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The exclusionary effects of inclusion today: (Re)production of disability in inclusive education settings

Key Words

Inclusive Education; Inclusion; Disability; Critical Disability Studies

Abstract

Current inclusive education practices remain entrenched in deficit-oriented discourses. An interrogation of these discourses is necessary to enact inclusion driven by diversity and collective belonging. This collective case study explored 10 cases of parent and child experiences in inclusive school settings and addressed the following questions: What disability discourses are (re)produced in inclusive school settings? What are the effects of these discourses on families' experiences of inclusion in inclusive school settings? Using disability discourses as sensitizing concepts, 5 themes were generated framed in 'disability as' statements: disability as fragile, deviant, currency, defining, and affirmative. Despite a shift towards inclusive rhetoric, normative and oppressive discourses permeated inclusive school settings examined in this study. Normative discourses produced the following effects: the Othering of disabled children, governance of disability, internalised oppression, ontological violence, and invisible work. Findings from this

study call for critical reflexivity on current inclusive education policies.

Points of Interest

- In this study we asked parents and disabled children about their experiences in inclusive school settings.

- Parents and children talked about how disability was largely viewed as negative by others, which led to the exclusion of disabled children in their neighbourhood schools.

- Findings from this study remind us that even if a school setting is labelled as inclusive it does not necessarily mean disabled children and parents *feel* included.

- Becoming aware of the negative messages about disability operating within inclusive school settings can help schools become more welcoming and inclusive of disabled children and their families.

Main Text Introduction

Historically, children who experience disability have been educated in special education settings, separate from their peers. Special education approaches have been critiqued within the Disability Studies in Education (DSE) literature for being entrenched in a deficit discourse with disabled children labelled as *Other* and in need of specialized services (Connor et al., 2008; Ferri, 2008). Special education and inclusive approaches to education differ in their philosophical underpinnings (Connor et al., 2008; Graham & Slee, 2008). Theories of inclusion assert diversity as the norm (Ferguson, 1995), place emphasis on equity and collective belonging (Lynch & Irvine, 2009), and acknowledge 'individual differences not as problems to be fixed but as opportunities for enriching learning' (Ainscow, 2007, 148).

Beginning in the 1980s, with a recognition that all students, regardless of ability, have the right to education alongside their peers (Ferguson, 1995; Underwood, 2008), a call to merge mainstream and special education into a single inclusive system emerged. Today, inclusive education is firmly situated at the forefront of international policy agendas (UNESCO, 1994; United Nations, 2006). The Convention on the Rights of Persons with Disabilities, in Article 24 articulates: 'States Parties recognize the right of persons with disabilities to education….States Parties shall ensure an inclusive education system at all levels and lifelong learning…' (United Nations, 2006). Furthermore, the Salamanca Statement and Framework for Action on Special Needs Education, calls on the international community to "adopt the principle of inclusive education, enrolling all children in regular schools unless there are compelling reasons for doing otherwise" (UNESCO, 1994, p. 44).

There is growing evidence supporting the value and benefits of inclusive education approaches for both disabled and non-disabled children. Brown et al. (2004) assert there is no evidence to suggest that disabled students educated in mainstream settings are at an academic disadvantage. In support, Dessemontet, Bless, & Morin, (2012) found that disabled children included in mainstream education did just as well or made slightly more progress in literacy skills than disabled children in special education settings. Furthermore, Cosier, Causton-Theoharis, & Theoharis, (2013) found a strong relationship between time spent in mainstream education classrooms and disabled students' achievements in math and reading. In addition to academic benefits, there are also ample social benefits to including disabled children in mainstream school settings (Lynch & Irvine, 2009). Benefits to the disabled child include an increase in peer acceptance and positive social interactions leading to life and social skill development (Copeland et al., 2002; Guralnick & Groom, 1988; McDonnell et al., 2003).

Benefits to the non-disabled peers include changed perceptions of disability with non-disabled children becoming more aware, accepting and adaptive to their peers (Giangreco et al., 1993).

Despite an increasing adoption of inclusive rhetoric, a gap between how inclusive education is *theorized* and how it is *enacted* persists (Artiles & Kozleski, 2007; Ferguson, 1995; Graham & Slee, 2008; Popkewitz & Lindblad, 2000; Slee & Allan, 2001). Inclusive education scholars argue that this theory-practice gap persists because, to a large extent, the normative assumptions underpinning special education policies and practices have gone uninterrogated and continue to permeate existing education settings despite the shift toward inclusive rhetoric (Boyd et al., 2015; Graham & Slee, 2008; Popkewitz & Lindblad, 2000). Theoretically, inclusion encapsulates both access to mainstream education spaces as well as an experience of inclusion, sometimes referred to as a sense of belonging (Andrews & Lupart, 2000; Ferguson, 1995; Thomas & Loxley, 2001). Problematically, current enactments of inclusion often fall short, placing emphasis on access to mainstream education spaces but failing to cultivate spaces of collective belonging (Lynch & Irvine, 2009). Labelling a setting as inclusive and allowing disabled students access to mainstream education settings is not enough on its own to confer an experience of inclusion.

