suggests that may be true and that expressions of heterosexism correlate to a host of other attitudinal factors such as rigid gender identity (Hall & LaFrance, 2012).

Studies like the one conducted by Hall and France on the use of "That's so Gay" reveal the presence of heterosexism among the young men who employ heterosexist language. While important, it is far from surprising. Another way of analyzing "That's so gay" would be to understand it as part of a conversational exchange that allows the individual adolescent boy who says it to become part of a group of other boys who share, at least superficially, heterosexist notions as a

way of bonding with each other, reaffirming gender norms and sexual identity. The attitude is not just internal but socially constructed through positioning in discourse. By repeated exposure of learning the storylines of heterosexual masculinity, young men reaffirm their identities and develop these attitudes. The positioning of something else as "gay" allows the young men the possibility of explaining close bonds with each other by simultaneously positioning themselves as outside of being "gay." These positionings of both self and other over time become a rich source of information about not simply that attitudes exist but that they themselves are constructed through dynamic social and dialogic interaction. This allows researchers to contextualize heterosexism as part of the development of masculinity among young adolescent boys. Initial research using critical methods like positioning supports this more nuanced approach (Korobov, 2005).

Researchers can therefore use positioning theory to understand the development of important constructs like attitude and generally may be most fruitful in process-focused inquiries involving talk. Positioning theory has only recently been applied to the study of disability and the investigations done reveal the potential for understanding inclusive education, reductive approaches to disability, and special education teacher preparation (Gable, 2014).

#### **Conceptual Metaphor**

Conceptual metaphor like positioning and FDA is often treated either as a precursor to or a product of discursive methods and qualitative analysis. It is only analogous to and not exactly the same as literary metaphor. The analysis of conceptual metaphor reveals how abstract concepts require grounding in

familiar concepts to be intelligible. This occurs when one conceptual domain is explained in terms of another. Classic examples include electricity in terms of water (ex. *flow*, *current*) (Lakoff & Johnson, 1980). Additional examples include how wellbeing is wealth (ex. Music has enriched my life; It is a poor man who has no love of himself), or harm beyond physical injury is physical injury (ex. the difficult election left the candidate scarred; ecologists are nursing the bay back to health) (Lakoff, Espenson & Schwartz, 1991).

The analysis of conceptual metaphor has long been used as a way to examine how language represents complex and often abstract concepts, including scientific theory (Baake, 2003; Brown, 2003; Cetina, 1999; Leary 1994). Examples abound from the thirty years of scholarship in English. In each example there is a mapping from one conceptual domain to a target domain and very frequently mappings across multiple domains (Turner & Fauconnier, 2002). Kövecses (2010) expanded the methods for studying and systematizing conceptual metaphor from the earlier work done by Lakoff and Johnson (1980). This is often simplified to signify simply that a concept is equal to a second concept.

Identifying conceptual metaphor in conversations can be tricky and only in the last ten years have clear methods emerged. Ten leading researchers spent six years developing a stepped approach to metaphor identification. The Pragglejaz group came to their unique name by agreeing to use the first letter of their first name to form the group name (Peter Crips, Ray Gibbs, Alan Cienki, Graham Low, Gerard Steen, Lynne Cameron, Elena Semino, Joe Grady, Alice Deignan, and Zoltán Kövecses). Research has shown the Pragglejaz model known as the Metaphor Identification Procedure (MIP) to be reliable and valid in

empirical research in cognitive linguistics, psycholinguistics, linguistics, discourse analysis and applied linguistics (Steen, 2001, 2002, 2005, 2007; Steen, Biernacka, Dorst, López-Rodríguez & Pasma, 2010).

The Pragglejaz Group propose a simple, four step method (2007, pg. 3). First, researchers read the entire text to establish a general understanding of the meaning. Second, the researchers identify the lexical units in the text. These lexical units can be words, compound words, parts of words, or entire phrases (typically in the case of idiomatic expressions). Then a series of subsequent checks are done on the lexical units. The researcher must identify the meaning of each lexical unit in the text and how it applies to the situation generally. The researcher must also determine if the lexical unit has a more basic contemporary meaning in other contexts than the one in the given context. The Pragglejaz group then suggests that "if the lexical unit does not have a more basic meaning in other contexts than the given context, decide whether the contextual meaning contrasts with the basic meaning but can be understood in comparison to it" (2007, p. 3). If one of the following two steps underneath step three are true than the lexical unit can be marked as metaphorical.

Once metaphors are identified, they should be compared to the existing master metaphor list to determine if the metaphors were reduced to their simplest meaning (Lakoff, Espensen, Schwartz, 1991). The examples of metaphors discussed earlier are on this list. With over two hundred pages of examples and 63 domains described, crosschecking the master metaphor list with the metaphors generated through research grants a degree of external validity.

**Discursive Approaches to Disability** 

Discourse and disability studies share complementary epistemologies, and political and cultural concerns. In the introduction I discussed the common models of disability advanced by disability studies scholars in part to make it clear that disability does not mean the same thing in every context and that disability studies scholars concern themselves with how disability is produced by culture. Scholars in disability studies have for at least two decades had interest and stake in understanding how disability is produced linguistically and culturally and have explicitly adopted discursive methods (Corker & French, 1999; Snyder & Mitchell, 2000). Many scholars in disability studies have also adopted Foucauldian style discourse methods to tackle some of the most common concerns of the second wave of disability studies including the construction of impairment within the social model of disability (Tremain, 2002, 2006). Recent work has elaborated these earlier works by deconstructing medical, political, economic, and identity-based and media discourses of disability (Grue, 2015). Grue's research has just started to gain international attention and is the first accessible and concerted effort to unite the two fields. It mostly operates at the level of cultural discourse, however.

More work needs to be done connecting the micro-discourses appealed to by disabled people to broader cultural discourses and models. The methods that can accomplish these huge goals are the ones discussed in the earlier part of this chapter: FDA, positioning and conceptual metaphor. According to Dan Goodley (2011), "discourses are used to make sense of who we think we are and are re/produced in social institutions" (106). In the context of the thesis project described in the following sections, researchers in the field of disability studies in education need to understand how educational discourses shape student

experience and how students themselves continue to reshape educational discourses. All of these approaches, while differing in the assumptions they make about an individual's thinking and culture itself, reveal how ablenormativity undergirds communication and action in a society or culture when language is taken as constructed.

Since so little work had been done in this field at either at the theoretical or practical levels, I first conducted a pilot study examining discourses of dyslexia on YouTube™. Because adolescents employ social media as a primary means of expressing both their political engagement and their identities, examining YouTube™ videos prompted me to formulate a series of questions to ask real students with dyslexia about their experiences in schools – based on voices like theirs – instead of my own.

## Results of a Pilot Investigation: Dyslexia on YouTube™

I conducted a critical discourse analysis of young people's talk about dyslexia on YouTube™. Using search terms like dyslexia, life story, narrative and learning disability, videos were retrieved, catalogued and excluded based on three criteria. First, in order to preserve the naturalistic aims of the research, videos must be of young people themselves talking about their disability. Second, videos must not be edited heavily, preventing the talk from being broken apart or non-sequential. Third, the videos had to not advocate the use of a specific intervention or research program. With these criteria applied, the list of qualified videos by and about young dyslexic people diminished from 300 to 8. One video was excluded post-hoc because it became unlisted.

I examined the words of seven young people who posted videos on YouTube<sup>TM</sup>. Across all seven videos, a variety of discursive actions related to dyslexia appeared: defining dyslexia; young people advocating for and supporting each other; reacting to being treated like a "dummy" and navigating passing and coming out as dyslexic online.

In the discursive formation of defining dyslexia, I showed how students took their impairments as de facto describing the conditions of their dyslexia. They described themselves, but also appeared to understand that not all dyslexic people may have the same symptoms. I termed this "seeking definitions, expecting differences." Further complicating this observation was that students described the panoply of co-morbid conditions associated with dyslexia, often attributing these other conditions to dyslexia. In this case they saw dyslexia as either "co-occurring," "entangled," or "heterogeneous." This suggests that, at least as reflected by self-initiated YouTube<sup>TM</sup> postings, impairments are difficult to define, personal and may be seen as coming with other concerns. This individualistic discourse fits neatly within medical understandings of dyslexia, but none of the students showed any negative attribution to the medicalized language. The efforts to define dyslexia initially appeared to relate more to ways in which medicalized language has become inseparable from self-descriptions. This poses a challenge for social model advocates who claim that the social model of dyslexia is the only model that people with disabilities can claim. Instead I show that when young dyslexic people appeal to medical terminology, they gain expert status on their condition, which allows them to speak about themselves. This is a problem in and of itself if we conceptualize disability

through a strict social model where medical terminology is associated with pathologization.

When dyslexia was explained in non-medical terminology, young people tended to articulate how others treated them like a "dummy." This dummy discourse positioned the young people outside prevailing discourses of merit, achievement and success and left them to reconsider how to respond to this treatment. In many ways, the "dummy" discourse stands in for dyslexia so that people without access to more medicalized language can describe those with the label. In all but one case, young people – described as dummies by school personnel or family – articulated a desire to advocate for and support others with the label. The "dummy" discourse appeared in stark relief against the discourses of dyslexia as a "gift" which the young people appealed to through invoking knowledge of brain differences. In their worlds, the brain differences did not make them dumb, it allowed them to claim that they were different and special.

All of the young people in my study aimed to support other dyslexic people. The very notion that other dyslexic people need support lends credence to the prevalence of the dummy discourse in daily life and the persisting ableism in educational settings. This also suggests that modeling dyslexia through the typical impairment/disability divide present within now decades old notions of the social model of disability is not the most effective. After all, young people themselves do not see medicalized language as problematic in self-descriptions and instead they position themselves as victims in a hostile environment in part to lend credence to their claim of advocate status. The need to speak for all dyslexics also shows that dyslexia is already an identity marker in schools and meaningful label for more than just reading remediation. The medicalized

language of their diagnosis gave them the language to claim being dyslexic because other than their poor reading skills, these students appear just like everyone else. Their experiences with difference gave the young people a reason for the postings that they made on YouTube<sup>TM</sup>.

One example from the study that reveals the complexity of the appeals is excerpted below from Kyle. Kyle's account of his dyslexia produces a discourse where dyslexia is a learning style associated with creativity. He rejects the understanding that dyslexia is a disability:

So dyslexia isn't really a disability and people shouldn't think of it that way, it's just a different learning style. Dyslexics are able to find solutions because they process information a different way. One of my pals Nlin Loki, he helped me realize that dyslexia was really more of a gift. It's how dyslexics are not really the same as an average person. A lot of dyslexics, myself and Nlin Loki included, we when we were younger and even still myself now we kind of feel bad because we think that we are stupid. To us it's like: "Oh you can't read." Or whatever. We think that other people look down on us or we should be like everyone else. We are not and we should embrace that. Dyslexics are generally more creative and more inventive than a lot of other people.

He attributes agency to people with dyslexia through categorization: "Dyslexics are able to find solutions." It is likely the dyslexia as disability discourse that also relates to the belief that people with disabilities may have reduced ability for agency. So here the discourses are revealed in dyslexia as deficit and dyslexia as gift (asset).

Kyle shifts from one understanding of dyslexia to the other using parallel structure and substitutions. Through association with his friend Nlin Loki, a young electronic music composer, Kyle claims group membership by substituting "We" for I; he then repeats the "we" to accomplish rhetorically the

shift in understanding: "We think that other people look down on us or we should be like everyone else. We are not and we should embrace that."

Kyle also positions himself as a member of a particular group of dyslexics. He is not just dyslexic. He is gifted because of his dyslexia and that becomes a more desirable subject position to inhabit within his discursive environment. He supports this position by stating, "Dyslexics are generally more creative and more inventive than a lot of other people." More importantly, to what or whom can Kyle attribute his shift in understanding? There are two answers to this question in the text. His interactions with Nlin Loki provided an alternative model for understanding dyslexia. This encouter occurred only because of his involvement in social media. By citing the YouTube handle, Nlin Loki, instead of a given name, Kyle signals he is referring to someone he knows from the internet, not personally. The internet as constructed by Kyle is both a context and a resource.

A lot can be learned from Kyle's complex discourses of dyslexia, his involvement with others and his effort to shift the discussion from disability to difference. By moving away from the language of disability he reveals the desire to pass as able-bodied even though he has a diagnosis and a label. He complicates this further by claiming that he is so unique. Analyzing Kyle allowed me entre into the world of being dyslexic today in the United States. The question remained, however, would other dyslexic students see their conditions in the same way as Kyle? How would they relate to portrayals of dyslexia in documentary film? How do they see themselves connecting to others around dyslexia in educational environments? Why do they seek the labels of learning

difference rather than disability? These questions became the research questions guiding the next three chapters of this thesis.

#### **Research Questions**

The research questions for the next three studies discussed in this dissertation emerged from a complex and dynamic engagement with previous scholarship, a pilot study and my practice as both a former special education teacher and an advocate for disabled people. Each study relates to a broader goal that I have as both a qualitative researcher and as an advocate for people with disabilities: to understand how talk about disability in life often conflicts inherently with the privileged representation in media and in the theorizing of disability studies in educational environments.

Building on the research I conducted in the pilot investigation described above, I pose a series of questions. In Table 1, I present the questions together with the type of data collected and methods used to address each one:

**Table 1:** Alignment between research questions, data and methods used

December assession	Data	Methods Used
Research question	Data	Methods Used
Article 1: How are the	Student interviews,	Foucauldian
discourses of the dyslexia	and The Big Picture	Discourse Analysis
constructed in educational	(Redford, 2012)	(Willig, 2010)
	(Redioid, 2012)	(Willig, 2010)
documentary film? How do		
	Student interviews	
metaphors of dyslexia exist?		(Kovecses, 2010)
Article 3: How has	Student interviews	Positioning Theory
educational language of		
		,
students take up or subvert these new discourses? Article 2: What conceptual metaphors of dyslexia exist?	Student interviews  Student interviews	Conceptual metaphor (Kövecses, 2010)  Positioning Theory (Harré & Slocum, 2003)

used by dyslexic students to pass as able-bodied?

These three questions also mirror the three levels of Haste's model of culture: individual in the case of conceptual metaphor, interpersonal in the case of studying passing, and cultural in the case of understanding discourses of the brain in educational documentary. As described earlier, Haste's model of culture is constantly interacting across all three dimensions and these research questions interact with each other to produce a broader conceptualization of the discursive world of the dyslexic student and ultimately the role of cultural understandings of dyslexia in shaping the educational system.

# **Study Design**

# **Access and Sample Selection**

For the last six years, I have been in a research partnership with the Holyoke School. In that time I have conducted case studies and interviews of faculty, staff and students in order to help the school get more information about their programming and organizational structure. I assessed their alumni services so that they can evaluate their own claims about college attendance and success. I agreed to complete this work in order to gain access to their students and to develop trust.

Holyoke is a unique school because of its mission to serve dyslexic students and other reading related disabilities. Founded in 1971, the school has historically been a place for students who were not successful in their local school environments. The staff at Holyoke takes being dyslexic for granted because all the students are learning disabled, and individualize their teaching

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<sup>&</sup>lt;sup>1</sup> This is a pseudonym.

styles to teach skills and strategies that promote access to high level content. This produces an environment that is student-centered, responsive to students' emotional needs, and often empowering.

Since I am looking at the ways in which young dyslexic people construct dyslexic identities in talk this is an optimum location to access my participants. In particular, because a number of Holyoke students participate in advocacy work with local schools and colleges, many of the students address their identities as learning disabled or dyslexic already. They speak to teachers about their struggles and misunderstandings. They describe the ways in which note-taking strategies have come to help. I came as a researcher but also as an advocate interested in sharing their stories and perspectives with the broader research community. This research was seen as part of their work as advocates.

# Site, Sample and Ethical Considerations

310 students attend the Holyoke high school and 162 of those students live on campus. Sixty percent of the students are publicly funded and 40% of the students pay tuition to attend. Class sizes range from 4-8 students and the teacher to student ratio is one teacher for every 3 students. Ninety-six percent of Holyoke students attend college. Since not all of the students have dyslexia at Holyoke, I selected my sample from student volunteers with the aid of case managers who know the students' learning profile. I did not directly review any of the students' case histories. All students' names and the school itself were made anonymous after the completion of data collection. Students and the school have been assigned pseudonyms. The original student names have been discarded, removed from databases, transcripts and interviews. The IRB

approved this study (Appendix 1). I reviewed the interview protocols with staff, faculty, and administrators and advocates for people with disabilities to ensure that no student might be emotionally unsettled by the questions during the interviews (Appendix 2).

### **Interviews and Focus Groups**

I interviewed 26 students once and then assigned students to focus groups of 3-4 students. During the interview, students talked with me about their understanding of their dyslexia and their experiences, using a semi-structured format that allowed me to dynamically assess what the student considered salient in that moment (Appendix 2). Students also had an opportunity to ask questions. Typically focus groups are seen as possessing additional ecological validity within qualitative research traditions and were examined as a validity check (Willig, 2010).

In addition to collecting information from the students, I collected interviews with educators who work at the school to determine the degree to which the discourses analyzed are part of a way of talking in this particular context. Because the environment is secluded and many students live on campus with their teachers, examining their talk in relation to each other serves as a way of checking the validity of my findings. Data from the focus groups with students and interviews with teachers was not incorporated into the articles directly, but instead informed my approaches to the data.

## **Data Analytic Approach and Strategies**

As stated previously, the articles do not treat language at face value or at a literal level. Instead, all come from the epistemological stance of taking language

as constructed. Another unique element of this approach is how methods are blended across the studies to achieve maximize robustness. While eclectic approaches to qualitative analysis have been used in psychology, efforts to systematize how these blend and relate to various epistemologies have only recently materialized (Frost, 2011). Table 2 shows the range of methods and epistemologies used throughout the studies in this dissertation and the epistemologies and cautions associated with taking up each below.

Table 2: Alignment between research questions, methods and epistemologies

Table 2: Alignment between research questions, methods and epistemologies				
Research question	Methods	<b>Epistemolgies &amp; Cautions</b>		
Chapter 3: How is the discourse of the dyslexic student constructed through visualizations and language of brain differences in educational documentary film? How do students take up or subvert these new discourses?	Foucauldian Discourse Analysis (Willig, 2010)	E: Historical roots in Post- structuralism; practical guidance in constructivist approaches to talk and image  C: Exhibiting that a discourse exists culturally and is taken up by young people reveals the dynamic interplay between cultural and micro-level discourses. Efforts have to be made to ensure the idenfication of discourses both salient culturally and among young people to demonstrate continuity.		
Chapter 4: What range of conceptual metaphors exist among young dyslexic students?	Conceptual metaphor (Kövecses, 2010)	E: Constructivist approaches to metaphor (Lakoff & Johnson, 1980; Danforth, 2007)  C: Metaphors operate like Discourses when they communicate the assumptions an individual takes for granted culturally. Not all conceptual metaphors operate this way so not all can be used in the analysis of the assumptions. Overinterpretation here would ignore the broad sets of conceptual metaphors frequent in talk generally.		
Chapter 5: How has educational language of	Positioning Theory	E: An interpolation of Yoshino's theory of Covering (2006) and		

learning difference been	(Harré &	Sieber's theories of disability as
used by dyslexic	Slocum, 2003)	masquerade (2008)
students to cover their		_
disability?		C: Covering disability may indeed
•		just be a means of protecting one's
		social and economic futures. The cost
		of that protection, however, is that
		others who identify with the label or
		who are labeled as disabled can be
		silenced or excluded.

