

Authenticating disability perspectives and advancing inclusive agendas that value disability identity in schools

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ABSTRACT:

Inclusive programming has traditionally been framed through a medical model with an orientation that is concerned about young people with disabilities functioning aptitudes relative to developmental normative standards. As a result, children and youth with disabilities often experience school and community predominantly through intervention services. This study accesses the narratives of two young men with autism spectrum having experienced separate intervention services delivered outside the regular classroom when attending public school in Nova Scotia, Canada. This research is part of a larger project that explored twelve young men with AS experiences in public school. Their in-depth narratives reveal the importance of authenticating disability voices and locating more meaningful forms of inclusion beyond tiered intervention practices to prevent exclusion and ableist assumptions about their identities.

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INTRODUCTION

This study argues for schools, communities, and other public spaces to prioritize the voices of young people with disabilities and disrupt ableist assumptions about their capacities and identities. Scholars in the field of inclusive education address the invaluable nature of accessing young people with disabilities first voice perspectives as it can reveal hidden structures of inequality in schools, including the disempowerment they can experience when receiving intervention programming outside the regular classroom (Miles & Singal, 2010; Reddington & Price, 2018; Vlachou & Papananou, 2015). As Bruce and Aylward (2021) reiterate the only qualified people to provide knowledge on disability experience are students with disabilities. Given this, disability perspectives are still not prioritized or largely taken into consideration when designing inclusive programs as the focus continues to be on the remediation of their impairments (Liasidou, 2013). There is also a paucity of research that explores children and youths' experiences with ableism. Ableism as Fiona Kumari Campbell (2009) explains ableism is a system of thinking that portrays disability as inherently negative and situates people with disabilities in a binary of normal/pathologized. Those bodies that do not fall into the category of normal are Othered and objectified. Campbell (2009) argues there is a requirement to attend to the ontologies of ableism in public spaces and how disability is socially constructed and predominantly framed in pathologizing ways. Explicitly, educators and child and youth professionals must critically examine the ways that young people with disabilities are compared to normative standards and how normative constructs create barriers to access. As Hodge and Runswick-Cole (2013, p. 311) emphasize "[a]bleism constructs bodies as 'impaired' and [positions individuals to feel] 'lesser, undesirable, in need of repair or modification and de-humanized'". In this paper, I draw attention to ableism as ableism is a concept in schools that is often not discussed where teachers have been trained to think about disability predominantly through a traditional intervention model rather than examining the oppressive ways that school contexts construct disability and create barriers for young people with disabilities. As Davis (1995, p. 23) states the focus should not be "so much on the construction of disability as on the construction of normalcy" as the core issue is not the person with a disability but the ways that achieving normalcy is constructed in public spaces.

This is evident in Canadian school systems where inclusive agendas for students with disabilities is centered

on fixing the impairment and bringing the body back closer to normality (Anderson-Chavarria, 2021; McBride, 2013; Reeves et al., 2020; Underwood, 2008). As McBride (2013) states most provinces in Canada implement an intervention model and "under these authorities, all jurisdictions in Canada either require or recommend that an individual program be designed and implemented for students identified as having special needs" (p. 5). As an educator for over 25 years in Nova Scotia, Canada, I have worked as a resource teacher and questioned the impact of intervention models on students with disabilities. A resource teacher is identified by the Nova Scotia Department of Education and Early Childhood Development (DEECD, 2018) as a teacher with specialized training to work with students with disabilities. The role of a resource teacher is to assess students with disabilities current functional aptitude to determine what types of intervention services a student might require (e.g., autism consultant, educational psychologist, speech-language) outside the regular classroom. These intervention services are described and framed in the Nova Scotia Students First Document through a multi-tiered system of supports (MTSS) aimed to address students' academic, social-emotional, and behavioral needs (DEECD, 2018). The three tiers of the multi-tiered system are reflective of older inclusive models formerly known as response to intervention. The first level of Nova Scotia's MTSS is delivered in the classroom with a universal core curriculum and core instruction for all students. The second tiered level is "small group with supplementary interventions for some students" outside the regular classroom and the third tier is "individual intensive interventions for a small percentage of students" which can include support outside the school building (DEECD, 2018, p. 5). The tiered intervention in Nova Scotia is comparable to other provinces in Canada.

