Editorial
Greetings!

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Aloha,

I am Patricia Morrissey, Director of the Center on Disability Studies (CDS), College of Education, University of Hawai'i at Mānoa. Since July 1, 2019, I also have been editor-in-chief of the *Review of Disability Studies: An International Journal (RDS).* I really miss Dr. Megan Conway, our former editor, and Genesis Leong, our assistant to the editor. Both did a spectacular job helping *RDS* thrive for 15 years. Theirs' are big shoes to fill! Going forward I will be aided by Sandra Shitanishi, Tom Conway, and we hope to hire an associate editor soon. In the meantime, be patient with us. Genesis will continue working at CDS full time on our *PacRim, an International Conference on Disability and Diversity*, in its 35th year, at the Hawaii Convention Center in Honolulu, held March 2-3, 2020. I am sure Genesis will help us when the need arises.

We anticipate that 2020 will be a busy year. We will be asking our current pool of reviewers to extend with us through March 31, 2020. By then, we will send emails asking who wishes to 'reup' and also reach out to potential new reviewers. This extension will allow us to use our cadre of reviewers to get through and publish the March 2020 issue of *RDS* without disruption.

We are also exploring new platforms to host *RDS*. We want to find one more user-friendly to authors and CDS staff. Don't worry, when we transition to a new platform, www.rds.hawaii.edu will still work.

The current issue of *RDS*, I know, is a little late. It should have been published in December 2019. With the holidays and transitions, we weren't where we had hoped to be on December 31, 2019. The COVID-19 pandemic has also impacted our timing for publication.

With all that said, let me share some programmatic activities that will happen in 2020.

First, the June 2020 issue of *RDS* will be a forum issue devoted to developments in Asia. Dr. Robert Stodden, CDS' former director, will lead this effort with help from our able editorial board, Sandy and me.

Second, at the recommendation of Dr. Sona Hill from Ohio State, a member of our editorial board, as an experiment we will open *RDS* to authors who do not speak English and we will take on the task of getting their research articles and policy analyses translated. Then, their articles will be published in English and their native tongue. Initially, we will solicit one author of

this kind to be published in the fall 2020 issue. If the process and experience prove a success, we will then open up RDS to submissions from any non-English speaking submitters. Because this is a labor-intensive activity, we will publish only one article in this manner for each issue in winter 2020 and all four issues in 2021. After that, more may be possible. I believe this is a ground-breaking activity in our discipline.

Third, I plan to make my future editorials something for us to ponder, trigger exchanges with me, and perhaps be a basis of a blog post. My background is in disability policy at the federal level. I would hope my editorials will lead to discussions about how federal policies are reflected, from the disability studies perspective, on the ground.

Thank you and Happy New Year.

My Bio Brief

I was Commissioner of the Administration on Developmental Disabilities (ADD) from August 2001 till January 2009. From 2004 to 2005, while serving as in that post, I was a member of the U.S. Delegation to a United Nations Committee while it drafted the Convention on Civil Rights for Persons with Disabilities.

Prior to that position I was a senior associate at Booz Allen Hamilton, providing consulting services to federal agencies, especially on accessibility in technology. I worked for the U.S. Senate Committee on Health, Education, Labor and Pensions for five years prior to joining Booz Allen. I played a central role in the drafting major disability legislation – the Individuals with Disabilities Education Act Amendments of 1997, the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1996 and 2000, the Rehabilitation Act amendments of 1998, the Assistive Technology Act of 1998, the Education of the Deaf Act Amendments of 1998 and the Ticket to Work and Work Incentive Improvement Act of 1999. I also worked for the U.S. House of Representatives, Committee on Education and Labor, also drafting disability legislation, including the Americans with Disabilities Act (ADA). I have written four books and assisted in the production of training videos on the ADA. After leaving the House committee staff before joining the Senate committee staff, I served as a consultant to Fortune 200 companies on ADA compliance.

I am a problem solver committed through varied venues and innovative strategies, to expanding opportunities for individuals with disabilities.

In addition to working at CDS, I am also the President of the U.S. International Council on Disabilities.

Research Article

A Critical Disability Studies Approach to 'Inclusive' Early Childhood Teacher Education

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Abstract: Critical Disability Studies (CDS) focuses on how normalcy is constructed and offers an important framework for questioning 'inclusive' early childhood practices. This article proposes a CDS approach to early childhood 'inclusive' teacher education that (1) develops a CDS pedagogy, (2) identifies ableist practices, and (3) questions and redefines 'inclusion'.

Keywords: Critical Disability Studies; Inclusive Education; Early Childhood Education

Introduction

Within the United States, when the term 'inclusion' is used in an educational context, it most often refers to the practice of placing children with disabilities into mainstream classrooms alongside their typically developing peers (e.g., Buysee & Hollingsworth, 2009; NPCI, 2009; Soukakou, 2012). The practice of educating children with disabilities within the least restrictive environment was made a legal requirement with the passage of the Education for All Handicapped Children Act of 1975 (P.L. 94-142). While this legislation ultimately makes it possible for children to be legally excluded from the general education classroom, it has also led to an increase in the number of children with disabilities in 'inclusive' classrooms (Kliewer & Raschke, 2002). The increasing number of children with disabilities in the general education classroom resulted in a research agenda focused on (1) parent and teacher perceptions of challenges and barriers to inclusion (Robertson, Chamberlain, & Kasari, 2003; Sainato, Morrison, Jung, Axe, & Nixon, 2015); (2) the impact of inclusive education on academic success and social development (Robertson et al., 2003; Sainato et al., 2015); (3) the development of procedures and best practices for inclusion (Barton & Smith, 2015); and (4) the implications of this body of research on inclusion for teacher education and professional development (Buysee, 2012; Buysee & Hollingsworth, 2009; Soukakou, 2012). Critical special education and disability studies in education (DSE) scholars began to call attention to the idea that 'inclusion' must be more than just a physical placement (Ferri & Bacon, 2011). The resulting critical studies demonstrate that teacher attitudes towards disability (Huang & Diamond, 2009), classroom dialogue and interactions (Franck, 2018; Naraian, 2011; Watson, 2017), and curriculum (Kilderry, 2004), all impact the 'inclusive' schooling experience of children with and without disabilities.

Over the past decade, the definition of 'inclusion' has broadened to mean the implementation of support to ensure that all children are able to physically, socially, and

academically have access to, and participate in the general education classroom (DEC/NAEYC, 2009). However, even with this broader understanding of 'inclusion', research from scholars in the field of critical disability studies (CDS) indicates that the value of 'inclusion' does not necessarily translate into practice as intended or described. Children from culturally and linguistically diverse backgrounds continue to be disproportionately represented in subjective disability categories (Connor, Ferri, & Annamma, 2016; Ferri & Connor, 2006; Losen & Orfield, 2002). Children with disabilities, and children from non-dominant backgrounds, continue to experience social, physical, and academic exclusion in the 'inclusive' classroom (Franck, 2018; Watson, 2017). The academic field of CDS "expands the understanding of disability from a health science perspective to consider it as a civil and human rights issue, a minority identity, a sociological formation, a historic community, a diversity group, and a category of critical analysis in culture and the arts" (Garland-Thomson, 2019, p. 12). CDS provides an important framework for preparing future teachers to implement critically inclusive practices.

This paper describes three foundational elements of a CDS approach to early childhood 'inclusive' teacher education programs: questioning and redefining 'inclusion', identifying ableist practices, and developing a CDS pedagogy. I'll begin by describing why a CDS approach to 'inclusive' teacher education is necessary in the first place. Then, I'll explain how I arrived at the three proposed elements of a CDS approach to early childhood 'inclusive' teacher education. I will describe each element, using theoretical vignettes to illustrate the translation into practice. Finally, I provide my suggestions for future work that incorporates a CDS approach to early childhood 'inclusive' teacher education.

Why Teacher Education?

Based on the 2017–2018 child count data, approximately 45% of children with disabilities between the ages of 3 and 5 years receive special education services within regular early childhood programs in the United States (USDE, 2018). In other words, almost half of preschool and kindergarten children with disabilities are educated in 'inclusive' environments, where 'inclusion' is defined as an educational placement that integrates students with and without disabilities. Barton and Smith (2015) compare 1989 and 2014 surveys about perceived barriers to effectively implementing 'inclusion' in preschool classrooms. They note that the attitudes and beliefs about 'inclusion' were rated the greatest challenge in the 2014 survey, a finding supported by the research of Huang and Diamond (2009) and Kwon, Hong, and Jeon (2017). While the category of attitudes and beliefs contains a number of concerns (e.g., lack of collaboration, lack of preparedness), both special educators and general educators expressed the belief that children with and without disabilities are more effectively educated in separate settings (Barton & Smith, 2015). Concerns about educating students with and without disabilities together in the same classroom are generally attributed to a lack of preparation (pedagogical and collaborative skills), resources (material and staff), and administrative support (Barton & Smith, 2015). This points to the importance of all early childhood teacher education programs preparing pre-service teachers

for the 'inclusive' classroom. In the following section, I'll explain why CDS provides a useful framework for reconceptualizing early childhood 'inclusive' teacher education.

Why Critical Disability Studies?

While teacher education research described above provides one story as to why CDS might be a useful tool for the early childhood 'inclusive' classroom, it is important to take a look at how 'inclusion' is defined and described by the field of early childhood. The Division for Early Childhood (DEC) and the National Association for the Education of Young Children (NAEYC) define early childhood 'inclusion' in their joint position statement:

> Early childhood inclusion embodies the values, policies, and practices that support the right of every infant and young child and his or her family, regardless of ability, to participate in a broad range of activities and contexts as full members of families, communities, and society. The desired results of inclusive experiences for children with and without disabilities and their families include a sense of belonging and membership, positive social relationships and friendships, and development and learning to reach their full potential. The defining features of inclusion that can be used to identify high quality early childhood programs and services are access, participation, and supports (DEC/NAEYC, 2009, p. 2).

This definition communicates a more progressive definition of 'inclusion', which focuses not only on the placement of young children with disabilities in the general education classroom, but also on the importance of providing all young children with the support they need to access and participate in the classroom. If the field of early childhood 'inclusion' has adopted such an approach, why is it necessary to consider what a CDS perspective might suggest about early childhood 'inclusive' education? In order to provide a brief answer to this question, I will draw on an example of how inclusion is described in the Division for Early Childhood of the Council for Exceptional Children's (2017) video, *Because it Matters*, published on their YouTube channel. In this video, a group of young children sit facing their teacher. Text appears on the screen, showing the labels of various children in the classroom (e.g., autism spectrum disorder, post-traumatic stress disorder, social emotional delay). Then, the text poses a question to the audience, "Can you tell the difference?" The video concludes with the statement, "Inclusion: Because it matters." The Division of Early Childhood's video implies that inclusion is important because it renders difference invisible. Despite articulating a more progressive approach to 'inclusive' education, the field of early childhood 'inclusive' education continues to construct difference as negative, and as something to be eliminated.

Towards a CDS Approach to Early Childhood 'Inclusive' Teacher Education

In this paper, I will propose three foundational elements of a CDS approach to early childhood 'inclusive' education: questioning and redefining 'inclusion', identifying ableist

practices, and developing a CDS pedagogy. I offer these specific elements based on my analysis of the ongoing divide between the fields of early childhood 'inclusive' education and CDS (Eilers, in press). This analysis reveals that the field of CDS is perceived as offering little practical application, while the field of early childhood 'inclusion' continues to make incremental shifts towards embracing a more critical approach to 'inclusive' education without being fully open to all that such a critical approach would require. The academic work that does merge the fields of CDS and early childhood 'inclusion' informs the three foundational elements I propose. First, this work highlights the taken-for-granted idea that 'inclusion' is best practice, and as such, falls outside the realm of practices that might need to be critiqued, indicating a need to explicitly introduce why it might be important to question and redefine 'inclusion' within early childhood 'inclusive' teacher education programs (Watson, 2017). Additionally, work by Burke (2015), Naraian (2011), and Watson (2016, 2017, 2018), demonstrates how a CDS perspective highlights ableist practices that impact the 'inclusive' schooling experience of young children. It is important for future teachers to develop the skill of being critically reflexive within the classroom, so that they might identify and respond to "the changing structures and meanings that define and restrict emancipation" (Meekosha & Shuttleworth, 2009, p. 64) within the classroom. Finally, and perhaps most importantly, programs that have incorporated disability studies into teacher education (Ashby, 2012; Naraian & Schlessinger, 2017; Oyler, 2011) suggest the need for future teachers to understand not only how to be critically reflexive, but how to use this reflexivity for the development of a more critical pedagogy. In other words, it is important to be able to critique the underlying meaning of 'inclusive' education, and to identify practices that are ableist, but it is essential that this critique leads to action.

Element One: Identifying Ableism in Dominant 'Inclusive' Practices

A CDS approach to early childhood teacher education "shifts attention away from the problems of disablism ('the Other') to the problems of ableism ('the same' or 'the dominant')" (Goodley, 2013, p. 637). Hutcheon and Wolbring (2012) provide a useful definition of ableism:

> Ableism as a concept describes, and is reflected in, individual and group perceptions of certain abilities as essential. Ableism can be treated as both a *hegemony* which promotes ability preference and as *an analytical tool* used to understand these preferences and their impact (p. 40).

Drawing on Hutcheon and Wolbring's definition, it is important that future teachers are prepared to recognize ableism as a hegemony, understanding the ways in which "ethnicity, class, gender, sexuality, and pan-national identities converge around the problems of disability as a consequence of attempts to maintain…ableist normativity" (Goodley, 2013, p. 637). Additionally, future teachers need to be prepared to use ableism as an analytical tool, examining the impact of how understandings of ability impact the schooling experiences of young children within the classroom. In order to develop these two competencies, pre-service teachers must first

"be fluent in the discourses of special education" (Oyler, 2011, p. 209). Indeed, as pre-service teachers enter schools and classrooms that employ dominant methods of 'including' young children, they need to understand the structure and processes of these dominant methods in order to recognize and challenge ableism. This will allow pre-service teachers to understand the "tensions…between an inclusive philosophy and the meritocratic structure of schools" (Rice, 2006, p. 260). In this section, I will discuss how a CDS approach to 'inclusive' early childhood education might provide pre-service teachers with both a thorough understanding of dominant methods of 'inclusive' education, and the tools to recognize ableist practices.

Barton and Smith's (2015) book, *The Preschool Inclusion Toolbox: How to Build and Lead a High-Quality Program* introduces the text as one that could be used to develop "program-level policies and procedures that promote preschool inclusion" or "as a text for graduate students in early childhood special education programs and early childhood programs" (p. 1). A CDS-informed teacher education program might utilize such a textbook in order to introduce pre-service teachers to current methods of 'inclusive' education, and to engage pre-service teachers in the practice of identifying ableist practices. Pre-service teachers could be assigned to read portions of the text alongside corresponding CDS literature. For example, pre-service teachers might read Barton and Smith's (2015) definition of 'inclusion', as well as their recommendations for socially including children with disabilities. Watson's (2016) article, *Talking Tolerance Inside the "Inclusive" Early Childhood Classroom*, could be simultaneously assigned in order to encourage pre-service teachers to problematize dominant methods of social 'inclusion', which "create a narrative about the marked child as Other, as lacking or deviant" (p. 4). Barton and Smith (2015) explain that the field of early childhood has transitioned away from using the term mainstreaming, and now utilizes the term 'inclusion' in order "to promote the full acceptance of each child as an engaged and participating member of his or her family, classroom, and community" (p. 36). The textbook primarily uses the term 'inclusion' to describe how to advocate for the placement of children with disabilities in the general early childhood classroom, and how to support children with disabilities using evidence-based practices. The following anecdotal example is given to demonstrate how a teacher, Elena, might make accommodations for a student with disabilities named David:

> Elena notices that David often has a difficult time initiating interactions with peers. She decides to include 'peer buddy' activities during center time so he gets more opportunities to interact with peers one to one. In peer buddy systems, the teacher intentionally pairs up children who have more advanced social skills with children with disabilities who are learning social skills… (Barton, Pribble, and Joseph, 2015, p. 118).

This vignette illustrates how the 'inclusive' and evidence-based practice of peer-modeling is meant to facilitate the social 'inclusion' of students with disabilities. When considering this vignette through the lens of CDS, the practice of peer-modeling can be problematized as an

ableist practice. Specifically, a CDS perspective triggers the questions: in what ways does peer-modeling "permit the Normal to exercise power" (Watson, 2016, p. 8)?; how does David's disability come to explain how he "might act and think" (Watson, 2016, p. 8)?; and what does the practice of peer-modeling suggest about the meaning of 'inclusive' education? Through this line of questioning, it becomes possible to see that the practice of peer-modeling, when framed as socially inclusive, "conceals power relations, the power of authority, and the power associated with discourses of the Normal" (Watson, 2016, p. 11). Simultaneously reading Barton and Smith's (2015) text on dominant methods of 'inclusion' and Watson's (2016) critique of such methods allows pre-service teachers to identify how ableism "create(s) an environment that is often hostile to those whose physical, mental, cognitive, and sensory abilities…fall out of the scope of what is currently defined as socially acceptable" (Rauscher & McClintock, 1996, p. 198).

Not only is it important for pre-service teachers to be able to identify ableism in daily classroom practices, but also it is essential for pre-service teachers to understand how ableism is entwined with race, class, and gender. While many traditional pre-service teacher education programs include coursework related to cultural competence, "few scholars actually practice it because the process of challenging traditional views often includes harsh and personal discourse" (Carter, 2002, p. 309). Additionally, early childhood teachers often hold beliefs that position children as 'too young' or 'too innocent' to actively negotiate ideas about dis/ability, gender, race, and class (Robinson & Díaz, 2006). A CDS approach to early childhood 'inclusive' teacher education must work to counter these beliefs, and to demonstrate that children come into the classroom with "a myriad of perceptions of difference that they have taken up from their families, peers, the media and other social sources and negotiated in the representations of their own identities" (Robinson & Díaz, 2006, p. 4).

