Disability and Deleuze: An Exploration of Becoming and Embodiment in Children’s Everyday Environments

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Abstract
Building on Deleuze’s theories of the becoming of bodies, and notions of the geographic maturity of the disabled body we formulate an emplaced model of disability wherein bodies, social expectations and built form intersect in embodied experiences in specific environments to increase or decrease the capacity of disabled children to act in those environments. We join a growing effort to generate a more comprehensive model of disability, which moves beyond a binary between the individual and the social. Drawing on in-depth case studies conducted with 13 physically disabled children, we consider the intersections between their primary environments (homes, schools and neighbourhoods) and the multiple subjectivities they embody. Ultimately we make a case about the importance of responsive, situated models of subjectivity for the development of adaptations, and that physical and social adaptations must respond to these children’s complex and varied needs and desires.

Keywords
children, Deleuze, disability, embodiment, geography

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I do feel excluded because I feel like the teachers understand every other perfectly able-bodied person in the classroom but when they get to us it is a mystery... We are trying to live our lives which are hard enough, without the added difficulty of you not knowing what we can do. (Louise, age 14, School Interview)

Following Deleuze and Guattari it has become common practice to ask not what a body is, but ‘what can a body do?’ – a refusal to accept the body as static ‘being’ but instead flexible ‘becoming’. Deleuze, however, also writes of ‘fixation’, or encounters which can decrease the capacity of a body to act, bodies comprised not only of flow but also of encounters that fix or limit the body’s power (Deleuze, 1978; Deleuze and Guattari, 1987). A failure to address these parts of Deleuze’s philosophy can lead to a deceptively smooth description of bodies. Our use of Deleuze reveals the specific, situated experiences of disabled people in everyday disabling environments, building on scholarship on ‘the creation of embodied geographies of disability’, to enliven the social model of disability (Holt, 2004a: 221).

In literatures on childhood development and disability, scholars have oscillated between context and subjectivity. Historically, ‘the normally developing “model” of childhood located processes of development within the individual, under-theorizing the role of socio-spatial processes’ (Holt, 2004a). More recent scholarship foregrounds socio-spatial processes in childhood development (Holt, 2004a; Horton and Kraftl, 2006), paralleling a shift in broader disability scholarship away from the ‘medical’ or ‘personal tragedy’ model of disability, which situates disability in the body of the individual, towards the ‘social model’, in which social and physical environments are understood to be disabling (Holt, 2004b; Hughes, 2009; Hutchinson, 2006; Shakespeare and Watson, 2002). But has the turn to the social gone too far? Lack of attention to specific bodies and particular experiences can result in a ‘disembodied approach’ (Hansen and Philo, 2007), ‘the absent presence’ of impairment (Shakespeare and Watson, 2002). The social model of disability risks conflating physical presence with social inclusion (Milner and Kelly, 2009), and presumes uniform standards of behaviour that ignore bodily differences, especially in studies of children (Morris, 2001; Wilton, 2009).

Disabled children’s experience of environments is complex, demanding multiple methods to reveal the interplay between inclusion and access.
Drawing on in-depth case studies we conducted with 13 physically disabled children aged 10–15, we consider the intersections between their primary environments (homes, schools and neighbourhoods) and the multiple subjectivities they embody. Engaging children’s views of social inclusion and physical accessibility were paramount, and to this end we conducted intensive 2–4-day visits with children across Ontario. These included actual tours of their homes, schools and neighbourhoods, GPS mapping of children’s routes, child-led tours, drawing and photos. Interviews were child centred, although parents sometimes participated. Given the complex descriptions children provided about their relationships with their environments, enumerating physical barriers didn’t adequately describe children’s experience of access. Building on critiques of environmental approaches advanced by Hutchinson (2006) and Hughes (2009), our research explored how different environments (regardless of the physical accessibility they afforded) signalled inclusion or exclusion in different normative contexts: multiple methods and a child-centred approach helped to uncover the interplay between social inclusion and physical access, and importantly site-specific variations: an identical physical barrier at school and at home (for example a stair) might be experienced very differently for a child depending on the norms and expectations surrounding that object in different places, and the nature of their disability.

The call to listen to both children and disabled people is more than an ethical appeal to inclusion (Badham, 2004; Barker and Weller, 2003; Garth and Aroni, 2003; Kitchin, 2001). It yields deeper conceptual insights, and in the context of our approach invites the possibility of ‘going beyond’ traditional ideas of voice/agency (Kraftl, 2013). We accept that any research, whether conducted with children or adults, is fundamentally co-created (Crang, 2003; Rose, 1997; Watson, 2009). In addition to children’s voices, our extensive observational field notes yielded insights about the role of space or the persistence of taken-for-granted norms that would not have been revealed through interviews alone (for example, a child might insist that a place was easy to navigate – perhaps in a desire to demonstrate competency – but a site visit would demonstrate considerable difficulties). At times our field researchers were called upon to interpret gaps or silences when body-language communicated experiences the child was unwilling to put into words. Often, these ‘silent’ forms of communication related to uncomfortable or complex experiences. In
this way we see our findings as a co-created expertise, a product of participants, researchers, and the spaces – virtual and actual – in which the research took place.