For instance, in the province of Alberta, the government's Standards for the Provision of Early Childhood Special Education (Alberta Minister of Education, 2006, p. 2) identifies that "through early intervention strategies" young children can "develop knowledge, skills and attitudes that prepare them for later learning". Similarly, Ontario's Ministry of Education (2021) states "special education programs and services primarily consist of instruction and assessments that are different from those provided to the general student population" (para. 1). They must also have in place procedures to identify each child's level of development and, learning needs, and ensure that educational programs are designed to accommodate these needs to facilitate each child's growth

and development. Whilst these provincial policies are in place, what is not clear is the effectiveness of programs in fully supporting children and youth with disabilities inclusive experiences in Canadian learning settings (McBride, 2013). Moreover, what is often not discussed or prioritized in education is the first voices perspectives of students with disabilities and their experiences with intervention services.

In this study, I share the in-depth narratives of two young men with autism spectrum (AS) who attended public school in Nova Scotia, Canada to gain in-depth knowledge about their everyday realities in school with intervention services. Their lived experiences shed light on the workings of ableism in schools, including their actions to reclaim their identities when expected to meet normative standards. The data shared in this paper is part of a larger research project that examined twelve young men with AS experiences with educational support services (i.e., resources, remedial learning centers, educational assistants). This inquiry aims to show the relevance and importance of accessing students with disabilities perspectives and to locate new ways to advance inclusive agendas where disability identity is valued.

Critical inclusive education

Critical disability scholars have problematized intervention model frameworks and how they place too much emphasis on children and youth's functional aptitude with a lack of attendance to the wider dimensions of their lives (Acevedo Espinal 2020; Cluley et al. 2020; Douglas & Martino, 2020; Douglas et al. 2021; Goodley et al. 2019; Reddington & Price, 2016; Reddington & Price, 2017; Reddington, 2019). Biklen (2000) defines critical disability research as work "that recognize[s] disability as a social construct" and the requirement to attend disrupt static medical discourses that only provide a narrow understanding of a person with disabilities identity. As Corker and Shakespeare (2002) explain it is the strong emphasis placed on a child's functionality relative to their medical signifiers that "seek[s] to explain disability universally and end[s] up creating totalizing, meta-historical narratives that exclude important dimensions of individual lives, abilities and of their knowledge" (p. 15). As such, the categorical definitions of disability continue to problematically produce an ability/disability system that marks the difference and informs our ideas about disability and normality (Garland-Thomson, 2002). This is strongly evident after examining tiered intervention models in Canada where the documents prioritize the remediation of bodily difference.

In the context of young people with disabilities attending school in Canada, there is a need to critique tiered intervention models that promote the idea that children with disabilities must be fixed, improved, and repaired to be successful (Campbell, 2009). As mentioned earlier, medicalized traditional approaches to inclusion rely on a binary logic of able/disable with limited attendance to the ways in which schools create oppressive barriers for students with disabilities. However, a critical disability approach can destabilize tiered intervention models of inclusion and account for the situated and emergent learner (Colebrook, 2017; Done & Andrews, 2020; Masney & Cole, 2020; Reddington & Price, 2018; Reddington, 2019; Taylor & Harris-Evans, 2018). In this paper, I apply a critical inclusive theoretical framework to locate alternative knowledge on disability experience beyond medicalized discourses and attend to the actualities of the disability experience. Such objectification experienced by young people with disabilities requires attendance.

METHODOLOGY

The data that follows is derived from a larger study where semi-structured interviews were conducted with twelve young men with autism spectrum (AS) between the ages of 18 to 34 years who had previously attended public school in Nova Scotia, Canada. Two semi-structured interviews with each young man were conducted. The decision to use a semi-structured interview was to support the meeting of the research aims and allow for exchange of dialogue between researcher and participant. A general interview guide was used to support the research and contained questions on the topics of school arrangements (i.e., rules, class structures, support services), social activities, including daily school practices (i.e. classes, free time, and daily routines). Additional visual methods were used in the second interview, namely: stock photography, paper, markers, and access to a computer. My decision to only interview young men rather than women emerged from my personal context of parenting a young man with AS. I also chose to focus on two young men's experiences rather than short excerpts from all twelve participants as I wanted readers to develop a deeper understanding of their personal lived experiences with special education supports. McKinney and Amosun (2020) explain by listening to the in-depth stories of people with disabilities we can begin to understand their desires to be independent and develop their own sense of belonging in the world. The time frame between the first and second semi-structured interview was approximately two weeks. The time

between interviews was used to listen to transcripts and prepare visual tools for the second interview. The first semi-structured interview consisted of face-to-face conversations with each participant about his schooling experiences following a general interview guide. The beginning of the second semi-structured interview involved asking the participant if he had anything to tell me that he perhaps forgot to share previous as well as time to member check regarding information from the first interview. After more discussion on school topics, visual methods were introduced, namely stock photography and the use of photo elicitation to understand better their schooling experiences. Photo elicitation in this study was a productive visual method to aid participants in telling stories.

