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Table of Contents

Editorial

Research Articles

Multimedia

Editorial
What is the Future of Disability Rights?

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Associate Editor for Research and Essays

I have been Associate Editor for Research and Essays for the Review of Disability Studies for over a year now. In that time I've been impressed and encouraged by the skill and commitment of the people at the University of Hawaii's Center on Disability Studies who edit and publish the journal. I have enjoyed, tremendously, the opportunity to get to know them, and other new members of the Editorial Board.

The Editor in Chief, Megan Conway, has been particularly good at not only continuing the good work done by previous editors of RDS but in building understanding among a disparate group of Associate Editors and creating a vision for the future of the journal. During much of the time I've been associated with the journal, she, and others at the Institute, have done a tremendous amount of work in keeping the journal going and in helping us integrate into the operation of the journal.

The result, as you can see in this issue, is representative of work being done across the board in disability studies and rehabilitation, which is possible due to the excellent level of contributions from authors but importantly to the commitment of the editing staff. I hope you will enjoy reading this journal and I encourage any of you not already subscribed to subscribe to it as well as to contribute to it.

I also would like to ask us all to think about the future of disability in our world through two older (but still capable of providing surprises) perspectives: technology and disability rights. Forty years ago, in the USA in particular, a number of advocates and organizations were consciously using the Declaration of Independence as a template for why disabled people's rights were inalienable, even if rights were at the time not well-established in US law or practice. Their efforts have led to (in the USA) an environment where disability rights in education and the community are based on Federal and state or local laws. An unanticipated consequence of basing rights and services on government-created laws results in a situation in which rights granted by a government can, logically, be taken away by a government. At the same time, the United Nations has (since 1948, at least) issued several "declarations" identifying human rights, and most recently the Declaration on the Rights of Individuals with Disabilities, based on a strong natural rights approach (that is, that certain rights are inalienable, even if not always exercisable, as in the Declaration of Independence). But, what happens to disabled people in an environment where technology, perhaps gene editing (currently occurring as CRISPR) or future genetic therapies can eliminate conditions like Down Syndrome, cystic fibrosis, and so on? Should a majority in a political system be permitted to take away the right to be as one is, as (say) a person with Down Syndrome? Another way to put this is to think about uses for technology of this sort that many of us might not think of as desirable: for example, should parents be able to prune any genetic condition that they wish?

The Deaf community is faced with technology that promises a "cure" for deafness, leading to a smaller and perhaps marginalized Deaf community. Why couldn't parents be able to edit genes for height, or body type, or hair color – or even (should they be pinpointed) genes that might contribute to sexual orientation?

Many of these discussions have been going on for years, but they will become more common and more important over the next 5, 10, or 20 years, as the ability of human beings to direct the future of themselves and their offspring moves from fiction and speculation to reality. No doubt, the pages of the Review of Disability Studies will contribute to the debates.

Research Articles

The Role of the Built Environment in Individuals with Mobility Disabilities' Physical Activity

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Abstract: This study explored the relationship between the built environment and the health behaviors of individuals with mobility disabilities. The findings suggest that individuals with mobility disabilities are likely to participate in light recreation activities more often if there are opportunities to do so within convenient pedestrian distance of their residence.

Keywords: disability, health behavior, recreation, pedestrian

Introduction

There are strong demonstrated associations between physical activity and health. Community-scale urban design and land use policies and practices may increase physical activity through sidewalks, bicycle lanes, nearby parks and open space, mixed land uses, and the connectivity, aesthetic and safety aspects of the street-scale built environment (Taylor & Lou, 2011; Heath, Brownson, Kruger, Miler, Powell & Ramsey, 2006; Saelens & Handy, 2008; Mowen, 2010; Kaczynski & Henderson, 2007). The design of the built environment is an important factor in the health of the general population (Jackson, 2003).

The impact of the built environment on health behaviors appears to be different across various demographic subgroups (Kremmers, De Bruijn, Visscher, Mechelen, De Vries & Brug et al., 2006). Individuals with disabilities represent 12% of the total population of the United States (Census, 2010), yet research on the impact of the built environment on the health behaviors, particularly physical activity, of individuals with disabilities, is limited (Rimmer, Riley, Wang, Rauworth & Jukowski et al., 2004). Although limited, these studies suggest that the aspects of the built environment that increase physical activity among the general population may facilitate physical activity in disabled populations (Spivok, Gauvin, Riva & Brodeur et al., 2008). However, these studies have primarily assessed accessibility to recreation programs and fitness facilities (Rimmer et al., 2004; Christensen, Holt & Wilson et al., 2010; Rimmer, Riley, Wang & Rauworth et al., 2005), environmental supports that effect physical activity (Spivok, 2008; Spivok, Gauvin & Brodeur et al., 2007), and community mobility as influenced by the built environment (Shumway-Cook, Patla, Stewart, Ferrucci, Ciol & Guralmik et al., 2002).

There is a significant need to address the information gap which persists regarding the effects of the built environment on the physical activity of individuals with disabilities. Built environment characteristics such as pathway texture, disconnected pedestrian ways, signage, and slope become more influential on individuals with disabilities' participation in physical activity than they do for in comparison to individuals without disabilities (Spivok et al., 2007), in addition to chronically inaccessible built environments (Spivok et al., 2008).

disability during January and February 2012. The questionnaire was also available in Spanish, with one respondent completing the Spanish language version.

Environment and Physical Activity Questionnaire

The self-administered survey instrument is based on an existing validated instrument, the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) (Washburn, Zhu, McAuley, Frogley & Figoni et al., 2002). PASIPD has been shown to provide accurate and reliable information regarding the physical activity of individuals with disabilities, where greater flexibility in

These conditions may result in fewer opportunities to engage in beneficial health behaviors (Rimmer et al., 2004), contributing to an increased risk for sedentary behavior and the associated disparities which persist in nearly every aspect of health among individuals with disabilities (AHRQ, 2007). Only 36% of individuals with disabilities engage in physical activity with some demographics reporting only 8% (Rimmer, 1999) in comparison to 56% of individuals without disabilities who engage in physical activity (Rimmer et al., 2004). The prevalence of sedentary behaviors among individuals with disabilities increases their susceptibility to chronic diseases and secondary health conditions (Rimmer, Braddock & Pitetti et al., 1996; Dannenberg, Jackson, Frumkin, Schieber, Pratt, Kochtitzky & Tilson et al., 2003). There is a need to address the effects of the built environment on the physical activity of individuals with disabilities.

Research Objectives

The purpose of this pilot study is to explore the role the built environment plays in relation to the health behaviors of individuals with disabilities, specifically physical activity. To do so, three research questions were examined: To what extent the physical activity of individuals with disabilities are affected by (1) the presence of public park space; (2) the connectivity of pedestrian infrastructure; and (3) the diversity of land use in the community. These built environment factors are some of those which have been shown to be related to the physical activity rates of the general population.

Methods

Population

The study setting corresponds with the U.S. Census designated Ogden-Clearfield metropolitan/micropolitan statistical area (MSA) in north central Utah, which encompasses 1,489 square miles of land area reflecting development and land use diversity patterns consistent with typical U.S. suburban/urban communities, a land use pattern assumed to be more likely to include the environmental factors of interest (public park space, pedestrian infrastructure, and diverse land uses in close proximity). The Ogden-Clearfield MSA has a population of 547,184 of which 49.8% are female, 88.1% are white, and 11.8% are Hispanic or Latino. Of the total population, 319,808 individuals are between 18 and 64 years of age, of which 8.1% (24,942) report being individuals with disabilities, and 3.4% (10,813) report having ambulatory difficulty.

The study focused on individuals with mobility/physical disabilities 18 years of age and older residing in the study setting. As there is wide variability in type and degree of disability, individuals with mobility/physical disabilities were included under the assumption that the physical activity of such would most likely be impacted by the built environment, and that the identified impacts may generalize to the larger population of individuals with disabilities. Participants self-identified themselves as individuals with a mobility/physical disability.

A self-administered Environment and Physical Activity Questionnaire was mailed to a sample population of 1040 individuals 18 years of age and older identified as having a physical reporting rate and intensity is required. The PASIPD was primarily modified to reflect a focus on the built environment. The resulting Environment and Physical Activity Questionnaire (EPAQ) is divided into eight short sections to assess basic demographics, the built environment context, and the major types of physical activity; stationary activities, non-leisure time pedestrian activities (activities of daily living), light recreational activities, moderate recreational activities, strenuous recreational activities, and muscle strengthening exercise activities.

The demographic section includes routine questions regarding age, gender, disability type, employment, and education. These questions were used to verify participant inclusion. Participants were also asked to rate their level of physical activity (Not active at all, Moderately active, Active, or Extremely active) and current health (Excellent, Good, Fair, or Poor).

The six physical activity sections were each a six part question differing only in the type of physical activity being assessed. Each section's questions include, for light recreational activities:The six questions are listed in Table 1.

Table 1
Sample physical activity questions.

During the past 7 days, how often did you engage in light sport or recreational activities such as bowling, golf with a cart, hunting or fishing, darts, billiards or pool, therapeutic exercise (physical or occupational therapy, stretching, use of a standing frame) or other similar activities?
Never (instructed to proceed to next section)
Seldom (1-2 days)
Sometimes (3-4 days)
Often (5-7 days)
On average, how many hours per day did you spend in these light sport or recreational activities?
Less than 1 hour
1-2 hours
2-4 hours

More than 4 hours
What was your primary activity?
Open-ended response
Are you able to do this activity within four blocks of your home?
Yes
No
Do you do this activity in a:
Public space or facility?
Private space or facility?
Do you require personal assistance to participate in your primary activity?
Yes
No

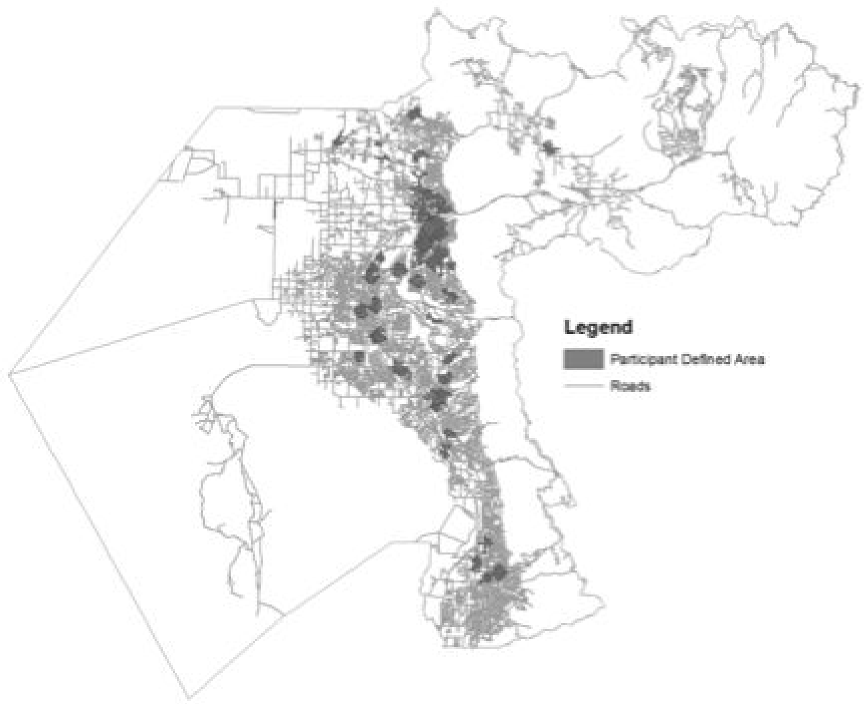
The built environment section asked participants to indicate the address of the street intersection nearest their home. This information was used to spatially model each respondent's immediate built environment, as was necessary to measure the built environment factors described below. Participants were also asked to assess the quality and ADA (Americans with Disabilities Act) accessibility of the sidewalks, public parks, and private recreation facilities within four blocks of their home (Excellent, Good, Fair, Poor, N/A). In addition, participants were asked whether their ability to participate in physical and recreational activities outside their home is affected by weather conditions.

Environment Factors

Based on the nearest street intersection for each respondent, a unique participant defined area (PDA) was calculated as a one kilometer network buffer using a geographic information system (GIS). One kilometer was selected to represent the distance an individual would be most likely to experience as a pedestrian (Lovasi, Moudon, Pearson, Hurvitz, Larson & Siscovick et al., 2008). Additionally, the distinction between perceived characteristics and objectively measured characteristics of the built environment breaks down beyond one kilometer (Lovasi et al., 2008). A network buffer, shown to provide more accurate representation than a circular area, with a 50 meter buffer depth was chosen to ensure that land use along the selected automobile/pedestrian network would be included, but that land not readily accessible from the automobile/pedestrian network would not be (Oliver, Schuuman & Hall et al., 2007). Each of the built environment factors was determined according to individual PDAs, which are shown in Figure 1. To be more easily understood by participants, the Environment and Physical Activity

Questionnaire described the one kilometer measure of the likely pedestrian environment, as the area within four blocks of the participant's home.

Figure 1. *Participant defined areas within the study setting*



Alternative text description – The image depicts all participant defined areas indicated within the study setting of Davis and Weber counties.

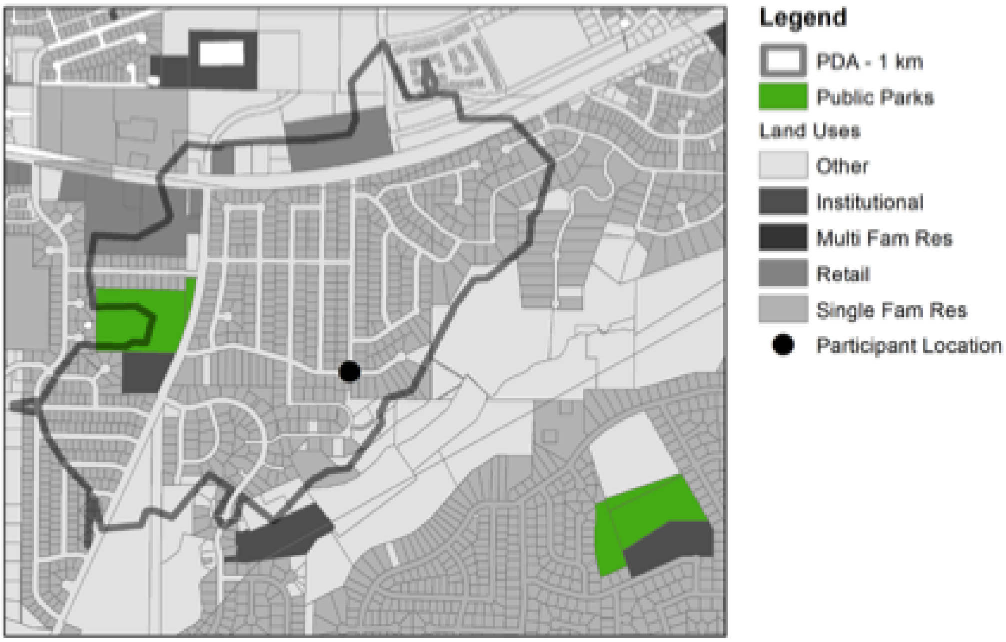
Land Use Diversity

The descriptive measure of pedestrian-oriented land use diversity is an entropy score describing the diversity of the distribution of four land use categories for each PDA determined according to the following equation;

$$\text{entropy} = - \{\sum_{k} [(pi)(\ln pi)]\}/ (\ln k)$$

where is the percentage of each of the land uses and k is the number of land uses. The equation results in a normalized value between 0 and 1 (where each land use is 1/4th of the total), the larger value representing greater diversity of land use. The four land use types considered are single family residential, multi-family residential, retail and services, and institutional. These land use types, and their description by entropy score, have been found to be a significant predictor of pedestrian behaviors (Brown, Yore, Ham & Macera et al., 2005; Brown, Yamada, Smith, Zick, Kowaleski-Jones & Fan et al., 2009) in suburban/urban environments. An example of the land use diversity and distribution for one PDA may be seen in Figure 2, the entropy score for which is .4618 due to the predominance of single family residential land use.