Overall post-structuralist approaches to language and social understandings of identity in talk are adopted. It cannot be assumed that because young dyslexic people take up any of this language that it somehow reveals deep internal states. Instead all of this work aims to explore what it means culturally that young people make these choices around language and dyslexia.

## **Limitations and Threats to Validity**

Site and Sample

The site selected for qualitative study poses both unique opportunities and challenges. The sample is relatively well defined because all of the students who are selected to attend this school have some kind of language-based learning disability as a primary diagnosis and many have a diagnosis of dyslexia. The school has a culture that encourages and models success for these students academically and emotionally.

This provides a unique challenge, however, because I expect that these students will have already had extensive experiences and coaching describing dyslexia. Many of these descriptions may come from teachers, case managers, counselors and administrators within the school itself so I conducted interviews with them to discover the possible sources for descriptions. I also realized during these interviews that students were watching educational documentaries such as

The Big Picture (Redford, 2012). They were also receiving specific coaching from the advocacy program to avoid the term disability and say difference instead. Because I knew this before I conducted the student interviews, I was able to ask clarifying questions about what the students themselves actually thought.

Many of the students were wealthy and almost all were white. This limited my ability to understand the complex relationships between race and learning disability that remain paramount among the concerns of the field. The students interviewed did accurately represent the diversity of the school itself since most of the school population was white and relatively wealthy.

# Method of Analysis

I have chosen to use discourse analytic approaches because it situates analysis between talk and culture and deconstructs how ideas are adopted, shared and blended. Instead, the purpose of the research as a whole is to generate and complicate the modeling of the relationship between the individual, groups and society. I intend to lay bare the theoretical assumptions that undergird much of practice and theory for dyslexic people while criticizing critical approaches to disability studies in education.

Specific concepts do present certain challenges. Agency in the discursive world may only have tenuous connections to agency as constructed through other means (Willig, 2010). Instead research relying on constructivist epistemologies tells us more about language in use and the meanings inherent in that language rather than the participant's real agency per se. This of course also depends on what the researcher determines as warranting further analysis. Since I am not dyslexic myself, I sought to manage my subjectivity and to keep track of

my analysis through various types of memoing to combine codes and remain sensitive to what the data were saying (Charmaz, 2006; Luttrell, 2009). I take full responsibility for any lack of sensitivity in the treatment of this data or this topic.

# **Chapter 2: A Conversation with Educational Documentary Film: Theorizing Contemporary Dyslexic Subjectivity**

#### Introduction

Media, popular books and educational documentaries influence cultural perceptions of dyslexia and ultimately dyslexic students themselves. Sometimes new ideas about dyslexia filter through the teachers that share popular resources. Sometimes they come from motivated parents who want to know more about dyslexia. Sometimes they come from the students themselves who are curious as to why they are experiencing difficulty with reading. This study on dyslexic subjectivity aims to connect the discourses used in media to those adopted by students. What students adopt and what they leave behind is of utmost importance for developing inclusive approaches in schools.

Students at a private school for dyslexic students disclosed during interviews that they had recently seen *The Big Picture* (Redford, 2012) during class. I probed students to report what they took away from the film and what it meant for them as young dyslexic people. Of the twenty-six students interviewed, ten shared their perspectives on *The Big Picture* explicitly. More students employed language that resembled language from the film, but the limitations of the timing of the interviews could not document this as a shift in language usage. Instead I postulate that students used this language because it is culturally intelligible and represents a common ground in conversation (Clark & Brennan, 1991).

Our discussions about *The Big Picture* (Redford, 2012) prompted a series of questions: what is the use of a positive, visible portrayal of dyslexic people and

who is a part of it? How do experts communicate the possibilities of dyslexic subjectivity through documentary film and which aspects of that subjectivity do dyslexic people express? Finally how does the positive portrayal of dyslexia relate to disability?

Because I am interested in understanding the culture and language use surrounding these films and among the students who watched them, I chose to use Foucauldian discourse analysis (FDA) to analyze the films together with interviews. Since the films themselves did not present unedited responses from students, I felt it was most important to interview dyslexic students to gain insight into what it meant to be dyslexic in schools. This preserves a component of naturalistic inquiry rather than a strict media analysis.

To maintain focus on the cultural level, I consulted other recent documentaries on dyslexia including *Embracing Dyslexia* (Macias, 2013) and *Journey into Dyslexia* (Raymond, 2011) where salient comparisons and contrasts emerged. I also found myself tracing information about the expert testimonials through the popular press and media that discussed dyslexia.

## Features of Educational Documentary Film on Dyslexia

Documentary film has been used to train and teach special educators about learning disabilities like dyslexia. Richard LaVoie's *How Difficult Can This Be: The F.A.T. City Workshop* (1989) and *Beyond F.A.T. City* (2005) define this genre of film. The *F.A.T. City Workshop* (Lavoie, 1989) displays teachers going through simulations staged by a teacher trainer so that they can come to some awareness of what it is like to be disabled in classrooms. The latter employs lectures to update practitioners on relevant and important research on learning disabilities.

Common features of educational documentary as a genre include long often still takes, interviews, and use of still images, cartoons and expert voiceovers. All of the contemporary educational documentary films use these components to communicate what it means to have dyslexia and support dyslexic students today. Table 1 includes a brief summary of these recent films.

**Table 1:** A table summarizing the content of recent documentaries about dyslexia.

Documentary and Date of Release	Tone, Audience and Expert Testimony	Types of Stories Present
The Big Picture (Redford, 2012)	Tone: Acceptance, individualized, some celebration of claiming the identity  Audience: Interested and educated adults, Students themselves  Expert Testimonials: Sally and Bennett Shaywitz	Many stories. Animated sequences throughout. <b>Traits associated with Dyslexia:</b> Creativity, art, perseverance, athleticism, Entrepreneurship, People skills, Reading
Embracing Dyslexia (Macias, 2013)	Tone: Accepting and developing some identity and pride associated with the identity.  Audience: Parents, Educators,	people  Mostly people without dyslexia describing the experiences of dyslexic people. One animated sequence at the end.
	Policymakers  Expert Testimony: Maryanne Wolf, Ken Pugh	Traits associated with Dyslexia: Athleticism, Entrepreneurship, Risk Taking, People Skills, Out of the Box thinking, Creative Jobs, Perseverance, Art, Visual acuity, Ease with Math Concepts, "Heart for other struggling people"
Journey Into Dyslexia (Raymond, 2011)	Tone: Acceptance and developing a substantial identity and pride associated with the identity.  Audience: Parents, Educators, Students	Many stories. Mostly dyslexic people describing their experiences. Lots of student voices from K-16 environments. A few

**Expert Testimony:** Maryanne Wolf, David Connor

animated sequences at the beginning.

Traits associated with Dyslexia: Athleticism, Mechanical Skills, Entrepreneurship, Art, Perseverance

The Big Picture (Redford, 2012) updates previous educational documentaries by using shorter takes, interviews with both experts and dyslexic people, and elaborate cartoon sequences. This fits the trends in contemporary documentary film where aesthetic features of the genre are equally important as the content (Renov, 2004). The widespread availability of digital video editing software and the proliferation of visual autobiographies, confessionals, and testimonials on YouTube™ and Facebook™ prioritize the subjects and subjectivities previously hidden or unavailable through mass media channels (Renov, 2004). These shifts toward a more integrated approach to content and aesthetics in documentary film prioritize feeling, experience, and corporeality over intellectualized takes on the self. According to Renov (2004), this development owes allegiance to "a new politics of everyday life" characterized by internal struggles and cultural shifts made visible for the first time (p. 171).

# Summary of *The Big Picture*

The Big Picture (Redford, 2012) weaves stories of four dyslexic students, Sebastian, Dylan, Skye and Allison, and their parents with experts on dyslexia like Drs. Sally and Bennett Shaywitz and successful adult dyslexic people including entrepreneurs Richard Branson and Charles Schwab, a famous lawyer David Boies, and Gavin Newsom, mayor of San Francisco. The overarching

narrative of the film chronicles Dylan's process of gaining acceptance to his dream college through the support of researchers, parents and teachers. Side narratives of dyslexic people and experts enrich and complicate Dylan's story by recounting alternate experiences. The plural narrative communicates that dyslexia affects different races, ages, genders and cultural backgrounds and that dyslexia is a common experience among "1 in 5 people" (*The Big Picture*, 2012).

The film is also about the experts themselves. With frequent appearances and voiceovers, the stories of the dyslexic students do not speak for themselves, but require the interpolation of information from experts to be presented as educational. Drs. Shaywitz become helpful characters there to diagnose, correct common myths about dyslexia and to support students through important life transitions: such as Dylan's transition to college.

The Big Picture (Redford, 2012) has been promoted by Home Box Office (HBO) and screened at Sundance film festivals. It comes with the significant backing of the Yale Center for Dyslexia and Creativity and the international networks of the founders Drs. Sally and Bennett Shaywitz. It is currently available on common movie streaming services and has nearly 22,000 likes on Facebook. The film's on-going promotion is loosely connected with Decoding Dyslexia, "a parent-led grassroots movement across the country concerned with the limited access to educational interventions for dyslexia within the public educational system" (2015).

## **Discursive Construction: Dyslexia**

As I watched and rewatched the *The Big Picture* (2013), I quickly realized the film was not just about promoting awareness of dyslexia. I approached the

film and popular literature critically through FDA by asking the questions: what is being constructed and what is being contested? The film is part of a movement to recast associations with the diagnosis of dyslexia. It is part of an effort culturally to redefine dyslexia and change how educational systems manage students with dyslexia.

The origins of this cultural shift are not completely clear. The popular press and educational documentary film offer some clues. Popular author and special educator Mary MacCraken introduced the idea of overcoming dyslexia through her novel about her teaching practice, *Turnabout Children* (1986). This was followed by a slew of other books about dyslexia including self-help titles like Ronald Davis and Eldon Braun's *The Gift of Dyslexia* (1994), Sally Shaywitz's smart and accessible *Overcoming Dyslexia* (2005), and Brock and Fernette Eide's *The Dyslexic Advantage* (2011). During the same twenty-five year period, thousands of teachers and students have been exposed to educational documentary films like Richard LaVoie's *How Difficult Can This Be: The F.A.T. City Workshop* (1989) and *Beyond F.A.T. City* (2005), and more recently films such as *The Big Picture* (Redford, 2012), *Embracing Dyslexia* (Macias, 2013) and *Journey Into Dyslexia* (Raymond, 2011) have been featured on cable television and in school auditoriums.

For example, Blake Charlton, a young adult novelist, wrote in *The New York Times* on May 22, 2013, "Though slow out of the gate — I couldn't read fluently until 13 — I went to Yale, then medical school at Stanford, and I published two fantasy novels with disabled heroes ... At every step, I used my diagnosis to my advantage, arguing that I had succeeded despite being dyslexic. It helped me stand out." This fairly typical trope of succeeding despite having a

learning disability comes up against what Charlton (2013) deems new: "Now a growing body of research suggests that I was unintentionally lying." He argues within the rest of the op-ed that his being dyslexic entails an inherent capacity for creativity – beyond the average non-dyslexic. Inherent to Charlton's self-description is an instrumental approach to having a disability: using the disability to come out ahead. Charlton presents his case as if all disabled people are capable of using their disability to gain advantage, and that his race, class or educational history had nothing to do with his success.

The Big Picture (Redford, 2012) features at least four people coming out as dyslexic. Writers Philip Schultz, Gary Karton, and Dav Pilkey have all come out as dyslexic in the last ten years, joining the discussions about creativity and dyslexia. The list of actors with dyslexia grows and becomes more diverse from Jennifer Anniston to Whoopi Goldberg, from Tom Cruise to Henry Winkler. Joining the chorus of dyslexic people coming out have been politicians, famous lawyers, financiers, and leaders in the technology industry. Each has attributed their success and creativity to dyslexia.

## **Discourses: Dyslexia as Disability and Gift**

I interrogated the construction of dyslexia in *The Big Picture* (Redford, 2012) and discovered two overlapping discourses: dyslexia as disability and dyslexia as gift. Identifying discourses of dyslexia present in the film, it became clear that expert voiceover and animated sequences were the main genre features that clarified and redirected associations away from medicalized definitions of dyslexia. This meant the film sought to augment and at times supplant the idea that dyslexia is disabling. Both discourses of dyslexia employed brain imagery

and dyslexic students appealed to the brain to make sense of both their disability and their gifts.

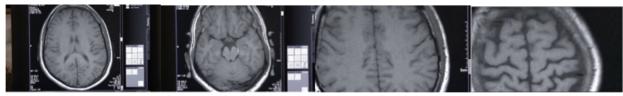
The first fifteen minutes of *The Big Picture* (Redford, 2012) uses voiceover and images of brain scans to validate the existence of dyslexia. Most of this voiceover is from Dr. Sally Shaywitz. In the context of both popular literature and documentary film, the recent focus on dyslexia must be credited to Dr. Sally Shaywitz. Regularly featured at professional conferences and now among the most outspoken advocates for dyslexic people, Shaywitz has motivated educators, diagnosticians, parents and children to focus on the capacities children with dyslexia have rather than merely emphasizing their deficits in reading. Important to Shaywitz's research has been the use of functional magnetic resonance imaging (fMRI) to reveal differences in brain activity between dyslexic and non-dyslexic peers while performing phonological processing tasks (Shaywitz, 2003).

The first images of brains start to define the discourses. This requires the repetition of brain imagery across the five-minute span while Drs. Sally and Bennett Shaywitz are talking. In the sequence, two types of brain imagery are used to explain and validate dyslexia as a diagnosis. First the images of the brain scans themselves are routinely seen in the background while experts are talking to reveal the newfound evidence for their assertions. Featured behind and mounted on the wall, they become markers of professional status, almost like medical degrees [Fig.1]. Further, the audience, seeing the doctors at work with young patients, knows that they are not detached experts but involved, caring practitioners.



Figure 3: Neurologist Dr. Bennett Shaywitz and Developmental Pediatrician, Dr. Sally Shaywitz in *The Big Picture* (Redford, 2012)

Since fMRI and PET scans are snapshots of brain activity, the filmmakers animated them to add visual interest. First, cross-sections of brain activity are shown in quick succession while a zoom moves from the base to the top of the brain itself. Bennett Shaywitz narrates, "We have made a great advance. We have made a hidden disability visible" (*The Big Picture*, 2012) [Fig. 2]. Not unlike Dumit's (2004) argument that PET scans, for some people, have validated the existence of schizophrenia, *The Big Picture* (Redford, 2012) employs brain scans as self-explanatory evidence – a sharp contrast with the very real and technical ways neurologists are taught to examine and read these images.



**Figure 4: Pulsing Brain Scan Cross Sections** 

The animation of the scans, rather than just providing visual interest, situates and localizes dyslexia and in a way, stands in for the person with dyslexia. Animated images of brains allow young people in the film and the audience of the film to see brain activity in dyslexic people, directly confronting the idea that dyslexic brains are idle. Instead of delving into scientific discussion of specific brain activities, here the brain imagery establishes credibility of the diagnosis,

reinforces the idea that dyslexia is a disability, and the experts themselves while explaining breakdowns in phonological processing through animation.

The representations of the scans animated representations of the brain while children are reading demonstrate breakdowns in phonological processing. Letters move through the brain on a conveyor belt and sometimes crash into each other. The inference to be drawn is that the dyslexic child, then, has a brain that does not process letters accurately; however, the voiceover continues to locate the problem in phonological processing. The letters crashing into each other highlight another aspect of the emerging discourse of dyslexia as disability: the inherent inability of dyslexic people to complete a routine task like reading. This is represented in an assembly-line motif that inherently values the individual brain as a processing center or factory that needs to be efficient to be effective.

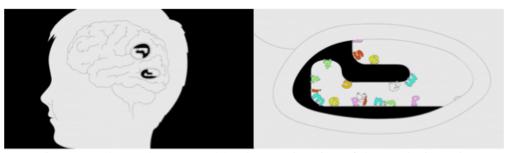


Figure 5: "The Broken Assembly Line" Animation of the Dyslexic Brain

Interesting contrasts emerge when comparing the medicalized language and images in *The Big Picture* (Redford, 2012) with other sources, however. In the documentary, *Embracing Dyslexia* (Macias, 2013), researcher Maryanne Wolf takes a more celebratory tone on the dyslexic brain:

"The first thing I want the world to know [about dyslexia] is that it exists. It is a different kind of brain that is a wonderful brain – a brain that has been here long before reading occurs. So the absolute first thing is that a reconceptualization of dyslexia for everyone...This is probably one of the

most interesting brains as a species. We cannot have it lost in its contribution to society."

Wolf and Shaywitz agree about the association between dyslexia and creativity as a gift. The documentaries themselves present a clear set of associations with the dyslexic brain. The animated brain images show a broken brain and Wolf's language shows a different and wonderful – potentially gifted – brain. These associations with the brain exist in tandem.

When young dyslexic people take up the language, *The Big Picture (Redford, 2012)* illustrates the dualistic nature of disability and the giftedness. One of the students I interviewed, Darryl explained, "Well, I mean, our brain is just wired differently so we get to see – we see differently basically. We might see words backwards if it's severe cases, dyslexia, or we might see – we might stumble on our words. But that doesn't matter, we still see the big picture, we're more creative." Here sight, in his incorrect recasting of dyslexia as a visual impairment, is both a weakness and strength – a disability and a gift.

# **Action Orientation: Having vs. Being Dyslexic**

One of the clearest differences in the action orientations within the two discourses of the dyslexic brain is the association with claiming dyslexia. If dyslexia is a disability then it is perhaps not useful to claim socially or publicly in ableist educational environments. If dyslexia is a gift then it is acceptable to claim and potentially differentiates someone from his or her peers in spaces that value achievement. The action orientations within these two discourses are different precisely because the individuals operating inside them have different agency. Therefore *having* dyslexia becomes a way of differentiating oneself from *being* dyslexic. If you have dyslexia

Young dyslexic people discuss the brain metonymically while also indirectly discussing themselves. In interviews with 26 dyslexic people who had all recently seen the movie *The Big Picture (Redford, 2012)* and discussed the film with dyslexic peers, the discursive use of the brain as a way of describing the self and distancing the self from dyslexia emerges. Fifteen of the dyslexic people mentioned the brain in describing their dyslexia during the interviews. The most popular claim was having a "different brain," often elaborated with electrical metaphors: "My brain is wired differently" or linguistic ones, "a learning disabled brain is just kind of like jumbled." Here the speakers isolate the brain as the source of the difference and the potential source of problems. It then allows them to distance themselves from simply being seen as broken. It becomes a part of the body that has a medical problem and part of the discourse of disability.