The stock photos used in the second interview were chosen from a public database. Selecting photos to assemble in a photo kit required great consideration as each photo had to be carefully chosen according to the goals of the intended research (Danker et al. 2017). In the end, the photo kit included 44 public stock images such as: a picture of a playground, an image of a hallway with lockers, a typical classroom, a school cafeteria, students in a playground, and students standing in a hallway. I then had to consider the line of questioning when exploring the stock photographs with participants. I wanted to use the photos to trigger memories on their own schooling. I, therefore, would ask questions like, 'does this picture remind you of anything about your schooling?' I would then get more specific. For example, when looking at a photograph of a classroom I would ask the participant, 'Do you remember your time in the classroom?', 'Where you sat?', 'Did you get help in the classroom?' During the second interview, some participants would talk at length after looking at a photo on a particular school topic, and other stock images would not evoke much of a response. The use of stock photos, however, proved to be helpful in generating some thoughts and ideas on their schooling. The data that follows prioritizes the realities of the young men's emergent experiences with tiered intervention supports. I begin with Adam's daily school experiences when receiving intervention supports followed by Bobby's.

Adam self-identified as a 21-year-old autistic black man at the time of the interview and he told me early on how he was raised in a low socioeconomic urban area in Nova Scotia. Adam shared how he had recently moved to a small, rural community after completing high school where he lived with his grandmother. Adam was frank in expressing his frustrations since finishing high school and how he struggled to maintain employment in his rural community. He profoundly disliked his minimum wage

job as a grocery clerk and felt constrained by the structure of his job. He particularly protested the strict supervision he experienced by the store manager. Adam strongly desired independence and emphatically stated how he disliked 'always being watched' by his employer. This led to Adam recalling the encounters he experienced at school with his educational assistant (EA). An educational assistant or teacher assistant is defined by the DEECD (2009, p. 1) as an individual who provides "support to students who are identified through the program planning process as requiring support with medical and personal care and/or safety/behaviour management".

Adam:

Adam early in the interview expressed his deep desire to be like everyone else and the irritation he embodied when having to be in the constant presence of his EA.

Adam: I never got to sit beside anyone as I was assigned an EA. Like everybody seemed to be very close to one another, like they were sitting beside one another and everything. And I was always with my EA.

Adam's description of how his peers were 'close to one another' yet he 'never got to sit beside anyone' signifies the separation Adam felt when experiencing school away from his peers. This oppressive relationship increases his socio-exclusion and impacts his daily experiences as he shares when describing his time at school with his EA.

Adam: My EA had this way of having to conduct things about how people should act and where things should be and everything, and it got on my nerves... What bothered me the most was that I always needed help with things because I couldn't do anything on my own. And most of the time I would usually be taken out of the class by an EA and sent to some other room where me and some other students that also had EAs would all be working together on the same thing during school. I was usually having to always be taken out of class during the middle of it and I had to go into this separate little room... I was brought all the way downstairs to this room away from everybody else you know and that happened a lot, that happened a lot I remember.

Adam's routine travel outside the 'typical' classroom creates issues of inaccessibility to class activities with his peers, disability stigma, and normative gazes. Adam bothered by his peripheral position emphasizes his displeasure, 'I had to go into this separate little room' ... 'all the way downstairs' ... 'away from everybody else'. He affectively wanted to experience school with his 'typical' peers.

Adam: I just wanna be around people my own age you know! I don't want to have to be always followed by an adult!

The intensity of his voice is powerful. He addresses the exclusionary practices when experiencing school alongside an educational assistant. It is the inequities within these intervention-tiered systems that frustrate Adam.

Adam: Like it would have been a whole lot better if I could have been able to at least you know be allowed to hang out in school, in town by myself without having an EA with me! [Adam raising his voice] but they wouldn't even allow that cause, I always needed help. I always had to stay in the cafeteria and eat my lunch. So, I never snuck off although I really wanted to! But, I knew I would get in trouble for it! ... I wish I could have been able to join them in town instead of having to stay in the cafeteria all that time.

Adam was restricted. He was told by authority figures to stay on school property. Adam affectively rejects the differentiation, but his fear of being reprimanded diminishes his capacity to disrupt his marginalized designation. His disability status territorialized him to the functional intervention properties of the school. Schools maintain authority with regards to what constitutes 'normal' and in this process governs the inclusion and exclusion of students with disabilities (Reeves et al. 2020). Here, we witness processes of ableism where normative ways of being and doing are superior and cast others as inferior (Campbell, 2009). Even though Adam was separated from his peers he continues to pursue authentic relationships with his nondisabled peers to disrupt his peripheral status.