We approached this co-creation process thoughtfully. In research with children, issues of power and vulnerability demand particular ethical attention. Contact with participants was made through referrals from Children’s Treatment Centres, who recommended children who had previously demonstrated interest in accessibility issues. In addition to obtaining standard letters of consent and assent from both children and parents, we also discussed participants’ ‘rights’ (for example, to anonymity, non-response and withdrawal) with them at the beginning of every encounter. As part of activating these rights we provided them with ‘stop’ and ‘go’ cards to help them communicate their needs and desires around the research process. As with our understanding of processes of ‘becoming’, co-creation in research is not endlessly smooth and flexible, but requires attending to inherent power dynamics in an ongoing and responsive way.

### Beyond the Medical or Social Model

In this article we adopt a comprehensive model of disability, moving beyond a binary between individual and social, to ‘retrieve’ the body within the social (Hall, 2000; Hansen and Philo, 2007; Imrie, 1999; Shakespeare and Watson, 2002), joining children’s geographers who have theorized embodied socio-spatial relations for children (Holt, 2004a; Horton and Kraftl, 2006). This broad turn includes disability activists who foreground their embodied experiences of disability (Hughes, 2009); disability theorists who have diverse ways of rethinking the body and disability (Garland-Thomson, 2002; Gibson, 2006; Inahara, 2009; Marks, 1999; Shildrick and Price, 1996); and geographers who describe the co-production of bodies and spaces (Longhurst, 1995, 1997; Moss and Dyck, 2002; Nast and Pile, 1998). They argue that places need to be understood at least in part through the bodies that experience them (Edwards and Imrie, 2003; Imrie, 2004).

Unpacking the binary of individual/social requires rethinking the singularity of body and identity. Disability studies is a fruitful place to do this, sitting ‘at the intersection of biology and society and of agency and structure’ (Shakespeare and Watson, 2002: 19). The body is mutable and ‘becoming’, ‘an intensely political site’ inextricably
linked to and co-created with its environments (Colebrook, 2000; Gatens and Lloyd, 1999; Gibson, 2006; Longhurst, 2001; Manning, 2009). Building on Deleuze’s theories of the becoming of bodies, and notions of the geographic maturity of the disabled body (Dorn, 1998), we formulate an emplaced model of embodied disability. Here bodies and built form intersect to yield spatially distributed, processual and performed concepts of identity and place (Colebrook, 2000; Deleuze, 1978; Deleuze and Guattari, 1987; Gatens and Lloyd, 1999; Longhurst, 2001). In attending to the specificity of the embodied experiences of our participants we are equally interested in smooth and in jarring or discordant movement/space, the oft-overlooked ordinary impacts of structured impasses (McCormack, 2008; Thrift, 1997). Our more nuanced focus on these materialities deepens theories of embodiment and provides pragmatic possibilities for action, inviting adaptations that are more responsive to the complex, varied needs and desires of disabled children in each environment.

Towards an Expanded Geographic Maturity

Why do we need a new model of disability? What should it do? Shifting our understanding of disability back towards the bodies and subjectivities of disabled people risks resurrecting the very sense of individual responsibility that disability scholars work so hard to critique. In attending to individual experiences of children, we want to celebrate children’s efforts to resist normalization processes and restrictions of their movement without, however, making them ‘responsible’ for limitations they can’t change or positioning them as responsible subjects (Gu-Ze’ev et al., 2001: 94, in Fisher, 2007: 294).

Dorn’s concept of geographic maturity foregrounds the ways in which the disabled subject must move back and forth between ‘an involved deliberative intuitive assessment of specific situations . . . and a kind of detached assessment of strategies required to intervene in the social fabric’ (1998: 197). This echoes the tensions we found in our research, as children navigated social norms that at times framed accessibility (such as the need to create physical environments that minimize bodily distress) in contrast to their own understanding of their capacities and desires.

approaches to evaluating ethical situations, and argues that neither is sufficient to describe the experience of a disabled subject. For Dorn, geographic maturity describes how the disabled subject ‘tacks’ between these two main points. In a dispassionate moral perspective the correct or ‘moral’ choice is based on a set of disinterested principles invoking appeals to law and universality, independent of the context, the subjects, or their feelings. This can produce a valuable notion of universal rights, which has particular effects on behaviours, built forms, and ideas of the self: In a situated ethic of care, the guiding values are more intuitive, contextual, and based on embodied experiences and feelings of care and trust. This can produce a more situational approach to understanding problems and a unique set of specific solutions. In moving across environments, different situations require different sets of skills – dispassionate moral maturity or situated caring. Dorn’s concept of geographic maturity draws from the Dreyfus model of skills acquisition, wherein the expert:

[...]the proficient performer, immersed in the world of skilled activity, sees what needs to be done, but must decide how to do it. With enough experience with a variety of situations, all seen from the same perspective but requiring different tactical decisions, the proficient performer develops an immediate intuitive response to each situation. (Dreyfus and Dreyfus, 1990: 242–3, emphasis in original, in Dorn, 1998: 145)

This model gives primacy to the built environment and flexibility to the individual’s position allowing them to shift and adapt their subjectivity according to the context. Dorn, however, generalizes his findings from the experience of a single subject, casting the private sphere as intimate, intuitive and caring, and the public sphere as objective and dispassionate. This polarized public/private dichotomy is not sufficiently nuanced in light of feminist scholarship on the complexity of private and public spaces (Blunt and Rose, 1994), and the differential normative contexts created by multiple publics (Fraser, 1990).

Geographic ‘maturity’ is an interesting concept especially in relation to disabled children and the question of agentic subjectivity: the decisions of disabled children face particular scrutiny because both disabled people and children are often considered ‘less capable’ – or less mature – within a model of agency that rests on an autonomous and ‘rational’ individual subject (Breckenridge and Vogler, 2001; Pole et al., 1999). We feel Deleuze can move us beyond the
singular and cognitively centred notion of subjectivity. A Deleuzian approach allows us a more flexible model of situated and constituted subjectivity in an ‘assemblage’, as the coming together of bodies, built form, social meaning, and adaptations (Deleuze and Guattari, 1987). In assemblage thinking, each of these components (bodies, built forms, social meanings) is an active constituent in the composition of forces (Robbins and Marks, 2010). This focus on assemblages allows that different combinations of bodies and environments surface different qualities of human identity and experience, in ways that are negotiated in situ, not predetermined, nor rigidly tied to a priori distinctions between public and private. For our purposes, the assemblage brings together these components in a way that may enhance or constrain the child’s capacity to act (Ruddick, 2012), and in which the child as ‘mature geographic subject’ negotiates various strategies. Capacity to act here is not just about physical access but also a sense of inclusion and even pleasure that impacts their overall affect. This approach requires understanding environments, bodies and disability, not as persistent states but as a ‘becoming’, constantly changing in relationship with each other.

In this context we are able to move beyond a reductive focus on access (i.e. the presence or absence of a ramp) to incorporate the experiences of children, their joy or satisfaction, in response to a combination of built form, social regulations and cultural norms which enhance or limit the possibilities for action, self-expression and belonging. It also involves loosening our grip on our idea of what is ‘right’ for these children, allowing space for multiple identities, multiple preferences and multiple ‘right’ ways of doing things.

Of course this raises a critical question. Without a transcendent notion of how to evaluate bodies’ actions or possibilities for action, how can we make political distinctions and choices about change? Ruddick (2012) suggests that we distinguish between ‘oppressive’ and ‘emancipatory’ assemblages based on the ways they constrain or enhance capacities. The ethical evaluation of such assemblages must begin with the Deleuzian question: ‘what can a body do?’ This is not a question about a static body in abstract space; it is a question about the emergence of a body’s becoming capacities in relation to the assemblage of meanings, social relations and objects (see Colebrook, 2000: 87). Building on this, encounters among children, other people and objects in particular places must be examined in ways that
look for potential enabling moments – moments that increase capacity. The concept of assemblage, moreover, troubles notions of the self-contained solitary individual attached to a fixed, interior agentic identity. Although we proceed from ‘individual’ interviews with children, it is to uncover the ways individuals emerge ‘constituted’ in the sense offered by Simondon (2009) in a process in constant negotiation with their milieu (Deleuze, 1997). We offer below a few examples of the impact different body–environment assemblages had on the capacity and experience of our participants. These examples demonstrate the insights we gain from an emplaced and embodied model of disability that attends to context as well as the capacities and experiences of the disabled children who negotiate these contexts.

**Falling and Crawling**

In the apparatus\(^4\) that manages the path of ‘normal’ childhood development, children must navigate a shifting constellation of coordinates by which normalcy is measured – points that oscillate between an emphasis on safety/dependence, risk/independence and normal/delayed development (Hulqvist and Dahlberg, 2001; James et al., 1998; Rose, 1999). The emphasis on one or the other of these coordinates does not just pertain to disabled children. They figure, for example, in the history of playground design for all children (Smith, 1998). But for disabled children these coordinates are amplified in a larger developmental framework, in which in the course of ‘growing up’, normal children are ‘expected to be able to turn over, crawl, walk ... et cetera within professionally determined windows of time’ (Valerie, 2007). The disabled children in our study had to negotiate a change in values assigned to movements such as falling and crawling in different environments.