Figure 2. *Environment factors for an example participant defined area*



Alternative text description – The image illustrates the public parks and various land uses within one participant defined area. The area is primarily comprised of single family residences, with some retail, multi-family residences and two public parks.

Public Parks

The descriptive measure of public park space is the percentage of each PDA's land area designated as public park space. The location and spatial configuration of over 200 public park spaces for the study setting were identified manually in the GIS system using each municipality's and county's addresses for public parks. An example of the public park distribution for one PDA may be seen in Figure 2, the percentage of which is 2.65.

Pedestrian Connectivity

The pedestrian network is defined as constructed pathways providing pedestrian circulation typical to the built environment (i.e. sidewalks, hiking trails, etc.). The location and spatial configuration of the pedestrian network were derived from roadways generally associated with pedestrian improvements (residential streets, collectors, etc.). The descriptive measure for pedestrian connectivity is the number of roadway intersections per PDA. This method has been shown to be an effective measure of pedestrian connectivity associated with physical activity (Saelens, Sallis & Frank et al., 2003) in suburban/urban environments.

Results

Ninety-four individuals returned questionnaires (9% overall response rate), only sixty four of which were completed sufficiently for inclusion in the study (6.2% effective response rate).

Of these, forty seven were completed by individuals who self-reported possessing a mobility/physical disability (17 were excluded; 4.5% inclusion rate). A general description of participant responses is presented in Table 21. Response Frequencies. Respondents' overall participation in stationary activity is high and, as was expected, participation in physical activity is low (see Table 32. Activity Participation Rates). Table 43 provides a synopsis of the study findings, the specifics of which are reported hereafter.

Table 2

Response Frequencies (%)

What is your age?	
18-34 years	10.6
35-51 years	25.5
52-64 years	31.9
65 years and over	31.9
What is your gender?	
Male	31.9
Female	68.1
Are you currently employed?	
No	80.9
Yes	19.1
Are you currently in school?	
No	89.4
Yes	10.6
How would you rate your level of physical activity?	
Not active at all	36.2
Moderately active	57.4
Active	4.3
Extremely active	2.1
How would you rate your current health?	

Excellent	6.4
Good	31.9
Fair	44.7
Poor	17.0
How ADA accessible are the sidewalks within four blocks of your home?	
Excellent	17.0
Good	29.8
Fair	31.9
Poor	21.3
How ADA accessible are the public parks or facilities within four block of your home?	
Excellent	17.4
Good	19.6
Fair	30.4
Poor Not Available	17.4 15.2
How ADA accessible are the private facilities within four blocks of your home?	
Excellent	4.4
Good	22.2
Fair	11.1
Poor Not Available	15.6 46.7
Is your ability to participate in physical and recreational activities outside your home affected by the weather? (Hot or cold temperatures, Ice/snow conditions, Rainy/wet weather, Sunny conditions)	
Yes	78.7
No	21.3

Alternative text description – Table 2 “Response Frequencies (%)” displays percentages of respondents’ answers to questions including: Age, gender, employment status, school status, physical activity, current health, ADA accessibility near one’s home (sidewalks, public parks, private facilities), and weather and how it might affect one’s ability to participate in physical and recreational activities.

Table 3.
Activity Participation Rates (%)

	Never	**Seldom (1-2 days)**	**Sometimes (3-4 days)**	**Often (5-7 days)**
9. During the past 7 days how often did you engage in *stationary activities*?				
	4.3	12.8	12.8	70.2
10. During the past 7 days, how often did you *walk or wheel* outside your home other than specifically for exercise?				
	17.0	21.3	27.7	34.0
11. During the past 7 days, how often did you engage in *light sport* or *recreational activities*?				
	59.6	19.1	17.0	4.3
12. During the past 7 days, how often did you engage in *moderate sport* and *recreational activities*?				
	82.6	15.2	2.2	-
13. During the past 7 days, how often did you engage in *strenuous sport* and *recreational activities*?				
	89.4	8.5	2.1	-
14. During the past 7 days, how often did you do any exercise specifically to *increase muscle strength* and *endurance*?				
	52.2	13.0	19.6	15.2

Alternative text description – Table 3 “Activity Participation Rates (%)” displays percentages of respondents’ answers to questions about physical activity.

Table 4
Activity Participation Correlation with Built Environment Factors

	Within 4 blocks	**Public Parks**	**Pedestrian Connectivity**	**Land Use Diversity**

	of home			
Stationary Activities				
Walk/Wheel outside the home				Negative
Light Sport or Recreation	Positive			Negative
Moderate Sport or Recreation				
Strenuous Sport or Recreation				
Muscle Strength or Endurance Exercise	Positive		Negative	

Alternative text description – Table 4 "Activity Participation Correlation with Built Environment Factors" provides a synopsis of the study findings, the specifics of which are reported hereafter.

Linear regression analysis conducted to predict physical activity participation levels from the built environment predictors (public parks, pedestrian connectivity, and land use diversity) did not indicate that the variables were linearly related, with the exception of muscle strengthening activity and pedestrian connectivity. The results indicate a moderate correlation (-.308) such that as the overall pedestrian connectivity increases participants engaged in muscle strengthening activity less. The regression line equation is:

$$\textit{Predicted Muscle Strengthening} = -0.13\ \textit{Pedestrian Connectivity} + 2.966$$

The 95% confidence interval for the slope is -.025 to -.001. Approximately 10% of the change in how often participants engaged in muscle strengthening activity was accounted for by its linear relationship with the surrounding pedestrian connectivity.

An independent-samples *t* test was conducted to evaluate whether individuals with mobility disabilities participate in physical activity more often if they have opportunities to do so within 4 blocks of their home, a convenient pedestrian distance. Each respondents' physical activity rate was grouped as either seldom (0-2 days per week) or regularly (3-7 days per week). The test was significant for light recreation ($t(19) = 2.85$, $p = .01$), as individuals who are able to do so within four blocks of their home engage in light recreation ($M = 1.60$, $SD = .507$) more often than those who do not ($M = 1.00$, $SD = .000$). This test also indicates that those who are unable to participate in light recreation within four blocks of their home do not participate at all. Participants reported that these light recreation activities included walking, shopping, and physical therapy performed at home.

The test was also significant for muscle strengthening activity (t(18) = 2.65, p = .016), as individuals who are able to do so within four blocks of their home engage in muscle strengthening activity (M = 1.70, SD = .483) more often than those who do not (M = 1.18, SD = .405). The majority of the activities participants reported as their primary activity were therapeutic in nature (resistance bands, stretching, walking, etc.). Further, the majority of participants reported engaging in these activities less than one hour daily (70.4%) in a private space or facility (72.7%), suggesting that these activities are taking place at home.

Independent-samples t tests were not conducted for moderate or strenuous physical activity participation as only one participant indicated participating often in moderate physical activity and one in strenuous physical activity.

A linear regression conducted to predict how often participants walked/wheeled outside their home from the environmental predictors (public parks, pedestrian connectivity, and land use diversity) indicated that land use diversity is moderately related (-.37) such that as overall land use diversity increases participants walk/wheel outside their home less. The regression equation is:

$$\textit{Predicted Walk/Wheel} = -1.971\ \textit{Land Use Diversity} + 4.068$$

The 95% confidence interval for the slope is -3.475 to -.468. Approximately 13% of the change in how often participants walked/wheeled outside their home was accounted for by its linear relationship with the surrounding land use diversity.

Binary logistic regression to predict participation in light recreation or muscle strengthening exercise, grouped as either seldom (0-2 days per week) or regularly (3-7 days per week), from the environmental predictors (public parks, pedestrian connectivity, and land use diversity) indicated that individuals with mobility disabilities residing in areas with more diverse land use decreased their odds for participating in light recreation by a factor of .008 (p = .032, 95% CI .000 and .649) (omnibus chi-square = 5.315, df = 1, p = .021). The model accounted for between 12.2% and 20.3% of the change in light recreation participation, with 100% of predictions for those seldom participating in light recreation and 14.3% of predictions for those participating regularly predicted successfully.

A linear regression conducted to predict participants’ current health from the environmental predictors (public parks, pedestrian connectivity, and land use diversity) did not indicate a relationship.

Examining where individuals with disabilities are participating in physical activity, whether a public or private space or facility, indicates that the majority of individuals with mobility disabilities use private spaces to participate in light recreation (68.5%), strenuous activity (55.6%), and muscle strengthening exercise (72.7%). Whereas public spaces are used for moderate physical activity (66.7%). That individuals with mobility disabilities are seldom participating in moderate (97.5%) or strenuous (97.6%) physical activity, while higher percentages are participating regularly in light recreation (17.1%) and muscle strengthening exercise (31.7%), suggests that there are not appropriate opportunities available in public spaces or facilities.

Discussion

Given the low number of study participants, the results should be examined with some caution. This study, similar to prior studies (Rimmer, 1999), indicates that individuals with mobility disabilities' participation in almost every form of physical activity is very low. As a result, it is likely that the discernible effects of environmental factors is small. In addition, it is unlikely that a single factor can fully elucidate the complexities of an individual with disability's relationship with the built environment. As such, we would expect the role the built environment plays in relation to the health behaviors of individuals with disabilities to be difficult to identify.

Indeed, at first glance the hypotheses that the physical activity of individuals with mobility disabilities are affected by (1) the presence of public park space; (2) the connectivity of pedestrian infrastructure; and (3) the diversity of land use in the community appear to be false when examined through a straightforward linear regression analysis. Closer examination reveals nuances in this finding.

The results indicate that individuals with mobility disabilities are likely to participate in light recreation activities more often if they have opportunities to do so within four blocks of their place of residence. The Center for Disease Control and Prevention (CDC) has long suggested that adults participate in moderate-intensity physical activity, the equivalent of brisk walking at three to four miles per hour most days of the week (Haskell, Lee, Pate, Powell, Blair, Franklin & Macera et al., 2007). For individuals with mobility disabilities, doing so appears to be related to the environment available as a pedestrian from their place of residence. Further, those individuals with mobility disabilities who do not have opportunities to do so within four blocks of their place of residence do not participate in light recreation activities. Participants indicated that these light recreation activities are primarily pedestrian activities such as walking or shopping. Such findings support earlier findings that the aesthetics and safety aspects of the street-scale built environment, which support pedestrianism, may increase physical activity (Taylor and & Lou, 2011; Heath et al., 2006). For individuals with mobility disabilities, the accessibility characteristics of the street-scale built environment must be added to these qualities. The quality of the street/pedestrian environment, within a walkable distance, is important for the support of individuals with mobility disabilities' participation in light recreation activities.

Similarly, individuals engaging in muscle strengthening activities are more likely to do so within four blocks of their home. Further, participants' reported activities, such as stretching, resistance bands, and walking, emphasize the importance of an individual's home and the immediate pedestrian environment.

Individuals with mobility disabilities indicated that public parks are used for moderate physical activity, however very few participate in moderate physical activity. As the findings suggest that there is not a significant difference in the presence of public parks between participants, it may be that there are not opportunities for physical activity which that are accessible to individuals with mobility disabilities in these parks. Where there are public parks with accessible recreation opportunities within convenient pedestrian distance, individuals with mobility disabilities may be more likely to participate in moderate recreation activities. Future research should examine the impact of public parks more closely.

As the poverty rate among individuals with mobility disabilities is disproportionately high (Erickson, Lee & von Schrader et al., 2012), these opportunities need to occur in close enough proximity as to not require additional transportation costs. Similarly, the results indicate that the majority of individuals with mobility disabilities do not use private recreation facilities, which may be the result of the cost of membership associated with these facilities. These findings underscore the importance of public opportunities within convenient pedestrian distance for individuals with mobility disabilities to engage in recreation activities, particularly those which cannot occur at the individual's residence.

It is likely that the lower socioeconomic level of individuals with mobility disabilities is a major factor in their physical activity opportunities and behavior. Socioeconomic status affects access to and safety for physical activity because of fewer facilities, poorer condition of these facilities, and unsafe environments due to criminal activity, etc. (Wilson, Kirtland, Ainsworth & Addy et al., 2004). As discussed previously, this condition likely resulted in the absence of an association between the presence of public park space or the diversity of land use and physical activity patterns.

The results suggest that land use diversity, or mixed land uses, are correlated with a decrease in participants walking or wheeling outside their home. While mixed land use areas have been shown to be related to the physical activity rates of the general population (Brown et al., 2009), mixed land use areas characterized by lower income generally lack features that support walking, such as well-maintained sidewalks and an aesthetic and safe street-scale environment characterized by trees, pedestrian amenities, and less traffic (Owen, Schuuman & Hall et al., 2004; Humpel, Owen & Leslie et al., 2002). The lack of these features may counter the effect of mixed land use to support pedestrian and physical activity. Similarly, a lack of aesthetic and safe public parks and open spaces, may limit the effects of these environments seen with less vulnerable populations. Future research should examine the relationship between individuals with disabilities, the quality of the built environment, and socioeconomic levels on physical activity as the sample population of this study was too small to examine socioeconomic and other demographic factors.

Future Research

Future research should examine the relationship between individuals with disabilities, the quality of the built environment, and socioeconomic levels on physical activity as the sample population of this study was too small to examine socioeconomic and other demographic factors. This study suggests ample opportunities for future examination, particularly with a larger sample size. Although difficult to acquire, an increased sample size is strongly suggested as individuals with disabilities' participation in physical activity is generally very low, and the complexity of their participation is quite high. For example, this study indicates that over 78% of individuals with mobility disabilities' participation in physical and recreational activities was affected by the weather. Unfortunately, no additional information regarding the impact of weather was collected during this study. Further examination in light of built environment characteristics which may mitigate the effects of weather conditions is warranted. Likewise, the role of social support in mediating participation was not assessed, and is recommended for future study.

An examination of participants' open ended responses to the types of activities in which they participated revealed a great deal of overlap between light, moderate, strenuous, and muscle strengthening physical activity categories, although each survey question included specific examples of each type. Walking, in particular, was noted across every activity, which also highlights the importance of walking as physical activity for individuals with disabilities. Future research involving a similar survey instrument should seek for increased validity of the measure, particularly for light and moderate recreation

Conclusion

While it is unlikely that a single factor can fully explain the complexities of an individual with disability's relationship with the built environment, there is a significant need to address the information gap which persists regarding the effects of the built environment on the physical activity of individuals with disabilities. This study suggests that individuals with mobility disabilities are likely to participate in light recreation activities more often if they have opportunities to do so within a convenient pedestrian distance of their place of residence.