Another student interviewed, George gives a strong explanation of how the wiring metaphor can blend brokenness and giftedness: "It's just my brain and my mouth aren't really linked ... Dyslexics use their whole brain to read so like we see a word and it goes throughout our whole brain and we say it whereas in a normal human they have that language spot...It's this little spot so it goes directly there and then directly to the mouth whereas [among] dyslexic people it goes all around the brain. Essentially dyslexic people have a stronger brain.

That's why dyslexic people are 20% smarter than others." Kovac's language choices move him quickly from having dyslexia to speaking for dyslexic people. Employing an authoritative tone throughout he gets most specific with the citation of the percentage when referencing intelligence.

A more complicated vision that shows the duality of having vs. being is described by Samantha in her interview with me: "In my brain, I'm seeing every

single thing differently... I see differently than what you see... So we are all seeing something different. It doesn't really mean I'm different from you." Samantha's vision of difference normalizes it. If everyone is different, then having dyslexia is normal. While Samantha comes to a logical conclusion reconciling dyslexia and normalcy, dyslexic people portrayed in *The Big Picture* (Redford, 2012) struggle with being seen as both dyslexic and normal.

Dylan, for all intents and purposes, is the protagonist of the documentary. Dylan is a college-bound senior with low grades, lower than expected SAT scores, and a desire to attend an elite liberal arts college. Dylan's mother, Kyle, expresses concern by wondering if the college admissions process was "going to confirm his worst fears about his academic future." Dylan wants to go to Middlebury, a private liberal arts college, is waitlisted, and then is described by Middlebury officials over the phone, as "having had too much support" because of which, "he would not be able to survive on his own." He then describes himself as working really hard to achieve good grades so that he could be in a position to go to college. He describes himself early on as "mostly wanting to be normal."

Dylan's story of struggle, support and ultimate success when he is admitted to Middlebury is completely colored by his negotiation of his normalcy and his ability to dynamically employ his identity as dyslexic to get support and see himself as gifted; but this story is used against him when officials see him as too disabled to survive without so much support in an elite private liberal arts school. When administrators discuss his differences openly and express concern about the supports he receives, he worries that he no longer is being treated

fairly in the admissions process partly because his disability appears to be a factor.

A college student older than Dylan, Allison, describes the difficulty in explaining the accommodations that she receives in school to her father: "My father who I love dearly, never really understood why I got extra time. It was some sort of marker that I had some issue that differentiated me from the other kids. Why would he want his daughter to be lumped with the special kids with the extra time? And I think that was kind of difficult." The fear of being "lumped in with the special kids" shows how dyslexic people negotiate normalcy to avoid the stigma of disability and cognitive impairment most explicitly.

# **Positioning and Practice: Framing Heterogeneity and Dividing Subjects**

The positionings and practice contained in the new discourses of "dyslexic brain is gifted" are revealed in the genre features of the documentary film. *The Big Picture* (Redford, 2012) ends with a three or four-framed montage of dyslexic people claiming their dyslexia. A long-assumed goal of disability activists, the sheer repetition of the dyslexic claims as identity reveals a cultural shift. In the first frame of the credits, Charles Schwab claims his relationship to dyslexia: "I'm Chuck Schwab and I am . . . a person who suffers from dyslexia." Immediately following Schwab's claim the frame splits into two showing David Boies stating "I'm David Boies and I am dyslexic," while Boies in the second frame receives an object from a person off screen in a public venue. This two-framed aesthetic, with one frame claiming dyslexia and the second frame showing activity progresses in a similar fashion when the third frame at the right in Figure 5 has Gavin

Newsom declaring, "I'm Gavin Newsom and I am dyslexic" and the left portion of his frame portrays him responding to reporters.



Figure 5: Film stills from the credits of *The Big Picture (Redford, 2012)* showing from left to right, Charles Schwab, David Boies and Gavin Newsom.

The aesthetics and content feel considered and important. Since there is no one route to explaining the emergence of dyslexia there is not one way of being dyslexic. *The Big Picture* (Redford, 2012) addresses heterogeneity by ensuring that every dyslexic person who participated in the documentary claimed his or her dyslexia. The framing first communicates both the heterogeneity in dyslexic experience and the strengths associated with being dyslexic. David Boies and Gavin Newsom are both dyslexic and successful public speakers and the framing shows that division. After Gavin Newsom's claim, a third frame enters the screen and Allison Schwartz is shown walking down the steps of a library, sitting and studying and claiming her dyslexia with "I'm Allison Schwartz and I am dyslexic." Here again the framing shows Allison studying and walking around her college campus, visually addressing the misconception that dyslexic students take their work less seriously or that they are not capable of attending college.



Figure 6: Film still showing Allison Schwartz from the credits of *The Big Picture* (Redford, 2012).

After Schwartz a shift occurs, however. Skye Lucas states "I am who I am" while one frame shows her talking to friends and the other displays her dancing. Skye disclaims her dyslexia. While not exactly resignation, "I am what I am," indirectly references difference while showing acceptance of that difference. When considered alongside her struggles with learning to read, her father's stating that dyslexia is not a disability but a difference, Skye's statement reveals a desire for acceptance of her dyslexia without having to disclose it: it both obscures her diagnosis and without the context of the film, reveals a generic difference. This happens two more times when the phrase "And I have dyslexia" occurs. The having of dyslexia instead of the being dyslexic distances the individual from dyslexic identity. Having versus being allows the speaker to be affected by dyslexia without taking on the identity separating the impairment from the individual.

As *The Big Picture* (Redford, 2012) ends, the frames continue to display a range of other dyslexic people in a cross-cultural, multitalented montage. Reviewing the full range of fifteen dyslexic people shown, only three avoid claiming dyslexia directly, thirteen are white, only five are male, and eight are college-age or older – distinctly a whiter, more adult and more female dyslexic grouping than might have been expected. Dyslexia is known to affect males more commonly than females and may affect different regions of female brains (Evans, Flowers, Napoliello, & Eden, 2013). The majority of individuals shown in the frames without audio display artistic (i.e. photography, crafting), musical (i.e. playing guitar, singing, dancing) or sports-related (i.e. soccer, baseball) activities. The emphasis is placed by the filmmakers and the dyslexic people themselves on elective, extracurricular, or out-of-school pursuits. Only two of the fifteen

individuals featured are studying, reading or working on homework. It is perhaps more interesting to capture the activity associated with sports, arts, or music, but it may be less fictive to display more students working on homework, studying or even reading, considering the argument that dyslexic students spend more time working than their peers. Other films like *Embracing Dyslexia* (Macias, 2013) and *A Journey to Dyslexia* (Raymond, 2011) similarly represent dyslexia as a whiter and more middle-class phenomenon than may be the case despite obvious efforts in the film toward inclusivity. This overrepresentation of white and middle-class subjects reflects how diagnosing dyslexia is complicated, cost-prohibitive and typically outside of the capacity of public schools.

# Subjectivity: Interviews vs. Documentary Films

Disparities emerged across interviews and documentary films in both practice and action orientation. This necessitates a different subjectivity across the data sources. In interviews Dyslexic people lay claim to being part of the normal range of human capacity. They do this by disputing previous notions of dyslexia as stupidity. But precisely because those associations still exist, they navigate the disability discourse either by describing themselves as having dyslexia or by defining being dyslexic as being normal and learning disabled. They also acknowledge the range of differences across dyslexic people, but the range considered is bounded by a middle-class, college-bound white sensibility. There are emotional complexities associated with the stigma of being labeled and the desire to distance oneself from the label, while needing it as a way to accept their differences. Once accepted, the label then needs to be hidden. Stewart

Hudson, an expert who testifies in *Embracing Dyslexia* (Macias, 2013), highlights this dynamic:

"Labeling is not always bad nor is it always good. And it can be disabling if what you are saying to child is dyslexia is a litany of deficiency, a list of things you ain't good at. It doesn't have to be that way. But we have a duty, we as adults have a duty to change perceptions so that people understand the talents that go along with dyslexia."

In this claim that they have dyslexia, a new opportunity emerges and different subjectivities are closed off. Claiming dyslexia is a political statement that demands notice, highlights struggle, rewards perseverance and aspires to get dyslexic people to see themselves as complex and as possessing strengths and weaknesses. This also allows dyslexic people to claim a desire to be normal and a pride in being different; a frustration with their struggle and a pride in creativity and being different; and needing academic accommodations and an unimpaired vision of what they can do on their own. The new dyslexic subjectivity in these documentaries and among the young people interviewed is distinct from previous generations of dyslexic people who have not received as much understanding or support.

# Dyslexia as Disability

- •Action Orientation: Subject is acted upon
- •Positionings: Patient, Bad Student
- Practice: Little to no movement between subject positions
- •Subjectivities: Validated, Having Dyslexia, Discriminated against

# Dyslexia as Gift

- •Action Orientation: Subject is active, empowered
- Positionings: Advocate, Good Student, Doctor, Artist, Lawyer, Entrepreneur
- •Practice: Movement between positions common
- •Subjectivities: Exceptional, Talented, Claiming Dyslexia, Group membership

Figure 7: Diagram summarizing the stages of FDA (Willig, 2010)

Unfortunately the examples given in the films so far have been too few and too homogeneous to make conclusions about how these new discourses of dyslexia as gift affect poor people or people of color.

# Criticizing the Discourse of Dyslexia as Gift

The argument that disabled people are exceptional and have special gifts is not a new one. Disability-studies scholars see correlations between abilities as ways of excluding people. Some dyslexic people may be expected to possess unique talents or skills, but what if someone has a disability, but none of the purported benefits? Are they less dyslexic, or less disabled? Instead the field of disability studies typically emphasizes the importance of recognizing differences while emphasizing solidarity. Able-bodied people pointing to unique gifts some dyslexic people may have presents them as heroic and better than other disabled people. Dyslexia's association with gifts aligns well with the overcoming narrative where the disabled person has overcome their disability while others

still "struggle" with theirs. Both associations with gifts and overcoming narratives serve to separate the heroic disabled individual from their peers.

Shaywitz also argues that perseverance is an important gift among adult dyslexic people: "Adult dyslexics are tough: having struggled, they are used to adversity; hard work and perseverance now come naturally. Having experienced failure, they are fearless, undaunted" (p. 366). These statements are rhetorically alluring because they relate hard work to success and previous failure to perseverance and may be true for many of her readers. What this positive message fails to acknowledge, however, is the persisting truth for many dyslexic people and people with learning disabilities that they are not receiving the supports they need in schools and that they may be working very hard to get those supports.

# **Opportunities Opened by the Shift in Discourse**

Historically, researchers within psychology, medicine and education have fallen into a deficit-based perspective when researching dyslexia, by simply targeting gaps in phonological awareness, reading fluency or comprehension; risks for depression (Alexander-Passe, 2006; Huntington & Bender, 2001), suicide (Huntington & Bender, 2001), learned helplessness (Borkowski, Weyhing & Carr, 1988) or low academic self-concept (Burden, 2005; Elbaum & Vaughn, 2003) and associated conditions like auditory processing difficulties (Veuillet, Bouihol, & Hung, 2011), attention deficit hyperactivity disorder (ADHD) (Germanò, Gagliano, & Curatolo, 2010) and dysgraphia (Behrman, 1987; Weekes & Coltheart, 1996). Interventions operating solely on these criteria

Teachers are responsible for implementing interventions for dyslexic students. Unfortunately, despite the relative awareness of dyslexia increasing, teachers still feel underprepared to teach dyslexic students. These teacher self-efficacy beliefs have shown to impact student's self-efficacy and the ability of teachers to conceive of dyslexia as anything other than a deficit (Gwernan-Jones & Burden, 2009). Researchers have both focused on training teachers to meet the diverse literacy needs of students (Darling-Hammond & Berry, 2006; Fuchs & Fuchs, 2006) and have assessed what pre-service teachers actually know about dyslexia (Washburn, Binks-Cantrell & Joshi, 2014).

In a brief survey of pre-service teachers in both the US and UK, Washburn, Binks-Cantrell and Joshi revealed a set of shared assumptions and misconceptions. The majority of teachers surveyed agreed correctly that dyslexia did not come from a lack of reading exposure at home. Many teachers also incorrectly thought that dyslexia was caused by letter reversals and difficulties with visual perception (Washburn, Binks-Cantrell & Joshi, 2014). These common misconceptions continue to persist and yet have so little to do with teacher practice. Few teachers outside of pre-kindergarten, kindergarten or at worst, first grade are actually involved in teaching letter shapes, and only appropriate therapists or doctors address visual acuity skills. Gwernan-Jones and Burden (2009) articulated this conundrum best when they emphasized how both teachers feel simultaneously interested in learning more about dyslexia, and relatively well prepared to meet the needs of their dyslexic students. By modeling attitudes like Gwernan-Jones and Burden, teacher's likely overestimation of their practice remains in stark relief against their dearth of knowledge.

Thinking of dyslexia through the lens of teacher knowledge applied in practice quickly reveals how easily teachers can become frustrated working with this population of students. Reports from students themselves suggest this as a norm. Dyslexic students are routinely thought of or treated as dumb or lazy by peers, parents and teachers – perhaps because contemporary classrooms employ the label of dyslexia to explain an otherwise normal child's struggle with learning to read (Riddick, 1995) or because teachers do not have access to information about dyslexia. Stupidity or laziness serves as observable explanation of reading struggles in the absence of a medical, psychological and neurobiological one (Gwernan-Jones & Burden, 2009). The continued lay belief in the dyslexic student as a "dummy" conflicts with the basic definition of dyslexia itself: that dyslexia is a reading problem in the face of a normal or high intelligent quotient.

Some work has started to address dyslexia from a critical socio-cultural perspective aiming to rectify the failure of medicalized approaches alone (i.e. Dale & Taylor, 2001; MacDonald, 2009; MacDonald, 2009b, Riddick, 2001). In an effort to contextualize the history of medicalization, *The Incomplete Child* (Danforth, 2009) shifts focus from the child to the system of research and researchers that have impacted how a learning-disabled child learns in schools. For example, shortly after describing the utility of the label of learning disability for helping a practitioner aid a struggling ten-year-old reader, he stresses how critics of the label describe schools:

Over the last three decades, the American public schools have misused the category of learning disability as a jargon-heavy, seemingly authoritative way of blaming individual students for the instructional and organizational shortcomings of the public schools. Rather than serving as a pathway to helpful treatment and support, the learning disability diagnosis has become a stigmatized ticket to an isolated classroom or school where the educational recipe consists of low academic expectations, an overrepresentation of students of color and those from low-income families, and decreased chances of high school graduation (15).

Danforth's argument is not so simplistic as to suggest that there is no role for medical, educational or psychological perspectives in helping dyslexic students or others with learning disabilities; instead, he criticizes how schools use and interpret that information. Danforth's history reveals how the label of learning disability has been applied disproportionately among low-income families and students of color. Some research supports this assertion for dyslexic students based on class (Vernon, 1999), racial (Hoyles & Hoyles, 2010), and first language differences (Hutchison, Whiteley, Smith & Connors, 2004).

Limited work has been done to examine how schools specifically conceive of dyslexia and services for dyslexic students. Some promising work from inclusive schools suggests that certain adaptive coping behaviors may predict long-term success: awareness of dyslexia, refusal to be defined by it, proactive orientation, goal setting, managing frustration, perseverance, knowledge of how to access appropriate help and flexibility in finding ways around obstacles" (Goldberg, Higgins, Raskind & Herman, 2003; Hellendoorn & Ruijssenaars, 2000; Madaus, Zhao, & Ruban, 2008; Nalvany, Carawan, & Rennick, 2011). Initial research aimed at teaching these coping strategies has produced small positive effects that maintain over a two-year interval (Firth, Frydenberg, Steeg & Bond, 2013).

#### **Conclusions**

The positive portrayal of dyslexia through personal testimony by experts, parents and dyslexic people obscures the complex social realities and barriers associated with getting a diagnosis, coping, identity development and advocacy. It may even provide an accessible and positive identity for young dyslexic people. The educational documentary films I reviewed all emphasized this shift, but never went so far as to suggest that dyslexic people should come together under the banner of disability. There are limits to what dyslexic people can accomplish through advocacy while relying on medicalized language, pity and identification with a limited diagnosis.

Describing dyslexia with clear class-based and racialized expectations and emphasizing strengths not all dyslexic people may have presents a positive, but opaque vision of dyslexia. This shift in discourse where perhaps only a select few benefit also argues for a professional and entrepreneurial career that not all dyslexic people may even participate in. At least it presents a positive association, but I ask, for whom? For how long?

Previous research on the life stories of adult dyslexic people by Michael McNulty (2003) suggests a mostly negative association with dyslexia over the life course. The young people's stories highlighted here suggest instead both a positive and negative association with dyslexia. I attribute this change in individual interpretations of the diagnosis of dyslexia

The film and the language of the students interviewed also relied on uncritical acceptance of a technocratic world. If one can be diagnosed as dyslexic using these fairly expensive and hard-to-access technologies, then one can also be successful. But too many students are diagnosed too late as dyslexic, agreement among practitioners on the value of the label is not universal, and

dyslexic students even under the best treatments are still lagging behind their normally achieving peers. These harsh realities come in direct conflict with the technocratic assumptions in educational rhetoric that students should be learning to be more competitive or entrepreneurial. These assumptions function to both empower and disempower dyslexic people.

Individual progress in reading and writing is still cherished and becomes a yardstick for the educational system's effectiveness. Educators and educational institutions by virtue of stressing a sense of "compulsive competitiveness" have created a culture of labels that reveals more about the nature of the educational culture and how we have come to assume it works than about the individuals themselves (McDermott & Varenne, 2009, p. 253). While educational documentaries may visualize difference, voice dyslexic identity and give positive associations where there previously were none, they also silence the complex stories of how dyslexia affects members of different racial and class categories differently. This discourse continues to perpetuate the myth that dyslexia only affects white middle-class people who are uniquely gifted and intelligent.

Future media and research should be careful about the reliance on negative associations with having impairment and equating having impairment with a disability. They give an opportunity to explain struggle and connections among dyslexic people, their families and in their schools. More discussion of how empowerment relates to diagnosis could disentangle the assumption that stigma does not exist and that knowing more about a struggle makes the struggle easier.

Future scholarship needs to take up the mantle of Beth Ferri and David Connor's (2006) critical analysis of the intersection between ableism and racism.

