Interrogating inclusion: Critical research with disabled youth who use augmentative and alternative communication

by

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy
Graduate Department of Rehabilitation Science
University of Toronto

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Abstract

This dissertation provides a critical exploration of the notion of inclusion, applied to the ‘case’ of disabled youth who use augmentative and alternative communication (AAC). Oriented by Bourdieu’s theory of practice, this study examined the lives and practices of youth who use AAC to better understand how they make ‘practical sense’ of inclusion and locate their place in the world. The objective was to illuminate the extent to which the constraints of social arrangements and conditions delimited the social interactions of youth who use AAC and shaped their understandings of inclusion. Using a novel critical dialogical methodology developed for the study, data were generated with 13 Canadian youth who use AAC by combining participant-generated photographs and a graphic elicitation technique termed Belonging Circles with interviews and observations. The study results make three substantive contributions to existing research on disabled children’s lives and children’s rehabilitation. First, the participants’ narratives reflected habitus - socially constituted sets of dispositions - that predisposed them to accommodate the devalued social positions and constricted conditions of existence imposed on them. From the points of view made possible to them, the youths’ practices represent logical and practical strategies for claiming inclusion that, paradoxically, reproduce and resist the systems of
categorization that constrain them. Second, by illuminating the life circumstances and delimited
life trajectories of youth in the study, the research vividly demonstrates that some forms of
‘inclusion’ perpetuate symbolic violence by keeping disabled youth ‘in their place’ through the
oppressive effects of misrecognised social norms, beliefs and values that privilege ‘normal’
badies. All study participants claimed inclusion but under constricted conditions of possibility
that were not of their choosing. Finally, while the youths’ practices primarily reproduced the
status quo, they also worked at the margins to curate locally produced forms of inclusion that
attempted to transform the ‘rules of the game’. These results make visible the mechanisms
involved in reproducing significant social inequities which constrain youth who use AAC. The
research suggests a need for systemic shifts past reified notions of inclusion toward fostering
social spaces where alternative ways of being in the world are positively valued.
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1 Introduction to the study

1.1 The trouble with inclusion

Inclusion is difficult to contest. As a word, it carries the weight of lofty ideals worth striving toward. The term has become ubiquitous and stands relatively unchallenged as a morally ‘right’ and ‘good’ strategy for organizing more just societies. There is nearly universal agreement that nations must work toward establishing inclusion as a human right. Still, precise definitions, dimensions and attributes of inclusion have proven illusory. In relation to disability, what does inclusion of disabled persons look like? Are there potential harms associated with various forms of inclusion? Is inclusion attainable, and if so, would that achievement of ‘inclusion’ negate the apparent ‘disability’ which necessitated a move toward inclusion in the first place? This latter question points to one of several troubling assumptions inherent in the notion of inclusion: it is tacitly understood as a move enacted by the dominant majority to ‘bring in’ the excluded other. Into what the other is to be included is not clear.

This somewhat circular line of questioning is an attempt to distill what I have come to think of as ‘the trouble with inclusion’. Titchkosky (2011) expressed this circularity aptly when she noted:

“It is the irony of the structures of an in/out dichotomy; the construction of who is out is intimately tied to who is in, and as we work at getting in, the production of who and what is out continues” (p. 27).

My queries accumulated in the context of children’s rehabilitation, where, as an occupational therapist, I have had extensive experience working with, and learning from, disabled children and their families. In particular, I was involved as a consultant in the area of augmentative and alternative communication (AAC)\(^1\) with children and youth who had little or no speech subsequent to neurological conditions such as cerebral palsy. Much of my work was community-based, where I observed the mediating effects of social, cultural and political contexts that

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\(^1\) The term AAC is used in several ways: it can be used to describe a variety of alternative communication systems and strategies that can include eye gaze, gestures, facial expressions or a human communication partner. The term also encompasses an array of assistive communication technologies that range from simple alphabet boards, pictures and symbol-sets through to highly complex and costly speech-generating computer technologies. Finally, AAC is a term used to describe an interdisciplinary professional field.
purported to be inclusive. Without question, access to AAC services and technologies can improve the lives of children with communication impairments, and has the potential to expand their social networks. Families report communication is more important than mobility (e.g. walking) to their disabled child’s overall well-being (Marshall & Goldbart, 2008). Yet, over time I observed tremendous gaps between what youth who used AAC were able to communicate (what might be termed communicative competencies) and the scant opportunities they were afforded to engage in communication interactions in real-world settings. Too often, I observed conditions of so called inclusion that, from my perspective, contributed to the ongoing marginalization and ‘muting’ of children and youth who used AAC. Moreover, accepted approaches to AAC intervention, across institutional and community settings, are steeped in biomedical perspectives where a considerable focus is placed on assessing various communication impairments, and where interventions most often target the individual child’s body and behaviours.

As an occupational therapist, my role included making recommendations to modify tasks or the accessibility of the environment, especially as these related to communication. The over-arching aim was to optimize inclusion by increasing opportunities for children who use AAC to participate in the ‘normal’ occupations and activities of childhood (attending school, learning to read and write, playing outdoors, gaining independence in self-care). Nearly all daily activities are inextricably linked with everyday communication acts. Thus, implicit in my professional role were assumptions that disabled children’s inclusion would be facilitated by addressing their ‘communication deficits’ and optimizing their communication abilities.

A turning point for me came as I led a clinical study (Teachman & Ettorre, 2008) aimed to increase opportunities for children and youth who use AAC to be included in their communities. We paired our youngest clients with an older youth mentor who had more experience using AAC, and jointly planned excursions into community spaces such as shopping malls, museums, or recreation centres. Through that initiative, it became clear that the measures used to assess whether or not the program was effective were poor proxies for the elusive inclusion that was our aim. For example, goal-attainment scaling was used to measure changes in youths’ pragmatic communication skills when interacting with unfamiliar people. This information was not without value, but could not help account for the broader social relations influencing youths’ interactions. Paradoxically, one of the most highly valued aspects of the program was the opportunity for
young people and their families to meet and share their common experiences of communication impairment. Most youth in the study had never met or interacted with another person who used AAC. Feedback, including that of parents, indicated that the sense of community and support afforded by being in an ‘AAC group’ was valued at least as much, if not more, than opportunities for ‘inclusion’ in the community at large.

This unsettled my assumptions about inclusion and surfaced underlying logics in children’s rehabilitation. For example, it is generally assumed that improvements in a person’s function will improve their ‘quality of life’. I was also more aware of power differentials between relatively powerful health professionals and the disabled youth targeted for intervention. That learning prompted many more reflexive questions about the aims and means involved in ‘rehabilitating’ disabled children, which fueled the direction of my doctoral work. To focus the research, I resolved to examine how youth who use AAC perceive inclusion, how their practices are shaped, and how pervasive ‘calls for inclusion’ influence their lives.

