Beyond Stigma: Disability Identity in School Contexts

Carlyn Mueller

A dissertation

submitted in partial fulfillment of the

requirements for the degree of

Doctor of Philosophy

University of Washington

2019

Reading Committee:

Katherine Lewis, Chair

Charles (Cap) Peck

Anjali Forber-Pratt

Margaret Beneke

Program Authorized to Offer Degree:

College of Education

University of Washington

Abstract

Beyond Stigma: Disability Identity in School Contexts

Carlyn Mueller

Chair of the Supervisory Committee:
Katherine Lewis
College of Education

This dissertation focuses on adolescent disability identity development and centers the expertise about this phenomenon in the lived experiences of students and adults with disabilities, and a larger context of disability community and culture. The purpose of understanding disability identity is twofold: first, to conceptualize adolescent disability identity development from within educational contexts, and second, to understand the impact of participatory research methods towards this development. To date, the scholarship around disability identity development and adolescents, particularly in the field of special education, has focused on development of social skills for friendships with nondisabled peers (e.g. Zambo, 2010) and negotiation (or attempted negation) of stigma, which is itself due to the overwhelmingly negative social and cultural meanings of the disability label itself (e.g. Kauffman, 2003; Shifrer, 2013). Teachers, themselves frequently nondisabled (Hart & Williams, 2009) attempt to support students academically and socially through this negotiation of stigma, from within their own training and personal experience as a nondisabled student (Linton, 1998). Changing this way of "managing" disability requires a shift in both the conceptual and methodological focus of disability from within the context of special education, and a shift from labeling disability as a feature of a person which must be remediated and normalized. Ware (2002) notes that this shift is "particularly significant in K-12 public schools, where schools reproduce an "understanding of disability warped by the shroud of shame, pity and tragedy in which the disabled students' needs, deficits, and problems are wrapped- constructing the student's institutional identity" (p. 152). Instead of assuming this institutional identity as a natural consequence of disability labeling, the study positions disabled students as knowledge holders and experts in their own identities. The first phase of the dissertation involved qualitative interviewing and reflection from disabled adults on their educational experiences and disability awareness in school, which informed and helped identified "levers" of disability identity that have an impact on growth, development, and awareness of each participant’s sense of themselves as members of a disability community. Following the interviews and participation of the disabled adults, the second part of the study involved participation of adolescents with disabilities in a large public high school special education program in the Pacific Northwest. The adolescent participants engaged in both qualitative interviewing about disability identity and a photovoice project where they discussed their identity experiences in school related to disability. Following this phase, the adult participants engaged with the students’ photovoice materials to identify shared experiences and identity resources (Gee, 2003) of disability identity development in school. Common shared disability identity resources included participation in self-contained special education courses and removal from general education; an initial realization of disability and difference; silence around disability in curriculum and from special and general education teachers; and attempts at participation in disability community in mostly online spaces. This study contributes to the theoretical and methodological conversations around adolescent experiences of disability in schools in a few important ways. First, it centers student meaning-making around disability as the major source for both data collection and This is the intolerable cost of special education and related disability research that treats individuals with disabilities as a subject under study and intervention, rather than meaning-makers, capable of creating community and solidarity, negotiating power and stigma, and articulating the changes that need to be made to make their communities more inclusive. Understanding these ideas about identity could potentially lead to developing schools and instructional spaces that support positive disability identity, which could have far-reaching impact on the academic and social experiences of students with disabilities in school.

Acknowledgements

I would not be in this final stage without an incredible circle of people who have reminded me at every possible moment I needed it that this work is valuable, and that I am also.

I am incredibly lucky to have a warm, open, and endlessly engaged and supportive committee. To Katie Lewis, who has been an incredible model for what it means to be real and honest about academia and the work that it takes to make it in this space; thank you for your guidance, making the implicit explicit and getting me to the finish line in such a kind way. To Cap Peck, who has been a constant in my life for five years and a never-ending source of encouragement, enthusiasm and jokes; I am so grateful for you and for your belief in me. To Maggie Beneke, who pushed me to think about my work in a vital, critical way, even when it felt scary; I am so grateful that you are always a sounding board. To Anjali Forber-Pratt, who has been my model of what it means to drive forward and believe in the work above all else; I am so grateful we hit wheelchairs and that you've taken me under your wing so wholeheartedly. To Kurt Johnson, who has been an incredibly thoughtful source of positive energy and connectedness; I am so grateful for your example. And to Beth West, who continues to be a source of inspiration (the good kind) and a model of integrity; thank you for giving me this chance and opening the door for me. I am running out of synonyms for support, and that's because there is no other way to describe how you all have so gently and thoughtfully brought me into academia and into my own voice. I hope I make all of you proud.

To my family and my chosen family: I am equally incredibly lucky to have you. To my parents, my sister and my amazing extended family, thank you for your belief in me, my ability, and my drive. Thank you for celebrating everything big and small and being there whenever I need you. To my cohort-mates, Mike, Xueyan, Jocelyn, Liz, and Abbey: I literally would not have made it out of UW without you (sometimes physically) and I am so glad to know each of you. To Sayaka, Aliza, Natalie, Jordan, Nathan, Pongkhi, Boris, Dalya, Lindsey, and every QualCrit participant and 422 team member since 2013 that I'm missing: thank you for your support (there's that word again) and reminder (sometimes strongly worded!) that I could have a life outside of meeting this goal. To Michelle and Simon: thank you for being my Seattle Goucher family, and taking such good care of me especially through food. To Lila, thanks for holding all of the energy and emotion of the last five years when I couldn't hold it by myself any longer, and for always picking up when I call. And to Aditi, my life fartner, who's been involved in or heard about every single part of this experience and who I can't imagine doing life without: this is fine. Everything's fine.

Dedication

For Cameron, Scott, Billy, Jamal, and all of the other current and former Best Buddies participants at Langley High School. Every single day, you guide the work that I do and the person I am.

Table of Contents

List of Tables

List of Figures

CHAPTER 1: SURFACING PSYCHIC DISEQUILIBRIUM

"When those who have the power to name and to socially construct reality choose not to see you or hear you…when someone with the authority of a teacher, say, describes the world and you are not in it, there is a moment of psychic disequilibrium, as if you looked in the mirror and saw nothing. It takes some strength of soul--and not just individual strength, but collective understanding--to resist this void, this non-being, into which you are thrust, and to stand up, demanding to be seen and heard."

(Adrienne Rich, Blood, Bread and Poetry: Selected Prose, 1979-1985)

In her prose, Rich, herself a feminist poet with a physical disability, describes a phenomenon certainly not unique to the schooling experiences of disabled students, but a resonant one: what are students with disabilities seeing when they look in the mirror? Who is in control of the image that they see?

To date, the scholarship around disability identity development and adolescents, particularly in the field of special education, has focused on development of social skills for friendships with nondisabled peers (e.g. Zambo, 2010) and negotiation (or attempted negation) of stigma, which is itself due to the overwhelmingly negative social and cultural meanings of the disability label itself (e.g. Kauffman, 2003; Shifrer, 2013). Teachers, themselves frequently nondisabled (Hart & Williams, 2009) attempt to support students academically and socially through this negotiation of stigma, from within their own training and personal experience as a nondisabled student (Linton, 1998).

Thus, to echo Rich, what disabled students see in the mirror is (if not nothing) a negative reflection: a deviation from the norm which is marked and labeled (Davis, 2006), and a stigmatized identity that should be privately minimized in order to survive in schools socially and academically. This reflection, whether acknowledged or not in schools, means students who are labeled with disabilities engage in a complex negotiation process around the stigma of their disability label, the social meaning of their disability and its intersections with other aspects of the student's identity, and the lack of visibility of disability in the curricula that surrounds students every day at school (Mueller, 2018). This negotiation process is often independent, silent, unrecognized and undervalued.

In this dissertation, I suggest an alternative. It requires a shift in both the conceptual and methodological focus of disability from within the context of special education, and a shift from labeling disability as a feature of a person which must be remediated and normalized. Ware (2002) notes that this shift is "particularly significant in K-12 public schools, where some of the earliest lessons about disability occur" and where schools reproduce an "understanding of disability warped by the shroud of shame, pity and tragedy in which the disabled students' needs, deficits, and problems are wrapped- constructing the student's institutional identity" (p. 152). Ware's framing of disability identity and the importance of K-12 schools as sites where this identity is developed helps frame disability as a collective identity experience not solely found in students' bodies, but co-constructed by teachers, peers, parents, and in moments like IEP meetings or transitions into and out of special education classroom settings. In this way, it's not just the concept of student disability awareness that needs shifting; since lessons about disability occur in educational settings and contexts large and small. Instead, I propose seeing disability as a fundamental, essential, and unapologetic aspect of students' conceptions of who they are in the world. Seeing disability in this way requires, and in fact demands, thinking about disability as a source of strength, creativity, belonging, and connection. As disabled performance artist Neil Marcus says, disability "is not a brave struggle or courage in the face of adversity. Disability is an art. It's an ingenious way to live." (Levin, 2010). The creativity and strength of those with disability is not an inherent skill or trait, but a response to particular societal and material conditions:

> Disabled people have to be ingenious to live in societies that are by their design inaccessible and by their inclination prejudiced against disability. It requires a great deal of artfulness and creativity to figure out how to make it through the day when you are disabled, given the condition of our society (Levin, 2010).

This is seemingly a subtle and sweet-sounding conceptual shift: wouldn't it be nice, one might ask, to think about disability as a binary, consisting only of good instead of bad? How hard could that be? Didn't we already accomplish that goal with inclusion? I argue that at the very heart of special education and related educational programs for students with disabilities lies an unsolved problem that denies not only the possibility of thinking about disability as good, but as anything other than solely bad. A medicalized view of disability ignores the rich activism, creative products, support systems, and ways of being which are inherent to the adult disability community and give it richness and complexity in the face of stigma and oppression. Including students with their nondisabled peers does not fix this problem; treating people with disabilities as if they're "just like everyone else," while well-intentioned, does not solve this problem. Depriving students of connections to the disability community and neglecting to educate them, intentionally and carefully, about a fundamental part of who they are does not solve this problem.

This way of thinking about disability involves critical engagement of the philosophies, goals, and values of special education itself (particularly for multiply marginalized students), which is focused on rehabilitation and at best accommodation of particular kinds of behavior and learning; this line of thinking and argumentation has been taken up in disability studies in education and critical special education discourses for decades (e.g. Artiles, Bal & King Thorius, 2010; Brantlinger, 1997; Florian, 2007; Skrtic, 1991). Here, I suggest another way to critically engage with special education: through thinking about shifting *individual students*' views of disability as a disembodied, stigmatized label that someone has "assigned" to (or identified inside) them, and dealing in part with the way the individual student makes meaning out of disability itself. This is the individual student's disability identity: the negotiation students do between the variety of messages they receive about disability, and the internal and external ways that students behave and act in the world based on this negotiation. Thus, while understanding the individual meaning making around disability identity is important and useful, what's also at stake is a discussion of disability as a shared identity phenomenon inside of schools and systems which constantly push against this idea to keep people with disabilities isolated from each other and focused on appearing "normal."

Partly as a result of the way in which disability identity has been discussed (and not discussed) in special education literature, there is a relative lack in comparison to literature on other marginalized identities that connects positive identity development with academic and educational outcomes for students with disabilities. This is an especially important gap in the literature given the focus on academic gains for students in relationship to disability, and represents more than just a methodological challenge, but a conceptual one. In literature that discusses the educational experiences of youth of color, ethnic studies and culturally relevant pedagogy and curriculum has benefitted from a body of research that connects racial/ethnic identity of students of color with academic achievement; that is, when students of color have positive racial identities, they are more likely to have higher grades (Altschul, Oyserman & Bybee, 2008) and graduate and go on to college (Chavous et.al, 2003). The research into ethnic studies courses and curricula that are designed primarily for members of the group under study show positive effects on their academic achievement, academic engagement, and personal empowerment. This body of research allows ethnic studies curricula to be placed in school-based curricular contexts (though not without controversy), because it has a direct impact on academic achievement and school outcomes for students of color. While the identity experiences of students of color and students with disabilities are not analogous based solely on an experience of "psychic disequilibrium" in schools (and this siloed approach does not account for student experiences which involve both intersections), there is also no parallel body of literature connecting, or even investigating, positive disability identity with academic performance that would help bolster the conceptual shift I propose here. Some critical theorists have critiqued academic performance and "smartness" itself as an outcome that is inherently racist and ableist (Leonardo & Broderick, 2011). In response, scholars have suggested a liberatory curriculum focused on connecting students to a sense of culture, community, and solidarity that reframes academic achievement from a set of standardized measures into engagement and cultural connection (e.g. Paris & Alim, 2017). If there is no body of literature to make an argument (focused on academic achievement based on identity development *or* cultural connection) for students with disabilities, what are the other ways in which understanding disability identity's potential positive outcomes can be considered?

Other fields that focus specifically on disability outside of special education, such as disability studies and broader social justice and critical literature, are beginning to take up this line of thinking and connection between a positive sense of disability, connection to community, and effects on overall senses of self (e.g. Forber-Pratt & Zape, 2017). In these contexts, disability is seen as a socially constructed aspect of human diversity, where people with disabilities have a sense of awareness and activism around power dynamics between able bodied and disabled people within inaccessible communities (e.g. Hahn & Belt, 2008). Important identity development theories have been developed around this sense of disability as a collective, critical, even political identity (e.g. Gill, 1995), though none of these theories have been empirically applied or studied with adolescents who have disabilities. In fact, while it is clear from within the field of disability studies that both disability identity and disability pride are important when considering the philosophy of teaching students with disabilities (e.g. Gill, 1997), there is a relatively small literature base to support this in practice. Smith et al. (2009) offers some broad suggestions towards this goal, including that educators “should take steps to help the students feel pride,” and “provide the supports students need, including the development of self-determination skills, to be fully visible and participating in life” (p. 2443). In both the disability activist community and in some sense in the field of special education, there is increased acknowledgement of the importance of thinking about disability from a liberatory, critically engaged, and empowered perspective (e.g. Fitch, 2013): but little movement forward in how to actualize this value.

This critical qualitative dissertation (Merriam, 2009) attempts to hypothesize a new way of understanding disability identity and awareness in adolescents. What follows is a case for shifting the current discussion of disability identity development from a solely individualized model to a collective, critical one; that is, to connect adolescents to a sense of participation and membership in a disability community which has a rich history, strong activist roots, and a positive sense of agency and view on disability itself. Despite its obvious power in the lives of adults with disabilities, this view of disability (and therefore disability identity) as socially constructed and shared among people with all kinds of impairments and disability labels has not made its way into the larger body of literature around special education (or its related practices, policies and interventions) with the same conceptual entrenchment as the medical model (Brantlinger, 1997). What results, then, is a fundamental divide in the way that adults who have positive disability identities understand those identities and engage in community, and the ways students are both taught and express their relationship to disability identity in schools. In this way, this dissertation attempts to harness the energy and knowledge from the adult disability community around collective community and shared identity, and explore what happens when this expertise is brought into schools for the purpose of building this kind of identity in adolescents. While there are several potential ways to investigate why this way of seeing disability has been mostly functionally left out of school contexts, including but not limited to a lack of people with disabilities in schools, curricula, or academia as experts on their own identities (Linton, 1998), this project is centered around beginning to explore collective disability identity in adolescents and argue for the adoption of this view of disability in special education contexts as a matter of conceptual, social, and academic importance for students with disabilities.

CHAPTER 2: THEORETICAL FRAMEWORK

In order to conceptualize and understand adolescent disability identity in a particular setting and to argue for, and towards, a collective view of disability in adolescents and schools, it's essential to understand the trajectory of a student through the many different "matrices" of identity at the intersection of adolescence and disability (Butler, 1993). At its heart, this exploration of developing adolescent disability identity is about the "personal reactions to special education contexts and teaching strategies," which places it in (albeit critical) conversation with other qualitative research in special education (Brantlinger, Jimenez, Klingner, Pugach & Richardson, 2005, p. 195). It is also, importantly, designed to follow a call from Smith, Gallagher, Owen & Skrtic (2009) to "take steps to help students feel pride" in their disabilities (p. 243).

I draw upon identity development processes theorized in adolescent identity literature, disability identity literature and collective identity literature, all within a broader context of disability culture that assists us as researchers in understanding the features that are unique to the identity experiences of adolescents with disabilities. Importantly, I contextualize disability identity development as a fundamentally intersectional process. Students experience disability and disability identity in differing ways based on related identities that often further "other" them in raced and gendered school and schooling contexts, or alternately can serve as ways of gaining privilege and power despite their disability label. Holding this intersectionality of identities is an important theoretical choice based on the extant research on overrepresentation in special education (Artiles, Kozleski, Trent, Osher & Ortiz, 2010), and the interest convergence of disability and race (Annamma, Connor & Ferri, 2012). This lens helps illuminate, among other differing disability experiences as they intersect with race, how the label of learning disability shifted over time into conferring particular rights and supports based on the advocacy of middle-class white parents (Sleeter, 1986). Most importantly, it follows the lead of many disabled scholars of color who have critiqued white disabled scholars and disability studies as a field for focusing on disability as if it existed in a color-evasive, single-issue vacuum (Bell, 2010; Miles, Nishida & Forber-Pratt, 2017). Following a continued discussion of "identity matrices," (Butler, 1993), I consider the literature on critical pedagogy and participatory research to present my theory of change and describe my dissertation study, which is focused on understanding and conceptualizing the connections between the individual and the collective, group and personal meaning-making, and disability and identity.

Models of Disability

There are two conventional lenses and ways to talk about disability, which are discussed (and critiqued) at length in the disability studies literature and embodied in broader disability work in the special education and general education fields. The medical model of disability, conceptualized by Shakespeare (2002) as when "problems arose from deficits in the body," is typically taken up in literatures that, using this orientation towards disability, attempt to intervene on an individual level to "fix" problems (p. 5). As a result, disability itself is understood from this model as a medical problem to be fixed with therapeutic or academic intervention, or an instructional problem to be designed around and structured so that the student achieves "like their average peers."

This focus on the individual and medical model of disability, and therefore disability as a problem centered inside a person who must necessarily fix that problem to be "normal," shapes identity development for adolescents with disabilities in particular ways. First, it frames disability as a highly stigmatized and stigmatizing category, which marks a student as different from the norm. Linton (1998) notes that this stigma is impervious to any kind of attempt at education designed for nondisabled students to understand disability: “no matter what kinds of overt lessons are taught at the school about respect for difference or other such seemingly committed agendas with weak impact, the hidden curriculum, the stronger message, is that children in special education are different, incompetent and unsavory, and because of their isolation, easily avoidable” (p. 63). Second, it shapes disability identities as ones that are fundamentally centered around “coping” with a disability: early models of disability identity in the psychological tradition map disability identity development onto stages of grief (Livneh, 1998). Even disability identity literature in special education, though a relatively small base, talks about adolescent disability identities where students have “low levels of agency,” “absence of goals and plans,” and “challenges with social relationships” (Weiner & Daniels, 2016, p. 571). Students with low incidence disabilities have also been found to have more negative self-concepts (Gans, Kenny & Ghany, 2003), lower levels of identity exploration (Pinquart, 2013), and an increased sense of needing to “manage” aspects of their identity for social inclusion, particularly in the context of co-taught classrooms (Barga, 1996). This devaluation of the experience of disability extends even to research and policy discourses: disability studies researchers have called for attention to “missing discourses of joy and happiness in relation to disability” that are lacking not only in research, but in policy and and practice designed to support people with disabilities (Sunderland, Catalano, & Kendall, 2009). A negative, stigmatized, devalued sense of disability is the context within which most students gain information about disability, make meaning out of their impairments, and hear feedback from teachers, family and peers about the impact of disability on how they are seen and understood.

In contrast to this medicalized context in which both disability and therefore disability identity are socialized in school, recent history has seen a rise in disability pride, activism, and connections made within a broader disability community outside of school environments. In fact, adult activists with disabilities report that, given the chance to "fix" their impairment and be cured of their disability (an unstated, but easily extrapolated goal of the medical model of disability), most would not make this choice (Hahn & Belt, 2004). This push towards pride, agency, and positive disability identity reflects a social model view of disability, in which the "problems arise from social oppression," and which conceptualizes disability as a problem of an ableist community's response to difference, not of an individual's deficit (Shakespeare, 2002, p. 5). Rather than considering disability identity as a solely individual-level process, then, the social model of disability begets a new way of seeing identity, where disability is an identity experience involving participation in a community with its own, unique culture.

Disability Culture

In *Vital Signs: Crip Culture Talks Back* (1995), disability activist Harlan Hahn (who Brown (2002) calls "perhaps the first scholar to write about disability being beautiful") muses about the shared behaviors of people with disabilities and notes: "If we don't have a food, we don't have a culture, right? Every culture has a food. And I once went around a room [of disabled people] and discovered that everyone went primarily to drive through restaurants, fast food places, because it was too hard to get in and out of the car and to go to a regular inaccessible restaurant."

Culture is obviously more complicated and theoretically complex than practices around obtaining and consuming food, and people with physical disabilities represent just one (non-monolithic) aspect of disability. Hahn's point, though, reveals a larger argument about the importance of understanding people with disabilities as sharing a collective, unified culture. This culture has unique values, behaviors, and ways of adapting and functioning in a world not built for their full participation, even to eat dinner. McLaren (2016) defines culture from a critical pedagogical perspective as “the particular ways in which a social group lives out and makes sense of its ‘given’ circumstances in life”, in addition to “a set of practices, ideologies, and values from which different groups draw to make sense of the world” (p. 36). Disability culture is seen in Brown (2002) as having particular features that extend this idea: most importantly, that it is “a set of artifacts, beliefs and expressions created by disabled people ourselves to describe our own life experiences” and focused “not primarily on how we are treated, but what we have created.” From this perspective, disability culture is primarily generated by those who have membership in the community in response to ableism and ableist social and societal structures. Disability culture, then, is different from identity development processes insofar as it is the *product* of people who identify with and participate in the community itself.

Gill (1995) furthered the idea of identifying features of disability culture and theorizes some of these core values of the disability community. These core values include shared beliefs in particular ideas, like an acceptance of human differences, interdependence, an acceptance of vulnerability and need for help, and a “tolerance for lack of resolution and dealing with the unpredictable” (p. 19). These shared beliefs emphasize a collective need for an accepting, inclusive, flexible, and cohesive community. They also include skills, like “disability humor,” “managing multiple problems, systems, and technology;” and an ability to “construct complex plans, taking into account multiple contingencies and obstacles” (p. 19). These skills are not necessarily inherent to individual people, but are the result of navigating a world that is inaccessible and often simply not built for disabled or “divergent” bodies and minds. Finally, disability culture includes particular ways of being in interpersonal relationships, including a “carefully honed capacity for closure in interpersonal communication” and the ability to “read others’ attitudes and conflicts in order to grasp the latent meaning in social messages” (p. 19). Interpersonal negotiation is an especially important skill and part of the ways of being for people with disabilities. This is due in part because people with disabilities are frequently interdependent on other people; having to ask for assistance, plan ahead to navigate inaccessible or potentially emotionally challenging environments, or generally being perceptive of others’ attitudes and reactions to disability are all a part of the reflexive skillset of people with disabilities developed over time (Shakespeare, 2002). These skills extend to both disabled and nondisabled people, but are primarily the reflection of negotiating spaces that hold nondisabled people as the norm.

All of these core values have potential salience in discussion of collective views of disability identity, which sees disability as a group in which one can have varying levels of commitment to particular values and categories of membership. As a result of the highly structured, competitive, exclusive (and ableist) nature of academia and other “official” sources of knowledge generation, much of the development of disability culture, and the thinking around this culture, begins in community and with activists and leaders who name the nuances of an experience of disability. Mia Mingus (2010) makes a distinction between those who are “politically disabled” and those who are “descriptively disabled” that reveals the kind of community knowledge and varied experiences around disability present inside broader disability culture. Descriptively disabled people are people who have had “the lived experience of being disabled,” and:

> May not talk about ableism, discrimination, or even call themselves ‘disabled,’ but they know what it is like to use a wheelchair, experience chronic pain, have people stare at you, be institutionalized, walk with a brace, be isolated, etc.

In contrast, Mingus (2010) writes that politically disabled people are those who are “descriptively disabled *and* [have] a political understanding about that lived experience,” including “an analysis about ableism, power, and privilege” and a sense of solidarity and connection to other disabled people. Mingus (2010) does not make an argument for the “righteousness” of one type of disability identification over another (though she notes that people who identify as politically disabled, especially disabled queer people of color, often experience and risk more stigma and isolation through that identification). She instead notes a nuance about the experience of disability and identity that is easily identifiable inside of disability community and culture, and unnamed inside of scholarly literature about disability or in contexts where the individual with a disability is the sole person identifying with that identity. Some of this nuance occurs because identity itself as a discourse (Foucault (1978), which signifies power and hegemony inherently.

Naming the cultural features of disability, then, is about more than just attempting to form community in the face of ableism. Specific beliefs, skills, identification, and ways of being in community with one another help identify ways in which adolescent disability identity is not talked about in schools (and could be), but *is* talked about in the lives of disability activists, self-advocates, and other adults with many different kinds of disabilities when they are given the opportunity to think about their disability with others and as a non-individual phenomenon. In this way, a comparison or way of conceptualizing the development of adult disability knowledge and participation in culture over time could inform adolescent disability knowledge development and re-situate it as a disability cultural issue, not an issue of normalcy.

Adolescent Disability Identity

Identity development in relationship to disability can be seen from many different perspectives, and it's this conceptual flexibility that has led Brubaker and Cooper (2000) to argue that identity as a concept is "called upon to bear far more theoretical, empirical and political weight than it can support" (Ashmore, Deaux, & McLaughlin-Volpe, 2004, p. 80). Identity, education, and learning are inextricably linked (Erikson, 1968; Gee, 2000). Many existing identity theories in education have focused on the relationship between racial identity and academic engagement and achievement (e.g. Ogbu, 1987; Steele, 1997; Delpit, 1995), suggesting that existing power structures facilitate deficit-based understandings of students of color that impact their academic achievement and identities. Adolescent identity development literature has a long conceptual and applied theoretical history in studying the containments of identity inside either individual mental functioning (e.g. Marcia, 1993), sociocultural processes of development (e.g. Rogoff, Baker-Sennett, Lacasa, & Goldsmith, 1995) or inequitable systems that create particular identity experiences for students (e.g. Tatum, 2004). The broad identity research base has attended to issues of difference and disability (particularly disability as a site for positive identity development) in only relatively recent history (e.g. Forber-Pratt, Lyew, Mueller & Samples, 2017; Bogart, Lund, & Rottenstein, 2018), and this literature has not focused explicitly on special education contexts.

In developing disability identity, individuals utilize identity resources (Gee, 2003) to create and draw from in order to understand what the identity means for their behavior, ideas, and embodiment of the identity. The use of the term resources helps link and identify both the *origins* and experiences of disability identity as illuminated by participants, and the *tools* that participants drew from to continue constructing that identity over time. Resources can be operationalized as a multi-faceted set of origins and tools of identity development, encompassing social structures and spaces (e.g. placement in special education), interactions between people (e.g. bullying), and broader cultural meaning-making about disability (e.g. medical & social models of disability). Thinking about disability identity resources helps identify the ways in which the origins of identity development are often inextricably linked to the tools that then reinforce or deconstruct that original idea. An example: often, an initial resource around disability is based in a medical model understanding; an earlier study on youth disability identity noted that students with disabilities described disability (both theirs and a general category) as uniformly negative and a problem based in individual bodies (Mueller, 2018). Students had plenty of school-based resources that reinforced that initial perspective: from experiencing bullying in response to their classroom participation, to separation from their "normal" peers.

Based on extant adolescent identity and disability identity research, I theorize adolescent disability identity as a fluid and personally constructed phenomena, capable of changing and shifting based on particular educational and social contexts (Nasir, 2009; Nasir & Saxe, 2003), where adolescents might feel more or less aware of their disabilities (Wortham, 2004; Collins, 2011). Drawing on disability studies literature that distinguishes impairment from disability (Shakespeare, 2002), disability identity (and particularly adolescent disability identity) must necessarily be both a personal and relational phenomenon as it definitionally is both an individual, body-"bound" phenomena and a societal one. It's possible to argue that identity around impairment is a personal process, and identity around disability a relational and collective one. It's also impossible to separate the internal and external identity aspects, as they are enacted in an individual's meaning making. Thus, adolescent disability identity formation and development includes both internal processing and external feedback, participation, and collective meaning making.

These contexts, subtly or not-so-subtly, send messages to students about the meaning of disability as a dividing practice (Foucault, 1982), or the social and spatial ways through which people who “exhibit difference” are subjected to objectification and separated from social groups (p. 266). These dividing practices are especially insidious when students exhibit multiple differences, and result in less and less subtle messages of separation and segregation. For these reasons, adolescent disability identity is a relational, personal and collective phenomenon, involving both internal and external negotiation (Shakespeare, 2002) and meaning making. For example, adolescents with disabilities negotiate a host of internal thoughts about, and experiences with their impairment and the meaning of that impairment to their broader sense of who they are. In practice, this negotiation might look like a student with learning disabilities observing his nondisabled peers react negatively to students with autism in school; this observation might result in the student hiding his learning disability (Mueller, 2018) or skipping his special education courses entirely in fear of a similar reaction.

This internal meaning making is constantly and irrevocably informed by a larger context of social meanings about disability, *and* the meaning of that disability to society’s broader sense of participation and visibility in particular communities (Gill, 1997). Part of the theoretical difficulty in talking about student identity development and awareness of disability comes from the often-misaligned negotiation processes of students, and ones of nondisabled adults. Calderón-Almendros & Ruiz-Roman (2016) see this as a problem located at the larger context of social meanings of disability and school and schooling reactions to that social meaning, where “the education of people with disabilities is still largely interpreted, even within critical theory, from the parameters of structural functionalism” (p. 253). That is, if the separate structures that serve students with disabilities were effective in teaching them, academically or socially; or if our way of seeing disability was shifted to be considered more inclusive, then the kinds of things we teach students with disabilities, the ways in which we do it, and the contexts in which this education happens will be justified. Instead, Calderón-Almendros & Ruiz-Roman (2016) suggest, “it still has not been assumed that, in the same way as the school legitimizes, sustains and strengthens the stratification based on social class, it also generates mechanisms that lead people with disabilities into poverty, exclusion and social devaluation” which then irrevocably shapes identity and relationship towards disability as a negative, stigmatized, devalued way of being in the world (p. 255). These are not individual level identity constructions or discourses- but they become that way by design. It’s these broader senses of participation and visibility in the disability community that this project is focused on.

Collective Identity

Another way to think about disability identity is as an individual’s relationship to a collective group. This study draws from Ashmore et al. (2004)’s collective identity theory, and understands disability identity as a personal process of commitment to a larger shared idea of disability and community, for both adolescents and adults. This commitment to membership in a larger disability community might include acknowledging and participating in shared history, knowledge, preferred ways of communicating and dealing with stigma and inaccessible environments. A collective identity is articulated in Ashmore, Deaux & McLaughlin-Volpe (2004) as different from personal identity constructs and definitions because “it is one that is shared with a group of others who have, or are believed to have some characteristics in common” (p. 810). It is “not only a belief in categorical membership (i.e., that one shares characteristics with a group of others) but also a set of cognitive beliefs associated with that category, such as ideological positions that define the groups' goals" (Ashmore, Deaux, & McLaughlin-Volpe, 2004, p. 82). A collective view of disability identity, then, might be operationalized as an individual's belief in their membership within the disability community, and a belief in core values of the community.

There are seven individual-level constructs that work together to define collective identity, informed by literature on social identity theory, social categorization theory, and broader theories of identity development. These constructs are each individually studied and tested in identity literature (e.g. Tajfel's (1982) discussion of social categorization), as well as understood as connected constructs. The operationalized definitions of each construct are drawn from Ashmore, Deaux & McLaughlin-Volpe's (2004) organizing framework on collective identity.

> **Self-categorization.** Identifying self as a member of, or categorizing self in terms of, a particular social grouping. Individuals may place themselves in a social category, and also assess the "goodness of fit" of that category.
>
> **Evaluation.** The positive or negative attitude that a person has toward the social category in question. Individuals may have private regard (or judgements made by people about their own identities) or public regard (judgements that one perceives others, such as the general public, to hold about one's social category).
>
> **Importance.** The objective assessment of an importance of group membership to the individual's self-concept and sense of themselves.
>
> **Attachment and sense of interdependence.** The emotional connection, involvement and perception of similarities between the individual and the group; the degree to which the

individual feels connected to the group.

Social embededdness. The degree that a particular identity is embedded in the person's everyday ongoing social activities and relationships.

Behavioral Involvement. The degree to which the person engages in actions that directly implicate the collective identity category in question.

Content and meaning. The self-attributed characteristics, ideology and narratives of a particular collective identity.

For the purposes of this dissertation, I will focus on three specific elements of collective identity: self-categorization, evaluation, and behavioral involvement. These elements were selected because of their importance (and in some ways, predisposition and relatedness to) the other elements in the framework: self-categorization, evaluation and behavioral involvement represent both the internal and external aspects of enactment of disability identity development, and points to collective identity around disability. Importantly, collective identity theory holds that "how an individual experiences and enacts his or her collective identity in any given situation depends on the contexts surrounding the person in the situation," which in turn suggests that contexts both directly impact and moderate the effects of particular situations and the collective identity itself (Ashmore et al., 2004, p. 104). In other words, when students with a collective disability identity look in the mirror, they see themselves as a member of a disability community.