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Leveraging Teachable Moments: Enlisting Teacher Candidates in the Empowerment of Parents of Children with Disabilities

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Abstract: Minority parents of children with disabilities are often marginalized in special education. With this injustice in mind, this paper reports on research on the potential of special education teacher candidates to participate in the empowerment of these parents as advocates for their children's rights.

Keywords: Teacher Education, Special Education, Parental Rights

Introduction

Four decades after the passage of Public Law 94-142, the precursor to the Individuals with Disabilities Education Act (IDEA), parents of children with disabilities are often prevented from being effective advocates for their children (Ong-Dean, 2009). This is particularly true of minority and poor families (Doucet, 2011; Hyman, Rivkin, & Rosenbaum, 2011). While IDEA articulates procedural protections for parents in painstaking detail, much of the time they are sidelined, unprepared to be effective advocates (Spann, Kohler, & Soenksen, 2003; Wakelin, 2008). The difficulty of navigating the complexity of the law's procedural protections, a culture of institutional and professional hegemony, and the ascendency of "expert" discourses in special education have systematically marginalized parents' voices and restricted parental participation (Ong-Dean, 2009; Morgan, 2005; Skrtic & Kent, 2013). Only the most capable parents with access to adequate economic, cultural, and social capital are able to challenge institutions and professionals and fight for their children's rights to under IDEA (Trainor, 2010).

Thus, despite IDEA's legal assurances and ethical prescriptions, special education—its structures, practices, and professional culture—is often complicit in the marginalization of parents of children with disabilities. The system and the discourses it perpetuates have distorted and watered down society's promise of justice to children with disabilities. Yet, IDEA's promise endures. Therefore, if the system cannot keep that promise, it is up to committed individuals to do so. This is where teacher education can show its commitment to the empowerment of parents and social justice. As it is, special educators play a role in the systemic disenfranchisement of parents but this does not have to be. Special education teachers are insiders who are in a position to assist parents in their advocacy for their children (Hale, 2013). The present research demonstrates the potential of teacher candidates to develop dispositions toward respect for and collaboration with parents and therefore become their advocates rather than their adversaries. It is up to us, special education teacher educators, to identify that potential in all teacher candidates and leverage it into "teachable moments" in which to support and encourage the development of such dispositions and to prepare teacher candidates to recognize the need for parental empowerment and resist the oppressive culture of professional dominance in special education.

A central purpose of teacher education must be to prepare future and novice special education teachers to understand, respect, and advocate for parents of children with disabilities. Special education teachers who are disposed to be true advocates for children with disabilities and their parents can become agents of needed change (Connor, Valle, & Hale, 2012).

In this paper, I describe the findings of research based on interviews with special education teacher candidates at the end of their masters in special education degree program. I start with an overview of the literature showing the historic and ongoing failures of special education to make good on IDEA's guaranty of empowerment of parents of children in special education. Next, I describe the theoretical frameworks that inform my analysis of the research participants' narratives. Subsequently, I describe my findings. Finally, I outline my conclusions and the implications of this research.

Parents and Special Education

Soon after the 1975 enactment Public Law 94-142 (IDEA), in became apparent that parents were frequently unaware of their rights under the law and that the obfuscations of professional discourse contributed to their ignorance. Compounding this, educators often excluded them from meaningful participation in their children’s Individualized Education Program (IEP) planning meetings (Valle, 2011). Culturally and linguistically diverse parents in particular experienced bias and disenfranchisement, regularly reporting being denied respect and support (Harry, 2008).

Parental dissatisfaction with special education remains common today. Interviews with parents show many feel that special educators are doing little or nothing to satisfy their children's needs (Spann, Kohler, & Soenksen, 2003). Many parents tell of their children’s rights being denied (Barton, 2007), and describe a lack of cooperative and supportive relationships with professionals (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004).

Social class position plays an important part in determining parental success in securing access to needed services for their children. Middle-class parents of children with disabilities are commonly more proactive advocates. They are generally more skilled than working-class and poor parents at employing social capital (access to social networks) to acquiring information and professional guidance (Horvat, Weininger, & Lareau, 2003). More privileged parents are also more likely to obtain expertise and technical knowledge, such as knowledge of their children’s rights under IDEA (Trainor, 2010) and are more apt to participate in IEP meetings (Wagner, Newman, Cameto, Javitz, & Valdes, 2012). Accordingly, they are more effective than lower income parents at advocating for their children.

Cultural and linguistically diverse parents of children with disabilities often experience discriminatory bias and institutional barriers in their dealings with educators. They face cultural biases (Alvarez-McHatton, 2005; Harry, Klingner, & Hart, 2005) and prejudiced judgments of their parenting (Alvarez-McHatton, 2005; Harry, Klingner, & Hart, 2005; Kalyanpur, Maya, & Harry, 2004; Klingner & Harry, 2006). They are often sidelined in the special education process due to failure of professionals to support them in overcoming procedural barriers and/or supply procedural knowledge (Angelov & Anderson, 2012; Kalyanpur, Maya, & Harry, 2004; Klingner

& Harry, 2006) or deliver acceptable translation services (Alvarez-McHatton, 2005; Klingner & Harry, 2006).

Theoretical Frameworks

This paper employs two theoretical frameworks. Disability Studies in Education (DSE) provides a critical lens—informed by a commitment to social justice—on the education of children with disabilities. Positioning Theory is a tool of narrative analysis that reveals how individuals and/or groups judge others against normative standards.

Disability Studies in Education

Disability Studies in Education is an interdisciplinary field of inquiry that takes a critical view of special education practices and knowledge traditions. A DSE perspective differs from those found in traditional special education in many fundamental ways. DSE contests the medical model of disability that is central to special education practice and research. Rather than seeing disability as an intrinsic characteristic of the individual, DSE recognizes disability as a socially constructed phenomenon as well as a civil/human rights issue. While this social model of disability acknowledges that individual differences may result from impairments due to neurological, biological, cognitive, or psychological variations, it identifies disability as the product of social, political, economic, and cultural structures and practices. Impairment is a part of natural human variation but disability (always considered a negative characteristic) is a form of oppression resulting from normative expectations and interactions in the context of social life (Baglieri, Valle, Connor, & Gallagher, 2011). DSE is committed to listening to and respecting the perspectives of individuals with disabilities and their families. Consequently, parents should be involved in all phases of educational planning for their children, and should be seen as an important source of knowledge and an essential alternative perspective on their children‘s needs. Special education teacher education informed by DSE principles prepares teacher candidates to recognize the parental role as such and to see themselves as advocates for their students and parents (Ashby, 2012; Nishimura, 2011).

Positioning Theory

Positioning theory focuses on how speech acts of individuals, groups, organizations, etc. position others in storylines in the context of a local moral landscape. Positions are collections of beliefs about the ways in which rights and duties are distributed in the course of interactions. The local moral landscape enforces particular normative limitations and opportunities for action within a storyline. The positioning act determines the distribution of the rights and duties within human interactions and delimits the repertoire of potential actions of positioned individuals (Harré, Moghaddam, Cairnie, Rothbart, & Sabat, 2009). Positions also indicate expectations of how individuals should carry out their rights, duties, and obligations. Positions are dynamic; they change with changes in social setting and with transformations in positioning individuals' perspectives and beliefs. At the level of individual interaction, examining a position requires paying attention to discursive practices and interpretation of speech and other discursive acts (e.g. gestures, expressions). Attention to discursive acts reveals storylines that emerge from significant episodes and/or discursive patterns (McVee, 2011).

The Research

The focus of this research is to explore special education teacher candidates' understandings of parents of children with disabilities. The participants in the study were 10 teacher candidates completing their Masters program in special education. Nine of the participants are native born working-to-middle class European Americans living in a Northeastern urban center in the United States. The tenth, Sonya, is a Russian immigrant. They participated in approximately 45-minute interviews in which they recounted their experiences with special education students and their parents. Their narratives provide windows into their dispositions relative to parents, parenting, and parental involvement in special education. Analysis of the participants' narratives mostly focused on the role parents played in the participants' narratives. Analysis of the transcripts revealed various storylines in which most of the participants positioned themselves as professionals, unquestioningly affiliating themselves with professional knowledge and practices. They often positioned parents as "in denial" of their children's disabilities, disengaged from their education, and even negligent in their care. Sonya alone expressed only emotional understanding with and desire to advocate for parents of children with disabilities. This is likely due to the fact that she is a parent and has a strong sense of social justice. Yet, while the other participants' characterizations of parents were largely negative and deficit driven, interesting contradictions (recognitions of parental rights and sociocultural context) emerged from the participants' narratives. These contradictions are key to the central argument in this paper—that despite the overwhelming negativity of the participants' positionings, hopeful avenues remain for teacher educators to influence dispositions, broaden perspectives, and engage compassion and understanding.

Discussion of Findings

Parent-Professional Encounters in Special Education as Moral Landscape

To interpret the participants' positionings, the storylines construed from discursive acts embedded in their narratives must be placed in the context of a moral landscape or domain. As noted above, individuals' speech acts represent storylines in the context of local moral landscapes. The local context of speech acts is infused with moral ascriptions and normative standards. This is the local moral landscape or domain through which storylines are woven and according to which individuals are positioned as participants in those storylines (Harré, Moghaddam, Cairnie, Rothbart, & Sabat, 2009).

Local contexts and macro-social forces contribute to constructing the local moral landscape through which storylines are drawn (Anderson, 2009). The participants' exposure to the perspectives of their cooperating teachers and their encounters with parents contributed to the local context. Macro-forces such as sociocultural biases and master narratives of "good" parenting also played a part in rendering the local moral landscape.

One important feature of the local moral landscapes through which the participants' storylines flowed is the morally fraught character of parent-professional encounters in special education. Special education is a professional field that endows practitioners with significant moral gravitas. Educators who enter the profession often do so out of a sense of benevolent humanitarianism, an unquestioned assumption of always acting in the best interests of children with disabilities. This presumption of benevolent intentions limits their willingness and readiness to reflect on special education practices and effectively inoculates them against outside criticism (Ware, 2002). Therefore, they are heavily invested in the rightness of their decisions. According to Hargreaves (2001), our moral choices and judgments and our sense of moral purpose are infused with emotional significance. Accordingly, special education teachers bring strong emotions (and emotional vulnerability) to parent-professional encounters. Parents, of course, also bring morally charged emotions to these encounters. Consequently, interactions between parents and professionals occur within a moral landscape infused with powerful emotions. Another feature of the moral landscapes in which the participants' storylines play is professional assumptions of knowledge about "right" parenting practices. Professionals are taught to believe that the knowledge bases of child development and developmental psychology are scientifically based and universally applicable across cultures. Therefore, they often see deviations from received norms as deviant or “wrong” parenting, requiring remediation (Kalyanpur & Harry, 2012). That which professionals often practice and generally endorse as “good” parenting is also reflective of class-based assumptions. The middle class model of interventionist and assertive parenting forms the basis of popular discourse and professional judgment and intervention (Lareau, 2003). In encounters between professionals and parents, issues of knowledge, compliance, authority, and morality often structure the moral landscape. Parents can be positioned as resistant to professional knowledge and authority. When they fail to comply with professionally condoned parenting practices, they can be positioned as morally suspect (Frigerio, Montali, & Fine, 2013).

It is important to insert a qualification at this point. As noted above and as will be shown below, most of the participants' representations of parents were overwhelmingly negative. Parents were depicted as disengaged and even negligent. While analysis of the participants' narratives indicate biases and preconceptions, it is only fair to acknowledge that in some cases their representations of parental behaviors may have been in some way accurate. Some parents, of course, do behave negligently just as some teachers show indifference to the needs of their students.

Positioning Selves as Professionals

Despite the fact that most of the participants were not yet working teachers at the time of their interviews, their narratives show that many of them positioned themselves as professionals. In other words, they took on perspectives of professional educators. This is evident from the ways in which they aligned themselves with professional knowledge and practices. Rarely is professional authority challenged in their parent storylines. For example, when Patricia complained about parents not coming to school for parent-teacher conferences, etc., she stated, “There’s so many different ways they (the school/teachers) try to reach out to family members and it's just they don't want any involvement it seems." Katelyn made a similar comment relative to parents' failure to be in touch with the school where she was doing her student teaching. She said, “The school tries to reach out to parents, for them to come. They have different things set up and the parents just don't show up.” Denise found it absurd that a father in her storyline would question professional wisdom about his son’s place in special education. In Catherine's storyline, she felt conflicted when her cooperating teacher tried to enlist her in forcing an intervention on a parent. While she was strongly averse to undermining the parent's autonomy, she did not doubt the teacher's benevolent intent. After all, she "did want the best for the child," Catherine believes. In fact, she questioned herself for hesitating to call child services. Jenny did not question a teacher's improbable claim that a mother kept her son "in a carriage and with the bottle until kindergarten" despite having been extremely critical of the woman's treatment of another child only moments before. When these teacher candidates were in a position to weigh the validity of professional against parental perspectives, they consistently aligned with teachers and schools.

Sociocultural Prepositioning

Prepositioning discourse identifies biographical "facts" and/or perceived character traits for the purpose of justifying positioning (Harré, Moghaddam, Cairnie, Rothbart, & Sabat, 2009). Most of the participants (7Seven of the 10) prepositioned parents by directly or indirectly attributing their perceived negative behaviors to characteristics related to their sociocultural and/or class status. Katelyn, Rebecca, and Denise directly associated sociocultural/class status with negative parental behavior. Rebecca expressed a belief that "parents really need to be held accountable… especially in schools… where you have kids… from lower socioeconomic backgrounds." Katelyn attributed parents' failure to "show up" at meetings etc. to there being "a lot of English language learners at the school." Denise described a mother's apparent indifference to her son's threat of suicide to her being "of a background where I feel like [her son] might be forgotten a little bit." Later, she was more explicit about what she meant by "background" when she ascribed her students' poor behavior to "some of these parents [being] English language learners themselves." Patricia and Catherine alluded to parents' poverty and minority status in their storylines. By way of supporting her storyline of disengaged and negligent parents, Patricia told of a student saying that "her sister was arrested for shooting someone and she was in jail." She also recounted that she had heard from teachers about "a child who was born addicted to crack. A crack baby." Young people jailed for gunplay evokes urban gang membership and the crack baby trope emerged in the 1980s as code for urban Black drug addiction (Alexander, 2010). Seemingly implying poverty, Patricia asserted, "The children were being neglected"—that "they were dirty" and "smelled terrible." Similarly, Catherine spoke about a mother who sent her daughter to school with "holes in her clothing. Her shoes were, like, basically caked with mud" and she had "ringworm on her head." Both Patricia and Catherine were expressing disgust at the parents' conduct. Disgust is an emotion of moral revulsion of directed at the sociocultural other. It functions as a mechanism of social exclusion, employed when people's behavior or appearance violates culturally established tastes or standards (Hargreaves, 2004).

Knowledge and Authority

Disparities in power and authority represent a major barrier to successful parent-professional partnership (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004). Schools maintain their dominance in relations with parents through claims of authority associated with professional knowledge/expertise (Leiter & Krauss, 2004). The mechanisms of this dominance are often professionals' use of exclusionary expert language, disregard for familial knowledge, and their expectations of parental passivity (Valle, 2011).