Misled and poorly examined enactments of inclusion have resulted in numerous challenges in the education context (Artiles & Kozleski, 2007; Ferguson, 1995; Graham & Slee, 2008; Slee & Allan, 2001). Teachers continue to feel ill prepared to teach children with diverse needs in mainstream classrooms (Lyons et al., 2016), often leading them to approach inclusion with avoidance and apathy (Mooney & Lashewicz, 2015). Disabled children frequently face reduced expectations for academic learning (Loreman et al., 2009; Mooney & Lashewicz, 2015). In addition, disabled children are excluded from aspects of school life such as drama, field trips,

and physical education because their needs are perceived as difficult to accommodate (Mooney & Lashewicz, 2015). Parents continue to be unsatisfied with the support and education their children receive in inclusive settings, frequently encountering tensions between their own perspectives, values, and expectations related to inclusion and those of the school culture and staff (Mann, 2016; Mooney & Lashewicz, 2015). Additionally, tightening budgets and increasingly diverse student populations put pressure on administrators to 'do more with less' (Mooney & Lashewicz, 2015). These challenges speak to the effects of naming educational contexts as 'inclusive' without shifting and committing to the philosophical underpinnings that inform inclusion as it was intended, contributing to the façade, or as Graham and Slee describe, the 'mirage' of inclusion (Ferguson, 1995; Graham & Slee, 2008; Slee & Allan, 2001; Young, 2008). To avoid this 'mirage', DSE and other scholars call for a transformational approach to inclusion in education as opposed to a reshaping and renaming of special education policies and practices (Connor et al., 2008; Graham & Slee, 2008).

There is a need to examine parent and child experiences of inclusion and exclusion in school settings in order to better understand the cultural shifts required to narrow the gap between how inclusion is theorized and how it is enacted (Lynch & Irvine, 2009). This collective case study examined nine parent and nine child experiences of inclusion and/or exclusion within education settings labelled as inclusive in an urban centre and surrounding areas in Alberta, Canada. By analysing parent and child stories through a discursive lens, we offer an examination of how disability is reproduced through existing policies and practices in 'so called' inclusive settings. Importantly, the value of inclusive education in supporting the rights of disabled children is not being questioned in this study. What is being questioned is the *way in which inclusion in schools is enacted*. Aligned with trends in the literature, this paper responds to the

call for research that critically examines inclusion and sheds light on potentially oppressive educational practices (Slee & Allan, 2001; Whitburn, 2017). Furthermore, by offering the perspectives of disabled children, this paper holds space for the voices of a 'hitherto silenced and marginalized' group (Slee & Allan 2001, p. 176), which is not only critical to the advancement of inclusive practices but also addresses an identified gap in the literature (Allan, 2010; Armstrong, 1999; Buchner et al., 2015; Byrnes & Rickards, 2011; Gibson, 2006; Goodley & Runswick-Cole, 2012; Gul & Vuran, 2015; Mike Oliver & Barnes, 2010).

Research Process

Collective case study methodology, informed by a critical disability studies perspective (Goodley, Runswick-Cole, & Liddiard 2016; Goodley & Runswick-cole 2015; Shildrick 2012), was used to examine child and parent experiences of inclusion and/or exclusion in education settings labelled as inclusive. Collective case study involves a collection of cases, similar and/or dissimilar, linked by some commonality (Stake 2006). Cases are analysed individually and compared and contrasted across cases, examining how the individual case contributes to an understanding of the collective (Stake, 2006). In our study, cases were defined as a parent-child pair. In this article we focus on the parents perspectives but also draw on children's accounts to provide context and nuances about the inclusion experience. The commonality across cases was the experience of attending a school(s) (past or present) labelled as inclusive within a unique context where an inclusion initiative has promised inclusivity in all education contexts. The critical disability studies perspective we adopted allowed for critical examination of the underlying assumptions surrounding disability and inclusion in school settings.

Alberta Policy and Practice Context

The purpose of this section is to situate this work within the provincial policy and practice contexts so that study findings can be understood in relation to them. Inclusion is firmly situated at the forefront of Canadian (Council of Ministers of Education 2008), and Albertan (Alberta Education, 2016) education policy agendas. Over the past decade, an ongoing review of special education in Alberta, Canada, has set the stage for a singular inclusive system merging the once separate special and mainstream education systems (Alberta Education, n.d.). Recently, an Inclusive Education Policy Framework was introduced. In this framework, inclusion is conceptualized as 'a way of thinking and acting that demonstrates universal acceptance of, and belonging for, *all* children and students' (Alberta Education 2016, 25, emphasis added). Inclusion is an 'attitude and approach that embraces diversity and learner differences, and promotes genuine equality of opportunities for all learners' (Alberta Education 2016, 32). According to the Alberta Education website, an inclusive approach calls for "flexible and responsive learning environments that can adapt to the changing needs of learners" (Government of Alberta, 2019). These learning environments may include: "instruction and support in a grade-level classroom with same-aged peers; individualized instruction in smaller group settings; a specialized classroom or setting; one-on-one instruction; a combination of all of the above" (Government of Alberta, 2019). With the introduction of this policy framework, all schools within Alberta have been labelled as *inclusive*. Despite being labelled as inclusive, schools in Alberta continue to enact a variety of educational practices including separate and/or specialized classes for children who experience disability. It remains at the discretion of each school to determine how they will create their own inclusion culture, which shapes how they interpret and enact the inclusive policy framework outlined by Alberta Education.

The latest available statistics indicate, an estimated 58% of disabled children in Alberta attend regular classes with the remaining 42% attending special education classes or special education schools (Statistics Canada 2001). A recent study in Alberta found supports and resources for inclusion are on the decline (Alberta Teachers' Association, 2015). Furthermore, teachers do not feel they have access to the multifaceted supports required to carry out inclusion in the classroom (Alberta Teachers' Association, 2015) and 25% of parents in Alberta report having difficulty accessing services to support their disabled child in school (Statistics Canada 2001). These statistics are also mirrored nationally (Inclusive Education Canada, 2017; Statistics Canada, 2001).