Research needs to explain how dangerous it can be to assume that all dyslexic people are white and middle-class and therefore share the same associations with discussions of exceptionality, empowerment and using disability to get ahead. This analysis is the start of an effort to document the shifts and expansion of discourses of exceptionality focused on benefitting white and middle class dyslexic students through media that is popular among teachers, schools and shown to students.

# **Chapter 3: Conceptual Metaphors of Dyslexia**

#### **Metaphor and Disability Studies**

Disability is not a metaphor. Disability has a very real material reality. Disability advocates, scholars, and activists have made that message clear for more than twenty years (Dahl, 1993; Gallagher, 2006; Johnson 2013; Shinn, 2014). Criticism emerged because the representation of disability in popular media and fiction was one-dimensional often serving as a trope. Some classic examples, borrowed from Barnes' (1992) exhaustive study, include the character of Tiny Tim in Charles Dickens' *A Christmas Carol* and Porgy in Gershwin's *Porgy and Bess*. According to Barnes (1992), both representations emphasize how disability is used narratively to elicit pity and sentimentality.

The problems with disability being used as a metaphor in cultural narratives have changed and made more frequent and frequently more nuanced. Now many characterizations include positive associations. Common treatments of dyslexia in contemporary television are much more complex. Rick Riordan's title character Percy Jackson in both the film *Percy Jackson and The Olympians: The Lightning Thief* (Columbus, 2010) and the young adult book by the same name discovers that his dyslexia slows his reading of English by causing letters to get jumbled and that his dyslexia also gives him a special knack for reading ancient Greek. Percy Jackson is a much more fully realized character with a disability. He is seen as possessing both challenges and gifts. The disability in this representation is seen as having mysterious, negative but sometimes-useful properties from birth.

Even if Percy Jackson's dyslexia use of letters being jumbled perpetuates myths associated with dyslexia, it is nevertheless more complex than the characterizations of simply pitiable characters. A less optimistic view of dyslexia is portrayed in the musical television series *Glee* (2009-2015). In seasons 4 and 5 (2012-2013), a recurring character Ryder Lynn (Blake Jenner) uncovers his dyslexia. Instead of his coming to terms with dyslexia being shown across episodes, it becomes a plot device for only two. His dyslexia is almost entirely inconsequential to his character and largely serves to explain away his struggles with academics in high school. No effort is made to connect his talents to his dyslexia.

Even the associations with disability in media have shifted since Barnes' criticism was levied. While no longer entirely negative, disability continues to be a metaphor for exclusion, isolation, suffering, malevolence or dependence. This representation of disability is not only ableist in its assumptions, but it also lacks imagination or insight into disability. It locates the disability inside the person and not in the societal structures that bar that individual from accessing the cultural world. In these ways the superficial use of disability in popular media perpetuates the divide between medicalized notions of the self and social model aspirations of disability rights advocates.

#### **Conceptual Metaphor**

Conceptual metaphor is different from cultural, media, and literary metaphor. In the field of cognitive linguistics, studies of conceptual metaphor and disability focus on analyzing how implicit understandings of disability influence how society and culture relates to the concept. Too few studies within

disability studies analyze conceptual metaphor to understand how disability is conceptualized.

Danforth (2007) urged the field of disability studies to take up conceptual metaphor as a way of understanding how schools and society could challenge binary modes of understanding children with disabilities: "normal vs. abnormal, healthy vs. sick, us vs. them." In his study of the conceptual framing of emotional behavioral disorder in American public education, Danforth reveals how unwanted conduct is constructed as emotional disturbance and how that framing relies on three conceptual metaphors: "mind as container" (ex. my mind can only hold so much), "emotion as diseases of the mind" (ex. she was sickened by love) and "emotion as psychic energy" (ex. he was driven by fear). Even the phrase, "acting out" commonly employed to describe unwanted behavior by young children relies on these metaphors and others such as "anger as heated fuel" (Gibbs, 1992, Danforth, 2007).

Danforth's article contributes to current approaches to conceptual metaphor by showing the dynamics of the metaphors used, their pervasiveness, and how they are mapped or blended. He also takes up the unusual, but recommended step of suggesting how new metaphors for understanding emotional and behavioral disturbance could be created to challenge the prevalence of "a small group of dominant, psychological metaphors" (Danforth, 2007, pg. 22). Robert Bogdan and Douglas Biklen (1982) initially advanced this methodological approach to confront pervasive and problematic conceptual metaphors. In that approach metaphors are not only the subject of the analysis but a potential product. Danforth (2007) furthers these by suggesting investment in theory development by labeled persons and their families, seeing "labeled"

individuals as living through particular social experiences within oppressed political positionings rather than a set of essential psychological characteristics," and emphasizing how solidarity can be used to challenge "division and hierarchy" (p. 23-24).

With this under consideration, I challenge how existing research on conceptual metaphors of dyslexia has narrowed the typology of possibilities to a mere dichotomy. I also demonstrate how young dyslexic people employ conceptual metaphors to resist solely negative categorization as part of an adaptive coping response to having dyslexia in schools.

#### **Proposing Dyslexia as Barrier**

Research on dyslexia has largely focused on familiar paradigms within educational science – treatment, intervention, and cures. Research suggests that genetic factors contribute to the development of dyslexia (Francks, MacPhie, Monaco, 2002) and dyslexia itself persists after intervention (Torgesen, 2007). Practitioners, psychologists, and researchers commonly think of dyslexia as a language-based learning disability, because young dyslexic people typically perform lower than peers in reading, writing, spelling, and sometimes mathematics. Research has also demonstrated the neurobiological roots of dyslexia by initially examining brain activity during phonological processing tasks using neuroimaging techniques, and then testing the effects of intervention on brain structures and functions. Despite the evidence that genetic factors contribute to the development of dyslexia, dyslexic students are too frequently misunderstood; consequently, they do not receive the instruction, accommodations, and assistive technology they may need to be successful.

In the social model of disability, disability is often seen as located in a barrier to access. For example, having a staircase instead of a ramp means that your building disables people with physical impairments. Disability is located outside of the individual and in the lack of access. This is a contrast with the medical model of disability where the individual is the source of disablement. Again, if someone with a physical impairment said moving around in a wheelchair is like trying to go up a staircase with a bicycle then a clear logical conceptual metaphor emerges: one where the impairment is a difficulty in an ableist world and a barrier to access. The barrier metaphor continues to pervade educational discourse.

Burden and Burdett (2007) categorized the cognitive metaphors used by young male dyslexic people into two groups: surmountable and insurmountable barriers. Burden and Burdett relate surmountable barriers to the individuals feeling as if they could overcome them (e.g. dyslexia is a lock and I have the keys; dyslexia is a maze but I can find my way through it). The insurmountable barriers were usually more negative (e.g. dyslexia makes me feel like my head has knife through it; dyslexia is like a big, illegible book with Satan next to it). Their study provided a useful dichotomy for understanding self-descriptions of dyslexia: one adaptive and the other troublesome. All of the metaphors identified and listed by Burden and Burdett do not match easily onto a "dyslexia as barrier" cognitive metaphor precisely. They may not employ the methodological precision with which a researcher must examine metaphor. Researchers should always make efforts to map conceptual metaphors onto externally validated categories contained in either previous research or the master metaphor list (Lakoff, Espenson & Schwartz, 1991).

In addition, Burden and Burdett characterize the barriers as expressions of individual problems like depression or learned helplessness instead of emerging from the educational environment. Below the entire list of primary data from the article is given to show original assignments.

Table 1: Metaphors of Dyslexia as a Barrier in Burden and Burdett (2007)

Table 1: Metaphors of Dyslexia as a Barrier in Burden and Burdett (2007)				
Type of	Definition	Examples		
Barrier		_		
Surmountable	Dyslexia is seen as a barrier that can be overcome	"A wall with paths going around it"  "It's like a lock and key. If you've got enough persistence you can sort of find that key to unlock that door. If you keep doing it, you keep unlocking all the doors, so eventually you get to the end passage. It's like a maze with doors that you've got to unlock, so you have to keep persisting."  "It's like a big blob of something sticky – it like sticks to you. You can't get rid of it really, but you can get rid of little bits."  "I think it is like an onion. It's got lots of different layers. One layer may be good and one layer may be like, half there, and one might not be. And say if you put a layer on, it would like, peel off, kind of thing. And you'd have to stitch it back on with like, PritStik, and, like, hold it there a while to make sure it stays."  "It's like when toddlers are crawling and they start to walk. Then they're slow on their feet but as they get older they learn how to run."  "Not being able to make a rugby tackle or something like that. When you miss a tackle, you feel disappointed in yourself. That's how I felt about spelling and that. When I can't get something into my head I feel disappointed. And then when somebody tells you it, you get it back."		
Insurmounta ble	Dyslexia is described as a barrier that cannot be overcome	"It's like a brick wall that just gets in the way all the time. It just stops you from getting what you want."  "It's like a maze with no entrance."  "It's like a bully pushing you around, not letting you do things like the little gremlins from the reading advert where they say 'Reading - you don't like that!"		

"A head with a knife through it, split on two sides with a knife going through the middle. There's another head with a head inside – the one on the inside sad and the one on the outside happy."

The problem is that many of the examples used by Burden and Burdett illustrate the use of multiple metaphors in the same quotation and do not fit the criterion of being a barrier. In the example of the onion in Table 1, dyslexia is not a barrier at all, but a constructed object because the layers come apart. This most closely aligns with "a problem is a constructed object" (Lakoff, Espenson & Schwartz, 1991). While that is only one example, a revised analysis may identify metaphors such as "dyslexia as container," "dyslexia as a journey," "dyslexia as an opportunity," "failure is death," or "success is life."

# Sample Description

Building on Burden and Burdett (2007), I asked twenty-six young people to provide personal descriptions of their dyslexia. I asked an analogic question embedded in a semi-structured, 30-minute interview: "Having dyslexia is like..." Only two students did not explicitly answer the question, describing it as too difficult to answer at the time. For the students who did answer the question, typically the metaphors emerged after a probing question of "why?" or "why do you think that?" from the interviewer. Important to the question's construction is that the students are describing what it is like to have dyslexia, not simply what dyslexia is.

All students attended a special private school in the northeastern United States for students with learning disabilities. All but three were aged 18 at the time of the interview. All but two of the younger students were involved in an

advocacy program where they shared their experiences with dyslexia with K-12 schools and university teacher training programs. Many of the students reported talking about language-based learning disabilities with each other and even joked about how it impacted their lives. The sample included an even mix of males and females, unlike Burden and Burdett's sampling of all male students. I have used pseudonyms for all of the participants to maintain their anonymity. Both Burden and Burdett's sample and the students in this sample attended private schools for students with dyslexia and not public schools.

#### Having Dyslexia is a Journey

Frequently, having dyslexia is considered as a hindrance or obstacle. Many of these constructions rely on the base conceptual metaphors of "life being a journey" and "forward motion is progress" whether or not the obstacles were described as being overcome. In this sample, all students who built on an obstacle metaphor described themselves as getting around, over, or carrying it with them. I am classifying the latter example of carrying dyslexia with them as an example of an implicit journey though it will be referenced as carrying a burden. Two students described having dyslexia as a journey directly; many more relied on implicit movement or journey metaphors to describe it. Katie said that having dyslexia is a "ride on a roller coaster. It has its ups and downs." First, the ride on the roller coaster is a simple journey metaphor. Katie's elaboration reveals two additional conceptual metaphors at the root of her evenhanded description of dyslexia: good times are up and bad times are lowering. Another student, Chuck, who described dyslexia as journey forayed into a poetic narrative:

"It's like an elephant running through a forest. [Why is having it like an elephant running through a forest?] Because the elephant is large and so is the forest, but the elephant is so large, that trees are that of toothpicks under the elephant's feet. And the elephant has no problem running through these obstacles, but the elephant passes the details, unlike other smaller animals, which would have to take their time and learn the details. The elephant can just trudge through it all and I would compare that to a dyslexic student because I would say that growing up with dyslexia, you do have the heart to carry on."

Kramer's vision of the elephant running through the forest at its root is still a journey metaphor. Instead of obstacles standing in the way or there being ups and downs, the elephant is oblivious to details that it is missing because it is so big and the details are so small. Here, having dyslexia is also related to the cognitive metaphors "not seeing something is not being aware of reality" and when he references the "heart to carry on" he borrows from the conceptual metaphor, "continuing to act despite difficulty is moving despite obstacles" (Lakoff, Espensen, Schwartz, 1991).

Katie and Chuck describe the experience of dyslexia as happening over time. This metaphor is the root of many of the additional metaphors – partially because of the prompt's focus on having dyslexia – but they remain important to the construction of the typology. It is also the root of the barrier metaphors proposed by Burden and Burdett (2007) because barriers are often presented as hindrances to forward motion.

Having dyslexia is a hindrance to forward motion

Many students employed conceptual metaphors that related having dyslexia to an obstacle or a hindrance to forward motion. This mirrors previous findings that disability is a barrier. Like previous studies on dyslexia as a barrier, these three examples show individuals overcoming dyslexia: Gabby described it

as a "barrier" which both "sets you back" and can be addressed by "using tools;" Marsha described it simply as an "obstacle course" which could be completed with "additional effort"; Samantha said, "It is like trying to get from point A to point B, but [you] have a lot of hurdles and speed bumps in the way, but you still get there." Every example above shows a slowing down on the journey because of having dyslexia, and in every case the student elaborated to insist that dyslexia did not foreclose the possibility of completing the journey.

# Having dyslexia is a burden

Unlike barrier metaphors, young dyslexic students also expressed some of their own conceptual metaphors that illustrated the burdensome nature of having a disability in a system designed for those who do not. Melissa shared a story: "It's like trying to swim in the winter in the freezing cold where you're like all right, I'm done but you have a destination to get to... Let's try to paddle our way through." Brooks' formulation sees dyslexia as a test of endurance, something to endure on a bigger journey with a goal at the end. Similarly, Steven argues that having dyslexia is "something that doesn't just go away, so you need to get along with it." Dyslexia, from his perspective, is a lifelong challenge. Lastly, Simon described having dyslexia as like having a plant "you have to water twice a day." He drew comparisons to most plants only needing water daily. So for Brett, having dyslexia is another responsibility or a more serious responsibility than others. Audrey characterizes having dyslexia as "an extra load. It is something that you have to carry with you all the time and you know you might be able to improve in it but you can't really get rid of it." In Audrey's account, it is clear that dyslexia is also a burden, but she uniquely mentions how it might

actually get easier to carry over time even if it doesn't ever go away. The emphasis on the persistence of dyslexia is important since research clarifies that dyslexia is a permanent condition.

# Having dyslexia is immobilizing

Darryl did not offer hope of continuing the journey in his metaphor: having dyslexia is like "being a rock in a river where everything is moving faster than you." The rock being immobile does not continue to move with the rest of the river. In this metaphor is also the recognition that the rest of the river moves without the rock and therefore a comparison is drawn between the rock and the rest of the river. This is also a metaphor of exclusion. Marcus used the metaphor of "being stuck on a plane on the runway." He added immediacy to the metaphor by mentioning "and "not being allowed to get up to go to the bathroom." Marcus' metaphor, like Darryl's, represents an inability to act even if a pressing need exists. Both metaphors also imply an inability to move in spaces where moving may be preferable to staying still.

#### Having Dyslexia is a Problem or Confusing

Having Dyslexia is a Problem

Four students used conceptual metaphors that indicated having dyslexia is a problem. Charisse starts out by equating having dyslexia with a "challenge." The metaphor underlying this is that dyslexia is a problem. When she elaborates why dyslexia is a problem she describes it as a constructed object: "like I'll break it down." Similarly Ariel described having dyslexia as a problem with a solution in itself: "It's kind of like needing to find like a piece of a puzzle, like everything is there, you just don't understand it. I guess it's like putting together a puzzle

because everything is there. You just need to find the right way to put it together." Both Charisse and Ariel describe dyslexia as a problem, and both extend the metaphor to emphasize some power over the problem: either by deconstructing it or by finding a solution in the problem itself.

Mimi similarly identified dyslexia as a problem with a solution though unspecified: "It's kind of like being pushed into a pool without knowing how to swim. I mean not like having to drown." Mimi mentioned a few more times in the subsequent explanation that she wanted to point out that having dyslexia was hard but not fatal and that others could not always tell when someone was drowning so it made sense to her to make the comparison. John also described having dyslexia as a problem: "It's like taking sound away from like a bat, because that's how bats see, and in the world we need to be able to read, but we can't do that, because it's different." Although, here having dyslexia makes a functional animal non-functional. John's metaphor of having a problem does not have a resolution. Instead it notes and marks the difference in reading. It is a clear representation of a deficit-model of disability.

# Having Dyslexia is Confusing

Conceptual metaphors of confusion also come up in three examples. In two of the examples, the metaphors refer to having dyslexia as overwhelming confusion. Naomi refers to having dyslexia as like "traveling to a foreign country... every single sign was in like six languages," imagining how she might feel in a situation unable to read the signs in a foreign place, lost and confused. Natalie describes a similar sense of overwhelming confusion coming from transition between places: dyslexia has "made me change schools multiple times."

Nic shares a similar metaphor that involves a potentially difficult or confusing search: "Trying to find the right shade of toasted bread." Nic then explains this: "I'd say that is the perfect shade of toast and you as a dyslexic need to find a way to get to that perfect shade or at least get there slowly." Naomi, Natalie and Nic all experience confusion related to movement between places and difficult, if not impossible, searches.

#### **Having Dyslexia is a Container**

Previously, Ariel described dyslexia as a problem and also found a solution to the problem inside the puzzle itself. In her example, the puzzle itself is a container that holds the solution. Container metaphors, while generally common among conceptual metaphors, occurred only twice in this sample. George described a complex container metaphor: "Dyslexia is like an onion because you have to peel each layer to get to the heart of it and to see what it actually is instead of like judging it by the outside." Dyslexia is both contained on the inside, is a constructed object and, indirectly it is suggested that external appearances are untrustworthy and inspecting an object is equivalent to disassembling it. All these metaphors interact in this one example that shows how conceptual metaphor can be multilayered. George makes a holistic argument about judging others while arguing for dyslexic people being more complex than other people.

#### Having Dyslexia is an Opportunity or Superpower

Having Dyslexia is an Opportunity

Ann said having dyslexia is like, "just because you don't succeed at something doesn't mean you can't try something else." Having dyslexia is

generally constructed as perseverance while also seeing each new encounter with failure as a new opportunity. Among the conceptual metaphors used in this sample, this set of metaphors communicating dyslexia as an opportunity, possession or superpower are generally positive and sometimes communicate connections to other dyslexic people along with feelings of different from the rest of society.