It is a function of the sociocultural context of teaching that educators feel threatened when their professional expertise is resisted, ignored, or doubted. Teachers retreat emotionally, taking professional distance from parents when they feel their professional bona fides are being questioned. This distance, of course, often leads to emotional misunderstanding and misinterpretation of parental intentions (Hargreaves, 2001). Accordingly, special educators will become defensive when parents challenge, ignore, or refute their professional knowledge/authority. Such resistance is seen as a violation of the boundary between the professional realm and the world of clients. In response to such violations, educators are moved to defend themselves, their professional expertise, and professionalism in general (Valle & Aponte, 2002). Defensiveness and emotional misunderstanding can lead to recriminations. Parents who fail to comply with or recognize professional authority may be positioned as also failing to assume moral responsibility for the well-being of their children (Frigerio, Montali, & Fine, 2013).

Several of the participants positioned parents in ways that indicate moral judgment for failing or refusing to recognize professional authority. Some positioned parents as "in denial," or refusing to accept professional judgments about their children's disablement or level of impairment. Others positioned parents as disengaged because they failed to assume their prescribed role in the educational process (e.g., homework enforcement) and/or negligent because they failed to respond to their children’s needs in professionally acknowledged ways. In each case, these parents were positioned as morally suspect for failing to acknowledge professional expertise or follow professional prescriptions.

Three of the research participants represented the parents as "in denial" in their storylines. Catherine and Rebecca positioned parents in storylines where their state of denial risked detrimental or dangerous consequences for their children. Catherine was concerned that a mother she considered negligent in multiple ways would not "acknowledge the fact that [her daughter had] an emotional disability." Accordingly, she felt the mother “really wasn't in tune to what I feel like a parent should be doing if your child has a disability." Rebecca positioned parents as dangerously in denial or over optimistic about their child's ability to complete homework. This was a hospitalized child, who, according to Rebecca, "threatened or tried to commit suicide" as a result of his parents pushing him to complete his work. The parents "believed that he's capable. I don't necessarily agree that he could've gotten through all of it. And they were pushing him and he threatened to kill himself."

In Denise's storyline, a father was positioned as foolish for his attempted denial of professional knowledge and wisdom. The storyline played out in an IEP meeting in which Denise and her co-teacher met with the parents of one of their students. Because the boy had been held back, the teachers felt he needed to continue in special education. While the mother was willing to sign the child's IEP immediately, the father resisted saying, "'Wait a minute. I want to take it home and read it. When you think you can get out of special ed?'" Denise related her co-teacher’s response in a tone of stating the obvious: “'He's been left back. He needs this extra help. Taking him out would be detrimental to him doing well.'" In the end, the parents signed the IEP, as written. "The mom said to sign it and they signed it," Denise concluded, as if it had always been a foregone conclusion.

In several of the participants' storylines, parents were positioned as in violation of prescriptions for "right" parental involvement or “healthy” levels of attention to their children’s needs. Parents were depicted as not responding to educators' efforts to engage them, failing to be available to support their children's learning, and/or even attending to their hygiene. Four of the participants (Jim, Patricia, Rebecca, and Katelyn) described parents as unavailable or unresponsive despite schools' efforts to reach out to them. They depicted parents as absent or unreachable. For example, Katelyn related, "I've been noticing in the school I'm at now. They have a lot of difficulty getting in touch with parents, let alone the parents reaching out to the teacher." Patricia reported that of the nine students in the self-contained class where she did her student teaching, "only two kids had parents who came in and actually represented them for report cards, parent-teacher conferences." In these participants' storylines, schools made extensive efforts to engage parents but to no avail. For example, Katelyn recounted that despite the school always providing "a translator and all the notices sent home are double-sided" parents "just don't show up." According to Rebecca, parents of children with disabilities who are "not involved" or "are really not reachable" are violating an implicit contract. She believes "that a parent of a special ed child" who has "agreed to go through the [special education eligibility] evaluation and acknowledge that their child… has different needs" should be "already willing to work with the school."

Denise, Patricia, and Catherine positioned parents as failing to acknowledge their prescribed support role in the school’s efforts to teach their children. Catherine and Patricia criticized parents for not enforcing or supporting students’ homework completion. Both of them cite this failure as further evidence in a larger picture of parental failure. Denise positioned the parents of a "cute little boy" who "can't identify letters or numbers and he's in the first grade" as failing to "partake in any part of his education." Given his academic deficits, she imagines that his parents “would want to be more involved." But they were not. Denise “can tell the difference between the kids whose parents are involved and the kids whose parents aren’t involved.” Children of good parents “always have their homework done. They come into school prepared. You know who’s doing their reading at home, who’s doing their letters at home. When things come back on time.”

The parents in Catherine, Patricia, Denise, and Jenny’s storylines were positioned as negligent parents, failing to adequately address their children’s needs. As discussed above, Catherine and Patricia's storylines positioned parents as neglecting their children's most basic needs. These parents were positioned as neglectful of their children's hygiene – sending their children to school in dirty and/or tattered clothes, "smelling terrible" (Patricia), and with untreated ringworm (Catherine). In her storyline, Patricia also positioned parents as neglectful of their children's emotional needs. She recounted that the students she worked with were "just desperate for love and attention." Both Patricia and Catherine considered reporting the parents in their storylines to Child Services.

Jenny and Denise attributed problematic student behavior and emotional volatility to parental neglect. Denise positioned a mother as refusing to appropriately respond to her son's disruptive behavior and emotional volatility. She did not even respond to his threat of suicide.

She explained the woman's apparent indifference by saying that he had "been in six different schools. And he's of a background where I feel like he might be forgotten a little bit." "Forgotten" clearly implies neglect. The "of the background" part of her comment was discussed above.

Jenny positioned the parents of two brothers she believed to be emotionally disturbed as infantilizing and enabling the boys, thus neglecting their parental responsibility to provide structure and discipline. She thinks "the parents like baby them." She even heard that the mother kept the youngest "in a carriage and with a bottle up until kindergarten." She speculated, “The fact that both are with IEP's and behave the way they do, makes me, I guess, a little skeptical" (about the mother).

Destabilized Positionings as “Teaching Moments””

While initially, most of the participants' positionings of parents appear largely deficit-based and generally negative, many of their storylines are complex, nuanced, and contain intriguing contradictions. These contradictions potentially represent purchase points [HD2] for teacher educators who seek to encourage parent-professional partnership. These contradictions represent potential "teachable moments" in which teacher candidates' own thoughts and/or feelings may become the foundation for the development of compassion and understanding towards parents.

Denise, Rebecca, and Katelyn positioned parents in negative storylines in which they portrayed them as disengaged yet each identified circumstance that appear to mitigate the negativity of their depictions. Both Katelyn and Denise demonstrated some recognition of the social context of parental involvement for the culturally linguistically diverse. Katelyn expressed concern that the parents of the students where she did her teaching were somewhat absent and unreachable yet then she was able to list some of the barriers that culturally linguistically diverse parents must face. She speculated that parents might feel embarrassed about not understanding the curriculum being taught their children. She also suggested that they might not be able to meet with or contact teachers because they work day and night. While Denise had a more comprehensive list of complaints about parents, she also recognized the culturally linguistically diverse parents face many barriers (transportation among others) that may keep them from getting involved "the way they want to."

Despite positioning parents of children "from lower socioeconomic backgrounds" as absent and unaccountable, Rebecca, of all the participants, articulated one of the most complete understandings of parental empowerment under IDEA. She recognized parents as potential sources of expertise and acknowledged that they "should also have input if they disagree or if they think something needs to be changed" in the education of their children. "The parent, I guess, is the professional of their child," she admitted then added that while professional expertise should be acknowledged, "the parent definitely should have the ability to override it…." This acknowledgment of the value of parental input and recognition of parental rights indicates a potential for becoming an advocate for her students’ parents.

An encouraging contradiction is embedded in Catherine's storyline of the negligent parent who sent her child to school "filthy." Even though she believed the student was being endangered by her mother's negligence, she "felt torn" when her cooperating teacher asked her to help document the mother's apparent neglect and subsequent resistance to intervention. She "didn't want to go against [the parent's] wishes." She found being asked to do so "a very traumatic experience." Catherine's positionings are complex. It is clear that she positions the mother as dangerously negligent and the child as a victim. Yet, she also positions the mother as having the right to maintain her parental autonomy. Subsequently, the cooperating teacher and her did not have the right to violate her familial sovereignty. Catherine’s inclination to recognize parental rights and authority is in complete alignment with the spirit and letter of IDEA.

Despite the negativity of Jenny’s positioning of the permissive and infantilizing mother she saw as possibly responsible for both her sons’ emotional disturbance, her narrative revealed a potential grain of doubt and therefore openness to alternative interpretation. In the midst of her narrative, she recalled, "The big thing I remember from your (my) class is 'don't blame it on the parents because you never know what's going on behind the scenes.'" While she goes on to restate her misgivings about the mother, she does show some recognition that she does not see the entire picture and that her assumptions are perhaps inappropriate.

Conclusion and Implications

Conclusion

Most of the participants engaged at some level in the seemingly pervasive conflict between professionals and parents. They fell into well-established modes of representation of parents in general, and minority parents in particular. They expressed a sense of discursive alliance with the teaching profession and with the discourse of mainstream special education. In general, they saw parents as in denial, disengaged, and/or negligent. Nine out of ten (excepting Sonya) positioned parents as in some way deficient in their storylines. From a DSE perspective, these results are further evidence of the mechanisms inherent in special education that contribute to professional dominance in parent-professional relations. This dominance, of course, functions to maintain the historical and ongoing denial of social justice to children with disabilities and their parents. As noted above, despite IDEA's explicit provisions for parental empowerment, a culture of professional hegemony and institutional barriers deny children with disabilities effective advocacy of their parents.

Yet, embedded in the participants' narratives is evidence of counter currents that offer more hopeful interpretation for those who seek social justice for children in special education. These budding teachers have within them the makings of compassionate advocates for parents of children with disabilities. As demonstrated above, the participants' positionings included many complicating and destabilizing contradictions. To varying degrees, they expressed sensitivity to the social context of parenting and recognition of parents' rights. The potential represented by these contradictions is the take away message of this research. The question is, though, how can we as special education teacher educators profit from the opportunities this potential represents and parley sensitivity and recognition into compassion and commitment to parental empowerment in special education.

Implications

How might special education teacher educators take advantage of and/or encourage the sorts of teachable moments presented by the participants? Can teacher educators create opportunities to destabilize biased positionings? Viewed through the lens of positioning theory, it is clear that the participants' negative positioning of parents had two problematic sources. They positioned themselves as the professional arbiters of sanctified knowledge of disability and as judges of appropriate parental participation and they positioned parents as being in some way deficient and/or in violation of moral standards. For the most part, they did not question the source or veracity of the standards to which they held parents nor did they show adequate curiosity or desire to know about the circumstances of the parents' lives.

It is up to teacher educators to provide teacher candidates with tools to develop self-knowledge and to develop understanding of the lived experience of parents. For future teachers to develop dispositions that encourage them to position parents as rightful advocates for their children’s rights under IDEA and empower partners in the special education process, teacher educators must support their students in becoming aware of and reflective about their beliefs, biases, and attitudes relative to disability and parental involvement in special education. Teacher educators must also prepare and encourage teacher candidates to be attentive, aware, and respectful of their students and their parents’ lived experience of disability and special education.

Pedagogical strategies and curricular structures may be helpful in supporting reflexivity and encouraging awareness of parental perspectives. One method of supporting the development of self-reflection and critical awareness is to ask teacher candidates to write critical autobiographies that focus on analysis of the personal impact of their encounters with disabilities (Baglieri, 2008; Jones, 2011; Oyler, 2011; Rice, 2006). Also, to allow teacher candidates opportunities to peer across the professional-family divide and experience the actual voices of parents, candidates can be asked to read the autobiographies and family narratives of parents dealing with their children’s disabilities. Additionally, parents can be invited to teacher education classrooms to tell their stories (Ashby, 2012; Baglieri, 2008; Jones, 2011; Peters & Reid, 2009; Rice, 2006).

Besides establishing assignments and other curricular elements to support candidates in developing self-understanding and knowledge of the lived experience of parenting children with disabilities, teacher educators need to be able to recognize and take advantage of opportunities, teachable moments where candidates' rigid preconceptions can be challenged and perhaps destabilized. One of my recent classroom experiences may provide a useful example. In a class session after having assigned a "disability autobiography" to my students, I had an interesting exchange with a student that may be illustrative. The disability autobiography assignment asked students to explore ways in which their encounters with disability had helped form their current beliefs and attitudes. In their autobiographies, several of the students described witnessing and/or experiencing teachers who were insensitive or even abusive toward students with disabilities. Also, many of the students described past experiences that helped them realize that individuals should not be reduced to their disabled identity; they should be seen as different not deficient. At one point in the class discussion, a student expressed frustration with a parent who resisted accepting her child's disability and therefore special education services. I suggested that the parent had been "in denial," hoping to expose this common teacher bias. She agreed enthusiastically. Since, I had pointed out earlier that many of the students' autobiographies had shown understanding and care for individuals with disabilities, I was able to tell the student that it was clear that she only wanted to help the child and that the parents had nothing to fear from her. She clearly felt reassured by this. Then I asked her if she felt she could vouch that the child's next teacher or the teacher after that would be as trust worthy. She was a kind and respectful teacher who would see past the child's disability but could she guarantee all teachers would be so? All of the students listening responded strongly to this question, several murmuring "No." She also responded in the negative. I continued. Therefore, could she understand these parents' fears and the reasonableness of their resistance? The student responded yes and many of her peers nodded in agreement. The students' autobiographical reflections had provided me with the basis for an impromptu session of Socratic probing. The student and her peers' preconceptions were challenged and they were placed, at least momentarily, in a state of cognitive dissonance. With focused and consistent effort (and perhaps some luck), the state of conceptual flux that accompanies cognitive dissonance might tip the balance of belief toward substantive change.

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Symbiosis by Persons with Disabilities: Perspectives from Interviews

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Abstract: This study reports on an interview perspective on symbiosis by persons with disabilities. A main theme, Elements of Symbiotic Collaboration, emerged from the data, along with several subthemes. Symbioses described by participants are closely related to the concepts of independence and interdependence in the Disability Studies literature.

Keywords: Symbiotic Collaboration, Independence, Interdependence

Introduction

As an occupational therapy practitioner, the first author occasionally observed instances in which clients assisted each other at various tasks in occupational therapy. For example, one client with mental illness and another with both cognitive and visual impairments collaborated and assisted each other on the respective craft projects each was doing. Informal observation suggested that the two clients were able to accomplish more on their projects via collaboration than if they worked on their projects individually. Moreover, they appeared to gain a sense of satisfaction from what they were to accomplish together. Finally, a sense of friendship emerged from their having worked together to attain a goal.

Instances such as this stimulated questions about the broader nature of collaboration by persons with disabilities and how they were manifested beyond the context of therapy. For example: when, why, where, and how do people with disabilities in the community collaborate with others in their lives? Is collaboration by persons with disabilities important to their lives, and, if so, why?