This dissertation is a critical exploration of the notion of inclusion, applied to the ‘case’ of disabled youth who use AAC. As I will show, the study produced rich descriptions and new theoretical insights that begin to address ‘the trouble with inclusion’. This was accomplished through a focused examination of the interrelations between disabled youths’ practices2 and the broader socio-spatial, temporal and political structures that mediate their lives. In this chapter, I introduce the dissertation by first setting out the research problem and aims addressed through the study. I introduce, in general terms, the critical approach within which I developed the study’s conceptual framework and a novel methodology which I describe in detail in Chapters 4 and 5. Next, I define key terminology before concluding with some practical notes on the organization of the dissertation and an outline of the chapters which follow.

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2 Throughout this dissertation, I use the terms ‘practices’ and ‘position-takings’ interchangeably, drawing on Bourdieu (1990a) who used both terms to refer to situated, observable behaviours, beliefs, perceptions and preferences that are understood as practical or logical, and that arise from the interrelationship between individuals’ daily subjective interactions and the broader social structures in which they are situated. I expand on these terms in Chapter 3 where I set out the conceptual framework of the study.
1.2 The research problem

Research has suggested that youth who are living with both physical and communication impairments are amongst the most excluded of disabled youth (Morris, 2001, 2003; Smith, 2005; Whitehouse, Watt, Line, & Bishop, 2009). Yet, with notable exceptions (Batorowicz, Campbell, von Tetzchner, King, & Missiuna, 2014; Bennett, 2011; Mitchell, 2010; Rabiee, Sloper & Beresford, 2005; Raghavendra, Olsson, Sampson, McInerney, & Connell, 2012; Wickenden, 2011a, 2011b, Simmons & Watson, 2014) very little research has been conducted with this group of young people. Until recently, youth who use AAC were largely excluded from studies with disabled youth because of presumed difficulties engaging them in research (Morris, 2003). As a result, little is known about how prevailing calls for inclusion affect the lives of youth with communication impairments. Nor is there information to help understand their practices in relation to inclusion. These knowledge gaps are significant limiting factors in designing programs and services that aim to promote social participation and improve life-opportunities for youth who communicate in ways other than speech.

Complicating the lack of knowledge regarding the inclusion experiences and practices of youth who use AAC is the broader problem of how ‘inclusion’ and ‘exclusion’ are conceptualized and understood in research and practice. Scholars, particularly in education, have pointed out the need to critique ways that inclusion is understood as a universal ‘good’, and to consider the impacts of inclusion processes on people who are identified as excluded (Graham & Slee, 2008; Holt, 2003; Swain & Cook, 2001). It is essential that the undergirding logics of existing and future inclusion practices and policies are critically interrogated, and informed by the perspectives of disabled people (Spencer-Cavaliere & Watkinson, 2010; Susinos, 2007).

In children’s rehabilitation, the notion of inclusion is a foundational construct and an underpinning philosophy; however, almost no research within rehabilitation has critiqued inclusion. Understanding inclusion/exclusion from the standpoint of youth who use AAC is vital but insufficient, unless examined in relation to socially prevalent ‘truths’ and norms that organize their sense of what is given, and how things ought to be in the world. This knowledge is urgently needed to inform the design of effective rehabilitation, health and social programs to best serve youth who use AAC, and to better understand how they are affected by the values, norms and
beliefs about disability and inclusion that are embedded in rehabilitation and society, more generally.

1.3 Research aims

Using a critical qualitative approach, this research begins to address the knowledge gaps outlined above. Specifically, the study aims were:

1) to contribute detailed descriptions of the lives and practices of youth who use AAC with a focus on their subjective experiences of inclusion; and

2) to interpret the interrelations among position-takings of youth who use AAC (how they accommodate, resist or reformulate inclusion in their lives) and their social positions in and across the social spaces they inhabit.

Accordingly, the research empirically describes the daily activities, social networks, personal geographies, and material environments of youth who use AAC, and critically interprets their practices in relation to dominant values and beliefs about disability and inclusion.

1.4 A critical approach to examining ‘inclusion’

The research is framed by critical social science perspectives (Eakin, Robertson, Poland, Coburn, & Edwards, 1996) and specifically draws on the work of Pierre Bourdieu (1989, 1990b, 2000) to conceptualize inclusion in ways that move beyond binary inclusion/exclusion formulations. Critical research is concerned with identifying and addressing marginalization and exclusion (Kincheloe & McLaren, 2005) and has been used to uncover possible unintended sources of marginalization in healthcare practices (see for example Duchan & Leahy, 2008; Gibson & Teachman, 2012; Hammell, 2006). A critical perspective questions assumptions or ideologies that underpin everyday practices, considers power relations that are at play, and acknowledges contradiction. Dialectical\(^3\) relationships are acknowledged between the micro-level of the individual and their macro-level social, political and economic contexts (Eakin et al., 1996). Critically-informed approaches in rehabilitation scholarship acknowledge that “practice and

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\(^3\) I use the term ‘dialectical’ to describe ongoing dynamic, interpenetrating and irreducible subject/object relations (Schwandt, 2007).
societal contexts determine what people think and do and … shape what people imagine is possible” (Townsend, Cockburn, Letts, Thibeault, & Trentham, 2007, p. 155).

A critical lens oriented my approach to the research problem by foregrounding relations that contribute to the persistence of social inequalities. This necessitated that I develop a conceptual framework for examining relations between the practices of youth in the study and the social contexts and material conditions of their lives. As a point of departure, I turned to the sociology of the late Pierre Bourdieu (1989, 1990b, 2000 – see Chapter 3) which oriented my analyses of those relations. I integrated visual methods with interviews in order to generate multifaceted data that could extend beyond participants’ points of view. The research provides previously missing descriptions of the lives and circumstances of youth who use AAC. However, the contributions of the work extend beyond the descriptive to offer a theoretically-informed and novel interpretation of the ways that youth who use AAC are affected by socially prevalent calls for inclusion of disabled people, and how they, in turn, contribute toward shaping values and beliefs about inclusion.

To achieve these ends, it was essential that the study design address challenges related to optimizing the quality of data generated with youth who communicated primarily in ways other than speech. I addressed these issues by drawing on Mikhail Bakhtin’s dialogism (1981, 1994) to theorize communication impairment and develop a new critical dialogical methodology for doing research with people who use AAC (discussed in Chapter 4). This innovative methodology acknowledges the multi-voiced, relational, and thus, dialogical nature of all research interviews, and grounded the study methods, which I describe in detail in Chapter 5. Bakhtin’s dialogism complements and is congruent with Bourdieu’s (1991) theorizing of language as symbolic power; however, I found Bakhtin’s work had greater resonance in theorizing communication impairment and addressing ‘authenticity’ concerns, raised by scholars, regarding the mediated nature of AAC.

As I discuss further on in Chapter 2, perspectives from youth who use AAC have been largely absent from research about disabled childhoods. To ethically portray the presence and agency of disabled youth, I take care to avoid representing participants’ views in ways that risk reducing the complexity and variation across their individual accounts to any single perspective on ‘youth who use AAC’ (Lehoux, Poland, & Duadelin, 2006). Additionally, I understood it to be my role
as the researcher, guided by my supervisory committee, to interpret ‘why’ and ‘how’ youth perceived and presented themselves in particular ways through the research. Following Lehoux (2006), I viewed that interpreting reasons or explaining why individuals hold particular views is primarily the task of the investigator, who reorganizes participant accounts into a framework, not to represent ‘truth’, but to make the dynamics of social relations more explicit.