Having Dyslexia is a Superpower

Jonathan provided the most elaborate example of an empowering metaphor of dyslexia. First he describes having dyslexia as like having a different way of thinking. Then when he elaborates he tells a story:

"Well like, we don't like -- I know me, the only way I get something is if another dyslexic person explains it to me... I know personally for me I'm more creative. So the more creative way of remembering things is how I remember it and like me, there's some things that I just can't do because I think differently."

Because Jonathan has dyslexia, he also has the superpower of being able to remember things creatively and thinking differently. Like any good superhero in comic books, Jonathan as a dyslexic also has a weakness. His gift of different thinking is offset by his inability to remember normally. This same metaphor emerges from AJ's interview that describes drawing as another power associated with dyslexia.

This most elaborated superpower emerges in Charles' description of himself conversing with his brother who is also dyslexic:

Because kids with language based learning disabilities are more likely to be ridiculously abstract, like me and my younger brother Ben, who is very, very dyslexic, you know, can read but very dyslexic – we'll talk about the most insane things. It drives my mother up the wall, she doesn't like sitting with us when we're having dinner. We'll talk about the most abstract things.

Charles' abstract thinking and creativity allow him to bond with his younger brother while annoying his mother. He goes on to detail his fantasy battles, discussions about superheroes and immortality. The connections he feels with his brother extend beyond a typical sibling friendship, in part because of their shared dyslexia. Since the young men understand each other, they feel no need to explain themselves to their mother or tone down their abstract conversations for her benefit. They bond because of their superpowers, which are inherent to having dyslexia.

#### **Having Dyslexia is Existence**

One example within the sample reveals an abstract metaphor of having dyslexia. Joy explained that having dyslexia is "A day that you can expect to never be the same." When probed, she elaborated: "Because each day is mostly like different and having dyslexia it's not the same... but there's always a different way to do things in." Joy's description of the day assumes a progression through days and that days do not remain the same. Joy's conceptualization of dyslexia is based on existence and does not assign a value to dyslexia itself – merely that it is different to have dyslexia and that various dyslexic people have different experiences. At the root of this is an acceptance of dyslexia as a real aspect of life.

#### Having Dyslexia is Being Included and/or Excluded

When Jonathan explained his experiences with dyslexia he describes himself as "getting it" when another dyslexic explains a concept to him. While metaphorically referencing understanding, he is also appealing to the

experiences of being included as a dyslexic among other dyslexic people.

Thomas similarly finds comfort and camaraderie in his sharing of abstract thinking with his younger brother. But in his story he excludes his mother, showing his potential for participating in both in-group and out-group processes.

The metaphors of being excluded also reflect their experiences. Both John and Naomi mention feeling left out: John's bat is not like the other bats and Naomi can't understand the common language. Interestingly enough, these metaphors appear to be relatively common across the conceptual metaphors of dyslexia because it stands to reason that when a comparison is made about dyslexics it references typically achieving peers, much like how Darryl's rock does not move with the rest of the river.

# An Expanded Typology of Conceptual Metaphors of Dyslexia

Previous research described dyslexia overall as negative associations especially by students in schools (Burden and Burdett, 2007) and across the life course (McNulty, 2003). The data analyzed here point to another possibility: that dyslexia is still a hindrance, but is typically managed and may even be a benefit. This may be further evidence that students in this sample conceptualize dyslexia as still a challenge in schools, but a challenge some young dyslexic students are ready to meet. Because the sample in Burden and Burdett's study (2007) matches the sample used in this study (in that both populations from which the samples were drawn have experience in a supportive and segregated school environment), these trends could be indicative of the shift toward more positive associations with dyslexia in the last eight years.

Table 1 below summarizes the general findings of this study.

Table 1: An Expanded Typology of Conceptual Metaphors of Having Dyslexia (Total of 28 Metaphors)

Name of Metaphor	Subcategories	Examples
(Number of	(Number of	
Responses)	Responses)	
Having Dyslexia is a journey (10)	Hindrance to forward motion (3) Burden (3) Immobilizing (2)	"It is like trying to get from point A to point B, but [you] have a lot of hurdles and speed bumps in the way, but you still get there." "Something that doesn't just go away, so you need to get along with it." "Being a rock in a river where everything is moving faster than you."
Having Dyslexia is a problem or confusing (7)	Problem (4) Confusing (3)	"It's kind of like needing to find like a piece of a puzzle, like everything is there, you just don't understand it."  "It's like traveling to a foreign country every single sign was in like six languages."
Having Dyslexia is a container (2)		"Dyslexia is like an onion because you have to peel each layer to get to the heart of it and to see what it actually is instead of like judging it by the outside."
Having Dyslexia is an opportunity or superpower (3)	Opportunity (1) Superpower (2)	"Just because you don't succeed at something doesn't mean you can't try something else." "Because kids with language based learning disabilities are more likely to be ridiculously abstract"
Having Dyslexia is being included and/or excluded (5)	Included (2) Excluded (3)	"Because kids with language based learning disabilities are more likely to be ridiculously abstract, like me and my younger brother Ben" "It's like taking sound away from like a bat, because that's how bats see, and in the world we need to be able to read, but we can't do that, because it's different"
Having Dyslexia is		"A day that you can expect to
existence (1)		never be the same."

Table 1 shows the range of metaphors created by young dyslexic people when given the opportunity to reflect on and explain their lived experiences. While no generalizable meaning can be attributed to the counts of the conceptual metaphors, it can be seen easily how frequently dyslexic students describe having dyslexia using journey metaphors (particularly difficult journeys) and characterize dyslexia as a problem or confusing experience.

#### The Potential Associations with Conceptual Metaphors of Dyslexia

The range of metaphors used by young dyslexics in this sample is much larger than the simple categorization of dyslexia as a barrier by Burden and Burdett (2007). Their categorizations do not account for the variety of associations young dyslexics make with their impairment. For example, George likens having dyslexia to peeling an onion and discovering all the layers. For him, dyslexia is a constructed object, a container, and potentially multilayered with discovery of new dimensions over time. Conceptual metaphors such as his do not fit within the barrier metaphors but also do not fit easily into positive or negative associations since we do not implicitly understand if knowing more about dyslexia is good or not and there is no clear resolution to his inspections.

Barrier metaphors tend to rely on journey metaphors in this sample. After all if overcoming an obstacle is an important component of interacting with a barrier metaphor then metaphors of forward motion and journey are implied. Since so many dyslexic students described dyslexia as something that could be overcome, a connection must be made to how overcoming metaphors operate. At the surface level, they have been used to describe disabled people as heroic by considering them only in light of the inherent struggle related to their disability

instead of their abilities. Simi Linton (1998) describes the limits of overcoming metaphors used by the non-disabled to describe disabled people:

The popular phrase *overcoming a disability* is used most often to describe someone with a disability who seems competent and successful in some way, in a sentence something like 'She has overcome her disability and is a great success.' One interpretation of the phrase might be that the individual's disability no longer limits him or her, that sheer strength or willpower has brought the person to the point where the disability is no longer a hindrance. Another implication of the phrase may be that the person has risen above society's expectation for someone with those characteristics. Because it is physically impossible to *overcome* a disability, it seems that what is *overcome* is the social stigma of having a disability" (p. 18-19).

Linton's critique of *overcoming* metaphors insists on the disabled person approaching language through solidarity with other disabled people. Linton correctly asserts that disabilities cannot truly be overcome and this fits dyslexia, which persists despite remediation. If Linton's proposition is that social stigma is what is overcome is true, then it would be reasonable to assume that young people who use *overcoming* metaphors to describe their relationship with and understanding of dyslexia seek to abandon stigma.

This self-description relies on individualism trumping involvement in a social category and that goes against the aims of the social model of disability and the disabled people's movement generally (Linton, 1998). If someone is looking out for him or herself in a way that demeans others, then the group itself is not moving forward. Since connections to a disability identity cannot be assumed, even for those who have received a diagnosis of learning disability, and little to no effort is made within schools to promote some sense of identity, it comes as a surprise that young dyslexic people are finding community with each other in schools at all.

#### The Ongoing Cultural Work of Solidarity and Community

These students are an exceptional example of the phenomenon of conceptual metaphor use. Since almost all of these students engage in advocacy work in educational settings, they are already mobilized to think about the problems schools cause for dyslexic students. Many of their teachers have learning disabilities and share their stories with them. I hypothesize that it is likely because of these factors and not in spite of them that they articulate such robust examples of conceptual metaphor. Therefore the persistence and ubiquity of *overcoming* narratives in this sample is a direct expression of the continuing denial of dyslexic identity, the emergence of some empowerment and the estrangement of disability from dyslexia despite the apparent overlap in conceptualization, terminology and legally protected status.

This work takes as its premise that it is more important to represent young dyslexic people in the complex subject position of being disabled in an educational system privileging ableist ways of demonstrating knowledge. Young dyslexic people primarily employ conceptual metaphors that suggest overcoming as a way of life, management of dyslexia as a burden or as confusion, and only limited experiences feeling powerful and proud of their difference. The overlap between having dyslexia being a journey and life being a journey does not appear coincidental.

The use of inclusion metaphors at all suggests an answer to Danforth's (2007) desire to come up with new metaphors for solidarity. While stopping short of solidarity for all disabled people, the belongingness expressed here by dyslexic people among themselves encourages further study of dyslexic group

identity and conceptions of claiming dyslexia, difference or disability. Simple expressions such as "the only way I get something is if another dyslexic person explains it to me" indicate a desire to learn more from each other than is currently the norm in either inclusive or separate school settings.

Monitoring how individual linguistic choices represent cultural assumptions is an ongoing responsibility of disability studies in education. These choices become meaningful measures of how far we have come as a field of study. Students with learning disabilities may not be universally feeling how much effort is being expended to educate school systems about disability. Promoting inclusive education has left a large constituency of students with learning disabilities grappling with their relationship to impairment and to disability generally.

# **Chapter 4: Managing Labels of Disability and Difference**

Labels have enormous power in educational settings affecting not only the student and their sense of self, but the student's teachers, parents, peers and school administrators as well. When I started having conversations with dyslexic young people about their experiences in schools, it was common to hear them say that they learned differently, and that they were not learning disabled. This shift in labeling and identity is frequently documented on organizational websites dedicated to supporting dyslexic students and their parents.

The Learning Disabilities Association (LDA) of New York State, for example, articulates the relationship between claiming learning disability status and legal protection:

LDA agrees that individuals with learning disabilities do learn differently and have as much to offer and contribute as individuals without learning disabilities. However, in the United States today, there are several laws in place to preserve the rights of individuals with disabilities to equal treatment. For school-aged children, the Federal Individuals with Disabilities Education Act (IDEA) ensures that students ages 3-21 will receive a Free Appropriate Public Education (FAPE) in the Least Restrictive Environment (LRE). IDEA ensures that children with disabilities will have the same opportunities and access to public education as their peers without disabilities. Under IDEA, there are currently 13 different disability classifications. In order for students to be considered eligible to receive the supports and services provided under IDEA, they need to be "classified" under one of these 13 categories. One of these categories is Specific Learning Disability (SLD). Unfortunately under IDEA there is no classification of Learning Difference or Learning Challenge. The same principle holds true for adults with learning disabilities whose rights may be protected by the Americans with Disabilities Act (ADA)

Even the first sentence emphasizes how learning differently is part of being learning disabled. No one advocates that students who identify as learning differently do not need legal accommodations and modifications. Instead researchers and organizations argue that perhaps through the association with everyone learning differently, more people need than receive them. The Learning Disabilities Association of New York is right, however, to caution parents and students against changing terminology that may affect legal protection. Many other organizations come to different conclusions either adopting a range of terms or specifying the alternate.

Invoking the phrase learning difference, difficulty, or style allows for students within educational settings with a range of learning disabilities to claim able-bodied status – essentially to claim being normal or like everyone else. This claim for normalcy may mete out some of the associations the label learning disability has with other disabled students who may not have the same cognitive strengths or experienced the same developmental milestones. While a linguistic shift, the movement away from identifying with disability may be an effort to persuade important stakeholders to perceive dyslexic students as more similar to their non-dyslexic peers.

#### **Educational Discourses of Learning Differently**

Describing oneself as learning differently is not an entirely new phenomenon in schools. Disabled students rarely refer to themselves seriously as *exceptional* or *special*. Instead students employ the language of teacher practice and school organization and administration to pass as able-bodied. When young dyslexic people describe themselves as different not disabled, they join a well

established discourse of learning differences, learning styles and learning modalities within the field of education.

Much of this discourse became popular with the critiques of a monolithic intelligence quotient inherent in Howard Gardner's theory of multiple intelligences (1983) communicated to thousands of schools and millions of teachers an explanation for something they may have already seen – disparities in academic performance. Since then educators and researchers have sought to frame differences in academic achievement through the lens of learning differently.

Frames of Mind (Gardner, 1983) delineated multiple intelligences to deconstruct prevailing notions of a single unified intelligence. Gardner proposed linguistic, musical, logical-mathematical, spatial, bodily-kinesthetic, intrapersonal and interpersonal intelligences as seven domains. While never Gardner's intention and despite his extensive efforts to correct misunderstanding, teachers began using rudimentary interest inventories and surveys to label students as linguistic, musical, or bodily-kinesthetic learners. This watering down of the theory of multiple intelligences taught students to explain away their poor performance as a mismatch between intelligence and teaching strategy employed.

This misunderstanding was popularized by a range of educational innovators and researchers aiming to apply these methods with students, including Mel Levine in his *All Kinds of Minds* institute and in *A Mind at a Time* (2003) and *The Myth of Laziness* (2004). Multiple Intelligences thinking built the foundation for Carol Ann Tomlinson's *The Differentiated Classroom: Responding to the Needs of All Students* (1999). In the 1980's and 1990's, educational publishers

built entire businesses around supplementary educational materials enabling teachers to use more visual and kinesthetic activities to reach learners without a primary linguistic orientation. The popularity of these approaches ensures their inclusion in teacher preparation programs.

Gardner himself has tirelessly criticized educators and the press for misinterpreting the theory of multiple intelligences and its conflation with learning styles. In a recent self-authored article for the *Washington Post*, Gardner details the differences between intelligences and styles by emphasizing that learning styles were already being discussed prior to his theory of multiple intelligences and that styles, due to their relatively incoherent framing and lack of generalizability across tasks, should be avoided in practice and deserve more research.

These are difficult distinctions for teachers who have been using this language for decades, however. The root of all of these distinctions within schools is the idea that students learn *differently*. Whether the words used involve modalities, styles, or intelligences, in schools and frequently in practice, educators invoke this discourse of learning differences to explain differences in performance and tailor instruction to students.

Criticism from a range of psychologists, educational researchers and neuroscientists – including Gardner himself – does not advocate teaching to specific learning styles in classroom settings. Kirschner and Merriënboer (2013) describe the 71 different reported learning styles as reported in Coffield, Moseley, Hall and Ecclestone (2004):

If we start from the conservative assumption that each learning style is dichotomous there would already be 271 combinations of learning styles... The truth might be that people are different from each other on so many style dimensions, and for each dimension in so many degrees, that it becomes totally impractical to take these differences into account in instruction.

Yet this approach to teaching is effective remains pervasive and an important consideration when examining cultural dimensions of teaching and learning.

## **Passing as Able-Bodied in Educational Settings**

The language shift from learning disability to learning difference disassociates the experience of difference from the category of disability. This is a dynamic process very similar to the sociological concept of passing. Passing occurs when one individual in a marginalized group passes as a member of another typically more favored group. In the case of learning disability vs. difference this is a preference between being seen as disabled vs. able-bodied.

Book-length studies document passing mostly from the perspective of race (O'Toole, 2003; Sollors, 1997; Wald, 2000), sexuality (Sánchez & Schlossberg, 2001; Yoshino, 2006) or gender (Meyerowitz, 2002). Studies of passing as ablebodied, while often cited and of critical interest to disability studies, are few in number (Brueggemann, 1999; Brune & Wilson, 2013; Kleege, 1999; Samuels, 2003; Siebers, 2008; Titchkosky, 2003), do not generally agree on any term other than passing itself, present such a range of social constructions of disability that they are difficult to relate to each other, and mostly ignore educational settings as sites of disabled identity formation. They also document passing as a dynamic and socially negotiated process, but one without details to explain the nuances of the process of passing.

The ability for any disabled person to pass is commonly believed to be associated with the visibility of the impairment. Researchers study passing

mostly among "objective" or visible disabilities. Within the assumptions of this dualistic structure (visible vs. invisible), legibility of disability needs a social context to be meaningful. Linton (1998) provides a classic case:

I was recently in an elementary school when class pictures were taken, and I learned that it is the custom for all the children who use wheelchairs to be removed from their chairs and carried up a few steps to the auditorium stage and placed on folding chairs. I spoke with people at the school who said they have thought about raising money to build a ramp to the stage ... I wondered, of course, why they have to take pictures on the stage when it is inaccessible (21).

Cases like this, in which children are picked up and posed like dolls to fit into the expectations of what they should look like and where they should have their photograph taken, is unnecessarily invasive – even offensive – but likely not uncommon. Acknowledging the need for access in the case above may be acknowledging difference in a space valuing similarity.

In another example, learning disabilities like dysgraphia, dyslexia or auditory processing disorder may not be marked in the body and therefore made visible to an able-bodied by-stander. In a typical classroom setting in the United States where students are asked to write quickly and effortlessly by hand, read fluently aloud to peers, and respond quickly and accurately to multi-step directions, these impairments may surface.

In the absence of a visible marker of difference on the student's body, the disabled student's fellow classmates may say or think that the disabled student is dumb or lazy. The teacher may also ridicule him or her for not working hard or fast enough, paying attention to the reading or listening "closely." In these cases, a simpler, cultural explanation – stupidity, laziness or lack of attention – erases the possibility that a disability may exist. For some conscientious teachers these

events may be cause for alarm or concern prompting the teacher to seek explanations and supports.

In school settings passing as within the range of human variation remains common. When disability does emerge as a possible explanation for struggle or difficulty in the classroom setting, it typically comes with the valence of getting tested, processed, certified and accommodated. Even after that process has occurred, unless students are placed in segregated settings, the accepted norm is that their condition be kept confidential. It is therefore rarely talked about outside of informal meetings between teachers or formal Individualized Education Plan (IEP) meetings where the student's voice – if present at all – is only one of many.

Passing in educational settings for students with learning disabilities such as the ones described above – especially in environments where teachers and administrators received little training on learning disabilities – often requires a process of recognition or "coming out." This in turn relies on the student learning enough about their disability to explain their specific needs, claim a diagnosis and demand support. Students may even have to demonstrate the persistence of their condition to continue receiving support learning a variety of ways of making their difference visible.

This study foregrounds the experiences of dyslexic youth in a specialized school setting and uncovers their relationship to passing via the educational discourse of learning difference. I am also interested in documenting the counter storylines of performing disability and coming out as ways of challenging the discourse of learning difference and on occasion claiming disability. To do this I

employ positioning theory because it is suited to dynamically modeling positioning through linguistic action within common storylines of passing.