Consequently, the first author undertook a study of collaboration by persons with disabilities. During the data analysis for that larger study, the concept of symbiosis emerged, defined here as a mutually beneficial two-way interaction of giving and receiving wherein the contributions of one party matched needs on the part of the other, and vice versa. In order to delve into the rich data around the concept of symbiosis, she decided to do a secondary analysis. The current, preliminary study represents an initial effort toward that end. We would like to first provide some background information from the literature regarding the important concept of symbiosis.

Literature Review

A dictionary definition of symbiosis is “1: The living together in more or less intimate association or close union of two dissimilar organisms…; esp[ecially]: MUTUALISM 2: A cooperative relationship (as between two persons or groups)…” (Merriam-Webster, 2005, p. 1266). The word “symbiosis” appears to readily apply when considering mutual, cooperative relationships between persons with disabilities and others in their lives, such as observed by the first author and described by her in the introduction, in which each partner to the symbiosis brings his/her different contributions as well as needs to the interaction. Nevertheless, the concept of symbiosis by persons with disabilities is minimally addressed in the occupational therapy literature or in health care literature in general. However, the phenomenon of symbiosis by persons with disabilities is directly relevant to a contemporary discussion of the concepts of independence and interdependence as they are discussed in the Disability Studies literature.

Independence

The concept of independence has long been addressed in the Disability Studies literature. Scholars argue that an antiquated definition of independence, stemming from the medical model of disability (Goggin, 2008; White, Simpson, Gonda, Ravesloot, & Coble, 2010), still prevails in rehabilitation and in society. This concept of independence focuses on whether a person can perform necessary self-care tasks and desired daily activities without the aid of another person. Conversely, persons with disabilities are considered dependent if they need assistance from another person throughout their day (DeJong, 1979; Nosek & Howland, 1993). Such dependence is considered undesirable and thus something to be avoided.

The Disability Rights movement and the Independent Living movement (White et al., 2010) revolutionized the definition of independence. Writers argue that instead of focusing on measures of functional ability, independence should focus on individuals being in control of their choices, their decisions, and their lives, thereby being self-determining (Longmore, 1995; Oliver, 1993; Parker, 1993: Scheer & Luborsky, 1991; Nosek, 1993). This is echoed by Milner and Kelly (2009), who report that “the most highly valued forms of participation were self-chosen activities that people undertook with a degree of autonomy” (p. 56). Nosek and Fuhrer (1992a, 1992b) provide a hierarchical model of independence with four progressive need stages of “basic survival, material well-being, productivity, and self-actualization” (1992a, p. 5) and developed a profile measuring independence based on the following four non-traditional components of independence: “perceived control over one’s life…psychological self-reliance…physical functioning, and…environmental resources (1992b, p. 3).

Interdependence

As the concept of symbiosis is synonymous with mutualism, defined as “1: the doctrine or practice of mutual dependence as the condition of individual or social welfare; 2: mutually beneficial association between different types of organisms” (Merriam-Webster, 2005, p. 820), symbiosis is a form of interdependence. According to Condeluci (2014), a disability advocate, interdependence “…implies interconnection, or an interrelationship between entities. It suggests a connection or partnership between the entities in an effort to maximize potential for both groups" (p. 8).

The concept of interdependence is flourishing among people with disabilities. According to Gill (1995), recognizing interdependence as a part of existence is a central value of the disability community. Longmore (1995) states that persons with disabilities have values which stem from their experience of interdependence, connection to, and affiliation with others. Jacobs (2002) views interdependence as having enormous value to empower people with disabilities because of increased connection and the resulting sharing of information and knowledge. White et al. (2010) discuss the interdependence model, which "stresses building social capital capacity among consumers to help them participate in their communities to the fullest extent they are able" (p. 237), while Condeluci (2014) discusses the interdependence paradigm as a major change from the medical model view of disability.

The Disability Studies literature provides a few examples of interdependence; each involves collaboration as a central component. For example, Scheer and Luborsky (1991, p. 1176) describe an elderly woman with disabilities who, upon her husband's demise, "lost…a valuable disability ally who helped her maintain physical comfort and functional capacity". French (1993a) discusses a case of interdependence between a social worker with blindness and his or her clients. Scheer and Groce (1988) discuss a community of persons with quadriplegia and paraplegia on Roosevelt Island, New York, which became an example of the value of interdependence among persons with disabilities. They provided "…each other support and informal counsel about various issues, from attendant care management, to advice about dating, to equipment repair and purchase" (Scheer & Groce, 1998, p. 35). Many of the residents in this community formed connections not only among themselves but with people outside the disability community as well. These examples suggest that a variety of forms of collaboration, including symbiosis, are involved in expressing the value of interdependence and point to the need to know more about the nature and impact of symbiotic collaboration.

Design and Method

The current study is a secondary analysis and employed a phenomenological, qualitative design to explore symbiosis by persons with disabilities. Phenomenology is often used in qualitative research as it provides an insider view on the particular experience being examined (Creswell, 2013; Patton, 2015). The study aimed to illuminate the perspectives of people with disabilities about their experience of symbiotic collaboration with others in interview data.

Participants

This study is a subset of a larger study of collaboration by persons with disabilities. The original, larger study had five participants. For the current study, a convenience sample comprised of three of the original five participants (two men and one woman) was used. All three of these participants were professional contacts suggested to the first author by a colleague who acted as a gatekeeper and initially contacted participants about the study and obtained permission for the first author to contact them about being in the study. The age range of participants was from 49 to 52 years. All of the participants had a physical disability; one had head injury, and two had quadriplegia. All of the participants were living in the community; two of them worked at jobs or professional careers and one participant was a hobbyist. Two of the participants had advanced degrees and one of the participants had received a high school education. Please refer to Table 1 for demographic information about the participants. Two of the participants were married; the third participant lived with friends. All of the participants were from the middle or upper socioeconomic class. All were involved with the disability movement during the 1970s in one form or another either through participation in demonstrations or by consciousness raising on their college campuses or in the community and some are still involved in the disability movement today. As such, the participants in this study were well aware of the Disability Studies' discussion of the concepts of independence and interdependence. In order to protect confidentiality in the reporting of participant data, the names of the participants for this study have been replaced with pseudonyms. Please refer again to Table 1 for pseudonyms for each participant.

Table 1. Participant Demographics

Name	**Age**	**Gender**	**Disability**	**Education**	**Occupation**
Brian	52	Male	Head Injury	High School	Hobbyist
Karen	49	Female	C1-C2 Quadriplegia	Advanced Degree	Attorney
Michael	52	Male	C4-C5 Quadriplegia	Advanced Degree	Manager

Alternate description - Table 1 provides participant demographics. Three participant's names are provided, their ages, gender, disability, education, and occupation.

Note: This study was approved by the Human Subjects Review Committee of the Institutional Review Board of Texas Woman's University, Houston.

Data Collection

For the parent study, data were collected through two in-depth, semi-structured interviews that explored instances and meaning of collaboration, as well as eleven participant observations, all of which were conducted by the first author. The first interview asked participants about their past experiences with collaboration, and the second interview asked them about their current experiences with collaboration. Interviews consisted of open-ended questions and were audiotaped. The first author met with participants in their homes or in private and quiet locations at their workplace. For each participant, each interview was one to two hours in length. There was about a two-week time frame between interviews for each participant.

The current study reports only on the interview perspective on symbiosis. A future paper delineating the results regarding symbiosis from a secondary analysis of the participant observations, and comparing them to the results from interviews reported here, is anticipated. Therefore, for the purposes of the current study, excerpts which were relevant to symbiosis from only the interviews were then isolated and provided to four data analysts. The relevance to symbiosis for these excerpts from the initial interviews was determined via open coding by the first author when she coded the original parent study.

Data Analysis

Audio taped interviews were transcribed. As mentioned above, excerpts determined from the first author's original coding of the parent study to be relevant to symbiosis from these interviews were then independently subjected to open coding (Creswell, 2013) analysis by the third, fourth, sixth and seventh authors, who were students of the first author. Initially, the data analysts engaged in practice coding to ensure consistency. Then, during the formal coding process, the first author met separately and regularly with each student to help answer any questions they might have about the transcripts they were coding or about coding in general, and to clarify that they were coding for symbiosis. For the purposes of this study, the term symbiosis was used to describe a collaboration between two individuals or groups in which members of each side of the collaboration bring different needs, abilities and/or contributions to the collaboration. In a symbiotic collaboration, each member's differing needs, abilities, and/or contributions to the collaboration complement those of the other member, resulting in a mutually beneficial interaction and outcome. Codes and categories related to symbiosis were identified (Creswell, 2013) individually by each data analyst for one excerpt at a time, until all examples of symbiosis in each excerpt were identified and coded. The data analysts then met regularly as a group to compare codes and discuss and develop categories and themes from the coded data. The first author acted in the role of facilitator during this process. Working together excerpt by excerpt, the data analysts grouped similar codes into subcategories, then collapsed these subcategories into categories, and then collapsed the subcategories into one overarching theme. A piece of data was included in the final analysis of the coded data if at least three out of the four coders agreed that it reflected symbiosis as defined for the study. Any disagreements among the data analysts regarding subcategories, categories and themes were discussed and resolved by consensus among all four data analysts. An outside consultant then reviewed all of the results, including representative quotes, subcategories, categories, and themes for the coded data and made recommendations to the researchers, which were followed.

Verification of Data

The first author used spot member checking to assist with verifying data. Member checking is an approach used in qualitative research (Merriam, 2009) to help insure greater accuracy of results. One of the three participants in this study was involved in the member checking process and reviewed and made comments on a portion of his interview transcripts.

Findings

One main overarching theme emerged from the data: Elements of Symbiotic Collaboration. Please refer to Table 2 which displays this theme and its subthemes about symbiosis.

Table 2. Overarching Theme and Subthemes About Symbiosis

1. Elements of Symbiotic Collaboration
a. Cognitive/Cognitive Collaboration
- Inter-Institutional Work - Inter-Personal Work
b. Physical/Cognitive Collaboration
- Family
- Attendant and Care Recipient
- Work
- Volunteer Work
c. Physical/Emotional Collaboration
- Family
- Work
d. Emotional/Emotional Collaboration
- Work

Alternate description - Table 2 describes the overarching theme and subthemes about symbiosis. These will be discussed below.

1. Elements of Symbiotic Collaboration

The overarching theme Elements of Collaboration has to do with the different components, structures, or aspects of symbiotic collaborations evidenced in the data. This theme contained four subthemes which represent the four general types of symbiosis which emerged: *Cognitive/cognitive collaboration; Physical/ cognitive collaboration; Physical/emotional collaboration; and Emotional/emotional collaboration;* to be reported below. Each subtheme (example: Physical/emotional) reflects the two elements that participants were bringing to the symbiotic collaboration. In turn, the sub-subthemes (example: Family) under each subtheme represent specific subtypes of these symbioses and reflect either the type of environment the symbiosis occurred in or the roles of those involved in the symbiosis.

1a. Cognitive/Cognitive Collaboration

This subtheme was reported by one participant and highlighted instances in which a cognitive symbiosis occurred between two parties. These cognitive symbioses occurred in the work environment or while the parties (either individual people or whole institutions) involved were engaged in an intellectual work task. They illustrated times when members of the collaboration brought their different knowledge and cognitive skills or abilities to the task at hand.

1a.1 Inter-institutional work.

A type of cognitive/cognitive symbiotic collaboration occurred at the inter-institutional level. Michael, a manager with C4 - C5 quadriplegia, spoke of how his workplace had collaborated symbiotically with the Better Business Bureau Consumer Education Foundation on providing technical assistance to businesses regarding disability rights:

> "Now, the Consumer Education Foundation…in a general sense…
>
> has no particular expertise or skill in the area or knowledge of disability rights…by the same token, our work group, our institution has relatively little knowledge compared to the Better Business Bureau about…the way business works…the way business people think, the way small businesses in particular are organized, the resources they have, the interest they have, what motivates and drives them, and so on and so forth. So… we…from a public service, uh, health promotion, uh not-for-profit perspective, are collaborating with an organization that views things from a commercial for-profit, uh, business perspective, and together we are able to achieve something that neither one of us could achieve independently."

This example illustrates how institutions championing the rights of persons with disabilities cognitively engage symbiotically by sharing their specific knowledge regarding important issues with other institutions in the community.

1a.2 Inter-personal work.

Michael also shared how he had worked with a colleague on a grant proposal for research on independent living, a topic of particular interest to persons with disabilities. Their work together consisted of a type of symbiosis in which they each brought their own cognitive talents to the project.

> "Well, I mean, she's a lot smarter than I ever thought about bein' and she [was] a far better writer, so…the most intellectually challenging…written tasks…were ones that she…volunteered to do, and those more mundane…documentary tasks were ones which I…quite naturally volunteered to…write….We often would go to conferences and

> congresses together and do both joint and individual presentations where we divided up…[the] materials- she would often talk about the demonstration itself where I would talk about some of the findings of the research we were doing."

This example demonstrates two people, one with a physical disability [C4-C5 quadriplegia] and one without a physical disability, symbiotically collaborating on cognitive tasks for a research project. This cognitive/cognitive symbiosis was not based on needs resulting from disability, but rather on the differing cognitive skills and interests of the collaborators.

1b. Physical/Cognitive Collaboration

Three participants described themselves as engaging in physical/cognitive symbiotic collaborations as well. In a physical/cognitive symbiosis, one member of the symbiosis contributed his or her physical strength or abilities to the situation in order to meet the needs of the other party, while, in turn, the latter contributed his or her cognitive abilities in order to meet the needs of the first party. These types of symbioses occurred in a variety of life areas, such as while participants were interacting with family, attendants, or co-workers.

1b.1 Family.

Brian, a hobbyist who had a cognitive disability resulting from head injury, spoke about the physical/cognitive symbiosis he experienced at home with the family he lived with, which included some persons with physical disabilities. He discussed how the family members with physical disabilities might ask him to do a physical task for them, which they could not do, such as take out the trash. Because they were aware of his memory deficits, they supported him cognitively by consciously limiting the number of sequential tasks or steps in a task they would ask him to do so that he would not forget the later steps. His use of the term "symbiosis" here describes the give and take he experienced at home when he helped people with physical limitations and they adjusted for his cognitive limitations:

> "They…are my helpers now. And I help them. That's one of the things
> I'm calling symbiosis. 'Cause of the…interaction we have. Where
> everybody helps each other. So I'm calling that a collaboration,
> or symbiosis, or I feel a lot of other adjectives that would describe it.
> But, the two current ones are symbiosis and/or collaboration."

1b.2 Attendant and care recipient.

Another form of physical/cognitive symbiosis occurred during interactions between participants who were either providing attendant care for one member of the symbiosis or receiving care from the other. This form of physical/cognitive symbiosis was mentioned by two participants and was best explained by Brian, the hobbyist with a cognitive disability stemming from head injury, who enthusiastically described how a symbiotic attendant/attendee relationship with someone who had a physical disability, allowed them both to achieve autonomy that neither could attain without the other:

> “Well… [A] is my memory, because I don’t have…one that works well; I’m his arms and legs, is basically the way it works. And, because I’ve helped him with the physical assistance he needs, he’s been able to… go a lot of places he couldn’t go otherwise because he…couldn’t get out of bed and into his clothes or into his wheelchair if [he] hadn’t had my help. And by the same token, if he hadn’t been helping me, I wouldn’t have been able to…do a lot of the other things that I’ve done since I have been helping [A] because of the help I’ve gotten from him…. neither one of us could be as independent as we are without the help of the other. And that basically says it all… [A] couldn’t put on his pants and get out of bed in the morning without my help, and I have troubles with my memory…so [I have] other kind of problems that I couldn’t deal [with] without [A]’s help. Or someone like [A]. That’s why I call it symbiosis. ‘Cause of the fact that we do help each other in the way we do… neither of us could be as independent as we are without the help of the other, or someone like the other person.”