One example of particular relevance to the field of early childhood 'inclusive' education is the disproportionate representation of children from culturally and linguistically diverse backgrounds within the special education system (Losen & Orfield, 2002; Reid & Knight, 2006). The special education eligibility determination process has long been critiqued for lacking cultural sensitivity, resulting in a disproportionate representation of culturally and linguistically diverse children, particularly within subjective disability categories (e.g., learning disability, developmental delay) (Ferri & Connor, 2006; Losen & Orfield, 2002). In response to this issue, the Individuals with Disabilities Education Act (1997) requires that assessments are "selected and administered so as not to be discriminatory on a racial or cultural basis" (1414.E.A.i). However, this statute has not made an impact on the disproportionately high representation of minority students in special education (Harry & Klinger, 2014). Additionally, once classified as a child with a disability, students from culturally and linguistically diverse backgrounds are more likely to be placed in segregated settings (Kozleski, 2016). In other words, the decision of "*what* category to place a student in is followed by another kind of decision in which constructions of

race interact with disability to determine *where* a student will be educated" (Kozleski, 2016, p. 114–115). Fergus (2016) explains that, "the research on disproportionality focuses mainly on the structural components of schools and less on the role of practitioner beliefs about race and cultural difference" (p. 119). After analyzing the results of a survey designed to measure teacher perceptions related to disproportionality, Fergus (2016) found that "as deficit thinking increased, cultural responsibility awareness, and knowledge decreased" (p. 126). A focus on practitioner beliefs about race and ability is of particular relevance for early childhood educators, as IDEA (1997) included a child find mandate, creating an environment in which teachers are expected to "hunt for disability" (Ferri & Bacon, 2011). The 'inclusive' early childhood classroom aims to 'include' students who have already been given a disability label, and students who are considered 'at-risk' because they come from culturally and linguistically diverse families and/or low-income families. Pre-service teachers must be exposed to literature that describes how "ability is constituted as property" (Ferri & Connor, 2014, p. 472) which is used "to justify segregating students with disabilities, as well as disproportionate numbers of students of color, English Language Learners (ELLs), and poor students (Ferri & Connor, 2014, p. 472). A CDS approach to early childhood 'inclusive' teacher education must explore the ways in which the 'inclusive' classroom can "unmask and expose the normalizing processes of racism and ableism as they circulate in society" (Connor et al., 2016, p. 14).

Vignette: Active participation in circle time

Olivia is beginning her student teaching practicum in an 'inclusive' preschool classroom. She spends the first week observing the classroom, participating in the daily routines and activities, and writing both anecdotal notes and reflections. In one reflection, she writes:

> *There are three students in the class with Individualized Education Programs (IEP). The teacher keeps a clipboard with each student's specific IEP goals. One goal that all three students have in common is that they participate in circle time by remaining with the class and engaging in activities (e.g. songs, read aloud) for ten minutes with no more than two redirections for five consecutive days. I notice that many of the students have a difficult time participating in the way that is expected of them during circle time. Students are directed to sit with crossed legs, but many need to be reminded several times. Also, the teacher uses the rhyme "One, two, three, eyes on me," and tells students that she knows that they are paying attention when she can see their eyes looking at hers. I think about what this direction suggests about the ableist norm of eye contact, which assumes vision as the only acceptable tool for accessing the classroom environment and indicating participation. Another thought I had, was that while many of the children in the class need reminders and redirections during circle time, the teacher is specifically tracking these reminders only for children with IEPs. What impact does tracking instances of redirection for just three children have on the teacher's perception of these students – of the other students? I notice that even though some students do not look at her while she is*

reading, they still seem to be listening and respond to questions at the end. These observations are making me wonder whether it might be important to allow for different types of active participation – Some students might need to sit in different positions, and some might need to stand. Some students might demonstrate that they are listening by looking, but others might be listening while looking at an object that they are feeling in their hands.

Olivia uses the data from this reflection when she begins to take over activities in the classroom. She tests out a different approach to circle time, allowing for variable means of active participation. Before beginning, she has a discussion with the classroom teacher in order to explain her rationale for trying out something new. It is important that Olivia has the opportunity to practice these types of conversations, as she will likely continue to encounter practitioners who might not take the same critical approach to 'inclusion'. Olivia is able to explain that she wants to understand what happens when the children are given the opportunity to participate in different ways during circle time. She leads circle time for a week, each day modifying the activities that she includes based on what she notices about the interests of students. Initially, the classroom teacher feels discomfort watching as some students lay on the ground, others held squishy toys in their hands, and one stood. However, Olivia is able to point out that the students contributed in ways that demonstrated their active engagement, despite the evidence of their participation taking a different form. Olivia's knowledge of dominant 'inclusive' practices, combined with her understanding of ableism as a hegemony and an analytical tool, allow her to navigate a complex situation.

Element Two: Questioning and Redefining 'Inclusion'

If we listen to teachers, education administrators and academics as they discuss inclusive education and the range of kids who present for schooling, we soon hear that we are a long way from where inclusive schooling should take us. There remains a firmly embedded notion of what a regular school is and more particularly, who it is for (Graham & Slee, 2008, p. 280).

As Graham and Slee (2008) explain, the process of including children into the 'regular school' is heavily laden with ideas about who the 'regular child' is, and what the 'irregular child' must do in order to be successfully included. McDermott (1993) asserts that in the absence of some 'normal' definition of learning, there would be "no such thing" as an abnormal learner (McDermott, 1993, p. 272). However, pre-service early childhood teachers are rarely encouraged to ask questions about 'inclusion'. In her book, *Inside the 'Inclusive' Early Childhood Classroom: The Power of the 'Normal,'* Watson (2017) reflects on twenty years of teaching:

My knowledge and teaching practice was built on clinical and 'scientific' 'truth', and my understandings of the child were entrenched within 'the medical model of disability'. I did

not know at the time that my knowledge, and my formidable allegiance to it, produced considerable constraints and limitations on the children I had taught. I lament the unquestioning and uncritical way I performed as a teacher and how I positioned myself (p. 4).

Watson's (2017) story demonstrates that the 'roles' of the teacher, the child, and the field of child development are highly engrained, and not often subject to critique. A CDS approach to early childhood 'inclusive' teacher education must encourage pre-service teachers to question how 'inclusion' "is framed by the political predisposition of exclusion" (Watson, 2017, p. 191). In this section, I will draw on the work of CDS scholars in order to conceptualize pedagogical activities that would encourage pre-service teachers to explore how the 'inclusive' classroom is constructed, and to consider a new way of defining 'inclusive' education.

Connor (2015) describes how he structures a disability studies course about 'inclusion,' which also serves as the only required special education course for pre-service general education teachers. His course begins with the history of special education and disability studies, as well as the analysis of media portrayals and real life observations of dis/ability, which encourage students to consider "What is normal?" (Connor, 2015, p. 135). While thinking about dis/ability as a social construction is often an unfamiliar task, Connor notes that, "Most people…are intrigued by looking at a familiar phenomenon such as dis/ability in a radically different way that triggers a deep, personalized response" (p. 125). Connor (2015) explains that this initial focus on theory is essential as "without the theoretical grounding of [disability studies/disability studies in education], practices appear to be understood on a very superficial level- as if 'what works' is largely free of theory and ideology" (p. 136). Drawing on Connor's (2015) approach, I conceptualize a CDS approach to the common practice of conducting classroom observations during pre-service training.

Early childhood teacher education programs often include a number of classroom observations, which help the pre-service teacher develop the skills to "assess developmental levels, interests, and the curriculum concepts and learnings that follow" (Vartuli, Snider, & Holley, 2016, p. 508). During these observations, pre-service teachers are often asked to focus on some specific element of teaching or learning, which coincides with the course material (Vartuli et al., 2016). For example, pre-service teachers might be asked to observe and reflect on the teaching practices used to facilitate the 'inclusion' of students with disabilities while reading about evidence-based practices for 'inclusion'. A CDS approach to this activity might begin in a similar manner, asking pre-service teachers to take a written record during a classroom observation, and to reflect on the observed 'inclusive' practices. After this initial observation, students would read Watson's (2018) article, *Interrogating the 'Normal' in the 'Inclusive' Early Childhood Classroom: Silence, Taboo and the 'Elephant in the Room,'* and conduct a secondary analysis of their observation data to explore how children are positioned as included/already

included/excluded within classroom activities and discourse. Watson's (2018) article provides an example of how to critically analyze 'inclusive' practices, and also presents an argument for critically thinking about the goals and practices of 'inclusive' education. In other words, this activity facilitates conversations about how to "further examine, understand and dismantle exclusion as it is present in education" (Watson, 2018, p. 143). This activity is aligned with CDS as its aim is to draw focus away from disabled children, and onto 'the abled' in order to identify how "Ableist processes create a corporeal standard, which presumes ablebodiedness, inaugurates the norm and purifies the ableist ideal" (Goodley, 2013, p. 640). This activity is, of course, just an introduction to a CDS approach to 'inclusion', and this line of deconstructive questioning must also lead to a reconstruction of 'inclusive' education.

From a CDS perspective, what is 'inclusive' education? After questioning 'inclusion', a CDS informed approach to teacher education should equip pre-service teachers to consider how they might redefine 'inclusion'. Given that 'inclusive' education suggests the need for the not-yet-included to conform in order to attain the status of 'included', should the term 'inclusion' even be used? It is important for these questions to be introduced as pre-service teachers engage with CDS theory and consider the implications for practice. I envision these questions serving as the topic for a final reflection, and culminating class discussion, within an introductory course on 'inclusive' education. I also view these questions as ones that must be revisited, within and beyond the confines of coursework, as it is essential to "continuously re-evaluate our analyses as both process and product" (Meekosha & Shuttleworth, 2009, p. 64).

When asking pre-service teachers to question 'inclusion', and to consider what this line of questioning means for practice, it is important that teacher educators engage in this same type of reflection. As I construct my own CDS-influenced definition of 'inclusive' education, I take note of Meekosha and Shuttleworth's (2009) reminder "that our understanding of what constitutes the modes of critical analyses we employ is not set in stone" (p. 64). In other words, the definition I set forth must be revisited in order to remain "in concert with contemporary lives, the complexities of alienation and rich hopes of resistance" (Goodley, 2013, p. 641). For me, the continued use of the term 'inclusive' education allows the term to signal "a political message, a dimension of criticality that a whole new word would fail to achieve" (Graham & Slee, 2008, p. 279). The use of quotations around the term 'inclusion' also aligns with the CDS goal of shifting the focus to "the centered-ness implicit in tokenistic attempts to 'include' the marginalized Other" (Graham & Slee, 2008, p. 279). Additionally, I would define a CDS approach to 'inclusive' early childhood education by drawing on Deleuze's (1987) notion of interdependency, which poses a challenge to the "conventional distinctions and separations between whole and 'broken' bodies" (Shildrick, 2012, p. 39). Shildrick (2012) elaborates on a Deluezian approach to CDS, suggesting:

> indeterminacy and instability are not unique to the anomalous body but stand as the
> conditions of all corporeality in as much as the finality and integrity of the normative

subject are merely features of a phantasmatic structure. As such, the 'disabled' body signals not some exceptional lack or failure, but simply one mode among multiple ways of becoming (p. 39).

My definition of 'inclusive' education focuses on de-centering the normal, or able-bodied, through ongoing reflection on teaching practice and procedures (e.g., special education eligibility processes, methods of assessing progress, and curriculum content), resulting in "imaginative approaches to teaching and learning" (Goodley & Runswick-Cole, 2010, p. 287). With this approach to 'inclusion', "By refusing to accept, and entertain as 'truth', the psychologizing and pathologizing stories, that are assigned to children, it may be imaginable to think and act differently within education, and see the child as a becoming subject" (Watson, 2017, p. 199).

Vignette: Critically defining inclusion.

A cohort of undergraduate student teachers are finishing the first year of coursework. They have spent five hours each week observing and student-teaching in 'inclusive' early childhood classrooms. They have read and reflected on work written by CDS and disability studies in education scholars, considering how this work might connect with what they are noticing in the classroom, and discussing these connections during seminars. In the following final reflection, a student connects her observations and course readings to how she is now thinking about defining 'inclusion':

> *One thing that I can't stop thinking about is how obvious it is that the students in my classroom who have disability labels are the ones who have to be included into the classroom community. I am noticing this the most when I observe how children with disability labels are supported to engage in social interactions with peers. There is a student in my class who has an autism diagnosis. He often gets very engaged in some activity on his own, but then is redirected to do the activity in a way that involves another student. It's clear that his play is not seen as acceptable, and the goal becomes to try to include him into the way that other children are playing. The other day, he was on the playground playing by covering his eyes, counting to ten, and saying "ready or not, here I come!" He then ran around the playground for a bit, and started the same process. It was clear that he was really enjoying this activity. After a little while, a few of his peers saw what he was playing, and joined in. I wondered - if his peers had not joined this activity, would he have been allowed to continue, or would he have been redirected? It seems that 'inclusion' is really about ensuring that children demonstrate behaviors, whether social or academic or physical, that are viewed as being acceptable within the classroom. This makes me think of Hutcheon and Wolbring's (2012) definition of ableism: "Ableism as a concept describes, and is reflected in, individual and group perceptions of certain abilities as essential" (p. 40). When I think about how I would like to define 'inclusion' moving forward, I want to be sure that I am constantly thinking about the 'why' behind*

any type of inclusive strategy: Am I asking a student to modify behavior because it might make me or others uncomfortable? If so, how could I instead focus on making difference valued. What I mean is, I want the 'inclusive' classroom to be a place that welcomes and normalizes the co-existence of many different ideas about what counts as a valuable skill.

This reflection will inform Anna's planning as she moves into her full-time student teaching. It will help her to think about what a CDS pedagogy might look like, and to reflect on the activities that she implements within the classroom. At the end of her student-teaching, she will look back at this piece and consider whether there are revisions that she would make after having put some of her ideas to the test. Having developed a practice of ongoing reflection, Anna will continue to revise and reconsider how she critically defines 'inclusion' as she moves into the field, beginning her work as an early childhood 'inclusive' classroom teacher.

Element Three: Developing a CDS Pedagogy

As the field of CDS receives criticism for its lack of practical application (Oliver & Barnes, 2012; Watson, 2012), it is imperative that CDS informed early childhood 'inclusive' teacher education prepare teachers to do more than just critique the current system of early childhood 'inclusion'. Teachers must have the opportunity to develop the skills to actually implement a CDS approach within their teaching. A CDS pedagogy is one that responds and adapts to context, constantly reflecting and evolving, responding to the ever-shifting notion and impact of ableism. In other words, to develop a CDS pedagogy is to develop the skills to think critically, to respond creatively, and to reflect regularly. Such an approach cannot be prescribed, and must give teachers the trust and autonomy to develop "imaginative and responsive forms of educational provision" (Goodley & Runswick-Cole, 2010, p. 287). However, in order to effect change within the system as it presently exists, a system that highly values clearly defined procedures and competencies, it is important to provide a clear picture of what a CDS pedagogy would look like, and how teachers should be prepared to develop such a pedagogy. In order to provide such a description, this section will include an extended vignette that describes the aspects of both teacher education and teaching practice.

Vignette: Within the system

This vignette captures what it means to develop a CDS approach to early childhood 'inclusive' education. First, teachers must be prepared to use CDS theory in practice – to draw on theoretical work in order to disrupt ableism within the 'inclusive' classroom. Next, teachers must be critically reflexive, continually asking questions about their approach to 'inclusion', and identifying what needs to change in order to challenge the dominant idea of the 'normal' child within the classroom. The semester begins, and it is time for a group of pre-service teachers to take on the role of full-time student teachers in their assigned early childhood 'inclusive' classrooms. They have spent time reading traditional 'inclusive' early childhood texts alongside critical approaches. They have grappled with hard questions: what does it mean to include?; what

is disability?; what is *ability*?; how do multiple identity markers impact the schooling experience of young children?; how has ableism played a role in the development of the field of early childhood education; and how does this history continue to shape approaches to 'inclusion' in the early childhood classroom? They have reflected on their experiences in the field-identifying ableism, considering how their pedagogical practice might challenge the construct of ability, asking questions after testing out ideas. They have written down their current way of thinking about critically approaching the 'inclusive' classroom. Now, it is time for them to put all of these ideas into practice during their student teaching practicum.

> *Jon, a student-teacher in an 'inclusive' preschool classroom, is observing a group of three children in the block area. Two children are building a tower together, and the third child comes over to the pair and holds up a picture card, which indicates that he is asking to join their activity. One child responds, "Yes," and moves over to make room for his peer to sit nearby. The other child looks over to Jon, and asks, "But why doesn't he just talk? Is he stupid or something?"*

Jon later writes about this interaction in an analytical reflection paper:

> *When I heard the question, "But why doesn't he talk? Is he stupid or something?" I noticed my own discomfort. I felt discomfort because, ultimately, I wished that this question had not surfaced in the first place. This question was one that I knew needed to be answered, and answered well. After all, ignoring or redirecting would only perpetuate the problem described by Watson (2018): "The children learn to separate from, and ignore difference, and feel awkward discussing it, as they have no sanctioned way to talk about it. The 'normal' discourses create the 'natural' and 'right' way to be, that is so taken for granted, that other ways have no expression and no legitimacy" (p. 153–154). But, I felt fear. I felt afraid that I would not give the right answer. And I realize now that a part of this fear was also related to the idea, which I am still working to challenge, that young children might not be ready to talk about complex issues like difference and disability. I remember the work of Robinson and Díaz (2006), which explains that the early childhood 'inclusive' classroom is heavily influenced by "the discourse of childhood innocence" (p. 171). This discourse of innocence limits the opportunities children have to "question, analy(z)e, test, and critique" (Robinson & Díaz, 2006, p. 171) ideas about diversity and difference. Instead of making space for the exploration of difference, early childhood teachers often communicate the idea that all children are to be welcomed and accepted without question (Naraian, 2011; Watson, 2017). In this type of environment, children learn not to ask questions, and opportunities are missed to "support children in voicing their ideas and concerns about different social issues…" (Robinson & Díaz, 2006, p. 172).*

> *In the moment, I chose to try my best to answer this question, and this is what I said:*

"Some of us use our voices to communicate with each other. Some of us communicate using sign language, pictures, computers, or other ways. All of these ways of communicating allow us to share our ideas, thoughts, or questions with other people. One way is not better than another. But, what I noticed, and what I think that we should talk more about, is that a lot of times communicating using spoken language is seen as the 'smart' way of communicating, and other ways of communicating are seen as being less smart. Why do you think that is?" While I felt the urge to tell the child that I would not tolerate the use of the word 'stupid', I did not want to close down the conversation, I wanted us to be able to work through where this idea comes from, and why this language is so harmful. We eventually talked through the use of the word 'stupid' and decided as a group that it was one we did not want to allow in our classroom. After our conversation, the child who initially asked the challenging question talked to his peer, asking if his words had hurt the child's feelings, and asking how he could repair this damage. The pair then spent time together because Jeremy wanted his peer to understand how his communication book works, a topic that he then introduced to the whole class.