1.5 Terminology

I introduce a few key terms here because they are central to discussing the young people represented in this dissertation. Thereafter, I primarily use footnotes to clarify my use of particular terms, and where pertinent, provide a rationale. Overall, I have endeavoured to pay attention to ‘what words do’. Words construct perceptions as much as they express perceptions (Bourdieu, 1989). A salient example is my use of ‘disabled youth’ which is consistent with the critical approach of the study. In this usage, disability is not constructed as a condition of individuals as implied by the phrase ‘with disabilities’. Rather, disability is experienced or made apparent because of social conditions such as prejudice, discrimination and social exclusion (Goodley, 2011; Morris, 2001; Schillmeier, 2008).

**Impairment** has been defined as “lacking part or all of a limb, or having a defective limb, organism or mechanism of the body” (UPIAS, 1976, p. 3). This definition expresses what are “real bodily variations” (Thomas, 2004, p.25) including the communication impairments discussed in this dissertation. Yet, it retains notions of impairment as **deficit** and **natural**, while obscuring considerations of its **social** production (Tremain, 2005). I agree with Hughes and Patterson who argued: “disabled people experience impairment, as well as disability, not in separate Cartesian compartments, but as part of a complex interpenetration of oppression and affliction (1997, p. 335). Thus, I see disability and impairment not as a binary couplet, but as dialectically intertwined and embodied. I concur with Thomas (2004) that “impairment is not the cause of disability, it is the raw material upon which disability works….the embodied socio-biological substance - socially marked as unacceptable bodily deviation - that mediates the social relationships in question” (p.25). Accordingly, I avoid defining the young people in the study solely by their impairments while making it clear that bodily impairments are social distinctions that place youth who use AAC in positions of relative disadvantage.
In this dissertation, I primarily refer to ‘youth who use AAC’ to represent youth as active communicators instead of defining them solely in relation to their physical and communication impairments. This group is made up of youth who have limited or no oral speech and who combine alternative means of communication, such as gestures, vocalizations, facial expressions, personal communication books and speech-generating devices, to augment or substitute for speech. In the AAC field, there are ongoing debates about how to talk about people with communication impairments (Alant, Bornman, & Lloyd, 2006). The phrase ‘people with complex communication needs’ has been promoted by some in the AAC literature (Beukelman, Ball, & Fager, 2008; Clarke et al., 2012; Raghavendra et al., 2012); however, the term remains poorly defined (Alant et al., 2006), and is not meaningful outside of the relatively small AAC discipline. More problematic from a critical perspective is the implication that individuals with communication impairments have ongoing ‘needs’ for intervention as opposed to constructing them as active communicators.

The term ‘non-speaking’ is often used to describe persons who use AAC. However, some individuals who use AAC are able to produce some amount of dysarthric (slurred and/or slow) speech that is difficult for most people to understand, and which professionals label as ‘non-functional’. Earlier iterations of my work included the term ‘non-speaking’, but through my interactions with participants who had a modicum of speech, I became increasingly uncomfortable with the binary conceptualization of speech implicit in the term, and elected to revise my writing accordingly. (I write about these interactions in more detail in Chapter 5.) To refer to a person with speech differences as ‘non-speaking’ negates their speech altogether, and reproduces dominant notions of what counts as speech.

It is important to acknowledge that people who use AAC are not a homogenous group. They are persons, of all ages, who experience communication impairments related to developmental neurological conditions, such as cerebral palsy, autism, acquired brain injuries, stroke or neurological degenerative diseases, as well as those who have limited or no speech subsequent to illnesses where they may require tracheotomy, intubation or ventilation.

1.6 Organization of the thesis

To conclude this introductory chapter, I provide an overview of the organization of the dissertation which is followed by a brief description of each chapter. My research is set out over
eight successive chapters, incorporating three manuscripts prepared for publication in peer-reviewed journals. I elected to produce a manuscript-based dissertation in order to 1) facilitate earlier dissemination of the research, and 2) further develop my proficiency in the essential tasks of writing and publishing research papers for specific target audiences. Compared to more conventional monograph styles, this approach necessitated a modicum of repetition across the dissertation as whole (e.g. in the introductory elements of the manuscripts). This document represents my independent doctoral work, completed with the guidance and supervision of my advisory committee. Accordingly, I use the singular first person ‘I’ throughout the dissertation. When submitted for publication, the manuscripts which comprise Chapters 4, 5 and 7 will shift to using the plural ‘we’ to acknowledge the role of my advisors.

The flow from conventional chapters to those that are manuscript-based is eased by brief explanatory chapter prefaces. For each manuscript, I have included an abstract and indicated, using footnotes, the target journal, status of the paper in the review process, and the purpose and general readership of that journal. A fourth published paper appears as Appendix 12. In that paper, I outline methods for doing research with people who use AAC which I developed in my role as a doctoral trainee for a different funded study, and which I continued to refine in this research. The paper was invited and peer-reviewed for publication in a new online repository of SAGE Research Methods Cases (Teachman, Mistry & Gibson, 2014). As with this entire dissertation, the paper reflects independent work. The authorship acknowledges the role of my supervisor, Barbara Gibson, who led the qualitative study, and Bhavnita Mistry, the study coordinator. The paper provides further evidence of my doctoral scholarship, and is highly relevant to the methods used in this study. The combination of the appended paper with the manuscripts in Chapters 4 and 5 makes clear the important, highly innovative methodological contributions of my doctoral work.

Moving on from this introduction, in Chapter 2, I explore and synthesize various literatures on communication impairment, youth who use AAC, and the notion of inclusion, to contextualize the study. I discuss the problems and knowledge gaps that my research begins to address, staking out a new research space at the intersection of “disabled children’s childhood studies” (Curran & Runswick-Cole, 2013) and AAC scholarship. Then, I trace the rise of inclusion as a dominant social discourse, and review literature that critiques binary notions of inclusion/exclusion. Bringing critical scholarship into conversation with empirical research with groups targeted for
inclusion, I suggest a more complicated and dynamic account of inclusion as subjective, situated in time and space, and produced through socio-spatial interrelations. This tentative rethinking of social inclusion resonates with Pierre Bourdieu’s reflexive and relational sociology.

In Chapter 3, I set out the conceptual framework that oriented this examination of ‘inclusion’ with youth who use AAC. I argue that Bourdieu’s topological theorization of social space offers a heuristic approach for thinking about youth who use AAC as agents ‘in place’ whose perspectives (or points of view) on inclusion are necessarily shaped by their social positions. I introduce Bourdieu’s conceptual toolkit and specify how, with some necessary modifications, it provided a lens for analyzing relations between the conditions of disabled youths’ everyday lives, their imposed social positions and their subjective position-takings (i.e. their practices as evidenced by how they presented themselves through the research).