Participant Recruitment

An invitation to participate was disseminated to the community through local organizations offering supports to disabled children and their families as well as through various parent groups on social media. Disabled children and their parents were sampled purposefully and by nomination. Recruitment was ongoing over the course of 18 months. Ethics approval was obtained from the University.

Participants

Inclusion criteria for child participants were: (a) school age (grades 4 to 12, approximately 9-17 years); (b) family/self-identified as experiencing disability or chronic medical condition (s); (c) currently or in the past attended an education setting labelled as inclusive; (d) sufficient English language fluency for participation in the interview process (the use of assistive technologies and/or communication devices/strategies were welcomed); (e) living within 200 km of the urban centre, and (f) one or both parents/guardians available to

participate in the interview process. Inclusion criteria for parent participants were: (a) primary caregiver(s) of a child recruited to the study; and (b) sufficient language fluency for participation in the interview process. Eighteen individuals participated in the study, nine children and nine parents, representing 10 cases (8 parent-child pairs, 1 child, 1 parent). Child ages ranged from 8-16 years. One child withdrew from the study after a change to the family situation resulting in a failure to respond to invitations to continue. One parent withdrew after an unexpected medical event occurred for the child. Despite withdrawals, decisions were made to include both cases in the cross-case analysis based on the rationale that collective case study is not limited to analysis of individual cases, instead analysis across the data is the defining feature. Ethical considerations to honour participants' time and the stories that were generously shared also support the inclusion of these cases. Parents self-identified that their child currently, or in the past, attended school in an education setting labelled as inclusive. See Table 1 for participant profiles, including reference to the type(s) of education setting(s) the child attended. Pseudonyms have been given to all participants and all data have been de-identified.

Data Collection

In-depth, semi structured interviews were conducted with both children and parents individually. Interviews were conducted in the participant's home or other participant identified location (e.g. local coffee shop). An attempt was made to interview parents first and children second, so that the parent interview could inform the child interview, providing the interviewer with contextual and practical information about the child's life. In an effort to 'question the practice of privileging adult's views over children's about issues related to children's lives' (Matthews 2007, 328), no parent verification of the child's account took place. In two cases the child was interviewed first by request of the parent. Ethical issues related to research with

children were attended to in the following ways: assent and consent were considered ongoing processes rather than one-off tasks; ethically-important moments related to disclosure, power, and representation were addressed through individual researcher reflexivity and team reflexive dialogues; and the ideals of safety, dignity, and voice were prioritized throughout the research process (Guillemin & Gillam, 2004; Phelan & Kinsella, 2013). All children could participate verbally in the interviews. Where comprehension of interview questions was a challenge, parents provided and modelled communication strategies. Parents were given the option of being present for child interviews and were present for child interviews in two cases. The semi structured interviews were designed to elicit data about parent and child experiences (past, present, anticipatory) of inclusion and/or exclusion in inclusive settings; perspectives on inclusion and inclusive education; and the social, cultural, structural, and institutional factors that shape inclusive practices in schools. An interview guide was used, outlining broad questions with probes that promoted deeper conversation (e.g. Can you tell me about your child's experiences in school? What has been challenging? What has been successful?). The interview guide was iterative, as such the guide was adapted as new insights were garnered to better reflect the experiences parents and children were sharing. This technique is a form of theoretical sampling, commonly used in qualitative research (Charmaz, 2006). All interviews were audio recorded and transcribed verbatim by a professional transcriptionist.

Data Analysis

In depth analysis was conducted for each case (8 parent-child pairs, 1 child, 1 parent) (Stake, 1995), followed by a cross case analysis (Stake, 2006). In phase one of analysis, line by line, initial coding (Charmaz, 2006) was conducted (i.e. coding used to ask what does the data suggest/pronounce? and from whose point of view? Theory is not explicitly used at this stage.),

putting a name to what presented itself in the data. The research team then examined initial coded data for themes. Out of this analysis, more specific research questions surfaced, one being the question for this project: What disability discourses are (re)produced in inclusive school settings? This question guided subsequent analysis (phase two).

In phase two, researchers returned to the data, drawing on critical discourse analysis techniques (Philips & Hardy, 2002; Wodak & Meyer, 2009) to examine the discourses or "social relations and organizations that are present, but not fully visible in the everyday world" (Griffith & Smith, 2005, 3). The following disability discourses (commonly referred to as 'theories' or 'models' of disability) were used as sensitizing concepts: individual/medical, social, tragedy, affirmative, and relational. Individual/medical discourses position disability as deficient, locating disability within the individual. These discourses assume disabled people are in need of 'fixing' or desire to become more 'normal' (Withers, 2012a). Social discourses characterize disability as a form of social oppression: people with impairments are disabled by aspects of their environments. Disability is positioned as the product of the built, social, cultural, political, and institutional environments (Oliver, 2009; Withers, 2012b). Tragedy discourses position disability as tragic, and like individual/medical discourses, locates disability within the person. Tragedy perspectives assume disabled people are unable to enjoy a meaningful life and evoke a charity response (French & Swain, 2004). Affirmative discourses counter tragedy discourses, in that disability is positioned as positive, generative, and a source of pride. These discourses assume disabled people have valued social identities and celebrate difference (Swain & French, 2000). Relational discourses acknowledge that disability is a form of social oppression while also acknowledging the embodied experience of disability-that there are realities that accompany an experience of impairment that can be negative (e.g. fatigue, pain) (Shakespeare, 2013).