Adam: I tried to get as close as possible to them (his peers). I spent a great deal of time listening to their conversations as much as I could. I couldn't really tell people anything that I wanted to do because I didn't really know how exactly, and I still don't really know. I kind of felt like I should have just approached them a lot sooner in the cafeteria.

Adam expresses his deep desire to connect with his peers, however, the designation of an EA in his constant presence embeds deficit driven assumptions about Adam capacities. Yet, Adam is determined to disrupt his routine functioning and disrupt the ableist ways that his EA and others construct his identity in school.

Adam: Sometimes during lunch time, I would sometimes go outside like not outside of the school [to town] and I would see people sitting around on the wooden benches

talking and sometimes I would move closer and try to join them, but I never really said all that much to them. I am not really sure if I would fit in with any of them at all you know, but I still kind of felt like I wanted to be around them and to see what it would be like. I liked it better when I was very close with them you know not just emotionally, but like in the physical sense.

Author: What did you like about it?

Adam: Well, because I get to see people and what they are doing you know and I would like it better if I was actually invited to be around with them, but I don't think they really understood what it is I wanted from them. I just wanted to be around them.

Adam liked the possibilities the wooden bench presented. His intuitive tactic to get closer to his peers by occupying the wooden bench exemplifies his capacity to revitalize his body and rupture his peripheral position. Adam's wanderings across his schooling years exhibit the creative potential to improve his social experiences and negotiate dominant normative discourses to locate new opportunities for himself. Adam's experiences also reveal how complex school can be in moments when a body is read as a certain kind of subject unable to escape the coded classification system. His narrative calls attention for educators to critically reflect on how they situate and position students with disabilities in their schools. Educators can unknowingly position students to be known predominantly through their medical signifiers and as a result, can have significant implications for how students experience school daily as evident in Adam's narrative.

I turn now to share Bobby's narrative when experiencing tiered intervention support services. Bobby self-identified as a 27-year-old young man with autism. At the time of the interview, Bobby expressed that he lived on his own in an urban apartment in Halifax, Nova Scotia. He told me that he was unemployed and actively searching for work. He equally shared his desire to meet people in his community and that he would often wander the streets in the neighborhood in the hopes of meeting people. Bobby accounts early in the interview identify his experiences with tier two and three intervention supports and how it affected his authentic connections to peers in school.

Bobby:

I started my conversation with an open question, "Tell me about your schooling, Bobby?". Without pause, he stated:

Bobby: I went to a special class with a handful of kids, and I was taught like any other student. We were in a separate class, and at the time I wasn't aware of how different I was, I was a little aware but not really aware.

Bobby recognizes the static dualistic nature of education; his body placed in a separate special class away from his typical peers. Bobby, however, refutes his special education status when exclaiming 'I was taught like any other student'. In reaffirming his position of being taught like his peers, Bobby destabilizes the notion of difference. However, upon greater reflection, Bobby affectively recounts his experiences with intervention services.

Bobby: I started to notice I was a little different. I started noticing things change about me, and I got in conflicts with people because of my personality, and that was when I really began to realize I was different because for the first-time people were going out of their way to make fun of me, but it wouldn't be like you're dumb or you're stupid. It would be a punch or a kick or something like that! So, when I got to grade six, I knew I was different.

Bobby recognizes the disparaging disability discourses and points out the ableist assumptions his peers make about his identity. It is the dominant forces of his classmates, their violent acts, and derogatory remarks that stratify Bobby to a lower position. Bobby's accounts show how constraining the school system can be for students with disabilities when experiencing intervention supports outside the classroom. Research shows that individuals with disabilities are associated with negative stereotypes (Payne, 2006) and that dominant medical model paradigms assume that the person with a disability is limited based on their impairment and consequently experiences discrimination (Bunbury, 2019).

Bobby: I think some of it was because some of them (classmates) grew up in different circumstances, and they were not taught how to deal with disabled people right so as a result they would say things like retard and stuff like that not knowing that you know, I am not a retard! I have problems reading and writing, but it doesn't make me retarded. So, some of it was they just didn't know any better. People can label me all they want; I don't care anymore.

Bobby tries to justify his classmates' oppressive actions and free his body from his medical designation when suggesting his classmates 'grew up in different circumstances' and emphatically exclaiming, 'I am not a retard!'. Bobby pushing back works to disrupt the negative stereotypes assigned to him. He then takes it a step further and de-

scribes his intentional acts to reclaim his identity.