To execute the research, it was necessary to theorize communication impairment and develop a methodological approach for optimizing data generation with youth who used AAC. In the manuscript which comprises Chapter 4, I present the novel critical dialogical methodology developed for the study to overcome issues raised in the literature about the ‘authenticity’ of accounts generated with people who use AAC. I elaborate on Bakhtin’s dialogism to contest conceptualizations of ‘voice’ as singular and autonomous, arguing that all interview talk is multi-voiced and therefore, dialogical. Thus, interviews mediated by communication technologies and/or a communication partner are no more or less authentic than those that involve putatively ‘normal’ speech. In Chapter 5, also a manuscript, I outline how I combined visual methods with dialogical interviews, applying the critical dialogical methodology that I had developed. Both chapters/manuscripts include examples from the study to illustrate the methodology and methods in action.

The study results follow in Chapters 6 and 7. The descriptive results appear in Chapter 6. In that chapter, I present 13 case narratives where the integration of visual data with participants’ accounts animates, in rich detail, the lives of the young people who participated in the study and their perceptions of inclusion. The chapter addresses the first study aim through in-depth descriptions of the daily activities, social networks, personal geographies, and material environments of youth who use AAC. Against these textured portrayals of everyday life, youths’ practices in relation to inclusion are illustrated.
In Chapter 7 (a manuscript), I build on and develop the results presented in Chapter 6 to address the second\(^4\) aim of the research. Oriented by my specification of Bourdieu’s key conceptual tools – namely habitus, field, and capital - I analyze the position-takings of youth who use AAC in relation to inclusion, showing how these can be linked, through the work of habitus, to the conditions of their existence and their positions in social space.

To conclude, in Chapter 8, I summarize the unique and important contributions of this dissertation. Noting limitations of the study, I highlight the key research results and suggest potential implications of my work for children’s rehabilitation, for advancing theory and methodology, and for future research.

\(^4\) Study Aim 2: to interpret the interrelations among position-takings of youth who use AAC (how they accommodate, resist or reformulate inclusion in their lives) and their social positions in and across the social spaces they inhabit.
Chapter 2
2 Background and literature review

2.1 Introduction

In this chapter, I contextualize the research beginning with an overview of communication impairment and AAC. I provide a brief history of the nascent professional field of AAC and discuss the relative lack of critical scholarship informing the discipline. Next, I narrow my focus to consider what little information is available about the lives and practices of disabled children and youth with communication impairments. I synthesize research that suggests these young people struggle for social acknowledgment and experience isolation which typically increases as they age. In the latter part of the chapter, I move to broadly consider the notion of ‘inclusion’, how it has evolved as a dominant social discourse in relation to disability, and how it has been conceptualized and critiqued in the extant literature. I look to what has been learned through the small number of empirical studies that examined ‘inclusion’ practices with groups identified as excluded. I conclude the chapter by reiterating the problems and knowledge gaps that this dissertation begins to address.

2.2 Youth who use AAC: Background and perspectives

2.2.1 Communication impairment and AAC

As noted earlier, people with communication impairments are not a homogenous group. The sparse demographic information available about people who require AAC is disconnected and often dated, making it impossible to accurately describe this group at a population level. It has been estimated that 1.3% of individuals world-wide have communication impairments that limit their ability to rely on speech for communication (Beukelman, 2005). Australian researchers found that up to 13% of children and youth in primary through secondary schools have some type of communication impairment (McLeod & McKinnon, 2007). Binger and Light (2006) indicated that 12% of Pennsylvanian preschoolers in special education needed AAC services. In 1991, Huer reported up to 82 percent of university students in the US who used AAC had a

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5 I use the terms ‘youth’ or ‘young people’ instead of ‘children’ respecting that many older children prefer this language (Tisdall & Punch, 2012). As with ‘childhood’ and ‘child’, I use the term ‘youth’ to denote a socially constructed but slippery category between childhood and adulthood that is not defined by a specific chronological age-range. At times, I use the term ‘children’, particularly in relation to childhood disability studies.
primary diagnosis of cerebral palsy, as opposed to more recent data (Binger & Light, 2006) where developmental delay was the most prevalent diagnosis across preschoolers requiring AAC services (38% of the sample). Overall, this information suggests youth with communication impairments represent a relatively small fraction of disabled youth. However, some researchers suggest the overall population with communication impairments is growing in parallel with increases in the incidence of autism, survival rates of children with developmental disabilities, and an aging population who experience concomitant cognitive and language impairments (Light & McNaughton, 2012). The under identification of children and youth who could benefit from AAC interventions hinders the funding and development of programs and services to support this group (Binger & Light, 2006).

A brief overview of the AAC field is in order, to provide context for the study. In the 1960s and 1970s, previously disparate disciplines converged around research aimed at developing knowledge, tools and strategies to assist individuals with communication impairments (Vanderheiden, 2003; Zangari, Lloyd, & Vicker, 1994). By 1983, an international group of engineers, therapists, teachers and researchers, along with individuals who used communication aids, coined the term ‘augmentative and alternative communication’ and founded the International Society for Augmentative and Alternative Communication. In 1985, the first peer-reviewed journal dedicated to the field of AAC appeared. Since that time, AAC has become a well-established international field. In Western countries, multidisciplinary teams from rehabilitation and/or educational institutions provide AAC assessment and intervention, and act as technology gatekeepers within complex regulated funding systems. Resources to serve children and youth who use AAC have been reported as inadequate, underfunded (Lindsay, 2010) and limited by socio-political factors, in particular, waitlists, distribution of services favoring larger metropolitan areas, and availability of pre-service trained professionals (Hodge, 2007; Lindsay 2010). For families and health care systems, long-term investments in AAC technologies, training and specialized professional expertise are associated with relatively high costs (Binger & Light, 2006).

Until recently, almost no research examined the experiences and perspectives of people who use AAC, in part, because researchers lacked access to well-described methods to guide them in designing studies and generating rich data with participants who had little or no speech (Carlsson, Ehrenberg, & Ehnfors, 2004; Philpin, Jordan, & Warring, 2005). A preponderance of
research in the field of AAC has focused on technology testing, anecdotal descriptions of language and literacy patterns among AAC users and their partners, or interventions directed toward the individual with communication impairments (Bedrosian, 1999; Light, 1999; McNaughton & Light, 2015). Historically, many AAC systems and devices were developed and tested with non-disabled research participants, in part, because of concerns about involving people with communication impairments in the design of AAC technologies (Bedrosian, 1995). Although the views of people who use AAC are more often incorporated in recent AAC research, there is still a relative paucity of literature focused in-depth on the lives and circumstances of people who use AAC. There is even less critical work examining how their lives are affected by dominant social norms and values that privilege ‘normal’ communication.