Identity and Power

The concept of identity itself is imbued with power dynamics that shapes the access students have towards developing collective identity in school contexts and, more broadly, in relationship to stigmatized identities. Disability itself, as Zola (1993) notes in Michalko (2002), often situates parents and children as having fundamentally different identity experiences:

> The vast majority of people who are born with or acquire such conditions [disabilities] do so within families who neither have these conditions nor associate with others who do. They are socialized into the world of the 'normal' with all its values, prejudices, and vocabulary. (p. 38)

This socialization into the "normal" world is not just family-based; the socialization also occurs in school contexts, where expressed goals of special education are to "identify children with unusual needs," with "incorporation of special help and opportunities in regular educational settings" (CEC Policy Manual, 1997). Often, special educators are at the intersection of both responsibility for their students "unusual" needs, and their socialization about disability, implicitly or explicitly. Teachers, "through their actions, indicate what is valued, who possesses value, and what kinds of behaviors are rewarded," which "intentionally and unintentionally provide feedback that helps shape adolescent identity" (Harrell-Levy & Kerpelman, 2010, p. 79). This dynamic has led some adolescent development researchers to consider the role of identity in school interventions, as teachers are "identity agents" (Schachter & Ventura, 2008) who interact with youth, participate in their identity formation, and reflect and mediate social influences in relationship to that identity. Identity agents who do not share the same identity as their students, in this case related to disability, involve especially complex relationships because the teachers themselves are concerned with normalcy and similarity to nondisabled students: Michalko (2002) notes that "one of the most 'abnormal' things about being 'normal' is attending to its production" (p. 82). The socialization into disability identity (and into ideas about normalcy), then, is supported by adults and authority figures who are, by virtue of the social world that socializes everyone into a stigmatized, medicalized view of disability, deeply engaged in categorizing, sorting, and imagining a world in which abnormality is to be identified and educated away.

Disability identity (or identification with a disability community), then, becomes a burden on individual students in response, not a source of collective community or pride. In some cases, students choose to use technology as a form of identification or of escapism from the socialization into normalcy. Asaka Park, an adolescent student with autism, notes in the *New York Times:*

> Every day at school, I isolate myself from most of my peers: it's a matter of time before they make these assumptions, before they postulate how my brain works. On social media, though, I'm a completely different person. I'm dynamic. I'm assertive. I'm people-oriented. (Park, 2019)

In response to this intentional self-isolation in response to stigma, Park turned to social media, because "cultivating my own space on the internet helped me thrive outside of the pigeonhole" and explained her behavior, helped others understand, and find hope and connection. Park found a way to control the way she was perceived, by widening her audience and the ways that she was able to connect with people in response to her perceived differences. This is powerful, and it is in response to power. Hammack (2010) notes that the process of identity becoming a burden is dependent on "the extent to which issues of power and status are integrated into analysis" of the identity itself (p. 177). In other words, attending to the individual or collective identity development of youth with disabilities divorced from an attention to the people and contexts that actively or implicitly devalue disability as an important identity experience only serves to privilege those ideas and "support a status quo of hegemony by undermining the claims of the subordinated" (p. 175). Special education, and related educational supports for students with disabilities enact this support based on able-bodied values and goals for disabled people, which situates disability as produced by able-bodied teachers and supports, not disabled students themselves. In response to this burdened identity, Hammack (2010) suggests that groups and individuals "often use strategies of enhancement that work within that system;" that is, adopt socially-sanctioned language, ways of being, and ways of interpreting and understanding disability labels that work within particular contexts to become like everyone else (p. 177).

Theory/ies of Change: Developing Adolescent Collective Disability Identity in School

Given the potential importance of research that attends specifically to disability identity development in youth, there is a distinction necessary here between the kind of identity development that happens "naturally" for adolescents with disabilities, and the kind of identity that *could* develop given the context of community with others who have disabilities, including role models and peer relationships. Much of the extant disability identity literature is focused on adults. Several studies of adult disability rights activists have emphasized the importance of connection to disability community during their educational experience (Caldwell, 2008; Smith, Gallagher, Owen & Skrtic, 2009). Caldwell (2008) emphasizes that this process of connection and relationship building as a youth later spurred a participant's involvement in disability rights advocacy and his identity development as a disabled activist. Collective identity development requires both belief in membership in a particular category, and associated cognitive beliefs (Ashmore et.al, 2004). Identity development (like one around a collective identity of disability) is a process that happens situated in particular contexts: contexts that both directly impact and moderate the effects of identity development. Ashmore et al. (2004) term this relationship "person in situation in context", and suggest that that contexts include "material, social structural, and sociopsychological components" that have consequences for identity development and making specific collective identities salient for an individual in that context (p. 103). Person in situation in context is an important framework for understanding the difference between developing an understanding of disability identity with the support and interaction of curriculum, peers, and personal reflection, and developing a disability identity absent these contexts and supports.

Intentional consideration of adolescent disability identity development as a collective phenomenon based in a broadly conceived disability culture necessitates certain kinds of ways of seeing the development of identity in school contexts. Giroux & Simon (1988) name schools as “sites of struggle,” and pedagogy as “a form of cultural politics” (p. 10). One way of conceptualizing interventions or curricular moves towards identity development is from a “top down” approach, where students must only be educated (by a teacher) on disability community history, values, and ways of being in order to both develop a connection to a collective identity and participation in disability community. This kind of work has been done specifically to support disability identity as a kind of “intervention” in mostly outside of school contexts, including Independent Living Center programming (e.g. Wilkie, 2011), hospital-based support groups (e.g. Block et.al, 2011), or youth-led organizing (e.g. YSOC & Zimmerman, 2007). In one case, a group of disabled girls were released from school early for an extracurricular program focusing on disability rights, sexuality and gender called the Empowered Fe Fes (Nussbaum, 2008). These studies are focused on outside of school contexts. These contexts are spaces where disability is explicitly named, and often are positioned in reaction to dominant educational discourses in school where “not noticing disability seems to be understood as an unquestioned good,” in a similar way that colorblind ideology suggests not noticing race somehow absolves educators and school systems of the consequences of racism (Lalvani, 2015).

Instead, and to echo Giroux & Simon's (1988) ideas of struggle and politic, I am interested in thinking about pedagogy as a *means* through which we might further understand individual meaning-making, identity development, and commitment to seeing disability in particular ways in adolescents. This positioning echoes Erevelles' (2005) call to radically transform the way we teach students about disability itself, to ultimately enable "all students to negotiate difference in creative ways that foster co-operation and interdependence rather than competition and radical individualism" (p.435). It also properly names schools as part of the source of identity development and meaning making around disability that students use as a way to define and understand themselves; Leonardo & Broderick (2011) note that schools, and the structures within schools such as pedagogy, curriculum, and other classroom practices, perpetuate an ideology of smartness wherein "some students are taught their intellectual supremacy and concomitant entitlement to cultural capital, whereas others are taught their intellectual inferiority and concomitant lack of entitlement to both an identity as a 'smart' person, and the cultural and material spoils that such an identity generally affords" (p. 2214). I suggest here that rather than solving the problem of a lack of disability identity in school pedagogy with a curriculum (and therefore potentially perpetuate the same ideologies already at work in schools), we should think about students with disabilities (and former, now adult, students with disabilities) as the source and starting point for correcting the problem. They are the experts, the meaning-makers, and the ones with the lived experiences, both current and past, which should inform the way forward of how to do the kind of transformative work that Erevelles (2005) and others call for.

This theoretical position is rooted in a theory of learning as centered on two major activities. Kumashiro (2000) suggests that "when students have both knowledge about oppression and critical thinking skills, they will be ‘empowered’ to challenge oppression” (p. 37). The activities presented in this study frame oppression in a few primary ways: through an acknowledgement of the silencing of disabled voices and experiences in naming problems they experience related to disability, and through a redefinition and reclamation of the very definition of disability from through a medical model to a social one. Secondly, learning, as both a desired outcome for students and as an active, constant activity in a classroom, is conceptualized as as a “transformation of consciousness that takes place in the interaction of three agencies- the teacher, the learner, and the knowledge they produce together,” (Lusted, 1986, p.3). Students progress and demonstrate this transformation of consciousness in their learning about disability by *unlearning* previously held, and likely negative, ideas about disability (Britzman, 1998). This unlearning might also look like challenging the structures which caused them to have negative ideas about disability in the first place.

In this way, students who do not “necessarily have the same or even similar experiences with oppression [or disability]” can access, make meaning, and take in (or not) the notions of disability history, culture and collective identity in many different ways (Kumashiro, 2000, p. 38). This access is significant when considering about student learning around identity, where (nondisabled and disabled) teachers and (disabled) students work together to transform each other’s negative and stigmatized conceptions of disability, and unlearn what they had previously thought to be true about themselves and others around them. While there is some important possibility to think about curriculum and pedagogy’s role in developing positive disability identities in adolescents (that is, in an evaluative way), I am not suggesting that there is a particular way in which students must understand, participate in, and/or pick up disability culture or collective sense of disability identity; I am instead suggesting that the opportunity to have a context in which disability is discussed in this way might afford certain shifts in thinking about individual identities of students.

Centering Disabled Student Voices in Research and Schooling

If disability is, as Neil Marcus says, an ingenious way to live; and disability identities are rooted in a rich culture of creativity, innovation, and strength, then why have people with disabilities - and particularly students with disabilities - been left out of conversations that help them talk about their identities and about the things that are currently challenging in their everyday lives? This question, while well documented in disability studies research where the longstanding observation is that stories are told *about* people with disabilities by nondisabled researchers and practitioners (Biklen, 1988; Bogdan & Taylor, 1976), has not been taken up in special education contexts. Perhaps this is because “on many occasions, educational agents hide or negate the conflicts that they have with the people that they are socializing”; that is, teaching students with disabilities to voice their experiences and the way they experience disability is counterintuitive to the stated or unstated goal of schools and schooling, which “forces the subject to submit to the ties of hegemonic concepts and deprives citizens of the ability for collective improvement” (Calderón-Almendros & Ruiz-Roman, 2015, p. 252). This is especially harmful for students with disabilities given the creative, inherently resistance-focused ways in which they are learning to negotiate life with a disability and the stigma that pervades that experience. hooks (1991) quotes Eagleton (1990), who argues that

> Children make the best theorists, since they have not yet been educated into accepting our routine social practices as "natural", and so insist on posing to those practices the most embarrassingly general and fundamental questions, regarding them with a wondering estrangement which we adults have long forgotten. Since they do not yet grasp our social practices as inevitable, they do not see why we might not do things differently (p. 2).

Part of centering disabled student voices in research and schooling, then, is to interrupt the processes that teach students that they are not the experts on their own experiences, and therefore are not capable of guiding teachers and researchers towards the problems, and solutions, that they see as fundamental in their lives. Calderón-Almendros & Ruiz-Roman note that “this is why it is necessary to make the conflict explicit, and to see power as a key factor in the understanding of human relationships,” especially because “one cannot sever differences from the very inequality upon which they are conditional” (p. 252). Pinar (1993) frames a discussion of the connection between curriculum and identity development simply, but definitively: “we are what we know” (p. 61). The central question of this dissertation, and of broadly giving students the tools to think about and express their relationship to disability is: who might they become when they know?

CHAPTER 3: RESEARCH DESIGN & METHODOLOGY

This study's research design and questions is an attempt to make the internal, invisible identity development processes around disability visible in particular special education contexts and to name the structures, resources, and experiences within school that influence this identity development in both positive and negative ways. The purpose of this inquiry into collective disability identity and adolescents is to conceptualize adolescent disability identity development from within educational contexts, and to understand the impact of participatory research methods towards this development. A secondary goal of this research project is to locate an expertise about disability identity development in the lived experiences of adults and students.

Rationale for Research

This study draws from a critical research tradition, where the goal is to "critique and challenge, to transform and empower," as it seeks "not just to study and understand society but rather to critique and change society" (Merriam, 2009, p. 34). In their discussion of the relationship between research with Native communities and "overstudied Others," Tuck & Yang (2014) detail axioms of social science research, including that "the subaltern can speak, but is only invited to speak her/our pain" (p. 227). In writing this dissertation, I am conscious of the fact that students with disabilities have frequently been positioned in special education literature (and in much related disability research) as the source of "fascination with telling and retelling narratives of pain": about the difficulties of being disabled, the differences from an imagined nondisabled, "average" peer, and the ways that nondisabled people might better develop programs to assist disabled students to fit in to particular "normal" social and educational contexts (Tuck & Yang, 2014, p. 228). In order to critique and change the conversation of disability identity development in schooling contexts, this project must accomplish three things: it should address the lack of literature on the positive disability identity development processes for youth, collaboratively design the kinds of supports that youth *and* adults with disabilities desire to see in school, and to understand and name the cultural politics (Giroux & Simon, 1988) at work in the development of disability identity in school contexts. To accomplish these goals and still remain conscious of and sensitive to the often emotional and deeply held experiences of living life with a disability, this project starts by centering the lived experiences of both youth and adults with disabilities as experts in their own development and trajectories in and around disability culture and awareness of disability itself. The study utilizes a critical research design that allows study participants to be positioned as experts in their own experiences, and myself as the researcher to make methodological and analysis choices that deal explicitly with power dynamics in research like the ones Tuck & Yang (2014) identify.

In relationship to the research questions, this project involves two “phases” including different critical qualitative methodologies, that all attempt to understand the impact of disability identity development in adolescents, while drawing from the accumulated knowledge of the adult disability community and positioning those with the lived experience of disability as the experts. The first phase involves interviews with disabled adults reflecting on their own disability identity and schooling experiences. The second phase involves a school-based study involving an interview with high school students on their experiences with and ideas about disability, with a photovoice photography project following that engaged students in conversations about their school experiences. A methodological approach that both honors, and emphasizes, the many different disability identities people might hold and understand is essential to the study and to the development of the methods used to understand this phenomenon. The two-phase study structure allowed me to build on extant literature that centers adults with disabilities in identity development (Forber-Pratt & Zape, 2017; Hahn & Belt, 2004; Gill, 1997; Putnam, 2005), while simultaneously holding that knowledge and experience as the source of expertise for development of school-based knowledge around disability identity with youth.

Researcher Reflexivity and Positionality

I am a scholar with physical and learning disabilities. Because research is a situated cultural practice, and therefore I bring “assumptions, values, expectations and repertoires of cultural practices” to my work, this study is informed by my embodied experience at every level, from theoretical reasoning to methodological choices to interpretation of the findings (Arzubiaga, Artiles, King & Harris-Murri, 2008, p.315). As a student with physical and learning disabilities, I struggled to negotiate the stigma and isolation that came from being in special education. It affected my academic experience in school, and left me with a drive to better serve, and to better hear, students with disabilities on their own terms. I approach my work from a disability studies in education perspective that is grounded in my own personal and professional experiences, which holds that disability is socially and politically situated in schools to mark particular bodies and minds as “abnormal.” Importantly, this theoretical and philosophical stance requires that I interrogate my own positionality and critically consider how my own body, mind, and history shapes my work. Sheldon (2017) notes that understanding researcher positionality is undervalued in special education research, which creates “a situation where much of the field of special education is comprised of writing about those with disabilities,” with insular discourse and deficit-based ideas about disability as the consequence (p 984).

As a white disabled cisgender woman, I also name the privilege I held in special education that affected my educational outcomes and led me to this dissertation. Even as I seek to understand the ways in which disability labels are stigmatized and stigmatizing for students, I recognize that in many ways, I am lucky to have received the special education instruction I was afforded in some part because of my race and class. This work, and this dissertation, is fundamentally intertwined with my own negotiation of my intersectional identities. It is also fueled by a deep sense of responsibility to the disability community to not only “get it right,” but to name the features of ableist, racist, and heteronormative systems that shape the experiences, and the identities, of disabled students in different ways every day (Annamma, Connor & Ferri, 2013). Holding this complexity of disability identity is a responsibility in this dissertation, in the kind of research I do, and the kind of researcher I am becoming.

This is deeply emotional work because I am invested in and familiar with at least some parts of my participants’ experiences. This emotionality is an essential signal, for me, towards understanding what is important to say and for others to understand (Boskovich & Hernández-Saca, 2019). It also motivates the reasons behind doing this work, however difficult the truths about disability identity may be. I am guided by hooks (1991) to remember that “it is not easy to name our pain, to make it a location for theorizing” (p. 11). This is true for me as a disabled adult academic, and it’s certainly true for the adolescents in the study who are just beginning to negotiate what disability means.

I have also been brought up and socialized in a research tradition that, historically, asks me (in my full embodiment) to not be present in the research space, the methodology, or in the analysis and writing of this dissertation (Sheldon, 2017). My experiences as a researcher prior to this study showed me that that is an impossible, if not irresponsible, rule. This is true on a practical level: my physical, visible disabilities make an interview about disability more complex. How the participants (in this study and others) interpret *me* is in some way related to how they interpret disability more broadly. In some ways, particularly with students who have invisible disabilities, there is a similar sense of shared experiences but differential power: my visible disabilities remind students of the “disability hierarchy,” (Deal, 2003), where I am more impaired and they are less. It’s also true on an emotional level: my invisible disabilities provide a potential source of connection, rapport and solidarity. This requires that I am present in the space enough in order to share in those experiences, and in order to do that, I must disclose my invisible disabilities and be able to share all of my relevant histories with participants; even here, in this methodology section. Given that research about disability (even in more critical, radical spaces) is generally done by nondisabled researchers, articulating my positionality and positioning it as a fundamental part of my research design is important in terms of representing a community of disabled people, and disabled scholars, who have historically not been allowed to lead in research or to describe their own experiences. I am grateful for the guidance of the disabled scholars before me who illuminate the path.

Research Questions

This project is framed around three major research questions that aim to understand the development of adolescent disability identity in relationship to collective and critical theories.

- What identity resources do people with disabilities engage with or experience in order to develop disability identity across youth and adulthood?
- What are the similarities and differences in collective disability identity development between adults and adolescents with disabilities?
- What role does school, schooling, and special education play in development of disability identity?

Research Methods and Study Design

In the sections that follow, I discuss my research methods for this critical qualitative study, including: (a) participants and school site selection, (b) data sources, and (c) data analysis strategies.

Participants and Sites

Since this project had two distinct phases that were deeply connected theoretically, it was necessary for me to think about participant selection for each phase as connected as well. Study participants for the adult phase of the study included four adults with intellectual, learning, and/or physical disabilities as well as autism, who identified themselves as a part of disability community and thought about disability as generally a positive part of their identities. Study participants in the school phase of the study were four students with intellectual and/or learning disabilities as well as autism (see Table 1 for participants by phase below).

Table 1

Participant Demographic Information by Phase

Phase	***Name***	***Gender***	***Pronouns***	***School Year***	***Disability Label(s) or Information***	***Race/Ethnicity***
<u>Adult</u>	Zeke	M	He/Him	Postgrad	Autism	Caucasian (White)
	Ilia	Trans Masculine	They/Them	Postgrad	Intellectual disability, Autism	Caucasian (White)
	Jackson	M	He/Him	Postgrad	Autism, Blind/Low vision (due to Albinism)	Caucasian (White)
	Maya	F	She/Her	Under-graduate (senior)	Learning disabilities, Physical disability (uses manual wheelchair)	South Asian (Indian)

School	Vanessa	F	She/Her	Junior	Intellectual disability, Learning disability	Caucasian (White)
	David	Nonbinary	They/Them	Junior	Autism, Learning disability	Caucasian (White)
	Bryce	M	He/Him	Senior	Intellectual disability, Learning disability	Caucasian (White)
	Quentin	Transgender	He/Him	Sophomore	Intellectual disability, Learning disability	African American
	Ms. Maddox	F	She/Her	Special education (Low Incidence) teacher	Nondisabled	Caucasian (White)

Adult participant selection. The first phase of the study involved adult participants. I selected adult participants for participation in the study based on two qualifying criteria: adult participants must have been labeled or diagnosed with their disabilities during school age or earlier, and they had to have participated in special educational instruction for some (e.g. a few pull-out interventions) or all (e.g. fully self-contained courses) of their school day during their K-12 schooling experience. I made initial interview requests for disabled adults based on my own knowledge of disability networks locally, and explained these inclusion criteria in an initial email to local disability networks and organizations in order to gather interested participants. One unexpected result of the adult participation selection process was that my initial email request was forwarded to a large, state-wide network of autistic self-advocates and allies; this resulted in a much larger population of interested participants than I had initially expected for the study, not all of whom met the inclusion criteria. In all, I received 20 interested participant email responses; of those, about 15 fit the two inclusion criteria, and 9 responded to a request for follow up email scheduling. From there, I scheduled two interviews with each participant. I selected four adult cases for the study based on their similarities to the student participants, including disability labels, percentage of time spent in general vs. special education, and intersectional identities; this choice was made based on the importance of "matching" similar structural and social experiences of school and schooling based not only on disability labeling, but on the kinds of experiences students and adults might have had as a result of that label.

School site selection. I recruited students from a local high school special education program with which I had previously collaborated. Their teacher, Ms. Maddox, coordinates the Low Incidence Disabilities program at the school site and taught a life skills course with students who had intellectual disabilities and were included in general education classes less frequently than their peers. This life skills course was a ideal recruitment site for this study because it already included a curriculum developed by Ms. Maddox that included disability identity and knowledge. It involved a different topic for each day of the week: social skills, healthy relationships, disability knowledge, career exploration and independent living. The social skills and healthy relationships themes included practice having face-to-face conversations with others, and identifying "pink flags" in difficult to decode social interactions (i.e., being asked to do something that might get you in trouble). Career exploration and independent living themes involved researching different interests and practice cooking in the school kitchen. The disability knowledge theme is of the most direct importance to the school phase of the study. Disability knowledge theme activities including reviewing each student's IEP, researching information about their disability labels, and role play practice asking for accommodations from teachers.

Student participant selection. After meeting with Ms. Maddox and discussing the goals and research questions of the study, she suggested I work with her 4th period life skills course.

This group of students included four adolescents, who ranged in class year from sophomore to senior. The students were labeled with intellectual disabilities, learning disabilities and autism.

Overview of Research Design & Relationship of Data Sources

This is a critical qualitative study, which informed the choice of data collection methods and analysis in a few important ways. Critical research "queries the context where learning takes place, including the larger systems of society, the culture and institutions that shape educational practice, and the structural and historical conditions framing progress" (Merriam, 2009, p.35). In order to critique "whose interests are being served by the way the education system is organized," I engaged in two particular methodological "moves" typical of critical research studies in order to understand disability identity in school contexts, that had methodological implications for the study (Merriam, 2009, p. 36).

First, I identified and critically examined discourses and school contexts (Merriam, 2009) for the ways that each perpetuate a particular (medicalized, often negative and stigmatized) view of disability identity. This examination led to methodological choices that centered students and adults as the meaning-makers and experts in their own identities, rather than centering the discourses and school contexts as the experts. I chose semi-structured (Merriam, 2009) and life history interview methodologies (Plummer, 2001) that gave the participants the most amount of control in telling their story about disability identity on their own terms. I also utilized participatory methodologies and activities within the school phase photovoice project (including the structure of the project itself and the inclusion of the "I am…" activity) that privileged the students' voice and meaning-making in multi-modal and expansive ways. That is, the methodological choices in the school phase allowed students to tell their own stories in many different ways as well as modes that they felt comfortable in (technological, arts-based, one-on-one and small group).

Since a responsibility of a critical study is to be conscious and considerate of power dynamics within the research design and context, an awareness of power dynamics also guided this work. Merriam (2009) notes that this awareness of power dynamics should include: “questions about who has power, how it’s negotiated, [and] what structures in society reinforce the current distribution of power” (p. 35). I let participants talk about their own experiences and histories as they revealed them, including their own disability identification and awareness of disability community. They named power structures, identity agents, and structural factors that upheld ableism and perpetuated a particular kind of disability identity as a part of this process, on their own. I also made methodological choices that re-designed the study itself, including shifting the photovoice cumulative community gallery from an in person one to virtual. In the following sections, I discuss each methological choice in more depth.

To understand important experiences and the development of disability identity and pride (or lack thereof) inside of schools, the first part of the project involved reflection from disabled adults on their educational experiences and disability awareness in school. These interviews informed my theory of change for the project and helped me identify “levers” of disability identity that have an impact on growth, development, and awareness of each participant’s sense of themselves as members of a disability community. Following the interviews and participation of the disabled adults, the second part of the study involved participation of adolescents with disabilities in both an exploratory and participatory and critically engaged way: that is, they discussed their own current knowledge of disability, their relationship to disability communities inside or outside of school and the “findings” from disabled adults’ experiences in school as potential sources of connection and solidarity in each session through mini-lectures on disability identity. These data collection choices were informed by my critical stance, where I intentionally involved individuals with disabilities in the inquiry process itself through these methods. Following this initial exploration of students' disability identities and any similarities or differences they draw from the adults with disabilities' experiences, the students engaged in a photovoice project identifying places in their school or community where disability issues are ignored, left out, unseen or unheard. This photovoice project involved both individual reflection and group processing of the photographs and narrations behind the photos. Overall, the study focused on people with disabilities as meaning-makers and change agents, capable of both describing their experiences and knowledge about disability, and about identifying the relationship between disability and schooling experiences. Table 2 describes the products of this dissertation and of the data sources described below.

Table 2

Data Source Products

ADULT PHASE	N	SCHOOL PHASE	N	CONNECTION PHASE	N
October-November		November-December		February-March	
Life History Interview	4	Focused Disability Identity Development Interview	4	Adult Written Reflections on Student PV (images & reflections)	3
Focused DID Interview	4	Teacher Interview	1		
		"Who am I" activity	4		
		Photovoice sessions			
		Class recordings	3		
		PV Journal Images	20		
		PV Journal Reflections	20		
		In class PV Image Reflections	3		

Individual interviews with disabled adults. I interviewed adults with disabilities in order to draw from their experiences and expertise with disability identity development over time and across different contexts. Individual interviewing is a widely used strategy in disability identity literature to investigate internal ideas, meaning-making and development of disability identity (e.g. Calderón-Almendros & Calderón-Almendros, 2016). I used it here as a strategy to investigate a similar phenomenon (and "location") of one individual's meaning making of a personal, relational and collective identity in ableist and politicized contexts. I conducted two interviews with each adult participant. First, in a life history interview (Plummer, 2001), I asked participants to talk about their development of disability identity in school over time (See Appendix A). Second, I used a semi-structured interview protocol and interviewed adult participants on three broad categories: the individual's personal schooling history, their knowledge and relationship to disability throughout their schooling years into adulthood, and major supports that they might wish they had looking back on their school experiences in support of their disability identity (see Appendix A). I based interview questions for the second protocol on extant disability identity literature that focuses on the development of those identities over time (e.g. Hahn & Belt, 2004).

While I had initially completed the adult phase of the study while simultaneously working to choose a classroom site for the study, the timing of the participant selection for both phases informed each other. It was important that the adult phase of the study "match" and inform the school phase; that is, that the adults shared similar disability labels and schooling experiences (including amount of time spent in general vs. special education environments) as much as possible with the students in the study so that experiences could be shared and participants could relate to one another. In this way, the four students who made up the school phase of the study (and their life skills classroom context) helped inform the final four adults selected for the adult phase of the study.

Initial interviews with disabled adolescents. The purpose of the initial interviews with disabled adolescents were to understand their process of identity development, the identity resources they used to shape that identity, and the ways in which (or if) they were thinking about disability as a collective identity. Individual interviews with disabled adolescents were semi-structured, following a similar structure as the second adult interview and with a mix of more and less open-ended questions (See Appendix C). I based the initial interview questions on the Ashmore et al. (2004) collective identity framework, with special focus to individual categorization around disability (a more internal aspect of disability identity) and relationships/awareness of others with disabilities (a more external aspect of disability identity). Each interview was approximately 45 minutes to one hour long and was voice recorded in the life skills mock apartment.

Photovoice. Photovoice is a participatory research method rooted in problem-posing education that focuses on “issues that people see as central to their lives” (Wang & Burris, 1997, p. 370). I chose to use a photovoice protocol to further understand individual students’ awareness of disability in their school communities in a creative, multimodal way. I utilized photovoice through asking students to participate in a project called “Photobombed: My Photos, My Voice” as a means to develop “effective and comprehensive strategies to address complex health and social issues” related to disability in their school and/or community (Nykiforuk Vallianatos, & Nieuwendyk, 2011, p. 104). The photovoice project typically involves four phases: initial interviews, photovoice trainings, taking and narrating photos, and participatory analysis (selecting photographs, contextualizing/telling stories about the photographs, and codifying emerging themes and issues) (Wang & Burris, 1997). Table 3 outlines the timeline and data sources for this phase of the dissertation. All of the photovoice sessions included Powerpoint presentations (an instructional choice that followed the format of the life skills course) that summarized the goal of the project, important ideas about disability identity, and the specific focus for the day (See Appendix B). In order to make the focus of the project fit into the existing thematic focus of the “disability knowledge” day in the life skills course, I worked closely with Ms. Maddox to make sure the format of each session integrated well into the existing structure of the class and of the other course themes. This format included incorporating a mix of “lecture” on disability identity in addition to class discussion and individual work.

Table 3

School Phase Timeline & Data Sources

Session	Activity	Artifacts for Analysis
Session 1	Initial classroom visit, met students, participated in classroom activity	Field notes
Session 2	Permission forms, intro project and discussion of disability identity	Field notes & audio recordings
Session 3	All permission forms returned; Bryce initial interview	Interview transcript
Session 4	Quentin initial interview	Interview transcript
Session 5	Vanessa initial interview	Interview transcript
Session 6	David initial interview	Interview transcript
Session 7	Photography mission, rules for taking photos (whole group)	Voice recording transcript, “I am” activity artifacts
	Teacher interview	Interview transcript
	Student photography mission: Students take photos individually and record in mission journals	Photovoice photos & reflections
Session 8	Group photography mission discussion with guided SHOwED discussion tool	Video recording & transcript, photovoice photos & reflections, in class photo reflections
Session 9	Group photography mission discussion with guided SHOwED discussion tool	Video recording & transcript, photovoice photos & reflections, in class photo reflections

"I am" activity. The goal of this activity was to understand whether students would name disability as a part of their own identities before the photovoice project proceeded, and to begin to build rapport and sharing between students about personal aspects of themselves (in this case, not necessarily directly about disability). Additionally, I was interested in the other identities and roles students would list as a part of who they were (independently or in place of disability identification). As an opening group activity to introduce the photovoice project, students completed a short activity that engaged them in reflecting on their multiple identities. I asked students to write, draw, or otherwise list in a 5 minute time period as many identities that they felt described them and who they were. I first gave a short example with a variety of roles and identities: sister, daughter, teacher, and wheelchair user. Next, students worked independently on the activity. I wanted to maintain each students' agency to write as many identities as they wanted during the activity, so I asked students to choose one or two "important" identities that they had written down on their paper to share out loud.

Photovoice training. Following the initial interviews and "I am" activity, I introduced students to the photovoice methodology and the tools and expectations for the project as a group, with two one-hour sessions in their life skills course. Photovoice comes with several ethical and privacy concerns; it is important that students are given guidelines for appropriate times for taking photos, appropriate ways of obtaining consent for taking photos, and other ways that they can successfully engage with the methodology. As a group, we practiced the "rules" for this photography project: no visible faces in photographs, no photos taken during class time, and no unsafe spaces that might get the student in trouble while doing the project. I gave students a photovoice guidelines handout to follow during their independent photovoice project time (See Appendix D). I audio recorded this photovoice training.

Photography mission. After the photovoice training, I provided students with a "photography mission": to take photos of places or things that they felt empowered or hindered people with disabilities in their school and/or community (See Appendix D). This mission was left intentionally broad, and thus results could have included physical/structural barriers, depictions of social experiences, signage, or videos which include "live recordings of their experiences as they move through their 'mission'" (Fujita & Arikawa, 2008). At the beginning of the photography mission discussion, I paired the photography mission with a short discussion of some of the experiences and stories from the interviews with disabled adults, including presentations to fit with the structure of the life skills course (which used Powerpoints as the main method to teach and guide discussion). Rather than "swaying" or influencing the students, the adult data included in these presentations provided an important discussion starting point and point of connection between the experiences of the adults and the experiences of the students.

Photos and photo narrations. I asked students to take 5-10 photographs that fulfill the mission over one week's time. After taking the photo, I also required students to journal in writing or record their thoughts while taking the photo: what were they meaning to depict? These narrations were short and could consist of bullet points or voice recordings if writing was not the preferred method for the student. The goal of these narrations was to capture the students' thinking and feelings while taking the photo, rather than doing any kind of deeper analysis of the problem or support the student is trying to show; this analysis process occured in more depth as a group in the gallery session.

Gallery session. After a week of collecting photographs addressing the mission, students came back together to review and discuss photographs with me in a "gallery session." Each participant shared the photographs that they consider most significant (Wang &

Burris, 1997), and then narrated the meaning of their images in pairs. This narration involved students writing responses to reflective questions using the SHOwED analytic tool (Shaffer, 1983; Wang & Pies, 2004) that address the real root issues at play in the space or situation depicted in the image (See Appendix E). The SHOwED analytic tool asks reflective questions to lead discussion and encourage reflection, including “what is really happening here?” and “Why does this situation exist?”. I included an adaptation of a question: “What does this tell us about disability?” After students discussed their written reflections in small groups, students came together as a large group to identify themes between their photos and their experiences: the places in their school and/or community where they felt comfortable being themselves, and places that felt like disability was not welcome or understood. I video recorded both gallery sessions.

Virtual photo gallery. Following the group’s discussion of the images, an important part of the photovoice methodology is a (broadly conceptualized) public display of the images (Nykiforuk et al., 2011). After the gallery session with students, I determined that my initial plan of presenting the students’ photos in a public gallery (and inviting the adults from the first phase of the study as guests) would be counterproductive to the current comfort level and readiness for students to discuss their identity experiences in a larger group. The students had difficulty sharing their experiences outside of paired small group discussions; they were frequently diverting the conversation to other topics (often on their cell phones or computers) and, in the initial interviews, talked about how these issues were often difficult to talk about. In a critical study, my awareness of the power dynamics between myself (as facilitator) and the students led me to make a decision that my initial research plan was not appropriate. Instead, I gave adult participants (with the permission of student participants) a link to a Google Drive folder with de-identified data from the photovoice project. This data included the “I am…” activity text responses, and photos with typed descriptions from the students’ photovoice handouts. I asked the adult participants to respond to the photos, photo descriptions, and “I am…” activity from their perspectives, and to reflect on their own schooling experiences in the process.