My main take away from this experience is that I need to continually be aware of how my own fear or feelings might get in the way of allowing children to explore topics of difference. I also need to be willing to try, to get it wrong sometimes, and to trust that the children are capable of leading and participating in conversations that, to me, seem tricky.

Moving Forward

How to do inclusion better…is not the challenge. It is instead recognizing and understanding that inclusion is framed by the political predisposition of exclusion (Watson, 2016, p. 191).

The field of early childhood 'inclusive' education articulates a more expansive understanding of 'inclusion', but continues to shy away from taking up a CDS approach. While CDS may appear to threaten the very existence of 'inclusive' education, Slee (2011) suggests that "inclusive education needs to be decoupled from special education" (p. 155). If we can reconceptualize 'inclusion' as a practice of continually interrogating "the power of the Normal" (Watson, 2016, p. 12), then a CDS approach to 'inclusive' early childhood education becomes possible. While a CDS approach can certainly be imagined, an exercise I have briefly carried out within this paper, it is essential that this imagination be paired with action. The 'critical' component of CDS instructs scholars to be engaged in ongoing reflection, paying attention to how changes in society require changes to approaches and analyses (Meekosha & Shuttleworth, 2009). At the same time, criticality must not only produce theory, it must translate this theory into action. In other words, "the task is always to balance the activist's cry for accessible conceptualization with the scholar's understanding of the complex, interwoven but continually

changing fabric of human societies" (Meekosha & Shuttleworth, 2009, p. 64). Future work should apply a CDS approach to early childhood 'inclusive' teacher education and present the affordances and challenges of developing and implementing this type of program. Additionally, this work must consider the role of the child within a CDS-informed 'inclusive' classroom. Children should be central to decision-making about educational goals and the processes for reaching their goals in order to "create a culture where they can be viewed as a person who is expert in their own life and not someone who needs help because they 'can't do it'" (Rodriguez, 2016, p. 255). Indeed, as Goodley and Runswick-Cole (2010) explain, "Disabled children are queer children: with the potential to subvert, rethink and reject normative, narrow, dull, limiting, disablist, respectable, middle of the road, conservative, traditional and exclusionary schools, classrooms and pedagogical practices" (p. 275).

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Research Article

An Outcome Evaluation Study of the UConn Online Graduate Courses of the Certificate of Interdisciplinary Disability Studies in Public Health

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Abstract: Healthy People 2020 addresses the need to increase disability-specific content in public health education. In 2014 the University of Connecticut Center for Excellence in Developmental Disabilities (UConn UCEDD) developed an online, interdisciplinary, graduate certificate in disability studies. Eighteen students provided evaluation data on the effectiveness of the Certificate as described in this article. Majority of participants reported applying knowledge gained in their other courses while half recommended a disability certificate course to others. Of those participants who are currently employed, 75% reported applying knowledge gained to carry out their current work position. Some students responded that at least a course like these with disability-specific content should be mandated for any health-related graduate program. Future implications for these findings include expanding disability-specific content across public health program curricula to increase the capacity of the future workforce to serve people with disabilities.

Keywords: Disability; Public Health; Education

Section 4302 of the Patient Protection and Affordable Care Act (ACA) established data collection standards for measuring disability status consistent with the International Classification of Functioning, Disability, and Health (ICF) (USDHHS, 2011). This model assumes humans function on three levels: 1) as a body or a body part, 2) as a whole person, and 3) as a whole person in a social context, and that disability is dysfunction at one or more of these levels: 1) as impairments, 2) as activity limitations, or 3) as participation restrictions (WHO, 2002, p. 9). The latest estimates from the Centers for Disease Control and Prevention's (CDC) Behavior Risk Factor Surveillance System (BRFSS) indicate that one in four adults, or 61 million people, are living with a disability in the United States (Okoro, Hollis, Cyrus, & Griffin-Blake, 2018). The BRFSS reports disability based on the following disability categories: hearing, vision, cognition, mobility, self-care, and independent living which are consistent with Section 4302 of the ACA. According to the BRFSS, the most common type of disability across all adult age groups was mobility (13.7%) followed by cognition (10.8%) (Okoro et al., 2018). This large number of people living with disability is significant because compared to people without disabilities, people with disabilities (PWD) experience health disparities across the social determinants of

health: education, economic stability, social and community context, neighborhood and built environment, and health care access (Yee et al., 2016; ODPHP, 2018c; Okoro et al., 2018). For example, PWD in general report higher rates of obesity, physical inactivity, and smoking and are less likely to receive preventive health care compared to people without disabilities (Courtney-Long, Romano, Carroll, & Fox, 2016; Krahn, Walker, & Correa-De-Araujo, 2015). Further, research documents that among those who are identified as having a disability, disparities in prevalence exist among disability categories, sex, race/ethnicity, socioeconomic status, among other descriptors (Courtney-Long et al., 2015; Okoro et al., 2018). From both a medical and public health perspective, disability historically has been regarded as an undesired health outcome to be prevented (e.g., Heaphy, Mitra, & Bouldin, 2011; Higgenson & Widerburg, 2009; Krahn & Campbell, 2011; Linker, 2013; McDonald & Raymaker, 2013).

As stated in *The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities*, "The health and wellness of persons with disabilities today is a matter of public health concern" (USDHHS, 2005, p. 21). However, a study conducted by the CDC and Massachusetts Department of Public Health revealed that only 50% of accredited public health programs and schools offer disability content within their curricula (Sinclair, Tannenhaus, Courtney-Long, & Eaton, 2015). Healthy People 2020 objectives for disability and health include increasing the proportion of U.S. Master of Public Health (M.P.H.)-granting public health programs and schools that offer graduate-level studies in the topic area of disability and public health (ODPHP, 2018b). Similarly, the 10 Essential Public Health Services highlight the need for public health activities to "assure a competent public and personal health care workforce" (CDC, 2018, paragraph 3), which needs to incorporate skills to include PWD in public health activities.

The UConn Certificate of Interdisciplinary Disability Studies in Public Health (disability certificate) was created in 2014 to address this gap in disability-specific content in graduate public health courses. The disability certificate is offered in partnership between the University of Connecticut Center for Excellence in Developmental Disabilities (UConn UCEDD) and UConn School of Medicine Department of Public Health Sciences Programs in Applied Public Health Sciences. It uses the 10 Essential Public Health Services as a framework for students to study the health and well-being of people with disabilities and their families, as well as the communities in which they live, learn, work, and play, and the populations of which they are a part. Key public health concepts addressed in the disability certificate courses are the social determinants of health, health disparities, disability as diversity, disability-related policy and legislation, disability surveillance, research ethics, self-determination, cultural competency, and evidence-based practice, among others. The disability certificate promotes interdisciplinary discourse and systems-level thinking. It is comprised of four graduate level courses offered entirely online to interested applicants who have earned at least a bachelor's degree. Because of the online format, students may participate from distances, an opportunity that traditional in-person lecture-style classes cannot offer. This also allows students from outside of UConn to pursue the courses and

the disability certificate. Students who matriculate into the program and complete the four courses earn a graduate disability certificate from UConn.

The disability certificate incorporates resources and information from expert public health agencies that include the World Health Organization (WHO), the CDC, the Department of Health and Human Services (HHS), the National Association of County and City Health Associations (NACCHO), the National Center on Health, Physical Activity and Disability (NCHPAD), Association of Disability Centers on Disability (AUCD) which includes the National Center on Disability in Public Health and Including People with Disabilities: Public Health Workforce Competencies, and Special Olympics, among others. The Sinclair et al. (2015) study identified this disability certificate as a resource for public health programs to develop and implement disability-specific coursework into their public health programs. Course titles and brief descriptions are provided below:

1. *Foundations of Public Health and Disability*: This course is an introductory survey of the ways in which disability, both developmental and acquired, is affected by, and interacts with, public health policy and practice. Upon completion of this course students will have a foundational understanding of a comprehensive set of issues of both acquired and developmental disability as related to the core elements of public health.

2. *Epidemiology of Disability*: This course introduces epidemiologic research design and delves deeply into epidemiology as it applies to monitoring the health status of people with disabilities, diagnosing and investigating health problems, evaluating personal and population-based interventions, and conducting research. It also critically examines sources of public health and epidemiologic data that exist.

3. *Disability Law, Policy, Ethics, & Advocacy*: This course provides an introduction to policy and law affecting people with disabilities and public health approaches to meeting their individual needs as well as the needs of broader populations. Students will learn the essential tools for enforcing laws and regulations that protect health and ensure safety and for developing new policies and plans that support individual and community health efforts inclusive of people with disabilities.

4. *Public Health Interventions in Disability*: This course critically examines public health systems and programs across the lifespan available to people with disabilities that impact health. It extends on foundational principles that are evidence-based and driven by epidemiologic studies of disability within the context of existing laws and policies. (UConn, 2019).

Learning objectives for each course align with foundational competencies determined by the Council on Education for Public Health (CEPH) public health program accreditation requirements as UConn's M.P.H. program is accredited by CEPH (CEPH, 2016). Each of the

four courses are designed to follow the same format so that students can become familiar with the layout, rubrics, and expectations across courses. Courses are broken down into modules which are several weeks that cover a common theme. For example, a module within the *foundations* course is titled "disability as a unique identity and as an individual experience." At the end of each module students complete an assignment to assess their understanding of that module's content. These assignments include short papers, presentations, and visuals. Students also complete a reflection at the end of every module to allow them to both synthesize the content and apply it to their personal and professional lives.

Disability Studies in Public Health

Disability studies, according to the Society for Disability Studies (SDS) "…sits at the intersection of many overlapping disciplines in the humanities, sciences and social sciences" (SDS, 2016). Disability studies "challenges the view of disability as an individual deficit and explores models and theories that examine social, political, cultural, and economic factors that define disability" (SDS, 2016). It also studies national and international perspectives, policies, culture, and history. Public health as a discipline is uniquely positioned to emphasize the importance of included PWD in all activities. As stated in the Institute of Medicine's *Future of Public Health* (1988), the mission of public health is "…the fulfillment of society's interest in assuring the conditions in which people can be healthy" (p. 40). This disability certificate uses a public health lens as a framework and incorporates disability studies to examine how culture, policy, history have shaped the treatment of PWD and their access to services including healthcare. There is a large emphasis on language and terminology used as related to PWD, as often medical terminology is the dominant syntax used by healthcare and other providers. Person-first language, identity-first language, intersectionality, and neurodiversity are all topics covered within the certificate to expand the understanding of disability beyond the medical model (e.g., Dunn & Andrews, 2015; Kapp et al., 2013, Moodley & Graham, 2015). PWD While public health is often closely affiliated with medicine and the medical model of disability, this disability certificate unpacks other models of disability early in the *foundations* course and carries the theme of 'defining' disability throughout the four courses (e.g., Wasserman, Asch, Bluestein, & Putnam, 2016). Healthy People 2010 described disability as "a demographic descriptor rather than a health outcome. It should be used to monitor disparities in health outcomes and social participation" (Andresen, 2011). These courses expand on this important statement. The courses also critically examine the advantages and disadvantages to using public health as a framework to study disability as public health is focused at the population rather than the individual within the U.S. and at an international level, as family and cultural understandings, perspectives, and values related to PWD differ (e.g., Cohen & Miguel, 2018; Ennis-Cole, Durodoye, & Harris, 2013; Ormel et al., 2008; Norwich, 2008).

Spotlight on *Foundations of Public Health and Disability*

The *foundations* course is the first course in the disability certificate sequence and is also recommended to students who cannot pursue the full certificate but are interested in disability and public health. The course consists of five modules: 1) introduction, 2) disability as a unique identity and as an individual experience, 3) disparity issues in the study of disability, 4) foundations of measurement issues for studying disability in public health, and 5) current and future issues in disability in public health. As is required for CEPH accreditation, the following is a sampling of a table that describes the learning objectives, CEPH foundational competency addressed, and the evaluation/assessment for *foundations* (CEPH, 2016, p. 18) (Appendix A).

Appendix B provides a sampling of the modules, topics, and readings from the *foundations* course. These readings come from an array of disciplines and sources related to disability studies including philosophy, sign language studies and D/deaf culture, gender studies, psychology, law, public health, special education, and others. While the courses use a public health framework and include content from public health or related sources, these courses were intentionally developed and are regularly updated to reflect the fact that disability spans across disciplines. The courses also incorporate the use of media such as YouTube, blogs, and credible websites to teach content. Each week's required reading for each course includes links to various media related to the week's topic. For example, during service systems: health within the *foundations* course, students watch the University of South Florida's Florida Center for Inclusive Communities (UCEDD), XCEL training video on how to provide excellent care for patients with disabilities (Perkins & VanZant, 2017).

Since its inception, over 175 students from 14 distinct academic disciplines have completed at least one of the courses in the disability certificate. To date, ten students have earned the disability certificate and another five are expected to complete it in the next calendar year. These students represent the following disciplines: public health, social work, medicine, psychology, speech, language, and hearing sciences, dentistry, and nursing. Some of the disciplines and degree programs represented by students who take these courses, in addition to public health, include audiology, nursing, school psychology, dentistry, medicine, special education, and biomedical engineering among others. The *foundations* course, the first in the disability certificate, is also part of the required curricula completed by Connecticut CT Leadership Education in Neurodevelopmental and related Disabilities (CT LEND) trainees, an intensive, interdisciplinary training program for graduate students in various disciplines to prepare them to be leaders to improve the health of PWD and their families (AUCD, 2019). The overall aim of this study was to evaluate student and employment outcomes as a result of taking at least one disability certificate course.

Methods

Participants

The 175 students who completed at least one of the four disability certificate courses between Spring 2014 and Summer 2018 were contacted via email invitation to participate. This study was approved by the UConn Health Institutional Review Board (IRB).

Procedure

Former students were contacted via the email address provided at the time when they were taking a course, but not all students provided an email address so could not be invited to participate. Invitations were sent to 78 eligible participants in early Fall semester 2018. Of these 78, six invitations were returned as "undeliverable", indicating these email addresses were no longer active. A follow-up invitation was sent to the 72 active email addresses two weeks after the first invitation was sent. The final sample (n=18) had a response rate of 25%.

The initial emails sent to former students contained a brief description of the nature of the evaluation study and details about participants, including an emphasis that participation was voluntary. The emails also contained a link to the survey for individuals interested in participating. Follow-up emails contained the same information as the initial email, but also included a statement thanking individuals who had already participated.

Evaluation Survey

Interested participants clicked on the link in the invitation email and were brought to the first page of the Qualtrics survey, the information sheet. This information sheet served as the consent to participate, as the IRB determined this study to be exempt and therefore did not require a more formal consent process. The information sheet provided information regarding the purpose of the study, study procedures, potential risks and benefits, information protection, participants' rights, and contact information regarding study content and rights. Participants were given the option to "accept" or "decline" participation.

The brief, 5–10 minute evaluation study itself consisted of a total of 17 open and closed-ended questions (Appendix C). It was pre-tested using several graduate students who did not take any disability certificate courses to check for clarity of language and accuracy of the skip-logic used based on participant responses. Content of questions related to knowledge and employment outcomes were informed by UConn UCEDD evaluation measures required for federal reporting.

The evaluation study collected the following participant demographic information including age, gender with which they identify, their status as a current or former student, and

their major/discipline while they were taking a disability certificate course. Participants then selected which of the four disability certificate courses they completed and the initial reason they enrolled in their first course. Participants were asked if they completed more than one course, if so, why they did, and if they completed the entire disability certificate. They then had the opportunity to select from a list of possible student-related outcomes as a result of taking one course including completing additional disability certificate course(s), applying to an additional degree program, applying to the disability certificate, applying the course content in other courses, and recommending the course to others. For participants who did not pursue the disability certificate, they were asked to select the single best reason why they did not from the following options: 1) did not know about the certificate, 2) did not fit into my plan of study for my degree program, 3) was not interested in the certificate, 4) was not eligible for the certificate, 5) financial barriers, or 6) had the option to write-in another reason. Participants then were asked to select from a list of options the best description of their current work setting and type of work. They were asked if their current work relates to PWD. Finally, 5-point Likert scales from "strongly disagree" to "strongly agree" captured data on employment-related outcomes on the following four areas: 1) increased knowledge in the area of disability and public health, 2) application to a position related to working with and for PWD, 3) application of knowledge gained to secure current position, and 4) application of knowledge gained to carry out current position.

Participants had the opportunity to provide written responses to answer the following questions: 1) What is the single most important lesson you learned from your course(s)?, 2) What recommendation(s), if any, do you have to improve the course(s)?, and 3) any additional comments. See Appendix C for the instrument.

Data Analysis

All data collected through Qualtrics were downloaded into a Microsoft Excel file, cleaned, and analyzed. Data cleaning included the removal of cases that met the following criteria: 1) declined participation, or 2) selected "N/A; I did not take any of these courses" as the response to item 4, "Which of the Certificate of Interdisciplinary Disability Studies in Public Health (disability certificate) courses have you completed (select all that apply)." Descriptive statistics were calculated for all included data.

In addition to data collected in the evaluation study, data from student reflections completed by each student in every course at the end of every module were included in the results to further describe the lessons learned from the disability certificate courses and to further qualitatively illustrate student outcomes as a result of taking at least one course.

Results

The total number of participants who opened the link in the recruitment invitation email and at minimum accepted participation was 19, however one did not meet the eligibility criterion of having taken at least one of the disability certificate courses. The final sample ($n = 18$) had a response rate of 25%. Almost 78% of this sample identified as female, 16.67% did not report a gender, and 5.56% identified as male. The average age of participants was 30.4 years (SD = 8.49).

Student-related Results

Majority of participants were current, Fall semester 2018 students (61.11%, $n = 11$). Eight unique disciplines were represented in the final sample including social work, public health, speech language, and hearing sciences, public policy, education, nursing, law, and medicine. The most common major/discipline was public health (44.44%) followed by "multiple" which included a combination of public health, medicine, law, and social work (16.67%). Almost 89% of the sample took 5501: Foundations of Public Health and Disability. The course with the fewest number of participants was 5504: Public Health Interventions in Disability. Over 55% of participants completed more than one course; of those, 30% completed all four and received the disability certificate. More student details can be found in Table 1.