As a sub-field within the broader field of rehabilitation, AAC has evolved within a framework of biomedical discourses that individualize and pathologize bodily difference, and tend to conflate impairment with disability (McLaughlin & Coleman-Fountain, 2014). Practice is premised on tacit understandings about the necessity of fixing impaired bodies, or intervening to help approximate ‘normal’ bodies in order to optimize ‘good’ outcomes (Nicholls & Gibson, 2010). Social factors, if considered, tend to be reduced and categorized as either ‘barriers’ or ‘facilitators’ of participation (Eakin, 2015). Relatively little scholarly work in AAC has incorporated critical perspectives, and almost no research has theorized communication impairment/difference (Marshall, 2014). As noted earlier, the first journal dedicated to AAC research and practice was founded in 1985. Shortly thereafter, Kovarsky and Crago (1990) called for ethnographic research to critically examine constructions of communication difference through empirical study of the lives of people labelled as ‘communicatively disordered’. Medicalization and negative labelling of communication differences produce an ‘othering’ of people with communication differences, Kovarsky and Crago argued, thereby reproducing and perpetuating exclusion. Terms such as ‘speech language pathologist’ and ‘communication disorders assistant’ point out the deficit-based assumptions underpinning the field. Kovarsky
went on to develop a body of work demonstrating how communicative (in)competence\(^6\) is constructed through social and clinical interactions (Kovarsky, Duchan, & Maxwell, 1999).

Nearly a decade after Kovarsky and Crago’s (1990) call, Woll and Barnett (1998) challenged the AAC discipline’s focus on the individual with bodily impairments as framed by psycholinguistic perspectives. To move clinical and research agendas forward, they recommended a shift toward sociolinguistic perspectives, citing exemplars from research about Deaf culture. In the latter, hearing impairment was (re)conceptualized as a characteristic shared among a minority linguistic Deaf community, rather than as an individual deficit. A decade further on, in research with children who had communication impairments, Komulainen (2007) queried the ways children’s ‘voices’ were represented in social research. Drawing on Bakhtin’s dialogism, she argued that “ideals of ‘normal’ and good communication that prefer rational, abstract thinking and actions, discriminate between different groups of people even though the aims were to meet the needs and individual rights of children” (p.23). Komulainen’s work cautions against privileging communication that is linguistic, verbal or textual. ‘Voice’ in her approach is understood as a socially constructed product of social interaction, rather than an individual property. In the context of communication impairment, she posited, physical movements and non-verbal utterances are often misinterpreted or even disqualified, when they may in fact be more important than the words involved in the exchange.

The works of these critical scholars demonstrate the potential for research to surface unquestioned assumptions such as the necessity of communicating ‘independently’ and as ‘normally’ as possible. While these ideals may present as natural and necessary within biomedicine, the reviewed literature suggests they might contribute to exclusionary processes. Yet, there has been little uptake of these ideas in AAC scholarship. For example, while Komulainen’s insightful and exemplary paper has been cited over 150 times, only two of those citations link to papers related to AAC.

\(^6\) Building on Kovarsky’s work, in a critical conceptual review of ‘communication competence’ (Teachman & Gibson, 2014), I argued for a shift away from focusing on the individual with communication impairments toward viewing communicative competence as a shared, socially incorporated and performed communication construct.
2.2.2 Lives of children and youth with communication impairments

I now review the small body of empirical research that has examined knowledge of the childhoods and day-to-day practices of youth who use AAC. In line with the aims of this study, I have not included literatures focused specifically on AAC technologies or clinical interventions in relation to youth who use AAC. In what follows, I present a synthesis of the handful of recent studies which begin to describe the daily activities, social networks, personal geographies, and material environments of youth who use AAC. The studies were undertaken in Canada, Australia and the UK and were informed by perspectives from youth who use AAC and/or their families. Consistent with emergent ‘disabled children’s childhood studies’ (Curran & Runswick-Cole, 2013), I recognize the effects of discussing disabled youth primarily in relation to their deficits and individualized problems, as reproduced in some of the review that follows. However, the discussion reflects dominant forms of representation in the literature, establishes current knowledge of the lives of youth who use AAC, and highlights the need for critical research.

Youth who use AAC typically have small networks of familiar communication partners (usually limited to family members and paid professionals) with whom they develop unique communication modes (Wickenden, 2001c). These methods rely on tacit understandings of how each partner in a conversation will act to support communication, and are less dependent on communication technologies, including speech-generating devices. Use of those devices is more common in formal settings and contexts (Murphy, Marková, Moodie, Scott, & Boa, 1995). Conversations involving AAC tend to proceed more slowly and require more effort than would be ‘normally’ expected, especially since many youth who use AAC rely on electronic switches (e.g. controlled by head or arm movements) to access communication technologies (Murphy et al., 1995). Youth reported feeling frustrated and angry when wheelchairs and speech-generating devices - which they hoped would support social interactions - instead prove to be unreliable and intimidating (Batorowicz et al., 2014; Wickenden, 2011a). Still, parents shared they hold out hope that their child’s future prospects would be enhanced by learning to communicate faster using AAC (Batorowicz et al., 2014).

Young people with communication impairments said they spend the majority of their time at home with family (Batorowicz et al., 2014; Wickenden, 2011a). For example, ‘hanging out’ at home in the kitchen was the most common leisure activity cited by youth in one study.
(Batorowicz et al., 2014). When youth who use AAC engage in activities away from home, they are most often accompanied by family members or support persons who provide mobility, communication, or physical support (King, Batorowicz, Rigby, Pinto, Thompson, & Goh, 2013; Raghavendra, Virgo, Olsson, Connell, & Lane, 2011). Outings are frequently structured around their siblings’ sport or leisure activities. Regardless of age, children and youth who use AAC said they have almost no interaction with strangers (Batorowicz et al., 2014). In a study with young (aged 6-9 years) children who use AAC, responses on a participation survey indicated this group have lower and less varied participation in activities outside of school, less friends, and fewer acquaintances than their non-disabled peers (Thirumanickam, Raghavendra, & Olsson, 2011). Strikingly, there is evidence that youths’ social isolation is increased as these already low levels of participation in recreational activities are further reduced in adolescence (Clarke et al., 2012). Limited social participation of youth who use AAC has been attributed, in part, to the constraints of communication devices. Parents and children report many communication devices are poorly designed for use in outdoor settings or in crowded noisy spaces (Batorowicz et al., 2014).

In school environments, youth who use AAC express feeling pressure to communicate as quickly as possible or risk losing the attention of listeners, who tend to be impatient. They also report that unfamiliar people tend to assume that all persons who use AAC have intellectual disabilities. Feeling upset and frustrated, youth shared they frequently cope by abandoning conversations (Batorowicz et al., 2014). Compared to their non-disabled peers, and children who have physical but not communication impairments, children and youth who use AAC have been shown to have less opportunities to communicate during the school day and fewer school-based friendships (Raghavendra et al., 2012). Parents report that, aside from immediate classroom staff, few educators are able to communicate with their child (Batorowicz et al., 2014).

Of the reviewed studies, Wickenden’s (2011a; 2011b) ethnographic work provides the most in-depth information about how youth feel they are positioned in social settings, and the practices they employ to downplay their impairments. Wickenden reported youth who use AAC struggle to be acknowledged and included. They feel diminished as people talk ‘around and through them’, or treat them like a much younger child. Central to Wickenden’s results is an appeal from youth to be identified more for the ways that they are like typical teenagers, than for their
differences. The research highlights the youths’ agency, suggesting they strategically downplay their impairments, and emphasize the ways they are the same as non-disabled teens.