Here Brian describes a type of long-term give-and-take physical/cognitive symbiosis in which he was the personal attendant for someone with a physical disability where each contributed a remaining capacity to compensate for the other’s impairment.

1b.3 Work.

Some physical/cognitive symbioses occurred while working together. Karen, an attorney who had C1-C2 quadriplegia, and (among other things) was unable to use her arms as a result, spoke about an enjoyable physical/cognitive symbiosis she experienced with a friend who did not have a disability:

> “…We opened up a gift shop that we both…ran together. She would help do all the…inventory and I would kind of run the shop in terms of deciding what to purchase and where, maybe where and how to display it, and then she would help with just, you know, gathering the items and physically laying them out in the store.”

This is yet another example of a type of physical/cognitive symbiotic collaboration; in this case, the friend contributed her physical abilities while Karen contributed the intellectual skills involved in decision making and design.

1b.4 Volunteer work.

Brian also mentioned a symbiotic process occurring in his volunteer work, wherein he helped others and they, in turn, helped him out cognitively so he would stay on track.

> “…If one of the volunteers asks me to help them with something I’d gladly do it…. [They might ask me to] go tell somebody something but I ask them for a note so I don’t forget…any of the details and what they want me to tell them....Somebody in the volunteer office might ask

> me to do something for them and I… gladly do it, 'cause I'm not doing anything else at the moment. Or if I am…doing something else I ask them to remind me what I'm doing when I get back with…whatever [they] asked me to go and get for them…so I can complete the task."

In this example, the individuals who asked Brian to do a task did not necessarily have a physical disability and may have been able to complete the task, but delegated tasks to Brian that he was physically capable of doing and that needed to be done so they could focus on other tasks. In return, they provided him the cognitive support he needed to do the task.

1c. Physical/Emotional Collaboration

Two participants mentioned physical/emotional symbiotic collaborations they engaged in with others in their lives. In these forms of symbiosis, one member contributed his or her physical abilities while having his or her emotional needs fulfilled in return. These forms of symbiosis occurred both with family members and at work and will be discussed below.

1c.1 Family.

Michael spoke about a physical/emotional symbiotic collaboration that occurred between him and a family member after he acquired his disability:

> "…My mother…shortly after I was injured…became my primary caretaker, and through her I was able to do a lot of things that I would not have been able to do under other circumstances….And at that stage of her life…she was having a difficult time coping with her kids being gone, and she was dealing with her own predisposition towards alcoholism, and I think the fact that she found herself occupied caring for me…was…to her a kind of…distraction from the…addiction which she had…and a way of …coping with that…addiction…and a consequential temptation…and she felt like she was really accomplishing something. Whereas, if she didn't have that…sense of responsibility and duty to care for me right in front of her…more than likely, and I think she knew it…she would have…been harming herself and her family."

In this example, Michael received from his mother the physical help and care he needed and was able to do things, and in turn this filled an emotional void for her and gave her a purpose.

1c.2 Work.

Karen discussed physical/emotional symbioses that she experienced in the work environment. One example of this type of symbiosis she provided was in her day-to-day work with her secretary:

> "…I'm a strong believer that when a person comes to work, your home life doesn't just go away. For example [B] must be available for her children, her husband, and her parents, so oftentimes she'll get calls from her family…she knows I'll read through my mail

> and I'll just make gestures to her to turn a page but she might be…
> you know, on the phone taking care of some business….It will be a[n]…opportunity for me to go through magazine…publications
> that I just need to kind of skim through, and so, basically what she's
> doing is turning pages. But she's actually concentrating on something else."

Due to her disability, Karen was unable to turn the pages, so her secretary physically turned the pages for her. Karen's contribution to this symbiosis was to permit her secretary to make personal phone calls while doing this task, thereby fulfilling some of her secretary's emotional needs regarding the well-being of her family. Through this physical/emotional symbiosis they were able to enfold their respective responsibilities together.

Another example provided by Karen of a physical/emotional symbiosis which occurred at work was in her work with her student:

> "So rather than me making the phone call to another attorney
> or colleague…I'll have them do that so they…can meet that person.
> And hopefully it's a helpful experience for them as well."

In speaking a little earlier in the interview regarding her interactions with her students:

> "…When you're in the role of someone who's trying to help the
> person you're with…learn about life in a different way, I find that
> to be particularly rewarding."

Here, the student accomplished the task of making phone calls, which Karen would have needed physical assistance with in order to accomplish. In turn, working with the student was personally rewarding for the Karen, and the student possibly experienced interesting career opportunities.

Yet another example of a work-based physical/emotional symbiosis Karen provided was in her interactions with her care attendant. This interaction was very different from the traditional employer/employee relationship and different from any she had had in the past. This attendant was more like a family member to her, traveling with her, going on camping trips with her, and spending holidays with her and her family:

> "I really believe that the kinds of things that she would do for
> me on a daily basis she would do because we liked each other,
> and we enjoyed being with each other. And she wasn't doing
> it just that it was her job. Although it was her job. But, she
> wasn't doing it for that reason alone. She was doing it for
> other reasons."

In this case, the care attendant provided physical assistance for Karen. Both women enjoyed the interaction and the care attendant received more than just pay for taking care of the participant.

1d. Emotional/Emotional Collaboration

In this type of symbiosis, parties to the symbiosis meet each other's emotional needs, and was mentioned by one participant as occurring in the workplace.

1d.1 Work.

This form of a symbiotic collaboration was described by Karen and involved again her interactions with her secretary:

> "And, you know, we both anticipate each other's, well maybe moods, or feelings for that day."

In this form of symbiosis each was respectful of the other's emotional needs by anticipating each other's feelings in order to better work together.

Discussion

The results of this study indicate that persons with disabilities engage in a variety of symbiotic collaborations in a range of environments and relationships, including work and home. Some of them, such as when Brian discussed his unusual symbiosis with a person with a physical disability (reported under "Attendant and Care Recipient" under the subtheme "Physical/Cognitive"), were more specific to persons with disabilities, as opposed to persons without disabilities. Other forms of symbiosis, such as the one between a participant's workplace and the Better Business Bureau Consumer Education foundation regarding disability rights (reported under "Inter-Institutional work" under "Cognitive/Cognitive"), is an example of a type of symbiosis that would be particularly valued by people in the disability community. However, it is also important to note that some of the symbioses that study participants engaged in were symbioses that someone with or without a disability could potentially engage in. An example of this would be when Karen and her secretary anticipated each other's moods (reported under "Work" under the subtheme "Emotional/Emotional"). This highlights the notion that persons with disabilities are not necessarily different from the non-disabled population in the types of symbioses they do. This is a refreshing finding, as, traditionally, people with disabilities have been treated as "different" and socially and physically separated from non-disabled persons as a result (Dear, Wilton, Gaber, & Takahashi, 1997). This finding is potentially liberating for persons with disabilities, because if non-disabled persons can come to realize that persons with disabilities are not necessarily different from them, this might encourage more positive interactions (Dear et al.), and therefore more symbioses between persons with disabilities and their non-disabled counterparts. This would provide persons with disabilities with more social capital, which could improve their community involvement (White et al., 2010). Also, the notion that symbiosis can be engaged in by non-disabled and disabled persons alike underscores the idea of the universality of interdependence among human beings. To quote Robertson (2001):

> "… all of us are much more dependent on others than we acknowledge, and yet we stridently, almost bizarrely, deny this reality and that of

> interdependence except then referring to *others*- young infants, disabled children and adults, and the elderly." (p. 123)

The literature about persons with disabilities and friendship reflect some of the findings of this study, particularly in the realm of cognitive support, emotional support, and physical/emotional collaboration. For example, Pottie and Sumarah (2004) reported on friendships between persons with intellectual disabilities and persons without intellectual disability at a community known as L'Arche in Canada. While the non-disabled friends often provided cognitive support with activities such as reading a menu at a restaurant or telling time, the friends with intellectual disability contributed to the friendships by providing emotional support. Although not actually part of a category named in this study, this example would readily fall into one that could be called "cognitive/emotional collaboration". Fisher and Gallagher (1988) discuss how women with physical disabilities often try to provide emotional support for their non-disabled friends as an attempt to balance out the amount of physical help they receive from the friend (p.180). This example echoes elements of the physical/emotional collaboration found in this study between Karen and her secretary, but is in the realm of friendship instead of work.

Williams and Robinson (2001)[A3] found that persons with intellectual disabilities, some of whom have "high support needs" (p. 61), often provide emotional support and do physical care or physical tasks around the home for their parents (some of whom are elderly or disabled) while the parents provide the support needed for their children with the intellectual disability. This reflects some of the aspects of physical/cognitive and physical/emotional collaboration found in the current study. However, Williams and Robinson found that such relationships were not often viewed as one of interdependence by the parent. They expressed that "understanding how to value and respect someone who nevertheless does need support, is a vital but unmet need in many families" (p. 61).

Many of the symbiotic collaborations described by the participants are closely related to the concepts of independence and interdependence in the Disability Studies literature. As the participants chose to engage in symbiotic collaborations, they further exemplify ways in which people with disabilities choose to be autonomous and in control of their lives. In this regard, some of these symbiotic collaborations allowed the participants to achieve the kind of independence envisioned by disability scholars (Brisenden, 1996; Condeluci, 2014; Longmore, 1995; Nosek, 1993; Oliver, 1993; Parker, 1993; Scheer & Luborsky, 1991). They are also example of situations in which people with disabilities were willing to ask for help and saw the positive aspects of interdependence with others, reflecting the value that members of the disability community place on interdependence.

They also exemplify values of community and connectedness that are espoused by disability activists. As French (1993b) states, "…giving and receiving help can greatly enrich human experience" (p. 47). The eagerness with which some participants spoke of their symbiotic experiences and the ability of such experiences to improve their lives in meaningful ways attest to that richness.

For some participants, symbiotic collaboration was an ongoing means to accomplish important life tasks and roles or achieve a level of independence that would not otherwise be possible. However, symbiotic collaboration had another equally important dimension of mutual benefit achieved by two people working together in close and constant proximity. Some involved in these symbiotic collaborations exchanged cognitive, physical and emotional support in remarkably reciprocal ways. There is also a form of intimacy in this relationship characterized by the unusual extent to which persons must share close physical space, orchestrate their respective actions, and share and be considerate of highly personal actions and information.

It is clear that some study participants felt overall that symbiosis was immensely beneficial to them. Through some of the symbiotic collaborations they discussed, participants were able to accomplish necessary and desired tasks they would normally not be able to, thereby achieving a better quality of life. As Condeluci (2014) mentions, "[Interdependence] suggests a fabric effect, where diverse people come together in a synergistic way to create an upward effect for all" (p. 8). In fact, Gooden-Ledbetter, Cole, Maher, and Condeluci (2007) found teaching interdependence to persons with disabilities in independent living programs to be a predictor of life satisfaction (p. 157). Williams and Robinson (2001) state: "…mutual caring [between persons with learning disabilities and their parents] is far more common than is recognized…" (p. 56). The current study suggests that symbiosis may be a phenomenon worth further exploration.

Interdependence is a complex issue. This notion is supported by Walmsley (1993), who found that receiving and giving care can simultaneously provide sustenance and frustration, and by The Roeher Institute (2001) who discuss the need for respectful interdependence between people with disabilities and providers of support. Also of particular note is the phenomenon of mutual caregiving between adults with disabilities and their young children and the consequent impact on the children (Aldridge & Becker, 1999; Pakenham & Cox, 2012). Further investigation of these topics is warranted.

The original study from which the data for the current study was derived was not about symbiotic collaborations, but rather any types of collaborations by persons with disabilities in general. As such, it is important to note that the current study is a preliminary study and does not provide an exhaustive list of the types of symbiotic collaborations that persons with disabilities engage in. Also, as there were only three participants in this study, and the participants were quite articulate, the results of this study cannot be generalized to the population of persons with disabilities; particularly to persons with disabilities who may not be as articulate. The concept of symbiotic collaboration needs further exploration with a wider and more varied range of participants.

Conclusion

Occupational therapy has adopted the following definition of independence:

> "[A] self-directed state of being characterized by an individual's ability to participate in necessary and preferred [meaningful and purposeful activity] in a satisfying manner irrespective of the amount or kind of external assistance desired

or required." (American Occupational Therapy Association, 2002, p. 660)

The use of symbiosis could be viewed as a unique adaptive strategy for people with disabilities. As the participant Brian stated: "I've chosen to collaborate to achieve the goals I've set that I couldn't have achieved without the collaboration of other people…" It is important for medical professionals, caregivers, and non-disabled persons to be aware of the value of symbiosis to persons with disabilities as a form of adaptation which can empower them in the attainment of meaningful life goals. Moreover, our own understanding of independence would benefit from a clearer underscoring of the tenets of autonomy and self-determination as well as the recognition that they often require a significant measure of symbiosis.

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[Dis]Ableing Educational Inequities: A Disability Studies in Education Perspective

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Abstract: Disability Studies is often viewed as only relevant to those with disabilities. What is forgotten or overlooked is that, at its core, schooling is about defining, locating, measuring, and remediating *ability*. This essay offers *[dis]ableing* as a lens for exploring and questioning the ubiquitous ways *ability* has increasingly become defined and constructed by notions of individualism, competition, and economic productivity. We begin with a description of the key principles borrowed from disability studies in education and apply a *[dis]ableing* lens to inaugural discussions of *Race to the Top* federal educational reforms in the United States in order to examine the hidden consequences for all students. This article concludes with new understandings about how educational inequities are perpetuated by the policies and practices that purport to dismantle them.

Keywords: Ableism, Neoliberalism, Race to the Top

Overview of the Issue

In a 2012 statement of business owners' interest in education policy, Chris Kershner, vice president of public policy and economic development for the Dayton (Ohio, U.S.A.) Area Chamber of Commerce, said:

> "The business community is the consumer of the educational product. Students are the educational product. They are going through the education system so that they can be an attractive product for business to consume and hire as a workforce in the future."[i]

Mr. Kershner's evaluation is unusual only in how openly he connects the assumed purposes of education to the interests of American business. He offers a local version of an understanding of students that is characteristic of international neoliberal reforms that equate students with products and that the purpose of education is to prepare students for the workforce (Barton & Slee, 1999; Goodley, 2007; Slee, 2011; Liasidou, 2013). Though it is important to note that national and local versions of these market-based reforms differ in how neoliberalism is shaped by particular cultural and political contexts (Brenner & Theodore, 2002; Dudley-Marling & Baker, 2012). While many others have recently written about the destructive effects of neoliberal logic on education globally and within the United States (e.g. Gulson & Pedroni, 2011; Hursh & Henderson, 2011; Furlong, 2013; Berliner and Glass, 2014; Ravitch, 2014) and particularly the impact of neoliberalism on the education of students with disabilities (e.g. Roulstone & Prideaux, 2008; Runswick-Cole, 2011; Dudley-Marling & Baker, 2012; Penketh, 2014), in this article we call scholars' attention to the use of ideas drawn from Disability Studies in Education for provoking new lines of inquiry about contemporary education inequities. We examine discourses drawn from President Barack Obama's July 24, 2009 introductory remarks for his $4 billion Race to the Top federal funding reform to highlight how contemporary education reform in the United States brings together ableism and neoliberalism. The Race to the Top is a grant competition for states to reform K-12 educational programs to align with federal educational policies calling for performance-based assessments for teachers and schools, standardization of curriculum, expanding the privatization of education with charter schools, high-stakes testing for students, and the implementation of statewide data collection systems to track students, teachers, and schools. This U.S. reform movement that launched in 2012 is a continuation of neoliberal efforts to redefine what it means to be able, basing it on what one can contribute to a capitalist society and not on what one can contribute to social democracy.