Table 1. *Student Information*

Item	Percent
Student status	
Currently a student	61.11%
Not currently a student; completed degree program	33.33%
Not currently a student; have not completed my degree/program	5.56%
Major/discipline	

Public health	44.44%
Speech, language, and hearing sciences	5.56%
Public policy	5.56%
Social work	11.11%
Nursing	5.56%
Education	11.11%
Multiple	16.67%
Courses	
5501	88.89%
5502	38.89%
5503	38.89%
5504	33.33%

Initial reason for enrolling in the first course.

Half of participants initially enrolled in their first course because of the topic area of that specific course, while a third initially enrolled to fulfill requirements related to their graduate degree programs. Others indicated that they initially enrolled in their first course because of the appeal of the online course format. Most participants who completed more than one course indicated they did so because they wanted to learn more or because the course was in a new topic area of interest (66.67%).

Completing the disability certificate.

Of those who took more than one course but did not complete the disability certificate, the most commonly reported reason for not pursuing the disability certificate was because additional

courses did not fit into their plan of study for their graduate degree (33.33%). About 17% of participants reported not taking any additional courses because they were not interested in pursuing the disability certificate.

Student-related outcomes

Almost 78% of all participants strongly agreed that their knowledge in the area of disability and public health increased as a result of completing a course, regardless of which course they completed. Figure 1 describes immediate outcomes for students as a result of taking one disability certificate course.

Figure 1. *Student outcomes as a result of taking one course*
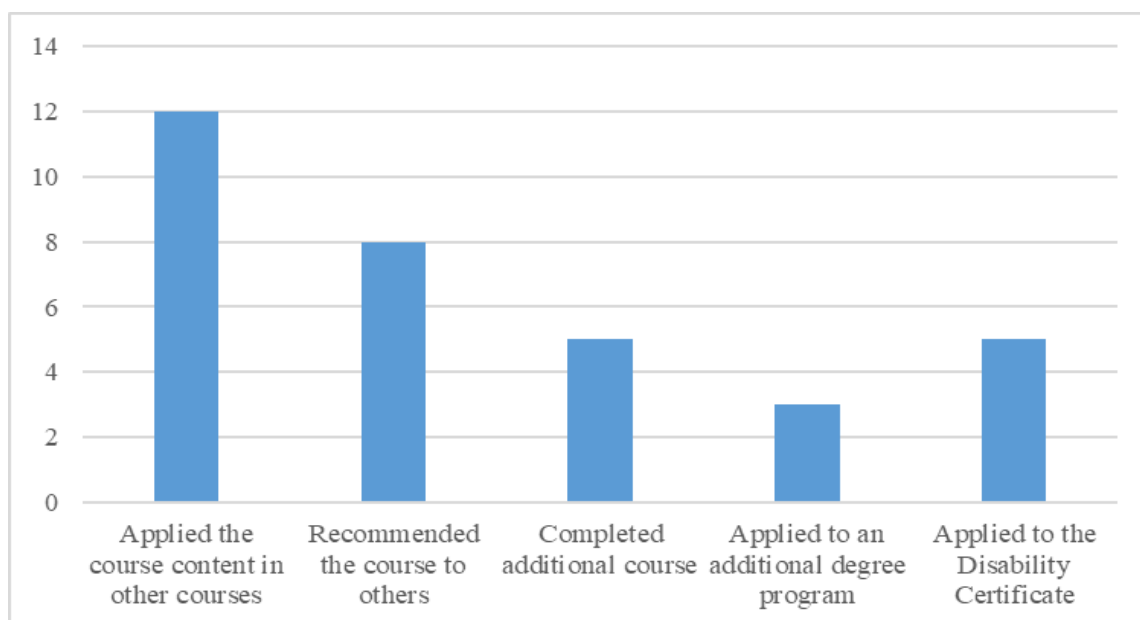

Image Description: Figure 1 is a vertical bar graph. The x-axis includes five bars: 1) "Applied the course content in other courses", indicating 12 students; 2) "Recommended the course to others, indicating", 8 students; 3) "Completed additional courses", indicating 5 students; 4) "Applied to an additional degree program", indicating 3 students; and 5) "Applied to the Disability Certificate", indicating 5 students. The y-axis include increments of two, with numbers starting from 0–14.

Employment-related outcomes

Two-thirds of participants are currently employed at work settings including clinical, research, education, and administrative settings. Of those currently employed, over 76% of participants indicated that their current place of work relates to PWD. About 28% reported clinical work or direct service provision as their type of work. A third of participants who are

currently employed indicated that they agree that they applied to a work position related to working with and for people with disabilities as a result of taking one disability certificate course. A third also indicated that they applied the knowledge gained from one course to secure their current work position. Finally, 75% of participants indicated that they apply the knowledge gained in at least one certificate course to carry out their current work position. Table 2 contains more employment-related information.

Table 2. **Employment Information**

Item	Percent
Work setting	
N/A; I'm a student	33.33%
Clinical, in-patient	5.56%
Clinical out-patient	16.67%%
Government agency	5.56%
Research facility	5.56%
Higher education/academia	22.22%
Non-profit	5.56%
Other	5.56%
Type of work	
N/A; I'm a student	27.78%
Clinical	16.67%

Other direct service provision	11.11%
Administration	5.56%
Education	11.11%
Research	22.22%
Other	5.56%

Work relate to people with disabilities

N/A; I'm a student	22.22%
N/A; I'm currently not employed	5.56%
Yes	55.56%
No	16.67%

Important Lessons and Reflections from Students

When asked, "What is the single most important lesson you learned from your course(s)?": participants had the opportunity to type in responses. Some examples include:

- "Disability is a complex topic which needs to be involved as an active conversation across academic disciplines."

- "The course helped me become aware of my own biases and stereotypes that I held about individuals with disabilities. My increased awareness allows me to better advocate for my clients and be a more compassionate and empathetic social worker."

- "The experiences of people with disability differ from person-to-person and the importance of person-centered care."

Data collection from student reflections completed at the end of each module within each

course also provide important evaluation information. These provide valuable insight and feedback about the courses and their content. Several themes have emerged from these reflections. Some students have inquired as to whether courses like these, especially the *foundations* course, are mandated for any health-related graduate programs, as the students themselves see the importance of the material. Some have indicated that completing at least one course has given them confidence to share what they have learned with colleagues and even supervisors, creating leaders in their respective fields with disability-specific knowledge. These courses themselves are interdisciplinary as they pull content from across disciplines. Then students come from different programs with different life experiences, creating an interdisciplinary 'classroom'. Students regularly reflect on how enjoyable and beneficial it is to work with those from other backgrounds who have unique insights and perspectives. Dental students in particular have reflected on their translation of knowledge into practice in their clinical placement sites to be more culturally competent and inclusive of PWD.

Recommendations from Students

Participants were also asked to provide any recommendations they have to improve the courses and overall disability certificate. The most common theme from these recommendations was related to the online course format. Some examples include:

- "Offer this in person! I realize it's intended for certificate-seekers, but this would be so much more engaging and impactful in a classroom setting,"

- "While I know the convenience of an online format is a major draw for many students, I would have been interested in participating in an in-person disability class or having either optional or mandatory in-person class meetings. The organization of the course certainly maximized class discussions, but I think in person discussions would have made the course experience even more engaging and lively."

- Other participants provided constructive feedback related to reducing the amount of reading and writing assignments and their difficulty managing online courses: "Foundations of Public Health and Disability was extremely difficult to manage along with a regular course load. Too many small assignments."

- "I found the online format much more and more challenging and hard to keep up with by the time I got to a 3rd class. They were classes I took outside of my degree program for my own learning. I would have preferred to have several in-person classes rather than write so much without speaking to people face to face."

Additional comments, as stated by one respondent included the following quote regarding topical interest in disability and public health:

My interest area is disability and public health and I have had difficulty getting training in this area. I was so pleased to learn about and take advantage of these courses. They provide much needed training that can be accessed from anywhere in the country.

Discussion

After five years, conducting a brief evaluation study of former students who took disability certificate courses allowed us to assess if and how students were using the information both as students and then later on as professionals in their respective fields and areas of employment. Results indicate that disability certificate courses are meeting the interests of students, not just in public health, but across academic disciplines. Majority of participants have applied course content in other courses and programs, thus exposing their peers to thoughts, ideas, and concepts which they otherwise would not learn in their specific programs as a result of the interdisciplinary nature of the disability certificate. Students are also pursuing employment related to working with and for PWD and incorporating their knowledge gained into these positions based on completing at least one course.

As indicated by the recommendations from participants, online courses have their drawbacks and are not the same as traditional in-person courses. More responsibility and time management on behalf of the student are required to manage deadlines and assignments within an online course environment. Further, some students enroll in one of these disability certificate courses not out of topical interest, but out of necessity to earn the minimum-required credits for each semester. These students may have no interest in pursuing the entire disability certificate, but at least were exposed in some capacity for some reason to disability and health content.

One limitation of this evaluation is the response rate. First, contact information was not available for all former students. Then, some contact information was no longer active. Some students have graduated and no longer have access to their student email address; others may have provided an email address which they do not check regularly, also shrinking the possible final sample pool. Participants represented 25% of the total possible sample. These participants self-selected to participate in this evaluation. Because they self-selected to participate it is likely that they had positive experiences in the certificate courses, thus potentially skewing responses and results toward positive outcomes. The steps described in the methods were taken to reduce the possibility of non-response bias, but those who chose not to or did not participate may be systematically different from those who did respond (Jacobsen, 2017, p. 111).

To get a more representative outcome of the certificate, other methods of increasing participation such as collecting multiple modes of contact information of students and offering incentives to participants may increase participation in future evaluations. These strategies and several other retention strategies identified in a systematic review by Robinson and colleagues (2015) include obtaining multiple contacts for each participant, including two who do not reside

with the participant. These data could be collected from students as they enroll in each course. Additionally, if this study were to be replicated in the future, students could be informed that they may be contacted in the future separate from academic participation (Robinson et al., 2015). There is literature that indicates that for academic research, invitations to participate in research that are personalized can increase the response rate (Heerwegh, Vanhove, Matthjis, & Loosveldt, 2005; Joinson, Woodley, & Reips, 2007; Saleh & Bista, 2017). Saleh and Bista provide 11 recommendations for online studies and response rates (2017). This evaluation utilized most, but not all 11 recommendations as most are required by any institution's IRB. Among the recommendations that could be adopted in the future include personalizing invitations to participate (recommendation 9) and being aware of the time constraints related to the time of year (recommendation 11) (Saleh & Bista, 2017). If conducted in the future, technology to personalize email invitations can be utilized.

Conclusion and Future Implications

PWD are often not included in discussions regarding groups who experience health disparities (Krahn et al., 2015), yet account for a significant part of the population (Okoro et al., 2018). In order for current and future public health practitioners to meet the needs of the population, including PWD, schools and programs of public health must build capacity in the future workforce to include PWD (Frankena et al., 2018; Griffen, Risley, Petros, & Welter, 2018). As more academic pre-professional programs move toward interdisciplinary scholarship, this disability certificate presents a unique opportunity for students to develop knowledge and skills essential to their future professions to work collaboratively with others to serve communities and to include PWD. Increased opportunities such as those presented by this online disability certificate will continue to build a competent public health workforce with a skill set related to serving all populations including PWD. Providing these courses online allows for distance learning, collaboration, and sharing of resources across disciplines, programs, and universities. However, even these disability certificate courses are electives; students are not required to take any of them in order to earn their M.P.H. or other degrees. Further, participants indicated that they did not have the space or time during their academic degree program to fit the entire disability certificate.

These results are indicative of a larger-scale barrier to ensuring a competent workforce as disability-specific content is not yet required by accrediting bodies that oversee degree-granting institutions. In some ways, students self-select into these courses as electives to learn the content; not every student who earns an M.P.H. can demonstrate that they have the knowledge and skills to apply public health concepts to include PWD and therefore cannot contribute to solving health disparities experienced by PWD. This disability certificate is a small example of a much larger network of resources working to ensure a competent public health workforce competent in including PWD into all public health activities.

More information about the disability certificate can be found at this website: https://ph.disability.certificate.uconn.edu/.

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Appendix A

Foundations of Public Health and Disability

Module	Topic	Learning objective	CEPH foundational competency	Evaluation/assessment
1. Introduction	Disability & public health	1.5 Describe how the 10 Essential Services apply to disability	Apply systems thinking tools to a public health issue (CEPH 22)	Discussion board 4: Pick a quote from the *Call to Action* no longer than a paragraph in length. Explain how this quote exemplifies the shift in public health efforts to include people with disabilities. How does this quote relate to *Healthy People 2020* objectives? How does it encompass the history of public health and disability? Module 1 interim assignment: Now with a background in public health, disability history, and the DD Act, create a 10 Essential Services Wheel that contains specific examples of how each service specifically applies to disability. In addition to creating a visual, provide a paragraph for each service explaining the specific contents and their application to disability to accompany the visual. Examples/applications should be as specific as possible and cited.

Appendix B

Key Reading Sample from Foundations of Public Health and Disability

Module	Topic	Key Reading Sample Citation
1. Introduction	Major determinants of health	(ODPHP, 2018a)
	Public health	(CDC, 2018)
	Disability	(Higginson & Widerburg, 2009)
	Disability & public health	(USDHHS, 2005)
2. Disability as a unique identity and as an individual experience	Models of disability	(Wasserman et al., 2016)
	Living with disability; self-determination	(Lee, 2012)
	Disability as diversity	(Moodley & Graham, 2015; Kapp et al., 2013)
	Cultural perspectives	(Larson, 2008)
3. Disparity issues in the study of disability	Social determinants of health, health disparities, & the lifecourse	(Krahn et al., 2015)
	Service systems: health	(National Council on Disability, 2016)
	Service systems: education, social services	(Bezyak, Sabella, & Gattis, 2017)
4. Foundations of measurement issues for studying disability in public health	Screening & surveillance	(USDHHS, 2011)
	Bioethics & research	(Frankena et al., 2018)
5. Current and future issues in	Beyond the US	(Norwich, 2008)

disability and public health	Future issues	(Griffen, Risley, Petros, & Welter, 2018)

Appendix C

Data collection instrument

1. Please enter your age in years: _____
2. Select the gender with which you most identify:
   a. Male
   b. Female
   c. Transgender
   d. Gender non-conforming
   e. Choose not to identify
3. What is your current status as a student?
   a. Currently a student
   b. Not currently a student; completed my degree/program
   c. Not currently a student; have not completed my degree/program
4. Which of the following Certificate of Interdisciplinary Disability Studies in Public Health (Disability Certificate) courses have you completed? (select all that apply)
   a. PUBH 5501: Foundations of Public Health and Disability
   b. PUBH 5502: Epidemiology of Disability
   c. PUBH 5503: Disability Law, Policy, Ethics, and Advocacy
   d. PUBH 5504: Public Health Interventions in Disability
   e. N/A; I did not take any of these courses
5. Why did you initially enroll in your first Disability Certificate course? (select one)
   a. Topic area of interest
   b. Recommended by an advisor/instructor
   c. Recommended by peer
   d. Met requirement for degree program (including Disability Certificate)
   e. Met requirement for a non-degree program (e.g., LEND)
   f. Appeal of online course format
   g. Other: please specify: _____
6. If you completed more than one course, why did you decide to take more? (select all that apply)
   a. N/A; I did not take an additional course
   b. New course in topic area of interest
   c. Recommended by an advisor/instructor
   d. Recommended by peer
   e. Met requirement for degree program (including Disability Certificate)
   f. Appeal of online course format
   g. Want to learn more
7. The following occurred as a result of taking one Disability Certificate course: (select all that apply)

   a. Completed additional Disability Certificate course(s)
   b. Applied to an additional degree program
   c. Applied to the Disability Certificate
   d. Applied the course content in other courses
   e. Recommended the course to others
8. What is the single most important lesson you learned from your course(s)?
   _____
   _____
9. What recommendation(s), if any, do you have to improve the course(s)?
   _____
   _____
10. Did you complete the Certificate of Interdisciplinary Disability Studies in Public Health (Disability Certificate)?
    a. Yes
    b. No
    c. I'm currently completing it

[Skip to question 12 if = yes; I'm currently completing it]

11. Which reason best describes why you did not pursue the Disability Certificate?
    a. Did not know about the Certificate
    b. Did not fit into my Plan of Study for my degree program
    c. Was not interested in the Certificate
    d. Was not eligible for the Certificate
    e. Financial barriers
    f. Other: please specify: _____
12. Which best describes your current work setting?
    a. N/A; I'm a student
    b. N/A; I'm not currently employed
    c. Clinical, in-patient (e.g., hospital, long-term care facility)
    d. Clinical, out-patient (e.g. community setting)
    e. Non-clinical, in-patient (e.g., hospital, long-term care facility)
    f. Non-clinical, out-patient (e.g. community setting)
    g. Schools (pk-12)
    h. Higher education/academia
    i. Government agency
    j. Research facility
    k. Non-profit agency
    l. Other: please specify:_____
13. Which best describes your type of work?
    a. N/A; I'm a student
    b. N/A; I'm not currently employed
    c. Clinical
    d. Other direct service provision
    e. Administration
    f. Education

g. Research
h. Policy
i. Other: please specify: _____

14. Does your current work relate to people with disabilities?
   a. N/A; I'm a student
   b. N/A; I'm not currently employed
   c. Yes
   d. No

15. As a result of participating in Disability Certificate course(s):

	Strongly disagree	Somewhat disagree	Neither disagree nor agree	Some-what agree	Strongly agree	N/A; I'm a student	N/A; I'm not currently employed
My knowledge in the area of disability and public health has increased							
I applied to a work position related to working with and for people with disabilities							
I applied the knowledge I gained to secure my current work position							
I apply the knowledge I gained to carry out my current work position							

16. What was your major/discipline while taking a Disability Certificate course? (select all that apply)
   a. Public health
   b. Medicine
   c. Dentistry

     d. Speech, language, and hearing sciences
     e. Human development and family studies
     f. Public policy
     g. Social work
     h. Education
     i. Natural science
     j. Nursing
     k. Engineering
     l. Business psychology
     m. Non-degree
     n. Other: please specify: _____

17. If you have any additional comments, please provide them here:

_____

Research Article

Preparing Preservice Teachers to Navigate Between Special Education and Disability Studies

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Abstract: The field of Disability Studies in Education (DSE) has been critiqued as failing to bridge or make explicit how DSE theory is translated into educational practice. This qualitative autoethnography study uses examples from the classroom to explore how teacher preparation programs can prepare preservice teachers to translate DSE theory into practice within traditional Special Education settings.