Interview with life skills teacher. After the first school session where I introduced the photovoice project and focus on disability identity with students, I conducted an interview with Ms. Maddox in order to understand her ideas about disability identity and how she structures the life skills course in response. This interview was important because it provided immediate context for how students were being taught to talk about disability and exposed to disability identity; Ms. Maddox as an identity agent (Schacter & Ventura, 2008) was an important part of understanding development of disability identity for this group of students: they identified teacher interactions as significant in terms of understanding disability as both Sa general concept and in relation to themselves. The interview protocol was semi-structured, focused primarily on gathering information and context both about the school, the students, and the ways in which Ms. Maddox understood disability identity (See Appendix F).

Data Analysis

I approached my analysis of data in three phases: the adult phase, the school/student phase, and the connection phase. I present the analytic plans for each portion of the data collection process below, with acknowledgement that each portion of the data necessarily informed each other and assisted in answering the research questions, in an iterative and ongoing manner.

First, I compiled scans of all written artifacts and utilized a transcription service to transcribe all audio and video data, and uploaded the data into Deedoose qualitative coding software. Next, each data phase included two coding cycles (inductive individual case coding and pattern coding), followed by thematic organizing of the first and second cycle coding. Each cycle of coding involved an “eclectic” method (Saldaña, 2013), with multiple coding methods and types. Eclectic coding “employs a select and compatible combination of two or more first cycle coding methods” and is usually followed by analytic memo writing and second cycles of recoding in order to synthesize “the variety and number of codes into a more unified scheme (Saldaña, 2013, p. 188). While the photovoice project included both interview and image/written text data which may have required a different set of analysis strategies, Capous-Desyllas & Bromfeld (2018) suggest an “eclectic” analysis approach for photovoice data that involves integration and coding of all of the parts of the photovoice process together (rather than separate analysis for each type of data), with two analysis phases: within-case and cross-case (p. 14). This eclectic approach allowed me to equally weigh the themes and ideas from the theoretical framework, individual participant voices, and my own ideas about inductive structures mentioned in the data in the initial analysis process.

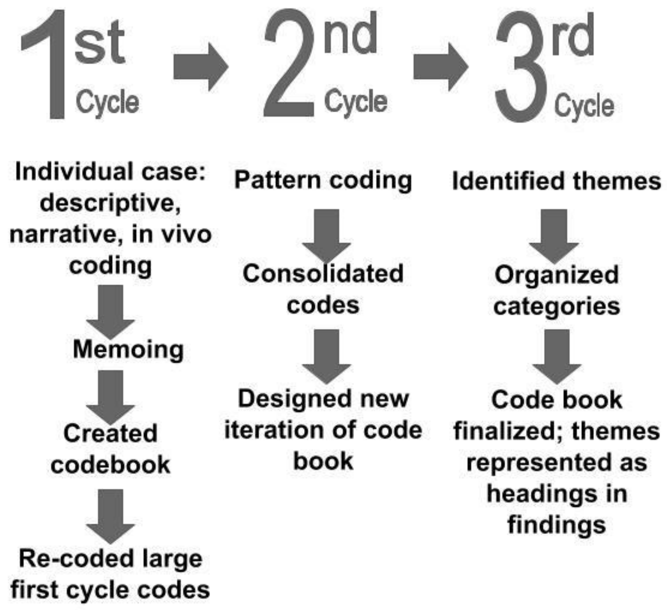


Figure 1. Cycles of analysis.

While data analysis was ongoing and each phase followed a broad three-cycle approach, the analysis processes differed based on the data sources of each phase. I completed data analysis and coding by individual participant inside each phase (adult, school) consecutively. I chose to code data by individual case in order to see individual identity experiences around disability, but presented the data analysis based on my collective identity theory framework involving group understanding of that identity experience (see Figure 1). The following sections provide an overview of each analysis process and their connections to the research questions from the study.

Adult individual interviews. After memoing, first cycle coding involved an “eclectic coding” scheme including descriptive, narrative, and In Vivo codes. I inductively coded the interview data, where the adults’ experiences led code formation for particular resources around identity development (for example, “realization of disability” represented the adults’ recollections of the first time that they recognized they had a disability and were ‘different’ than their peers in some significant way). Individual case coding (which I independently analyzed in order to maintain data trustworthiness) ended with seventeen initial codes. These codes included structural and descriptive codes, including “bullying,” “family”, and “media”; and in vivo codes, including “get over it”. Following the completion of first cycle coding for each transcript, I re-coded/re-themed three first cycle codes that had become too large for the scope of the analysis: “disability knowledge,” “regular,” and “cross disability solidarity.” These recoding choices can be seen in my attached codebook for the study (See Appendix G), for a total of nineteen codes. Finally, second-cycle coding resulted in my re-organizing into pattern coding and dividing/categorizing codes into specific contexts in order to discuss across different experiences.

School phase: student individual interviews and photovoice data. To explore the similarities and differences between the adult and student participants in order to understand disability identity development, disability pride, and community involvement over time, I began analysis of the school phase with the codes from the adult phase. This choice allowed me to see the ways that the adults and students’ experiences differed, and the different kinds of behaviors students and adults engaged in as they negotiated school with a disability. Similar to the adult phase, I coded the student individual interviews and photovoice projects using a two-cycle coding scheme. First cycle coding included an “eclectic” coding scheme with descriptive, narrative and In Vivo codes from the adult phase of the study. Because the adult codes did not fully capture the range of student themes, I inductively identified several additional codes in the coding scheme as new resources and ideas arose that were separate or not present in the adult phase data. These codes included structural and descriptive codes (e.g. “accommodations”, “creativity”). Second cycle coding of the student individual interviews and photovoice project (photos, reflections) involved a similar process of re-organization of codes into categories of collective identity development.

Data Representation

After completing coding phases, themeing the data, and drafting findings, I followed the recommendation of arts-based researchers (e.g. Leavy, 2004) who suggest an approach towards data analysis and representation that engages the researcher in creating art in response to the data. I chose to do this in the form of data chapter summaries. The rationale for this representation of data is twofold. First, including different forms of data representation can shape and change how different phenomena are understood, because understanding is mediated by form (Eisner, 1991). I hoped that representing data using arts-based methods would allow my data to reveal the many different layers of identity development and ideas about disability in a way that supported, and extended, my written analysis. Second, Butler-Kisber (2002) cites Denzin (1997) and suggests that arts-based representation in qualitative research “help disrupt the hegemony inherent in traditional texts and evoke emotional responses that bring the reader/viewer closer to the work, permitting otherwise silenced voices to be heard” (p. 230). This representation is especially important in studies that utilize photovoice methodologies, where the participants are asked to engage in arts-based methodologies themselves. Capous-Desyllas & Bromfield (2018) argue that in their arts-informed photovoice data analysis using collage, visual art afforded particular lenses for analysis and representation:

> Visual art allowed for a better understanding and facilitated the capturing of the complexity of the stories that the participants shared that accompanied the photographs that they took; something [that] wasn’t possible with using traditional methods of analysis. (para. 36)

While some qualitative literature suggest collage as a useful method for representing findings, poetry (particularly “found poems,” where words from interview data or other study materials are arranged in new orders to create poetry), has also been used as a data representation method. Richardson (1994) wrote found poetry in response to sociological interviews; Lahman, Teman, & Richard (2017) explored poetic forms in response to their experiences with the institutional review board; Butler-Kisber (2002) created found poetry in response to a participant's particularly rich personal experiences and stories. Found poetry allows the researcher to "re-create lived experience and evoke emotional responses" (Richardson, 1994, p. 521). It also constrains the range of words and resources that one can use in order to represent the data, frequently to the participants' own words and explanations in the same order they were presented in the text.

For these reasons, and to provide another form of art in the dissertation to explore and represent identity, I chose blackout poetry to serve as findings chapter summaries. Blackout poetry (sometimes called mark out or erasure poetry) is a method popularized by artist Austin Kleon which involves selecting particular meaningful words or phrases from an existing body of text, and marking the other text so that only what is selected is visible. I created each chapter summary from selected pages of interview data that related to the focus of the chapter (i.e., adult interview data for the adult findings chapter). I worked to summarize the findings, themes, ideas, and experiences from the chapter in the interview data at hand, linking the poem to my memos and written notes about the chapter itself. The result was an additional way to understand and communicate the ideas from each phase of the study.

Data Trustworthiness

I utilized three strategies in order to ensure the data from this study was trustworthy, involving personal reflection as well as interaction with participants and fellow researchers. I describe the strategies, which include member checking, memoing, and peer debriefing, below.

Member Checking

Because of the two-phase structure of the study, and the multiple opportunities (both with adults and students) that were built into the structure, member checking was an embedded part of the methodology of the study. I gave adult participants multiple opportunities to share their experiences across different interviews, and to describe or explain their previous experiences in more depth. In preparation for the second adult interviews, I wrote notes and frequently asked questions in the interview protocol that referred back to the first life history interview and particular experiences or ideas that the participant then expanded on. In this way, adult participants were able to refer back to, or shape my perception of, their experiences as I reflected it back to them in the process of our conversations. Adult participants were also able to see the "results" of their interviews (as shared with students) synthesized in the form of the student data, which gave them a chance to see how I had interpreted their experiences and shared it with the adolescent participants; and the ways that the students had responded to those experiences. While the adult participants did not see the Powerpoint materials used during the school phase, as part of the virtual "connection" phase I gave the adult participants access to the students' photovoice project materials (photos, photo descriptions, I am…activity). This method allowed the adult participants to see how the students had agreed with, taken up, or built on those experiences: for example, when I mentioned that the adults had often experienced bullying, the students remarked out loud that they had experienced a lot of bullying at their school as well. While it might appear that the method of sharing the adult experiences with the students primed the students to identify with those experiences, I considered this a way to understand disability identity on a collective level: what does it mean when students are identifying with shared experiences, even when they are painful?

Memoing

In the process of coding and in order to generate and refine both cycles of coding, I used Saldaña (2013)'s reflective questions for memoing on each transcript. The process of memoing on each transcript revealed answers to important issues both methodologically, thematically, and in response to the data. See Appendix H for a summary of the reflective questions I completed for each interview transcript.

Memoing also allowed for ongoing and iterative opportunities for member checking and in relationship to data trustworthiness (Merriam, 2009), because it allowed me an opportunity to reflect on the questions or contradictions I had observed between how participants talked about disability in one setting (i.e., an initial or life history interview) and again in another (i.e., the more focused interview or photovoice group discussion). Memoing also informed the formation of the Powerpoint materials that summarized the adult ideas about disability identity for students, and the selection of student photovoice materials (and framing of those materials) to send to the adult participants for the connection phase.

Peer Debriefing

During the process of data collection and analysis for this study, I was involved in a weekly qualitative research group that informed the methodological and analytical choices for the study. Peer debriefing (Creswell, 2000) allowed for a research lens on the study that was separate from the school and participant context, and could serve as a source of feedback as I made choices in reaction to that context. During peer debriefing, I brought coded data to the group to receive feedback on the themes and patterns I saw in the data. My peers asked questions, provided written and verbal feedback, and helped me see patterns I had not previously identified. Peer debriefing contributed to the findings' significance and organization in ways that sometimes reorganized, but most often confirmed, my initial analysis.

Orientation to Findings & Overview

In the following chapters, I turn to discussion of findings from the adult, school, and connection phases of the dissertation. The findings of the study in both the adult and school interview phase attempt to identify the identity resources (Gee, 2003) of disability that people with disabilities recognize as significant in building their understanding of disability identity and awareness over time. The use of the term resources helps link and identify both the *origins* and experiences of disability identity as illuminated by participants, and the *tools* that participants drew from to continue constructing that identity over time. Resources can be operationalized as a multi-faceted set of origins and tools of identity development, encompassing social structures and spaces (e.g. placement in special education), interactions between people (e.g. bullying), and broader cultural meaning-making about disability (e.g. medical & social models of disability). Thinking about disability identity resources helps identify the ways in which the origins of identity development are often inextricably linked to the tools that then reinforce or deconstruct that original idea. An example: often, an initial resource around disability is based in a medical model; an earlier study on youth disability identity noted that students with disabilities described disability (both theirs and a general category) as uniformly negative and a problem based in individual bodies (Mueller, 2018). Students had plenty of school-based resources that reinforced that initial perspective: from experiencing bullying in response to their classroom participation, to separation from their "normal" peers. This discussion of identity resources serves to understand the importance of disability identity in school contexts, and the relatively unheard or misunderstood experiences around disability identity from students past and present.

CHAPTER 4: ADULT PHASE FINDINGS

"I can't control when my autism's going to be an issue for other people. The neurotypicals are the ones who control that. I have to dance that dance no matter what."

The first phase of the study had two major purposes. First, a purpose of this phase was to hear disabled adults' reflections on the development of their disability identity over time in school contexts. While adults with disabilities have reflected on their own disability identity in disability studies literature, an important second purpose of this phase was to explicitly ask adults with disabilities for their recommendations for intentional development of disability identity in schools, based on their reflections. This phase, and its findings, helped inform and shape the school phase of the study in important ways that are described in more detail in the next chapter.

The adults in this phase of the study represent four distinct experiences of disability, four distinct disability labels (and combinations of labels), and four different intersectional experiences of gender and race. Their disability identities shaped their schooling experiences and changed over time. As an orientation to those different experiences, I first present "portraits-in-progress" of each participant (Connor, 2008).

Zeke, a white autistic male, walked with his shoulders hunched and a sharp, thoughtful expression fixed on his face, as if he was decoding a difficult problem before beginning the interview. He wore cargo shorts and bounced a pen between his thumb and pointer finger during our conversation. Recalling his past experiences with school, he occasionally turned away from the table and spoke in short sentences before asking for a break or a change in the question. He spoke intensely about issues affecting the autistic community, reminding me multiple times that research had not caught up to the needs of "his people."

Jackson, a white male with autism and vision disabilities related to albinism, requested that all of his interviews be conducted over the phone, as it was easier to hear my voice and focus on the conversation than it would be to use video and track eye contact (a difficult challenge due to his nystagmus, made more so because of his autism). Later, he shared that he was often self-conscious of his albinism, which meant his hair and skin were “startlingly pale”. His voice was kind and thoughtful, and he often interrupted my questions to enthusiastically extend an idea or to share another story from school. When I reached out for participation in the final study phase, he emailed back within minutes and said he had been wondering when I’d follow up.

Ilia, a white transmasculine autistic person also labeled with intellectual disabilities, had to shift their first interview for this study into a Skype session where they fed their baby simultaneously during our conversation, their quiet cooing and reassurance picked up by the voice recorder. They wore a shirt and tie, a small brown stuffed animal tucked carefully into their shirt pocket which they sometimes took out to rub against their face for comfort. They were passionate and enthusiastic, their voice rising with excitement when they shared a dream of one day running for political office.

Maya, an Indian woman with physical and learning disabilities, set out a small plate of cookies for our interview at her family home, rolling around their fully accessible kitchen in her pink wheelchair. She laughed easily and cracked dry, sarcastic jokes at a million miles an hour, occasionally at my expense. She was full of plans for her future classroom as an elementary school teacher and spoke equally fiercely, though with her trademark sharpness, about her advocacy for disability issues on her college campus.

Across contexts, participants developed a disability identity through common identity resources and experiences. Frequently, these commonalities were considered negative:

participants reported experiencing loneliness and bullying, as well as difficult interactions with teachers. Participants also reported positive disability resources and experiences: participating in outside organizations, becoming aware of the social model of disability, accessing disability cultural resources, and participating in disability advocacy all led to developing disability pride. Importantly, the adult participants also mentioned that their process of identity development (including experiences and resources towards that development) occurred in the context of an initial realization of a disability label, embodied experiences of disability, and awareness of intersectionality of their identities. What follows is a discussion of the general identity development processes (or initial processes of coming to understand disability) undertaken by the adults, and then the generally positive or negative valence of those experiences; in other words, the ways that disability identity was oppressed and discouraged, or positively protected and developed for adults over time.

Development of Disability Identity

Adult participants, in the process of talking about the development of disability identity over time and across contexts, named three processes that were not necessarily positive or negative, nor time-specific: they represent the ongoing attempts at coming to understand disability, or what Gill (1997) might extend as “a yearning of wholeness and belonging” that involved both understanding of the disability label itself, the embodied experiences of that disability and impairment, and the ways that the disability identity comingled and shaped other aspects of the individual’s identity. These development processes included an initial realization and negotiation of a disability label, embodied experiences of disability, and awareness of intersectionality.

Initial Realization and Negotiation of a Disability Label

For the adult participants reflecting on their experiences in youth and school, the process of understanding disability often involved an initial experience of naming or labeling where the participants "realized" they had a disability. In all cases realization about disability for these participants involved communication about a disability label to the participants by parents, teachers and peers, and what followed was a period of internal processing. Rather than a specific moment, the "realization" of disability represents the meaning-making that participants engaged in with the information that they received about their own disability label.

Interestingly, the gap in time between the labeling or identification and the realization of disability was relatively large for this group of participants. In all cases, participants were labeled with disabilities in elementary school or earlier, but began to wrestle with the meaning of that disability label later in school (late elementary and middle school) or in some cases, in high school. Participants had varying knowledge about their disabilities. Sometimes, the realization of a label of a disability came as a surprise. Zeke remembered first noticing a difference between the way his classmates were treated, and the way he was treated:

> I would get really self-conscious when other students would bully me. I eventually noticed, maybe like third, fourth, fifth grade, that other students maybe weren't having to go through that. I wasn't sure. Definitely negative. First, second, third grade, I assumed that's what all the other students were going through. When I officially received my Asperger's diagnosis in fourth grade, I think that's when I started putting the pieces together and realizing maybe it's because of that.

In this way, connecting bullying with the realization of a disability label provided Zeke a way to attribute the negative experience he had in school to his differences from his peers. For Zeke, having the disability label as a definitive answer allowed him to understand the reasons why his peers were bullying him to a specific difference in his own way of interacting with the world. Ilia also attributed their realization of disability to interactions with others (also negative), this time their teachers and family members:

> The school finally let it out of the bag that I was autistic. They put me in an autistic social thinking group. And I was like, but my dad says I don't have that. And they were like, yes you do. That's how I found out I was disabled. I was put in special ed and nobody told me what my disability was. I knew I couldn't read really well and I had learning issues, sensory issues and why I couldn't understand conversations sometimes. All of those, why I had obsessions over things...all of those things, nobody explained it to me until my junior and senior year of high school.

For Ilia, understanding their disability later in life and as a result of a school-level designation into a specific context, was again an affirmation of internal understandings of experiences that they had already been aware of. Like Zeke, the disability label was confirmation of a personal experience and awareness of difference.

For other participants, their disability realization was not a distinct event. Maya mentioned that she did not have a singular moment of realization about being disabled, particularly because of her multiple disabilities, both physical and invisible: “So for me, it's like I've never considered a time when I wasn't disabled, I just always have been.” Jackson expressed a similar idea:

> I always knew from day one that I had both of my disabilities. There was never any kind of surprise or revelation where I discovered that I was disabled, so it was just normal for me because that's just what it was.

Jackson and Maya’s idea that disability was a constant in their lives, while contrasting with Ilia and Zeke’s distinct moment and assigning of a disability label that confirmed their beliefs and ideas about themselves, express a similar point: disability identity involves an internal awareness of the impairment itself, whether that occurs in response to comparison with nondisabled others or constantly over time.

Even if participants didn’t have a distinct memory of realizing they had a disability, they continued to negotiate and wrestle with the meaning of their disability label and the sources that they learned about their disability from. Sometimes, this was about the very nature of disability itself. Ilia remembered wondering about the cause of their disability: “It was like, wait a second, I'm going to have this until the day I die, is it my fault?" Zeke and Maya seemed to use their realization of disability as a way to negotiate school more effectively, even if it meant denying the effects of their disability. Zeke recalled trying to appear "part of a mold":

> I had more of a definition around what was going on, and I had words to explain it, finally. I could contextualize it and still ...That's when I started maybe caring about trying to change a little, trying to fit into the mold. But, still, it didn't fit right into me. I'm having to run two operating systems in my head simultaneously.

For Zeke, realizing disability may be a relevant identity (or at least something that affects the way individuals operate in the world) was not just a process of recognizing difference, but of trying to change or "fix" it almost immediately. While Zeke named this behavior as like running operating systems (his autistic operating system, and his neurotypical operating system), Maya remembered harnessing her knowledge of her disability labels to access accommodations in school and to address her needs in a different way:

> Yeah, because I didn't have an understanding of my learning disability probably until middle school. And then I got a more full understanding when I was in high school, 'cause that was more when I got actually tested. I got tested enough to know that about dyslexia and stuff, but that was just so that I could get on meds to focus in class. And then later on it was like, I need all the accommodations for the tests.

Maya's focus on her understanding of her learning disability as connected to testing and accommodations allowed her to better negotiate school structures that required this kind of knowledge in order to advocate. She was able to identify her learning disability as a largely school-based phenomenon: where the labeling of the difference and the accommodations for that difference contained a certain set of rules and "fixes" that were in her reach if she could use the right vocabulary.

In the process of realization and acceptance of a disability (and, for some participants, an attempt at fixing it to appear more normal), participants had to negotiate conflicting ideas about disability between their own meaning-making and others. These conflicting ideas were often related to others' reactions to particular disabilities. Maya noted a difference between reactions to her invisible and visible disabilities, which affected her own realization of the impact of disability on her identity:

> So it was high school that I started to gain a full understanding of my learning disabilities. But until then, I was like, disability is your physical disability. And also, I still think that it's the one that has the most impact. You don't get stared at. If you have a learning disability or an invisible disability, you don't get stared at everywhere you go. We get stared at no matter what we're doing.

Maya's awareness of different reactions to her various disabilities helped her make a distinction between her own internal realization of disability, and others' perception of impact of impairment. She explained this dynamic further:

> Honestly, half of the time I don't think of myself as disabled. I only think of myself as disabled when I have to draw attention to it, or its actually going to impact the thing I'm going to do next. But other than that, I'm like, what?

Maya compared her own reaction to her disability labels to others' ideas and found that often, other people felt much more strongly about the impact of her disability on her life than she might have. Ilia engaged in a similar awareness of others' ideas, so that it might help their own understanding about disability internally. They wished that the "realization" of disability would have been scaffolded and supported earlier on in their life and school trajectory. They noted that when they were told about their disability label, they "started studying it like nobody's business" and even "realized that this described everything about" them. In hindsight, they mused:

> I wish somebody would have just sat down with me and told me, "Ilia, you have a developmental disability. You're going to have this for the rest of your life, but that's okay and we're going to help you with this. And yes, you're going to have struggles but we're going to help you and we're going to try and find you the accommodations you need, and you definitely need some accommodations".

Ilia made an important distinction here between the potentially negative ways that people had talked about disability with them in the past, and the ways that naming both the positives and negatives of disability should have been combined in some way with a show of support from important teachers and adults in their lives. This support was not about overcoming the disability, but about the required accommodations and different ways of navigating the world that were otherwise figured out independently on their own. In this way, Ilia and Maya’s focus on other peoples’ awareness of their disability paradoxically shaped, or conflicted, with their own internal identification. Importantly, neither framed disability as a negative thing: only that they had noticed an outsized difference in others’ awareness of their disability labels, and felt a need for support and reassurance that this outsized awareness wouldn’t have a negative impact on their school experiences.

Participants also remembered a process of coming to understand the many different meanings that their disability label might hold. This meaning shifted across contexts, times and phases of their lives, but the process of negotiating a disability label often involved creating a definition of disability that was based in language of adults. Two participants remembered an early definition of what disability was in their lives. Jackson recalled that his understanding of disability was primarily centered in his own experience, rather than an early awareness of disability as a broad concept: “it made me feel sort of other, separate, from everyone else, but I didn’t really fully understand what it was on its own. It’s just something that made me different.” Zeke remembered feeling a similar sense of difference, but also temporality: “my autism was just personified as something that I needed to grow out of. Or something maybe temporary.”

In the process of coming to self-categorize as having a disability and being a part of the disability community, participants first named the ways in which their initial realization of disability was important towards a later, more complex understanding of disability. The initial realization process did not occur absent others’ ideas about disability, but it was the internal negotiation in response to the initial realization that caused them to understand how disability might apply to them.

Embodied Experiences of Disability

An important question in this study focuses on where knowledge about disability comes from. There is some significant tension, both in theory and in the lived experiences of participants, between the words people used to describe disability and the embodied, fundamentally personal and individual experience of impairment. While negotiating understanding a disability label was a significant source of disability identity, participants also named embodied experiences of disability that seemed to differ from knowledge of a disability label. This is the difference between thinking about disability as a phenomenon that someone assigns to you, versus the ways that disability affects experiences of individuals.

Participants thought a lot about their own impairments, and the ways that those impairments impacted them and their relationships with others. Maya recalled processing her disability differently than others, even in her own community:

> I didn't have that deep sense of loss that a lot of people seem to have, or that huge desire to not want to be disabled. A lot of people go, their whole thing is this drive towards walking again. And I'm like, I don't really care about that. It sounds like a lot of extra effort.

Maya did not have a strong need to change her physical embodiment or the ways that she navigated her world in a wheelchair. She recognized that other people in her community may have felt an (internal or external) push towards changing their body or walking again, but Maya instead thought about that as effort she did not want to extend. In some way, Maya's multiple disabilities allowed her to see a wide range of responses to disability, and to make sense out of those as a collective before making a judgement about effort and response to societal pressure. On the other hand, Jackson's multiple disabilities meant that he often thought about the impact of each disability, together and separately, on his own internal feelings about himself. On the one hand, it was “almost impossible to tell where the autism ends” and Jackson began: so much so, that he just didn’t “think there is a difference. It’s just a part of [him]. Not in the label, it’s more the artificial part.” With his vision impairment, he is able to picture what life might be like without it: “it would just enable some things.” The embodied experience of autism, though, was difficult to separate:

> With the autism, what would I be like without that? That’s almost impossible. It’s so part of the mind and so enmeshed in everything about me that maybe my life might be better, but it would be a different person living that better life. It wouldn’t be me.

While that lack of separation between autism and his sense of self seemed to be acceptable to Jackson, he also named several strategies that he used in order to feel in control of his disabilities. These strategies included forcibly training himself not to stim, and practicing conversations with others in order to socialize. He recalled needing to have these strategies in order to “get out ahead” of awkward social interactions with others, but also for his own “self-preservation, just to be able to cope with the situation without breaking down.” Forcibly training himself not to stim came out of a sense of embarrassment about that behavior:

> It’s kind of embarrassing. My mom always called it “happy hands,” where I’d get excited. My hands would shoot up. I had a habit, I would call it “Thinking Thing” where I’d pick up an object and I’d kind of spin it around in my hand to stimulate. It was my own kind of, I was embarrassed by it. If I did it in public, I would feel really like, ‘Ugh, that was dumb!’

For Jackson, this control over his stimming brought him a sense of empowerment, because it was a change he “could do, and could choose to do.” He felt that the stimming was a crutch for managing stress and anxiety around socializing, and instead he wanted to “be able to, I don’t know, stand on my own and not need that.” In some ways, the ways that participants negotiated embodied experiences of disability were as much about their own comfort being disabled, as it was about building relationships with others in response; unsurprisingly, part of this process was participants reflecting on internalized ableism, either explicitly (in Ilia’s case) or implicitly (in Jackson’s case, where he felt embarrassed after he engaged in self-stimming behavior). This is a potentially troubling part of the process of identifying with disability; naming, and understanding, the ways that an embodied experience of disability fundamentally involves challenging negative ideas and perceptions of disability itself.

Integrating Disability with Other Aspects of Self

Some sociological research (Barnartt, 2001; Barnartt & Altman, 2015) has framed disability in terms of a "master status", or the "primary identifying status of an individual that shapes an individual's interactions and relationships with others and dominates all other statuses." Participants frequently spoke about their disability labels and identities in relationship to other aspects of their lives and selves, suggesting that disability was not a "master status," and could not be understood as separate or distinct without the benefit of understanding other intersectional aspects of identity. These intersectional aspects included race, gender, and sexual identity; and sometimes, several aspects surfaced at once in a single, compounded moment or experience.

Gender. For Jackson, becoming aware of the socialization he experienced related to his gender conflicted with messages he had received about how "normal" people without autism expressed emotions. If "normal" people were supposed to be highly attuned to others' emotions and respond to them, he noticed distinct times in which that rule didn't seem to apply. He reflected:

> I knew, even as a little kid, as a little boy playing in the playground with whatever little boys, if one of them falls off something and gets hurt and starts crying, all the other ones around him freeze. They're like, "What's happening? I don't know how to deal with this." They'll scatter like cockroaches because there's this emotional vulnerability that's happening right now and no one knows how to deal with it and we'll just run away from it.

Jackson's belief (reinforced by cultural and social messages) that boys are not supposed to cry or show emotions progressed into adulthood, just as Jackson was learning to express emotions he felt around his own disability and the negative social effects he experienced. It was important to Jackson that he was able to suppress emotions and therefore vulnerability, like he saw other boys around him doing:

> I started to internalize it and I know a lot of other guys must have, it's that when you get hurt either emotionally or physically or whatever and you feel yourself wanting to cry, you choke it down as hard as you can because you know as soon as you let the emotions out, as soon as you start displaying that vulnerability, anyone who's around you who might support you will immediately abandon you. They'll run away from your emotional display, so you choke it down as hard as you can. I think guys learn how to do that from an early age, that as soon as they feel the emotions coming on, they fight back against it really hard because they're afraid of being abandoned.

Jackson’s awareness of the ways that gender stereotyping intersected with emotional expression was not expressly shaped by his autism, but ideas about gender shaped the way that he noticed others expressing their emotions and, more importantly, vulnerability in particular settings. Jackson looked for rules about how emotions could be expressed by people around him; he received a message in response that boys could not have emotions, which then simultaneously fed into stereotypes about how people with autism might express themselves. Ultimately, Jackson was able to note the connections between his autism, and cultural and gendered ideas about emotional expression, intertwined, and how these ideas were reinforced across multiple intersections:

> Autistic people are actually incredibly empathetic, it's just the emotions don't find their way to the surface and we don't know how to express them or communicate them. On the inside, I was just this emotional tempest falling apart, but on the outside, I'm just blank-faced and standing there. As a guy, there's a general social pressure to keep it under the vest anyway. I feel like this, I'm suppressing it, but also that I should suppress it.

Jackson’s reflection around gendered ideas of emotion both were shaped by, and shaped, his ideas about his autism. Importantly, this reflection was focused on societal ideas, not his own needs to express emotions (or to keep them to himself, whichever is more preferable). Jackson negotiated multiple intersections of identity, cultural rules about how those identities were expressed, and consequences of those expressions.

Race and National Origin. For Maya, who was adopted from India as a baby to a physically disabled white mother and nondisabled white father, the process of integrating disability with her racial identity and sense of national origin was complicated. She felt herself becoming more and more interested in Indian history, often instead of (whitewashed, US-centric) disability history that was more accessible because of her mother's identity and connections to disability community:

> I actually probably cared more about Indian history than I ever did about disability history. 'Cause I always have mom here to tell me about disability history. I learned everything, I had so many resources for disability history. And we had an Indian community. My mom started an Indian adoption group, and so I know tons of adopted Indians. It's a different experience to know adopted Indians versus to know Indians and to have that history. So that was more of, I needed to know where I came from, whereas with disability I was like, its happened, there's all this information here, I don't need it from there.

Maya's desire to connect with Indian history and sense of "where she came from" as an adoptee was more important to her than connecting to disability community, even when both were encouraged and facilitated by her parents. Where her parents were able to share some identities and experiences inside both communities (as adoptive parents, as a disabled parent), neither of them were able to share the experience of being a woman of color with a disability, which Maya talked about as significant identities that worked together to shape her behavior, particularly in situations where she found herself having to advocate for her own needs. She wondered about engaging stereotypes or how she might be perceived by others:

> If I were to show my confrontational side or my aggressive side, then am I just your typical woman of color being aggressive? Which sometimes I am, but I have to wonder if that's what I care about. And sometimes I don't care. But on one hand, I like to be powerful and stand up for things. When people screw up parking, you park in my access aisle, I promise to god I will call the cops on you, and wait to yell in your face.

Maya's negotiation of her racial identity and desire to know her own history, the stereotypes that she was aware of engaging as a result of that identity, and her desire to self-advocate worked together to create a hyper-consciousness of the ways that people may react to her whole embodiment. Maya did not want to be seen solely as a woman with a disability fighting for access to parking, nor as a woman of color desiring connection with her own history. The ways in which disability and race worked together for Maya also made her aware of others in her life who may be trying to segment each of those identities and therefore to take away some of the power that Maya wanted to hold: her parents, strangers, and any others who suggested that one specific aspect of her identity was more significant to her than another.

Sexual Identity. Though Zeke identified as heterosexual, he mentioned that his classmates attributed his behaviors to being gay, rather than to his autism. These perceptions often resulted in bullying as well as compounded difficulties for Zeke as he attempted to carve out a place for himself in school. He recalled trying to negotiate multiple ways that other people tried to label and make sense out of his autism by using sexual identity as another marker of difference, which resulted in depression for Zeke as he attempted to explain his autism to his classmates:

> But, I definitely remember I was just really depressed sophomore year on, just because I had internalized a lot of the negative messages I had received about my disability, and just about the fact that people thought I was gay.

Zeke, like Jackson, connected perceptions of disability and cultural ideas about gender and sexual identity. In this case, Zeke noted that if he socialized and behaved a certain way (whether or not he identified himself as autistic or attempted to explain his behaviors from inside the confines of the disability label), it instead signaled something about his sexual identity that he couldn’t control, often with significant and violent consequences:

> Other students really weren't educated on what autism was, what the differences were. Being in [a rural area], they thought my autistic mannerisms was because I was gay, so I definitely encountered a lot of direct homophobia, definitely got assaulted a lot of times because of it. It's just that categorization of the "other". When you're just a little different, across that uncanny valley, people aren't going to let you forget that.

While Jackson and Maya talked about identities that they actually held and the ways that those identities shaped perceptions of disability (and vice versa), Zeke had a different experience.