**Falling**

For case study participants, falling had very different meanings at home and school, meanings that affected the use of mobility devices, potential for movement, social interaction and safety. Although all the children had some experience of falling both at home and at school, overall they talked more frequently about falling, being pushed or bumped into, and hurting themselves at school. They voiced more distress about falling at school, and demonstrated an
almost unsettling lack of distress about falling at home. Different ways of dealing with falling in these two environments demonstrate how malleable the meaning of falling can be, and the effect these differences have on the social rules that children navigate and their embodied experiences in different spaces.

At home falling was accepted, or at least considered ‘natural’; accepting falling seemed to be part of considering children to be normal and fine (rather than abnormal or engaging in dangerous or problematic behaviour). Parents and children, when possible, tend to resist the normalizing pressures found in more public environments (Fisher, 2007; Goodley, 2007). This at times led to the acceptance of behaviours that seemed inappropriate or unsafe to the researchers; for example one child, Darlene, described how ‘flopping’ into the bathtub was her normal mode of entry, despite frequent slipping and hard landings. Another child, Brittany, talked about falling at home and showed us various bumps and scrapes (including very scabbed elbows), but she and her mom were fairly nonchalant about it... they called falling, ‘taking a Bambi’. In more extreme instances (four cases), children were described in both children’s and parents’ accounts as able to walk independently, despite field researchers observing frequent falls. In some cases falling at home was portrayed as something children should take responsibility for. One research assistant (RA) described walking to the park with an 11-year-old boy as follows:

As we were walking, 50 Cent fell many times. He literally fell (hard) to the ground, once on the pavement and a few times while we were walking through the field to get to the park. After he fell, his sister instructed me not to help him get up – because he had to learn.

(Excerpt from field notes, 50 Cent, Home Interview, May 2009)

In contrast to acceptance of falling at home, by this child’s account, his teachers and administrators at school considered falling something to be avoided at all costs. The school discourse seemed to be that children do not and should not fall. In fact, 50 Cent had recently switched to using a wheelchair full time at school because teachers determined that he had been falling too much.

50 Cent did not like using his wheelchair at school; he reported being ‘bored’ in comparison to when he was not restricted to the wheelchair. He could no longer get to some favoured places around
the school because they were inaccessible with the wheelchair. 50 Cent was also less concerned about falling at school than his teachers were. The RA noticed how 50 Cent described a situation in which he fell at school:

50 Cent actually was a bit amused by the situation when he fell out of his wheelchair . . . a typical 11-year-old boy who loved the competitiveness of the games at the gym that he was trying to win, and fell and got a bit hurt as a result.

The RA continues:

He seems to have very little independence at the school. This surprised me because, even though he has serious mobility impairments, he actually can walk around and navigate his home. If the school, or at least areas of the school (such as his classroom) were set up appropriately, he would actually be able to navigate these spaces without getting hurt. (Excerpt from field notes, 50 Cent, School Interview, May 2009)

In this instance 50 Cent was isolated by a combination of prohibitions by risk-averse teachers, spaces that were inaccessible to a wheelchair, and insufficient spaces that could support his walking. While children described safety as being important at school, in some instances the lack of acceptance of falling and the desire to keep them safe led to restrictions on their mobility. In turn, this caused other kinds of social pain and confinement. Burns et al. (2013) have argued that perception of risk often plays a part in disabling experiences, the idea of being ‘at risk’ can be used as a form of psycho-emotional disablement. Disabled people, like the rest of the population, choose to engage with potential risks in a range of ways that reflect their lives and experiences.

The ideal solution would be to make both home and school environments fully accessible to the range of mobility choices 50 Cent wanted to use. In the interim we can see how 50 Cent’s family’s efforts to normalize his frequent falls at home may have prevented him from receiving help and adaptations he could have benefited from, while the zero tolerance approach to falling at school impacted his mobility and social interactions in ways that distressed him. It seems the rigidness of expectation in both places – for extreme independence at home or no-risk behaviour at school – reduced the possibilities for 50 Cent and inhibited the creation of body–environment
relationships that are safe and allow freedom to move in accordance with his own desires. Comparing the two spaces provides additional insights. At home he is independent but frequently injured, at school he is wheelchair-dependent but safer from physical harm. In moving between these two roles/environments 50 Cent cultivates a geographic maturity which allows him to apply the knowledge gained in one space to the experiences in another, resisting the restrictions at school because of his experience at home.

Crawling

Crawling was also contentious and anxiety inducing for children. It evoked desire, conflicting interests, social stigmatization and medical intervention, perhaps because the move from crawling to walking upright is canonized as a marker of childhood development, measured by doctors and anxiously monitored by parents (Rose, 1999). Observations of children and their parents, and children’s descriptions of school, made it clear that their preferences went against what many parents and teachers considered safe, healthy and socially acceptable. Negotiations around crawling were complex. Many children crawled at home but not outside the house or in front of non-family members. As one RA observed during a child-led house tour: ‘Brittany got down the stairs by sliding on her bum. She seemed a little embarrassed when her family told us that she slid down the stairs’ (Excerpt from field notes, Home Interview, January 2009). Another child said that she presumed the RA would want to see her walking around her house, even though this was not her preferred or usual way to move at home (Elizabeth, Home Interview, April 2009).