Keywords: Disability Studies; Special Education; Teacher Preparation

I arrive a few minutes before the start of the school day, and Jessica, who describes herself as an autism teacher, greets me. She greets me in the school office, and I can tell she is genuinely excited to see me, as I am to see her. She was a student in my undergraduate methods course many years ago, and I remember her as incredibly articulate and outspoken in her advocacy for students with significant disabilities. Today I am visiting her self-contained classroom because she has agreed to participate in a research project exploring the current practices and beliefs of teachers who educate students with significant disabilities.

She motions for me to follow and begins describing her students and classroom. Like a proud mother, she brags about her students' recent progress. One student has started using a communication device, and another student has recently started to read a few words. As we reach the door of her classroom, she pauses, looks at me, and in a confessional tone says, "it's not perfect, it's reality."

A maze of three-quarter high walls greets me upon entering her classroom. Jessica takes the lead, and we weave through the maze to a horseshoe table that is positioned in front of a whiteboard. She offers a verbal tour of her classroom, "[e]ach student has a workstation where they begin the day completing their work basket tasks. Depending on the schedule, students then rotate through a variety of stations." Pointing to a row of cubicles, she continues, "we follow Applied Behavioral Analysis (ABA) and Treatment and Education of Autism and related Communication and Handicapped Children (TEACCH)." As she continues to share, I am no longer listening. My thoughts have taken over, and I am growing anxious. What happened to Jessica? My reaction is visceral as if I've been punched in the gut. I feel betrayed. I did not teach Jessica to use ABA. The room is devoid of typical learning materials, replaced with three-quarter walls that resemble cubicles that you might find in an office building. Learning is referred to as work, and Jessica speaks in the behavioral jargon of "first you work, then you get a break." This

teacher is not the same Jessica who sat in my method course advocating for inclusion and the rights of individuals with disabilities. To be continued below…

Introduction

Using qualitative autoethnography and the learning processes of boundary crossing (Akkerman & Bakker, 2011), this paper examines the intersection of Special Education and Disability Studies in Education (DSE) in teacher preparation. As a scholar and educator who aligns with a DSE perspective, I struggle with how my identity of DSE scholar and educator might be reconciled with my (reluctant) identity of a former special educator who works primarily in special education public school settings and prepares future special education teachers. Keeping in mind the vignette from above, I question if I have prepared students for the 'realities' of the classroom. As a professor in a special education teacher preparation program, I wonder, *what might I do differently? How can I best prepare special educators to resist, negotiate, and successfully navigate special education systems from a DSE lens?* Given this context, the following research questions have framed this paper. How do DSE scholars and educators bridge DSE theory with teaching and learning in the classroom? How do I (we) negotiate the boundaries between Special Education and DSE? How do I (we) prepare preservice teachers to negotiate and navigate the contradictory fields of Special Education and DSE? This question of how we, as DSE scholars and educators, make DSE theory relevant and useful to teachers working within the field of Special Education is timely and vital. As Cosier and Ashby (2016) so eloquently remind me, "whether teachers agree with the system in place or not, they still have to work within it" (p. 4). In turn, we must understand how to prepare teachers to work within it.

Special Education and Disability Studies in Education

Special Education, as enacted in public schools across the United States, is premised on the medical model of disability. Underlying the medical model of disability are a number of empiricist assumptions that inform the practice and delivery of special education services and supports. Foremost, disability is perceived as an objective reality, and through proper testing, evaluation, and intervention, an individual labeled with a disability can be treated, remediated, or cured (Gallagher, 2004, 2005; Iano, 1990, 2004; Skrtic, 1995, 2004). Educators teaching from a medical model framework, thus, seek to set aside personal experience, beliefs, or background to 'objectively; discover the 'truth' of teaching and learning. From this understanding, disability exists independent of the social and cultural context, instead of residing within the individual.

When applied to students in classroom contexts, these assumptions are problematic. Under the premise that adherence to the medical model will result in learning and growth, teachers assume the role of a technician and follow a prescribed set of techniques (Iano, 1990). This type of instruction fails to consider a student's cultural, social, or economic backgrounds and

how they may intersect and impact on the classroom context. From a medical model framework, instruction is reduced to a set of skills to be mastered and often narrow in its curricular focus.

An alternative understanding of disability is the notion of disability as socially constructed (Berger & Luckman, 1966). In contrast to the medical model, a socially constructed understanding of disability acknowledges that differences among individuals exist; however, the meaning we ascribe to those differences are a matter of interpretation and dependent upon social, cultural, and economic contexts. That is, we, as educators, have the power to make differences matter more or less depending on the meaning we ascribe to difference. From this perspective, students labeled with disabilities are understood within their educational settings, and the onus for learning does not solely reside on the student's ability to change his or her perceived inherent deficit. Instead, educators and students collectively examine and explore the educational environment to consider what instructional routines, practices, or contexts that hinder a student's learning. Educators recognize and acknowledge how classroom climate and culture, coupled with students' backgrounds and experiences, may construct students as disabled, and they actively seek ways to construct those spaces and practices differently.

Disability Studies in Education (DSE) is a field of study that explores the process of teaching and learning as socially constructed and thus, disability as socially constructed. From this framework, traditional Special Education structures, systems, and practices, such as the medical model and the subsequent practices that often prevail, are critiqued as inequitable, unjust, and disabling (Brantlinger, 2005). Continually evolving as a field, DSE has been challenged in that:

> one of the criticisms of current disability studies approaches is that they tend to be too focused on theory and too unconcerned with practice. . . . in our efforts to advance social interpretations of disability, it is the case that we have ignored the genuine needs of practitioners for conversations between theory and practice and concrete examples of social interpretations in practice (Gabel, 2005, p. 16).

To this end, scholars and educators have begun to explore and examine the pragmatics of teaching and learning from a DSE framework (e.g., Cosier & Ashby, 2016; Heroux, 2017; Lim, Thaver, & Poon, 2008; Young & Mintz, 2008). This exploration is timely as it relates to teacher preparation. Heroux (2017) explains:

> pre-service teacher preparation program must analyze their current practices and evaluate their effectiveness for preparing high-quality, future special educators for increasingly diverse classrooms. While preparation informed by the medical model of disability is necessary for ensuring that pre-service teachers are knowledgeable about how special education services are delivered across the U.S., it does little in the way of preparing them for addressing how disability is defined and represented in society (p. 10).

This paper contributes to this literature by describing concrete teaching examples that illuminate the tensions between special education and DSE and seeks to understand these 'realities' in ways that inform how we might best prepare preservice educators to negotiate such 'realities.'

Methodology and Methods

In my struggle with how to embed the social model and a DSE framework within the field of Special Education, I have come to understand the necessity of locating myself within and between the boundaries of Special Education and DSE. Making explicit how I attempt to work within and between these two often competing and contradictory systems is a useful reminder of the challenges teachers in the field encounter and the importance of bridging DSE theory with practice. By locating my own teaching stories within and between these boundaries, I use autoethnography to explore how we can prepare teachers to work within Special Education systems and from a DSE framework.

Autoethnography is the critical examination of the self in relation to a broader social context (Ellis & Bochner, 2000). As described above, one of the challenges tothe field of DSE is how to bridge DSE theory with practice. By connecting this larger challenge with personal stories of navigating between two seemingly conflicting and contradictory fields, autoethnography serves as a useful tool. That is, I use my personal teaching stories to illuminate the challenges of bridging DSE theory as an avenue to develop a deeper understanding of how we can prepare preservice teachers to teach and learn within the field of Special Education.

To carry out this exploration, I use journals, field notes, and a methodological log to examine my personal experiences. Gallagher (1995) described a methodological log as a place to record field observations, explore ideas, and reflect on the data and research questions. My methodological log contained hundreds of pages of transcribed entries that included: 1) dated entries of documented conversations with colleagues, educators, and students, 2) sketches of ideas, 3) graphic organizers depicting possible theory, and 4) reflections.

To analyze this data, I engaged in the process of journal writing and reading relevant literature and theory to interpret and understand these experiences. I reconstructed significant moments by writing short narrative vignettes. I looked across these narratives for specific themes, and in doing so, I found these experiences were complicated and messy. My experiences shifted between old and new understandings about disability, teaching and learning as I attempted to make sense of and integrate these understandings with my teaching 'realities.' While my understanding of disability, as well as teaching and learning, grew in sophistication over time, these understandings were also mediated by the contexts I found myself navigating. Thus, reconstructing stories through writing vignettes served to both analyze the data and illustrate how I have negotiated the boundaries between Special Education and DSE, while also highlighting the complexities in such negotiations.

Findings and Discussion

Below I use a layered approach to share my findings and discussion. First, I identify three teaching examples that represent critical moments in my thinking about DSE and Special Education. I reconstruct these experiences in the form of narrative vignettes. Following each vignette, I offer discussion by drawing from the theoretical framework of boundary crossing to analyze the experiences. Akkerman and Bakker (2011) define a boundary as "a sociocultural difference leading to discontinuity in action or interaction" (p. 133). My experiences within and across DSE and Special Education represent a boundary space where "new understandings, identity development, change of practices, and institutional development" (p. 142) emerge. To understand these experiences at the boundary of Special Education and DSE, I use three learning processes identified by Akkerman and Bakker (2011). These processes include identification, coordination, and reflection.

There is no Going Back

In a graduate seminar class, I am introduced to the work of Terry Jo Smith (1997). I am assigned to read her manuscript titled 'Storying the Moral Dimensions of Disordering: Teacher Inquiry into the Social Construction of Severe Emotional Disturbance.' When I am assigned this reading, I am both a part-time graduate student and a special educator, teaching in a self-contained classroom for students who are labeled with behavioral disabilities.

My classroom consists of six students who range in age from 11–13 years; five students are male; one student is female. They share the marginalized statuses of minority, low income, and disabled. My instruction consists of one-on-one lessons with each student using a direct instruction curriculum. Each lesson is scripted and requires both teacher and student to engage when cued with the appropriate response. The Boys Town Model, a prescriptive behavioral management system, provides a rigid classroom structure and culture wherein students learn 'appropriate' social skills and are rewarded or penalized within an elaborate point system.

When I begin reading Smith's (1997) manuscript, I am captivated, and I immediately feel a connection to her experiences. In a striking scene, Smith describes an encounter with a student at a bulletin board located in a hallway outside the classroom. The student, Gary, is destroying the bulletin board and Smith is called upon to stop him. In full grandiose fashion, she expresses a willingness to die in his honor and convinces Gary to step away from the bulletin board. She learns he feels humiliated because he is identified as a student with an emotional disturbance on the bulletin board—for all to see. Smith allows Gary to remove his name from the bulletin board, but her peers later criticize her for her 'unconventional' methods. That is, she used humor, treated Gary as a person, respectfully communicated, and demonstrated empathy. Like Gary, she, too, is labeled 'crazy.' For Smith, this incident leads her to question her purpose, the profession, and how she defined students.

I read this manuscript. I reread it. I am Terry Jo Smith. I realize that I, too, am 'crazy.' My student's name is Jay. He is intelligent and curious, while also nervous, untrusting, and belligerent. On the day that I so vividly recall, Jay comes to school wearing a hat. As I greet him at the door to walk him to class (because I've been told that I can't possibly trust him to walk himself to class), he is wearing a hat. Hats are not allowed. I feel myself tense, anticipating the interaction to come. Without so much as a greeting, I order, "Jay, remove your hat." Refusal. He ignores me. Again, I instruct, "Jay, I need you to remove your hat. I need you to look at me, say okay, and do it right away." Refusal. I watch his stance grow more rigid. My associates direct the other students to hush and begin to step out of the way, taking up sides. "Jay, I will deduct a point, if you do not follow my directive," I repeat my command. I deduct a point. Then another point. "Jay, you have lost three points, and you will now go to the time-out room." We face off like a gunfighter and gunslinger in a duel. He refuses to move, and I, regrettably, physically remove him with the assistance of an associate to a padded room. He stays there for the remainder of the morning because he refuses to take off his hat or follow my directions to look at me, do what I say, and check back with me. In the early afternoon, he draws me a picture and slips it under the door. Although the Boys Town Model dictates that this is not protocol and I should not accept it, I do because I am desperate. He has drawn a picture of himself wearing a hat. In a speak bubble stemming from his mouth, he has written, "bad haircut."

I never asked Jay why he wouldn't take off his hat. I didn't consider that as a sixth grader, he may have an excellent reason to wear his hat. I never allowed Jay the opportunity to speak freely; I failed to treat Jay humanly. I sucked. I hated teaching.

The nagging feeling that exists in the shadows of my teaching is revealed and named in Smith's manuscript. I am comforted by her 'craziness' and her suggestion something is amiss in our educational system. Through her critique of special education, she helps me name the conditions of marginalization and oppression. In doing so, I begin to take responsibility for my role in constructing spaces where inequalities play out. I begin to ask: what am I to do? How do I act on this new knowledge? And, while I desire to return to a time that I might perceive as easier, more comfortable, there is no going back. Yet, I am also unsure of how to move forward.

Identification

In the above vignette, I describe my first encounter with Disability Studies in Education—a beautifully written autoethnography by Terry Jo Smith (1997). In this paper, she describes her experiences teaching students labeled with behavioral disabilities and her realization that her students are not the ones who are "emotionally disturbed." This article conveys an alternative perspective that creates the space to explore the multiple meanings of disability and special education. Smith's story causes me to begin to question the tenets of special education, and in doing so, I begin to compare and contrast Special Education with the alternative lens of DSE. I begin to understand how significant the differences are between DSE and Special Education.

This teaching story marked the moment when my sense of identity as a Special Education teacher changed, and the boundaries between Special Education and DSE emerged. I wondered, *how can I be both a special and disability studies educator?* Akkerman and Bakker (2011) describe this experience as a process of identification. Identification entails an examination of the core values, beliefs, and identities of two intersecting boundaries or practices. In the process of identification, an individual defines one practice or boundary in light of another. That is, a practice or boundary is compared to another in an attempt to understand how each practice may be similar or different. As individuals, like myself, begin to understand the differences between the practices or boundaries, they often seek to understand how each can coexist, leading to reconstructed practices or boundaries without necessarily overcoming the discontinuities.

Drugs Deals

My students and I climb the stairs to Mr. Sampson's sixth-grade general education classroom. We quietly sneak into the room and take our seats in the back row. On this day, like all other days, I've prepared 'my students' with verbal instructions, including expectations that border on thinly veiled threats. In the strongest teacher voice I can muster, I say, "I expect you will sit keeping your hands and feet to yourself. Do not disturb the person next to you, and I should see your eyes at the front of the classroom. Do not talk unless you've raised your hand and are called upon. And, remember," I plead, "this is Mr. Sampson's room, and we must show him that we belong here by following his rules." Johnny rolls his eyes at me, and I invoke a small bribe, "This is your opportunity to earn 100 points. I know many of you need these points to earn the opportunity to go on the field trip later this week." Ashamed with the speed at which I capitulate to bribery, I avoid any further eye contact.

When math begins, I take my position, standing in the back corner of the room. I listen and watch as my co-teacher reviews the homework from the day before. I grow restless in the corner and decide to circle the room. Weaving in and out of desks, I glance over the shoulders of students to be certain everyone is following along. As I pass along the back row, I give Johnny a gentle nudge and a small smile that is intended to convey the message: "you're doing great, keep it up." I have the lesson plan that Mr. Sampson shared with me just this morning. In the plan, I've noted the various accommodations that 'my students' require, such as scaffolding and breaking down concepts into steps. Because I didn't have an opportunity to plan with Mr. Sampson, I am a bit uncertain as to the overarching objective and how 'my students' might 'keep up.'

As Mr. Sampson begins to introduce the new concept, I am inclined to join him at the board so that I might break his verbal explanation into a list of steps written for all to see on the whiteboard, but I hold back. I've made a certain, if albeit uncomfortable, peace with our co-teaching arrangement. That is, my students and my very presence in Mr. Sampson's math class came about in what might be described as a 'drug deal' of sorts that entailed me 'selling' what I could offer his classroom in an effort to secure a co-teaching arrangement. I shamelessly

provided the security of an extra body in the classroom, additional support in the form of supervision and a willingness to take on shared grading responsibilities. In the act of hustling my way into his classroom, I convinced myself that once granted access, the terms and nature of our agreement could eventually be renegotiated. Months into the school year, I still wander the rows, serving more as a watchdog associate than a co-teacher. On this day, like every other day, I keep an eye on 'my students' and take note of where their learning breaks down so I can provide additional instruction once we return to the special education classroom.

Coordination

In the teaching story above, I attempted to acquiesce to the expectations of the general education classroom, while at the same time trying to quietly meet my students' needs with the necessary special education supports and services. I struggled with the concessions I was making to integrate my students into the general education classroom, as well as what I was asking of my students. Essentially, I was expecting (and bribing) students to 'hide' certain parts of themselves or set aside particular needs to appear as though they belonged in the classroom. I began to equate these efforts as drug deals in that I was selling or offering up my soul (i.e., my values and beliefs) and asking my students to do the same in a desperate attempt at inclusion. I felt conflicted by my new understanding of teaching and learning from a DSE framework and my desire to provide an opportunity for my students and me to be part of the general education classroom no matter the cost. As I began to realize that making these concessions did not accomplish what I had hoped, I grew weary and burnt out. Although my students were in the general education setting, they experienced additional oppression by the denial of or suggestion that they should hide their differences and accept the denial of any necessary accommodations.

Akkerman and Bakker (2011) describe the learning mechanism of coordination as the process of seeking procedures that allow for diverse perspectives, but without disrupting traditional practice. The concept of coordination helps me to make sense of this teaching story. In the process of coordination, communication and collaboration are established with the goal of maintaining the flow of work; however, there is not necessarily consensus between the two practices or boundaries (Akkerman & Bakker, 2011). Coordination includes four elements. First, there is a communicative connection that is established across the boundaries in the form of a shared boundary object. In this example, the shared general education lesson plan served as the boundary object because it provided a common structure within which the general education and myself were connected around a common purpose.