This article introduces "[dis]ableing"[ii] for exploring and questioning the ubiquitous ways ability has increasingly become defined and constructed by notions of individualism, competition, and economic productivity. In what follows, we will describe the components of what we are calling "[dis]ableing." Reminiscent of Balkins's (1987) discursive deconstruction toolkit, [dis]ableing is a collection of strategies and principles for examining ableist inequities – the ways we use taken-for-granted understandings of ability and disability that privilege those constructed as abled while perpetuating discrimination and bias toward people identified as disabled. We attempt to"[dis]able the Race to the Top" in the sense that we expose, denaturalize and disrupt key underlying ableist assumptions revealed in President Obama's introductory comments to the reform.

Assumption of disability attaches not only to those marked as physically disabled. Sexed, raced, gendered, classed, ethniced, and otherwise marginalized bodies are likewise deeply marked by ableist inequities (e.g. Campbell, 2009; Söder, 2009; Collins & Valente, 2010; Valente & Collins, 2010; Erevelles & Minear, 2010; Valente, 2011a; Artiles, 2011; Baglieri et al., 2011; Valente and Boldt, 2015). Educators concerned about inequities experienced by traditionally marginalized communities are keenly aware of the long history of educational "tracking" in this country. So too are they aware of the cultural resistance to changing this and other school sorting practices which on the surface are argued to be about "accountability" and "equity" and "meritocracy" yet are known to result in the over-representation of students from racial and ethnic minority groups, students from lower income families, and bilingual students considered "English Language Learners" in special education and "lower track" classes (Ferri 2009; Ferri & Connor 2005a, 2005b; Oakes, 1995; Oakes, Wells, Jones & Datnow, 1997). Deficit perspectives of race, disability, gender, class, sexuality, and language inform how *ability* and *disability* are defined as well as how these definitions are used to place and displace people in marginalized, exclusionary, and even abusive educational settings (U.S. Office of Civil Rights, 2012, 2014)

These cultural beliefs about deficits and differences also inform teaching practices and school policies that are coming under much scrutiny as of late. For instance, the U.S. Department of Education Office of Civil Rights (2012; 2014) reports on special education revealed long-hidden evidence about the widespread abuses and mistreatments experienced by black and Hispanic students, who in 2010-2011 made up over 70% of the students arrested or referred to law enforcement officials. 44% of the students subjected to mechanical restraint were black students. Nationwide half of the third and fourth graders being left back were black students. In an *Education Week* special issue analyzing and reporting on this Office of Civil Rights data, U.S.

Secretary of Education Arne Duncan responded, “We are not alleging overt discrimination. These are long held patterns of behavior. Many educators may not even be aware of these discrepancies” (Education Week, 2012). To this, many critics would also add policymakers such as President Obama and Secretary Duncan, both never classroom teachers themselves, are misguided in their belief that *Race to the Top* policies will level the playing field for minority students.

Critics call attention to research on the historically large number of minority group student populations deemed to be in need of “fixing” or remediation as evidence of the long held patterns of discrimination. Educational anthropologists point to almost a century of ethnographic studies describing the cultural politics of educational underachievement in an American educational system that is hyper-competitive and where students are compelled to not only learn but also learn more and more efficiently than their classmates (e.g. Erickson, 1987; Jacob & Jordan, 1987; D’Amato, 1987; Artiles & Trent, 1994; Varenne & McDermott, 1999; McDermott, Goldman, Varenne, 2004). This melding of ableist assumptions with neoliberal principles of competition to create winners and losers defines education in ways that impact all students (Bowles & Gintis, 2002; Runswick-Cole, 2014). This will be evident in our discussion of selected public artifacts from phase one of the *Race to the Top* competition.[iii]

Framing Disability Studies in Education and [Dis]ableing

The field of Disability Studies in Education (DSE) is an international and applied subfield of disability studies that addresses the socio-political constructions of *ability* and *disability*, rejecting the deficit perspectives that historically pervade special education deriving from the conformist agenda of behaviorism, cognitivism, and more recently neoliberalism (Gabel & Danforth, 2006; Ware, 2006; Barton & Armstrong, 2007; Connor, et al 2008; Gabel & Danforth, 2008; Valle and Connor, 2011; Wills, Morton, McLean, Stephenson & Slee, 2014). Varenne and McDermott (1999) smartly note “culture, the great enabler of humanity, is also in the same movement the great disabler” (p. 142). Disability Studies in Education works to examine the ways cultural teaching practices enable and disable students.

Scholarship in Disability Studies in Education calls attention to the problems of schooling becoming increasingly more about defining, locating, measuring, and remediating *ability*. The concept of [dis]ableing culls from disability studies in education and emerging scholarship that focuses on the cultural politics and denaturalizing of *ability* and *disability* as well as schooling (Artiles, 2003, 2011; Valente, 2011b; Connor, Gabel, Gallagher, & Morton, 2008; Danforth, 2009; Dudley-Marling & Gurn, 2010; Ferri and Connor, 2006; Gabel, 2005; Snyder, Brueggemann, & Garland-Thompson, 2002; Skrtic, 1995; Collins, 2013; Boldt & Valente, 2014). Our use of the term *[dis]ableing* also draws from and parallels critical race theorists’ application of *raceing* (Morrison, 1992) and queer theorists’ use of *queering* (Warner, 1993). Most notably these works attempt to take a seemingly esoteric theoretical stance and make it applicable to specific issues. A [dis]ableing lens can make disability studies in education scholarship a useful and accessible tool for scholars who may not be as familiar with questioning ableist thinking.[iv]

It is important to note [dis]ableing is not meant to be conceptualized as a rigid set of procedures but instead as a fluid framework open to borrowing from the vast array of diverse disability studies in education and likeminded scholarship, with its rich tradition of traversing disciplinary boundaries. Readers need to be cautioned against reading [dis]ableing as a fixed set of analytic procedures for looking at ableist policies and practices in neoliberal times. The examples we describe herein are not an exhaustive review of *Race to the Top* but a snapshot of the inaugural public moments of *Race to the Top*. However these examples do serve to illustrate how systemic an issue the newest version of ableism is and they point to the implications such a redefinition has for all students and schools. In their ethnographic analysis of sociocultural factors going into the assembling and dissembling of educational policy and its implementation in No Child Left Behind, Koyama and Varenne (2012) inscribed the term "policy as productive play" to recognize the complexities and uncertainties of the inevitably "temporal, incomplete, and always-becoming processes" going into interpretations and enactments of these educational policies and practices as they are experienced by students and their teachers (p. 157).

In what follows, we describe four core components of what makes up a [dis]ableing perspective for use in generating provocations to serve as a useful blueprint for future use of the [dis]ableing for those who are interested in understanding the ways ability and disability are discursively constructed in public and policy discourses. We illustrate the application of [dis]ableing to generate questions about the discourses circulating around Race to the Top. We will conclude with suggestions for future lines of making use of the [dis]ableing lens that offer possibilities for uncovering the hidden ways educational inequities are constructed, reproduced, and contested by the realities of ableist policies and practices.

Key Components of [Dis]Ableing

Four key principles compose and guide our application of the [dis]ableing lens. It is hoped these principles together can comprise a "habit of mind" to position the [dis]ableing researcher to counter assumptions about *ability* and *disability*. [Dis]ableing does not solely explore the language or semiotic representation at hand, but the ways in which these discourses shape the potential for human action and social identities. This [dis]ableing lens is designed to disentangle the planes of influence (Rogoff, 1990) on the text while also making visible the possible ways in which a text acts on (or shapes the action of) human subjects.

Tool 1: Defamiliarizing the Familiar

Postcolonial scholar Julia Kaomea (2003) explains that "defamiliarization" originates with Russian formalist Victor Shklovsky and that it is a literary tool to "force[s] us to slow down our perception, to linger, and to notice" as we read texts and phenomena (p. 15). Defamiliarization in Russian is *ostraneniye,* which translated into English means "making strange" (p. 15). Following Kaomea (2003), we will attempt to defamiliarize the familiar by looking into how the most recent educational policy of the *Race to the Top* put forward by the Obama administration discursively constructs students as well as their educational potential and future possibilities.

Tool 2: Destabilizing Ability-Normative Constructs

Valente (2011a) explains regulative and normative artifacts are a result of cultural climates. These regulative and normative artifacts are materialized in institutionalized and symbolic classification and codification systems (Valente, 2011a). For example, when dichotomous constructs such as fe/male, non/white, homo-hetero-bi-trans/sexual and dis/abled are denaturalized, they show their material selves to be ubiquitous, vague, and idealistic (Butler, 1999; Valente, 2011a). The "ideal" fe/male, non/white, homo-hetero-bi-trans/sexual and dis/abled person is non-existent – unachievable (see also Haraway, 2004; Valente, 2011a). We assert that *ability-normative constructs* are those that determine or prescribe -- whether through unconscious assumptions, explicit discursive statements, or visual cultural narratives -- what it means to be an *abled self* in a particular context.

Tool 3: Identifying and Disrupting Neoliberal Self-Sufficiency Myths

[Dis]ableing works to identify and disrupt neoliberal self-sufficiency myths that often are used to frame what can and should be achieved by and with an individual with a *disability*. Beth Blue Swadener's (2003) work on decolonizing schools describes how the neoliberal stakeholder agenda can be evidenced by the "privatization" and "marketization" not only of the institutions but also of the consumers and their discourses. Swadener (2003) explains if one "survey[s] the landscape of neoliberal and conservative policies related to our field, one cannot escape the related discourse of blame" (p. 137). Rodolfo Leyva (2009) seconds Swadener's concerns by speaking specifically about *No Child Left Behind*, writing that the "essentialist ideals of meritocracy, selfishness, and competition that are advanced by [a] neoliberal[-ist]" agenda is evidence that "the education system is largely seen as the ultimate arbiter of innate intelligence and ability, as well as the benefactor of hard-work and merit" (p. 365).

Tool 4: Locating the Inclusion/Exclusion of Narratives Shaping Discourses

The [dis]ableing avowedly privileges counter-narratives, insider accounts, and experiential knowledge. Grand narratives that unquestionably privilege the views of majority society and these dominant medical and scientific discourses can be challenged and upended by counter-narratives, which "lend a political dimension to everyday practices" (Certeau, p. xvii). Counter-narratives work against larger societal discourses by validating and valuing the lived experiences of people often categorized as *different* (e.g. Bell, 1987; Ladd, 2005; Ladson-Billings and Tate, 2006; Mutua and Swadener, 2004; Solorzano and Yasso, 2001a, 2001b). These counter-discourses are a strategic tactic for challenging assumptions of difference and superiority. *[Dis]ableing* purposefully works to locate counter-narratives to uncover tensions, contradictions, and moments where this discursive system of ableist oppression and subjugation comes to the surface.

[Dis]ableing the Rhetoric Underlying *Race to the Top*: Guiding Questions and Examples

The following section illustrates the generation of example critical questions using [dis]ableing as a lens for understanding two inaugural texts from *Race to the Top:* 1) the transcript of President Obama's announcement of the *Race to the Top* (7-24-09); and, 2) Secretary Duncan's letter to the governors of the states that competed in Round #1 of the Race (3-29-10).[v] The purpose of this is not to provide a comprehensive of the rhetoric that underpins *Race to the Top,* but to provide a snapshot example to serve as a starting point for conversations about the consequences, intended and unintended, of contemporary reform policies and practices that dogmatically view market-based solutions as a panacea for perceived school and social ills. Perhaps more important, these *Race to the Top* policies and likeminded discourses are doing the cultural work of *creating the need* for a panacea and then *providing the solutions* that unsurprisingly benefit the neoliberal agenda (Swadener, 2003).

What Narratives are Included and Excluded that Inform or Shape the Text/Policy?

This question attempts to "defamiliarize the familiar" by making the narratives themselves strange and to uncover how they are informed and shaped by larger discourses that are then enacted as policies and practices (Kaomea, 2003). Also this question works to make familiar storylines "strange" so that their meanings and lineages are no longer taken-for-granted or masked.

In applying this question for the two sample artifacts described above, we tracked four narratives operating across both texts (see Table A).

(1) Competition, high expectations and rewarding winners drives improvement and achievement (both for states and for students).

(2) America's future depends on preparing students for competition in the (international) workforce.

(3) "Data" (singularly defined as test scores) are the best way of measuring student and teacher performance.

(4) Educational reform is a matter of equity, which is important for economic reasons.

Table A, Example of a [Dis]Ableing Analysis

What narratives are included and excluded that inform or shape the text/policy?	**What forms of positioning are enacted by those narratives?**	**How are ability and disability performed in those narratives?**	**What assumptions about physical and cognitive capacities undergird those performances?**
(1) Competition, high expectations and rewarding winners drives improvement and achievement (both for states and for students).	(1) There are winners and losers. Winners are positioned as "bold" "creative" "leaders" whose accomplishments earn rewards. Losers are expected to learn from winners, modify performance, and try again.	(1) Ability is performed as leadership, effort, earning rewards. Dis/ability is not performed.	(1) Ability-normative assumptions that everyone has same resources and can and should compete on same terms.
(2) America's future depends on preparing students for competition in the (global) workforce.	(2) Students are positioned as workers whose purpose is to serve the economic growth of the country and global economy. Teachers are positioned as trainers for corporations, not educators for a social democracy.	(2) Ability is performed as productive labor. Disability is unproductive.	(2) Ability-normative assumptions that everyone has same resources and can and should compete on same terms.

(3) "Data" (test scores) are best way of measuring student and teacher performance.	(3) Positions education as a data-in/data-out endeavor. Students are to demonstrate skills and teachers and schools will be judged accordingly.	(3) Ability is performed by adherence to rules, order, re-producing knowledge. Disability is therefore a transgression.	(3) Everyone has the same set of test-taking skills and literacies.
(4) Educational reform is a matter of equity; equity is important for economic reasons.	(4) Equity is positioned as a matter of economic necessity.	(4) Ability is judged by economic productivity.	(4) Ability and disability is localized within individuals. Degree of economic reward is a reflection of hard work and intrinsic value.

Alternative description of Table A "Example of a [Dis]Ableing Analysis" showing the results from tracking four narratives operating across both texts.