Unlike falling (not enjoyed but treated as a cost of increased mobility or independence), some children said they preferred crawling to other kinds of mobility because it was faster and more efficient. This was despite frequent physical injury. In gym class dodge ball or volleyball games, Nick complained his wheelchair was slow: he could go faster on his knees, and crawling made him a more valuable team player, ‘I could get 500 points for my team on my knees.’ However it was also ‘not fun’ because it necessitated getting his knees ‘drained’, a painful removal of accumulated fluid accrued due to excess pressure. So for Nick, crawling was negotiated between affective coordinates of pain (in his knees), desire (to go fast, play the game and score
points), and rules and boundaries (he was not allowed to crawl). He resisted the rules by doing something he was ‘not allowed’ to, and accepted the painful consequences, all while grappling with clear enthusiasm and a desire to play the game well (School Interview, May 2009). Nick navigated these options in a flexible way, sometimes prioritizing the fun of the game and other times the health risks, depending on the context. This flexibility can make adaptations and rules a moving target, and demonstrates how they might benefit from a more nuanced approach.

Given normative assumptions about children’s vulnerability and markers of development (Rose, 1999), we could respond to this situation by arguing that Nick, 50 Cent and other disabled children make ‘unhealthy’ choices and lack a sufficiently developed sense of consequences. However, given the range of difficulties these children expressed – from frustration over restricted mobility due to constrained movement options, to physical harm due to risks taken to engage in preferred play – we posit that there is no fixed moral position from which to assess or evaluate these actions and preferences; to do so would make our evaluations less responsive to their realities. Rather than interpreting children’s falls and injuries as indicative of an incorrect response towards safety, we argue that children are negotiating (rationally and emotionally) a much wider set of motivations, and making decisions based on a broad set of experiential criteria.

Simply validating children’s preferred movement is insufficient: the desire not to use a mobility device may be motivated by the pressures of an intolerant environment and the social value of upright walking. The desire to be considered ‘normal’ may override concerns for safety or experiences of pain. Disabled children fall far more often than their non-disabled peers, and often endure more serious consequences (Raman et al., 2009). This is not acceptable, but neither are the less tangible social injuries. The other pains and desires of children who want to walk, crawl or move in ways that they find effective also need to be considered. Children already navigate a range of locationally specific value systems, which are formulated largely by adults in each of their primary environments; and children lose out when their own embodied experiences, emotions and assessments are not part of what shapes the social rules and built forms.

This dilemma turns on the distinction between an abstract morality, considered independent of context (i.e. physical health
should always take precedence over playing, or falling is never acceptable) and a situational ethics, which considers the combination of factors which intersect in a given location for a particular child, including children’s rights, dangers of paternalism regarding the informed choices of disabled persons (von Benzon, 2010), risk to dignity (Perske, 1972; Schloss et al., 1993), and long-term medical risks of particular behaviours. Far from passively conforming to their environments, disabled children act as mature geographic subjects, navigating environments (literally and figuratively) with insight, generating their own multiple subjectivities, adapting their identities to changing environments to generate the best possible fit in that given time and place. Garland Thompson captures this ‘dynamic encounter between flesh and world’ (2011: 592) in the term ‘misfit’ – an alternative to the impairment and the social model of disability. When the context changes so does the ‘fit’. We argue that different ‘fits’ enable or constrain disabled children’s actions and experiences. Research on normalization practices in schools suggests that much more energy is spent teaching children to conform than exploring their unique strengths and capacities (Holt et al., 2012). In a framework of flexible emplaced subjectivity, crawling inside one’s home may generate possibilities for resistance and further becoming, not just signal a failure to meet developmental expectations. The proliferation of these combinations derives crucially from the enhancement of a child’s capacity to act in unique ways in different environments.

**Tables and Timing: Disabled Children’s Experience of Adaptations**

As with our analysis of bodies and movement, accommodations and adaptations to enhance accessibility had different meanings for children in different environments. Discursive formulations framing the meaning of the private space of the home (Blunt and Rose, 1994; Varley, 2008), the normalizing expectations of schools (Foucault, 1991, 2005; Tremain, 2005), and the political qualities of the ‘public’ sphere (Fraser, 1990; Habermas, 1989) help us to understand children’s descriptions of their experiences in different environments. For example, a member of the Youth Advisory Committee described how getting off the couch at home was infinitely easier
than in a public place ‘because at home you can stick your bum up in
the air and do whatever it takes to navigate the space’ (Youth Advi-
sory Committee meeting, January 2007). ScHaN (School, Home and
Neighbourhood Accessibility: Physically Disabled Children’s
Assessments) participants used accessibility adaptations in all three
environments, but spoke most about adaptations at school. They had
notably different responses to similar adaptations in each environ-
ment: generally parents and children expected to find accessibility
adaptations (such as ramps or railings) in shopping malls (7 suggest
this), but the same adaptations might be upsetting to children at
school because they were designed in a way that marked difference
(10 critiqued adaptations at school). In spite of similar mobility
issues, the absence of these adaptations was often not considered
an issue at home.