While his classmates knew he was autistic, they attributed his behavior to sexual identity in a way that both engaged harmful, stereotypical, and incorrect ideas of how gay people may behave, and simultaneously separated Zeke farther from his school community because of that perceived stereotype. In this way, Zeke's autistic identity was shaped by others' perceptions of his behavior and their attributions of that behavior, however inaccurate.

Instead of thinking about disability as a master status, the participants in this study demonstrated a complex internal process of integration, and meaning-making, around their disability as it intersected with other aspects of their identity in order to produce particular outcomes and interactions in school. Zeke identified this experience as holistically about being across an "uncanny valley": not a disability-focused one, but a difference-focused one in which all of the potential ways a person could self-categorize with disability were simultaneously potential ways in which they could feel disconnected and separated. This was true even in cases where the identities were privileged ones: for Jackson, being a cisgender male constrained his emotional experiences in ways that further influenced how his autism was seen and interpreted as others. In this way, participants were seeing themselves not only as solely "people with disabilities" (though this was a salient and unique identity experience), but also naming the ways that their disability labels complicated or informed their way of seeing other aspects of their identities.

Oppressive Identity Resources & Experiences

While the adult participants named ongoing processes of identity development that shaped disability identity, many of the identity resources and experiences that they mentioned encountering along the ongoing processing could be considered oppressive. These identity resources and experiences negatively impacted the integration of disability into the individual's positive sense of self. These oppressive identity resources and experiences (that is, the negative temporal or material interactions, relationships and feedback that participants received) were also primarily based in school contexts. The oppressive identity resources and experiences included awareness of peers' ideas about disability, school silence about disability, teacher interactions and feedback, and experiencing loneliness.

Awareness of Peers' Ideas about Disability

Many participants remembered becoming extremely conscious of the opinions, ideas and reactions that peers had to their disability labels. These reactions occurred so often, and so violently, for some students that they were considered bullying. However, participants also remembered a more general sense that their peers saw them as separate, or confusing, or often just different from them. In response, some of the participants worked to make their nondisabled peers feel more comfortable, often distancing themselves from other disabled peers in the process.

Three of the participants reported experiences with bullying that were directly related to their disability. For Ilia, the bullying occurred outside of the classroom, and was directed at students who had been pulled out of class: "We were the punching bags. I was ostracized at recess and so were a lot of other kids that were in the same situation I was in, had IEPs, was taken out of class." Zeke echoed this experience: "I know a lot of the students were doing it just to set me off, because it was entertaining for them, because they were making up for their own home lives." Zeke's experience with bullying contrasted with his own ideas about his disability, which led to some internal 'mediation': "In a lot of ways, I just didn't care that I was different, but I was having to mediate that with the bullying, just the ostracization I had to go with."

Jackson remembered bullies 'latching on' to his visible disability, albinism, which he got teased for. He said the bullying was "one-off incidents where [he] was in the wrong place at the wrong time and someone was in a bad mood" or "non-ruthless teasing." It was important to

Jackson that despite the bullying, he never felt completely isolated; instead, the bullying felt like a natural phenomenon:

> It’s never that I felt that I was being ostracized or deliberately excluded: it was just the natural attractive force of the other people towards each other that just displaced me. [It’s like oil and water]: water naturally forms a structure with other water molecules, and the oil molecule just gets pushed out.

While participants experienced bullying and isolating interactions with their peers, they more frequently remembered a sense of their peers discomfort or unsure attitudes towards their disability, which provided them a window into how others (outside of their families) thought about disability. Participants remembered experiences with peers where they got direct feedback about the impact of disability label on others’ perceptions of them. Maya had a very developed idea of the inner dialogues of other people when they meet her for the first time:

> If people don’t know me, they do make judgements. The minute somebody meets someone in a wheelchair, the things going through their head, a lot of people go, ‘oh I want to be friends with that person. But how do I do that and what does that mean? Are they going to think I’m weird if I don’t? But what if I do and they think I’m weird and then they won’t want to be my friend? [They say] ‘All I wanted was to be her friend but it’s too complicated.’ Or they’re like, ‘do I offer my help now? What do I do?’ But then I tell people I’ll ask for help, but then I don’t ask for help, so I’m lying.

Maya’s idea of other people’s internal monologues is constructed based on her experience with others’ discomfort around her physical disability. Sometimes, this discomfort resulted in people desperately trying to connect by talking about an illness or broken leg, which meant that they “knew what it was like.” To that, Maya laughed, “I go, get out of my face, go away, I never want to speak to you again.” Another way this discomfort manifested itself, in her mind, was being treated in a special or sanitized way:

> Because my god, you’re an awful person for treating [people with disabilities] like a normal human being. Some of the people I respect the most are the ones who are willing to call me a bitch to my face. I don’t particularly want to be friends with those people who thought I was that, but I respect them because they had no problem treating me the way any normal person should.

For Maya, potential friends' confused, cautious, or even super-sanitized interactions with her were all signals that she had to facilitate their becoming comfortable with disability. To do this, she welcomed all interactions, even if it meant they may insult her. This process of making other people comfortable with disability was a common theme for participants, based in an intense pressure to be "normal" in school. The way that the participants accomplished the goal of being "normal" varied based on their individual experiences, but each mentioned the importance of appearing similar to their nondisabled peers. Zeke mentioned a phenomenon common in the autistic community that he began engaging in at age 13, in middle school:

> Masking is essentially appearing indistinguishable from your peers. Where people would not necessarily know you're autistic, just based on their initial perception of you. Whether or not that's hiding your stimming, or making eye contact, or having a conversation in a neurotypical way, or just being interested in neurotypical things. I think of it as a very extreme form of code switching, where not only are you changing the way you talk, but you're changing the way you act, and think, and focus. It's super draining and exhausting.

Jackson remembered a "normal conversation" being an important goal in social interactions with his peers, "so that everyone feels comfortable and at ease." Perhaps more importantly, a normal conversation was important because Jackson noted that "the last thing [he] wanted to do is draw more attention to [himself]."

Often, the way special education classes were set up (to involve taking students out for long periods of time) worked against the participants' attempts at appearing like their nondisabled peers. Jackson remembered that his feeling of "otherness" seemed to "lessen a little bit if I stopped going to the full special ed classes, probably like fourth grade." Instead, his teachers started adapting resources and materials for Jackson in the general education class, which caused "the feeling of otherness to be come a bit less."

If masking autistic behaviors or attempting to appear normal was not an effective strategy, participants turned to educating their peers about disability in various ways in order to make their peers feel more comfortable. Zeke called his disability label “a target on my back” that was often “difficult and isolating.” This target eventually led to him disclosing his disability in new contexts as a way to temper the effects of that target:

> People can just tell, they can just pick up that I’m different in some way. And when they can’t really explain it, usually terms like ‘creepy,’ or ‘weird,’ or ‘crazy’ are used. So I eventually realized, it’s in my best interest to disclose when I can.

This disclosure often came at the expense of Zeke’s own comfort, and instead Zeke ended up focusing on making other people around him feel comfortable with disability. He notes:

> The focus was pretty much on me. Having me assimilate, having me accommodate others. The expectation’s always been that I’ll meet neurotypicals halfway, in a neurotypical way. But that is much more than halfway for me, and that just takes up so much more energy.

Maya echoed the need to accommodate nondisabled peoples’ knowledge of disability, this time related to accessibility of spaces she might interact with others:

> I understand that if no one has an understanding or awareness, no one thinks about the fact that if you invite people over to your house, does it have steps? Or if you’re going to have an event in so and so room, is there an elevator? No one thinks about those things.

School provided a very concentrated way in which participants heard the perspectives of their peers about disability issues. Not surprisingly, stereotypes of disability were rampant. Jackson recalled riding what his peers called “the short bus”:

> I don’t know where I picked that up. I think that’s just what all the other kids called it. Because at school, all the long buses lined up, and then the short bus would be out front. All the kids would notice it and I don’t think really…they knew disabled kids rode that, but I don’t think they really knew what the real deal was.

Maya also recalled riding “the short bus”, but used that experience (and its inherent selectivity) it as a kind of power with her classmates:

> I had my own bus, but I got to take my group of friends, so I had to select special people. If I named them, they were allowed on my bus. If I didn’t name you, you weren’t allowed.

Similar to Jackson, Ilia and Zeke thought that their classmates just didn’t quite have an idea about what disability truly meant. Ilia sensed “a lot of resentment” from their peers, because “they probably thought, ‘Oh, they don’t have to do as much as we do.”

The participants were not the only people with disabilities in their school settings. Their recollections of, and relationships to, those other students are an important source of information around identity development. Jackson and Zeke recalled having complex reactions to being associated with students who had more significant disabilities. Zeke remembered a stigma around students in more restrictive class environments: “there was definitely the self-contained special ed students, and I didn't want to be associated with them, because they felt much different from me. There was that one stigma.” Jackson named a similar sense of difference between him and other students with more severe disabilities, but one that gave him an opportunity to reflect on his own ideas about his disability:

> I do remember even when I was in the special ed classes I still felt kind of other, because most of the kids in my class were much more severely disabled and required much more concrete assistance, like either severe mobility problems, or they were completely blind, things like that. When I was in the normal class, I was more disabled than the "normal students", but when I was in the disabled classes, I was less disabled than the "disabled students". I was always in this weird middle place.

Zeke put his classmates’ knowledge in the context of broader ideas about disability:

> I think that the other students just didn’t know, really, what to do with it, ultimately. I was trying to use it as an explanation for why I moved through the world in a different way, and just with the ways kids are socialized and people are socialized in the world, it’s that whole “got to fit into this box” sort of thing. The kids were replicating the messages they got from their parents, from their peers, from their teachers.

While the participants themselves named several different ways in which their peers had expressed their discomfort, they attributed that discomfort to many external factors that all pointed to a lack of information or understanding of disability. In this way, an awareness of others’ ideas about disability was often intertwined with a need to facilitate the knowledge, and comfort, of their peers. Facilitating the comfort of others around disability was sometimes a conscious choice, done in order to gain new friendships or stop negative interactions. Sometimes, participants used the resources that came along with disability (i.e., the “short bus”) in order to gain some sense of power back in relation to the need to educate others, and to have that education result in a positive interpretation not just of disability, but of the individual themselves.

Teacher Feedback About Disability

Teachers were an important resource for students as they moved through their school day and developed disability identity. Often, teachers focused on disability through one of two lenses: normalcy or advocacy. Ilia recalled teachers bringing up disability “when a student would be hyper, they would tell them, ‘Oh, you need to take your ADHD medication.’” As an adult, Ilia named their interactions with teachers as encouraging internalized ableism, as teachers discouraged friendships between students with disabilities in favor of the students appearing normal. They remembered them telling Ilia: “you’re not retarded, don’t associate with those people [other students with intellectual disabilities], even though those people I relate with the most. Don’t associate with them.”

While Ilia’s experience was more extreme, other participants remembered their teachers being unprepared to have open discussions about disability. Jackson thought “there was just a profound gulf of difference. Rather than supporting that difference, they tried to change it.” Zeke suspected his teachers didn’t have proper training to negotiate disability in the classroom:

> They were just really frustrated because they didn’t have the right tools. They didn’t have the right outlooks. I would often get yelled at by some of my teachers when I was having a meltdown, or just doing weird…normal autistic stuff, weird for neurotypicals.

All of the participants thought that the teacher interactions they remembered, particularly interactions that were negative or steeped in ableism, were the result of a lack of shared experience with disability. Ilia thought that having an autistic adult in the school environment “would have been really empowering, would have made me feel more comfortable in my identity. I would have been better able to advocate for my fellow autistics in the system.” Jackson noted that autistic teachers would be especially attune to teaching finite social situations that are difficult to navigate, because “they understand the difficulties and can help.” Maya’s experiences with nondisabled teachers taught her that “if you don’t have a disability yourself, or have any knowledge of it, it’s not something you can learn in a training.” Zeke named not just teachers, but the system that encourages this kind of identity difference in schools: “The special ed system didn’t really prepare me for adulthood in a lot of ways. I’m not really sure why. I think a lot of it is just that the system isn’t built by us. It’s not built by people who understand what it’s really like.”

Jackson, Maya, Zeke and Ilia point to an important lack of not just supportive conversations *about* disability in schools and classrooms that could have supported their identity development, but instructors, role models and other adults *with* disabilities who lead that conversation and otherwise participate in school life. Instead, the adults recalled learning about disability (and therefore learning about themselves) through a largely able-bodied filter from teachers who were both responsible for their education and in large part for their ideas about what disability meant.

School Silence About Disability

The adult participants reported no inclusion of disability in their curriculum, either for themselves as disabled students (in special education, learning about disability itself) or in general education (learning about disability alongside other aspects of diversity or as part of a critical focus on social justice in the classroom). This lack of intentional opportunity to talk about disability is in contrast to the bullying, implicit ableist assumptions, and other experiences that occur without “intervention” as a result of disability in school. Instead, participants shared that they had very little guided or planned discussions of disability as part of class curriculum or towards greater understanding of disability itself, for the individuals with disabilities or their peers. Ilia remembered:

> People didn't really talk to me about what disability meant. I didn't get to learn disability history. The closest we learned about was about Helen Keller. And so I didn't know about people with intellectual disabilities. Nobody really talked to me about that community and how I was in that community.

Jackson attributed the lack of intervention that Ilia identified as related to societal ideas about disability:

> The extent of it was that if you have a disability, we will accommodate it as best we can to get back to the normal topics of discussion. It always struck me as something that wasn't part of the curriculum because it didn't make the cut.

While curriculum was an important place that disability was not mentioned or included, the disability community was also notably left out as leaders and experts in schools. As an adult, Zeke realized that schools are not equipped to break the silence around disability, because "they don't have any autistic adults around just advising them on this sense of identity and what this experience is really like. So the school system and the administrators are left to make their own assumptions and ideas." This lack of representation "produces a situation where the teachers aren't really well trained, they don't really know what's actually going on, they make their own assumptions and it produces really undesirable outcomes."

The undesirable outcomes that Zeke identified were not just related to identity development, but to decision-making by teachers that had an impact on the everyday school experience for the adult participants. Two participants remembered being pulled out of their general education classes to participate in special education instruction. This instruction occurred in a separate classroom, often just one on one with a teacher and instruction focused on their disability. Each participant made a distinction between their "regular" classes and these special education environments, which were separated and often involved the student missing out on elective time and instruction with their general education peers. Jackson remembered “basically during another period of class like music or art, they would take me out and I would go to the special ed room and then go back to my regular class when that was done.” During that time, Jackson practiced reading with large print books due to the effects of his nystagmus, which was the only time that Jackson was able to use these resources.

The experience of removal from general education was significant for Jackson and Ilia both because of the way they framed the difference between “regular” and “special ed” classes, but also because of the effect that their removal from special education affected the other students’ perception of them. Ilia connected removal from general education with an increase in bullying, because “it caused a very unhealthy environment, because the other kids…I don’t think they knew where we were going when we were taken out of class.” Without an awareness of disability identity, the social implications of disability labeling, or the effects of things like removal from general education without any kind of acknowledgement or facilitation, the silence around disability was perpetuated by teachers and left to the students to be responsible for in their own ways.

Experiencing Loneliness

Many of the participants reported experiencing loneliness as a part of their trajectory in developing disability identity. The feeling of loneliness was connected primarily to school contexts, where participants may have felt disconnected from their peers (with and without disabilities). Feeling lonely, while an internal emotion and experience, is also representative of a lack of participation in a broader community.

A feeling of loneliness seemed to be connected to an internal process of emotion in negotiating identity and perceptions of others. Isolation, and an accompanying feeling of loneliness, sometimes functioned as a strategy to guard against stereotypes of disability. Maya remembered feeling herself separating from others in reaction to her interpretation of their ideas about disability: “Well at some point in middle school, I got very closed off. I don't know, I built up a bunch of walls, and I didn't want to be seen as weak, so I became extra tough and kind of scary.”

Importantly, while participants frequently named or remembered experiencing loneliness when they reflected on their school experiences, the experience of loneliness was not a feeling that many of the adult participants shared with others or even named themselves when they were younger. Loneliness and isolation was not a stagnant or constant phenomenon; and neither was it something that felt safe enough to share. Zeke felt a shift in his loneliness, and his language about it, over time: “I didn’t meet any others easily until high school or college. I was lonely. I was isolated. I couldn’t really put words, describe that, until I was much older.”

Other participants reported experiencing loneliness into high school and college, and in some cases felt regret about not “resolving” their loneliness earlier on in their lives. Reflecting on this regret, Jackson remembered the pressure to focus on academics over building social relationships and community with his peers:

> “[In college] was still pretty isolated, just kind of on my own going through it. People would know who I was; they would recognize me from class, but I never really formed any direct connections with other students. I never joined any groups, which I profoundly regret now, but I didn't realize at the time that it was as important to do as it was. In that sense, it was pretty similar to my high school experience. I just kind of kept my head down, focused on my schoolwork, and just got through.”

For Jackson, this loneliness and isolation had real consequences for finding work after graduating college. He noted that in part because of his social isolation and lack of social network, he “dropped into unemployment for years,” a common experience for disabled adults. As he told the story of his difficulties with employment, he remembered an experience in high school that unfortunately signaled this compounded experience of loneliness and isolation, to come:

> Because I even had this feeling in school. I just had this vague feeling that my adult life was going to be really hard, but not for any specific reason, just this kind of general feeling of foreboding. I remember it was very palpable one time when I went [with a family member to a corporate office]. He took us on a tour and I was walking through just the general office environment with cubicles and water coolers and all this stuff. I almost had a break down in there because I just had this incredibly palpable feeling that I can't do this. This is part of a world that I'll never be part of. I won't be able to function in this kind of environment. This incredibly oppressive weight, yeah. I just wanted to curl up into a little ball and disappear because I'm not going to be part of this world.

An important feature of how each individual thought about loneliness was in reaction to cultural and societal ideas about disability that made each individual feel separate, different, and incapable of participating in the “normal” world. This experience of loneliness shaped not only their initial ideas about disability, but the eventual choice to reach out to more community-focused ideas that would shape their identity around disability in more positive ways.

Protective Identity Resources and Experiences

In contrast to the negative identity resources that were mostly school-based for participants, protective identity resources and experiences (that is, those that shaped or developed disability identity in a positive way) were primarily based in disability culture and community. These resources and experiences were mostly found in either “outside” community spaces in adolescence, or in adulthood through engagement with social media or disability role models. These protective identity resources and experiences include awareness of the social model of disability, participating in disability organizations, and accessing cultural resources.

Awareness of the Social Model of Disability

Whether or not the participants were able to name it using a specific term, the social model of disability was a major resource in terms of developing a disability identity over time. Zeke explicitly named the social model as a way he was able to reframe negative ideas about disability:

> I follow the social model of disability. In that, it's society that disables me. [In school], I absorbed the negative message that society has around disability. It's almost framing disability as a challenge, and something to be overcome. In a lot of ways, it might be easier to buy into that message, because you don't have to realize just how much society goes against people with disabilities. The social model helped me reframe that narrative.

Ilia named barriers around acceptance for disability as a major way that she came to "justify" having a disability identity: "a lot of [struggles in school] doesn't have to do with the disabled person, it has to do with policies that's not created for them. So I'd rather get those barriers [removed] than to not identify as disabled."

Maya and Jackson did not name the social model explicitly, but discussed ways that their thinking had changed over time, and was influenced by the idea that disability is created in inaccessible environments. This perspective impacted ideas about independence, and experiences in special education. Maya discussed her shifting ideas about independence over time, especially as she navigated inaccessible environments that frequently required her to ask for help:

> If you had asked me back in high school, I would have said that independence meant that I was doing everything completely 100 percent by myself. And for the longest time, and I think it probably started in middle school, I just had this idea that I could never ask for help because people would think I would need help all the time with everything. I don't want that. I still don't. But now I can still feel independent and ask for help, because sometimes I just can't push up the giant hill.

Jackson reflected on his experience in special education, and used the social model (indirectly) to evaluate that experience based on the tools that it had equipped him to use in inaccessible environments:

> On the vision front, I feel like special ed did pretty good by me. They practiced, they put me through large print readers and stuff to get me reading. They'd give me printouts of

> notes when I needed them, using monoculars, being able to read bus schedules and ride the bus, logistical things. I feel like that was pretty good.

While it would be easy to see the social model as a justification for getting rid of labels in favor of a completely accessible society, Zeke focused on a different point that illuminates both the social importance of disability identity, and the resources that participants have to develop that identity:

> In a perfect world, sure, we wouldn't need labels. But it's also, people need supports. Having these labels to describe what kind of supports they will require is useful. We are, in a lot of circumstances, focusing on the labels and seeing the labels as negatives, rather than providing the supports.

Part of the internal negotiation that participants reflected on involved reframing negative ideas about disability into positive ones. Pride in disability meant different things to each participant; however, in all cases, it involved reframing old or previously held ideas about disability that took time to develop and shift. Jackson felt a shift in his own thinking when he reframed difference into "uniqueness":

> I wasn't ashamed of it, so I wouldn't say that. Proud of it, I guess in the sense that I understood in some way that it gave me a unique life experience and a unique perspective that was uncommon. In that sense, I was just proud of that because it was basically rare. Something that less people had, so I would say it was more special to me.

Reframing disability as a difference that makes you unique was helpful to Jackson, because he was able to see himself as one of a few in a positive way, rather than a negative, isolative way. Similarly, Zeke's internal ability to resist others' ideas about autism eventually caused him to feel proud of his disability:

> "I realized that I'm not going to grow out of my autism. I'm always going to be autistic, no matter how much therapy they try to throw at me. Just realizing that, 'Hey, maybe it's not a bad thing,' now that I'm not receiving all of those negative messages from the other students, and my parents, and everyone else. It's a positive reframing of the identity."

Developing more positive senses of evaluation of disability identity involved exposure to different philosophical ideas that reframed disability from a medical to a social model. This reframing of disability did not immediately cause the participants to want to identify with a disability community; instead, it allowed them to think back on their school experiences and reflect on the barriers in school that caused them difficulty, rather than the barriers within themselves.

Participating in Disability Organizations

Since school was generally a place where participants experienced bullying and negative feedback about their disability from peers, many of the participants looked to other, outside organizations to develop disability identity and awareness more positively. Zeke, Ilia and Maya specifically mentioned organizations, summer camps and/or sports teams that involved only other people with disabilities as participants. This distinction was important; if school was at best full of complex negotiation of nondisabled peoples' perceptions of disability (and, as discussed, this negotiation often resulted in loneliness and bullying), then the outside organizations offered a different way of seeing disability: that it might be a source of interest, rather than shame. For Ilia, participation in Special Olympics helped them re-frame their own disabilities:

> "But when my fellow friends who also are intellectually disabled got me introduced to the Special Olympics, and people started talking to me about the fact that I had a disability. I started getting curious."

Eventually, participation in the Special Olympics led to further participation and activism for Ilia, and further allowed them to explore how they might identify with the labels other people had assigned to them:

> "After, when I got involved with [large, state-wide advocacy groups] and all of the self-advocacy movements is when I started identifying with [autism]. Before I was just identifying with ID [intellectually disabled] or DD [developmentally disabled]."

Zeke mentioned a summer camp for people with autism that he attended, where "there were others around there who had similar experiences" that caused him to develop a sense of identity around disability. He thought it was especially important that the camp wasn’t structured to involve intervention:

> We were away from home for like a month, with other kids who either are neurodiverse, or have physical disabilities. It's just letting us be kids, not doing any of that therapeutic stuff that a lot of the special needs camps that I see around here are doing.

The summer camp experience allowed Zeke to focus on developing relationships with other people who shared similar experiences; this process had a positive effect on Zeke’s ideas about himself and what he had to do in order to minimize his disability:

> Just seeing that there were so many other people like me, that really helped raise my self - confidence. In high school, I think in some ways I was more okay with who I was, but I was also very much focusing on masking as well. Had that ‘being indistinguishable from peers’ thing going on.

As an adult, Zeke currently coordinates a large, state-wide autistic meet up group that connects people together based on their shared histories, experiences and interests. The first time Zeke attended the meetup group as a participant, he felt immediately understood:

> There were people who were there who got it, who go through the same thing I do. I didn’t have to explain myself. I always have to explain or justify my people’s existence. It’s one of the first times I really didn’t have to do that when having a conversation around autism. I realized that we need more of these groups everywhere.

Maya, in part because of her mother’s connections to the local disability community, had the most experience with outside organizations that gave her a sense of community around her disability. This included adapted basketball, swimming and rowing teams; an afterschool academic program for students with a variety of physical disabilities; attendance at national disability conferences; and a local university program for students transitioning to college. This amount of participation in outside organizations allowed Maya to begin to notice differences in the social hierarchy of the disabled community that the other participants didn’t name:

> At [a university transition program], this maybe sounds weird, but everyone’s disabled. So we’re already all equal there, but it is a chance for…everyone there is a little bit cliquey. As much as we say it sucks, it kind of doesn’t. It sucks for the people who don’t end up in

> the cool crowd, but for those who do, it’s probably their first and only chance where they have been considered a cool person. Some of them are in the cool crowd in their regular community, but part of me wonders, is that out of pity? No one says it out loud, but that’s a huge thing. Is that out of pity?

Maya’s idea of being “in the cool crowd” in an all-disabled community, contrasted with the automatic suspicion that comes with the same status in a community of disabled and nondisabled community, differed from her experience in her afterschool program:

> [It was] not always awesome, because I only had a physical disability, a lot of them had intellectual disabilities or other things that cause them behavioral problems and stuff. So there was no one really on my intellectual level. Well technically, yes the wheelchair meant I apparently had to go to a special place, I didn't ... and I'm sure they could have sent me somewhere else.

In this way, Maya’s numerous participations gave her both a large set of relationships and experiences with other disabled people, and a more complex (and sometimes hierarchical) idea about disability itself. At the other extreme, Jackson did not participate in any outside organizations related to his disability while he was in school. In adulthood, he mentioned that sometimes, his feelings of anxiety about socializing worsened when he was around other autistic people. Nevertheless, he mentioned currently trying to work up the courage to go to a local autistic meetup group after an earlier experience with autistic groups that “was such an awkward experience, it kind of scared [him] off.” He was motivated to try again, though, for a particular scenario in his mind: “I guess the absolute best-case scenario is I would hope to make a friend, like an actual friend, which I'm trying to think of the last time I made a real friend.”

In the absence (and sometimes, active discouragement) of disability community in school contexts, participants identified places and spaces outside of school where they became behaviorally involved with disability. These spaces were sometimes complex, causing internal questioning about disability hierarchy that recalled how participants distanced themselves from more significantly disabled peers in school. Most often, though, participants recalled their participation in outside, disability-focused organizations as comfortable, affirming, and rare in their lives and identity development.

Accessing Cultural Resources

While it’s important to frame disability as more than just a shared experience of oppression, Ilia pointed out that disability culture itself is a unique phenomenon because people with disabilities “have their own culture, we have things that we share in our experiences and oppression.” None of the participants recalled learning about disability culture or history in their school experience. Instead, each individual participant developed their sense of disability identity and disability culture alongside it through different cultural resources, with varying levels of success. Online groups and searches were one way in which participants tried to learn about disability. Zeke did “some Googling about autism and the Disability Rights Movement, and came to a lot of Reddit and Facebook threads” which involved “dysfunctional people just being weird and sad with each other.” Ilia recalled watching media, like the movie The Ringer, about an nondisabled person posing as a Special Olympics athlete, which employed an almost entirely disabled cast and was widely praised in the intellectual disability community. In the movie, Ilia remembered identifying with the intellectually disabled athletes’ as they worked out how to handle the “intruder” in their community: “The athletes, they all knew he was fake. They could tell he wasn’t part of the community. But once he started being himself, they were more willing to work with him.”

Maya and Jackson discussed the importance of role models and familial learning as a cultural resource. Maya’s first wheelchair was originally her mother’s; when she was adopted from India, Maya’s mother taught her how to “practice going up the hill and coming back down.” Jackson remembered his older brother, who also has a visual impairment, as “kind of a guidepost to see what was coming up" as far as future experiences and concerns. For his autism, though, Jackson wished for "someone who is just really similar to me who could tell me, 'hey, this is what's going to happen and you need to deal with it now while you have the chance.'" This lack of autistic role models in Jackson's life affected his later identification with the disability community:

> I don't feel like I'm part of any kind of larger disabled community. I feel like I'm just a person with disabilities, but I don't feel any kind of group identity from that really. It was just something that I had and I know other people have it. I needed role models who were more similar to me whose experience I could directly relate to.

While Jackson did not report a strong connection to the disability community as an adult, he was able to self-categorize as someone with a disability and name the things that he needed in order to eventually find that collective identity and community.

In similar ways that participants found connection and community in outside organizations and activities, they reported developing a connection to disability culture as part of their behavioral involvement. Connecting to disability culture involved media, familial knowledge, and online groups; importantly, it occurred outside of school and often into adulthood before the participants became exposed to these resources to connect to culture and community.

Discussion

Maya, Jackson, Ilia and Zeke's life histories and ideas about disability identity provided a number of rich resources for understanding this phenomenon in school contexts, as well as over time and into adulthood. Their ideas and stories about disability identity development, as well as disability awareness and knowledge in school contexts, helped form a multi-dimensional, multi-faceted view of the resources, experiences, and processes that students have to draw from in order to help understand who they are in relationship to a disability label and a collective community of disability.

A major context in which participants made meaning out of their disability label came through different experiences and identity resources in school, which were primarily oppressive and negative. While the school-based focus of the study was made clear to participants as a part of the process of completing both the life history and semi-structured interview, participants independently noted that their conception of who they are (and the positive and negative resources they used to develop that idea) were rooted in school contexts. In the process of analyzing the data based on the collective identity framework, excerpts included in this findings chapter were most frequently coded as related to school experiences, settings and relationships. This is important for the broader context of this study as a justification for intentional discussion and development of disability identity in school.

While the findings presented in this chapter were broken up into different aspects of collective identity development, there were many times during the analysis of this phase of the study that those lines became blurred and often difficult to delineate. This is the nature of identity development: the participants became who they are because of the totality of these aspects of collective identity, and because of the constant meaning-making, consciously and unconsciously, that they engaged in in different contexts. Some of this meaning making was painful; some of it led to community and solidarity. Some of it led to reinforced negative cultural ideas about disability; some of it led to adult commitments to advocacy. Ultimately, the adult participants were engaged as students in sorting through an immense amount of feedback about the meanings of their disability labels and the (positive or negative) internal reactions they had to that meaning. In a cultural, social and individual context where being labeled with a disability meant experiencing loneliness, bullying, separation from peers, and other negative outcomes as a part of an individual's interpretation of a fundamental part of who they are, it might even be considered an unintended consequence that these participants also developed disability pride and participated in disability communities in adolescence and adulthood.

The participants' experiences hold extremely valuable lessons and implications for work with adolescents who have disabilities. One of the benefits of reflecting on a life history or previous experience in school is that the participants can name the things they were deeply needing, wanting, or missing in their school experiences. Current schooling contexts can benefit from these stories. A goal of doing identity research with school-based implications is to minimize the negative resources that people experience in forming identities. While many of the resources discussed in this phase of the study are directly shaped by or occur in school settings, there are some things that are beyond the control of teachers, classrooms, curriculum and peers. The participants themselves echoed this need for more direct, explicit discussion around disability identity in their interviews. Zeke implored teachers to do this work: "Just reinforce the idea that it's not their fault, it's quite okay to have a disability. Success means being able to make the choices that you want. They have the right to be supported in the way they need." The participants' stories offer opportunities to intentionally strengthen and name disability as an identity experience in school, so that the things that are beyond the control of schooling contexts may be counteracted by a context that is offering guided and supported opportunities for students with disabilities to explore that label and that aspect of who they are.

Chapter Summary

Chapter 4: Struggle for meaning

[redacted]

[redacted] social relationships and hierarchies of all kinds [redacted] making meaning out of disability [redacted]

[redacted]

[redacted] self-advocacy [redacted] in order to be seen [redacted] how they want to be seen, [redacted] in [redacted]

[redacted] the struggle [redacted]

[redacted]

CHAPTER 5: SCHOOL PHASE FINDINGS

"Normal is people that are highly intelligent in everything and smart and can keep up with others and everything. That's what it's like for me. But I can't be like that. I don't work like that."

The second phase of the study was designed in response to the thoughts, perspectives and suggestions from the adults in the first phase of the study. The adults overwhelmingly named school as a place where they remembered significant negative experiences that developed their disability identity. In this phase, I attempted to both investigate current ideas about disability the students held, as well as open up an intentional conversation about disability identity in the context of a life-skills course. These inquiries supported my research questions, which focused on three major ideas: particular identity resources that adolescents drew on in order to form and develop disability identity, the role of school and schooling in this development, and the similarities and difference between identity development between adolescents and adults.