This question also encourages the [dis]ableing researcher to consider the narratives that are *not included*. The two texts selected as data do not include narratives that question or reject the assumptions of these four aims listed above or raise issues (such as the Office of Civil Rights does) of educational inequities experienced by students with and without disabilities from marginalized groups. As a matter of fact, equity is hardly ever explicitly stated as a goal in *Race to the Top* artifacts but the *appearance* of equity is always front and center.

For example, in his introductory comments to kickoff the Race to the Top President Obama begins by thanking Matthew Austin, the African-American student who introduced him at the ceremonial press conference, and the President returns to reference Matthew at several points during his talk. At the time, an eighth grade honor student at Howard University Middle School of Mathematics and Science, Mathew was selected to introduce President Obama at the press conference held July 24, 2009:[vi]

> "Thank you for the outstanding introduction from Matthew. And Matthew's teacher, you're doing obviously an outstanding job -- although I understand Matthew's mom is also a teacher who has also won awards for her outstanding work. So the acorn doesn't fall far from the tree. We are very proud of him…[F]ixing the problem in our schools is not a task for Washington alone. It will take school administrators, board presidents, and local union leaders making collective bargaining a catalyst -- and not an impediment -- to reform. It will take business leaders asking what they can do to invest in education in their communities. It will take parents asking the right questions at their child's school, and making sure their

> children are doing their homework at night. And it will take students -- I'm not worried about Matthew, but all the other ones -- (laughter) -- including my daughters -- showing up for school on time and paying attention in class. Ultimately, their education is up to them."

And so Matthew becomes the face for the charter school movement and for students who are constructed as abled through their taking of responsibility for their own success, complying with the educational goals of "school administrators, board presidents and local union leaders" as well as "business leaders." Rather than providing an understanding of the realities that complicate the achievement of what is termed "taking responsibility" experienced by the majority of black students in schools, Matthew's story is used as *support* for the neoliberal restructuring of American public schools through the language of the market. The implicit message is that all children (including the President's) are capable of being like this well-spoken, hard-working African American middle-schooler. While we do not doubt that Matthew has worked hard, this narrative perpetuates the subtle blaming of so-called educational "failure" on teacher unions for supporting collective bargaining rights. It urges businesses to continue to invest in the massive transformation of public schools into charter schools. It suggests overly-simplified solutions to school success such as the power of parents who possess the cultural capital to navigate school bureaucracies (like Mathew's award-winning-teacher-mother does for him) and parents who make their children do their homework and be on time for school (like President Obama does for his children), and as his mother did for him (Obama, 2004). What this sound-bite rhetoric reveals is the perpetuating of narratives of educational "failure" to be about the need for teachers, businesses, parents, and students to simply show up and *will* themselves to better schools. But all this is just the surface. The [dis]ableing lens provides a telling look at what lies beneath the surface of such policy rhetoric as President Obama's announcement for the *Race to the Top.*

Further Provocations: To the Victor Belong the Spoils

To further illustrate what the application of the [dis]ableing perspective reveals, we focus here solely on the narrative of competition and its emphasis on rewards for "winners." In the accompanying Table A, we provide a synopsis of each remaining narrative and its possible implications.

The narrative of competition, with its underlying message that "to the victor belong the spoils," was evident from President Obama's initial announcement kicking off the *Race:*

> "That race starts today. I'm issuing a challenge to our nation's governors, to school boards and principals and teachers, to businesses and non-for-profits, to parents and students: if you set and enforce rigorous and challenging standards and assessments; if you put outstanding teachers at the front of the classroom; if you turn around failing schools -- your state can win a Race to the Top grant that will not only help students outcompete workers around the world, but let them fulfill their God-given potential."

In this announcement, the President begins immediately by thrusting American schools, communities, teachers and children into a literal race for funds and figurative race against workers around the world. He follows with an emphasis on "rigor" and "challenging standards" which immediately positions the current school climate as deficient. As if the fundamental issue has been a lack of "rigor" and "challenging standards," this rhetoric excludes needed discussions about inequitable distribution of resources for schools, institutional racism, or poverty in which students and their families live. Defamiliarizing this position makes evident that there is an entire context and history left out and there is no agreement as to what the terms "rigor" and "challenging standards" mean. It leaves out the entire deeply troubled history of how racism, classism, language policy, and disability have been written into the heart of being judged as abled in school through standardized testing and through assignment to tracks such as special education or gifted and talented (Connor & Ferri, 2005). It disguises the history of standardized testing and notions of rigor as they were designed and function to weed out the very students that Race to the Top (and NCLB) pretend to be supporting. The very name - *Race to the Top* – demonstrates that there will be winners and losers, since only one person can win a race. The contradiction between the market assumptions of *Race to the Top* and the rhetoric of helping all children be winners goes unmarked. Such larger discourses distract us from the real problem of inequities that come from poverty, under-resourced schools, and an educational system that only values high-stakes tests as a barometer of school and student achievement.

What Forms of Positioning are Enacted by those Narratives?

"Positioning" is derived from the work of Bronwyn Davies and Rom Harré (1990). Davies and Harré use positioning to describe the process through which people are placed into different identities (roles, categories, storylines) through culturally and historically situated discursive interactions (Collins, 2011). Positioning is typically applied dialogically to social interactions, with particular attention paid to the role of response in taking up or resisting subject positions. [Dis]ableing questions work to make visible what roles are created and made available to occupy within the discourses of the text.

This constrains real possibilities for people. It hurts children who are unwilling or unable to compete in this so-called "rigorous or challenging" race, whose bodies or minds exclude them from standardized ways of knowing and being. It limits curriculum to that which can be easily quantified, leading to the much decried reduction of American school curriculum to those few content areas that are tested as well as an impoverished perspective on what is worthwhile to learn about and do with those content areas. It positions teachers who choose to work with such children as non-participants, underachievers, and generally deficient. It also sets the stage for considering "low-achieving" schools as deficient.

What Assumptions about Psychological, Physical and Cognitive Capacities Undergird those Performances?

When conducting an inquiry using a [dis]ableing perspective, it is important to identify and disrupt the taken-for-granted ways of knowing and being that are embedded in the narratives that shape the text. Assumptions about physical and cognitive traits and capacities, which undergird performances, perceived to be successful or unsuccessful need to be recognized and identified before they can be disrupted (Collins & Valente, 2010).

Both Duncan and Obama make statements that assume that all state competitors have the same resources and will to compete, that they need only "put their best foot forward," and (like Matthew) they will become "winners:"

> "To the winners, I congratulate you. To others who applied, I salute you for your hard work, and I look forward to receiving even stronger proposals. To those who have not yet applied, I invite you to put your best foot forward." [Duncan's letter]

Duncan and Obama's rhetoric provides a window into the thinking of twenty-first century educational reform efforts that insist all students should be held equally "accountable" *irrespective* of how they experience (or do not experience) their education and *irrespective* of the context (e.g. well-resourced suburban or under-resourced urban schools) in which their education occurs. Obama makes these points clear during the announcement of the first round of winners:

> "I am absolutely confident that if I do my part, if Arne does his part, if our teachers do their part, if you do yours, if the American people do theirs, then we will not only strengthen our economy over the long run, and we will not only make America's entire education system the envy of the world, but we will launch a *Race to the Top* that will prepare every child, everywhere in America, for the challenges of the 21st century." [Obama's announcement]

Elsewhere we have explained these reforms are devaluing the diverse ways humans can contribute to the world and this movement for *ability* to be judged based on the performance of productive labor (as defined by global economic interests) is ushering in a new neoliberal version of *ableism* (Collins & Valente, 2010; Valente & Collins, 2010). These educational inequities that stem from neoliberal ableism are caused by the values that this pattern of thought attaches to differences in achieving the "standard." Baglieri and Knopf (2004) succinctly explain, "the question is not whether we perceive differences among people but rather, what meaning is brought to bear on those perceived differences" (Baglieri and Knopf, p. 525). Newer versions of educational reforms and *ability* not only demonstrate a lack of attention to how perceived differences are unevenly treated and valued but also debatably evidences a level of active complicity in furthering educational inequities purportedly in exchange for a competitive edge in the global marketplace. These reforms discount the direct link poverty and race have on academic achievement and obstinately perpetuates the belief that competition is the panacea for bringing about equity for poor and minority students.

Conclusion: New Directions

As discussed earlier, the field of disability studies can be dismissed as only relevant to those with disabilities. For instance, Lennard Davis (2006) points to the sustained growth in the scholarly literature by radical educators that deals with the production and reproduction of hegemonic practices and policies, remarking that it is troubling "critical theorists who have promoted such views, have been silent on disability, inclusion, and special education" (Davis, p. 226, 2006 citing Bowles & Gintis, 1976; Apple, 1979; Giroux, 1988; Freire, 1968, 1973, 1987). What is also often forgotten and need to be addressed is that, at its core, schooling in today's hyper-competitive age is becoming more about defining, locating, measuring, and remediating *ability*. We propose disability studies in education scholarship and more specifically *[dis]ableing* as a lens for examining not only how *ability* is defined and constructed in current educational policies and practices, but also for making visible the consequences that those definitions have for students with perceived differences of all types. This article uses a disability studies in education framework and [dis]ableing as a lens for demonstrating the need to critically examine the cultural discourses and institutional practices that lead to educational sorting, legalized segregation and other forms of educational inequities.

In an inclusive social democracy, differences are the norm. The ways schools, teachers, parents, policy makers, and citizens respond to those differences determines whether the United States lives up to his purported goal of equity for all through public schools that are educating students to be citizens in a social democracy. Narratives of competition, as noted earlier, are prevalent in the current cultural climate as evidenced by *Race to the Top* and its emphasis on competition and rewards for “winners.” Equity as illustrated by the *Race to the Top* means that everyone is allowed to compete on same field both for students and for states in competitions. Equity also means conformity – that schools and students must compete in this *Race to the Top* in a prescribed way (through high-stakes testing) or risk receiving no money and more scrutiny.

[Dis]ableing points to the presence of a narrative of competition that creates subject positions of winners and losers and non-participants. In the language of RTT documents, losers are expected to learn from winners, modify their performance, and try again. Winners accept the terms of race and are ready to compete and “to do what works.” Finally, losers are expected to be unhappy with the terms of the race and gear up for the next round. A chief concern is that the newest version of education reform pulls us away from democratic ideals of equity and citizenship toward redefining ability in schools to not be about these ideals but instead a worker in the future global economy.

The *Race to the Top* is just one example of an educational policy that *appears* to be about equity and inclusion and yet in practice works to define, locate, measure and remediate *ability*. *Race to the Top* ultimately ends up providing the logic (and funding) for a system of segregated education based on who is a “winner” and who is a “loser.” When it comes to legislative mandates that reinforce ableism, *Race to the Top* is not “new” or “special” (see for example, Beth Ferri’s analysis of *Response to Intervention* in Ferri, 2011). As we have already argued, what is new is that today’s version of reform in education brings together ableism and neoliberalism. This newest reform movement redefines what it means to be *able*, basing it on what one can contribute to a capitalist society and not on what one can contribute to social democracy. In a social democracy it is not about victors or spoils, instead it is about valuing the diverse ways in which everyone *can* contribute to the richness of all our lifeworlds.

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[i] Link: http://wosu.org/2012/news/2014/08/25/business-groups-defend-common-core-house-hearings/

[ii] Our use of the term [dis]ableing is conceptually unrelated to the British use of the term "disabling." For further readings see articles that appear in the *Review of Disability Studies* by Gilson & Depoy (2015), Hemingway & Priestley (2014), and Wilde (2010). In addition, see the special issue of the *Journal of Literary and Cultural Disability Studies* entitled "Disabling Postcolonialism" co-edited by Barker and Murray (2010).

[iii] We recognize that there are newer iterations of *Race to the Top* competitions that focus on additional state competition phases, early childhood, teacher education, and district-level competitions, the ableist assumptions in the discourses of phase one have not changed in more recent iterations.

[iv] For a rich discussion of ableism see Fiona Kumari Cambpbell's (2009) *Contours of Ableism.*

[v] A complete transcript of President Obama's remarks is available at http://www.whitehouse.gov/the-press-office/remarks-president-department-education.

Mr. Duncan's letter to the governors may be downloaded at http://www2.ed.gov/news/pressreleases/2010/03/03292010.html

[vi] Video available at http://www.whitehouse.gov/video/President-Obama-on-Race-to-the-Top

Film Review
Becoming Bulletproof

Reviewed by Dr. Yohai Hakak
University of London, UK

Director: Michael Barnett
Producer: Theodore James
Running time: 1h 20m

Becoming Bulletproof is a beautifully made and life-affirming documentary film about a mixed group of people, some with disabilities, some without. They meet for a few days during the summer once a year as part of the inclusive arts project Zeno Mountain Farm (http://zenomountainfarm.com/), in order to make a movie. The documentary follows the group after they decide to make a mini-western in the California desert called *Bulletproof*. The process of making this film (and the results) as captured by the documentary are unique and refreshing for several reasons.

Since people with disabilities are still vastly under-represented in front of the camera or behind it, this positive representation of people with disabilities acting in a film together with people without disabilities and in a wide range of roles, is refreshing. A range of disabilities are represented though many have Cerebral Palsy. But, the documentary does a much bigger service to the discussion about disabilities in the way that it portrays the relations between the different participants in the making of the movie.

Common stereotypes of people with disabilities often show them as passive recipients of services or support provided by “non-disabled” people. In *Becoming Bulletproof*, they are partners and collaborators in a joint effort to create together, and they bring into play unique talents and strengths. As described in the film by Peter Halbey, the co-founder of Zeno, “The mission of Zeno is to support life-long friendships between people with and without disabilities”. There’s no mention of “helping”, “supporting”, “assisting”, just creating friendships and having fun. The power of such an approach is unmistakable and grabs you as a viewer instantly. The long trail of awards the film has received so far is a good indication of that. The participants, both those with and those without identifiable disabilities are clearly having a great time. AJ Murray, the film’s hero who has Cerebral Palsy, sums it up when he thanks the organizers for enabling him to “feel significance, dignity and purpose” through participating in the film.

Becoming Bulletproof brings us into the lives of several young disabled people we get to know and love. The organizers and their warm, open and down-to-earth conduct are a joy to observe. After watching *Becoming Bulletproof* I was left wondering again about the artificiality of the distinctions between people with and without disabilities. Have I crossed it once I started wearing glasses? Or did my wife once she dislocated her knee and started using crutches?

As a lecturer in social work, I was left thinking about how can we develop such positive, warm and playful spirit in our students in the caring professions? How can we help them create interactions that are full of positive energy and creativity? Social Pedagogy scholars talk about the “common third” as a shared area of activity which is external to the subjects involved in the interaction. Making *Becoming Bulletproof* fulfilled this exact role. Relationships that revolve around the common third are characterised by notions of equality and respect and the eradication of unequal power relations. “Through a common or joint activity the users and the professionals enter a subject –subject relation in which the professional is meant to “forget himself” and the things around him – and devote him/herself entirely to the process and activity…the pedagogical challenge is to be able to realise activities which don’t reflect the interests and needs of only one part, but instead seek to establish a *common* and *productive* activity” (Hatton, K, 2006). Judging by this unique documentary, such common third has an immense positive power we should seek to nourish.

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DISSERTATION ABSTRACTS

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