Second, there are concerted efforts at translating that boundary object to bridge the boundary practices. In this case, the lesson plan was translated between general and special education knowledge and practice to meet the needs of all students in the classroom. To do this, I worked to find a balance between the general education expectations and the special education accommodations and services my students required to be successful in the general education

setting. However, in the example above, I understood that I needed to be careful so that my students' needs did not appear to be so significant as to justify pull-out instruction. Thus, I attempted to make the classroom run as smoothly as possible without drawing any attention to my students. These efforts represent the third element of coordination—that of routinization. Routinization is achieved when coordination becomes automatic, and the boundary is seemingly overcome. For me, routinization and merely overcoming the boundary was problematic. While it appeared that diverse practices were in place to sustain an inclusive classroom, there remained a majority practice, and without genuine consensus, the boundaries and dominant practice remain intact. My efforts at coordination silently maintained oppression under the guise that we can all live and work together (Akkerman & Bakker, 2011).

Undercover Cop

. . . [continued from above] I remain in Jessica's classroom all day. I begin to feel like an outsider in her class. These are not the instructional strategist that I taught her. I taught her about cooperative learning, project-based instruction, and community-driven classrooms, but I witness students sitting in isolation for long periods, working on worksheets or receiving one-on-one instruction. Although she warned me that her class was 'not perfect,' I feel conflicted as I seek to understand what happened to Jessica. She is proud of her classroom and seeking my approval, but I am reluctant. How can I approve of practices so counter to what I believe to be good instruction? Do I merely go along with the instruction I am witnessing? Alternatively, do I say something?

It is apparent that Jessica has worked diligently to structure a classroom that adheres to the principles of TEACCH and structured teaching. The students rotate to various stations, complete work tasks, and respond with automaticity. The class runs like a well-oiled machine, but I am distraught. I do not want to offend her, so I tell her that it is obvious how much she cares for her students and how hard she works on their behalf. This part is true. What I don't tell her is that I am deeply disappointed. I don't ask why she so quickly embraced a deficit understanding of her students and the accompanying medical model that characterizes traditional special education practice. I sense this would deeply trouble her, and as I look around, I imagine she might not have had much choice. I attempt to understand what led her to these instructional practices. She is a new special education teacher surrounded by veteran teachers and a school district that uses a particular curriculum and behavioral approach for students with autism. She is, I come to realize, just doing her job—the job the district asked her to do. However, I wonder if I have done my job in preparing her?

Reflection

The opening and above vignettes provide an example of the process of reflection. Reflection refers to the potential of a boundary to facilitate and explicate differences between

practices that lead to learning something new about one's own and others' practices (Akkerman & Bakker, 2011). As Jessica's former professor, I found myself in a unique position as I entered her classroom. With the lens of both a researcher and teacher, I immediately identified a boundary between what I had taught Jessica and the practices that I witnessed. In conversation with Jessica, I was unable to indict her practices out of respect for her and her willingness to participate in the research, but I was also distraught and conflicted. How did Jessica come to teach from a medical model framework? My immediate inclination was that Jessica sold out; however, I also sensed that her story and experiences were more complicated than merely selling out. How did Jessica shift from a social model view of disability during her undergraduate coursework to medical or deficit understanding? How did she reconcile these two differing frameworks? To answer these questions required reflection and a willingness to call into question my instructional practices. I contemplated: *What are the realities that new teachers encounter? How do they make decisions? What concessions must they make? How do I, as a professor, better prepare my students for the 'realities' of the classrooms they will encounter?*

I also worried that I was offering approval to Jessica. It was evident that she was seeking my approval. Did my presence imply approval? Should I have asked her harder questions? This approach would have been disrespectful, I fear, and not productive. However, if I choose not to confront her, have I sold out? Was I condoning these cubicle workstations and the underlying ideology that understands students as objectives in need of training? I felt like an imposter, pretending to go along with practices I so profoundly abhorred. However, on reflection, I also began to understand the constraints, the complexities that lead me to better understand how the Jessica that I knew as an undergraduate was now a part of a larger system. I felt caught in the middle. When I considered Jessica's circumstances, I found myself making concessions that would be counter to my DSE identity. However, I was hesitant to be more direct with Jessica out of fear of sacrificing my 'cover.'

Reflection is the process of perspective making and taking. Whereas perspective making requires an individual to make explicit his or her understanding and knowledge of a particular issue, perspective taking requires one to attempt to understand through the lenses of another. In observing Jessica's class and her instruction, I became keenly aware of my early experiences as a special education teacher. I recollected how challenging it was to teach from a DSE framework within structures premised on the medical model. Memories of Jay and co-teaching came rushing back to me, and I began to understand how Jessica might find herself teaching special education, attempting to navigate the boundaries of Special Education and DSE and why she might have started our conversation with an apology of sorts, "It's not perfect, it's reality." Jessica, like my former special education self, was attempting to do the best she could.

Reflection that leads to learning something new about one's own and others' practices in ways that inform future practice is difficult. In contrast to identification or coordination, reflection leads to enhanced, altered, or improved understandings of the world and changes future

practice (Akkerman & Bakker, 2011). As I use Akkerman and Bakker's (2011) learning processes of identification, coordination, and reflection, it is reflection that illuminates my pivotal moments of identification, my efforts at coordination, and the continued challenges that special educators encounter teaching from a DSE lens. Through such reflection, I understand there remains much work to be done in preparing teachers to transform the boundary between Special Education and DSE.

Implications

When I examine my teaching stories at the boundaries of DSE and Special Education through the learning mechanisms of identification, coordination, and reflection, several implications emerge for how we, as DSE scholars and educators, prepare preservice teachers. First, undergraduate teacher preparation coursework must include multiple opportunities to examine the fields of Special Education and DSE critically (Heroux, 2017). A thorough examination of each field through a lens of equity, social justice, and diversity should be undertaken. First-person narrative accounts of disability, analysis of the history of Special Education and DSE, including the disability rights movement, and contextualizing disability within political and social spheres are vital components within teacher preparation programs (Connor, 2016). Teacher preparation programs should include spaces for preservice teachers to examine their values and beliefs, and how these beliefs align with various frameworks and understandings of disability. Conversations that center on how theory underlines and informs practice are vital.

Drawing again from the first vignette, I can vividly remember feeling something amiss in my teaching, yet I did not have the means to identify that feeling or make sense of my growing dissatisfaction with teaching. It was not until my graduate work did I encounter the social model and DSE, and while not too late, I remember wondering why I had not been exposed to these ideas sooner. When I reflected on my experiences in Jessica's classroom, I sensed from Jessica that she, too, was conflicted. Although I witnessed what I perceived as some questionable curricular decisions and instructional strategies rooted in a medical model, I also observed how she was well-intended, caring, and an advocate for her students. In her initial greeting to me, she commented that "it wasn't perfect" and in doing so, she conveyed some recognition that she, too, was uncomfortable with the overall nature of her classroom. Without the opportunity to explicitly identify and explore the social model of disability and how various instructional practices align or are counter to the social model in her teacher preparation coursework, Jessica had not learned how to align her instructional practices or push back when given a curriculum that contradicted what she had learned in her teacher preparation program. Thus, teacher preparation programs must also prepare preservice teachers to be boundary workers.

Boundary workers are individuals who encounter discontinuity in their actions and interactions when they find themselves at the intersection of two boundaries (Walker & Nocon,

2007). Boundary workers are located at the heart of discontinuities and can assist in opening windows into the work that occurs in boundary practice (Akkermann & Bakker, 2011; Waitoller & Kozleski, 2013). Walker and Nocon (2007) suggest that successful boundary workers possess the ability to teach and learn "within a given context to (a) understand and negotiate the meanings, through the use of material and symbolic artifacts and (b) to understand and negotiate the meanings through engagement with others" (p. 180). The role of the boundary worker is to create connections between the practices of the overlapping communities (i.e., DSE and Special Education) and to facilitate the transactions between them by introducing new elements of one practice to another.

In teaching our preservice teachers to be boundary workers, a useful strategy is the notion of 'working the cracks' (Collins, 2000). Collins (2000) describes the ability to 'work the cracks' as 'resistance from the *inside*.' That is, a person located within an oppressive structure capitalizes on small opportunities by virtue of his or her membership within the structure, to initiate change through pecking away at "cracks and fissures that represent organizational weakness" (p. 282, italics original). Although Collins (2000) employs the concept to describe individuals within positions of authority in bureaucratic organizations, teacher educators can use the idea to teach preservice teachers how to use their membership in the field of Special Education to introduce and advocate for change that translates DSE theory into practice.

As we prepare preservice teachers to 'work the cracks,' the learning mechanisms of identification, coordination, and reflection can be explicitly taught to preservice teachers as strategies they can use in both 'working the cracks,' as well as a means of understanding their work within and between DSE and Special Education. For example, preservice teachers who begin to understand disability through the social model will no doubt encounter the learning mechanism of coordination in their learning as they seek to make sense of how to teach from the social model. In anticipation of this quandary, teacher preparation programs can prepare students to recognize the benefits and challenges of the learning mechanism of coordination in their teaching. For instance, while coordination seeks to embed diverse practices, for example, Universal Design for Learning, within classroom settings, there is often an absence of genuine investment or widespread change on the part of the broader system or classroom. A parallel system is often established that, while representing a certain degree of progress, also presents barriers to more profound change. As preservice teachers participate in field experiences or student teaching experiences, opportunities exist to observe, discuss, and problem-solve around such issues related to coordination.

Concerning reflection, preservice teachers can be taught how to reflect in ways that require them to practice the skills of perspective taking and making. As they work to expand their understanding of the classroom contexts and educators' actions and motivation within those contexts, readings, activities, and discussions should center on examining the perspectives of stakeholders, including administrators, paraprofessionals, parents, and other educators. For

example, Connor (2016) provides an example of how teachers might analyze a school's culture to understand the various perspectives of educators and administrators, resources, priorities, and contextual factors to enrich their understanding of the dynamics impacting potential change and to strategically plan for short-term, immediate, and long-term action.

Finally, although I chose to present my teaching stories linearly to highlight each learning mechanism, I find that my teaching stories and experiences are not linear. Instead, the learning mechanisms described by Akkerman and Bakker (2011) work concurrently, often dependent upon my positionality, as well as the social, cultural, and environmental contexts that I continually navigate. Making explicit one's journey by sharing teaching stories and deconstructing these stories with and for preservice educators is essential. Understanding and recognizing how one moves in and out of, across and between these learning mechanisms is vital to change and transformation. If we, as DSE teacher educators, desire to translate DSE theory to practice, we must be willing to share our experiences in ways that give others opportunities and permission to share and reflect on their journeys.

Last, we must continually reevaluate and reflect on the structures within which we work, the practices we purport, and how these practices align with the 'realities' of schools and classrooms. We cannot teach from the 'ivory tower,' but instead must build networks and partnerships with schools and teachers to understand the contexts within which they teach and the challenges they encounter. We must model the notion of 'working the cracks' (Collins, 2000) and while "most days do not involve dramatic, enormous victories" (Danforth, 2016, p. x), one must hold onto the notion that change occurs through small shifts that begin with hope—the hope of something better.

Conclusion

The first qualitative study I remember reading was an ethnography by Elliot Liebow (1967) titled Tally's Corner. In this ethnography, Liebow seeks to understand the experiences of young black men from urban settings by immersing himself in their daily lives. He witnesses illegal activities, overhears and is privy to rich and indicting conversations, and struggles with the moral and ethical quandaries that emerge, as he moves between membership within the street community and his role of researcher. I identify with Liebow in that my positionality as both a DSE scholar and a reluctant member of the field of special education often results in feeling like an undercover cop located within and between the boundaries of Special Education and DSE. How do I seemingly 'go along' when I abhor the very tenets of the field of Special Education? While I struggle with this question, the experiences that I have teaching and learning within the field of Special Education expand my understanding of the 'realities' that teachers encounter. I find myself living in an in-between space, and while it is messy and uncomfortable, I recognize such space as useful in helping me understand how to prepare preservice teachers to bridge DSE theory with traditional Special Education classroom practice.

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Research Article

The Absence of a Disability Measurement System in the Disbursement of the District Assembly Common Fund for Persons with Disabilities in Ghana: How the Most Vulnerable are Denied Access

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Abstract: This paper studied the access criteria to the DACF for PWDs Fund by interviewing two DFMC members each across 13 districts. The results show the selection criteria are subjective, deny the most vulnerable access and recommended the use of a social policy-oriented disability measurement system to determine equitable access.

Keywords: District Assembly Common Fund for Persons with Disability, access criteria, Ghana

Introduction

A study from 2011 has shown that Persons with Disabilities (PWDs) in developing countries have a worse standard of living as compared to their counterparts in developed countries (Ofuani, 2011). Ghana's Population and Housing Census Report, in the same vein observed that PWDs in Ghana are poorer than their counterparts living without disabilities and emphasized the need to eliminate the developmental gap between PWDs and other citizens in the country (Ghana Statistical Service, 2014). This disparity led to the passage of Ghana's Persons with Disability Act (715) in 2006 (Ghana Statistical Service, 2014) which established the National Council for Persons with Disabilities (NCPWD) to spearhead the protection of the rights of PWDs (Gyamfi, 2013). Subsequently, in March 2007, Ghana became a signatory to the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and the 119th State to rectify the CRPD and the Optional Protocol in 2011 (Gyamfi, 2013).

In fulfilling these legislative initiatives, the government of Ghana instituted the District Assembly Common Fund for Persons with Disability (DACF for PWDs) as one of the cash transfer social insurance programs that targeted the social and economic development of Persons with Disabilities (Ghana Statistical Service, 2014). The NCPWDs reckoned that such cash transfer social insurance programs require institutional disbursement guidelines for effective implementation. Thus, the NCPWD with other stakeholders developed the "Guidelines for the Disbursement and Management of the District Assembly Common Fund for Persons with Disability". The Disability Common Fund is a 2% (now 3%) allocation of the District Assembly common Fund (DACF) transferred from the Central government to District Assemblies quarterly (Gyamfi, 2013). The NCPWDs guidelines direct disbursement of the funds to the areas of awareness raising on PWDs issues, PWDs organizational development, skills training, income

generating activities, education of PWDs and the provision of technical aids (Guidelines for the disbursement and management of the district assembly common fund allocation to persons with disability, 2010).

Though the NCPWDs Guidelines are operational, there are allegations that District Assemblies continue to channel DACF for PWDs into other purposes against the dictates of the guidelines (District Assemblies Common Fund Secretariat, 2014). Recently there is the gradual introduction of political interference such as Metropolitan, Municipal and District Chief Executives (MMDCEs) using the funds to organize press conferences during disbursement especially in election years or feasting during festivities (SEND-Ghana, 2017). Funds are unduly delayed such that transfers for the fourth quarter of 2016, and the four quarters of 2017 were received as late as January 2018 (Ghanaweb, 2018a). The Fund is susceptible to political influence to the extent that the DCF Administrator issued a new distribution guideline which excludes farmers, traders, babies, students, persons under 18 and above 60 with disabilities (myjoyonline.com, 2018). The NCPWD guidelines also leave much to be desired in areas of defining issues of qualification, quantum of benefit, frequency of accessibility and so on, which are being determined by political actors. Thus, the impact on the economic conditions of the beneficiaries is highly variable (Edusei et al., 2016).

To address these, research has shown, the lack of data on the rate of disability and population has led to the insufficiency of the DACF for PWDs (Ghana Federation of the Disabled, n.d; Naami & Mikey-Iddrisu, 2013). The reason being that it results in a mismatch between the quantum of money released to the Districts and the volume of applications to the fund. The bid to support all applicants makes the program inadequate to make any meaningful changes in the lives of beneficiaries (Adamtey, Oduro, & Braimah, 2018; Adjei-Domfeh, 2015; Agboga, 2015; Edusei et al., 2016). The Ghana Statistical Service (2014) agrees that a disability measurement is needed for effective and efficient policy making while other research focus on the timely release and the increase of the Fund from 2% to 5% of the DACF (Edusei et al., 2016; Naami, 2015). CSOs such as SEND Ghana advocate for the need to increase the monitoring of the use of the funds (SEND-Ghana, 2014) based on their observations that it is a challenge to acquire data that evaluates the impact of the Fund on beneficiaries (SEND-Ghana, 2014). Researchers have advised, the Government of Ghana should find better ways to disburse to ensure fairness and monitor the implementation of the DCF (Adamtey et al., 2018; Naami, 2015; SEND-Ghana, 2014).

Ghana, based on the social model implements policies aimed at PWDs (Ghana Statistical Service, 2014), however, these policies and more so, the DACF for PWDs, do not achieve the purpose of meeting the needs of the most vulnerable PWDs. This is because of the disregard of disability measurement mechanisms to inform the disbursement of the DACF for PWDs. This study is relevant because it would bring to light how disability classification methods used in the

distribution of cash transfer programs could advance the effective disbursement and management of the DACF for PWDs, make data available to improve monitoring and evaluation, and claims to increase the Fund would be backed with available data. The aim of this research is to deepen understanding of how the Disability Common Fund is distributed at the district level, vis a vis characterization of beneficiaries, criteria for selections, and the disbursement process. This would enable policy makers and development partners alike, to better understand existing disbursement challenges, and to re-strategize to ensure improved services. The specific objectives were to

- identify the basis of selection of beneficiaries for the Fund

- assess how transparent the selection process is devoid of local political intervention

- recommend how to improve the selection of beneficiaries to achieve any meaningful impact.

To achieve these objectives, we conducted a desk study to gather data on the status of the fund during 2019. We found that there is a lack of the perspectives of fund managers on the state of the fund in the existing body of literature, as previous studies focused solely on the perspective of beneficiaries. To fill this gap, we used questionnaires to collect data from members of DFMCs from 13 districts in the Upper East Region of Ghana.

The paper has four parts: One reviews literature relevant to Social Insurance Programs and Disability classification, two presents the research methodology and discusses data analysis techniques, three discusses findings, and four concludes with recommendations for the improvement of the Disability Common Fund.