Bobby: I would fuck with their lives [other students at school] and do whatever I could! I would say, 'I heard so and so was having an affair with you' and then this would start a catfight and I would watch these two girls start scrapping. People were jerks to me and after months and months of figuring out who they are and what their hobbies were if they kept doing it, I would get into their personal lives and say ok what can I do. I don't want to kill these people or break their property. I just want to take them down a couple of notches right.

Bobby in relation to his dominant peers reframes his identity to one of possibility by stirring rumors. By spreading rumors, Bobby is challenging the notion that his embodiment is inherently problematic. Waddington and Michelson (2007) suggest gossip is a potentially rich source of informal narrative knowledge that can illuminate understanding and can aid in the process of change. Bobby then describes his intentional acts to revitalize his identity and feel empowered.

Bobby: The best thing I found that worked was to go around my peers in high school with an empty liquor bottle in my hand. Just walk around with it because I find if people think I am drunk they will treat me better than if they think I am mentally ill right. Oh, he is drunk right. I don't know why, and I don't care if they think there is a bottle in my hand, they are nicer to me and will not mess with me as often...all I am really doing is holding a bottle but when they see a bottle, they don't tend to say much... they leave me alone.

Within Bobby's newly created space as a fake drunk, he creates new possibilities for himself, and he takes huge risks to achieve a renewed sense of self. To accomplish this, requires Bobby to take extreme measures by performing drunk and breaking rules by carrying an empty liquor bottle. Bobby's actions support research that shows that people with disabilities learn to cope with social identity, and often reconstruct their identity and "own biography from scratch" to gain acceptance (Lejzerowicz, 2017, p. 19). Through his actions as a performative drunk, Bobby transgresses the hierarchical social order. Within this newly created social space, Bobby reclaims his identity. His narrative reveals the requirement to challenge the power of 'normal' that continues to define participation and access to meaningful school experiences (Ashby, 2010). Thus, the construct of the 'normate body' coined by Garland Thomson's (1997) carries with it cultural capital and social power (Ashby, 2010).

The term *normate* usefully designates the social figure through which people can represent themselves as definitive human beings. Normate, then, is the constructed identity of those who, by way of the bodily configurations and cultural capital they assume, can step into a position of authority and wield the power it grants them (Garland-Thomson, 1997, p. 8, emphasis in original).

Bobby's experiences draw attention to the requirement to counter normative constructs and foster school spaces where disability is viewed as a viable identity. Reeves et al. (2020) remind us of the pressure for students with disabilities to meet expectations where the desire to 'fit in' can become so inescapable that the original intentions of inclusion get lost. There is a need to shed light on exclusionary practices and the unconscious biases that devalue disability identity. That is, practitioners, teachers and professionals working with young people must create inclusive spaces that prioritize and see disability as a viable form of subjecthood.

CONCLUSION:

The findings from this study identify the constraints tiered intervention model systems have on students with disabilities everyday realities in school. The young men's first voice perspectives reveal the exclusionary effects of tiered intervention practices and the immense energy it takes to challenge exclusionary practices. We also see from the young men that they are active agents of change and have the capacity to negotiate static normative assumptions and ableist structures. This work shows the importance of professional development in creating more inclusive agendas and challenging ableism (Arrah & Swain, 2014; Buli-Holmberg & Jeyaprabhan, 2016; Wah, 2010). As Hehir (2005, p. 17) states, "[p]rogress toward equity is dependent first and foremost on the ac-

knowledgment that ableism exists in schools". Schools and communities must locate equitable meaningful opportunities for students and in the process challenge normative constructs that position students with disabilities on the periphery.

As Buli-Holmberg and Jeyaprabhan (2016) reiterate there is a lack of expertise and understanding on what it means to provide authentic inclusion by classroom teachers. Explicitly, we must shift to include more disability awareness learning opportunities where disability is understood and seen as a viable and proud identity in schools. The Institute on Disability culture formed in 2014 express in its mission statement the importance and relevance of "promoting pride in the history, activities and cultural identity of individuals with disabilities throughout the world" (Institute of Disability Culture, 2021). With this, to advocate for disability justice within school systems. Jampel (2018, p. 3) explains disability justice is "the framework of the social movement to end ableism in conjunction with ending other systems of oppression". Disability in the context of young people in schools and communities is a commitment to address discrimination, ableist attitudes and barriers to access for young people with disabilities (Jampel, 2018). A school that prioritizes disability justice does not isolate students in separate spaces for intervention and does not perpetuate ableism within school settings rather it shifts to authenticate disability identity where diversity is valued.

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