Sensitizing concepts offer 'ways of seeing, organizing, and understanding experience…provid[ing] starting points for building analysis, not ending points for evading it' (Bowen, 2006; Charmaz, 2003, 259). Using an iterative process, across cases, similar codes were collapsed and related codes were clustered together into categories. Categories were then iteratively expanded, refined, linked, collapsed, and mind-mapped to form themes. Researchers returned to the data to confirm generated themes reflected what was present in the cases. Finally, data categorized under each theme were revisited to explore the relationship between discourses and their effects. The following questions guided this final step of analysis: (1) what are the explicit and implicit messages about inclusion/disability? (2) who is affected and what are the effects? And (3) who has authority in the construction of disability/inclusion? The researchers engaged in reflexive dialogue sessions on a regular basis during data collection and analysis phases, which further contributed to the generation of the findings.

Results

This study used parent and child stories, elicited in interviews, as a window to view the (re)production of disability in inclusive education settings. Five overarching themes representing competing disability discourses were generated and framed in 'disability as' statements: disability as fragile, deviant, currency, defining, and affirmative. The themes generated represent not only the discourses themselves but also examples of their effects on parent and child experiences of inclusion.

Disability as Fragile

Within parent and child accounts, disability could be constructed as fragile within inclusive school settings. The disabled child was often perceived by teachers and educational

assistants as vulnerable, delicate, and in need of protection. This (mis)portrayal often led to exclusion. Parents and children described situations where disabled children were given non-physical, less competitive, or solitary tasks such as taking attendance, score keeping, or tossing a ball against the wall. Parents described teachers and educational assistants as wanting to 'protect' the disabled child from the 'chaos' in the hallways during breaks, by advocating for the child to leave class early.

As a result of perceived child fragility, school staff were described as nervous, cautious, and at times, uncertain how to support the child. Christine, a parent participant, describes how one educational assistant was removed because 'she was too scared to even sit next to [her son]'. Lisa, another parent participant, describes how perceived fragility led to school staff viewing supporting her child as 'extra work':

> Lisa: so yeah we're learning, but yeah a lot of it is environmental, and people don't, unless we hire an actual aide to go with her…nobody wants her right, because they don't want the extra work. They don't have the time, they don't have the, you know, the knowledge
> Interviewer: It's just getting over that…
> Lisa: initial fear…like seeing oh she's in a wheelchair...

Fragility and safety formed a point of tension for parents as they negotiated competing demands. Ellen, a parent participant, describes this tension:

> I always say to [the school staff], I want to scare you enough that you're going to take it seriously…But I don't want to scare you so much that you're going to be like oh my gosh I don't want her in my class what can I do to get her out of it?...I want you to treat her normally, but I need you to know that…this is serious and this could happen if you don't follow what needs to be followed. (Ellen, Parent)

On one hand parents acknowledged their child's impairment came with real risks – often associated with medical complexities. On the other hand, parents did not want these risks to overrule or override options and opportunities.

Underestimation emerged as an object of the fragility discourse. Parents and children described a common frustration that educators underestimated children and assumed they would not, and could not, go on to achieve commensurate milestones as their peers (e.g. graduate with a diploma, go to post-secondary, get a job). An example of this was described by one parent who had to advocate for her child to take a higher-level math as the school assumed her child would not go on to college.

Disability as Deviant

Parent and child stories revealed a series of normative assumptions that permeated the school settings they discussed. Most school settings appeared to be organized with a 'typical student' in mind, rather than centred in principles of diversity and collective belonging. Schools were depicted as heavily reliant on diagnoses and 'codes', placing emphasis on learning differences. This positioned students with disabilities as both socially and medically deviant or in violation of dominant norms and expectations within the school community.

Sociocultural expectations surrounding socialization patterns and behaviour in the classroom (e.g. ability to sit still, attend to a task, listen, complete tasks independently, ask for help, etc.), were discussed as excluding the disabled students who were deemed unable to meet them. Mark, a teen participant, described struggling when his educational assistant insisted on him staying in class despite his difficulty mitigating sensory input: 'she gets me to work through things that aren't really the best things for me to work through…her idea of getting [me through education] is…push past it'. Parents and children described expectations that students 'fit'

within normative processes, practices, and structures. Breanne, a parent, described the goals the school outlined for her child, Blake, as being 'more about compliance and [the teacher] having the power' than development of Blake's unique gifts and talents. Schools were frequently discussed as failing to adjust, accommodate, or meet the individual/specific needs of children: 'they want kids to be self-sufficient…and that's their theory and that makes sense for typical students…but unfortunately, they use the same theory on all students' (Judy, Parent).

The discourse of deviance positioned disabled children as 'lazy', 'manipulative', and 'bad' by other actors in the inclusive school setting. Joan, a parent participant, discussed how Oliver's expressive and receptive communication delays were commonly misunderstood by school staff, which led to him being inappropriately blamed for things. In another example, Christine discussed how school staff frequently described her son as choosing to behave poorly despite her explanations that his behaviour is the consequence of impairment to his central nervous system.

Parents and children frequently described tensions between the school's interpretation of a situation and their own. Ellen, a parent participant, described the school's perceptions of her child's absences as excessive despite her explanations that they are for surgical procedures: 'she's going in the hospital for surgery not because we're going on vacation'. Akhil, a child participant, described how learning can be difficult for him: 'sometimes I—I can't do the work because I'm stressed out or I can't figure out how to do it….or the teacher says and, no Akhil, you—you have to uh, do it all by yourself when I really need that help'. In all these examples, blame was placed on the child rather than attending to the normative assumptions embedded within school and classroom expectations.