Adaptations at School

The uniformity of western school environments (Foucault, 1975;
Rose, 1999), with their concomitant emphasis on children’s confor-
mity and normalcy, makes it understandable that some adaptations in
integrated schools (often added on in an ad hoc fashion) are anxiety
provoking, because children felt singled out by them. However, anxi-
ety was not produced by all adaptations. For instance, automatic door
buttons were uniformly valued. Other adaptations drew unwanted
attention, or created unanticipated effects that made desired partici-
pation/inclusion difficult.

Many (9) children reported having adapted desks in order to
accommodate their mobility devices. They described these desks
as being a different size, height and shape from the others in the
classroom and for many seemed to be a source of anxiety signifying
exclusion. For example Luigi, a 12-year-old girl, noted that
while everyone else in the class sat at tables in groups of two, she
sat alone at a special (adjustable) desk that she did not like. She
also said:

Luigi: I sit next to the door.

Mom: They ordered a table specifically for her ... it looks like the
others but it has adjustable legs.
Luigi: Now it doesn’t stop squeaking, when I move it doesn’t stop squeaking. I don’t want to move because every time I move it makes sound.
(Luigi, School Interview, June 2009)

When asked what she would like to change about her classroom, Luigi said she would like to change her desk ‘because it is different and it squeaks’.

Bartman (an 11-year-old boy) also felt his desk stood out, noting his desk was ‘a lot bigger than everyone else’s desk . . . not small enough to be called a desk [compared to] everyone else’s tiny desks’. While it met the criterion of being wheelchair accessible, Bartman experienced the desk as isolating. Although these seem to be small easily rectified problems, they hold a larger symbolic significance for these children and three others who had similar concerns. Another child, who had a centrally located, typical desk, indicated that his desk was his favourite place in the classroom. The amount of discussion time the desks occupied, and the tone the children used to describe them, suggested it was not just the squeak or the size of the desks that was problematic, but also the signal of exclusion or inclusion they represented. Considered in the assemblage of child–body–classroom–meaning, the desks designed specifically to increase children’s physical accessibility in fact provoked sadness or frustration, ultimately constraining children’s freedom and possibilities. The classroom assemblage, sedimented to signal the uniformity of a ‘normal subject’, constrained disabled children, who felt singled out by the different appearance of their desks, lessening their overall capacity in that environment.

Many schools also made temporal and locational adaptations to allow disabled children to get from one class to another on time. Many of our participants were instructed to sit close to the door and leave the class 10 minutes early to avoid the crush in the halls or to accommodate a slower pace. However, this often meant they missed 10 minutes of class, including assignment announcements, descriptions of homework and other end-of-class activities. Their frustration was palpable. Louise (age 14) said:

My timing schedule’s all messed up. I had to have access to the door without disturbing the teacher because the teacher would still be teaching when I left . . . [SIGH]. Because they didn’t want anyone
else in the hall when I was leaving because they didn’t want me to get hurt. (Louise, School Interview, May 2009)

The need to leave class early, and constraints of adapted furniture or the room itself, restricted where children could sit in a classroom and amplified their sense of exclusion. Louise, who sat in the corner to facilitate her early exit, noted:

I felt I was put in the corner. Eventually I got . . . I don’t want to say I got used to it . . . it is just another day, it is just a spot to sit, it doesn’t really matter, I’m not in the class to get the perfect spot – I’m in class to learn, but it would have been nice to have been a little more centralized in class. (Louise, School Interview, May 2009)

Computer use was another issue: Two children reported really liking working on computers, using them for playing and recreation when other avenues, like school yards, were not accessible to them. However, when they were the only one using a computer in the classroom some (3) found it stressful. For example, the cord of Bartman’s computer crossed a gap in the room and was considered a tripping danger for the other children. Bartman was quite distressed and said it was an ongoing source of discomfort for him in his class. In his perception this issue created tension between him and everyone else in the class (including the teacher). He felt they were annoyed with him for the potential hazard of this adaptation (Field notes, Bartman, School Interview, April 2009).