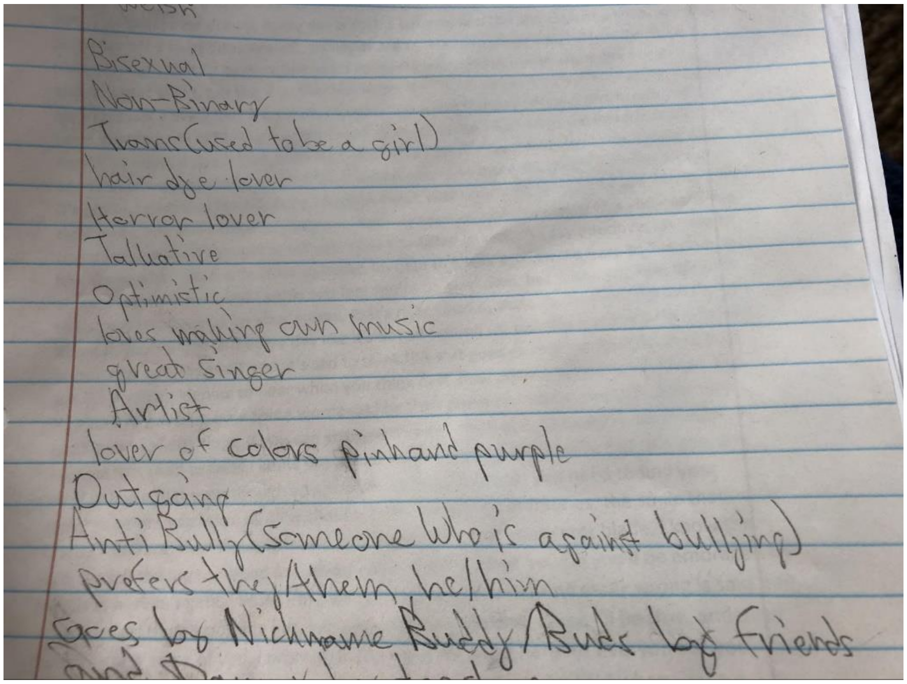
These questions (and the finding from the adult phase that school is an important site for disability identity development) supports a broader call from inside disability studies literature, that encourages educators to address and include disability explicitly in curriculum and educational contexts. Smith, Gallagher, Owen & Skrtic (2009) offer some guidelines and standards for educators who are aligned with, and supportive of, the goals of the disability rights movement, field of disability studies, and connection between disability and social justice. Disability pride and identity is included as a guideline and practice for educators, following collaboration with those in the disability studies in education community (Smith, Gallagher, Owen & Skrtic, 2009). Disability identity and pride are discussed in this context as not just intertwined, but also important in resisting dominant narratives of disability in schools:

> Exploring the intricacies of disability identity includes choosing and taking pride in it, in contrast to societal expectations of overcoming, adapting, and making disability irrelevant and invisible (Smith et al., 2009, p. 243).

In this chapter, I explore some of those intricacies. The school phase of my dissertation included four data sources: qualitative student interviews, a photovoice project including photos, reflections, and an "I am…" activity; and an interview with the students' life skills course teacher. I include all of these data sources in this chapter on "school findings" as they all represent the collective set of data that students used to both represent, and reflect, their identities around disability. These findings explore the current resources students have in forming disability identity, whether these resources were brought up by the students or developed in the context of the more structured and intentional photovoice project. The resources have many shared points of affinity with, as well as important deviations from, the adult interview findings discussed in an earlier chapter.

The students in this phase of the study were "in the process of becoming" (Greene, 1971). As in the earlier adult chapter, I present "portraits-in-progress" of each participant (Connor, 2008), including their hand-written responses to the "I am" activity by way of introduction.

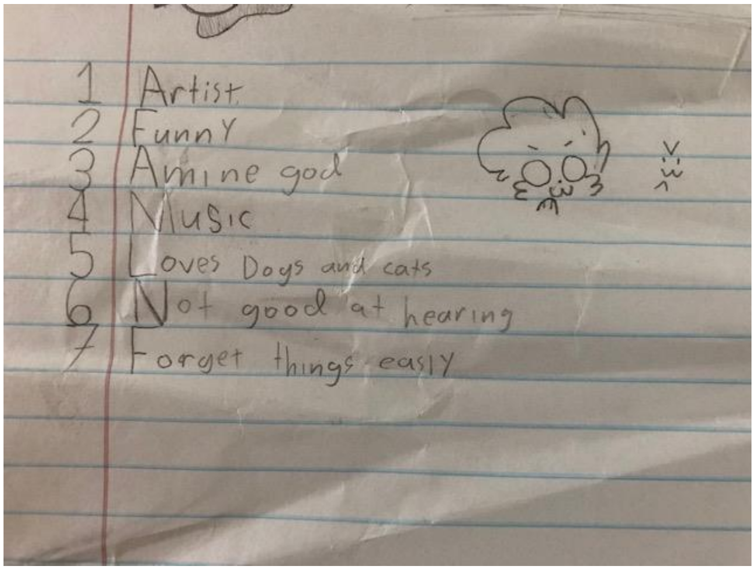
David, a white nonbinary student labeled with autism and learning disabilities, attended the first day of the school sessions in a bright yellow Pikachu costume, their Converse covered in hand-written song lyrics that they traced over in sharpie as the class began. They were energetic, talkative, and gregarious: eager to raise their hand and participate, and just as eager to answer with a seemingly disconnected thought from the original question. David was enthusiastic about the discussions and interview process, even as they openly named difficulties in their own life around suicidality, depression, and conflicts with other students. Their matter-of-fact way of sharing their own experiences belied the pain they had been through.



Bisexual
Non-Binary
Trans(used tobe a girl)
hair dye lover
Horror lover
Talkative
Optimistic
loves making own music
great singer
Artist
lover of colors pinkand purple
Outgoing
Anti Bully(someone Who is against bullying)
prefers they/them he/him
goes by Nickname Buddy/Buds by friends

Figure 2. *David's "I am…" activity: bisexual, non-binary, trans (used to be a girl), hair dye lover, horror lover, talkative, optimistic, loves making own music, great singer, artist, lover of colors pink and purple, outgoing, anti bully (someone who is against bullying), goes by nickname Buddy/Buds by friends.*

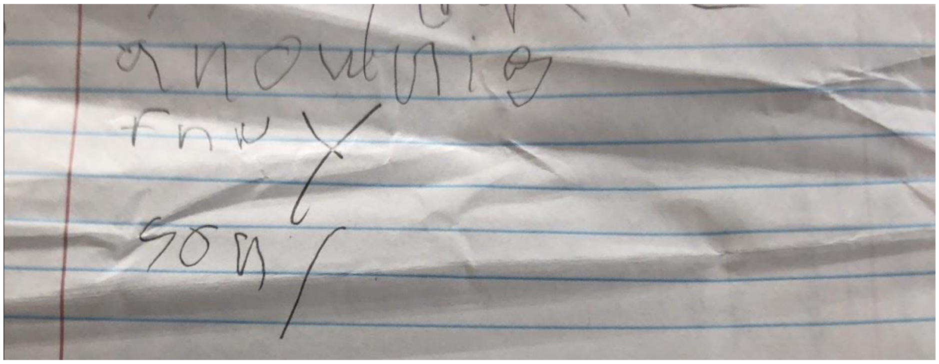
Quentin, an African American cisgender male student labeled with intellectual disability and learning disabilities, spent the majority of his time before and after (and sometimes during) class with focused on a spiral notebook, drawing anime and cartoon characters and doodling. Often, these drawings were in response to the "action" in the classroom. Once, after I asked Quentin to share a photo and reflection from his photovoice project, I looked over to find him drawing a small cartoon animal with a speech bubble: "stop asking me stuff." He was gentle, quiet, and thoughtful; several times in the study, he shared his experiences with a preface that what he was about to share was personal and he had never shared before.



1 Artist
2 Funny
3 Amine god
4 Music
5 Loves Dogs and cats
6 Not good at hearing
7 Forget things easly

Figure 3. *Quentin's "I am…" activity: artist, funny, amine [anime] god, music, loves dogs and cats, not good at hearing, forget things easily.*

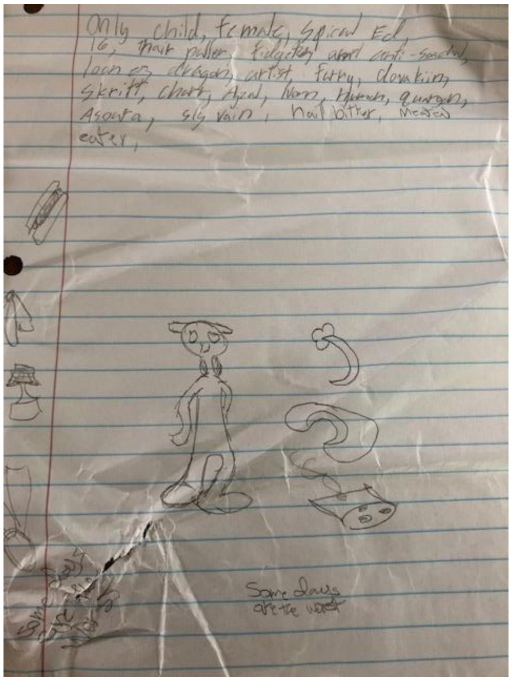
Bryce, a white cisgender male student labeled with intellectual disability and learning disabilities, blasted rap music from his cell phone constantly like his own personal entrance music into the life skills classroom. He answered most questions, from me or his peers, monosyllabically; he seemed to enjoy the back-and-forth negotiation to get him to eventually participate and engage in more depth. Several times, he interrupted conversation in the class to tell the other students about a cool car he had seen at his afterschool job at a car dealership, or how much money his friend made as a professional hockey player. He was full of bravado and charisma, fist-bumping teachers and talking about his plans to make millions.



anouinig
fnny
son

Figure 4. *Bryce's "I am…" activity: annoying, funny, smart.*

Vanessa, a white cisgender female student labeled with intellectual disability and learning disabilities, walked into class in the second day of the school sessions crying and pulling out a few strands of her patchy buzz cut hair. She had been called the "r-word" by a peer in a previous class period. In a few short minutes and after time on her own to gather her thoughts, she came to the group smiling and cracked a joke about David's sharpie-covered shoes. She was responsive and conscious of her peers in the classroom, reacting to their stories and photos, reminding them of the rules for the project, and admonishing them when they talked out of turn.



Only child, female, Spical Ed,
16, hair puller, fidgiter and anti-social,
loves dragons, artist, furry, dovakiin,
skritt, charr, Azeal, Norn, Human, quargon,
Asoka, sly vain, nail bitter, Measo
eater,

Some days
are the worst

Figure 5. *Vanessa's "I am…" activity: Only child, female, special ed, 16, hair puller, fidgety and anti-social, loner, dragon, artist, furry, dovakiin, skritt, charr, Ayzal, ivorn,[imaginary fantasy characters], human, quargon, asoura [imaginary fantasy characters], sly, vain, nail biter*

Each student in the school phase of the study developed disability identity through several major experiences and identity resources. Interestingly, several of these resources and experiences were similar to those mentioned by the adult participants. These included initial realization and continued negotiation of disability labels, as well as embodied experiences of disability. As in the adult phase, some resources were inherently negative: students reported feeling isolated and lonely, as well as being bullied by their peers. However, students in the study reflected positively about certain resources that were considered negative to the adults: this included removal from general education into self-contained classes and use of accommodations in school. Students also noted resources that were not mentioned by the adults with disabilities, including social media and online experiences, and a strong interest in art making, music-making, and themselves as artists in general.

Supporting an earlier study of disability knowledge in adolescents (Mueller, 2018), the adolescents in this study were deeply engaged with internal meaning-making about their disability label and the ways that disability affected their social relationships and school experiences. Because of the context of this study (and the ways that disability had been talked about in the life skills course up to this point), students often used similar language to their teacher to describe their thoughts about disability, or named their discomfort with talking about disability in different terms. Importantly, this does not mean that students were not engaged in thinking about disability as an aspect of who they were; if anything, the following resources demonstrate students who are just beginning to gain the skills to talk about processes that have been at work for some time.

Importantly, while the adults named particular culturally-focused resources such as the social model of disability as important to their development of disability identity, this did not surface in the interviews and therefore it is not represented in this findings section. What follows is a discussion of the resources found in the school phase, organized by similarities and differences in conversation with the adult participants.

Similar Identity Resources

Negotiating a Disability Label

In the beginning of the school phase, the “I am…” activity gave students a chance to reflect on different aspects of who they are. It also gave me, as the researcher, an opportunity early on to see if students would independently list disability or aspects of their disability label as part of their identities without prompting. Two of the four students listed disability in some way as a part of their identity. Interestingly, rather than listing specific labels or IEP-based language, both Vanessa and Quentin listed behavioral aspects of their disability. Quentin wrote he was “not good at hearing” and “forgot things easily” as an aspect of his identity. Vanessa listed both aspects of her specific disability (“fidgety, anti-social”), but also named “special ed” as part of her identity. David and Bryce did not list anything related to disability as a part of their “I am…” activity.

The students who named disability as part of their “I am…” activity also identified themselves as having a disability in their interviews, but their ways of describing disability differed. Quentin continued to talk about his disability in terms of specific behaviors he struggled with in school:

> My disability is basically my…how I forget and stuff, because, I used to know how to do divide-bys for like a week or two weeks, I forgot all about how to do that and stuff. And how to read what a…basic, well, and stuff. And I’m really mad about it and stuff.

Vanessa, on the other hand, called herself “special ed” in the activity but called herself autistic in her interviews. She also named some complexity between her own internal ideas about the label versus what others might say about it:

> With autism, I have it. Yes I am autistic, but then you can just look past and also say a person. Yes I have a weird sense of humor, yes I’m very dark, but I don’t mind being called autistic. I do mind being called mean names and stuff, or “this person is disabled,” in a mean intent. You can be disabled and be fine with that, but you can also have people call you disabled and they have more of a tone in their voice, in their face. You just have to be careful with it.

Interestingly, both Vanessa and Quentin talked about disability as a concept in remarkably similar ways. Quentin thought that disability meant that “a person can’t do well like everyone else because everyone has different minds, different emotions and everything.” To Vanessa, disability was “not being able to do something, but that’s not what it means to me. It’s just…I guess you’re different. But everyone’s different. I don’t know.” There is tension in both of their definitions of disability: between disability as a deficit in an individual, followed almost immediately by the idea (or trope) that everyone is different in some way. The idea that “everyone is different” surfaced multiple times throughout the entire school phase.

In both cases, Quentin and Vanessa are beginning to explore what it means not only to name aspects of disability as part of their identity, but to try out different language and perspectives to describe that identity. Quentin focused on the specific deficits he saw as a result of his disability that affected school. Vanessa was highly aware of disability as a concept that was connected to her internal ideas and comfort level with being autistic, but also about her reaction to others’ judgement of the label. This carried into the photovoice project, where she took a photo of the life skills room’s mock-bedroom, used for practice making beds and putting away laundry. Vanessa took a photo of the room and then described her reasoning for taking the photo in the group discussion.

***Figure 6.* Vanessa’s “Dark classroom bed” image**

Vanessa described:

> It shows how disabilities are sometimes hidden and aren't always visible. It also shows I'm really accustomed to dark rooms. A dark room with peace and quiet ... I am going to go straight to sleep. And it's good or bad. It's just in the middle, sort of. What's good about it is, to know that you aren't alone with having invisible problems. And it shows just how you sometimes have invisible problems.

While the photo itself was not depicting disability directly (except for its association with the life skills class), Vanessa used the photo to talk about an experience of having an invisible disability and, occasionally, “invisible problems” that other people might share if they are named that way.

In contrast, two students seemed to be at a different place in wrestling with disability and talking about it as a part of who they are. David and Bryce, who did not list disability as an aspect of who they were in the activity, had more complex ideas about that identification in the interviews. David said they “more or less” saw themself as a person with a disability, but this identification had more to do with their definition of disability: “I don’t think ADHD is technically a disability, but I sort of consider it, like the impulsivity. I think it makes half of me who I am. Or some of it." Bryce had a similar sense of vacillating between identifying and not identifying with disability, but in reaction to the negative connotations of the disability label itself. This vacillating even occurred in a quick back and forth exchange:

> Carlyn: Do you see or think or yourself as a person with a disability?
> Bryce: No.
> Carlyn: No? Why not?
> Bryce: Because. My life's good. It's great. I'm living life to the fullest and doing whatever I want.
> Carlyn: So disability means that you have something bad in your life?
> Bryce: Yeah, yeah, pretty much yeah.
> Carlyn: Do you have a disability yourself?
> Bryce: Yeah. Yeah.

Bryce and David wrestled not just with whether to consider themselves as people with disabilities, but with the proportion of themselves that that disability label might impact, and the meaning that the disability label had in response. To Bryce, having a good life and having a disability were incongruous. To David, disability impacted only certain parts of himself or his life, so disability itself could be segmented and separated from the "rest" of who he was.

As students internally negotiated their disability label, each began to express their ideas and thoughts about it in different ways. Whether they named it as part of their identity or not, each student was internally engaging in a complex negotiation around whether disability was a positive thing, or a negative thing; whether disability affected every aspect of who they are, or a part, and whether disability was a wholly engrossing label, or something that made just school difficult.

Whether or not students were ready to discuss their disability identity publicly, in school contexts, or with a teacher, they were certainly engaged in meaning-making and processing about the impact of that disability label on their lives in school. Masking a disability, while a salient resource for the adult participants in the first phase of the study, was not an explicit or stated goal for the students in this phase of the study. Instead, students are engaged in defining the bounds of normalcy (and often situating themselves as “not normal”).

Embodied Experiences of Disability

Adolescent participants were engaged with attempting to make sense out of the labels that had been assigned to them. Adults with disabilities discussed the ways that their impairments impacted their relationships with others; adolescent impairments processed the meaning and embodied experience of a disability through comparison to peers.

Interestingly, all of the four students responded very strongly and differently when asked if they might take a magic pill that would take away their disability (a similar question asked of adult participants in a study of disability activism (Hahn & Belt, 2004)). Quentin and Bryce responded that they would take the magic pill. Bryce thought a magic pill that would take away his disability would then “make him smarter.” For Quentin, taking the magic pill meant he would have an easier time in school, academically and socially:

> I would work more easily, and I wouldn’t have that much help. And I would pretty much kind of study more better because, if I study anyways, I’m going to forget. It affects how I’m doing all around, everything.

In both cases, taking a “magic pill” would not have a material impact on their social or internal lives in relationship to disability (i.e., one might imagine students taking a magic pill to remove disability might increase popularity or self-esteem). Taking the magic pill instead pointed towards better performance inside of school and in relationship to academic skills and abilities.

David and Vanessa both said they would not take the magic pill, but had two very different explanations for why they would not make this choice. Vanessa mentioned that she felt that she might not need it: “I don’t think I would. I can overcome it. I can just overcome them naturally. I don't want to…I'm taking pills for anxiety and stuff already." David connected taking the magic pill with getting rid of a big part of who they were as a person:

> I would say no, because mainly to me that's just taking away on who you truly are. You're basically erasing who you are, you're not being yourself, and you're just doing something completely different, which is not normal for you. So I would say no.

Vanessa and David, in contrast to Bryce and Quentin, focused on the magic pill as impacting what they saw as a large part of who they were. For David, this "part" was a positive; any removal or change of his experience meant a negative change from how he thought about himself. For Vanessa, taking the magic pill took away a sense of her own agency and control of her disability, in one sense through "overcoming" the disability label and in another through her choice to take a different medication.

All four students' answers reveal important ways of understanding their ideas about disability and disability identity, and about each of their embodied experiences of disability. For Quentin and Bryce, their acceptance of the magic pill is wrapped up in an idea about what removing disability might *do* for them, their embodied experiences of what it means to have their particular disabilities (especially around perceptions of smartness), and their performance in school. Quentin especially was engaged in comparisons and categorizations between himself, his abilities, and others':

> I have a slow mind and stuff. And a lot of people have pretty fast minds and people have medium minds and some people have slow minds. I can't work that usual…like everyone else does and stuff.

Quentin's identification of himself as having a "slow mind," in comparison to everyone else's "fast minds," demonstrates his comparison and awareness of his own abilities and others'. Importantly, Quentin uses a deficit lens to talk about himself in comparison to others: his slow mind is unable to work at everyone else's usual pace. He is not concerned with either reinterpreting his mind as different or “special,” but instead matter-of-factly notes that his mind is just slow.

For Vanessa, choosing not to take the magic pill might give her some control over “fixing” her disability on her own. This was a concern, as she thought about her future and what she perceived as possible after high school and beyond:

> There is a lot of jobs that can give you a lot of money, even if you went to high school because you need to be super smart and get good grades to go to college, but I won’t be able to go and stuff. Because it’s highly intelligent stuff and I would forget it. If I was really smart, I might forget stuff, and it wouldn’t be good because I’d go to class and I would forget stuff.

Vanessa points to an awareness that her disability will continue to have an impact outside of high school and into her adult life. She is conscious of wanting to participate and be successful outside of school, but cannot imagine how that might be possible without a magic pill that would take away her disability. While many of the students focused on what having a magic pill could do for them in the moment and in their current school context, Vanessa’s awareness was focused on curing her disability for the long term plans she had for herself.

For David, who didn’t initially identify as having a disability in his “I am…” activity, choosing not to take the magic pill was an affirmation that disability was a part of their identity and the way they saw themself as a whole. Interestingly, the idea of disability as a part of a whole came up even as they struggled to decide whether disability was important to them, or an annoyance:

> I don’t really care that I have this disability, as long as people still see me for who I am. I have to deal with being a little bit impulsive, because I feel really bad when, let’s say if I slam the laptop down out of impulsiveness, I would feel really bad immediately after. But I just feel really bad if I just did that.

David’s distinction between his internal feelings about disability from others’ perceptions of his behavior comingled with a deeper point: disability was not a concern for David, as long as others' saw him for "who he was." Presumably, this is as a person with a disability, which would then explain some of his impulsive behaviors: but it was important to David that disability not be the only descriptor. While these are individual answers to a complex and theoretical question about what it means to internally negotiate disability, each of their answers reveals a way in which the identity resources around disability are already at work in shaping students' differing ideas about disability and what place it holds in each students' lives.

Integrating Disability with Other Aspects of Self

While the "I am…" activity was an important way to see whether students named disability as a part of their identity independently, what was also illuminated in this activity was the myriad other ways that students identified themselves. Some of these were self-identified personality traits (Bryce wrote "annoying, funny, smart"; David wrote "optimistic, talkative") some of them were roles (Vanessa wrote "only child," Quentin wrote "anime god") and some of them were intersectional identities (David wrote "nonbinary," Vanessa wrote "female"). While two of the students named disability either explicitly or implicitly as a part of their identities, what was more prevalent and significant were other aspects of students' identities. This raises two important points of divergence from the adult interviews: for the students, disability was not necessarily prevalent in terms of defining themselves, particularly to other people. While disability might be a significant part of their experiences in the world and in school at this point, it was not an identifying factor in the same way that they might readily identify themselves as nonbinary or even as an anime god. This is not a necessarily surprising finding or starting point: if disability has primarily been constructed as a negative aspect of individual bodies and minds, students have received plenty of feedback that identifying with disability as a part of who they are is by definition identifying with that stigma.

This prevalence of other identities, and the process of integrating all of those identities, continued into the interviews. Each student, when asked to describe themselves, chose to use either traits, roles or intersectional identities that were separate from disability. David noted, “I make music, I am the president of an anti-bullying club that I just started and got set up. I can play the drums. I can play the guitar. I love horror movies.” Bryce also started with roles and strengths: “I work on a farm, I know a lot about cars, I know a lot about firearms, I know a lot about sports. I’m traveling to Dubai for soccer.” Vanessa started defining herself in terms of her family: “My mom is a dispatcher for First Student, my dad works with…he’s not a zookeeper, but he’s one of the people that works with monkeys for vaccines and stuff like that.” Here, again, students are not mentioning (implicitly or explicitly) disability as a part of who they are; they are instead focusing on knowledge they have, roles they play, or people they know that help shape who they are.

Awareness of Others with Disabilities

If the students were not mentioning themselves as people with disabilities explicitly, who would they identify as disabled in their school or broader community? Overwhelmingly, students were aware of people with disabilities in their school and community who had either visible physical disabilities, or more significant disabilities that affected their communication. Quentin noted that having other friends with disabilities held special benefits:

> It can let you get in some good conversations with others that do have it [disabilities] and stuff too. Because then you have something that’s similar to theirs, or if they have a disability and you have a disability, they would probably want to hang out with you more and know what yours is like too.

Quentin identified an important step towards seeing disability as a potential source of connection between people, that first occurs inside framing disability as a negative or neutral idea. If disability is something that exists inside of an individual and affects that individual’s life, it's important to meet other individuals who share that experience to relate to and confined in. In contrast, Vanessa and David specifically mentioned relationships and friendships with peers with disabilities as a way to compare themselves. Often, they defined their own abilities in relation to what their peers could not do, and peers who are seen as less than or more needy (instead of a shared disability community). Vanessa explained:

> Most of these school friends are more, they need more help than I do with life. I can do most of my homework by myself or stuff like that, and I can walk around outside, or ride a bus by myself. They can't really do that. Even though I really don't think I want to drive a car, they definitely couldn't unless they had really, really good help.

Even while defining their peers in ways that highlighted their impairments, David seemed to form genuine connections with the students who had more significant disabilities:

> People here, like I know one of them, he's the guy in the stroller. He's someone that I've known for a long time, since 6th grade. And I've been friends with him for as long as that. I'd always feel it in my face to see, for example, him have a big smile. It brings me to basically pure happiness.

These relationships seemed to impact the way that Vanessa and David thought about themselves in relationship to disability. David wanted to pursue a career working with students with disabilities, which had resulted in a job at the Boys and Girls Club where they met a young deaf student: "there's always this kid who speaks sign language and who's deaf and so I try to help him with that. And I'm learning sign language, so I can communicate with him." Vanessa, on the other hand, was more conscious of her behavior in reaction to disability as a result of interacting with the students who had more significant disabilities:

> I'm going to, mostly by accident, like unconsciously, I'm going to talk maybe in a baby voice to them because, I don't know, that's just the way I've…not all the time, but I'll do that because they have more stuff going on. I don't want to stress…maybe they're not stressed at all, but I don't want to stress them out because they're precious.

Vanessa's consciousness of the differences between the "precious" students and herself also impacted her behavior around them, versus her nondisabled peers:

> I think I'm more friendly with the needed help kids. I'm more friendly than with regular people, which is weird. I shouldn't just be treating the more special ed, special needs kids better than a regular student, because I don't know what this regular student has. It's easier to talk to these special needs, these extra help people because they take things differently than what I do.

While both Vanessa and David were more conscious about disability and difference as a result of their relationships with peers who had more significant disabilities, this consciousness did not necessarily seem to extend to their own experiences with disabilities (outside of an acknowledgement that they seemed comfortable being with those peers). This consciousness could be the beginnings of development of disability community: a shared understanding of experiences, and a sense of comfort in that shared understanding. However, another way to understand the relationships between the adolescent participants and their peers with more significant disabilities is through a lens of the "hierarchy" of disability, where people with more significant disabilities are somehow less able than those with less visible or significant impairments. Vanessa and David especially are engaged in comparison and the beginnings of this hierarchy, certainly; but what is also present is the beginnings of genuine relationships and connections between peers that, at least at a very basic level, made the participants feel comfortable in a way that they couldn't explain but could name.

Awareness of Classmates' Knowledge of Disability

Adult participants recalled their peers' confusion and separation from them because of their disability. Often, this confusion and separation wasn't viewed as deliberate or even malevolent; instead, it was identified as being borne out of an awareness of difference that wasn't often discussed openly. The adolescent participants noticed a similar sense of awareness of difference, but with a more mixed sense overall than the adults' perceptions of their peers discomfort with disability.

Quentin and David both agreed that their peers have mixed reactions to disability. Quentin thought that "some people would be helpful and try to help, and there's others that are just rude and think that people that are disabled are not like them and everything." David expanded on this idea:

> It just depends on the person. Some people might think it's stupid, it's dumb. Most people, though, I feel like, that I know, feel like it's okay to have a disability. And I try to spread that word around a lot, that it's okay.

This more complex view of what their peers might think about disability seemed to have evolved over time. David recalled how they had initially been afraid to disclose their disability to their friends:

> They're okay with it. I've always thought in the past like, "oh, maybe I shouldn't tell them. Maybe I shouldn't say this, maybe I shouldn't say that. And then I realized when I'm in 9th grade I should be comfortable saying it. I mean, if I'm not ready to, then that's OK. If so, then don't. But if I needed to, if it was really personal, I would have them be pulled aside for a second then I would tell them.

Interestingly, while the adolescent participants reported relatively positive ideas about disability from their peers, their social experiences in school varied significantly. Vanessa and Quentin reported feeling lonely, and having most of their social connections online. Through the photovoice project, the differences in social relationships in school were further illuminated. Bryce represented multiple spaces in school (including the cafeteria, soccer fields, and gym) where he felt comfortable because he could hang out with his friends freely. Alongside an image near the locker room, he wrote: "this is a place I hang out with my friends. It is near the gym. We can play music here without getting into trouble."

Figure 7. **Bryce's "Downstairs Near Locker Room" image**

In contrast, Vanessa depicted multiple places where she felt comfortable because she could be alone (empty hallways, outside waiting for her job placement transportation). She took a photo of a rarely-used room in the library to describe where she felt comfortable: "this room is actually in the front end of the library. I feel safe here and I like to be in this room as it's mostly quiet and only [the librarian] goes in there."

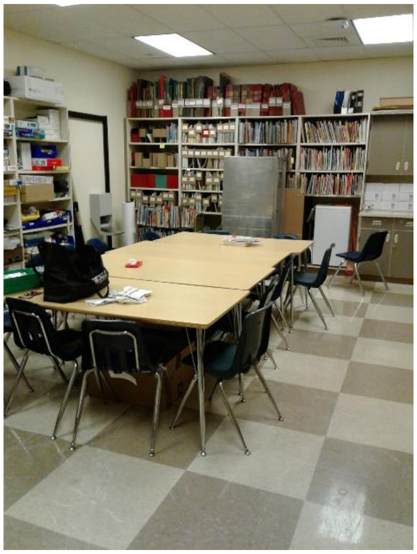


Figure 8. **Vanessa's "Back quiet room" image**

Both adult and adolescent participants noted that they were aware of their classmate and peers' perceptions of disability issues; but the adolescent participants were more frequently describing those perceptions as neutral. Ideally, this would lead to a more positive and inclusive social experience; in practice, this varied by participant and was depicted in several different ways both in the interviews and photovoice. Obviously, some variation in the social experiences of participants would be seen across any group of disabled and nondisabled students; but what appears to be at work here is a mismatch between what participants *should* be experiencing given the more neutral, less negative views of disability they reported in their school, and what they *are* reporting they experience socially.

Experiencing Bullying

While the adolescent participants initially said that there was mixed peer reactions to the meaning behind their disability labels, bullying was, similarly to the adult participants, an extremely prevalent shared experience in school. In fact, three students named bullying as the hardest part of navigating school with a disability. This bullying took many different forms, from taunting to physical altercations. Vanessa noted that the worst part of having a disability was that "people make fun of you," especially when she was feeling uncomfortable: "it's just more over people making fun of me or like me making people feel bad because I'm really irritated or bothered." In Vanessa's case, she was wrestling with both her peers' perceptions of her disability, and her own confusion about why her moods might change that would then impact interactions with those peers and cause negative interactions that might lead her to feel uncomfortable or bullied. Quentin also connected his peers' ideas about disability to the kinds of interactions he had in school, especially in relation to judgement about his disability:

> It's kind of a little embarrassing and everything. 'Cause you don't know if people are gonna judge you 'out it. You don't know if anyone is gonna think about it…behind your back and talk crap about it.

Sometimes, the bullying extended into physical altercations. Bryce was quick to say that he had never experienced bullying himself "because of his size," but he had seen people bully his disabled teammates and friends in the high school's unified basketball program, which involves both disabled and nondisabled participants:

> My buddy was getting picked on, and I decided to deal with the problem while it was happening. [The friend is] not good at sports and stuff. My friend body slammed him [the bully] through the ground, and I took him out.

Here, Bryce is both naming the ways that he saw bullying happening to people with disabilities in his school, and identifying a (particularly risky) way in which he responded to that bullying, even though it didn't impact him directly. This is a particularly important way of responding to bullying as a reaction to disability that the adults did not seem to report in their own recollections of these experiences: pushing back and responding in a physical way (and therefore becoming a bully themselves in reaction). Quentin shared a similar strategy when he himself was the victim of bullying:

> There was one time here. But that was in freshman year. He [a peer] stole my pen that costs kind of a lot of money and stuff and it's also my art pen. And he keeps going, what he did was he took it out my bag, and he keeps looking at me, and when someone looks at you, you look back at them. He keeps flipping it and stuff at me, looking at me. And I told [a teacher] "That's my pen and he took it," and he's like, "No, it's mine," and stuff. And he's acting like he bought it and everything. And I got it back and he came to my desk and was being rude and stuff. So I standed up and he hit me and after that I hit him back. Yes. And he got moved from the history class because he inflict first. But classes were coming out, freaking out and stuff. But he was grabbing me and trying to throw me on the ground. But he couldn't do it because I was too big.

Quentin and Bryce, in describing situations where they had gotten in physical fights in response to interactions with peers, did not explicitly name disability as the reason for these altercations; however, in both cases, disability is an unnamed issue at work. In Bryce's case, a comparison about ability to play sports on the unified team (and a friend's inability to keep up with their peers) caused teasing, which led to the altercation. In Quentin's case, a peer who stole an important item from Quentin and then proceeded to taunt him with it played directly into Quentin's difficulties with social interaction. While Quentin did initially try to use the "proper" way of solving problems in school through bringing in a teacher, both Bryce and Quentin eventually decided to take the conflicts into their own hands and directly, and physically, address the issue with their peers separate from their teachers and school structures that didn't address the complexity of the incidents that were at work.

In contrast, David chose to address the bullying experiences they had in school, and that their peers had, through using school structures to their advantage. David started an anti-bullying club at the high school, in part in response to their own experience with bullying:

> I've been bullied always, since 1st grade, I think. I've had some dark thoughts, but I'm out of that. I've gone to the point where I thought I was isolated, but like I said I've gone out of that stage, around 6th or 7th grade. Because I realized that I have friends who cared and family and I realized that it just wasn't my time to go.

The anti-bullying club's purpose was focused on "where people are actually safe." The club functioned as "a safe haven for people who've been bullied, or who bully others who have stopped." There was only one rule of the anti-bullying club: "no sharing others' experiences." While the club included all students and was not explicitly focused on bullying people with disabilities, David noted that they had "some autism education stuff in there" as a part of the club.

During the photovoice project, David shared a photo of the anti-bullying club poster that they had made, and shared:

> You see a picture of my binder which has the agenda for the day inside of it. I took it because it shows how much I wanted to get this club made. I also took it because it reminds me how much bullying happened before the club was even made.