While this small body of research provides valuable information about the experiences and perspectives of youth who use AAC, much of the work is undertheorized and remains at a descriptive level. The research reflects a focus on the challenges and limits confronted by young people with communication impairments but not how they make sense of and respond to their disadvantaged social positions. None of the reviewed studies critically interpreted youths’ accounts in relation to the social positions they occupied, or the effects of broader social values, norms and beliefs in which they were immersed. Wickenden’s (2011a) work goes some way toward illuminating strategies youth used to try to improve their social positioning, but neglects considerations of the logics underlying their strategic representation of themselves as ‘like other teenagers’.

In summary, my review of the current state of knowledge about youth who use AAC suggests that this group is under-researched, even in relatively wealthy countries. While there has been a dramatic increase in research about disabled children, a relatively small fraction of studies have involved youth who use AAC, and the majority of these are focused on evaluations of clinical or technological interventions. From the few recent studies that examined the lives of children and youth who use AAC, it is apparent that they experience isolation that increases with age, and struggle to participate socially beyond the family sphere. Wishing to be seen more for the ways that they are like other teens, they work to downplay their differences. There is an urgent need for more research in general, and critical research specifically, to better understand the lives and practices of young people who use AAC, how they are affected by calls for inclusion, and how to best improve their life chances. Given that inclusion is generally assumed to play a crucial role in optimizing disabled children’s lives, improved understandings of how it is conceptualized and enacted are crucial. Accordingly, I move next to review how the notion of inclusion has been conceptualized and critiqued in research and scholarship.

2.3 The rise and “iridescence” of inclusion

I begin by tracing the rise of inclusion as a dominant set of values and beliefs which idealize inclusion as a ‘universal good’ and a moral imperative. Against that background, I discuss the work of scholars who have critiqued inclusion, rejecting simple binaries of inclusion/exclusion.
Critical interrogations have highlighted ‘iridescent’ (Roulstone, 2010) depictions of inclusion, positing it as “something that looks quite different depending on the viewpoint of the observer” (p.428). I then review the scant empirical research exploring perceptions of inclusion with diverse groups of people identified as excluded.

2.3.1 Historical shifts toward inclusion

The goal of fully including disabled people in society has been enshrined in international documents and legislation (UN, 2006; WHO, 2001), enacted through state policies and institutions, and understood as a human right and a desirable achievement. In these ways, the notion of inclusion has been reified. In the current climate, there is little room to question the authority or morality of calls for inclusion. One way forward involves looking backward to view inclusion within a historical context. When seen as a point along a progression of social movements aimed to reduce the oppression and exclusion of disabled people, it becomes easier to query how inclusion has since been taken up to achieve particular ends, and how things might be otherwise. Past movements calling for segregation, normalization, and integration of disabled persons have each, in turn, purported to offer solutions to the ‘problem’ of disability. Yet, each has largely fallen out of favour and given way to inclusion-directed mandates.

Pervasive calls for inclusion were prefaced historically by evolving social awareness of the oppressive conditions imposed on disabled people. In the 1960s, at least among Western countries, the social philosophy of difference, or segregation, was being replaced by one of normalization (Weber & Bennett, 2004). This entailed a move from approaches that condoned separating people with ‘differences’ from mainstream society, which had been seen as necessary and beneficent, toward promoting their integration into mainstream society. ‘Integration’ became a byword for equality and was a precursor to the inclusion movement (Weber & Bennett, 2004). Over the course of the 1970s and 1980s, the principle that disabled persons are entitled to the same rights as all other persons was expressed in ground-breaking Canadian statutes and common law (Tardif-Williams, Trent-Kratz, & Donato, 2009). In 1982, the Charter of Rights and Freedoms constitutionally guaranteed equality for persons with mental or physical impairments, marking Canada as the first nation in the world to explicitly enshrine equal rights for disabled people (Tardif et al., 2009).
These developments had implications for disabled children, especially in relation to education. As recently as 40 years ago, disabled children and youth in Ontario were educated in institutions, such as residential or training schools, separate from the general or ‘mainstream’ education system (Weber & Bennett, 2004). Through the 1970s, the standard of providing the ‘least restrictive environment’ gained traction and was formalized into US law through the Individuals with Disabilities Education Act of 1990. Canadian approaches to inclusive education were/are closely aligned with the US model set out by that Act (Weber & Bennett, 2004). These changes in the landscape of education were primarily framed within rights-based rhetoric intended to support the integration of disabled students into mainstream education settings. Critics noted that ‘mainstreaming’ disabled students often produced conditions where the young person was “in their neighborhood school, but not really of it” (emphasis added) (Weber & Bennett, 2004, p.14). This occurred as disabled students were placed in segregated special education ‘resource rooms’ or ‘self-contained classrooms’ within schools where they were socially isolated from non-disabled students because of their ‘special needs’.

The inclusive schools movement that emerged in the mid-80s called for the elimination of the entire continuum of ‘special education’. This movement called for ‘full’ inclusion, arguing all students should be grouped with their same-aged peers regardless of any differences. Full inclusion was set out as a basic human right, and as morally superior to the provision of segregated classrooms within mainstream schools. This stance on full inclusion was considered radical by many, and continues to be vigorously debated in relation to which types of ‘placements’ are in the best interests of disabled children (Tardif-Williams et al., 2009). Contra the notion of full inclusion, some educators have advocated for ‘meaningful’ inclusion. In this formulation, exclusion of disabled students from mainstream classes is perceived as a reasonable and acceptable practice because, it has been argued, merely accessing a physical space, such as a mainstream classroom, does not necessarily produce the sense of community belonging, acceptance and interdependence incorporated in conceptualizations of meaningful inclusion (Tardif-Williams et al. 2009). These developments and debates point to the multiple and sometimes competing understandings of inclusion that are ‘in play’ in the contemporary field of education.

In children’s rehabilitation, it is generally accepted that inclusion is an overarching and desirable goal for disabled youth. Yet, conceptualizations of inclusion and exclusion in relation to
disability are largely unexamined (Hall, 2010). Health and rehabilitation programs tend to regard
disability as an individual problem unrelated to discriminatory social practices (Titchkosky,
2011). Tacit assumptions that tend to conflate impairment with disability persist, in spite of
evidence showing that improvements in function are not directly linked with increased social
participation (Gibson et al., 2009; Wright, Rosenbaum, Goldsmith, Law, & Fehlings, 2008).

Having considered the ascendance of inclusion, I next consider alternative views on inclusion –
namely those contributed by critical scholars and people who have been labelled ‘excluded’ and
‘in need of inclusion’.

2.3.2 The iridescence of inclusion

In a compelling critique of shifts in disability and employment policy in the UK, Roulstone
(2010) described the underlying core principles undergirding the policy shifts – namely
citizenship, inclusion and equality – as theoretically ‘iridescent’. He explained: “iridescence
refers to something that looks quite different depending on the viewpoint of the observer”
(p.428). Roulstone’s point was that while it was difficult to take issue with these principles, there
was an urgent need to critically examine gaps between the rhetoric and the reality of policies
founded on those ideals. Disability scholars, like Roulstone, have drawn attention to alternative
and less prominent points of view on inclusion. This section brings critical scholarship
concerning inclusion alongside empirical research that explored points of view from persons and
groups targeted for inclusion.