## **Storylines of Passing through Positioning Triad Theory**

Passing is a dynamic social process that in the case of this study was conducted via an analysis of conversational interactions during a semi-structured interview. After hearing many students describe themselves as learning differently and not learning disabled, I asked a series of questions to analyze how and why students made this shift. These questions were placed at two different points in the interview to allow students to shift perspectives if they chose. The questions were as follows: 1) Is dyslexia a disability? If so, why? If not, why?, 2) Are there any benefits/advantages to having dyslexia? 3) Are students with dyslexia disabled? What makes them disabled? 4) Are there any other descriptions of dyslexia you have heard? How do you feel about them?

Students told stories in response providing both personal and social remembrances. They relayed information about what it meant to be disabled and what it meant to learn differently. Often they did this through a complex set of self-positionings that changed as they spoke. This led me to analyze these self-positionings in regards to the two positions most frequently adopted: being learning disabled, and learning differently.

I introduced positioning theory in chapter 1. I expand on that introduction to explain the positioning triad: positions, linguistic actions and storylines. Both positions and linguistic actions have been described in detail before. Storylines are both constructed by positions as well as constrain the possible positions someone can take up. In this way they are similar to micro-

level discourses. Harré and Slocum (2003) provide a useful example of this interactional nature of the positioning triad: "Positioned as the class dunce, one may be 'required' to perform also as the class clown. One has an ascribed duty to play the fool" (p. 128).

Students emphasized the importance of four major storylines that occurred in tandem with linguistic actions and positioning. These storylines included two storylines that involved the linguistic action of claiming learning differences (passing as able-bodied and differences as gifts) and two storylines that involved the linguistic action of claiming disability (coming out and performing disability). The sections below detail the examples of these storylines from the interview data.

## **Storylines of Learning Difference**

What does it mean for students who do not identify with disability but are formally diagnosed with one to construct disability? When I asked if they thought dyslexia or other language-based learning disabilities were disabilities, the majority of students interviewed indicated that they did not think that dyslexia or language-based learning disabilities were actually disabilities. This was primarily an effort to construct an alternative position of having a learning difference. As Amanda describes:

Well, when I think of a disability, like when someone says the word disability, it makes me think of someone who actually has, like, an actual disability. Like wheelchair or mental and I don't like that. So, like, when someone – for instance – I don't know if I really like the word disability at all. I think it could be learning difference, because we are different but we're also unique and we have – I think that everyone who has a learning difference has something great to offer ... you actually take your learning difference and you make it big ...It's something different and they're unique.

Within Amanda's answer to my question, she reveals how "not liking" disability is because of its association with mobility and cognitive impairments. The introduction of and claiming the learning difference position is an effort to distance herself from those associations and to claim with some insistence that someone with a learning difference has a benefit to offer the world. She does this first through normalization of difference ("we are different") and then the claim of uniqueness. Her language-based learning disability is something that sets her apart and also above her peers, and is not a social stigma like disability. Almost all the students interviewed used the language of difference rather than disability through similar processes of positioning.

Another example from Samantha normalizes learning differences by claiming that everyone is different:

I would say that in my brain, I'm seeing everything or everyone sees everything differently than what I see. I see differently from what you see. I may look at a picture and I might see something different that somebody else sees. So we're all seeing something different.

In Samatha's equivocation I see erasure. She replaces the position of disability with one of learning differences. And there are a variety of reasons for doing so. Because of her experiences with being labeled and treated differently in school, difference is a more socially acceptable and potentially less stigmatizing way of describing herself. Simon similarly labels disability as "a really strong word that doesn't fit" and Chuck added: "I mean, we all have different ways of learning. We all have different interests. So it's just a different way for us to comprehend words." This relativistic use of the term different allows for a range of both positive and negative attributions whereas the term disability is almost universally viewed negatively.

Some students, however, recognize that claiming disability has its benefits for access to services, including John and Mimi Both vacillate between both discourses of learning difference and disability and emphasize the ability to move between them. Mimi describes this in detail:

I like to call learning disabilities learning differences because once you say the word disability, people immediately think mental disabilities, like autism or Down's syndrome... and that's hard for people to really think about, because they're often called retards. It's hard to be called that and to think of yourself like that. That's the only reason why I don't like the word disability, but also disability gets you services in college and gets you services in high school even. So once you say you have a disability or your neuropsych says you have a disability, you're instantly covered under 504 ADA or IDEA too...It's kind of like a mix. Like the term disability has its pros and cons. If you could change the term disability into being a difference and still be covered under those laws, then I would love it.

Within the position of disability there are legal benefits that are conferred and yet there are social benefits of avoiding the stigma associated with other disabled people. Most particularly, disability is disavowed because of disability's negative association generally and many students mentioned a desire to avoid being called dumb, stupid or "retarded."

The adoption of the learning difference position reveals a fairly clear set of possibilities. Students view the position of disability as a negative attribute associated with other people who have mobility or cognitive impairments and therefore disability is an undesirable identity to claim unless it gives access to necessary accommodations. On the other hand, students employ the linguistic action of claiming learning differences to pass as able-bodied, because 'everyone learns differently.' A diagram illustrating this process of positioning is shown below:



Figure 8: Passing as Able-bodied Storyline

Benjamin also stated clearly that dyslexia was not a disability but a learning difference. He added: "I've learned is that we tend to have a more creative mind than the average person, because we think that we don't think rationally as much, you know." He creates a new storyline *differences as gifts*. The initial claim of learning difference continues the trend of distancing the participant from disability. Claiming learning differences, however, introduces and normalizes the difference and moves into a place of exceptionality – above all other peers. This discursive movement from one to the other shows the initial benefits of passing to then claim creativity, sometimes genius, and other times entrepreneurial or "people" skills. The *differences as gifts* storyline is illustrated below:



Figure 9: Differences as Gifts Storyline

Not all students used the expression *learning difference* to pass as ablebodied and then move to an almost super human positioning. Naomi describes how in school other students often thought of her as different or stupid because of her disability and that by cultivating her creativity in the arts she became recognized more for her talents. "I'm a very visual learner but my brother is a very auditory learner. Does that mean he is visually-learning disabled?" She continues, "I mean you could argue that people who learn in a normal public school wouldn't thrive here. Does that mean they are undyslexically-disabled?" This movement to question the role of context in determining her disability is the reason she uses the term *learning difference* because, based on her practice of positioning, everyone could be learning disabled in the right environment. She also points at the absurdity of claiming a word like dyslexia that has such a circumscribed role in her life.

The position of learning difference reveals how the position of disability leaves the speaker more constrained. Disability allows for being seen as a bad student or a failed student whereas the position of learning difference opens up the possibility of passing, being a successful student, and using difference to interrogate any normal subject position that an able-bodied student might inhabit. Her practice of considering subject positions she does not inhabit allows her to criticize the context-dependent nature of disability. Passing in Naomi's story reveals how the position of difference, particularly the claim of being a visual learner and an auditory learner instead of dyslexic, permits her access to passing as able-bodied.

Claiming Disability: Coming Out and Having a Dyslexic Moment

Marcia agrees that dyslexia is a disability and, unlike other students who sought to distance themselves from disabled people, she describes herself within a range of possible disabilities: "Because there are all different types of disabilities, like mental or physical, and all that stuff. Obviously, it's not as severe, but I think it still can be categorized as a disability." By claiming disability her positioning does not change immediately but it opens up the possibility of seeing oneself as one among many other disabled people.

Natalie builds on the position of dyslexia as disability. She claims that it is a disability and contextualizes it within a paper she recently wrote about Orlando Bloom having dyslexia. Natalie argues that while Bloom considers dyslexia a gift, she has never seen it that way and that "it might be that it hasn't paid off." So while there may be some hope in adopting the differences as gifts storyline, she distances herself from it by simply claiming disability.

Another student, George describes how, despite efforts by peers and some of his teachers to have him change his language to learning difference, he resisted:

Yeah, I never say difference. In my speech I didn't even change it to difference. It isn't - - it's different but it's not like out of this world different. It's something that inevitably could be seen... I would say it isn't as severe as for example being a paraplegic but it is severe enough to be classified as a disability because you have trouble... even with full treatment you still have brilliant people that can't read or write well and so I would classify it. Just because there are people successful with it doesn't mean that it should be written off because there are people that are successful.

George has extensive experience traveling to schools and speaking about his dyslexia. He wants his audience to hear him say disability instead of difference. His advocacy includes a holistic picture of having a learning disability instead of a denial, passing or covering up of it. His pragmatic approach to interpreting the

storylines discussed above and himself in terms of his dyslexia leaves room for a range of human capacities and failures.

Marcia, Amanda and George challenge expectations that young dyslexic people do not identify with or claim their disability. While they remain the minority they present a different storyline for dyslexic young people who are aware of, sometimes proud of disability. I characterize this storyline as coming out and illustrate it below:



**Figure 10: The Coming Out Storyline** 

In the cases above the linguistic action of coming out and claiming dyslexia and disability does not change the positioning but it forces a different association with that identification: a realistic and positive one potentially connected to others in struggle.

#### **Performing Group Identity by Having a Dyslexic Moment**

Most of the students at the school where the interviews were conducted reported having "dyslexic moments." When younger students with dyslexia would make a mistake, goof or even miss a goal in soccer, everyone would blame dyslexia. There is obviously little to no relationship between dyslexia and soccer. The accomplishment here is that making fun of every mistake and blaming disability allows students to release some of the pressure and trauma they faced

in schools. It involves the linguistic action of having a dyslexic moment that promotes group cohesion and bonding and builds self-confidence by laughing in the face of failure. The process of positioning is illustrated below:



**Figure 11: Performing Group Identity** 

Darryl shared a moment from reading aloud, a particularly difficult task for many students with dyslexia: "I don't know, if you read something wrong, not in class, but with your friends, you're like 'oh that says something like pizzeria butt face' or something, I know it doesn't say that. Like 'oh, dyslexic moment." "Dyslexic moment" emphasizes his disability among a peer group that shares the same struggles. It at once excuses him for his failure while allowing everyone including the speaker to laugh at struggle. This also allows students who position themselves as having a learning difference to make fun of their prior and current selves.

Jonathan feared that people would find out about his dyslexia and now adopts the phrase "dyslexic moment" to give him permission to make mistakes and feel supported:

And like I remember at my old school like I would be like I was dyslexic, I knew I was and I knew like I had trouble learning so like, I wouldn't want to talk to anybody, I didn't want anybody to find out so like I had a little bit more distance. In here I'm just like if I get an answer wrong or if I create the clock wrong then I'm like 'dyslexic moment'.

Having a dyslexic moment allows students to move through the positioning of being a bad student or a failure instead of being stuck in it.

# Modeling Passing and Identity in Talk about Dyslexia and Disability

The four storylines when taken together reveal a complex set of possibilities for young dyslexics that occur across the sample. The relative frequency of these storylines is presented below in Table 1. Counts were done across all transcripts, with each student being able to represent each storyline once. Only one interview did not show any of the storylines with the student simply responding that he did not know what he thought.

Table 1: Management of labels by young dyslexic people across four storylines

Label and	Positions	Implications and	Frequency
Storyline	Available	Associations	Count
Learning	Having dyslexia,	Avoiding negative	14
Difference:	Perceived as able-	associations with disability;	
Passing as able-	bodied	striving for normalcy	
bodied		through relativistic	
		approaches to difference	
Learning	Having dyslexia,	Positive association while	6
Difference:	Perceived as	individualizing talents/gifts	
Differences as	exceptional and	g g	
gifts	talented		
Disability:	Having dyslexia	Positive association with	5
Coming out		other people with	
O		disabilities	
Disability:	Having dyslexia	Positive association with	8
Performing	0 ,	shared struggle	
group identity			
~ .	•	•	

While the majority of students employed the storyline of learning difference to pass as able-bodied, some positioned themselves as exceptional in some way. Many students also admitted to "having dyslexic moments" to bond with each other through their experiences with dyslexia. Between these two storylines there was the most overlap.

### **Managing Disability and Theorizing Passing**

Throughout this study I have examined how the management of labels overlaps with passing as able-bodied and sometimes even performing disability to emphasize group identity. These storylines connect to other theoretical formulations in interesting and productive ways. By theorizing connections to masquerade, covering and coming out, as experiences in disabled lives, I show how the storylines presented by these young dyslexic students are grounded in the experience of managing disability.

# Masquerade

One of the founders of disability studies in America, Tobin Siebers (2008) details how theories of masquerade from feminist and queer studies inform the experience of passing as able-bodied. Drawing inspiration from Riviere's essay "Womanliness as a Masquerade" (1929), Siebers details how putting on disability can be a way for invisible disability to be read in cases where it is needed. Riviere famously performed womanliness to get ahead in academic circles dominated by men. Since "ability appears unmarked and invisible because it is the norm, while disability, as an affront to ability feels the full and persistent force of an ideological impulse," the disabled subject through masquerade may make the revelation that disability exists while pointing out that the masquerade does not.

Remember the case of "having a dyslexic moment." While the failure may be real, the attribution of that failure to the disability itself may be tenuous. To an untrained or able-bodied observer this process of having a dyslexic moment could be considered harsh, insensitive or an effort to elicit pity. All of these

reactions are based on the assumption that there is something negative with claiming dyslexia and mocking it.

Disabled people performing disability has a different history of revealing very clearly to able-bodied audiences the need for normalcy and not the need for inclusion especially in the case of freak shows. Freak shows frequently a part of public amusements at the end of the 19<sup>th</sup> century in both the UK and the US forced disabled people to perform normal acts in an effort to point out their difference to able-bodied audiences. While freak shows are mostly a relic of the past, the aesthetics continue in spaces as diverse as social media passing around heroic and inspirational images of visibly disabled people reminding able-bodied people to be stronger or better.

Siebers' formulation of masquerade does not clarify the student's need for services and supports in educational settings. Unless a need for supports or accommodations is shown, schools routinely deny them. Stories abound of young people with disabilities not asking for accommodations for fear school staff and teachers may discriminate against them. Because the students in this study come from a space where they have had extensive and long-term interactions with other young dyslexic people, some masquerade likely emerges from the formation of an in-group precisely because they know they are going to get accommodations and support and not be discriminated against. Other settings may not present this opportunity or construct as readily.

#### Covering

School culture is tightly regulated by all of the participants in it. This is demonstrated very easily through the language still used to differentiate able-

bodied students from their disabled peers. As an example, The Council for Exceptional Children is still the largest professional organization supporting special education in the United States. The terms exceptional and special exist euphemistically to cover up how unspecial and unexceptional special education actually is. Students routinely invoke phrases like "he's special" even among themselves in special education settings to differentiate themselves from peers. If disabled students are given modified or different assignments, students without disabilities want to know why the teacher will not accept the "easier work" from them. Psycho-educational assessments and teachers, informally, rank students' disabilities from mild, moderate to severe, placing clear boundaries on the potential and humanity of each student and ultimately their future prospects even before new teachers have an opportunity to meet them. And it should be a surprise to no one that these judgments inform the limits of what teachers try to accomplish with each student. Perhaps Simi Linton (1998) put it best when she explained: "an entire profession, in fact a number of professions are built around the word *special*. A huge infrastructure rests on the idea that *special children* and special education are valid and useful structuring ideas... Special can be understood only as a euphemistic formulation, obscuring the reality that neither the children nor the education are considered desirable and that they are not going to 'surpass what is common.'"

A student in these settings with an invisible or mostly undetectable disability will likely find ways to pass as able-bodied to cover up his or her disability to fit in and in the best circumstances "be included." Covering, unlike theories of masquerade or passing, starts from the perspective of covering up sexuality and expands on race-based covering (Yoshino, 2006). Yoshino theorizes

three processes, presented in a chronological order through his autobiographical examples: 1) *conversion* in which he wanted to become heterosexual, 2) *passing* in which he wanted to be perceived as heterosexual by others, and 3) *covering* in which he finds ways to downplay the visibility and importance of his gayness in the workplace. Yoshino's personal formulation of covering's progression can be mapped easily onto the paradigm of invisible disabilities, though the realities of claiming disability continue to be more intricate and dynamic than a simple progression through three distinct phases.

Inherent to Yoshino's distinction between *passing* and *covering* is an implied coming out phase that happens between them. "Coming out" as disabled or claiming disability has been discussed extensively (Linton, 1998; Samuels, 2003; Solis, 2006) and yet the emphasis in educational settings is often only placed on "coming out" to receive the accommodations a disabled person may need, not on the presumption that "coming out" involves joining a community of similar people. This study largely replicates those results with only six students discussing coming out and only three of them mentioning some connection – however distant – to other disabled people.

Disability studies also takes a very clear stance on "conversion," not unlike queer studies. Instead of "conversion," though, cures are still frequently sought if not actually achieved in the case of dyslexia. Many intervention services and some programs purport to cure or at best normalize students with learning disabilities and many students still find solace in those beliefs even long after they have been disproven. An excellent case of this rests in Meares-Irlen syndrome that suggested by putting tinted glasses on students they would be able to read more accurately and fluently. No empirical evidence suggests that

these lenses work and yet they are still sold to and used by students and school districts.

## **Desiring Community**

The desire to be like everyone else among the students in this study is definitely greater than the desire to connect with other disabled people.

Nonetheless the in-group connections fostered through humor and friendly banter among these students reveal a human need to connect with each other.

Across all of the storylines, the individual is prioritized over the group. The constraints of the sample and data collection techniques do not grant access to more private spaces with these dyslexic students so it is hard to know how supportive they are of each other, but the initial references suggest that humor was the means by which many of them communicated their support – even at times when teachers or other adults in the setting expressed dislike for that kind of support.

Storylines in this study served as one of many multilayerd linguistic possibilities that students navigate in talk. Applying positioning theory to the case of managing labels allows researchers to model the dynamic and continuous nature of these storylines. That some students may stop short of taking a new position or use the same linguistic action to accomplish different rhetorical and potentially social goals.

In a complementary approach of analyzing linguistic actions culturally, Jan Grue (2011) describes modeling disability discourse and its importance for future research:

Qualities that are best understood on a finely graded or continuous scale (health, physical fitness, appearance, etc.) become divided

according to a dichotomy of able-bodiedness and disability, with considerable consequences. Being classified as disabled will, at least in most social democracies, entitle one to a number of rights and benefits. But such a system also keeps wheelchair users out of workplaces with staircases, and blind people from working in offices that do not invest in either text-to-speech or Braille translation. Analyzing disability in its social context, therefore, has become a multitudinous enterprise that is critical in basic attitude and extensively concerned with the mechanics of discourse.

Perhaps the root of examining disability discourse as it relates to the social and medical models for students with invisible disabilities like dyslexia in schools, is interrogating when, where and how students pass as able-bodied. After all in Grue's formulation, it is the appearance of and silence around able-bodiedness that produces oppression – especially in the case of employment.