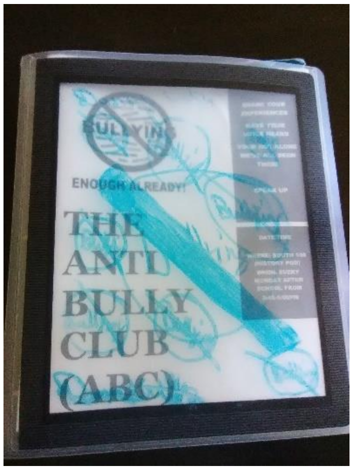


Figure 9: **David's "D's club" image**

While the experience of bullying or of seeing bullying happen and responding to it, was universal across all four participants, the function of bullying as a resource for building disability identity seemed to vary across participants. For Quentin, Vanessa, and Bryce, it became a way that their ideas about disability were reinforced: both as "proof" of their peers' negative ideas about disability, and in their visibility as people with disabilities in classrooms. David, in contrast, used their experiences with bullying to (eventually) remind themself that they had support systems of people who loved and were supportive of them. This kind of reframing of those negative social experiences allowed David to take steps to help other students through the formation of the club.

Different Identity Resources

While many of the identity resources that adolescent participants discussed were similar to the adult participants (e.g. experiencing bullying), adolescent participants named particular resources that were different, and significant, for their development of disability identity separate from the adults. These resources included engagement with social media and the internet, development of creativity, and self-advocacy around accommodations.

Using Social Media and Technology

Social media, video games, and the internet in general were mentioned frequently in the adolescent interviews. In some respects, this technology functioned in much the same way as it might for students without disabilities: as ways for students to play multiplayer games, beat difficult levels independently, learn new things, or connect with friends over similar interests. In fact, all four students mentioned interacting with technology was important to them.

Media also represented a way for students to engage with ideas about disability more broadly. The adult participants mentioned developing disability knowledge through online groups and searches; David also recalled learning about their disability through the internet:

> I wanted to know what it meant. Because I just thought it was random letters in random orders put together. But then I looked it up and I found that it’s basically, I forget what it’s called, hyper-act something something, hyperactive disorder. And I thought okay, and then I actually found out on it in an informational YouTube video. That people who have ADHD take medication for it and if they drink coffee it can actually calm them down.

During his photovoice project, David chose to take a photo of their coffee pot to demonstrate their learning about ADHD and their attempts to counteract the effects of the ADHD medication, which made them feel sleepy and de-energized. In their image description, they wrote: “I like to stay energized for school. I found out on YouTube that if you have ADHD and drink caffeine than you become better.”

***Figure 10.* David’s “My wake up call” image**

After documenting his story about learning to manage his ADHD via information from the internet, he brought the image to the whole group discussion and shared with the group:

> Since I have ADHD and take medication for it, I try to drink coffee in the morning to help me stay energized but also calm at the same time. I found out that it's what's inside that matters, and I used to be really energetic, but now I'm not unless I have caffeine.

Whether or not the information he gained from the internet was valid or a reliable way to manage ADHD, David was actively seeking out information through social media in order to manage their disability on their own. This is not only an important use of media, but a way for David to understand (and share) an aspect of their understanding of their disability label.

Technology and media, though, also became an important tool for students to demonstrate what they thought about developing social connections as students with disabilities. Vanessa enjoyed playing solitary games like Minecraft, because she "could be a bit impatient [with other players]" when she "couldn't control them." In contrast, in a solitary game, Vanessa had some control over her (virtual) world: "I like to have other people in the world…but in a world that I've made, I want to keep it as safe as possible." Bryce enjoyed multiplayer games, because he communicated with a team and enjoyed "bossing people around" on his team. Vanessa and Bryce, interestingly, reported having opposite social experiences in school: Vanessa mentioned that she didn't have very many friends inside of school (and especially outside of her special education classes or the video game multiplayer technology), while Bryce mentioned his "homies" frequently. In both cases, though, using technology reinforced the way that they thought about themselves in relation to other people: and in both cases, it was about controlling, or leading, others in a virtual world of their own making.

The students also mentioned movies, television, and video games as a way that they saw disability represented. Bryce said that while he couldn't remember a specific example of disability on television, he knew that when it was on, “it was like some [expletive] problem, or something. Something that we need to fix.” When he reflected more on this ‘disability as a problem’ idea that was represented in media he saw in television and movies, he thought it was “a good thing, because helping makes life better.” For Bryce, seeing disability represented as a problem through media was a good thing, because it positioned other people (presumably nondisabled people) as “helpers,” to fix the problem of disability. In the photovoice project, Quentin took a photo of an interpretive drawing he had made, which he said was an anime-style drawing of a character from the video game “Five Nights at Freddy’s” (See Figure 11).

Figure 11. Quentin’s “Five Nights at Freddy’s” image.

In his image description, he wrote: “This shows people can do what others can’t do from time to time.” When he was asked to choose a photo to discuss and expand on during the whole group discussion of the photos, he first wrote out his thoughts on what he wanted to say about the photo: “Everyone is different. Once you let it out you can be true to yourself and everyone.” With the group, I asked what the video game photo showed about disability. He shared:

> It’s about people, well, these guys, basically, they help each other out on things that they’ve been keeping inside, and not talking about or doing anything about it. And they’ve got to be true to themselves.

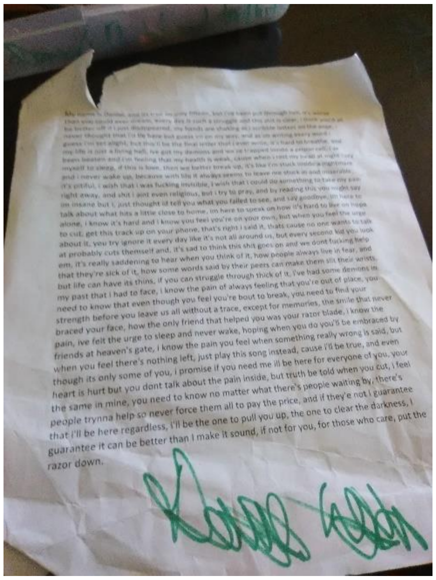
While the video game character does not have a visible or stated disability, and the character Quentin drew does not actually seem to be related to the video game itself, Quentin used his drawing of the character to share an idea about difference between people (especially that “everyone is different,” a common theme that surfaced across the students), as well as an idea that you should be truthful to who you are. In this way, even when media did not explicitly name disability or when the photo was not related to disability, students used their resources to share ideas and make meaning about disability despite that lack of representation.

The students seemed to identify that the internet and social media was a place to escape “the real world,” or develop relationships with others who have disability. The students saw it as a chance to create their own worlds, gain information, and learn about disability, whether students were using social media, technology and broader television and movies to develop social relationships with others or to develop ideas about disability, the usage of these media and technology raised questions about what is “real” and what is virtual; what is in each student’s control in terms of their perception of themselves and their peers’ perception of them, and how they project ideas or use media to talk about issues of difference and disability.

Developing Creativity

One unexpected resource for identity development in relation to the adolescent participants was creativity and connection to the arts. In the “I am…” activity, two students (Quentin and David) wrote “artist” as a part of their identity; Vanessa mentioned in the photovoice group discussions that she enjoyed all kinds of art and had “taken a lot of classes.” The theme of art and creativity also surfaced in both the interviews and photovoice projects, as students both named themselves as engaging in many different kinds of art activity, as well as using art to express who they were. For Quentin and David, art (music and drawing especially) provided a way for them to feel confident about themselves, and was often talked about alongside games as important to the students. David said that they felt most successful “when I finish a song or when I finally beat a game, or something like that. Either in my club, lunch, or there’s some other place to sit down and sing.” Quentin said that he was most successful “when drawing or playing games. I am good at playing games and good at fixing things.”

While many nondisabled adolescents might identify themselves as being creative, enjoy art classes and even think of themselves as artists, this group of students connected art and creativity to disability and school in an important way. Davi , similarly to Quentin’s “Freddy” drawing, used art-making in their photovoice project to tell a story about their experiences with school and disability. In both the initial interview and the photovoice project, he brought a rap song to share that detailed his experiences with mental illness, bullying, and using art as resistance to uplift others. Where Quentin’s “Freddy” drawing was a “projection” of disability onto a nondisabled character, David’s rap explicitly discussed their experiences from their own perspective.



[illegible] it's pitiful, i wish that i was fucking invisible, i wish that i could do something to take my [illegible] right away, and shit i aint even religious, but i try to pray, and by reading this you might say im insane but i, just thought id tell you what you failed to see, and say goodbye, im here to talk about what hits a little close to home, im here to speak on how it's hard to live on hope alone, i know it's hard and i know you feel you're on your own, but when you feel the urge to cut, get this track up on your phone, that's right i said it, thats cause no one wants to talk about it, you try ignore it every day like it's not all around us, but every second kid you look at probably cuts themself and, it's sad to think this shit goes on and we dont fucking help em, it's really saddening to hear when you think of it, how people always live in fear, and that they're sick of it, how some words said by their peers can make them slit their wrists, but life can have its thins, if you can struggle through thick of it, i've had some demons in my past that i had to face, i know the pain of always feeling that you're out of place, you need to know that even though you feel you're bout to break, you need to find your strength before you leave us all without a trace, except for memories, the smile that never braced your face, how the only friend that helped you was your razor blade, i know the pain, ive felt the urge to sleep and never wake, hoping when you do you'll be embraced by friends at heaven's gate, i know the pain you feel when something really wrong is said, but when you feel there's nothing left, just play this song instead, cause i'll be true, and even though its only some of you, i promise if you need me ill be here for everyone of you, your heart is hurt but you dont talk about the pain inside, but truth be told when you cut, i feel the same in mine, you need to know no matter what there's people waiting by, there's people trynna help so never force them all to pay the price, and if they'e not i guarantee that i'll be here regardless, i'll be the one to pull you up, the one to clear the darkness, i guarantee it can be better than i make it sound, if not for you, for those who care, put the razor down.

Figure 12. **David’s “Music” image**

David's rap lyrics, performed during the interview, include their own experiences:

> *It's like I'm stuck inside a nightmare and I never wake up, because with life it always seems to leave me stuck in and miserable, it's pitiful, I wish that I was f***ing invisible, I wish that I could do something to take my pain right away, and I ain't even religious, but I try to pray, and by reading this you might say I'm insane, but I just thought I'd tell you what you fail to see…*

As well as speaking to the experiences of others:

> *I know it's hard and I know you feel you're on your own, but when you feel the urge to cut get this track up on your phone, that's right I said it, that's cause no one wants to talk about it, you try to ignore it every day like it's not all around us, but every second kid you look at probably cuts themselves, and it's sad to think this s*** goes on and we don't f***ing help em…*

Finally, David's rap ends on a hopeful note that attempts to reach out to anyone who is struggling, and resists the isolation and stigma of mental illness and self-harm:

> *I know the pain you feel when something really wrong is said, but when you feel there's nothing left, just play this song instead, cause I'll be true, and even though it's only some of you, I promise if you need me I'll be here for every one of you…*

When asked about the photo of the rap lyrics in the photovoice discussion group, David wrote down their thoughts on the image and shared:

> You see a typed-out version of a song I made recently. I took it because I love making music. It shows how creative I am, and I reflect on all my songs to keep pushing myself even further to make more music.

Interestingly, David's description of the image does not engage the content of the rap itself. They wrote instead about the creative process, and how much they enjoy the creation of music and the ways it pushes them to be better. It is divorced not only from their experiences in the song, as well as the ways they attempt to reach out to an imagined "other" person who may be struggling with similar issues as David. David's vivid descriptions of what is unseen (presumably by adults), and the ways they write about support for people through these unseen emotional experiences, are incredibly rich and deeply felt; and at least in the photovoice discussion and interview, left unexplained.

In these ways, the arts and development of creativity played an important role across many of the experiences of both Quentin and David especially around identity. The arts served as a way for each student to define themselves; it also served as a way to process pain and school experiences; and it served as a way to open up discussion of issues that may not otherwise be seen by adults (or even peers) in their lives. The arts were especially encouraged in particular contexts, especially inside special education and their life skills course, where they were allowed to draw during free times or to express their learning.

Participation in Life Skills/Special Education Classes

While the adult participants mentioned removal from general education into special education classes as a highly stigmatized resource that developed identity around disability, the adolescent participants generally noted that their life skills class, and other special education classes, were a safe space. Bryce especially represented his special education instructional environments in the photovoice project, both in terms of physical spaces and the instructional methods used in those spaces that made him feel comfortable as a person with a disability. The physical space seemed to be important on its own. Bryce's photo of the life skills class was accompanied by a reflection on his time there: “Main classroom and unified basketball sign. The people that care about me and unified basketball. I have been here about 2.5 years.”

Figure 13. **Bryce's "BHS Unified sign & SW 208" image**

The physical special educational spaces were also important for Vanessa. She also felt that the life skills classroom was a safe space, based on the size of the group and its designation as an explicitly "special ed" space:

> This class is nice, because it's the smallest. It's all special ed, this is a special ed class. This is not special ed help, such as…there's a second teacher, she's more of an IA. But it's literally two boys, maybe three boys when Bryce's here and me. It's small, it's comfortable, It reminds me of home and it's nice.

While access to physical special educational spaces were important to Bryce and Vanessa, what happened inside of those spaces was equally important in terms of developing a safe space. Bryce focused on specific items in the classroom that helped him learn, which were not available in the general education classrooms he went to for electives. He reflected on the image: "A green stool. This is my favorite seat in class. I can move in this chair. I need to be physical to learn best."

***Figure 14.* Bryce's "Stool" image**

The feeling of self-contained classes as a safe space extended to other places in school that, while not necessarily "marked" as explicitly special ed, involved services or people who were connected to disability issues in some way. Vanessa and Bryce took photos of places in their high school that they had positive associations with in relation to disability, again because of what the space made them feel or allowed them to do (versus what the space was designated to be).

Bryce's image and description of a classroom number helps illuminate this distinction:

***Figure 15.* Bryce's "SW227" image**

Alongside the image, he reflected: "this is my speech room where I meet with the SLP. I get to talk a lot in this room about myself. I like to talk." While the room where Bryce received speech services changed based on scheduling, he chose to take a photo of the last room where he worked with his speech therapist. In this way, Bryce found places he felt comfortable (and places where he could talk about himself with an adult) in multiple spaces tied to his disability, rather than a single place in the school that was marked as "special ed."

Developing Self Advocacy Skills and Knowledge of Accommodations

An important feature of the life skills course centered around self-advocacy. Because of this focus, it might be expected that students would feel comfortable receiving accommodations and asking for them in academic spaces. For Vanessa, this was true:

> Well, I have my IEP, so I can tell a teacher that in the IEP I have these amendments, and these adjustments, and modifications if the time arises, if I feel like I need to listen to music to calm down or focus on my work, I can ask. "This is in my IEP. May I please, can I please, listen to music?" Or, "May I have a snack? May I take a walk? May I put my head down for a little bit?" Like go outside or sit down. "May I please draw for a while? Like take some time off this work? I know I need to get this done, but I'm stressing out here. I need some calming down.

David also mentioned their IEP knowledge in talking about how they advocated for themself in school:

> I mean, I know for a fact that I can have extra time because it says on my IEP, so I would just go to ask the teacher. I know that this is late, but on my IEP it says yadda yadda yadda, so can I please have some extra time? And then they would probably just say yes. Or they would have to.

The idea that teachers would "have to" give students their accommodations if the students asked exposed a larger point about how students conceptualized both self-advocacy and access to accommodations, and how they conceptualized the "good things" about having a disability. For David and Bryce, having a disability meant access to accommodations in school. For David, the "easier work", "having that little bit of help when you need it" and "people going a lot easier on you" were good consequences of a disability label. Bryce said "a scribe and using calculators" was the best part of having a disability. Access to accommodations and building self-advocacy skills in relation to those accommodations, gave students some power in relation to others in school that was positive around their disability.

An extension of this power, and a more nuanced version of self-advocacy around disability, came in the way that students said they would respond to people who said they wouldn't be able to do something because of their disability. Overwhelmingly, students said they would try to push back or ignore the people who might have negative thoughts about their disabilities. Quentin said, "I basically ignore them, and don't really talk to them. Until they basically apologize to me or don't talk about it anymore." Bryce said, "I don't care, I'll still do it. Because I don't take garbage. I won't listen to them." David said they would "prove them wrong, or at least try. And then tell them, well I tried, is that good enough?" The students' insistence that the best part of disability was the accommodations, and their focus on pushing back on people who think less of their abilities, was a student-interpreted and motivated kind of self-advocacy that arose from their lived experiences.

Discussion

Bryce, David, Vanessa & Quentin's stories, perspectives and lived experiences thus far with disability present what Chuck Close would call a "portrait in progress" of the development of disability identity: while each student is already bringing so much history and knowledge about disability drawn from their individual and cultural worlds, these identities are still very much in process. In some ways, this is a good thing: the ways that disability identity was shaped over time, especially positively, for the adults has yet to unfold for the adolescents. In other ways, some of the resources that the adolescents already drew from to form their disability identity (comparison to normalcy, bullying) have already shaped a stigmatized and complex view of what disability is and can be, that is regularly confirmed by the teachers in their lives. In either respect, what is important about the findings from this chapter is the process of naming the individual resources that adolescents have access to, and to begin to chart a process over time of the development of disability identity that has, thus far, been rooted in a mostly medical model idea of disability.

While the findings presented in this chapter were separated by similarities and differences to the adult phase findings, it’s important to understand them in the context of the collective identity framework that supports the study. In the process of analyzing the data for this findings chapter, excerpts from both the photovoice project and the individual interviews were most frequently coded as related to school experiences, settings, and relationships, similarly to the adult phase. Importantly, the adolescents did not report any behavioral involvement or cultural resources around disability in the same way that the adults did, suggesting that they did not have access to a broader disability community, sense of culture, or membership.

While many of the resources involved similarly named experiences to the adult participants (i.e., bullying), the adolescent participants seemed to be engaged in pushing back against these resources in ways that re-shaped both their experiences in school and their relationship to disability. This idea was seen even in the resources that adults did not share: development of creativity and internet/social media activity were two major ways in which students were able to escape many of the negative resources they had about disability identity in school, and regain some control over both their self-image and social relationships in a more comfortable context. In this way, the adolescent participants were not simply passive recipients of a stigmatized identity, even divorced from some of the positive cultural resources that adults had access to; they were engaged in shaping their own identities and reframing stigma constantly, whether consciously or unconsciously.

Chapter Summary

Chapter 5: Creative medicine

[redacted]

[redacted] the [redacted]

[redacted] "problem" of medicalized discourse [redacted] pervasive, but [redacted] students [redacted] on their own terms [redacted]

[redacted] reflect [redacted] Creativity, [redacted] to imagine something different for themselves and others; [redacted]

CHAPTER 6: (VIRTUAL) CONNECTION PHASE

“Not everyone with a disability can leverage it into a strength, but those who can do so may find they bring a unique perspective to their endeavors.”

In a typical photovoice project protocol, the project culminates in a public display of images or other usage of the photographs for public benefit around changing an issue from the community. The original design for this dissertation involved a similar public display of the students’ photos and descriptions, and connection between the adult and students interviewed for the study. This plan had a few obvious benefits in theory: first, it would provide the adults in the study a chance to be the kind of role models they needed as youth; second, it would provide the adolescent participants opportunities to interact with adults who shared their experiences; third, it would demonstrate a new way of involving the disability community in special educational settings as experts and advisors in a particular identity experience. However, as the school phase progressed, there were indications in both the student interviews and discussion of photographs that led to a shift in the plans for a third “phase” of the study. As the students shared more about their experiences, it became clear that students had not had practice discussing their identity experiences and ideas about disability with others before the project. Students were clearly engaged in the one-on-one interviews, eager to talk about their experiences and to share what they thought about disability. In contrast when the group discussion of photographs began, students became suddenly highly distracted, even appearing nervous or reticent to share their photos or writings with each other in the life skills classroom space.

When is it appropriate to name a part of who you are? When should we expect students with disabilities to be comfortable with talking about the (socially-inflicted) challenges of what it means to have a disability? When should we expect them to be able to name their strengths, and the particular and very real positive consequences of having a disability as well? Who decides?

In this dissertation, I let the students' behavior guide my responses to those questions. When it became clear that the process of talking with each other about their lived experience of disability was a stretch for all of the adolescent participants, I began thinking of ways to allows the adult participants see the impact of their stories on the school phase, and to protect the adolescent participants' process of coming to openly, confidently, and comfortably talk about disability as a part of who they are. The two could happen simultaneously, but not if I followed my original dissertation plan and not if it involved the youth having to share parts of their experiences with strangers, even if they had a shared identity. Handily, though, the students had already given me a clue through their usage of technology for how I could resolve this methodological hiccup and also respect where the adolescent participants were in their process.

Two of the four adult participants responded to the request for participation in the (now virtual) gallery walk. The results of the gallery walk connected the adults' recollections and recommendations around development of disability identity in school in some important ways. First, it validated the shared experiences of school and schooling in developing disability identity. There were important points of connection and validation of the students' experiences from the adults; and, as the adults reported, validation of the adults through the students' stories and depictions of their experiences. What follows is an analysis of the adults' comments on the adolescent participants' virtual gallery walk materials.

Points of Connection and Solidarity

Both Ilia and Jackson found points of connection with the photos and reflections in the virtual gallery walk. Ilia noted that the images "reminded me of my days in school," and especially that "photos of different parts of school reminded me how hard it was." Jackson identified strongly with Vanessa's photos of empty, out of the way spaces in school, either where she felt safe or described situations where she avoided those spaces:

> The pictures of quiet, isolated places where they feel comfortable is a very familiar experience for me. Back in school I would stake out certain areas where I felt comfortable and go there frequently to get away from the bulk of the crowds. The picture of the hallway really drives this point home. There were certain areas I didn't like to go because they were usually crowded and loud, which made me very stressed and uncomfortable.

Jackson also recalled his experiences with bullying as he noticed David's anti-bullying club flyer, and appreciated that David was able to resist and organize around an issue that Jackson had throughout school as well. Jackson found the anti-bullying club an important step forward:

> The anti-bully poster indicates an unfortunate reality for many with disabilities, especially in school. I faced some bullying as well, as did others I knew with disabilities. Thankfully it seems like these days there's more push back against this kind of thing, and cultural norms see it as less acceptable than it used to be. There's still a long way to go, but I'm hopeful.

Given Ilia's focus on developing community with disabled people and simultaneously wanting access to general education curriculum, she wrote specifically about David's photo of the history book and commented on how much it excited her that students with disabilities were getting access to general education. She wrote:

> I glad to see a photo of a history text book. I want know that students with disabilities are getting access to history. Especially those with intellectual disabilities.

As with Jackson's point of identification with the anti-bullying poster, Ilia's awareness of David's love of history (and his ability to access the history curriculum at all) seemed to represent a shift between the schooling experiences that Ilia had, and the experiences and choices David has in his. Ilia identifies as an advocate for disability issues and participates in many different kinds of disability community work: this work is the kind of cultural resource that has allowed her to see why access to history is worth fighting for.

Points of Explanation

Two of Jackson's comments about the virtual gallery walk pointed towards overarching ideas about disability, and attempts to explain where the adolescents were in their developmental process of coming to understand their disability and develop disability identity. Jackson pointed to Bryce's photos of the fidget and stool to note that Bryce was showing "an awareness of the challenges they face, and a process of exploration to discover what coping mechanisms are most effect[ive]." Similarly, Jackson pointed to David's anti-bullying poster as another coping mechanism, to "mitigate the difficulties they encounter." Jackson called this process of exploration "a very common, and natural process for those with disabilities." This commentary suggests that Jackson is framing disability as something that needs to be coped with, but he places the onus of that coping (and the ability to successfully do so) in the hands of the adolescents. This is an interesting extension of the social model of disability resource that came up in the adult phase of the study: what happens when, in the face of an immediate impossibility for an individual with disabilities to restructure their world into an entirely new form, they must learn to "cope" in a world that is not built for them?

Discussion

In the virtual gallery walk, Jackson and Ilia were able to see some of their own experiences and history in school mirrored back for them. While these experiences and histories were often characterized as hard or difficult by both the adults and the adolescent participants, the adult participants were able to recognize (perhaps in ways that the adolescents wouldn't name) the ways that the adolescents were resisting those difficult situations. In this way, the virtual gallery walk not only gave a window into the ways that many of the same difficult resources around disability identity development were still present in schools and in adolescents' lives, but also presented some ways in which the adolescents were speaking back to those identity resources in ways that the adults had not.

In a pilot version of this study, an adult participant recognized the lack of role models in her life as she reached adulthood through hearing someone else name their lack of knowledge of how disabled people became adults. One of the benefits of the kind of cross-generational connections made, even virtually, through this dissertation is that the experiences that are shared across the adolescent and adult groups are validated even just in and through their sharing and naming. Even through naming that there *are* adults with disabilities, the adolescents learned the possibility of becoming adults themselves, with disability instead of without. This validation of experiences happened in two different instances: first, when the adults' experiences were included in the school phase introduction of the photovoice project and to introduce the concept of disability identity, and second, here in the "connection phase" where the adults accessed the virtual gallery walk. In some ways, the "connection phase" is a misnomer: these connections have occurred since the conception of the study and since the adults began to reach back into their memories of themselves as youth with disabilities. The challenge, moving forward, is to strengthen, solidify, and explicitly develop these connections further for everyone; for a community of people who are seeking role models and points of solidarity with each other.

Chapter Summary

Chapter 6: Connectivity

[redacted] a “connection” [redacted]

What function does it serve? [redacted]

[redacted] develop community [redacted] when [redacted] school means identity discouragement. [redacted] shared experience [redacted]

[redacted] a group conversation [redacted] talking about the stigmatization [redacted]

CHAPTER 7: IDENTITY AGENTS

"Oh my gosh, guys, she's standing up!"
"She can stand up."
"That's true. I can."
"She can stand up, and walk around, it just hurts."

"I never truly tell them I don't have a disability. I'm working on things too. We all are."

In their discussion of teachers as identity agents, Harrell-Levy & Kerpelman (2010) note that teachers' specific actions and feedback in the context of their classrooms shapes identity for adolescents. Through "the expectations they set, the feedback they provide on student performance, and the student behaviors they encourage or discourage, teachers influence adolescents' day-to-day exploration of their identities" (p. 79). In this study, there were two people in the role of identity agents specifically focused on disability, with countless other influences outside of the classroom environment that also shape and influence disability identity development, albeit less directly. The "identity agents" in this study shaped disability identity as a part of the schooling context, and ourselves became resources for that identity development based on our teaching, life experiences, and views and philosophies on disability. The life skills teacher, Ms. Maddox, and myself as the researcher and photovoice project facilitator directly engaged students in discussions of disability, and attempted to shape disability identity and awareness of disability in general through specific activities that helped adolescents "learn who they are and how they fit into society" (Harrell-Levy & Kerpelman, 2010, p. 79). The excerpts that framed this chapter are in some ways a direct response to Adrienne Rich's thoughts on a need to mirror identity for students: what happens when I, as a researcher, am the mirror for the participants? What if they look in the mirror, and see someone with "more significant," more visible, more stigmatized disabilities than they want to see in themselves? What happens if their nondisabled teacher does this mirroring? How might all of this complexity reveal itself in the data?

In this chapter, I will explore the intricacies of identity agents in the study, in the form of interactions in the photovoice project between myself and the students, and an interview with Ms. Maddox. I begin by exploring my own positionality as a facilitator who shares an experience of disability (if not the specific disability label) with the student participants. Following this, I then discuss Ms. Maddox' thoughts on her professional role developing disability identity, the language and practices she uses to accomplish this goal, and her thoughts on the importance of disability identity in her students' lives.

Disabled Facilitator/Researcher

Perhaps unsurprisingly, my presence (and my wheelchair's presence) affected the trajectory of my interviews and of the discussions we had about disability. Sometimes, these interactions began with a simple observation, which then provided a window into how the students were thinking about disability. In the quote that framed this chapter, Bryce was surprised that I was able to stand up to adjust the camera tripod that was filming our photovoice group discussion. He exclaimed out loud to his classmates: "Oh my gosh, guys, she's standing up!" Vanessa and David quickly jumped into the interaction: "She can stand up." "She can stand up and walk around, it just hurts." They assure Bryce that his ideas about disability were too narrow, and let him know a possible reason (without asking me) why I might choose to use the wheelchair in some situations and walk in others. I interjected to affirm Vanessa's idea that I can get out of my wheelchair and walk; the other students have seen me do this, and they have seen peers they're more familiar with get out of their wheelchairs as well.

The students' curiosity about my wheelchair continued into other photovoice group sessions. In one, I maneuvered my chair excitedly while I was talking, which caused an accidental wheelie that caught Bryce and Vanessa's attention immediately:

> Bryce: Wait, can you wheelie?!
> Carlyn: Yeah, but not intentionally, apparently.
> Bryce: No, I meant like, keep it up and go forward.
> Vanessa: No, she cannot.

The student's awareness of my wheelchair, and conversations between them about my disability and what I can and cannot do, powerfully demonstrate not just the interactions between me (as a mirror of disability) and the students, but between the students themselves. They are constantly aware of, and checking each other's, ideas about disability and about the correct or incorrect assumptions each of them make about disability as it is ascribed on other peoples' bodies. In some ways, this is a two-way mirror: a student makes a surprised interjection that cuts to their ideas about disability, which causes other students in the room to want to define the bounds of what disability means for certain bodies (in this case, mine) alongside their own. There is flexibility in this boundary-drawing, that seemed to be important to the students as they talked about me as if I wasn't in the room. In other words, if the students are capable of thinking about disability flexibly when it is ascribed to other people, then they are able to think about disability flexibly when it's ascribed to themselves.

My ideas and choices about my own disability embodiment (which, in this context, are methodological) inform these conversations between students. I could have walked into the room or chosen to sit at a table in a "regular chair" without my wheelchair, but I did not. Part of this had to do with the way I had structured the photovoice group discussions and resources, which required me to explicitly name myself as a part of the disability community. I did this repeatedly as a part of the group photovoice project. In one example, I framed disability identity using my own experiences:

> If you're proud of having a disability, it can help you in school, because you do better in school. You might know the things that you need in school to be successful, right? It can also help you socially with your friends. Everybody with a disability has a disability identity. So do I have a disability identity? Yes, absolutely I do.

In my own role as an identity agent, I focused on making myself, my own identities, and my experiences visible to students, alongside the experiences of the adults that were drawn from their interviews; it was important to me that my disability experiences be visible in the space just as much as my voice.

It would be convenient (politically and personally) for me to suggest that students' lack of interactions with disabled adults caused a hyper-awareness of an authority figure who in any way mirrored any experience of disability. Of course, with that conclusion in mind, they would be aware of my wheelchair; of course they would name someone else's difference as they were noticing it (and being asked to notice it) in themselves. My embodied experiences of disability, though, were more often windows into knowledge of disability as it was taught to them by nondisabled people as identity agents, than it was an affirmation of our shared difference and disability.

Nondisabled Teacher

Ms. Maddox, as another identity agent in the context of the students' lives around disability identity, structured her study skills course with a specific focus on disability knowledge, but made different choices than I had in the ways that disability was presented to students inside this goal and class structure. She had come to understand disability identity as important because of her role in students' lives. As a high school teacher, she was often "the first person who has told them that they have a disability.” Being the first person to tell a student about their disability label was fraught with complexity:

> It breaks my heart when kids come to me, and it’s like an “aha” moment, and then they feel bad about it, because they feel like people have lied to them for 14 years and never told them what it is actually like…and then at what point are they ready to hear that? Some kids pick it up, and they understand it right away. It’s like Bryce and Quentin and David have a harder time for it because they’re socially trying to compensate all day long for the fact that they do struggle.

Ms. Maddox’ role as an identity agent led her to develop certain dialogues and ways of speaking about disability. While these dialogues weren’t necessarily all the same with each student (and were not developed or supported by teacher training, professional development, or other professional support systems), she tried “to frame disability in, ‘everybody has something they’re working on, it’s never something to be ashamed of, and look at all these amazing strengths that you have.’” This way of talking about disability to her students meant that disability, while “part of who they [the students] are,” was also an identity that could apply to anyone, at any time. For this reason, she chose not to tell her students that she did not have a disability, since she herself was working on things. Working on things, then, became the criteria for disability in Ms. Maddox’ classroom and therefore a way that disability identity was constructed.

Ms. Maddox’ sense of her students active compensation for their disability labels led her to notice other ways that they may have been “coping” in school settings. She noticed that, to her, the students seemed to turn to technology in order to build a “new” environment where they felt comfortable:

> Compensation and social media are the two things that like…I see things like kids with intellectual disabilities on their phone, and living in their fictional self-created lives online. More than I see them living in the real world.

Her students' "fictional, self-created lives online" were troubling to Ms. Maddox, not just because of the potential safety and privacy concerns typical for teenagers unleashed onto the internet, but because of how her students interpreted "real" and "virtual" friendships. As an identity agent for her students, she held certain expectations about the social relationships her students had in school:

> They don't want to face their peers. They don't want people to know that they have a disability. And so they hide it via social media. It's my biggest issue that I deal with with kids right now. Quentin truly believes that his weekend he spent with friends. And I'm asking him, 'What friends? What did you guys do?' 'Oh, we just chatted on social media.' All day long, they're just chatting with people that aren't real."

Ms. Maddox was not only concerned with her students real and virtual friendships, but the relationship these virtual connections had to how her students thought about their disability identities and the disability community in general. These ideas weren't necessarily positive:

> I truly believe it's because, I mean, they don't have any real connections. And I think a lot of it stems from, they're so exhausted from having to socially try to mask their disability all day long, that when they go home they'd rather just check out and start talking to other people. More than likely I bet those people all have disabilities. They're all lonely.

In painting people, particularly disabled people, who use the internet to connect as "all lonely," Ms. Maddox shares ideas about the inherent worth not only of individuals choosing their own modes of connection, but of her own ideas around what it means to form those connections. Connection here singularly means face-to-face and not about disability; it seems to be unquestioned that the internet or social media spaces could be positive identity development spaces for disability or disability community, let alone spaces she herself could develop as the teacher focused on helping her students with their "social masking."