Similarly (10-year-old) Nick also found it stressful to use his classroom computer. His classmates wrote by hand, but his need for the computer (due to his impairment) made him feel excluded. He did not understand why he was not allowed to write like all the other children. Nick’s distress was apparent in his body-language: when telling this story, he lowered his head, avoided eye contact and stared into his lap. His computer (paradoxically an aid to his learning) was the most difficult thing for him at school; ‘that’s what I hate about it’ (Nick, School Interview, May 2009). It was not the equipment per se but the fact that using the computer in his classroom set him apart from the other children while they worked on paper. In contrast, he ranked the computer room as one of his favourite places at school: here all the children, including Nick, used computers at the same time.
Adaptations at Home and in Public Places

The children exhibited markedly different attitudes towards adaptations in their homes, schools and neighbourhoods: they underplayed the need for adaptations at home; were often distressed by adaptations at school (when they felt singled out); and were unapologetic and enthusiastic about the need for adaptations in public spaces (parks, malls, restaurants, etc.).

Children were notably less distressed about adaptations (or the lack thereof) at home than at school. And families were more open to unorthodox movements as children negotiated home space. This parallels Fisher’s conclusion that ‘knowledge learned within the private sphere can contribute to more inclusive forms of care that do not construct difference as a problem or an abnormality to be resolved’ (2007: 285). Sometimes, especially if the house had major adaptations like wider doors or renovated accessible washrooms, children spoke about them with pride. But generally, questions about home adaptations/modifications sparked less conversation with RAs than adaptations outside the home. Many children took a less critical stance towards their homes than towards their schools: 11 children made critical comments about accommodations at school while only 2 criticized their homes (a total of 38 individual critical comments were coded for adaptations at school while only 4 were coded for home and 4 for neighbourhoods). At home most children indicated that some things were great and others ‘not perfect’, but overall acceptance and comfort was the most common attitude towards mobility in the home. Things at home were basically ‘fine’.

This response was complicated by the observations of the RAs. In the majority of ScHaN case studies (9 out of 13), RAs noted the absence of small adaptations and changes that would have greatly improved the accessibility of homes, for example moving kitchen dishes to lower cupboard shelves or moving furniture out of mobility pathways. These barriers seemed to go unnoticed by the children and their families. Common accessibility standards for public places (American Disability Association, 2010) indicate that adaptations such as lowering counters would have improved children’s quality of life. The concept of home has a complex history within social geography: it is a space with which people intimately identify but it has also been criticized for being used to shelter certain static, bounded
and privileged identities (Varley, 2008). In fact, feminist scholars have foregrounded injustices hidden in the privacy of home, and the dangers of assuming the social sanctity of home space (Boyd, 1997). These insights are equally relevant to the relationship of disabled children to their homes: in our study, for example, children’s and parents’ acceptance of difficulties navigating the home were not always helpful. We might infer that, in some cases, the children’s need to ‘belong’ at home could mask the need for change even more strongly than at school. In spite of struggles with access in the home, it is important to note that most of the children expressed confidence, competence and a sense of capability at home, taking pride in their solutions to mobility challenges, like balancing on the back of their wheelchair to reach the closet, or sliding from the upper to lower mattress to get around on a bunk bed.

If the children expressed discomfort around adaptations at home they appeared at the boundary between the more private and public spaces of the home. For example, some children were uncomfortable with adaptations in more public places of their homes because they didn’t appear normal. One child said that she didn’t want double railings on the stairs in her house because ‘it would look weird’ (Elizabeth, Home Interview, April 2009). Given the clear desire among families to maximize the quality of life of their disabled members, we conclude that where no lack of resources prevents adaptations being made, other socio-spatial forces inhibit families from recognizing the need for change. The acceptance that was so valuable to children at home could also result in the absence of important adaptations that could have created more possibilities for the children in these homes.

Though it may be useful to use values found at home to critique dominant public discourses of normal appearance and behaviour (such as those found in schools), the private sphere cannot be cast as exempt from its own normalizing strategies, nor does the home only hold a singular set of social values. ScHaN case studies revealed several normalizing discourses at work in the homes of all participating children – some children and parents emphasized the desire (and sometimes requirement) that the disabled child be an independent member of the household, and/or emphasized a desire for their homes to appear and operate like typical homes. Sometimes these discourses were contradictory, for example the adaptations that might facilitate
children’s independence made houses appear less like other homes. We cannot then presume that children’s capacity is only constrained in some environments (e.g. schools) while others remain ‘natural’ and enabling (e.g. homes). Intersecting forces of material spaces, meanings and identities are at work in all environments, albeit with varying expectations and intensities.

In contrast to their descriptions of adaptations at home and school, all participating children said unequivocally that they liked having adaptations in (non-school) public spaces, including the homes of family and friends. They expressed enthusiasm for ramps or lifts at friends’ and grandparents’ houses, especially if they had been put in specifically for them. Rather than making them feel isolated or different, these changes seemed to encourage feelings of importance, belonging and inclusion. A lack of adaptations in public spaces, such as insufficient accessible parking spaces and narrow shop aisles, however, sparked energetic discussion, even a sense of entitlement and outrage at their absence. This suggests that the children were either more comfortable being vocal about public spaces or had a more developed sense of their rights to access in public spaces than they did elsewhere – a stance which resonates with the idea of ‘dispassionate moral maturity’ invoked by Dorn as one of the possible subject positions inhabited by disabled people, most common in public environments.