When the disabled child was cast as deviant, it positioned them in need of change to fit the environment or otherwise face exclusion, locating the problem in the child rather than the exclusionary practice/environment:

> It's the adapting to gym class because my class likes to play like um, basketball and like the things I can't really do…and it's hard to adapt to those kind of things when you can't reach the – like actually throw stuff. (Maddie, child who uses a power wheelchair).

Another example of this is provided by Lisa, who describes Kayleigh's exclusion from art class because of her inability to conform to classroom expectations.

> Oh at her old school she got kicked out of art…because she would cut things and they'd fall on the floor and she couldn't get down on the floor to clean up, so [the teacher] stopped letting her go to art. (Lisa, Parent discussing her daughter who uses a power wheelchair)

Deviant discourses were, at times, represented in the stories of parents and children. Parents described fear that their child would become a 'burden to society' (Jennifer, Parent) or 'systemically dependent' (Breanne, Parent) if they were not able to attain a certain level of independence. When asked about disability, children identified aspects of their bodies that didn't work. For example, Kayleigh stated, "my disability is my legs", and when asked about participating in a gym activity she stated she couldn't because she was unable to stand.

Disability as Currency

Resource allocation and funding for supports were objects created in a discourse of disability as currency. As described by parents, supports for disabled children in the school settings were largely based on diagnostic labels rather than demonstrated need. This discourse positioned schools as gatekeepers, who had to determine which children were 'disabled enough'

to receive supports. Jennifer, a parent participant, discussed the limited control she had in determining the supports her child accessed:

> You can have a child who is extremely disruptive, who has extreme delays in different areas, but without the right wording on their coding, they don't get supports and you're on your own....It's really a naming game...if you get the right name on your child, you get support.

Breanne, another parent participant, discussed her frustration with the school needing the 'right' label to get her son the supports he required:

> We did the eight hour multi-disciplinary assessment for autism…and they diagnosed him with severe ADHD and mild OCD…I brought him back to the school with that diagnosis and the principal that year said…that diagnosis wasn't going to give [the aide] they needed to support him. So one day Cole came home with…a letter in his backpack from a privately hired psychologist that said he has oppositional defiance disorder (Breanne, Parent).

When a child's experience did not fit within the rigid diagnostic categories used by the school, currency was lacking and supports could not be garnered. This is evident in one mother's description of a conversation she had with a school staff member: 'he doesn't look autistic….I'm like well they don't generally come tattooed, but I'll check, you know. Like what does autism look like to people?' (Sara, Parent). Christine, another parent participant, also discusses how her son's impairments could not be described by a single diagnostic label:

> the complicated thing is that a lot of his sensory and his OCD overlap and he has a language disorder [that] overlap[s] with say, ASD….and so people don't know what box to put him in….and because he doesn't have an overlying label that has been very difficult for us in the education system (Christine, Parent).

Parents across interviews discussed having to advocate for their child to receive adequate supports. They attributed the need for this advocacy, in part, to limited resources within the

school and the rigidities within support provision processes. Many parents expressed frustration that their child had to share an educational assistant with other children due to limited funding. In response, parents frequently drew upon individual/medical disability discourses to 'prove diagnoses' and secure funding for their child. Parents articulated this being out of a need to 'play the game' rather than a genuine desire to label their child. Parents even discussed seeking additional assessments to acquire diagnoses to take back to the school to qualify for more funding.

The disability as currency discourse could position a child's impairment as a funding opportunity by the school. Anne, a parent participant, described this: 'so in some cases I find that they're just putting the words on the paper to just keep her coded…so they can get extra money for her'. Breanne, another parent participant, discusses how the school was motivated financially to diagnose her child and therefore they did not always set him up to succeed. Instead they 'would do things like set him up to fail…to prove that he was a behaviour problem'. Simultaneously parents described receiving messages that their child was 'expensive' and using up valuable resources. One mother asserted:

> there's not enough support for inclusion and there's not enough teachers, and class sizes are too big and—so [I] hear that argument [frequently]—but the only thing I hear is that are you suggesting we take [my kids] out? Like if there's not enough resources for all the children are you saying…that kids with disabilities shouldn't be in the regular classroom? And most would say no that's not what they're saying, but they are saying there's not enough resources for all children in the classroom—remove yours please (Breanne, Parent).

Disability as Defining

Within parent and child narratives, deficit focussed funding structures and the emphasis on identifying, labelling, and categorising a child's impairment resulted in a discourse of

disability as defining, or an ascribed disability/impairment identity. In one of her stories, Sara, a parent participant, represented deficit-oriented language that had been used in the school setting: 'he's…a code 80 and they put him on a bus with a bunch of 40 kids'. In another example, Christine, another parent participant, described her son, Alex, having overheard his teachers at school, coming home and asking, 'do I have a touch of autism?'. The message that to really 'know' the child one must know their diagnostic label(s) was shared across cases. This is evident in Jennifer's perception that a diagnosis enabled her to better understand her son:

> Ah! I get it. This is what we have. Okay, so he's got—he's got Asperger's, but he also has Tourette's and he also has OCD and he also has generalised anxiety and he also has sensory processing. And all of a sudden, all these little pieces, it's like we had all the edges of the puzzle, but we didn't have that centre piece, we didn't know what we were looking at (Jennifer, Parent).