Discussion

As identity agents, Ms. Maddox and I were both socialized into particular ideas and conversations about disability that we then transmit in intentional and unconscious ways to students in this study. It’s important to note that Ms. Maddox’ ideas about disability are not unique to her, nor would they be considered particularly wrong or offensive if compared to the dialogue around disability in the rest of the field of special education. As an unsupported identity agent, she replicates particular ideas about disability to her students that are opposed not only to my orientation as a disabled identity agent, but from the recommendations and expertise of the disabled adults in this study as well. In most ways, I am also an unsupported identity agent: no research literature, practical guides, or best practices supported my conversations with students other than the adult participants’ ideas and my own history and instincts. What this exploration of identity agents points to, then, is a lack of information on all sides: even from the “experts,” on how to support and develop disability identity intentionally and to do it in a way that honors the histories and experiences of disabled students who have come before.

Chapter Summary

Chapter 7: An important part

[redacted] disability identities [redacted] - it's one part of who you are, right? [redacted] So, what happens if you're proud [redacted]: How you feel about it is important. [redacted] our own ways of thinking [redacted] matter [redacted]

CHAPTER 8: Discussion

"Academe is very much about the generation and swapping of stories, and there are some stories that the academy has not yet proven itself responsible enough to hear."
(Tuck & Wayne Yang, 2014, p. 223)

In the preceding results chapters, I presented the analysis from both phases of the study: beginning with the qualitative adult interview data, that then informed the school phase of the study which included qualitative interviewing, photovoice methodology and other related activities in the context of the work within the life skills class. In this chapter, I discuss the findings across the different phases and highlight ways in which each phase of the study can be understood in relation to each other. The purpose of this dissertation was to conceptualize adolescent disability identity from within educational contexts, utilizing the knowledge and experience of both adult and student participants towards answering three central research questions. In this chapter, the results from the study are discussed in relationship to this purpose and in conversation with extant scholarly and activist thinking around disability identity. I explore the results of the study towards an ultimate goal of consideration of disability identity in school and special educational contexts in explicit, and intentional ways. To this end, implications for special education and related disability research are offered as a way to push the conversation about disability identity forward in school contexts in particular. Finally, I present limitations of the current study.

Collective Disability Identity in School Contexts

In this study, collective identity around disability was discussed differently between the adult participants and the student participants. While this may be an unsurprising finding in part because the adult participants were intentionally recruited through particular networks that included activist and community organizing work around disability, the goal of thinking about collective identity in relationship to disability in this way is to understand the conditions and features that *held back* development of positive disability identity until the participants were in adulthood and out of school. In the following sections, I discuss similarities and differences in collective disability identity development between adults and adolescents with disabilities, name identity resources that participants used to form their disability identity, and the ways that school and schooling shaped those experiences and a broader identity around disability.

Self- Categorization

Both adults and students self-categorized as having a disability. The ways that they self-categorized, and the social meaning they ascribed to this categorization, differed by participant and by group of participants. In this way, self-categorization to be less a binary (categorization/no categorization), and more about the shades of meaning assigned to that categorization. In general, the adults in this study self-categorized as politically disabled, and the adolescents in this study (at this point in time) self-categorized as descriptively disabled (Mingus, 2010): this difference in self-categorization came as a result of particular social processes and interactions that constrained students in particular into this kind of categorization in particular.

Both the adults and students went through a process of initial realization of disability, embodiment of disability and negotiation of disability labels that guided the process of self-categorization as both a single temporal moment and a continuous process afterwards. Importantly, this process did not follow the linear identity development process suggested in the adult disability identity development literature (e.g. Livneh, 1998). Most often in this process, the adult participants had grown to include the social model of disability in their self-categorization and definition of disability over time. The adolescent participants, in contrast, were more likely to either define disability in terms of the medical model, or through making a distinction between disability as a global experience and disability as a phenomenon they experienced. They also echoed their teachers' dialogues and ideas about disability, through a globalization of difference that categorized everyone as having a disability because everyone is working on something about themselves. These identity resources, which positioned disability as a negative thing or at the very least a fixed feature of a person that required work to overcome, shaped adolescents' ideas about identification and categorization of disability away from one of pride (as in the adults) and towards one of self-categorization, with caveats. In this kind of self-categorization, disability is something you "have, but you're also…," or adolescents could name, but only in the context of what they were doing to overcome this aspect of their identity. Through the "I am…" activity, the adolescent participants demonstrated that they may not have self-categorized as disabled in relationship to other aspects of their identity. This lack of inclusion of disability is less a demonstration of the *ability* to self-categorize as a part of the disability community, and more a demonstration of the students' lack of understanding of disability as a community itself (in the same way as they might see gender, sexual identity, or particular roles as signifiers of community). These findings around self-categorization of disability contrast with special educations' conception of students with disabilities as having lower levels of identity exploration (Pinquart, 2013) or more negative self-concepts (Gans, Kenny & Ghany, 2003) inherently; instead, their experiences and development of disability identity is heavily affected by negative discourses available to them in schools and perpetuated by teachers, peers, and community.

Self-categorization, as the initial step in collective disability identity development, is important and significant because it involves the earliest interactions and decision-making around whether or not individual participants integrated disability as an aspect of their identities.

This decision-making process was weighted and guided by many external identity resources and experiences, including interactions with teachers, parents, and in particular classroom settings. The weight of the self-categorization of disability, regardless of the ways that participants chose to self-categorize, was important across all participants.

Evaluation

The participants' self-categorization was influenced by another component of collective identity, evaluation. Evaluation in the collective identity framework has two components, private and public regard. Interestingly, private regard was mostly positive for both the adult and student participants: adults and students talked about their own individual ideas about disability in ways that both acknowledged their difficulty navigating inaccessible or ableist spaces. They were simultaneously able to separate that difficulty from the embodied experience of disability, which was not necessarily negative or steeped in unconscious or internalized ableism. In some ways, this was an unexpected finding: having negotiated contexts that had over and over again reminded each participant that disability was undesirable, it might be expected that they would themselves internalize that undesirability and see it affect their individual evaluation of not only the concept of disability itself, but themselves in relation to disability. In some ways, this positive private regard for disability is a counternarrative: despite the negative stigma of disability, despite the pervasive medical model ideology in schools, participants still held a sense of positivity around the identity and the ways that it had impacted their own lives. This positive sense of disability identity in the face of so much negative feedback is the kind of "discourse of joy" and resistance missing from disability research writ large (Sunderland, Catalano, & Kendall, 2009; Paris & Alim, 2017).

Public regard was influenced through the inclusion of teacher and parent perspectives about disability, which shaped the social meaning that each participant ascribed to their self-categorization as a person with a disability. In general, public regard was positive for the adults: while they had experienced negative reactions to their disability from parents and teachers in their schooling experience, their later evaluation of disability was influenced by social media, community groups, and other connections to people with disabilities (including role models and social relationships) that in some significant way counteracted their earlier experiences. Evaluation of disability and of the relative fit of that aspect of themselves in relation to other parts of identity depended on time, distance from school and schooling, and more positive interactions than what they had previously experienced.

The adolescents in the study, in contrast, were still negotiating the negative interactions and perceptions of disability that are pervasive in their home and school environments, which influenced their evaluation both of disability identity itself and of the fit of that aspect of identity in relationship to their experience. This evaluation was in part guided by their teacher, Ms. Maddox, who had particular ideas about disability that were reinforced in the life skills course and repeated in each students' individual interview. As an identity agent around disability identity (Schachter & Ventura, 2008), Ms. Maddox played a fundamental role in the development of understanding of this identity for her students. She was influential both in the evaluation of fit of disability identity for each individual student, as well as the social meaning making that the student engaged in in relationship to disability identity. Her own identity around her ability (and lack of disability), steeped in ideas about how "normal" students behaved and particularly interacted socially, shaped her students' conceptions of what was possible for them and, perhaps more difficult, what they should expect of themselves.

This negotiation of evaluation of disability led to a surprising finding for the school phase of the study: the importance of virtual worlds, social media spaces, and creative expression where disability was redefined, if not rendered irrelevant. Ms. Maddox explicitly named the fact that her students were exhausted from school and masking their disability to remain normal, and therefore used virtual worlds and online spaces as places where they could let go of this masking. The students instead reported that they used their virtual worldmaking and participation, alongside creative skills, in particular ways that sometimes connected them to disability community and, more frequently, gave them some level of control over how they were seen and perceived in a space of their choosing. There is a tension here between the social expectations of reacting to a stigmatized label. Ms. Maddox assumes that her students want to, and spend all day, attempting to hide their disabilities and masking their differences in favor of a façade of normalcy. This, she assumes, ultimately makes them lonely and pushes them into online spaces where they may make dangerous and uninformed decisions that lead to negative interactions. In response, she creates social skill curriculums focusing on able-bodied norms of face to face communication and safety rules that help them engage socially in expected and sanctioned ways, “despite” disability. In tandem and simultaneously, her students seek out online, virtual spaces where they are able to explore disability on their own terms, express themselves, and in some way circumvent all of the public evaluation of disability entirely. These spaces include social media platforms like Instagram, where Quentin posted his manga art and interacted with others who had disability; multiplayer online games, where Vicky felt some ability to control her peers and their strategy for the game; and YouTube, where Danny looked up information about his ADHD. They engage in spaces where they feel in control, feel successful, and feel like their talents and abilities are foregrounded over the stigmatized aspects of themselves.

These conflicting responses to stigma around disability, and the evaluation of impact of that stigma on disability identity, supports two potential outcomes. In one, students might take up their disability labels and reclaim them in face to face social interactions with their peers; teachers and school systems might encourage students to find community with other disabled people and nondisabled ally peers through reclamation of their disability identity. In the other, students might be encouraged to engaged in spaces where disability becomes “irrelevant” because the conditions are structured so that their preferred skills and modes of communication are foregrounded. Each potential outcome of understanding the ways that students have responded to public regard of disability has an impact on the daily practice of teachers and other school community members who help shape this identity. Either requires a shift in the way that they explicitly name disability and foreground the meaning-making of their students in that naming, particularly in reaction to stigma.

Behavioral Involvement

Many of the adults reported negative school and schooling experiences that pushed them away and discouraged them from identifying with disability as an aspect of their identity earlier. These negative school and schooling experiences included removal from general education, bullying and negative interactions with their peers, lack of discussion of disability or inclusion in the curriculum, teacher feedback, and general loneliness and isolation in their experiences. After experiencing these negative school and schooling experiences and identity resources around disability, the adult participants later went through a process of resource and community seeking that involved media, community organizations, and relationships outside of school that eventually shifted their views of disability and disability identity. This process of seeking out resources, where the adults engaged in actions that implicate or involve disability as a part of their individual identity, was an important feature in the ways that adults felt more positively about their connections to disability in adulthood. This process of seeking out resources to counteract negative ideas about disability fostered in school-aged years looked different for each participant. Some adult participants found it through disability sport (i.e. in participation in the Special Olympics), some found it through community activism (through participation in local government initiatives around disability or identity-specific support groups), and some involved participation in media (online support group networks). For the adults, seeking out resources around disability involved this behavioral component and active involvement in community with other disabled people. This behavioral involvement was a choice and led to generally positive outcomes and connection to disability culture and community.

In contrast, student participants did not have much behavioral involvement with disability identity outside of the kinds of “assigned” involvement through special education classwork participation. While Bryce mentioned a few interesting social interactions around his unified sports team which included other people with disabilities, the students were mostly engaged in distancing themselves from special education contexts, disability-focused contexts and from other people with disabilities, especially when nondisabled people may see this distancing and interpret it favorably. One interesting way that students *did* engage behaviorally with disability came through connections with their peers in the low incidence disability courses who had more severe disabilities than they did; this behavioral involvement positioned the student participants as “helpers” and role models rather than peers or members of a community with shared experiences. Students did not mention media, community groups, or other behavior around disability in the same way as the adult participants with the exception of online spaces as potentially disability-friendly.

This study provides justification for the importance of understanding and explicitly naming disability identity as an important developmental phenomenon inside school contexts, particularly special education. Disability identity development, particularly if left unexamined and unmet with support and development, has material, social and academic implications for students' lives. In the following sections, I discuss the ways that this study points to a further need for disability identity research in school settings, with accompanying focus on practice and support for teachers involved in supporting the identity development process.

Implications

This study has a few important implications for the study and development of disability identity in school contexts. The study builds on disability studies literature and activist calls for understanding the importance of disability identity development, as both a unique phenomenon and as an identity that has positive implications if shaped and developed intentionally. Additionally, the study provides justification for this intentional development of disability identity inside of special education contexts in particular, as a matter of conceptual, academic, and individual importance for the field and for the people it serves. Moving forward into a research agenda that holds the importance of disability identity as a constant, I present three implications for special educational literature and related disability research that considers development of this identity: three levers that, based on this study, push both the disability identity literature forward as well as the related systems (school & special education) that shape this identity.

Authentic Discussion of Disability

First, a clear implication from both the adult and school phases of the study is the need for authentic conversations about disability at all levels of school and schooling. Discussions about disability were reported by both the adults and students to be either focused on academics and accommodations, or entirely left out of school contexts. Instead, adult participants reported desiring frank conversations that included support in navigating inaccessible or difficult school systems, but primarily focused on positive and communal aspects of disability that push back against dominant deficit perspectives.

This study presented an attempt at exploring what authentic discussions of disability might look like if led primarily by students using a creative, participatory research tool. Several components of this study facilitated authentic discussion of disability. First, the context of the classroom (where students had already had practice discussing their disability labels, IEPs, and accommodations) facilitated student readiness to discuss disability as an aspect of their identity. They were able to talk about their disability labels and how those labels affected their experiences in school, both socially and academically in terms of accommodations. This initial, foundational knowledge was an important entry point for students around developing an understanding of disability from a social, and collective, model. Second, the multi-modal nature of the study (where the photovoice project included writing, using cell phone photography, small and large group discussion) gave students multiple opportunities to practice discussing issues around disability on their own and with others. Third, having a disabled researcher/facilitator in the classroom caused students to interact with each other around disability in different ways than having a nondisabled facilitator/researcher or teacher may have. These factors facilitated authentic conversation about disability both because they explicitly named disability as a social phenomenon, and because they gave students an opportunity to authentically engage and share their experiences on their own terms with someone who identifies as having a disability.

In future studies, curriculum, or “interventions” focused on disability identity in special education or related contexts, it is important to facilitate authentic conversations around disability as they were facilitated in this study in various ways. These authentic conversations about disability are distinct from conversations that generalize or essentialize disability or an experience of disability. For example, many of the students expressed in their interviews and photovoice gallery sessions an idea that “everyone is different”: this idea was also echoed by their teacher, Ms. Maddess. While it’s true that everyone is different, an authentic conversation about disability might make a distinction between differences that have social meaning based in particular power structures, and the ways that those differences might shape student experiences in school. In this way, an authentic conversation about disability shifts convenient and easy explanations about disability and its impacts into ones that are focused on disability as a social, and collective, experience. This does not negate the necessary conversations about disability, impairment, and legal accommodations: the adults in the study in fact reinforced just how important those conversations were towards understanding disability as a part of their identity. This study demonstrates the need for the conversation to expand, and continue, from that point.

Community with Disabled People

Authentic conversations about disability can occur with (well-equipped) nondisabled facilitators and teachers. Importantly, though, another implication of this study involves building opportunities in school for community with disabled “others.” It is impossible to build resistance to ableism (and to teach this resistance) with nondisabled people as the only source of knowledge about disability. This implication arose directly from the reflections of the adult participants, who wished for disabled role models in school who may have been able to talk to them about disability in a more informed way from their own embodied perspectives and experiences. Schools and special education programs interested in focusing on the development of disability identity may first consider focusing on representation of disability not only in their curriculum, but in the staff in their school setting. Building community around disability necessarily involves this representation as a first step.

However, this study also demonstrates the power and potential of special educational spaces, where there is natural community around disability between students that may not be named or harnessed towards development of collective community and identity. This study demonstrates a shift towards utilizing existing special educational spaces towards this goal. Particularly in spaces which focus on “helping” the student understand how to navigate school or community (i.e., study and life skills elective courses) in relation to disability, building community looks like intentionally including disabled adults in the curriculum, encouraging connections between students with disabilities, and resisting dominant narratives that discourage students with disabilities from identifying with that aspect of themselves.

Broadening Meaning of Social Connection

Alongside broadening the potential of special educational contexts to facilitate disability identity development, this study (and the student participants in particular) raised an important question about the ways that we encourage disabled students out of connection with each other and with disabled community. In this school context, the life skills course focused on social skills and communication as a content area. This focus is typical of many similar courses in special education programs in other schools, districts and areas. While the focus on social skills is important, the students named online spaces and virtual connection with others as a way that they felt comfortable, confident, and most like themselves. In the online spaces, they were able to connect with other people who had disabilities. Adults with disabilities recalled and currently used social media and internet resources to access disability cultural resources. What is at stake here is a need to not only value online modes of communication and connection and to teach safe skills around communicating virtually, but to consider online spaces as valuable and legitimate spaces for human connectivity and development of disability community.

Teaching social skills as a content area in the way that only values face-to-face communication with nondisabled peers only serves to further isolate students with disabilities, who may find more connection and community in online spaces or other ways that may directly facilitate authentic conversations about disability. It also positions nondisabled modes of communication as the “normal” mode; as the only way that people can and should communicate and form connection with each other. Rather than focusing on teaching students with disabilities to communicate through this “normal” model, teachers and other school community members should be encouraged to help their students seek out community and relationships in ways that are both safe and comfortable for the student, even if this is done virtually or using modes of communication that are not valued by nondisabled people.

Limitations and Future Research

The study has a few important limitations that affect the scope of the work, discussion of findings, and future directions for research. These limitations involve participant selection and characteristics, scope and timing of the school phase, and data analysis.

First, I recruited adult participants through local disability community networks that leaned heavily, though not exclusively, towards particular kinds of participants (activists, engaged and knowledgeable about disability) and orientations towards disability in adulthood. This choice was done in part because of the critical stance of this dissertation, which holds that people with lived experience in the identity should be the ones guiding recommendations and development of that identity in school contexts. I also focused on centering experiences of adults who generally had a positive outlook on this aspect of their identities. The adults in this study were interested in participating in a discussion of disability identity; they found it important, sought out community or at least found it exciting to consider the possibility of that community, and were generally interested in learning more about disability. While I do not consider this a limitation that fundamentally alters the *outcome* of the comparisons I made between adults and student participants (and in fact, it was important to find “good examples” of adults with disabilities who were able to talk about their disability identity in active and collective ways), a limitation of the study is that it involves adults who at least consider disability a fundamental and important part of who they are, rather than providing a wider range of potential orientations towards that identity (both positive and negative). The conclusion of the study is not that it’s important to develop opportunities for the students in the study to become like the adults; but to interrogate the kinds of schooling experiences that both shared in order to create more positive, engaged, and community-driven opportunities to consider disability as an important part of students’ whole selves.

Similarly, Ms. Maddox’s courseload and guidance into selection of a particular life skills course and period limited the amount of choice I had about the student participants included in the study. The students themselves had a varied range of orientations and ideas about disability, but a wider range of disability categories and labels (particularly students with more visible disabilities) may have varied the kinds of discussions and identity development resources that were named in the study. Because Ms. Maddox chose the classroom setting for the study, my ability to choose participants was limited. Additionally, once inside the chosen classroom setting, the study was connected to an existing curriculum structure which meant that the thematic fit for the study only happened one time per week. This limited the amount of time that I could collect data to once a week for one school quarter (October-December). Since data was only collected for nine sessions, both the kinds of claims that can be made about students’ disability identities, and the kinds of rapport and relationships developed in the context of the study, are limited. Potentially expanding the length of the study into a year- (or even semester-) long course could expand opportunities for building both rapport between myself and between students, and comfort with individual students in talking about their own experiences.

A limitation of the data analysis process, while guided by recommendations of arts-based researchers who use visual data in their analysis process, has to do with the collective analysis of photographs, video recordings, written text, and interview data alongside each other. This data analysis strategy, while affording a way to see common themes across each data category, also collapsed potential differences in findings between, for example, the photography data and the interview data. Future analyses using photovoice as a method could include separation of the photography and written data from the interview data to facilitate this comparison. This would afford a more structured comparison between the interview data (i.e., the language students use and where they heard or learned that language) and the photovoice data (i.e., the student-led interpretations of disability).

This study provides several possibilities for expansion in order to include participants (particularly adults) who did not have such a strong orientation toward disability activism or collective disability identity, or different schooling contexts that may afford different conversations about disability identity. First, adult participant selection could involve mechanisms for recruitment that do not directly involve disability activism or community connection (i.e. hospital or therapeutic settings). Similarly, school and student participant selection (and the context in which those students receive special education services) could be intentionally changed for different results. While this study focused on self-contained special educational contexts that only involved students with disabilities, the disability studies literature is clear in calling for curriculum and instruction around disability that also involves nondisabled students. The purpose of this kind of curriculum then also necessarily expands into conversations about allyship rather than collective group identity of disability. Possible expansions of this kind of discussion of disability identity may also include co-taught courses or other general education settings that include both students with and without disabilities.

Another potential possibility for expansion has to do with the context of the special education course. While Ms. Maddox was an able-bodied teacher, a potential future study may engage classrooms or contexts where there is a disabled teacher (visibly or invisibly) who is open about their identity with students in a way that Ms. Maddox explicitly was not. This change in the identity agent in the special education course may afford different kinds of dialogues, vocabulary, or ideas about disability that would be interesting to understand in relationship to identity development of students.

Conclusion

This study contributes to the theoretical and methodological conversations around adolescent experiences of disability in schools in a few important ways. First, it centers student meaning-making around disability as the major source for both data collection and understanding (or as McDermott (2015) has said, “the individual is a unit of concern, insight, and hope, but not a unit of analysis” (p. 340)). This is the intolerable cost of special education and related disability research that treats individuals with disabilities as a subject under study and intervention, rather than meaning-makers, capable of creating community and solidarity, negotiating power and stigma, and articulating the changes that need to be made to make their communities more inclusive. If services and contexts that shape disability identity continue to remain ignorant and unconscious of their impact on those identities, students across the lifespan will continue to report that their senses of selves, their understanding of a fundamental part of who they are, and their possible connection to community will continue to be shaped by deficit ideas.

Importantly, this study was also structured around methodological choices that point towards thinking about disability identity in school in explicit ways and provide ways forward to begin this conversation in research and practice. The usage of photovoice in particular allowed students' ideas about their own embodied disability identities and connections to an idea about collective identity around disability to be the main source of learning. Understanding these ideas about identity could potentially lead to developing schools and instructional spaces that support positive disability identity, which could have far-reaching impact on the academic and social experiences of students with disabilities in school.

In closing, I am reminded of my own experiences in school as a disabled youth that have led me to be incredibly moved by the vulnerability, bravery, and thoughtfulness of my participants. I did not have a single friend with a disability for my entire schooling experience and did not learn about disability history until I sought it out in graduate school. Constantly positioned as the intelligent, easy and unchallenging student, I was more frequently labeled as the "teachers' aide" in my special education courses than I was a student or even a peer. While flattering (and effective) praise, I am motivated now and through this dissertation to suggest that asking students to be intelligent, easy and unchallenging should not be the goal of school or used as a way to counteract or overcome disability. Asking students to learn about themselves, to build solidarity with their classmates, to connect themselves to histories and communities, and to advocate for themselves and others should instead be paramount. The study participants have suggested many ways that they themselves have subversively accomplished these goals on their own, inside and in reaction to school; it's time for us to listen.

References

Annamma, S., Connor, D. & Ferri, B. (2012). Dis/ability critical race studies (DisCrit): Theorizing at the intersections of race and dis/ability. *Race Ethnicity and Education, 16*(1), 1-31.

Artiles, A.J., Bal, A., & King Thorius, K.A. (2010). Back to the future: A critique of response to intervention's social justice views. *Theory into Practice, 49,* 250-257.

Artiles, A.J., Kozleski, E.B., Trent, S.C., Osher, D. & Ortiz, A. (2010). Justifying and explaining disproportionality, 1968-2008: A critique of underlying views of culture. *Exceptional Children, 76*(3), 279-299.

Arzubiaga, A.E., Artiles, A.J., King, K.A., & Harris-Murri, N. (2008). Beyond research on cultural minorities: Challenges and implications of research as situated cultural practices. *Exceptional Children, 74*(3), 309-327.

Ashmore, R.D., Deaux, K. & McLaughlin-Volpe, T. (2004). An organizing framework for collective identity: Articulation and significance of multidimensionality. *Psychological Bulletin, 130*(1), 80-114.

Barga, N. K. (1996). Students with learning disabilities in education managing a disability. *Journal of Learning Disabilities*, 29(4), 413–421.

Bell, C.M. (2011). *Blackness and disability: Critical examinations and cultural interventions.* Germany: LIT Verlag.

Biklen, D. (1988). The myth of clinical judgment. *Journal of Social Issues, 44*(1), 127-140.

Block, P., Rodriguez, E.L., Milazzo, M.C., MacAllister, W.S., Krupp, L.B., Nishida, A, & Keys, C.B. (2011) Building pediatric multiple sclerosis community using a disability studies framework of empowerment. In A. C. Carey and R.K. Scotch (Eds.), *Research in Social Science and Disability* (85-112). London, England: Emerald Group Publishing Ltd.

Bogart, K.R., Lund, E.M., & Rottenstein, A. (2018). Disability pride protects self-esteem through the rejection-identification model. *Rehabilitation Psychology, 63*(1), 155-159.

Bogdan, R. & Taylor, S. (1976). The judged, not the judges: An insider's view of mental retardation. *American Psychologist, 31*(1), 47-52.

Boskovich, L., & Hernández-Saca, D.I. (2019). Stepping towards healing about learning disability at our intersectionality: How learning disability pain and privilege structured our schooling experiences. In E. Hurd (Ed.) *The Reflexivity of Pain and Privilege: Auto-Ethnographic Collections of Mixed Identity.* Leiden, The Netherlands: Brill Sense.

Brantlinger, E. (1997). Using ideology: Cases of nonrecognition of the politics of research and practice in special education. *Review of Educational Research, 67*(4), 425-459.

Brantlinger, E., Jimenez, R. Klingner, J., Pugach, M. & Richardson, V. (2005). Qualitative studies in special education. *Exceptional Children, 71*(2), 195-207.

Britzman, D. P. (1998). *Lost subjects, contested objects: Toward a psychoanalytic inquiry of learning.* Albany: State University of New York Press.

Brown, S.E. (2002). What is disability culture? *Disability Studies Quarterly, 22*(2), 34-50.

Butler, J. (1993). *Bodies that matter: On the discursive limits of sex.* New York, NY: Routledge.

Butler-Kisber, L. (2002). Artful portrayals in qualitative inquiry: The road to found poetry and beyond. *The Alberta Journal of Educational Research, XLVIII*(3), 229-239.

Calderón-Almendros, I. & Calderón-Almendros, R. (2015). ‘I open the coffin and here I am’: Disability as oppression and education as liberation in the construction of personal identity. *Disability & Society, 31*(1), 100-115.

Calderón-Almendros, I. & Ruiz-Roman, C. (2015). Education as liberation from oppression: Personal and social constructions of disability. In R. Sarroma & F. Kiuppis (Eds.), *Inclusive Education Twenty Years after Salamanca* (251-260). New York: Peter Lang.

Caldwell, J. (2011). Disability identity of leaders in the self-advocacy movement. *Intellectual and Developmental Disabilities*, *49*(5), 315-326.

Capous-Desyllas, M., & Bromfield, N.F. (2018). Using an arts-informed eclectic approach to photovoice data analysis. *International Journal of Qualitative Methods*, *17*, 1-14.

Catalano, R. F., & Hawkins, J. D. (1996). The social development model: A theory of antisocial behavior. In J. D. Hawkins (Ed.), *Delinquency and crime: Current theories (*149– 197). New York: Cambridge University Press.

Chavous, T., Hilkene, D., Schmeelk, K., Caldwell, C. H., Kohn-Wood, L., & Zimmerman, M. A. (2003). Racial identity and academic attainment among African American adolescents. *Child Development*, 74(4), 1076–1090.

Council for Exceptional Children. (1997). *CEC Policy Manual: Section 3, Professional Policies: Special Education in the Schools.* Retrieved from https://www.cec.sped.org/Policy-and-Advocacy/CEC-Professional-Policies/Special-Education-in-the-Schools

Connor, D.J. (2008). *Urban Narratives: Portraits in progress: Life at the intersections of learning disability, race, and social class.* New York, NY: Peter Lang.

Creswell, J.W. & Miller, D.L. (2000). Determining validity in qualitative inquiry. *Theory into Practice, 39*(3), 124-130.

Davis, L.J. (2006). Introduction: Normality, Power and Culture. In L.J. Davis (Ed.), *The Disability Studies Reader* (1-14). New York: Routledge.

Deal, M. (2010). Disabled people's attitudes toward other impairment groups: A hierarchy of impairments. *Disability & Society, 18*(7), 897-910.

Delpit, L. (1995). *Other people's children: Cultural conflict in the classroom.* New York: The New Press.

Denzin, N.K. (1997). *Interpretive ethnography: Ethnographic practices for the 21st century.* Thousand Oaks, CA: Sage.

Disability Rights Washington. (2017). Portrait of the Whole Person Curriculum. [PDF file].

Eisner, E.W. (1991). *The enlightened eye.* New York: Macmillan.

Erikson, E.H. (1968). *Identity: Youth and crisis.* New York: Norton.

Erevelles, N. (2005). Understanding curriculum as normalizing text: Disability studies meet curriculum theory. *Journal of Curriculum Studies, 37*(4), 421-439.

Fitch, F. (2003). Inclusion, exclusion, and ideology: Special education students' changing sense of self. *The Urban Review, 35*(3), 233-252.

Florian, L. (2007). Reimagining special education. In L. Florian (Ed.) *The Sage Handbook of Special Education*. London: Sage Publications.

Foucault, M. (1978). *The history of sexuality. Vol 1: An introduction.* New York: Vintage.

Foucault, M. (1982). The subject and power. *Critical Inquiry, 8*(4), 777-795.

Forber-Pratt, A.J., Lyew, D.A., Mueller, C., & Samples, L.B. (2017). Disability identity development: A systematic review of the literature. *Rehabilitation Psychology, 62*(2), 198-210.

Forber-Pratt, A.J., & Zape, M. (2017). Disability identity development model: Voices from the ADA generation. *Disability and Health Journal, 10*(2), 350-355.

Fujita, H., & Arikawa, M. (2008). Animation of mapped photo collections for storytelling. *IEICE Transactions on Information and Systems, 91*, 1681–1692.

Gee, J.P. (2000). Identity as an analytic lens for research in education. *Review of Research in Education*, *25,* 99-125.

Gans A.M, Kenny, M.C., Ghany, D.L. (2003). Comparing the self-concept of students with and without learning disabilities. *Journal of Learning Disabilities, 36*(3), 287-295.

Gill, C.J. (1995). A psychological view of disability culture. *Disability Studies Quarterly, 15*(4), 16-19.

Gill, C.J. (1997) Four types of integration in disability identity development. *Journal of Vocational Rehabilitation*, *9*(1), 39-46.

Giroux, H.A. & Simon, R.I. (1988). Schooling, popular culture, and a pedagogy of possibility. *The Journal of Education*, *170*(1), 9-26.

Greene, M. (1971). Curriculum and consciousness. *Teacher's College Record, 73*(2), 253-269.

Griffin, P., Lee, C., Waugh, J., & Beyer, C. (2004). Describing roles that Gay-Straight Alliances play in schools: From individual support to school change. *Journal of Gay & Lesbian Issues in Education 1*(3), 7-22.

Hahn, H.D. & Belt, T.L. (2004). Disability identity and attitudes toward cure in a sample of disabled activists. *Journal of Health and Social Behavior*, *45*(1), 453-464.

Hammack, P.L. (2010). Identity as burden or benefit? Youth, historical narrative, and the legacy of political conflict. *Human Development*, *53*, 173-201.

Harrell-Levy, M.K., & Kerpelman, J.L. (2010). Identity process and transformative pedagogy: Teachers as agents of identity formation. *Identity: An International Journal of Theory and Research, 10*(2), 76-91.

Hart, R.D. & Williams, D.E. (2009). Able bodied instructors and students with physical disabilities: A relationship handicapped by communication. *Communication Education, 44*(2), 140-154.

hooks, b. (1991). Theory as liberatory practice. *Yale Journal of Law & Feminism*, *4*(1), 1-12.

Kauffman, J.M. (2003). Appearances, stigma, and prevention. *Remedial and Special Education, 24*(4), 195-198.

Kumashiro, K.K. (2000). Toward a theory of anti-oppressive education. *Review of Educational Research*, *70*(1), 25-53.

Lahman, M.K.E., Teman, E.D., Richard, V.M. (2017). IRB as poetry. *Qualitative Inquiry, 00*(0), 1-15.

Lalvani, P. (2015). “We are not aliens”: Exploring the meaning of disability and the nature of belonginess in a fourth grade classroom. *Disability Studies Quarterly, 35*(4).

Leavy, P. (2009). *When method meets art.* New York, NY: Guilford Press.

Leonardo, Z. & Broderick, A.A. (2011). Smartness as property: A critical exploration of intersections between whiteness and disability studies. *Teachers College Record, 113*(10), 2206-2232.

Linton, S. (1998). *Claiming disability: Knowledge and identity.* New York: New York University Press.

Lusted, D. (1986). Why pedagogy? *Screen, 27*(5), 2-16.

Marcia, J.E. (1993). The ego identity status approach to ego identity. In Marcia, J., Waterman, A., Matteson, D., Archer, S., & Orlofsky, J. (Eds.), *Ego Identity,* 3-21. New York: Springer Verlag.

McDermott, R., Goldman, S., & Varenne, H. (2006). The cultural work of learning disabilities. *Educational Researcher, 35*(6), 12-17.

McDermott, R. (2015). Does “learning” exist? *Word, 61*(4), 335-349.