Disability Classifications and its Implication for National Intervention Programs and Projects

The concept of disability is relatively new and not clearly defined. This notwithstanding, the World Health Organization (WHO) based on the medical and social models of disability though careful not to define "disability" arrived at a widely accepted view of who a Person with Disability is. The WHO in the Convention on the Rights of Persons with Disability (CRPD) stated *"persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others"* (World Health Organization, 2001). This reflects a "marriage" of the medical and social models. The medical model argues that the individual is disabled by their impairment, while the social model views disability as socially constructed barriers (Barnes & Mercer, 1997; Fougeyrollas & Beauregard, 2001; Thomas, 2004). The social model was developed to rectify the shortfalls of the medical model which ignored the role of society in its view of disability as impairments to be mitigated by

medical attention and social welfare policies (Employment and Social Affairs, 2002). In the view of Palmer and Harley (2012), the social model though popular, did not deal with the shortfalls of the medical model. It did not solve the issues of PWDs and has no defined framework which can be applied to solving practical problems of PWDs or research (Palmer & Harley, 2012). Acknowledging that disability models must be easily applicable to practical field work, the WHO developed the International Classification of Functioning, Disability and Health (ICF) model. Some Scholars opined the ICF is less a conceptual model than it is a classification system (Bury, 2000; Leonardi, Bickenbach, Ustun, Kostanjsek, & Chatterji, 2006; Mont, 2007; Palmer & Harley, 2012). The focus was on practicability and shaping disability research by offering common vocabulary for research, improvement in data collection, and assessment (Berg & Cassells, 1992). The application could dissolve the sensitivity of issues of selecting beneficiaries of social safety net programs for both political actors and professionals involved (Berg & Cassells, 1992). Thus, the WHO was positive the ICF having evolved from a typical health statistic tool to a more popular survey for social policies would aid development policy making at different level across and within countries (Hemmingsson & Jonsson, 2005; Pavli, 2017; World Health Organization, 2001).

The literature demonstrated that the ICF framework was developed from merging several existing measurement systems. In the same breath, several post ICF framework disability measuring mechanisms were developed based on the ICF framework. Thus, Disability Classification systems are not exclusive of each other but adopts aspects to improve (Wright & Boer, 2002). The Barema classification scheme one of the oldest, is an arbitrary ordinal scale which attaches progressive percentage values to grade disabilities for accessing any social insurance program (Admon-Rick, 2014; Council of Europe, 2002; Fratello & Scorretti, 2002; Wright & Boer, 2002). More recent schemes are those assessing care needs which evaluate and factor in the amount of time a care giver needs in assisting a beneficiary. Functional capacity method gives the assessor the room to describe the degree of disabilities using some predetermined variables, which is preferred in assessing ability for job placement (Employment and Social Affairs, 2002; Wright & Boer, 2002). More detailed functional capacity methods are Katz and Lowton indexes (the Activities of Daily Living (ADLs) and Instrumental Activities of Daily Livings (IADLs)) based on behavioral theories of human function (Berg & Cassells, 1992).

Clearly, the use of classification methods to translate disability into numeric figures makes determination of disability status a more efficient and standardized process to ensure equity in public funded social policy for PWDs (Admon-Rick, 2014; Mashaw, Reno, Burkhauser, & Berkowitz, 1996). However, Pavli (2017) argues the cultural context must be considered in labelling people using a classification system to avoid further degrading effect on the identity of the disabled (Pavli, 2017). Drabek concluded altogether, using classification to label based on activities a group or an individual can perform brings about marginalization (Drabek, 2014). Some question the theoretical rigor of the classification methods. To Imrie, the ICF for instance is

conceptually underdeveloped since it is not established on adequate theoretical underpinnings (Imrie, 2004). These criticisms notwithstanding, Berg and Cassells (1992) support WHO to argue, classification methods are gaining worldwide acceptance because their advantages outweigh the problems which are expected with every developed system (Berg & Cassells, 1992).

In applying this within a national context, disability policies, laws and institutions of a country are shaped by governments' conceptualization and understanding of disability (Drake, 1999). Therefore, in determining state welfare programs for PWDs, issues such as, is disability present; does it qualify for benefit; is it sufficiently severe to qualify for the benefit; is it from an appropriate cause for the benefit; will it persist long enough for benefit to be worth allocating must be considered (Wright & Boer, 2002).

There exists in developing countries a vicious cycle of disability and poverty. The chances of PWDs emerging from poverty are slim because of unavailable or insufficient safety net programs. There is also the lack of enabling legislation to promote PWDs empowerment. Even when available, weak implementation defeats the purpose of enactment (Naami & Mikey-Iddrisu, 2013; Ofuani, 2011; Tsengu, Brodtkorb, & Almnes, 2006). To change the situation of PWDs, academics emphasis the need for social support programs. In this context, it is prudent to identify those in need in the face of severely limited resources (Naami & Mikey-Iddrisu, 2013; Palmer & Harley, 2012; Pavli, 2017). To achieve this there ought to be data on PWDs; however, most developing countries including Ghana do not have adequate data on the assessment of PWDs (Edusei et al., 2016; Gyamfi, 2013).

Ghana's most researched cash transfer program targeted at PWDs is the DACF for PWDs. The literature demonstrates that the aim of such programs is to reduce poverty among all PWDs. To ensure the success of such programs, PWDs must play a central role in the empowerment process. Thus, creating the enabling environment for self-discovery, self-development and self-awareness to reverse the perception that PWDs have less potential in the quest for development (Ghana Statistical Service, 2014; Naami & Mikey-Iddrisu, 2013; Ofuani, 2011; Tsengu et al., 2006). In view of the relevance of the DACF for PWDs, there is the call for the need for increase and timely disbursement of the funds (Edusei et al., 2016).

However, it is contestable whether the increment of the fund can have an impact on improving the economic conditions of the beneficiaries because the process of disbursement needs to be reconsidered. Funds are allocated to economic activities that are restricted to rural craft of localities and have no market value. Where new skills are introduced, there is the lack of tools and materials to practice. Clearly, the fund is not adequate to make any meaningful changes in their lives considering the mismatch between the huge volume of applicants and the funds (Edusei et al., 2016; Slikker, 2009).

In our view, there is the need to shift the focus from research that points to increasing of the DACF for PWDs to research that seek ways the use of the available resources can be maximized. Considering the economic situation in Ghana, the calls to increase the DCF will not be heeded. There is the urgent need to look critically into the disbursement of this cash transfer program. The rationale is how best to identify the target population in need, providing sufficient support and graduating them off the program to make room for others as well.

Study Design

The first point of call for the researchers was to review the literature on the District Assembly Common Fund for Persons with Disability. The findings are presented in the discussion section below. Based on the review we observed a gap in the literature which solely focused on the perspective of the beneficiaries of the Fund. We therefore made the conscious effort to interview only members of the Disability Fund Management Committees to give a different perspective to the debate. This paper used this approach because there exist enough publications based solely on the perspective of beneficiaries. Despite the existence of a large body of literature on the Fund, the researchers' knowledge gained through the implementation of development projects across the region indicate the persistence of the inefficiency of the Fund. Therefore, the researchers consider interviewing the Fund Management Committees innovative in understanding the fund's disbursement.

Study Population and Sample Size

Two committee members were interviewed across all 13 districts of the Upper East Region (the second poorest region in Ghana) excluding the two newly created districts. In total, 26 respondents were purposively sampled to participate in the survey. Of this number, 13 respondents were PWDs who were representing the GFD or the NCPD on the Fund Management Committees. Six of the total respondents were female. The Upper East branch of GFD, the Upper East Regional Coordinating Council and the Regional Department of Social Welfare endorsed this study by providing introductory letters for data collection.

### Field Data Collection Techniques and Analysis

The study used a survey and gathered data through questionnaires with both closed-ended questions and opened-ended questions. This made it possible for the researchers to solicit information from committee members who are part of decision making concerning the disbursement of the DCF. The questionnaires were self-administered, however, the researchers assisted in the clarification of questions where it was necessary. Respondents who needed translation of questionnaires into the local language (Frafra) were assisted by a research assistant. The service of a translator was procured to translate the research questions to respondents with hearing disabilities. The personal aids of respondents with visual disabilities ensured the

appropriate recording of the responses of their employers. The completeness and confidentiality responses were prioritized by researchers. The collected data was analyzed with the Statistical Package for Social Science (SPSS) and Microsoft excel for the generation of frequencies and tables. Responses to open-ended questions were analyzed thematically using the software MaxQDA and some responses quoted in the data presentation and discussion sections. Secondly, a desk study to ascertain the status and efficiency of the Fund. It compared the amount allocated to the districts within the scope of the study and the number of PWDs to which funding was targeted.

Presentation and Discussions of Findings

Findings from Desk Studies

The result of our desk study gave us insight into the current financial status of the DACF for PWDs. As shown in Figure 1, the DACF for PWDs has been increased from 2% to 3% of the DACF transferred quarterly to all districts. The most recent record of the DACF secretariat indicates the Upper East region received 6,196,023.23 Ghana Cedis (GH¢) ($1,290,838.17 at Bank of Ghana exchange rate of GH¢ 4.8 to $1 on 12/02/2019) for the second quarter of 2018. This sum to an average of GH¢ 413,068 ($ 86,056) for each of the 15 districts in the region. Therefore, the DACF for PWDs average GH¢12,392 ($2,582). Of this amount, 5% is to be set aside for administrative and sitting allowances of the DFMC, 10% each set aside for training of disability organization leaders and registration of PWDs onto the National Health Insurance Scheme as directed by the Administrator of the Disability Common Fund. In reality, an estimate of GH¢ 9,294 ($1,936) is spent on six thematic areas as stipulated in the disbursement guidelines (District Assemblies Common Fund Secretariat, 2018). These are: advocacy/awareness raising on the rights and responsibilities of PWD; strengthening of OPWDs (Organizational development); training in employable skills/apprenticeship; income generation activities (input/working capital); some educational support for children, students and trainees with disability; and provision of technical aids, assistive devices, equipment. The Upper East Region has about 39,838 PWDs, thus, each district on the average has 2,655 PWDs. Our analysis of the findings would be based on the assumption that 2,655 PWDs are to benefit from GH¢ 9,294 ($1,936) for a period of every four months. (District Assemblies Common Fund Secretariat, 2018; Ghana Statistical Service, 2014; Ghanaweb, 2018b, 2018c). Though the DACF for PWDs was recently increased, the actual amount disbursed hovers around 91.44% of the disbursed Fund from source.

Figure 1

A Scenario Based on the DACF Disbursement in 2nd Quarter of 2018

A Scenario Based on the DACF Disbursement in 2nd Quarter of 2018
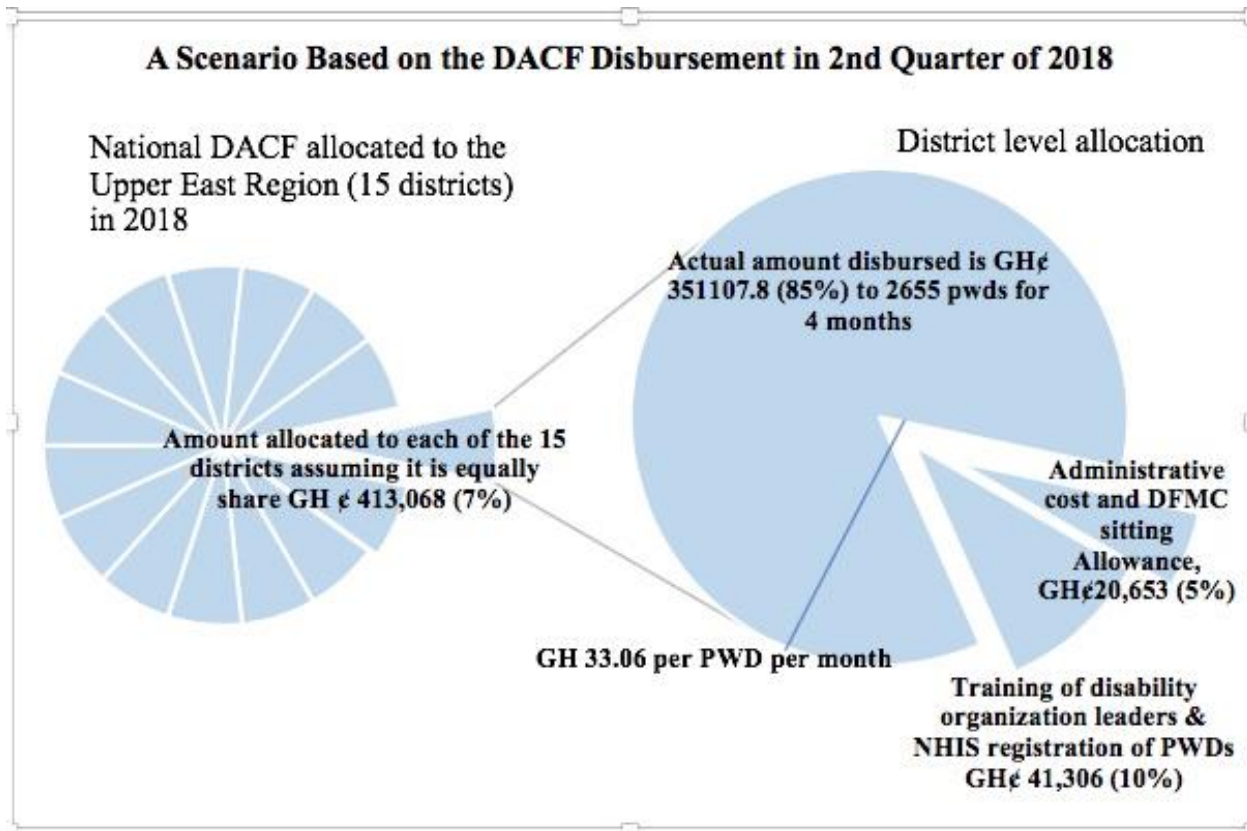
This paper like many others had a confirmation of 80% and 57.7% from respondents about the insufficiency and delayed disbursal of the funds respectively. Some often-cited publications on the insufficiency of the Fund such as Naami & Mikey-Iddrisu (2013) and Edusei et al. (2016) deduce from these findings, the need for an increment and timely disbursement.

Finding a Nexus between Data from Literature on the Fund and Field Data from the Perspective of the Fund Management Committees

From our survey, 57.7% of the respondents from the DFMCs confirmed funds from the national disability fund are not disbursed quarterly as stipulated in the guidelines. Therefore, 61.5% confirmed the funds are not disbursed from the district level to beneficiary PWDs regularly.

As a result of the above, DFMCs receive volumes of applications for funding hence the need to satisfy a large group of applicants. Therefore, a majority of 80% agreed there are complaints about the insufficiency of the disbursed funds.

Emanating from the above, 92.7% of respondents agreed that more than 50 PWDs benefit from each disbursement round. All respondents said this represents more than 50% of total applicants and the decision is based on needs of applicant, requested budget, type and feasibility of business.

In accordance to the DFMC guideline training in employable skills/apprenticeship and income generation activities are prioritized as 100% of the respondents agreed that the unemployed are prioritized in the disbursement of the fund. Nevertheless, 25% also indicated that funds are extended to PWDs employed in the public sector. In making such decisions, a majority of 80.7% of respondents indicated that they are influenced in deciding who benefits from the Fund by the capacity of the applicant to perform activities of daily living.

When researchers sought to know if available data was the basis for the selection of Fund beneficiaries, 65.4% of the respondents indicated in the affirmative. However, upon further interrogation, 70.6% indicated the data available is only a collection of names of PWDs in the various districts whiles 29.4% of respondents said the data includes type of disability.

To ascertain how transparent and equitable the process of disbursement was, the researchers sought to find out about the independence of the DFMC from district level political actors. Impressively, 96.2% of the respondents are aware of their sole responsibility in decision making about the beneficiaries of the fund. However, 25% of respondents also agreed that political figure heads such as District Chief Executives have influence in the decision making.

Answers to the Research Questions

How the DFMCs Select Beneficiaries of the DACF for PWDs at the District Level

In the implementation of public funded social policies and programs aimed at alleviating hardships of PWDs, scholars have recommended the use of databases derived from classification methods which ensures determining eligibility and equity (Admon-Rick, 2014; Mashaw et al., 1996). In our finding, though most districts (65.4%) have data on PWDs under their jurisdiction, these databases can be described as a "collection of names" at best. The other 34.6% have no data on PWDs in the district at all. The inadequacy of data which classifies PWDs according to their needs translates into issues of difficulty in determining the eligibility of beneficiaries and equity in the disbursement of the DACF for PWDs Fund.

Scholars have argued that the economic and social situation of PWDs can become better when the most vulnerable are identified and assisted in the face of resource limitation (Naami & Mikey-Iddrisu, 2013; Palmer & Harley, 2012; Pavli, 2017). However, this research finds the implementation of the DACF for PWDs goes against the above. A majority of 80.7% of the respondents indicated they considered the capacity of the applicant to perform activities of daily

living whiles only 3.8% considered the amount of time needed by a care giver in supporting the applicant. This meant the most vulnerable PWDs have no access to the Fund because they are deemed as not able to utilize the disbursed resource. We contend, this is discriminatory against those who need the fund the most. Furthermore, 92.7% of the respondents indicated more than 50 applicants benefit in each round, thus, from the available average funds per researchers' calculation (GH¢9294), a beneficiary will receive an average of GH¢ 186 ($ 38.75). This is insufficient as stated by earlier research such as Edusei et al. (2016). The implication is that applications with budgets close to this figure stand a chance of being approved since it is based on requested budget, type and feasibility. Such meager amounts cannot be used in engaging in any sustainable income activity. Hence, beneficiaries recurrently apply each disbursement round which denies others access. A respondent said, "…*they* [PWDs] *keep changing their identities to get the money* [DACF for PWD] *more than once…*".

The transparency of the selection of beneficiaries of the DACF for PWDs

In the decision-making process concerning the disbursement of the funds to beneficiaries, 96.2% of the respondents indicated that it is solely done by the DFMC and by the involvement of PWD association leaders. However, the implementation of other thematic areas such as the provision of assistive devices and the procurement of equipment for income generating activities involve district political heads. The involvement of political figures leads to misappropriation of the fund. One respondent mentioned *"… sometimes the big men* [MMDCE] *order for the funds to be taken for other purposes. Sometimes too they also bring their list* [PWDs belonging to same political parties as political heads*] to be given the money before anybody…"*.

Based on our findings, we argue that the recommendations of the major academic works on the topic such as Naami & Mikey-Iddrisu (2013) and Edusei et al. (2016) are valid to a large extent. However, due to the recent increment such recommendations would not likely to be considered amidst the cry of politicians about the scarcity of resources for social spending. Therefore, we argue for urgency in tackling systemic challenges with the disbursement of the DACF for PWDs Fund to ensure effectiveness, efficiency and impact of the Fund even in the face of limited resources.

Study Implications and Recommendations

1. Our findings strongly suggest that the disbursement of DACF for PWDs has no empirical basis for the selection of who benefits from the fund or not. The criteria of the DFMC based on individual's ability to perform some daily duties, type, budget and sustainability of the income generating activity further creates barriers for most vulnerable PWDs who cannot perform these tasks.