Calls for inclusion originated in social change movements with intents to decrease oppression
and exploitation, and improve life conditions and opportunities for disabled persons (Prince,
2004). However, as the rhetoric of inclusion infused political spheres, it became conflated with
citizenship and equality in ways that suggested responsibility for the inclusion process rested
primarily with disabled persons (Roulstone, 2010). Critics have noted that, when framed within
dominant neo-liberal7 discourses of equality and humanitarianism, understandings of inclusion
veered away from beliefs in the inherent dignity and expected interdependence of all human life
that were promoted by disability activists (Prince, 2012; Roulstone, 2010; Vanier, 1998). The

7 Neoliberalism is a theory or set of political economic principles that promote the view that human flourishing is
best achieved by liberating individual freedoms, and the role of the state is to create institutional frameworks that
emphasize private property rights, free markets and free trade (Harvey, 2005).
notion of integration was premised on conformity and alignment with dominant norms by disadvantaged groups (Ravaud & Stiker, 2001). Inclusion, thus, has multiple meaning and applications. It can imply being a part of a situation without being forced to conform to rigid norms; equally, it may stand as “a synonym for simple presence, simple admittance and simple tolerance” (Ravaud & Stiker, 2001, p. 500).

Critics have suggested that, left unexamined, policies aimed toward inclusion might be enacted in ways that unwittingly contribute to harms, in particular, the expectation that disabled people should manage the burden of ‘fitting in’ to ableist environments on their own (Swain & Cook, 2001). Merely being physically present in mainstream social spaces does not necessarily result in positive interactions, and could potentially add to disabling and exclusionary experiences (Holt, 2003; Milner & Kelly, 2009). Rehabilitation has been implicated in what Ravaud and Stiker (2001) described as a subtle “passion for assimilation through normalization at all cost” (p.508). Blinded by this passion, it is all too easy to assume that inclusion goals will be enabled through extraordinary investments toward approximating ‘normal’ bodies. However, Ravaud and Stiker point out that the classification processes inherent to rehabilitation are difficult to reconcile with the social cohesion implied by inclusion (Ravaud & Stiker, 2001). A core function of rehabilitation is to evaluate, categorize, rank and label impaired bodies in order to align them with the services, interventions, programs and funding that are deemed appropriate.

In a particularly salient sociological review of inclusion, Allman (2013) posited that “architectures of inclusion” (p. 1) benefit those already included, as much or more than those ‘in need of inclusion’. Like Prince (2009), Allman called for researchers to provide more situated and subjective accounts of inclusion and exclusion, since:

For all that is known about social stratification, the tendency…has been to consider inclusion and exclusion from an observational standpoint. This has occurred through policy analysis, historical analysis, and even consideration of some of the socio-biological correlates of inclusion and exclusion. What is less well known and less well developed are approaches for understanding the subjective experiences of social inclusion and social exclusion. (2013, p. 11)

The small amount of empirically grounded research that has critically interrogated inclusion/exclusion in the context of people’s lives and practices contributes insights that counter
dominant conceptualizations of inclusion and suggest a way forward for my examination of the lives and practices of AAC users. An example comes from Hargie, O'Donnell, and McMullen’s (2011) study of the interface (borderland) areas of Northern Ireland which demonstrated that disadvantaged youth valued their local network of friends and did not identify as excluded. In contrast, adult employers and educators perceived this group of youth as excluded from ‘normal’ society because they experienced high rates of unemployment and economic deprivation (Hargie et al., 2011). The youth had come to view segregation and life in their borderland ghetto as natural and tended to act in ways that maintained, rather than challenged, the status quo. Other research with women living in poverty demonstrated inclusion is not experienced as a simple binary of inclusion or exclusion, nor is it stable or necessarily desirable (Ponic & Frisby, 2010). Instead, women said they experience ‘moments’ of inclusion that co-exist alongside experiences of exclusion. The women’s accounts challenged portrayals of marginalized groups as passive recipients of inclusion processes (Ponic & Frisby, 2010). Similarly, disabled women actively critiqued exclusionary practices in relation to power and privilege inequities (Welsby & Horsfall, 2011).

Other interdisciplinary research spanning rehabilitation, education and disability studies has suggested that centric notions of inclusion reproduce normative social standards and tend to obscure or marginalize alternative ways of understanding what is possible or doable for disabled people. In rehabilitation, for example, inclusion is often idealized in relation to deeply ingrained social values and beliefs about what people ‘normally’ can and should do in relation to their life stage, gender, and social class (Njelesani, Teachman, Durocher, Hamdani, & Phelan, 2015). Education-based research that examined disabled children’s inclusion in physical activities demonstrated inclusion is primarily a subjective experience, and not reducible to more objective observations about simply being ‘in’ the game (Spencer-Cavaliere & Watkinson, 2010). School-aged disabled children reported that they feel excluded by peer teasing or bullying, and struggle to gain entry into play, especially in less formal settings such as school recess. When they do enter into physical activities, they reported feeling like legitimate players only if they are able to take up valued roles in the activity. While a sense of competence was valued by children in the study, they attributed greater importance to the sense of belonging and acceptance they derive from having friends in the game. In disability studies, research has shown that when inclusion is conflated with ‘normal’ levels of participation in work and ‘typical’ social activities, it
contributes to the marginalization and stigmatization of disabled persons (Hall, 2010; Holt, 2003; Milner & Kelly, 2009).

To summarize, my review of these studies brings into question assumptions about the positive value of being included in the ‘centre’ of mainstream spaces (Graham & Slee, 2008), and highlights interrelations among a person’s positioning within social hierarchies and their internalized perceptual schemas (the ways they come to understand the world). The limited critical research available echoes and supports the notion of inclusion as iridescent, that is, as relational and perspectival. Meanings of inclusion vary with one’s social position, and thus, are multifaceted, relational and open to interpretation. Rather than thinking of inclusion as a unidirectional journey by disabled people toward mainstream contexts, these scholars and researchers call for de-centering inclusion so that “instead of being either included or excluded, we are all, at once, both half in and half out” (Titchkosky, 2011, p. 21). Critical scholarship suggests that radically rethinking inclusion requires deconstructing the normative centre from which exclusion processes are derived, where the normative is naturalized, and the Other is named and excluded (Graham & Slee, 2008; Swain & Cook, 2001). Surfacing the assumptions that underpin dominant understandings of inclusion is crucial for better understanding how these social ‘givens’ are incorporated and shape disabled youths’ dispositions and practices.

This review also points out an urgent need for research about ‘inclusion’ that examines the social conditions and social arrangements of disabled persons’ lives in relation to their practices and subjective experiences of inclusion. A relational analytic approach is necessary to support interpretations that go beyond describing participants’ experiences to account for: how dominant values and beliefs about inclusion are incorporated by disabled persons; the a priori social structure of spaces deigned ‘inclusive’; and the processes whereby emplacement of disabled persons in putatively inclusive spaces shapes their points of view and the ways they make sense of the notion of inclusion.