McLaren, P. (2016). Critical pedagogy: A look at the major concepts. In M. Pruyn & L. Huerta-Charles (Eds). *This fist called my heart: The Peter McLaren reader.* Charlotte, NC: Information Age Publishing.

Merriam, S.B. (2009). *Qualitative research.* San Francisco, CA: Jossey-Bass.

Michalko, R. (2002). *The difference that disability makes.* Philadelphia, PA: Temple University Press.

Miles, A.L., Nishida, A. & Forber-Pratt, A.J. (2017). An open letter to white disability studies and ableist institutions of higher education. *Disability Studies Quarterly, 37*(3).

Mingus, M. (2010, July 6). Reflecting on Frida Kahlo’s birthday and the importance of recognizing ourselves for (in) each other [Blog post]. Retrieved from: https://leavingevidence.wordpress.com/tag/identity/

Mitchell, D. & Snyder, S. (Producers). (1995). *Vital Signs: Crip Culture Talks Back* [Motion picture]. United States: Fanlight Productions.

National Center on Secondary Education and Transition (NCSET). (2006). Youth Leadership Forums: Providing leadership development opportunities for youth with disabilities. *Information Brief: Addressing Trends and Developments in Secondary Education and Transition, 5*(3), 1-6.

National Council on Independent Living (NCIL). (2017). Disability Pride Toolkit and Resource Guide. [PDF file].

Nussbaum, S. (2008). The Empowered Fe Fes: A group for girls with disabilities. In A. Harris (Ed), *Next Wave Cultures: Feminism, Subcultures, Activism*, 105-120. New York: Routledge.

Nykiforuk, C.I.J., Vallianatos, H., & Nieuwendyk, L.M. (2016). Photovoice as a method for revealing community perceptions of the built and social environment. *International Journal of Qualitative Methods, 10*(2), 103-124.

Ogbu, J.U. (1987). Variability in minority school performance: A problem in search of an explanation. *Anthropology & Education Quarterly, 18*(4), 312-334.

Paris, D., & Alim, H.S. (2017). *Culturally sustaining pedagogies: Teaching and learning for justice in a changing world.* New York, NY: Teacher's College Press.

Park, A. (2019, June 5). I'm a disabled teenager, and social media is my lifeline. *The New York Times.* Retrieved from https://nyti.ms/2Xqucqw

Pinar, W. F. (1993). Notes on understanding curriculum as a racial text. In C. McCarthy and W. Critchlow (Eds.), *Race, Identity, and Representation in Education*, 60–70. New York: Routledge.

Pinquart, M. (2013). Self-esteem of children and adolescents with chronic illness: A meta-analysis. *Child: Care, Health Development*, *39*(2), 153-161.

Rich, A. (1986). *Blood, bread and poetry: Selected prose 1979-1985*. New York: Norton.

Richardson, L. (1994) Writing: A method of inquiry. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research,* 516-529. Thousand Oaks, CA: Sage Publications, Inc.

Rogoff, B., Baker-Sennett, J., Lacasa, P., & Goldsmith, D. (1995). Development through participation in sociocultural activity. *New Directions for Child and Adolescent Development, Spring* (67), 45-65.

Saldaña, J. (2013). The coding manual for qualitative researchers. Thousand Oaks, CA: Sage.

Schachter, E.P., & Ventura, J.J. (2008). Identity agents: Parents as active and reflective participants in their children's identity formation. *Journal of Research on Adolescence, 18*(3), 449-476.

Shakespeare, T. (2002). The social model of disability: An outdated ideology. *Research in Social Science and Disability, 2*(1), 9-28.

Shaffer, R. (1983). Beyond the dispensary. Nairobi, Kenya: Amref.

Sheldon, J. (2017). Problematizing reflexivity, validity, and disclosure: Research by people with disabilities about disability. *The Qualitative Report, 22*(4), 984-1000.

Shifrer, D. (2013). Stigma of a label: Educational expectations for high school students labeled with learning disabilities. *Journal of Health and Social Behavior, 54*(4), 462-480.

Sleeter, C.E. (1986). Why is there learning disabilities? A critical analysis of the birth of the field in its social context. *Disability Studies Quarterly, 30*(2).

Sleeter, C. E. (2011). *The academic and social value of Ethnic Studies: A research review*. Washington, DC: National Education Association. [PDF file].

Smith, R.M., Gallagher, D., Owen, V., & Skrtic, T. (2009). Disability studies in education: Guidelines and ethical practice for educators. In J. Andrzejewski, M. Baltodano, & L. Symcox (Eds.), *Social Justice, peace and environmental education: Transformative Standards*, 235-251. New York: Routlege.

Steele, C.M. (1997). A threat in the air: How stereotypes shape intellectual identity and performance. *American Psychologist, 52*(6), 613-629.

Sunderland, N., Catalano, T., & Kendall, E. (2009). Missing discourses: Concepts of joy and happiness in disability. *Disability & Society, 24*(6), 703-714.

Tatum, B.D. (2004). Family life and school experience: Factors in the racial identity development of black youth in white communities. *Journal of Social Isseus, 60*(1), 117-135.

Tuck, E. and K.W. Yang. (2014). R-words: Refusing research. In D. Paris and M. T. Winn (Eds.) *Humanizing research: Decolonizing qualitative inquiry with youth and communities*. Thousand Oaks, CA: Sage Publications.

Wang, C. & Burris, M.A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior, 24*(3), 369-387.

Wang, C., & Pies, C. (2004). Family, maternal, and child health through photovoice. *Maternal and Child Health Journal, 8,* 95-102.

Ware, L.P. (2002). A moral conversation on disability: Risking the personal in educational contexts. *Hypatia, 17*(3), 143-172.

Weiner, J., & Daniels, L. (2016). School experiences of adolescents with Attention Deficit/Hyperactivity Disorder. *Journal of Learning Disabilities, 49*(6), 567-581.

Wilke, N. (2011). Finding a sense of belonging through disability culture and pride. *Impact, 24*(1), 2-4.

Youth Speak Out Coalition and Zimmerman, K. (2007). Making space, making change: Models for youth-led social change organizations. *Children, Youth and Environments, 17*(2), 298-314.

Zambo, D.M. (2010). Strategies to enhance the social identities and social networks of adolescent students with disabilities. *Teaching Exceptional Children, 43*(2), 28-35.

Appendix A: Disabled Adult Interview Protocol

Interview 1: Life History Interview

As you know, I am researching disability identity development, and as part of that am trying to hear as many stories of disabled adults' experiences with disability and school as I can. Could you tell me about your experiences? I'll listen first, I won't interrupt and I may take a couple of notes that I'll ask you questions about later, so please take the time that you need and as I said, I won't interrupt you. Can you talk with me about the life experiences you've had with disability, the events and experiences that have been important to you up until now?

Interview 2: Focused Disability Interview

Youth Disability Identity

Can you start by talking about your schooling experiences around your disability when you were growing up- what kinds of school settings were you in? Did you have mostly inclusive classes, or self-contained

What do you think you thought disability was when you were in school?

Did you have a clear sense of what disability meant to you? How do you think you would have defined it?

How did you feel to be a person with a disability in your youth/teenagerhood? Did you feel proud of it?

Did you feel that you belonged to a disability community when you were in school? What did that community look like, or did you have a sense of that community at all?

Did you ever learn about any disability history or anything about disability rights, community, etc. in school?

Did you have friendships or social relationships with other students who had disabilities in school?

Adult Disability Identity

How do you define disability now, in adulthood?

Was there a shift or difference in the way you thought about disability in your youth to the way that you think about it now?

What do you think caused that shift?

Do you feel like you're part of a disability community?

Wishes/Wants for DID

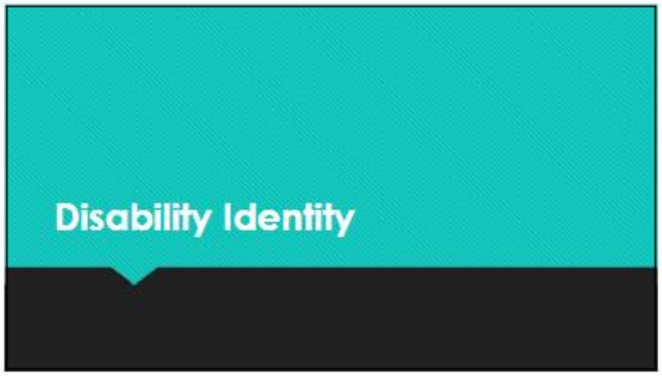
If you could go back to your high school or other educational experiences, what do you wish you had known about disability?

What do you wish was included in school to support the development of your own disability identity today- what would you need to do that?

What do you think schools are missing in order to teach students with disabilities *about* disability?

Appendix B: Disability Identity School Session Powerpoints

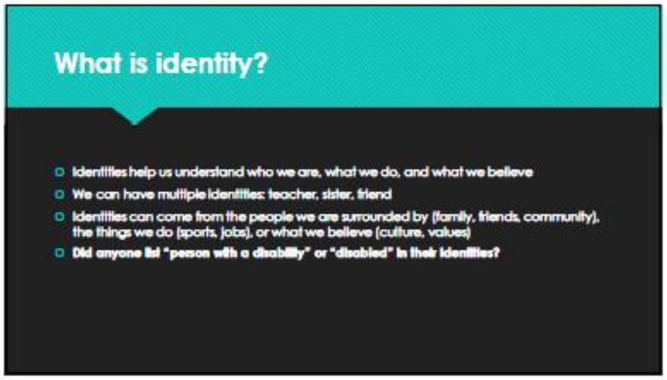
Session 1.



Disability Identity

Who are you?

List as many things that you can think of that describe you. These could be roles (for example, athlete) or family relationships (sister), gender, race, etc.

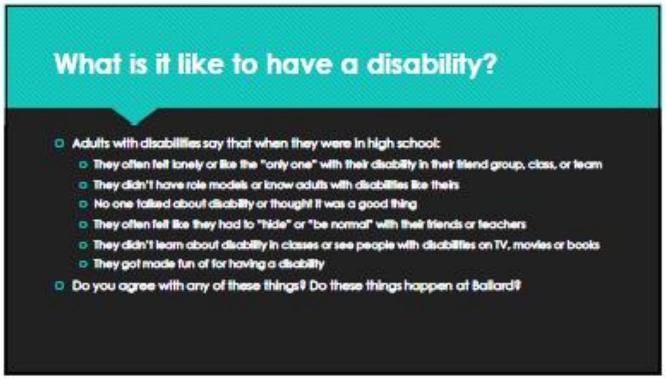


What is identity?

- Identities help us understand who we are, what we do, and what we believe
- We can have multiple identities: teacher, sister, friend
- Identities can come from the people we are surrounded by (family, friends, community), the things we do (sports, jobs), or what we believe (culture, values)
- **Did anyone list "person with a disability" or "disabled" in their identities?**

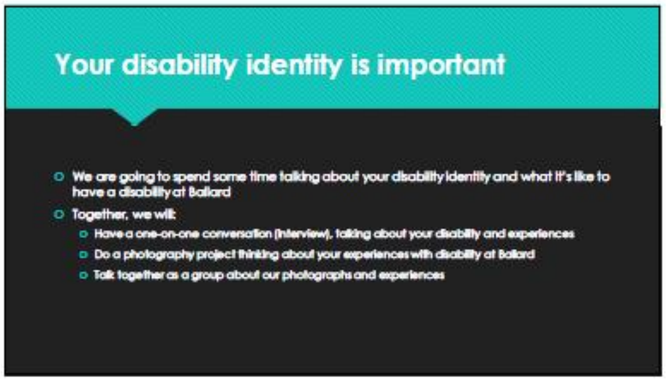
Disability identity is a unique identity

- **Disability identity** is the ideas you have about your disability and the connections you have with other people who have disabilities
- If you are proud of having a disability, it can help you in lots of different parts of your life: with friends, in school, etc
- Everyone with a disability has a disability identity- even adults!
  - Do you know any adults who have disabilities? Any adults with disabilities like yours?



What is it like to have a disability?

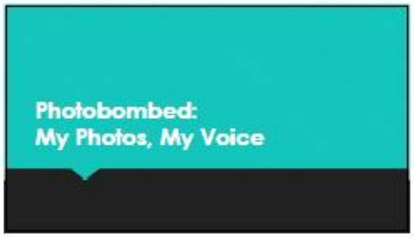
- Adults with disabilities say that when they were in high school:
  - They often felt lonely or like the "only one" with their disability in their friend group, class, or team
  - They didn't have role models or know adults with disabilities like theirs
  - No one talked about disability or thought it was a good thing
  - They often felt like they had to "hide" or "be normal" with their friends or teachers
  - They didn't learn about disability in classes or see people with disabilities on TV, movies or books
  - They got made fun of for having a disability
- Do you agree with any of these things? Do these things happen at Ballard?



Your disability identity is important

- We are going to spend some time talking about your disability identity and what it's like to have a disability at Ballard
- Together, we will:
  - Have a one-on-one conversation (interview), talking about your disability and experiences
  - Do a photography project thinking about your experiences with disability at Ballard
  - Talk together as a group about our photographs and experiences

Appendix B continued: Session 2



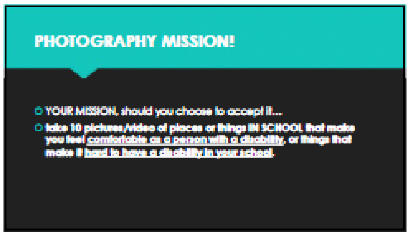
Photobombed: My Photos, My Voice

Disability identity is a unique identity

- **Disability identity** is the ideas you have about your disability and the connections you have with other people who have disabilities
- If you are proud of having a disability, it can help you in lots of different parts of your life: with friends, in school, etc
- Everyone with a disability has a disability identity- even adults!
- In this class, we practice talking about our disabilities, becoming comfortable with knowing what we need and how to ask for it in school

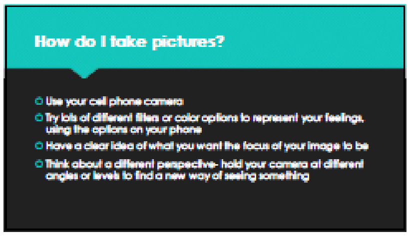
Photography project

- We've done interviews talking about what you know about disability
- Now we will use art (through photography) to talk about disability and your experiences at school



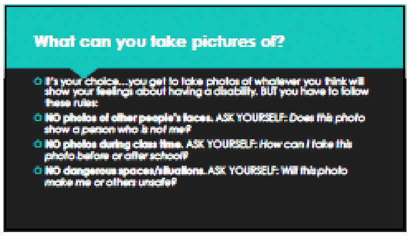
PHOTOGRAPHY MISSION!

- YOUR MISSION, should you choose to accept it…
- **take 10 pictures/video of places or things IN SCHOOL that make you feel comfortable as a person with a disability, or things that make it hard to have a disability in your school.**



How do I take pictures?

- Use your cell phone camera
- Try lots of different filters or color options to represent your feelings, using the options on your phone
- Have a clear idea of what you want the focus of your image to be
- Think about a different perspective- hold your camera at different angles or levels to find a new way of seeing something



What can you take pictures of?

- It's your choice…you get to take photos of whatever you think will show your feelings about having a disability. BUT you have to follow these rules:
- **NO photos of other people's faces.** ASK YOURSELF: *Does this photo show a person who is not me?*
- **NO photos during class time.** ASK YOURSELF: *How can I take this photo before or after school?*
- **NO dangerous spaces/situations.** ASK YOURSELF: *Will this photo make me or others unsafe?*

Let's practice: Does this photo follow the rules?

- Is it dangerous?
- Is it during class time?
- Does it have other people's faces in it?

Let's practice: Does this photo follow the rules?

- Is it dangerous?
- Is it during class time?
- Does it have other people's faces in it?

Let's practice: Does this photo follow the rules?

- Is it dangerous?
- Is it during class time?
- Does it have other people's faces in it?

Let's practice: Does this photo follow the rules?

- Is it dangerous?
- Is it during class time?
- Does it have other people's faces in it?

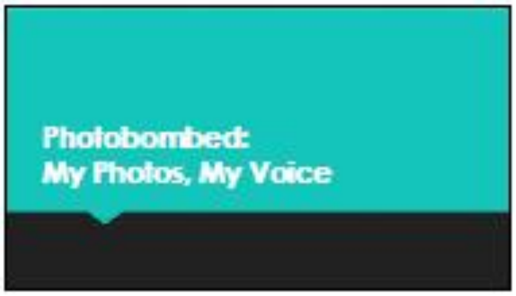
What do I do after I take a picture?

- Use the photovoice book I give you to write down a short reflection on why you took the image
- Think about:
  - What does it show?
  - What does it tell about your experience in school with having a disability?
  - Does it remind you of an experience or a memory?
- **Spelling doesn't matter,** we will just use these to remember what you took photos of and why
- You can also record a video of yourself answering the questions if that's easier- make sure you save everything on your phone!

Steps to do the photovoice project

- Take 10 images with your camera phone (following the rules above).
  - You can take as many images as you want, but write about 10 in your journals
- Write up a short "journal" of why you took each image in your photovoice book. These can be as long or as short as you would like, but should say what the image represents for you.
- Have your images and photo journals ready to talk about by **December 10.** We will share them together as a group!

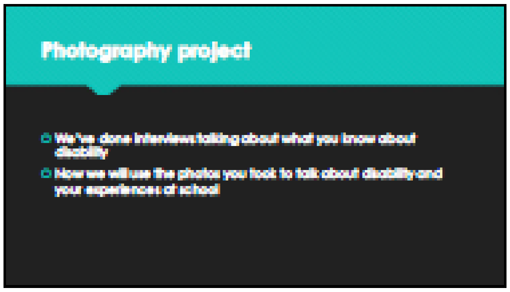
Appendix B continued: Session 3



Photobombed:
My Photos, My Voice

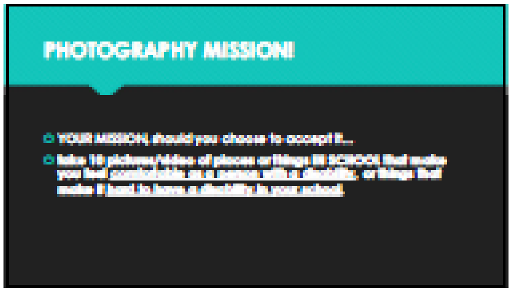
Disability identity is a unique identity

- **Disability identity** is the ideas you have about your disability and the connections you have with other people who have disabilities
- If you are proud of having a disability, it can help you in lots of different parts of your life: with friends, in school, etc
- Everyone with a disability has a disability identity- even adults!
- In this class, we practice talking about our disabilities, becoming comfortable with knowing what we need and how to ask for it in school



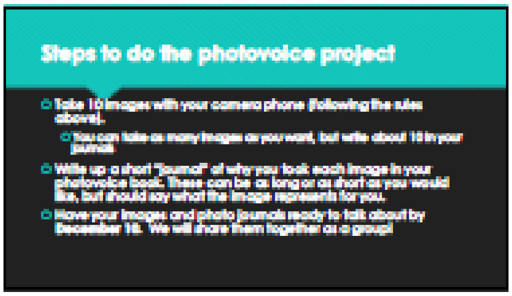
Photography project

- We've done interviews talking about what you know about disability
- Now we will use the photos you took to talk about disability and your experiences at school



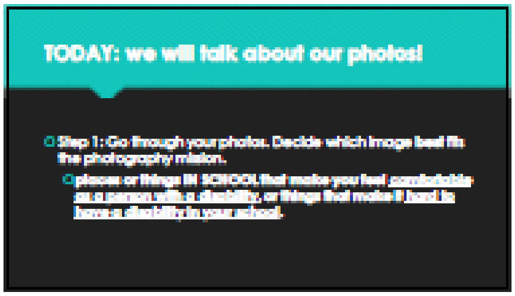
PHOTOGRAPHY MISSION!

- YOUR MISSION, should you choose to accept it…
- take 10 pictures/video of places or things IN SCHOOL that make you feel comfortable as a person with a disability, or things that make it hard to have a disability in your school.



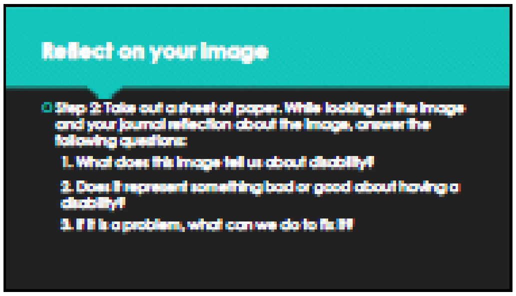
Steps to do the photovoice project

- Take 10 images with your camera phone (following the rules above).
  - You can take as many images as you want, but write about 10 in your journal
- Write up a short "journal" of why you took each image in your photovoice book. These can be as long or as short as you would like, but should say what the image represents for you.
- Have your images and photo journals ready to talk about by December 18. We will share them together as a group!



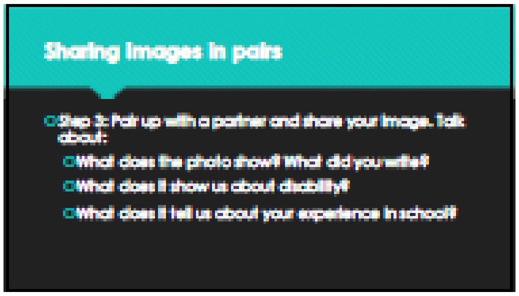
TODAY: we will talk about our photos!

- Step 1: Go through your photos. Decide which image best fits the photography mission.
  - places or things IN SCHOOL that make you feel comfortable as a person with a disability, or things that make it hard to have a disability in your school.



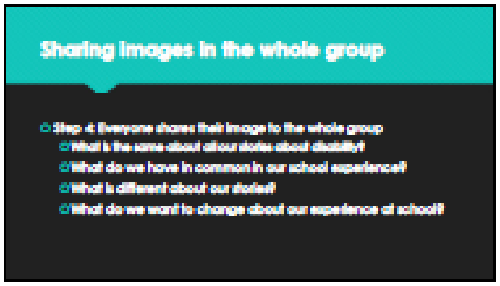
Reflect on your image

- Step 2: Take out a sheet of paper. While looking at the image and your journal reflection about the image, answer the following questions:
  1. What does this image tell us about disability?
  2. Does it represent something bad or good about having a disability?
  3. If it is a problem, what can we do to fix it?



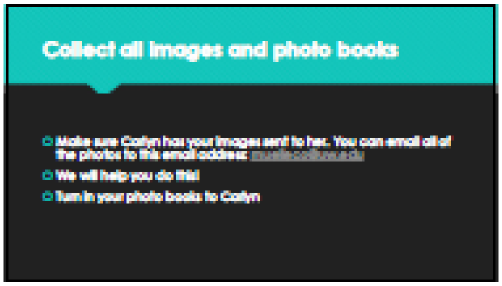
Sharing images in pairs

- Step 3: Pair up with a partner and share your image. Talk about:
  - What does the photo show? What did you write?
  - What does it show us about disability?
  - What does it tell us about your experience in school?



Sharing images in the whole group

- Step 4: Everyone shares their image to the whole group
  - What is the same about all our stories about disability?
  - What do we have in common in our school experience?
  - What is different about our stories?
  - What do we want to change about our experience at school?



Collect all images and photo books

- Make sure Caitlyn has your images sent to her. You can email all of the photos to this email address: [illegible]
- We will help you do this!
- Turn in your photo books to Caitlyn

Appendix C: Disabled Student Interview Protocol

Tell me a little bit about what school is like for you.

What are the places where you feel most comfortable in school?

Where do you feel least comfortable in school?

What does the word disability mean to you?

Do you see yourself as a person with a disability? (Self-categorization)

Do you like being a person with a disability/disabled person? (Evaluation)

Is it important to you to identify as a person with a disability? (Importance)

Do you have friends and role models with disabilities? (Social embeddedness)

Do you advocate for yourself and other people with disabilities? Do you advocate for yourself in school? (Behavioral Involvement)

What are some positive things about having a disability? What are some negative things? (Evaluation)

What do you think are some messages you hear about disability? Where do you think you heard those messages from? (Content/meaning)

How important is disability to who you are? (Self-categorization/Social embeddedness)

Appendix D: **Photovoice Booklet** (Text only, book formatted for students)

What am I doing again?

PHOTOGRAPHY MISSION!

Your mission, should you choose to accept it, is to: take 10 pictures/video of places or things that make you feel comfortable as a person with a disability, or things that make it hard to have a disability in your school.

Save all of your images in your phone and have your images and descriptions ready to talk about by JUNE 8. We will share them as a group.

Follow these steps to complete the photovoice project:

- Take at least 10 images with your camera phone that fit the mission above.
- Write up a short description of why you took each image using this book.
- Keep both the images and book safe.

What can I take a picture or video of?

As the photographer, you have the ability to take photos of whatever you think best shows your thoughts and feelings about having a disability. HOWEVER, you must follow these rules:

- NO photos of people's faces.
    - Ask yourself: *Is this photo invading someone's privacy?*
- NO photos during class.
    - Ask yourself: *How can I take this photo before or after school?*
- NO dangerous spaces/situations.
    - Ask yourself: *Would I get in trouble for taking this image?*

What do I do after I take a picture?

Use the attached sheets to record your thoughts about why you took the photo. What does it show? What does it tell about your experience in school with having a disability? Does it remind you of an experience or a memory?

Appendix D continued.

Image name (something to help us identify the image): ______________________________

Appendix D continued: **Photovoice Booklet**

What do we see here? Why did you take this picture? What does it show?

____

____

____

____

____

Image name (something to help us identify the image): ______________________________

What do we see here? Why did you take this picture? What does it show?

____

____

____

____

____

Image name (something to help us identify the image): ______________________________

What do we see here? Why did you take this picture? What does it show?

____

____

____

____

Appendix E: Photovoice Gallery Session SHoWED Method

What is really happening here?

____

____

____

____

____

Why does this place, situation, or concern exist?

____

____

____

____

____

What can we do about it?

____

____

____

____

Appendix F: Teacher Interview Protocol

-Can you tell me how you came to teach and organize the class in the way that you do?

-What brought you to the structure and content that you have now

-How do you talk to students about disability- what do you tell them?

-How were you taught to talk about disability with your students (if at all?)

-How do you wish disability was talked about in school or other classrooms?

-How do you handle students asking questions or googling information about disability? Do you experience this? How do you handle it?

Appendix G: Codebook
ADULT PHASE

CODING OPERATIONALIZED DEFINITIONS

1st Cycle Codes: Structural and Descriptive

Self-contained- separate classrooms for students just with disabilities
Regular-referring to general education classes, which makes special education/SWD non-regular
Disability silence-missed opportunities to talk about disability in conversation, classes, curriculum or other interactions in school
Teacher talk- ways teachers talk about disability
Bullying- negative or contentious interactions around disability between students
Disability knowledge- ways of describing what disability is, or remembering what disability meant at an earlier time
Family- relative's ideas or talk about disability
Realization of disability- a particular instance or series of instances where people recognize that they have a disability or recognize the meaning of their disability label
Outside organizations- participation in activities outside of school that build disability knowledge and identity
Disability pride- feeling good about having a disability
Loneliness- feeling isolated or misunderstood in relationship to disability
Media- depictions of disability in television, books, popular culture, or school curriculum
Cross-disability solidarity-an understanding that disability issues are not just relative to one's own disability labels, and knowledge about other disabilities
Disability culture- an understanding or belief that people with disabilities have their own unique traits and ways of understanding in the world
Disability advocacy- working for the betterment of people with disabilities, in micro or macro ways

1st Cycle Codes: In Vivo

"Taken out"- Removal from general education classroom while class is going on into a separate, special education small group class or context

"Get over it"- Expressions from others (usually nondisabled people) about disability, especially to overcome or mask the traits of disability

Appendix G continued: Codebook

Adult 2nd Cycle Codes

Identity Development

Realization of disability- a particular instance or series of instances where people recognize that they have a disability or recognize the meaning of their disability label

Disability knowledge- ways of describing what disability is, or remembering what disability meant at an earlier time

- **Classmates knowledge-** ideas that others in school have about disability
- **Disability label-** an individual's ideas or negotiation of the external meaning of their disability label- often, what it means to have a "learning disability" in school or from others' perspectives
- **Embodied experiences of disability-** the internal negotiation or experience of disability- feelings about the disability, noticing comparisons and/or remembering memories

Intersectionality- mentioning other aspects of identity alongside or separate from disability, especially where it shapes the marginalization of the individual (i.e., not a privileged identity)

Positive/Protective Identity Resources and Experiences

Disability pride- feeling good about having a disability

Disability culture- an understanding or belief that people with disabilities have their own unique traits and ways of understanding in the world

Disability advocacy- working for the betterment of people with disabilities, in micro or macro ways

Social model- Talking about disability in terms of structural issues/accommodations in an environment

Outside organizations- participation in activities outside of school that build disability knowledge and identity

Media- depictions of disability in television, books, popular culture, or school curriculum

Negative/Oppressive Identity Experiences and Resources

Family- relative's ideas or talk about disability

Bullying- negative or contentious interactions around disability between students

Disability awareness-an understanding that disability issues are not just relative to one's own disability labels, and knowledge and acknowledgement about other people with disabilities

"Get over it"- Expressions from others (usually nondisabled people) about disability, especially to overcome or mask the traits of disability

Self-contained- separate classrooms for students just with disabilities

Normality-Conscious comparisons or behaviors that the person uses to appear "regular" or normal in school or social school settings

Disability silence-missed opportunities to talk about disability in conversation, classes, curriculum or other interactions in school

Teacher talk- ways teachers talk about disability

Appendix G continued: Codebook

"Taken out"- Removal from general education classroom while class is going on into a separate, special education small group class or context

SCHOOL PHASE

1st Cycle Codes: Structural and Descriptive (from adult phase)

Self-contained- separate classrooms for students just with disabilities
Disability silence-missed opportunities to talk about disability in conversation, classes, curriculum or other interactions in school
Teacher talk- ways teachers talk about disability
Bullying- negative or contentious interactions around disability between students
Disability knowledge- ways of describing what disability is, or remembering what disability meant at an earlier time

> **Classmates knowledge-** ideas that others in school have about disability
> **Disability label-** an individual's ideas or negotiation of the external meaning of their disability label- often, what it means to have a "learning disability" in school or from others' perspectives
> **Embodied experiences of disability-** the internal negotiation or experience of disability- feelings about the disability, noticing comparisons and/or remembering memories

Family- relative's ideas or talk about disability
Realization of disability- a particular instance or series of instances where people recognize that they have a disability or recognize the meaning of their disability label
Outside organizations- participation in activities outside of school that build disability knowledge and identity
Loneliness- feeling isolated or misunderstood in relationship to disability
Media- depictions of disability in television, books, popular culture, or school curriculum

1st Cycle Codes: Structural and Descriptive (New codes)

Friendships- Relationships with others, social interactions inside or outside of school
Internet/online activity- Playing online video games, using social media apps, socializing on the internet
Accommodations- Knowledge of IEP/legally required tools or teaching strategies
Self-advocacy- Asking for required accommodations in class, or other activities that encourage the individual student to ask for what they want or need
Creativity- Participation in art activities or considering oneself as an artist
School experiences- Stories about classroom or school-based situations related to disability
Judgement of others- awareness and/or fear of others' ideas about disability negatively impacting the student
Other definitions of self- ways that students described themselves other than in relationship to disability

Appendix G continued: Codebook

Awareness of others with disabilities-relationships, friendships, or noticings of others with disabilities
Overcoming- Expressions from others (usually nondisabled people) or self about disability that conceptualize it as something that can be fixed or solved for the person to become normal

School 2nd Cycle Codes

Personal Context- Internal Processing
Disability knowledge- ways of describing what disability is, or remembering what disability meant at an earlier time
  Classmates knowledge- noticing ideas that others in school have about disability
  Disability label- an individual's ideas or negotiation of the external meaning of their disability label
  Embodied experiences of disability- the internal negotiation or experience of disability- feelings about the disability, noticing comparisons and/or remembering memories
Realization of disability- a particular instance or series of instances where people recognize that they have a disability or recognize the meaning of their disability label
Loneliness- feeling isolated or misunderstood in relationship to disability
Creativity- Participation in art activities (drawing, music, poetry), or considering self as an artist
Other definitions of self- ways that students described themselves other than about disability
Overcoming- Expressions from others (usually nondisabled people) or self about disability that conceptualize it as something that can be fixed or solved for the person to become normal

Personal Context- External Sources
Family- relative's ideas or talk about disability
Friendships- Relationships with others, social interactions inside or outside of school
Outside organizations- participation in activities that build disability knowledge & identity
Awareness of others with disabilities- relationships, friendships, or noticing others with disabilities
Overcoming- Expressions from others (usually nondisabled people) or self about disability that conceptualize it as something that can be fixed or solved for the person to become normal
Media- depictions of disability in television, books, popular culture, or school curriculum
Internet/online activity- Playing online video games, using social media apps, socializing

School Context
Self-contained- separate classrooms for students just with disabilities
Disability silence-missed opportunities to talk about disability in conversation, classes, curriculum or other interactions in school
Teacher talk- ways teachers talk about disability
Bullying- negative or contentious interactions around disability between students
Accommodations- Knowledge of IEP/legally required tools or teaching strategies

Appendix G continued: Codebook

Self-advocacy- Asking for required accommodations in class, or other activities that encourage the individual student to ask for what they want or need

School experiences- Stories about classroom or school-based situations related to disability

Judgement of others- awareness and/or fear of others' ideas about disability negatively impacting the student

Awareness of others with disabilities-relationships, friendships, or noticings of others with disabilities

Appendix H: Analytic Memoing Categories for Reflection (adapted from (Saldana, 2013))

- Reflect on and write about how you personally relate to the participants and/or the phenomenon.
- Reflect on and write about your study’s research questions.
- Reflect on and write about your code choices and their operational definitions.
- Reflect on and write about the possible networks (links, connections, overlaps, flows) among the codes, patterns, categories, themes, concepts, and assertions.
- Reflect on and write about an emergent or related existing theory.
- Reflect on and write about any problems with the study.
- Reflect on and write about any personal or ethical dilemmas with the study.
- Reflect on and write about any future directions for the study.