Dyslexic students invoking discourses of "learning differences" also lay claim to gradations of difficulty instead of merely being counted out of participation in learning in schools. They hypothesize that something is difficult for everybody. They show tremendous resilience in the face of bullying, by making positive attributions to their differences. Some dyslexic students also claimed access to feelings of struggle, which pushed them to continue to work harder. Even the acknowledgement and realization by some students that disability itself is socially determined and context dependent gave them permission not to claim their disability, but to deny that it even exists.

While many students saw their community as other able-bodied students, fewer students, only five in this sample, described themselves as disabled - some fervently so. Claiming disability, while certainly discouraged by the school they attended, remained a critically important part of the self-presentation of students like George. This study points to the difficulty for young dyslexic students – even those involved in advocacy work and surrounded by their peers – to escape

medicalized formulations of disability. As long as the storylines of learning difference allow access to normalcy, students easily map the discourse of disability into abnormal.

#### **Conclusions**

Dyslexia and other language-based learning disabilities remain the most prevalent disabilities in educational settings and yet so little scholarship from the field of disability studies in education has focused on the students' experiences. The previous three studies were in small part an effort to reverse this trend. Using three different methods and examining three different processes happening at the individual, social and cultural levels of Haste's model of culture (2009), I revealed a fairly cohesive story for how this small sample of students perceives and describes dyslexia from the vantage point of their specialized setting.

#### An Integrated Model: Dyslexia as Learning Difference not Disability

The three studies discussed in this dissertation revolve around a shifting cultural discourse of dyslexia. Students are now claiming difference and eschewing disability and this has an interesting set of ramifications and linguistic actions associated with this shift. They are also avoiding, for the most part, claims of a minority status or a group identity with other disabled people. This shift away from previous discourses of dyslexia maps on to shifts in understanding models of disability. The shift is illustrated below in Figure 12:

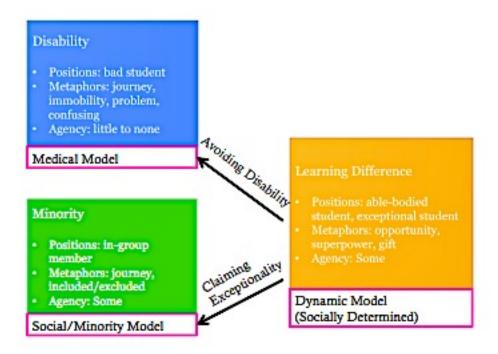


Figure 12: The Discursive Shift to Learning Difference

This model shows how previous efforts to locate disability either within a medical or social/minority model of dyslexia do not represent the ways young dyslexic people represent their learning disability in talk. By starting with the assumption that their disability is just a difference that may give them ablebodied privilege in some settings, or even better, allow them to explain some unique gift or talent, they give themselves more agency and control over their discursive world. Claiming learning difference does not preclude them from claiming disability for either legal rights or group membership among other dyslexics though it does tend to limit their linguistic options when wanting to connect to other people with disabilities.

The persistence of the negative associations with disability is troubling but not surprising. Many of the storylines investigated in chapter 4 revealed how the movement to learning difference was most likely an effort to avoid identifying with other disabled people. Most cited among these people were those with

Down's syndrome or pejoratively referred to as "retarded." Ableist attitudes are not unique to able-bodied people and the stigmatization of cognitively impaired people by cognitively able but learning disabled youth is especially troubling. More work needs to be done to explain connections across different categories of disablement and how stigmatized differences of any kind can lead to these hierarchies. The ability for dyslexic youth to fit in socially with their peers is also likely a product of the continued isolation of cognitively impaired students within schools and communities.

While the discursive options for dyslexic students seem to have expanded, a range of factors are still affecting their material realities. From diagnosis to accommodation, dyslexic students are still experiencing difficulties. The promise of learning differences presents a positive but opaque vision for the future. It is limited in its own linguistic shifts away from a history or marginalization, struggle and solidarity. By casually adopting the language of difference to appeal to ablenormativity and passing as able-bodied or worse, claiming some exceptional skill or talent, dyslexic students are inevitably isolating themselves socially and culturally. Some overlap between claiming learning difference and disability suggests that at least some dyslexic students are claiming both but they are not the majority in these studies.

Cultural production in the last seven years has provided widespread representation of dyslexia and that has had a tremendous impact on how young dyslexic people navigate the social and cultural world of schools. Young dyslexics today have grown up reading Rick Riordan and watching some of these cultural representations of dyslexia on *Glee*. Since my work is only cross-sectional and not longitudinal I cannot claim that these students are adopting a

particular position, discourse or model because of their age or exposure to these representations. It could prove fruitful to future researchers to examine these trends over time. I would like to answer questions such as: once removed from school settings do dyslexic people continue to experience difficulty navigating and accessing resources? Do they tend to identify with other dyslexics and/or other disabled people? How do their self-descriptions or conceptual metaphors change? Do they continue to describe themselves as merely different? These questions must be left to future researchers to take up.

#### **Suggestions for Future Research**

The three chapters in this dissertation and their focus on language and discourse also starts to fulfill a need for disability studies to listen closely and critically to young people with disabilities and frame our agendas with that knowledge. But I think these voices could be joined with others across movements, history and even from other people with dyslexia and other learning disabilities in mainstream settings.

Contained within this brief conclusion are three directions for future study building from the findings contained in the chapters of this thesis. Each recommendation both focuses on one chapter particularly while reflecting the general need to grow connections between disability studies, discourse studies and studies of dyslexia.

#### **Expanding Brain-based Differences in Dyslexic People to Neurodiversity**

Since dyslexic students often rely on discourses of differences to refer to themselves and their brains, more connections need to be made between neurodiversity movements within disabled people's movements and traditional

intervention work with dyslexic students. As Darryl Morris (student cited in Chapter 2) makes clear: "our brain is just wired differently." Katherine Runswick-Cole (2014) describes the neurodiversity movement in the following four points:

- Some people believe there are neurological (brain wiring) differences in the human population, of which autism is one.
- Some people see autism as a natural variation among humans (not a disease or a disorder), just 'a difference'.
- These views of neurological (brain wiring) differences and natural variation are those of the neurodiversity movement.
- The neurodiversity movement wants to be considered as a political grouping comparable with those of class, gender or race. (1117)

The surface level articulation of the political goals is clearly aligned – though dyslexic people have only recently began to claim openly their diagnosis as identity. Runswick-Cole (2014) also cautions that the desire by neurodiversity movements to move beyond an "us" and "them" identity politics leaves disabled people, and autistic people specifically, in the category of "them."

The larger narrative that Runswick-Cole (2014) targets about neurodiversity continues to engage with neo-liberal identity politics, but has also simultaneously failed to produce the kind of solidarity across all disabled people because of the focus on the brain's association with personhood (Ortega, 2009). Not all disabled people have brain-based differences, after all, and nor do they have to if they want to remain only supportive of people who identify as neurodiverse. But it seems like the entire neurodiversity movement may be leaving out core constituencies by avoiding closer examination of the potential inclusion of dyslexic people and perhaps even people with traumatic brain injury (TBI), as both are normal expressions of the range of being supplied with a brain and thus people. This subverts the exclusivity claimed by both groups to

difference discourses and challenges the construction of Runswick-Cole's "them." Confronted with the reality that transcending a neo-liberal political climate may indeed be impossible, perhaps, the movements like the neurodiversity approach offer opportunities for new coalitions and new ways of organizing, especially in social media environments and increasingly in higher education settings (Griffin & Pollak, 2009).

#### A FAIR Curriculum for a Start

Work needs to be done to introduce meaningful inclusive curriculum. In 2011, California passed the Fair, Accurate, Inclusive and Respectful (FAIR) Education Act that requires textbooks to cover more information explicitly about LGBT and disabled people. While curriculum developers work to make available a full range of resources on these topics, more work could be done to advocate for bills like the FAIR Education Act to other states and countries and for researchers to document the effects on attitudes about disability and LGBT concerns among teachers and students. An inclusive curriculum remedies access to and the legality of teaching these materials to students in all public schools. An inclusive curriculum at Holyoke school about disability could have engaged politically minded students with their disability and with others fighting for inclusion instead of relying on individuals to develop their own political consciousness.

Solis (2006) articulates this in his work with students with learning disabilities: "by focusing on students' lived realities, and not on their cognitive limitations as the curriculum often dictates, they can thrive and gain meaningful knowledge." Since so many students with disabilities in schools are never

exposed to clear and powerful stories of people with disabilities in history or contemporary culture, any hint of success or celebrity becomes a fascination – a possibility.

Connecting the academic and social troubles young dyslexic people face in schools with a culturally relevant and sensitive curriculum focused on politicization and empowerment makes available resources previously obscured. Yet, I suspect since curriculum frequently relies on unimaginative explorations of cultural concerns and disability history tends to emphasize physical impairments, veterans and white people, dyslexic students may be left without clear historical role models. Curricula may not challenge a sense that all dyslexic people are white, or understand that everyone being able to read is a fairly recent expectation of civilization. For too long, efforts to understand the curriculum in K-12 settings for students with disabilities have been focused on gaining access only, instead of insisting on representation.

### **Avoiding Covering and "Learning Differences" as Euphemism**

With additional information available within the school curriculum and among advocacy groups, students feel less compelled to cover their disability and hide their needs. In the absence of those outcomes, researchers using cognitive linguistic and discursive psychological methodologies must continue to confront the constructions of "difference" that erase the disabled people's lived experiences in schools. The adoption of non-specific and euphemistic language rooted in presumptions about what education and learning are about erect additional barriers between disabled people and threaten to undermine the historical goals of solidarity and group membership.

More research could be done among non-disabled students to see how the language of learning styles, learning differences and multiple intelligences pervades classrooms to explain otherwise inexplicable or taboo differences in academic achievement among students. If students with disabilities are using the same language as poor students, students of color, and immigrant students and if their teachers endorse this language, how does that reflect the desire to depersonalize and simultaneously internalize the problems with disability? These kinds of questions could build from the growing and now substantial base in disability studies in education on race and disability particularly (Connor, 2007; Connor & Ferri, 2006).

At the root of the debates about learning disabilities vs. differences is the continued insistence on replacing a term that becomes offensive with one less offensive. This *euphemism treadmill* – a term coined by Steven Pinker (2003) – in studies of people with disabilities has been running a long time, requiring activists and scholars to work tirelessly together to quash unproductive and politically obscurantist language as it emerges. The contemporary example of young dyslexics identifying with the expression "learning differences," especially in the context of being confronted with disability as a reality, while initially empowering, threatens to derail, discontinue or fragment disabled people from their histories.

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# **Appendix 1: IRB & Renewal Forms**

# HARVARD UNIVERSITY COMMITTEE ON THE USE OF HUMAN SUBJECTS Request for Renewal of Approval

INVESTIGATOR: (name, campus address)	Additional Contact Person: (if any)	
Aubry D. Threlkeld		
Telephone(s): 617-417-2671	Telephone(s):	
Email address: aubry.threlkeld@gmail.com	Email address:	

#### **PROJECT TITLE:**

CUHS application number (if known) -- #F -

**FACULTY SPONSOR** *(for student/staff applicants)*:

Supervising lecturer, instructor, or graduate student: (if applicable, in addition to the above)

SPONSOR'S E-MAIL ADDRESS: helhaste@aol.com

RENEWAL REQUESTED FOR: (maximum one year) 1 year

**from** June 2012 **to** June 2013.

**FUNDING SOURCE:** (include grant # if known) N/A

1. Please summarize--briefly--your research procedures. What do subjects do, or what is done to them? What information is gathered? (Use additional pages if necessary.)

I plan on interviewing adolescents with dyslexia about their experiences in school so far.

2. How many subjects have completed participation in the study? 1

How many are currently participating? 0

How many have withdrawn? 0

Provide the reason for withdrawal. N/A

How many have yet to be recruited? 35

3. Have procedures described in your original human subjects application changed? If so, how? (Append copies of any new instructions, tests or questionnaires. List new sites or datasets being added)

- 4. List any assistants who have left since the last review. List any new assistants or other investigators being added, AND their roles and qualifications. . (Use the Study Personnel Form available at <a href="http://cuhs.harvard.edu/#forms">http://cuhs.harvard.edu/#forms</a> for projects with more than one additional person.)
- 5. Since the last CUHS review, have there been any interim findings? If so, please attach a summary of the interim findings.
- 6. Describe any new, unanticipated risks that arose during the course of the research. What precautions have you taken to minimize the risk to subjects?
- 7. Describe any harm (physical, psychological, social) experienced by subjects and any complaints received. What happened? How was the problem resolved? What measures have you taken to guard against similar occurrences?
- 8. Since the last CUHS review, have there been any publications in the literature relevant to this research that contain findings that could affect subjects' willingness to participate? If so, please attach copies and a summary of the findings.
- 9. Since the last CUHS review, has there been any change in your assessment of the risk-potential benefit profile of the study, based on results to date? If so, please explain.
- 10. Please attach to this application the current consent form, information sheet, or script for informing subjects about the study.
- 11. If this study is conducted at multiple sites, with local IRB approval, please attach current IRB approvals from those sites, and any reports or communications from sites that contain information about subjects' experiences, unanticipated problems, or potential risk to subjects.

**APPLICANT'S SIGNATURE:** 

**DATE:** 5-20-12

(For non-faculty applicants)

I have reviewed this completed application and I am satisfied with the adequacy of the proposed research design and the measures proposed for the protection of human subjects.

FACULTY SPONSOR'S SIGNATURE: HELEN HASTE

# **Appendix 2: Interview Protocol**

#### Semi-Structured Interview Guide: Student

## **Interview Script:**

Thank you for coming. Before we get started on the interview I wanted share my reason for interviewing you. I have seen the Holyoke students talk about their experiences in school. I have been moved by their stories. So I thought it might help teachers and researchers learn more about dyslexia and how people talk about it by gathering some of these stories. In order to make sure I get as much information as possible, I have prepared a list of questions. I also want to hear what you think is important for me to know. The interview should last approximately 30 minutes.

#### **Basic Information**

Do you consent to be recorded today?

What is your name?

How old are you?

Where are you from originally?

How long have you attended Holyoke?

Why are you here?

Who made the decision that you come?

What was your involvement in that decision?

What is easy for you in school?

What particular struggles do you have with school?

Are you dyslexic?

How did you find out you are dyslexic?

How would you describe your dyslexia?

# **Prior Experiences**

Do you feel like your experiences learning to read in school were similar or different from other students? Why?

Tell me about a time when you felt very successful in reading in school ... Tell me about a time when you felt supported when reading in school ... .

# Present cultural understandings

Is dyslexia a disability? If so, why? If not, why?

Are there any benefits/advantages to having dyslexia?

Are students with dyslexia disabled? What makes them disabled?

Many students with dyslexia experience being called dumb in school.

Have you ever heard a student or a teacher call a fellow student, dumb or stupid? How did you react? How did you feel?

Have you ever been called dumb or stupid, yourself?

Do you feel that schools adequately help kids with struggles like yours? What other descriptions of dyslexia have you heard?

# Scenarios

What would you say to six or seven year old who has just being diagnosed with having reading difficulties?
What would you say to a teacher who has just been assigned to work with

students with dyslexia?

Do you have any questions for me?

Thank you for telling me your story. I am very happy to have met you and listened to your experiences.

### **Curriculum Vitae**

# AUBRY D. THRELKELD PO Box 380306 / Cambridge, MA 02238 / (617) 417-2671 / aubry.threlkeld@gmail.com

### **EDUCATION**

### **ACADEMIC APPOINTMENTS**

### HARVARD UNIVERSITY

2008-present

Departmental Teaching Fellow for Women, Gender & Sexuality Studies (WGS)

Junior Tutorial Board Member

Teaching Fellow for WGS

Graduate Multimedia Fellow

Teaching Fellow in Literacy & Research Methods

Presidential Instructional Teaching Fellow

TUFTS UNIVERSITY	2013, 2015
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Visiting Lecturer in Disability Studies

PACE UNIVERSITY 2005-2007

Adjunct Lecturer in Special Education

# NEW YORK CITY DEPT OF EDUCATION

2003-2007

District-based Instructional Coach for Literacy School-based Instructional Coach for Literacy Curriculum Designer & Trainer for iTeach/iLearn Initiative Special Education Teacher

 Taught grades K-8 in substantially separate special education classroom environments

### OTHER PROFESSIONAL EXPERIENCE

### THRELKELD EDUCATIONAL CONSULTING

2010-present

Founder and Educational Consultant

### HARVARD COLLEGE

2010-present

Resident Tutor for Adams House

- Advised 40 undergraduates on academic & career choices in education
- Served as a BLGTQ and Sexual Assault Sexual Harassment (SASH) counselor

Managed the Pool Theater scheduling 46 student and faculty productions

# HARVARD UNIVERSITY

2014-15

Co-convener for Mahindra Symposium on the Future of LGBT Politics

# HARVARD GRADUATE SCHOOL OF EDUCATION

2008-2010

Research Assistant for Strategic Education Research Partnership (SERP) Research Assistant for Improving Comprehension Online (ICON)

# **NEW TEACHER PROJECT**

2005

New York City Teaching Fellows Advisor

# MIDDLEBURY COLLEGE ADA OFFICE

2000-2003

Assistive Technology Evaluator

# **COURSES TAUGHT**

"Analyzing Culture: Dialogue, Discourse & Theme." Head Teaching Fellow. Harvard Graduate School of Education, Cambridge, MA. Fall 2008; Spring 2010; Spring 2011; Spring 2012; Spring 2013; Spring 2014; Spring 2015.

"Senior Tutorial." Departmental Teaching Fellow. Studies of Women, Gender & Sexuality, Harvard College, Cambridge, MA. Fall 2012- Spring 2013; Fall 2013- Spring 2014; Fall 2014-Spring 2015.

"From Men to Boys: Masculinity in Post-War Hollywood Film." Teaching Fellow. Harvard College, Cambridge MA. Spring 2014.

"Introduction to Disability Studies." Lecturer. Tufts ExCollege, Tufts University, Somerville, MA. Spring 2013.

"Analyzing Writing about Sexual Abuse on College Campuses." Independent Study. Studies of Women, Gender & Sexuality, Harvard College, Cambridge, MA. Spring 2012.

"Intersexuality & the Internet." Independent Study. Studies of Women, Gender & Sexuality, Harvard College, Cambridge, MA. Fall 2011.

"Introduction to Qualitative Research." Psychology & Doctoral Seminar Leader. Harvard Graduate School of Education, Cambridge, MA. Fall 2009; Fall 2010.

"Masculinities." Teaching Fellow. Studies of Women, Gender & Sexuality, Harvard College, Cambridge, MA. Fall 2010.

"Alcohol & Rape Policy on College Campuses." Independent Study. Studies of Women, Gender & Sexuality, Harvard College, Cambridge, MA. Fall 2010.