Children expressed frustration with the emphasis on their diagnosis, impairment or assistive technology as foremost to their identity, discussing how it prevented others from seeing them more fully as students, friends, playmates and peers. Maddie, a child participant, described: 'sometimes, when you go to a new school its hard being the kid in the wheelchair'. She described how others saw her wheelchair first, while her close friends did not distinguish between her and her wheelchair, instead they saw their friend.

Disability as Affirmative

In contrast to the predominantly deficit-oriented discourses produced and reproduced within the school setting, parent and child participants also asserted affirming discourses across interviews, drawing attention away from deficits towards strengths. It was important to parents that their children's strengths be recognised by school actors: 'seeing his strengths, cause I mean

he does have autism, but with that come[s] a lot of strengths too' (Joan, Parent Participant). Other parent participants, including Jennifer, discussed the generative aspects of their child's impairment—that their child is more accepting of others and compassionate. Child participants discussed not seeing a difference between themselves and others, sharing the same diversity of hopes and dreams as their peers. Claire, a child participant, put it this way: 'me, I plan to go to a university and then probably live my life like everybody else. The house, vehicle, a job'. Other children hoped to graduate high school, attend post-secondary, and pursue careers in farming, writing, and the arts.

In addition to viewing their disability as negative and neutral at times, child participants also viewed their disability as positive. Child participants discussed liking the equipment and adaptive technology they used. They also described participation in 'extra' tasks (for example, taking attendance to the office), having extra time to take tests, or not having to go outside for recess in the winter as opportunities or advantages.

Discussion

The findings from this study strengthen the assertion made by other scholars that a disjuncture between how inclusion is understood theoretically and how it is enacted in school settings persists (Artiles & Kozleski, 2007; Ferguson, 1995; Graham & Slee, 2008; Popkewitz & Lindblad, 2000; Slee & Allan, 2001). Despite a move towards inclusive rhetoric, powerful negative and oppressive disability discourses continued to permeate school settings labelled as inclusive in the urban centre and surrounding areas examined. While current theory on inclusion boasts a valuation of diversity, current enactments of inclusion commonly embody ableist assumptions that (re)produce normativity and position disabled children as Other. This is, in part, because the normative assumptions that underpin a special education approach have gone

uninterrogated in policy and practice and continue to be (re)produced under the guise of inclusion (Graham & Slee, 2008; Slee & Allan, 2001). The findings of this study, disability understood as: fragile, deviant, currency, and defining, are evidence of the (re)production of normative, ableist discourses that ultimately lead to the exclusion of disabled children in education settings labelled as inclusive through acts of Othering, governing, and potentially in some cases, internalization. In response to these acts, disability is also reframed as affirmative, resisting deficit-oriented understandings of disability and their effects.

Exclusion by Othering

Current enactments of inclusion 'imply a bringing in; that presupposes a whole into which something (or someone) can be incorporated' (Graham & Slee, 2008, 278). This 'whole' is imbued with ableist assumptions which uphold certain ways of doing and being as superior while casting others as inferior (Campbell, 2009). Through processes of ableism, normative ways of being and doing remain invisible and are defined through the naming of the non-normative, the Other (Campbell, 2009).

Storied as fragile, vulnerable, delicate, lazy, and deficient, disabled children in this study were Othered. Reflecting individual/medical disability discourses, in school settings, disabled children's impairments were frequently problematized instead of problematizing socio-cultural rules, norms, and expectations. Emphasis on impairments as deficits resulted in parents and children feeling immense pressure to conform to normative ways of being and doing. Onus was frequently on parents and children to change aspects of the individual child, so they could 'fit in', rather than on changing aspects of the socio-cultural environment. This pressure to 'fit in' can become so pervasive that the original intentions of inclusion become lost. In the following

example, Anne, a parent participant, advocates for her disabled daughter to not be associated with another disabled child to safeguard her daughter's position within the 'mainstream':

> once this other little girl came in [with] the wheelchair that had the same condition, [the school] stuck them together all the time and Maddie didn't like that. Like she was like why do I have to hang out with the kid in the wheelchair…so it's hard to find the fine line because you want them in the inclusive program…so they can be in the mainstream, but then you're constantly fighting….fighting to keep them inclusive…I'm all about…making them inclusive and stuff, but Maddie's worked really, really hard to be accepted by the other kids (Anne, Parent)

In this example, the parent and child work to distance themselves from disability, even at the expense of others, to appear closer to the 'norm'. This results in a hierarchy of disability and the furthered Othering and exclusion of disabled children.

Despite being labelled as 'inclusive', school settings continue to position the disabled child as Other. Individual disability discourses construct disability as deficient and deviant, cultivate a pressure to overcome and/or diminish difference, and (re)shape inclusion into a force of assimilation, as opposed to a valuation of difference.

Exclusion by Governing

Foucault's work on governmentality has been used to reveal hidden relations of power in the school context (Ball, 1990; Graham, 2006; Johnson et al., 2014; Marshall, 1996; Popkewitz & Brennan, 1998; Popkewitz & Lindblad, 2000). Foucault's work demonstrates how disabled people are "gradually, progressively, really and materially constituted through a multiplicity of organisms, forces, energies, desires, thoughts [and so on]" (Foucault 1980, p. 97). Counter to what would be expected within an inclusive setting, in this study, schools reproduced governance discourses in their systems of labelling and categorizing impairment (Phelan & Ng, 2014).