This paper recommends the need to roll out a project that would measure the disability status of all PWDs, categorize them and decide on which bases disbursement of the fund should be made. Here, this data would allow PWDs with capacities to engage in economic activities to be given substantial one time off budgetary allocation and other supports to establish their income source. This would pave the way for weaning them off the fund. This would free up substantially subsequent funds for the regular allocation to PWDs categorized as unable to perform such activities.

2. The disbursement process is also impeded by district political heads such as the MMDCE. The DCE has no role per the NCPD guidelines hence must abstain from interfering in determining the beneficiaries of the Fund.

   It is recommended that the Regional Coordinating Council of the region and by extension the government of Ghana indicate to all MMDCEs to desist from discriminating on the basis of political affiliation in the disbursement of the Fund. The NCPD should also review the current guidelines to mandate all DFMCs to have a database at the district level that is fed into a national database to inform social policies targeted at PWDs.

Limitations of the Study

The research focused only on the Upper East Region of Ghana out of all sixteen regions. Responses were also sampled from 26 members across all districts. This region is also the second poorest region, hence more PWDs expect to rely on the DACF for PWDs. There are poor regions with higher number of PWDs hence the situation may be more critical. There are also major metropolitan areas with high number of PWDs but less reliance on the Fund. It would be difficult, therefore, to generalize the findings to represent the situation of the whole country. This notwithstanding, there is the lack of any measurement to inform social policy intervention towards PWDs or any other social group.

Conclusion

Moving away from the usual studies of the impact of the DACF for PWDs, this study focused on the criteria for and transparency of the disbursement process across 13 districts in the Upper East Region. The study found that there are no empirical criteria informing the disbursement of the fund. Reliance on the ability of individuals to perform some tasks further creates barriers to most vulnerable PWDs. The study also finds the gradual introduction of using the funds to satisfy patron-client networks of local political heads of districts amongst PWDs. The study recommends the need to use a social policy-oriented disability measurement system to identify PWDs in need of one-time support and PWDs who require regular support. The Regional Coordinating Councils that have oversight responsibility over MMDCEs and the Common Fund Administrator must ensure that these political heads desist from manipulating the Fund for political gains.

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Special Announcement

Global Perspective on Disability Studies:

Expansion of Submissions to Those in an Author's Native Language Other than English

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Patricia Morrissey
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Indian Institute of Technology Madras

The Review of Disability Studies: An International Journal (RDS) is pleased to announce an experiment within the journal section 'Global Perspective on Disability Studies' and the 2020 call for submissions. We welcome research papers of no more than 20 pages and other submissions of no more than three pages. We will consider one research paper and one other submission of no more than three pages for each issue beginning in April 2020 for this journal section. We will assume the responsibility and cost of translation. Accepted submissions will be published in the author's native language and in English in the October and December issues of the journal. This is truly a multilingual conversation, and we would like to take on these arrangements step by step. Should this endeavor prove viable in terms of cost and time, we will continue it throughout 2021 and decide by January 2022, whether to make it a permanent feature. Please submit at https://rdsjournal.org, (deadline April 30, 2020). For additional questions please contact (rdsj@hawaii.edu).

Our experiment in bilingual publishing will open the door to new authors for English-speaking journal audiences and to those who speak an author's language (other than English). We hope this will offer opportunities to be published to individuals who do not write in English, especially those with disabilities who have a lot to share, but neither the time nor resources to arrange for technically acceptable translations into English. They may concentrate on what they want to share on a myriad of topics – activism, corporeal pain, structural violence, discriminatory interpersonal bonding, and caregiving – and leave the translation to us. Those of us who speak English will have access to fresh voices who can expand our perspectives about having a disability and teach us new strategies for promoting meaningful, sustainable community equality for all minds and bodies!

Authors are welcome to make submissions in their own languages, no matter the range and scope of their demographic reach. We will make use of the services of translators around the

globe, who will make these submissions accessible in English. Authors may draw insights on the following broad themes when making submissions that are native to their disability cultures and communities.

- Strategies to expand access and opportunities for success in varied contexts – education, employment, health care, housing, transportation, leisure, policy development, civic engagement, and decision making.
- Emotional registers and disability
- Transnational, Black, and Indigenous narratives of disability
- Traumatized communities and historical memory
- Madness, resistance and resilience
- Experience and commentary on trauma, torture, and imprisonment
- Cultural memory and disability history
- Disappearing languages, dialects, and disability
- Language of charity, human rights, and disability
- Sign languages and disability pride
- Disabilities, orature, and folklore

About RDS

Focus and Scope

The *Review of Disability Studies: An* International Journal (RDS) is an open-access journal that provides an international forum for people with disabilities, academics, professionals, artists and creators from all backgrounds and expertise to express ideas relevant to disability studies and people with disabilities.

RDS is a peer-reviewed open access academic journal that is targeted towards any person interested in disability studies. We have readers and authors from all over the world. We accept submissions covering a range of disciplines within disciplines as well as creative works expressing ideas in the area of disability. The journal is published four times a year, and each issue runs approximately 50 pages. The RDS journal contains the following sections:

1. Research & Essays (anonymous peer reviewed articles of a scholarly nature)

2. Forums (collections of articles on special topics or geographical areas, conference proceedings, student or "up and coming disability scholars" collections)

3. Creative Works (poetry, photography, film, fiction, visual arts)

4. Global Perspectives (narratives from across the globe, commentary, curriculum, teaching texts and resources, strategies for integrating disability studies into various disciplines, community updates on social justice struggles, and historical pieces or discussion concerning disability).

5. Multi-Media Reviews (reviews of films, social network sites, blogs, online magazines, websites, notes on performance arts enriched by disabilities)

6. Notes from the Field (announcements of conferences, jobs, events, new publications, other current happenings)

7. Disability Studies Dissertation Abstracts (abstracts of dissertations that add value to the disability studies field)

Global Perspectives on Disability Studies Article

Cross-Border Collaboration to Assist Individuals with Disabilities: Despite a Border Wall, a Common Goal Unites People

Burris R. Duncan, MD, Francisco Trujillo,
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ARSOBO (U.S. and Mexican entities) & The University of Arizona

Abstract: An informal needs assessment along the Mexico-United States border resulted in a cross-border organization; Arizona Sonora Border (ARSOBO) Projects for Inclusion, referred to colloquially on both sides of the border as 'ARSOBO.' Individuals with disabilities have been trained to construct high-quality, low-cost medical devices they themselves use, for others who need them. Cross-border resources emerged, enabling ARSOBO to grow and approach self-sufficiency.

The border between the United States (US) and Mexico (MX) is 70 miles from Tucson, Arizona, US, yet the contrast between the two sides belies this short distance. On the Mexican side of the border, resources are limited, individuals with disabilities have little help from the government and must adapt. Medical devices that are necessary to overcome social, economic, and educational barriers are much more difficult to obtain south of the border than in the northern side. The following Mexican program, ARSOBO for Inclusion was initiated by an informal needs assessment conducted on both sides of the US-MX border, and implemented with both local MX and US resources, is decreasing these barriers.

A Needs Assessment Dictated a Conference Agenda

In 2008, public health students and faculty from the University of Arizona (UA) in Tucson, Arizona, US, conducted an informal needs assessment in several towns and cities along the border region in Arizona, US and Sonora, MX to determine the content for the annual Border Conference on Disabilities. Two UA faculty members interviewed health care workers who provided care for individuals with disabilities in several towns and cities from Nogales, MX to Douglas, Arizona, US. And a UA Master of Public Health student conducted a similar assessment on the MX side of the border. Author, Dr. Burris Duncan helped in formulating the needs assessment and the conference agenda. He has worked for over 20 years as a pediatrician at Children's Rehabilitation Services in Tucson and during that time frequently volunteered at St. Andrews Children's Clinic in Nogales, AZ, a clinic that serves Mexican children with disabilities who live south of the border.

The conference was sponsored by the UA's Sonoran University Center of Excellence in Developmental Disabilities (UCEDD) and *Desarrollo Integral de la Familia* (DIF) Nogales, MX was held in Nogales, MX. The goal of the conference was to educate care providers and to open a factory after the conference that would help alleviate some of the needs that were found. The factory would train individuals with disabilities to construct needed medical devices and provide the devices to indigent families at a price they could afford.

The needs assessment revealed the following:

1. Individuals needing a wheelchair, experienced extreme difficulty navigating the rough terrain of their neighborhoods, as streets and sidewalks are not always 'friendly' for conventional wheelchairs that had been provided by well-intended individuals or non-governmental organizations (NGOs).
2. The number of individuals with lower-limb amputations had grown exponentially. This is largely secondary to complications of the diabetes epidemic in Mexico (WHO, 2017), and prosthetics were beyond the budgets of most.
3. Individuals who are hearing impaired could not afford hearing aids or batteries so the elders were isolated from their families and friends and the children had extreme difficulties in school.
4. There is a lack in medical devices, because of this many individuals were not only socially isolated but devices for employment opportunities were non-existent.

These four themes thereby informed the mission of the Mexican factory, later known as ARSOBO, that would be created after the conference.

After the Conference

Shortly after the conference, an NGO in MX and a 'sister' NGO with tax-exempt status in the US were established—both with the same name. The name of the NGOs reflect the cross-border orientation and purpose: ARizona SOnora BOrder (ARSOBO) Projects for Inclusion.

Once individuals' needs were identified, appropriate resources had to be found. The University of Arizona Foundation provided initial funding to purchase equipment and supplies for the conference that included a session on constructing an all-terrain wheelchair. After the conference, additional external funding and resources were needed. A Rotary Club in Tucson, Arizona, US, connected with a Rotary Club in Nogales, MX and a grant from Rotary International was obtained. UA faculty felt they could be a resource to secure additional funding. Oftentimes, external resources can be difficult to obtain, may not be aligned with or adequate to meet the needs, and are usually not sustainable. Thankfully, hidden resources within this resource-limited community soon emerged eliminating the need for other grants.

Every community has people and it is in people where hidden resources can be found. Some people have talents (what they were born with), some have skills (what they were trained to do), and some have passions (what they love to do) (McKnight, 1995). A Nogales, MX third-generation resident with the inherent talent to assist individuals with disabilities was hired to organize and direct the Mexican NGO. A conference workshop was conducted by a technician wheelchair user, and who had acquired the skills to construct an all-terrain wheelchair, the RoughRider. This wheelchair was designed by Ralf Hotchkiss, a wheelchair user, specifically for developing countries that have the toughest of terrains (Whirlwind Wheelchair International, 2018). The director of the *Centros de Capacitación Para el Trabajo Industrial* (CECATI)–a technical training school in Nogales, MX–had a passion for this project. He donated space and also paid for the utilities. The talents and skills of other individuals from diverse disciplines were engaged, as were the passions of many who were connected with institutions and commercial entities on both sides of the US-MX border. Two years later, the space at CECATI had become insufficient and *Parque Industrial de Nogales Sonora* (PINSA) donated a 4,500 square-foot warehouse, rent-free, and paid for the utilities. The City of Nogales, Sonora, MX, had recently donated land and the *Maquila* (factory); and the Association gave sufficient funds to build a facility. It opened in July of 2019, thus enabling continued expansion of the factory.

Thus, when local resources are identified, interested individuals become receptive and energized, allowing their resources to be enlisted (talents, skills, and passions). Collaborators have the potential to positively impact the lives of individuals with disabilities and unite communities despite border walls. This certainly has been the case for ARSOBO.

ARSOBO's Mission, Principles, and Partnerships

ARSOBO's mission is to provide medical devices, made by individuals who use the same device, to alleviate barriers and enhance the potential of those with a disability. ARSOBO has three principles:

1. Train and hire individuals with a disability to construct the medical equipment they themselves need and use.
2. Charge for medical devices, but only based on what an individual or family can afford. The remaining balance of the full-cost is supplemented from donations and/or grants.
3. Work toward a self-sustainable 'social business,' a business where the 'bottom line' is to benefit the social good of the community.

ARSOBO is a cross-border project that includes provision of three different types of affordable medical devices at affordable prices with costs subsidized for those with limited incomes. Two individuals who are wheelchair themselves construct the RoughRider, both a standard and a customized wheelchair for individuals with neurologic and/or neuromuscular problems. Two individuals, each with a prosthetic leg, fabricate prostheses with the assistance of

volunteers from Hanger Clinic: Prosthetics & Orthotics, Inc. in Tucson, Arizona, US. Youth with hearing-impairments from Nogales, MX assisted in monthly hearing health clinics conducted by audiologists from the UA Speech, Language, and Hearing Sciences Department who select and distribute high-quality, low-cost, hearing aids (Dean & Velenovsky, 2018) (See Figure 1.).

Figure 1. ARSOBO Cross-Border Project

Figure 1. Image Description: Figure 1. includes a colleague of five ARSOBO™ pictures. The picture in the far left, includes two employees building all-terrain wheelchairs appropriate for the regional landscape, and even customize them for children with developmental disabilities – these employees also use the wheelchairs themselves. The picture in the upper-middle, includes two employees posing in the factory, each with an amputated leg who have been trained to fabricate prosthetics. The picture in the lower-middle, include employees working on a prosthetic leg. The picture in the upper-right, includes a youth patient with a hearing-impairments from Nogales, MX, who is participating in a monthly hearing health clinics conducted by audiologists, from the Speech, Language, and Hearing Sciences Department at the UA, who select and distribute high-quality, low-cost, hearing aids. The picture in the lower-right, includes another photo of the youth patient.

ARSOBO also serves as an extramural site to expose students to this social model and the richness of the border community. This project offers volunteer and internship opportunities for UA Master of Public Health candidates, as well as students from the Colleges of Medicine, Nursing, Audiology, and Management and engineering students and faculty from Universidad Tecnológica in Nogales, Sonora, MX.

ARSOBO Achievements and Next Steps

Since ARSOBO opened in 2012, 413 RoughRider wheelchairs (one-third customized) have been constructed; 335 individuals now have a prosthetic limb, enabling them to walk without crutches; and 708 individuals have an appropriate high-quality hearing aid.

In 2016, public health students from UA and nursing students from Nogales, MX conducted semi-structured home interviews of 35 recipients of an ARSOBO medical device. The purpose was to assess the services ARSOBO was provided and the impact the devices had on their lives. The results were positive changes, which included improved ambulation, greater social inclusion, improved interaction with family and friends, and decreased feelings of social discrimination. Interview findings also highlighted recipients' hesitancy to return for adjustments and prompted logistical changes to insure follow-up appointments. Findings also prompted the engagement of physical therapists from both sides of the US-MX border to provide rehabilitation services for recipients of prostheses (Aubert-Vasquezet. al., 2017).

A large international door-lock manufacturing company, Dormakaba, recently opened an operation in the industrial park and contracted ARSOBO to assemble the bolts and nuts necessary to install the locks. This partnership not only allows ARSOBO to employ additional individuals with a disability, it provides continuous income, enabling ARSOBO to begin the road toward accomplishing the third goal of becoming a self-sustaining, social business. Dormakaba is largely based on ARSOBO's example, several *maquilas* (or factories) in Nogales, Sonora have begun to hire individuals with a disability.

Conclusion

Approximately 15 million people reside in the 42 US counties and 39 Mexican municipalities along the US-MX border; 86% reside in 14 pairs of 'sister cities.' ARSOBO demonstrates a cross-border program that has the potential to diminish artificial physical barriers and unite these border communities to solve public health problems.

Burris R. Duncan, MD, has been on the faculty of three different pediatric departments; the University of Colorado (10 years), the Universidade Federal do Rio Grande do Norte in Natal, Brazil (3 years), and the University of Arizona (30 years). During his tenure at Colorado and Arizona he taught medical students and pediatric residents and had a panel of patients with chronic conditions that he personally followed and was on call for after clinic hours. Most of these patients were special needs children with complicated multi-system problems. He has conducted multiple research projects, most of which developed from individual problems he saw in his patients and where he felt there was not a sufficient readily-available answer in the medical literature. He has more than 60 published articles in peer-reviewed medical journals and 20 chapters in medical textbooks. His international experience extends over the past 30 years and has

included clinical work, teaching, research, field work, and administrative responsibilities in more than a dozen different countries. He has worked extensively with the Section on International Child Health with the American Academy of Pediatrics and is a co-founder of ARSOBO.

Francisco Trujillo, is a lifetime resident of the border region of Nogales and recently acquired permanent resident status in the U.S. He has a bachelor's degree in Industrial Engineering from *Instituto Tecnologico de Nogales*, worked for fifteen years for three US Companies in Mexico under the *Maquiladora* Program, is a former director of the Nogales Sonora Chamber of Commerce and in the last twenty years has worked with three nonprofit organizations: Borderlinks, ARAN, and (for the last ten years) as co-founder of ARSOBO Projects for Inclusion operating in Nogales, Mexico.

William Neubauer, MD, is the immediate past chairman of the board of directors for the ARSOBO U.S. entity and a business owner in Tumacacori, Arizona. He has worked extensively to provide free medical clinic and treatment services for various populations, including those in the Arizona-Mexico border region and for rural communities in Bolivia. He is a former commander and chief of surgery for the United States Public Health Service Hospital (1974–76), has performed approximately 25,000 major surgical procedures during his time in private practice as a general surgeon (1976–2004), and has served as chief of general surgery for a number of local hospitals and medical centers. Dr. Neubauer has also served the community through his service on multiple boards for local nonprofit organizations such as the Border Community Alliance, Community Foundation of Santa Cruz County, the Health Committee of the Arizona Mexico Commission, and the Boys and Girls Club of Tucson.

Heidi L. Pottinger, DrPH, MPH, MA, is originally from the U.S.-Mexico border town of Nogales, AZ. Over her career, she has focused extensively on advocacy, education, nonprofit, research, and service efforts. Since 2014, she has worked to help lead a multi-site clinical trial for young children with cerebral palsy, and as a board member for ARSOBO's U.S. entity and volunteer for the MX entity. She has served in various roles as chair, co-chair, and member of the Integrative Touch for Kids (ITK) research and evaluation committee – ITK supports families whose children have any type of special health or medical need with integrative healing therapies and wellness education – and in 2017, was recognized by the American Public Health Association Disability Section for her work with ITK evaluating their pediatric hospital program. Dr. Pottinger is also founder and executive director of Child Health & Resilience Mastery (CHARM), a Nogales, AZ nonprofit that empowers children and families to strengthen resilience in health-promoting ways. Previously, she was director of clinical research for the Muscular Dystrophy Association national headquarters.

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