"Parenting & Literacy." Teaching Fellow. Harvard Graduate School of Education, Cambridge, MA. Spring 2010.

"Literacy & Content Learning in Middle & Secondary Schools." Teaching Fellow. Teacher Education Program, Harvard Graduate School of Education, Cambridge, MA. Spring 2010.

"Introduction to Quantitative Research." Teaching Fellow. Harvard Graduate School of Education, Cambridge, MA. Fall 2009.

"Reading Difficulties." Teaching Fellow. Harvard Graduate School of Education, Cambridge, MA. Spring 2008; Spring 2009.

"Introduction to Educational & Developmental Psychology." Adjunct Lecturer. Pace University, New York, NY. Summer 2007.

"Literacy in the Content Areas." Adjunct Lecturer. Pace University, New York, NY. Fall 2005; Spring 2007.

"Assessment & Evaluation of Students with Special Needs." Adjunct Lecturer. Pace University, New York, NY. Spring 2006; Fall 2006; Spring 2007.

"Collaboration & Consultation in Inclusive Classrooms." Adjunct Lecturer. Pace University, New York, NY. Winter 2005-2006; Spring 2006.

"Introduction to Classroom Teaching in Middle School Environments." Adjunct Lecturer. Pace University, New York, NY. Summer 2005; Summer 2006; Fall 2006.

# AWARDS, SCHOLARSHIPS & GRANTS

Emma Gildersleeve Lane Fund Bok Center Excellence in Teaching Award HGSE Doctoral Travel Grant Edmund J. Curley Fund Jeanne Chall Doctoral Research Grant HGSE Data Collection Grant Graduate Multimedia Fellow Larsen Family Fellowship CASE Fellowship AmeriCorps Volunteer Grant AmeriCorps Education Grant New York City Teaching Fellows Scholarship	2014-2015 2014 2013-2014 2012-2014 2013 2013 2013 2007-2011 2008 2006 2005 2003-2005

### FORTHCOMING PUBLICATIONS & MANUSCRIPTS IN PROGRESS

Threlkeld, A. "Who has heard of 'Crip' Heard?" [Drafted]

Threlkeld, A. "The Changing Subject of Inspiration Porn: What Disabled Animals Say about the Persistence of Pity Online" [Drafted]

Threlkeld, A. "Reading Dyslexia as Disability." [Dissertation Submitted]

Threlkeld, A. *The Best Parking Spot and 20 other Myths about Disabled People*. [Book Proposal under consideration]

MacMaster, C., Murphy, C. & Threlkeld, A. (eds.) (2015). *Graduate survival and success in the United States*. New York, NY: Peter Lang Publishing. [Under Contract]

# PEER REVIEWED PUBLICATIONS

Threlkeld, A. (2015). "Diagnosing disordered doctoral programs." In MacMaster, C., Murphy, C. & Threlkeld, A. (eds.) (2015). *Graduate survival and success in the United States*. New York, NY: Peter Lang Publishing.

Threlkeld, A. (2013). "Teaching children's literature about same-sex parenting: A critical queer literacy approach." In Lawrence, S. (Ed.) *Critical practice in P-12 education: Transformative teaching & learning*. New York, NY: IGI Global.

Threlkeld, A. (2013). "New Media as Assistive Technology: From Barriers to Beginnings. In DaCosta, B. & Sook, S. (Eds.) *Assistive technology: Research, practice & theory.* New York, NY: IGI Global.

Threlkeld, A. (2008). "Virtual disruptions: Traditional & new media challenges to heteronormativity in education" prepared for Futurelab & The British Ministry of Education. Published online:

http://www.beyondcurrenthorizons.org.uk/evidence/identities-citizenship-communities/

### **CONFERENCE PRESENTATIONS**

Threlkeld, A. "Cars, Guns and the Biggest Phallus: Queering Amputee Fetishism in Male Culture." Pleasures, Sexualities and Disabilities: Challenging Perceptions, Igniting Desires. Canadian Sociological Association Annual Conference. Ottawa, Canada. July, 2015.

Threlkeld, A. "A New Narrative of Dyslexia." Annual Conference of the Disability Studies in Education (DSE) Special Interest Group of the American Educational Research Association (AERA). Victoria Institute, Melbourne, Australia. July 27, 2014.

Threlkeld, A. "Why The Heroic Cyborg of Inspiration Porn Makes Us Mad." Annual Conference of the Disability Studies in Education (DSE) Special Interest

Group of the American Educational Research Association (AERA). Victoria Institute, Melbourne, Australia. July 25, 2014.

Threlkeld, A. "Dyslexia on YouTube™: What Teachers Can Learn From a Critical Analysis of Video Blogs." Annual Conference of the Council for Exceptional Children (CEC). Philadelphia, PA. April 11, 2014.

Threlkeld, A. "Teaching Children's Literature that Features Same-Sex Parents: A Critical Queer Literacy Approach." Annual Student Research Conference (SRC). Harvard Graduate School of Education, Cambridge, MA. March 28<sup>th</sup>, 2014.

Threlkeld, A. "From On-line to In-class: What Educators Can Learn From Young People with Dyslexia on YouTube™." Annual Conference of the Disability Studies in Education (DSE) Special Interest Group of the American Educational Research Association (AERA). University of Canterbury, Christchurch, New Zealand. June 7-9, 2013.

Threlkeld, A. (panel moderator). "Perfecting Friendship / Perfecting Democracy: Same-Sex Romantic Pairings as the Basis for American Freedom" with Michael Bronski, Michael Amico, Ivy Schweitzer, Robert Reid-Pharr, & Lisa Merrill. F.O. Matthiessen Symposium. Harvard University, Cambridge, MA. April 12, 2013

Threlkeld, A. "Young People Defining Dyslexia Online: A Critical Discourse Analysis." 9<sup>th</sup> Annual Critical Disability Studies Graduate Student Conference. York University, Toronto, Canada. April 6, 2013.

Muscarella, M. & Threlkeld, A. "Is He the Man?': Evolution of Medical Discourses of Intersex and Identity on *60 Minutes*"." Graduate Consortium on Women and Gender Studies. Massachusetts Institute of Technology, Cambridge, MA. April 5-7, 2013.

Scontras, G. & Threlkeld, A. "Introduction to Teaching at the College Level." Bok Center for Teaching & Learning Annual Conference. Harvard University, Cambridge, MA. August 28, 2012.

Threlkeld, A. "Promises & Barriers: Developing Teachers of Struggling Adolescent Readers." MACURE Research Roundtable. Massachusetts Reading Association 41<sup>st</sup> Annual Conference. April 9, 2010.

Threlkeld, A. & Francois, C. "Promises & Barriers to Professional Development of Teachers of Adolescent Struggling Readers in a Specialized Reading Intervention." Annual Student Research Conference. Harvard Graduate School of Education, Cambridge MA. March 26, 2010.

### **INVITED TALKS**

"Freaks/Supercrips/Overcomers: Approaches to Examining Common Disability Narratives." Guest Lecture. Advanced Qualitative Methods Seminar, Harvard Graduate School of Education, Cambridge, MA. April 17, 2014.

"Seeing Horror: A PTSD Reading." Guest Lecture. Harvard College, Cambridge, MA. March 26, 2014.

"'It's a Lovely Fucking War': Politics, Trauma and Representation of the Vietnam War Veteran in Post-War Hollywood Cinema." Guest Lecture. Harvard College, Cambridge, MA. March 26, 2014.

"Complicating Critical Discourse Analysis." Guest Lecture. Advanced Qualitative Methods Seminar, Harvard Graduate School of Education, Cambridge, MA. April 17, 2013.

"Constructing Dyslexia On-line: What Educators Can Learn from YouTube™." Guest Lecture. Reading Difficulties Seminar, Harvard Graduate School of Education, Cambridge, MA. April 16, 2013.

"Introducing Critical Discourse Analysis." Guest Lecture. Advanced Qualitative Methods Seminar, Harvard Graduate School of Education, Cambridge, MA. April 10, 2013.

"Teaching Vocabulary to English Language Learners." Guest Workshop. Red Clay School District, Wilmington, DE. January 10, 2013.

"Academic Vocabulary for Success." Guest Workshop. Ysleta Independent School District, El Paso, TX. January, 7, 2013.

"Pedagogical & Curricular Strategies for Teaching Introductory Courses." Guest Presentation. Women, Gender & Sexuality Studies Brown Bag Lunch Series. Harvard University, Cambridge, MA. November 16, 2012.

"Targeted Reading & Mathematics Intervention." Guest Presentation. PS36M, New York, NY. September 25, 2012.

"Backward Design and the College Syllabus." Guest Presentation. Pedagogy Potluck, Studies of Women, Gender & Sexuality Studies, Harvard College, Cambridge, MA. August 14, 2012.

"Response to Intervention in Tier 1: Addressing Student Needs through Differentiation." Guest Presentation. PS/IS 41, Brooklyn, NY. June 7, 2012

"Applying Critical Discourse Analysis." Guest Lecture. Advanced Qualitative Methods Seminar, Harvard Graduate School of Education, Cambridge, MA. April 6, 2012.

"Positioning and Picket Signs: Westboro Baptist Church and Informed Reactions." Guest Presentation. Advanced Qualitative Methods Seminar, Harvard Graduate School of Education, Cambridge, MA. March 2, 2012.

"Seeking Definitions, Expecting Differences: A Thematic Approach to the Stories of Young People with Dyslexia on YouTube™." Guest Lecture. Reading Difficulties Seminar, Harvard Graduate School of Education, Cambridge, MA. April 11, 2012.

"Differentiation Strategies for Science & Mathematics." Guest Presentation. El Paso Independent School District, El Paso, TX. January 2, 2012.

"Rigor & Relevance? How to Support Academic Language Growth in English Language Arts & among English Language Learners." Guest Presentation. New York Department of Education, New York, NY. December 9, 2011.

"Targeted Reading & Mathematics Intervention." Guest Presentation. New York City Department of Education, New York, NY. December 8, 2011.

"Differentiation Strategies in the Content Areas." Guest Presentation. IS 250Q, Queens, NY. October 19, 2011.

"Instructional & Assessment Techniques in English Language Arts." Guest Lecture. Orange County Department of Education, Costa Mesa, CA. November 11, 2011.

"Non-fiction & Content Area Reading Strategies." Guest Presentation. Peoria Unified School District, Peoria, IL. September 21, 2011.

"Assessing Reading Comprehension Thinking Strategies." Guest Presentation. PS129M, New York, NY. August 26, 2011.

"Teaching through Primary Sources." Guest Presentation. PS129M, New York, NY. August 19, 2011.

"Using Primary Sources & Visual Materials in Social Studies." Guest Presentation. Kanawha School District, South Charleston, WV. August 11-12, 2011.

"Differentiation Strategies for Science & English Language Arts in the Middle School Special Education Setting." Guest Presentation. Clint Independent School District, Clint, TX. August 8, 2011.

"Targeted Reading Intervention." Guest Presentation. PS129M, New York, NY. August 5, 2011.

"Differentiation Strategies in the Elementary School Classroom." Guest Presentation. Jefferson County School District, Shepherdstown, WV. July 26-27, 2011.

"Differentiation Strategies for Science." Guest Presentation. El Paso Independent School District, El Paso, TX. July 18-19, 2011.

"Targeted Reading & Mathematics Intervention." Guest Presentation. New York Department of Education, New York, NY. June 28-29, 2011.

"Differentiation Strategies for Secondary Math, Social Studies, Science & Language Arts." Guest Presentation. Las Cruces Public School District, Las Cruces, NM. June 13-16, 2011.

"How to Analyze Primary Sources." Guest Presentation. New York City Department of Education, Brooklyn, NY. June 7, 2011.

"Teaching Strategies for Writing, Grammar, Usage & Mechanics." Guest Presentation. PS129M, Newark, NJ. May 21, 2011

"Critical Discourse Analysis." Guest Lecture. Advanced Qualitative Methods Seminar, Harvard Graduate School of Education, Cambridge, MA. April 7, 2011.

"Targeting Reading & Math Intervention." Guest Presentation. PS98M, New York, NY. March 4, 2011.

"Early Childhood Thematic Instruction." Guest Presentation. Riverton Street Charter School, St. Albans, NY. January 31, 2011.

"Content & Non-fiction Reading Strategies." Guest Presentation. Peoria Unified School District, Peoria, IL. January 28, 2011.

"Traits of Good Writing K-6" Invited Workshop Series. PS.150K, Brooklyn, NY. January 5, 13 & 19, 2011.

"Q: An Introduction to Qualitative Research in Education." Guest Presentation. Early Childhood Literacy Seminar, Harvard Graduate School of Education, Cambridge, MA. November 11, 2010.

"Applying Differentiation Strategies to the Secondary Classroom." Guest Presentation. Putnam County School District, Charleston, WV. October 11-12, 2010.

"Using Podcasts, Blogs & Wikis in Education." Guest Presentation. Jackson Public School District, Jackson, MS. July 30, 2010.

"Curricular Design & Teaching Academic Vocabulary." Guest Presentation. Jackson Public School District, Jackson, MS. July 29, 2010.

- "From Learning to Write to Writing to Learn: Reaching all Learners." Guest Presentation. Jackson Public School District, Jackson, MS. July 28, 2010.
- "Meeting the Needs of Struggling Readers through Differentiation." Guest Presentation. Jackson Public School District, Jackson, MS. July 27, 2010.
- "Non-fiction Reading Strategies & Assessing Comprehension." Guest Presentation. Jackson Public School District, Jackson, MS. July 26, 2010.
- "Response to Intervention in Tier 1: Differentiation & Content Management." Guest Presentation. PS/IS 41, Brooklyn, New York. June 10, 2010.
- "Applying Foucauldian Discourse Analysis: Masculinity & Heteronormativity." Guest Lecture, Advanced Qualitative Methods Seminar, Harvard Graduate School of Education, Cambridge, MA. April 4, 2010.
- "A Case Study of Educational Leadership: Landmark School." CASE Foundation Lecture. Harvard Graduate School of Education, Cambridge, MA. April 22, 2009.
- "Modeling Emotional Traits of Adolescents with Learning Disabilities." Guest Lecture. Harvard Graduate School of Education, Cambridge, MA. March 11, 2009.
- "Applying Foucauldian Discourse Analysis: Masculinity for example." Guest Lecture. Advanced Qualitative Methods Seminar, Harvard Graduate School of Education, Cambridge, MA. December 12, 2008.
- "Adolescent Literacy Interventions at the School-level." Guest Lecture. Reading Difficulties Seminar, Harvard Graduate School of Education, Cambridge, MA. April 22, 2008.
- "Institutional & Individual Approaches to Reading Difficulties." Guest Lecture. Reading Difficulties Seminar, Harvard Graduate School of Education, Cambridge, MA. April 15, 2008.

### **OTHER CONTRIBUTIONS**

Threlkeld, A. (2015). Five ways to reduce ableism in the college classroom. Bok Center for Teaching and Learning, Harvard University. Published online.

Erikson-Shroth, L. (Ed.) (2014). *Trans Bodies Trans Selves*. London, UK: Oxford University Press. (Advisor on Disability Issues).

Threlkeld, A. (2013). Confronting sexist language and behaviors in the college classroom. Bok Center for Teaching and Learning, Harvard University. Published online: <a href="http://blog.bokcenter.harvard.edu/2013/09/26/confronting-sexist-language-and-behaviors-in-the-college-classroom/">http://blog.bokcenter.harvard.edu/2013/09/26/confronting-sexist-language-and-behaviors-in-the-college-classroom/</a>

Threlkeld, A. (2013). Multitasking. Bok Center for Teaching and Learning, Harvard University. Published online: http://blog.bokcenter.harvard.edu/2013/09/11/multitasking/

Threlkeld, A. (2013). Teaching Tip: Think-Pair-Share. Bok Center for Teaching and Learning, Harvard University. Published online: <a href="http://blog.bokcenter.harvard.edu/category/tips-tricks/">http://blog.bokcenter.harvard.edu/category/tips-tricks/</a>

Threlkeld, A. (2012). Product Field Test: Smarty Ants Pilot Investigation. Published online.

Threlkeld, A. (2012). Product Field Test: Smarty Ants Summer Pilot Investigation. Published online.

Eidelman, H. & Threlkeld, A. (2012). Mixed methods evaluation of Smarty Ants: Assessing program aims & implementation of a pilot study. Published online.

Threlkeld, A. & Callahan, M. (2011). Research White Paper Smarty Ants Reading World: Meeting the Needs of English Language Learners. Published online.

Threlkeld, A. & Callahan, M. (2011). Research White Paper Smarty Ants Reading World: Meeting the Needs of Students Learning English as a Foreign Language. Published online.

Threlkeld, A. & Nathan R. (2011). Research White Paper Smarty Ants Reading World: Comprehensive PreK-2 Reading Curriculum Based on Respected Research & Literature. Published online.

Kuttner, P. & Threlkeld, A. (2010). "Q: Introduction to Qualitative Methods in Education." Website for Harvard Graduate School of Education. Published online: http://www.isites.harvard.edu/qualitative

New York City Department of Education. (2007). *District 75: High School Units of Study*. New York: New York City Department of Education.

### PEER REVIEW

International Journal of Inclusive Education, *Peer Reviewer*Teaching Education, *Peer Reviewer*Considering Disability, *Full Reviewer*AERA Annual Conference, *Graduate Student Reviewer*Journal of Political Psychology, *Peer Reviewer* 

### PROFESSIONAL MEMBERSHIPS

American Educational Research Association

 Qualitative Research, Disability Studies, Queer Studies, Critical Educators, Narrative Studies SIGs

# Council For Exceptional Children

Divisions for Learning, Emotional & Behavioral Disabilities
 Phi Delta Kappa

### **CERTIFICATIONS**

New York State Special Education K-12, Permanent Teacher Certification

## **TECHNICAL SKILLS**

Productivity/Course Management: iLife, Elluminate, Blackboard, iSites, Prezi

Research: EBSCOhost, SAS, STATA, Dedoose, Atlas.ti

Video Production: Final Cut Pro, iMovie

### **LANGUAGES**

Spanish, Italian & French Anglo-Romani can translate scholarly material

heritage speaker

### REFERENCES

Helen Haste, Ph.D.

Visiting Professor, Harvard Graduate School of Education Professor Emeritus, Bath University

Caroline Light, Ph.D.

Director of Studies, Women, Gender & Sexuality Studies, Harvard College

Linda Schlossberg, Ph.D.

Assistant Director of Studies, Women, Gender & Sexuality Studies, Harvard College.

Michael Bronski

Professor of Practice in Media and Activism, Women, Gender & Sexuality Studies, Harvard College

Catherine Snow, Ph.D.

Patricia Albjerg Graham Professor of Education, Harvard Graduate School of Education

Jennifer Thomson, Ph.D.

Professor, University of Sheffield