Schools maintained authority with regards to what constitutes 'normal' in a school setting and as a result governed the inclusion and exclusion of disabled children. Entrenched in individual/medical disability discourses, schools insisted upon the flagging, assessing, diagnosing, and labelling of any child that deviated from the norm (Whalley Hammell, 2006). As with many school systems, in the Alberta school context, diagnostic labels are used to determine funding and support. This connection between funding and diagnosis works to maintain power imbalances in the school setting, disempowering parents and children and over-empowering school authorities (Graham & Slee, 2008).

The governance of disability in inclusive school settings has profound exclusionary effects. Through categorization and labelling, the disabled child was set apart from others and portrayed as requiring 'extra' support to be included. This contributed to the construction of the disabled child as 'expensive' and 'inconvenient'.

Funding structures within the school setting left parents and children with little control over the funding (and therefore support) they received to participate in important aspects of school life (e.g. recess, field trips, classroom activities, etc.). Parents and children frequently discussed feeling frustrated when limited or inadequate support led to exclusion from activities. Exclusion from these aspects of school life are significant and limit children's opportunities to participate in child culture, form and strengthen relationships and friendships, and feel a sense of belonging in the school community.

Despite claiming to value diversity, rigid funding structures in inclusive school settings contribute to the governance and control of disability. The labelling and categorization of impairment sets disabled children apart. Furthermore, the connection between diagnostic labels

and funding constructs accommodation as (too) challenging, ultimately leading to the exclusion of disabled children from important aspects of school life.

Exclusion by Internalization

Counter to inclusive rhetoric, in this study, a culture of disableism that 'pathologizes difference, individualizes impairment, and maintains ableism' was cultivated within inclusive school settings (Goodley and Runswick-Cole 2011, 609). As active social agents, parents and children negotiated dominant, ableist disability discourses, knowingly and unknowingly producing, reproducing, resisting, and holding discourses in tension with one another.

Current enactments of inclusion, embodying ableist underpinnings, reject the disabled child as they are and demand they reshape themselves to be 'normal' or as close to 'normal' as possible (Graham & Slee, 2008). Constantly confronted with their Otherness, children experienced forms of ontological violence, a "violence against being or existence" within inclusive school settings (Zizek 2008; Goodley and Runswick-Cole 2011). With disability (or moreover, impairment) constructed as an ascribed identity or 'label', disabled children were limited in how they chose to identify or express themselves and their disability experiences. Simultaneously, disability was constructed as deviant and fragile. Together these discourses deeply devalue the disabled child. Unknowingly internalizing and reproducing these discourses, children described their bodies as deficient and problematic, and parents worried their child would become a burden to society. Rigid funding structures also elicited the reproduction of tragedy-oriented disability discourses by parents as they sought to 'prove' diagnosis and secure funding and support for their child. Parents unknowingly and knowingly reproduced deficit-oriented diagnostic labels and even advocated for assessment to have their child labelled and relabelled (Angell & Solomon, 2014).

Despite claims of inclusion, inclusive school settings cultivated a disableist culture wherein disabled children were subjected to ontological violence and experienced internalized oppression. These findings warrant attention. Ontological violence and internalized oppression have significant implications in the lives of disabled people, negatively impacting mental and physical wellbeing.

Responding with Resistance

Parents and children also resisted and held discourses in tension with one another. Parents and children were active rather than passive social actors, continuously working to reconcile their own beliefs, understandings, and experiences related to disability with the discourses that surrounded them in the inclusive school setting (Priestley, 1999; Whitburn, 2017).

Parents and children held individual and tragedy-oriented disability discourses in tension with affirming, social, and relational disability discourses. Drawing on affirming disability discourses, parents described their child being accepted 'as they are' as one of the most important aspects of inclusion. Parents were less concerned with their child's academic performance or ability to meet normative expectations and more concerned with their child feeling a sense of belonging, being accepted by their peers, and celebrated for their differences. Parents placed a high valuation on diversity, emphasizing that all children have something to bring to a classroom setting and that inclusion of disabled children can enhance learning for all students (Rix & Matthews, 2014).

Ascribing to social disability discourses (Barnes et al., 2002), parents identified aspects of the social, cultural, and built environments as the greatest barriers to achieving inclusion—not their child's impairment (Buchner et al., 2015). Children were frequently excluded when material aspects of the school or community limited accessibility (e.g. inaccessible washrooms,

fieldtrip destinations, transportation, and classrooms). Parents problematized the dominant

individual disability discourse that requires the disabled child to adapt to the environment,

asserting the need for the environment to adapt to their child instead (Oliver & Barnes, 2010).

In addition to material aspects of the environment, socio-cultural expectations were also

found to be disabling. Disabled children were frequently underestimated by actors within the

school (i.e. administration, teachers, etc.) and portrayed as underperforming, unable to contribute

within the classroom, and requiring specialized support. Parents and children countered these

discourses problematizing attitudes and socio-cultural expectations rather than impairments.

Resisting dominant discourses in the pursuit of inclusion is effortful and requires a great deal of

(invisible) work (Nespor & Hicks, 2010). Although families often resist dominant negative

valuations of disability, to continuously assert affirming discourses that run counter to a

disableist culture is tiresome and difficult (Goodley & Runswick-Cole, 2011).