Interestingly, one child indicated that she felt she was treated differently in school than in public spaces, even by the same classmates, whom she found were friendlier in the public spaces than they were at school (Louise, School Interview, May 2009). This behaviour can also be understood within a model of emplaced flexible subjectivity, as it is not only disabled children whose subjectivity and embodiment change in different environments: all subjects find themselves interpolated into different positions as a result of the assemblages they are part of. Part of the challenge and advantage of this approach to understanding disability and accessibility is recognizing that one part cannot change without the whole assemblage being affected. In this way the capacity of disabled children in any given environment is also connected to the capacity of every other body in that environment. ‘What can a body do?’ does not just refer to the body of that individual child but the body of the whole assemblage. When the connections and possibilities for the disabled child are constrained, the
entire assemblage is diminished – and we live collectively in more limited worlds. Finding adaptations that work to maximize the capacity of these children is not just something that benefits disabled children, but ultimately benefits us all.

Conclusions

How do disabled children navigate the limitations and possibilities of their social and physical environment? When are adaptations non-adaptive? How might they be improved? Our research investigates the lived experience of disabled children through Deleuzian concepts of body and assemblage to offer a more nuanced concept of embodiment. More important, perhaps, it offers practical suggestions for how to develop better ‘fits’ for children with disabilities.

Using Dorn’s concept of geographic maturity as a point of departure we suggest that geographic maturity is negotiated differently within and between different assemblages; that we cannot presume a priori that one context is more or less inclusive than another; that we must explore the varied strategies and attitudes of children as they navigate multiple environments; and that, to move towards a true sense of inclusion, we must start from the child’s viewpoint. How children perceive, navigate, conform to or contest different discursive cultures and physical infrastructures of home, school and neighbourhood is key. We need to work with children across their multiple environments, using a much broader range of analytical tools to gain insight into the kinds of adaptations that will really work for a diverse array of children with mobility impairments.

Our research clearly demonstrates that we can’t evaluate an adaptation on its own terms, separate from built form and sedimented meanings in varied contexts, including assemblages of children and teachers in the school, or family and friends in the home. Adaptations are meant to increase possibilities for action, connection and involvement. But their efficacy cannot be predetermined. Improving the child’s environment must account for both the built form and its negotiated social meanings – considering the subjective experiences of the child, through consultation with children. Adaptations in homes should consider the ways children might downplay frustrations they might be more willing to vocalize in other contexts (public spaces or schools). Adaptations in schools should be designed with
the awareness of children’s desire to appear normal, and the need for social conformity in these contexts, and should not themselves constitute additional markers of difference. Greater efforts should be made to address the way different assemblages undermine or enhance the effectiveness of adaptations and the capacity of disabled children. Adaptations that are made solely on the basis of considerations of physical health and safety, or that make children stand out in environments where they want to blend in, may be better than nothing but may not unlock the full capacity of the children they aim to enable.

We have theorized beyond a model of disability that is strictly ‘social’ or ‘biological’, using the Deleuzian concept of assemblage to better understand the emergence of subjects in spaces, and the ways assemblages enable or constrain actions for ‘individuals’ in those spaces. These assemblages should not attempt to enhance the body’s capacity to act by achieving conformance to a universal norm (the right way to walk, for example), but respond to the specific context: enhancing capacities might be achieved through change in built form, in social values, a stronger sense of entitlement and belonging, or combinations of all of these things. These insights can help us revise our understanding of pre-given and uniform criteria for accessibility (for example, wheel-able surfaces for chair users are often too slippery for cane users). Access to this knowledge must start in collaboration with children, drawing on their expertise and experience ‘knowing what they can do’. This is the first step towards true inclusivity.

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Notes
1. All children’s names are pseudonyms chosen by the children for the purposes of this research.
2. In her seminal study on children’s labour, Olga Nieuwenhuys (1994) demonstrated the critical importance of this kind of field observation, as many mothers were ‘unaware of the symbiotic role’ that their daughters played in household labour.
3. For example, in our study we included an inclusivity circle, which the child could point to, coded in red, yellow and green to indicate varying levels of the child’s sense of inclusion. At times in the course of the interview it became clear that some children were reluctant to keep pointing to the red zone either because the fact of exclusion seemed obvious to them or because they were uncomfortable with the resurfacing of the experiences under discussion.
4. We are using ‘apparatus’ in the way Rabinow and Rose (2003: 10) describe when they say, ‘Foucault uses the word apparatus to mean a device oriented to produce something – a machinic contraption whose purpose in this case is control and management of certain characteristics of a population.’
5. Youth Advisory Committee (YAC) of Holland Bloorview Kids Rehabilitation Hospital members served as consultants on the project.

References


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