Limitations & Directions for Future Study

As with any study, there were several limitations and considerations. Only a selection of

disability discourses were used as sensitizing concepts in analysis. There are many others that

could have been used and would have illuminated different aspects of parent and child

experiences. One parent and one child dropped out of the study, resulting in incomplete pictures

of two cases. During data collection, parents could participate in child interviews. This likely

shaped what information children chose to disclose. Time and resources limited the range of

possible actions for this study, making it difficult for researchers to utilize any arts based or

creative participatory methods to offer richer engagement with children's perspectives. The

interview format for data collection with children limited the depth and perhaps variety of

information obtained from child participants. As this study focussed specifically on parent and

child perceptions, limited insight into the ways school actors resist dominant discourses and assert affirming discourses was gained. Finally, this was a small scale study limited to a specific geographical area. The nature of this work was not to produce specific generalizable results but instead to raise questions that can be taken up and considered in other geographical regions.

This study revealed a series of rich themes that warrant further exploration including: the work of parents in the pursuit of inclusive education, the relationship between schools and families, the social inclusion of disabled children in school settings, and the inclusion of disabled children in child-driven culture (the 'unstructured' parts of school). Additionally, future research investigating instances of education professionals resisting dominant disability discourses and embracing affirmative discourses while working in/for the system might shed light on ways or avenues for change from within (Ng et al., 2015). The findings of this study appear predominantly negative, lacking examples of positive experiences of disability and inclusion. We did not purposefully sample for negative experiences, however, what parents and children chose to disclose was predominantly negative. This is not surprising as existing literature discusses the ways parents remain unsatisfied with how inclusion is enacted in school settings (despite viewing inclusion as a desirable and important outcome) (Lynch & Irvine, 2009). This points to the need for additional research that specifically seeks to understand what conditions support an experience of inclusion. Additionally, there is a continued need for research, which, like this paper, takes a critical perspective on inclusion and disablement in the school context. Finally, a more in-depth analysis of the child perspective on inclusion in schools is warranted.

Conclusion

Using disability discourses, this study illuminated (1) how disability is (re)produced in inclusive school settings and (2) the exclusionary effects of these (re)productions. Parent and

child (re)productions of disability hold valuable insights that can be used in the examination of current school policies and practices. Deficit oriented (re)productions of disability as tragic, deviant, currency, and identity illuminated a disableist school culture that persists under the façade of inclusive rhetoric. Parents and children, positioned as active social agents, negotiated ableism and disableism within inclusive school settings (re)producing, resisting, and holding individual/medical, tragedy, social, affirming, and relational disability discourses in tension. The disableist school culture produced the following exclusionary effects: the Othering of disabled children, governance of disability, internalised oppression, ontological violence, and invisible work. Despite intentions to promote inclusion in the school context, current school-based policies, practices, and structures perpetuate a deficit discourse and negate affirmative and generative perspectives on disability and identity.

Inclusive rhetoric alone is not enough. If inclusion is to be *experienced,* and not just talked about, rhetoric must be accompanied by a cultural or paradigmatic shift, 'a fundamental change in the way we think about differences among people, in how we choose to organize schools in order to educate people, and in how we conceive of the purpose of that education' (Gartner and Lipsky 1987, p. 388; Simons and Masschelein 2005, p. 218). Without the interrogation of oppressive normative assumptions present within education philosophies, structures, and practices, students will inevitably continue to experience exclusionary effects regardless of how the institution is labelled. Importantly, the intent here is not to suggest a return to segregated education policies and practices but instead to draw attention to the existing theory-practice gap in inclusive education and impress the need for practices of inclusion to reflect the theorisation that has occurred in the literature. Findings from this study, join others (Goodley and Runswick-cole 2015; Hodkinson 2012; Whitburn 2017b; Slee 2013), in a call for critical

reflexivity on current inclusive education policies and practices to consider how to close the

theory-practice gap thereby mitigating the exclusionary effects of inclusion today.

Declaration of Interest Statement

No potential conflict of interest was reported by the authors.

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Table 1 Participant Profiles

Parent	Child	Child Age	Child Grade	Impairment as described by Parents	Education Settings Discussed
Lisa	Kayleigh	10	3	Spastic Quadriplegic Cerebral Palsy	Included in mainstream classroom
Judy	Claire	15	10	Pervasive Developmental Disorder Not Otherwise Specified	Included in mainstream classes and attends 'study hall' once a week to receive additional learning support
Christine	Alexander	11	5	Irlen Syndrome, Anxiety, Obsessive Compulsive Disorder, Sensory Processing Disorder, Hypotonia, Fibromyalgia, Chronic Fatigue Syndrome, Dysgraphia, Apraxia	Included in mainstream classroom with Educational Assistant; previously home schooled
Breanne *Child interviews not completed	Blake	10	4	Chromosomal Abnormality, Seizure Disorder, Global Delays	Included in mainstream classroom
	Cole	13	7	Attending Deficit Hyperactivity Disorder, Obsessive Compulsive Disorder	
N/A *Parent interview not completed	Mae	14	9	Blood Disorder, Cerebral Palsy	Included in mainstream classroom
Jennifer	Mark	16	10	Autism Spectrum Disorder, Tourette Syndrome, Sensory Processing Disorder, Language Processing Delay	Included in mainstream classroom; Previously home schooled

Sara	Akhil	8	5	Twice Exceptional, Sensory Processing Disorder, Obsessive Compulsive Disorder, Anxiety	Included in mainstream classroom; Has also attended separate program for children labelled as "twice exceptional" physically located in mainstream school
Anne	Maddie		9	Arthrogryposis, Muscular Dystrophy	Included in mainstream classroom with Educational Assistant
Joan	Oliver	11	5	Autism, Tourette Syndrome	Included in mainstream classroom
Ellen	Danielle	12	9	Genetic mitochondrial disease	Included in mainstream classroom with Educational Assistant