These critical social science perspectives on inclusion informed my research and served as signposts as I examined perceptions of inclusion with youth who use AAC. In conducting the study, I began with the following stance: inclusion cannot, and should not, be reduced to a universal ‘good’, nor is it neutral; inclusion is wholly dependent on the perspectives made possible by a person’s social position; and reducing inclusion to simply being ‘in’ a physical
space, is an impoverished way of conceptualizing inclusion. From this point of departure, I set out to explore how social relations unfold to produce disabled youths’ sense of inclusion (and/or exclusion) in particular spaces.

2.4 Conclusion

In this chapter, I reviewed the extant literatures related to AAC, communication impairment, the lives of disabled children, and inclusion in order to position the study’s substantive focus and conceptual approach. I first introduced the discipline of AAC. The development of systems and technologies that support people with communication impairments to express themselves has, and continues to have, important positive impacts. However, evidence suggests these same systems and technologies can also have negative effects, for example, inhibiting some types of social interaction and obscuring other alternative communication modes. The field is dominated by biomedical perspectives that problematize and pathologize the individual with impairments. The small amount of critical work in AAC suggests potential harms are associated with normative assumptions which privilege oral speech and ‘normal’ bodies. In reviewing this work I have suggested that there is a need for more critical research in AAC to help understand how social interactions are mediated by communication impairment and alternative communication modes. Critical analyses add value to research results by insisting that the personal and the social are always intertwined (Eakin et al., 1996). Following scholars in emerging “disabled children’s childhood studies” (Curran & Runswick-Cole, 2013), the critical approach of my research interrelates ‘private troubles’ with public issues and adopts the stance that impairment is not (only) an individual problem, but instead, is irreducibly linked with the social.

Although there has been a burgeoning of research about disabled children, there remains a deficit of research done with children and youth who have communication impairments. In part, this neglect can be attributed to the paucity of well-described methods and the challenges of generating rich data with this group. The few studies examining the lives of children and youth who use AAC suggest they have limited social interaction outside of their immediate family and are increasingly isolated as they age. The scant research suggests more questions than answers. None of the reviewed studies critically interpreted youths’ accounts in relation to the social contexts in which they were immersed in order to account for the objective conditions and power relations that shaped their practices. Yet, this type of analysis is necessary in order to improve
understandings of how dominant inclusion discourses impact the practices and social positions of youth who use AAC. By attending closely to the accounts of youth in this study, my work acknowledges their role in co-producing data for this research. However, the critical stance of my work goes beyond ‘giving voice’ to interpret how youths’ presentations of their lives and their understandings of inclusion have been shaped by their social positions, and by the values, norms and beliefs that underpin calls for inclusion.

In the second part of this chapter, I began by tracing the rise of inclusion in the Western imaginary, and then turned to scholarly critiques of the over-simplified binary of inclusion/exclusion. The reviewed research demonstrates a need for understandings of inclusion to be better informed by disabled people who are targeted ‘for’ inclusion. These missing perspectives are part of the ‘trouble with inclusion’ that I set out to explore through this study. However, as I have noted, the value added through a critical stance lies in the interpretation of youths’ subjective experiences in relation to the objective conditions of their lives. Accordingly, this study examines the interrelations among youths’ perceptions of inclusion/exclusion, the social positions that delimit their points of view, and the values, norms and beliefs that structure the various social spaces they inhabit.

Moving forward through the chapters that follow, my research attends to the issues outlined above and explores how youth who AAC are positioned across various social spaces in the course of everyday living. I examine the mechanisms through which youth internalize and draw on socially agreed upon values, norms and beliefs to position themselves in relation to pervasive calls for inclusion; what they come to understand as natural, true, possible or likely in their lives; and how they take up particular stances and strategies to make sense of their lives in relation to their family, their non-disabled peers and others in their schools and communities.
Preface to Chapter 3

In the next chapter, I outline the conceptual framework of the study and situate it within broader critical perspectives concerned with identifying and addressing marginalization and exclusion. To achieve the study aims, it was necessary to construct a conceptual framework that would allow my analyses to move beyond oversimplified and idealized conceptualizations of inclusion. To meet this challenge, I turned to the conceptual ‘tool box’ developed by the late French sociologist Pierre Bourdieu. Bourdieu’s central concept of habitus – the social world embodied - affords analyses of how disabled youths’ perceptions of inclusion are shaped by dialectical relations between their habitus and their imposed positions in and across fields they traverse. The chapter unfolds in two parts. I begin by providing an overview of Bourdieu’s theory of practice. Then, I specify Bourdieu’s theorizing for examining inclusion with youth who use AAC.
Chapter 3
3 Conceptual framework: Rethinking inclusion with Bourdieu

3.1 Introduction

Pierre Bourdieu (1989, 1990b, 2000) was one of France’s most preeminent and prolific sociologists and theorists. For Bourdieu, all human action and interaction work to reproduce or transform the social order in one way or another. He argued that social relations, including determinations of ‘who belongs where’ are produced through ongoing struggles between persons and groups over power to determine which values, beliefs and norms order social life. Bourdieu’s core project involved uncovering the invisible mechanisms that produce and reproduce unequal patterns of relative advantages and disadvantages across generations in societies, irrespective of historical or geographical setting (Bourdieu & Wacquant, 1992). Only through making these underlying mechanisms visible, he suggested, can steps be taken toward shaping more humane societies (Bourdieu & Wacquant, 1992). Accordingly, Bourdieu’s sociology resonates with this study’s focus on ‘inclusion’. A reflexive Bourdieusian approach affords analyses of the relations between disabled youths’ ‘emplacement’ in disadvantaged positions within socio-spatial topographies (what Bourdieu termed fields) and their practices or position-takings (the mostly pre-reflexive ways they navigate their place in the social order in their everyday lives.

In this chapter, I introduce key aspects of Bourdieu’s theory of practice and align them with the study aims to construct a novel conceptual approach for examining relations between dominant inclusion discourses and disabled youths’ perceptions and presentations of inclusion. In particular, I argue that Bourdieu’s key concept of habitus provides an analytic link for examining relations between two ‘moments’ or instances of inclusion. First, inclusion can be analyzed in relation to disabled youths’ objective positions in society, and second, as youths’ subjective position-takings (practices). Through habitus, these two are reciprocally linked. Following Bourdieu (2000), neither point of view on inclusion (objective or subjective) is adequate on its own. Instead, the researcher aims to analytically “hold together” [italics in original] these two “by relating position-takings to the positions from which they are taken” (p. 189). Bourdieu posits a dialectical relation among persons’ social positions, habitus (embodied dispositions) and
That is, each is shaped and delimited through ongoing dynamic, interpenetrating and irreducible relations.

In a novel application of Bourdieu’s work, I sketch out a framework for analyzing ‘inclusion’ as a stake in struggles over how social worlds are envisioned, and as a practice that, paradoxically, reproduces dominant (and dominating) visions of the social world. As I have argued in the previous chapter, dominant inclusion discourses are undergirded by centric worldviews where ‘normal’ bodies are positioned as ‘in’ and dominated impaired bodies are positioned as ‘out’. The complex interplay of power relations implicated in Bourdieu’s vision of social worlds provides a useful ‘antidote’ to counter idealized and oversimplified notions of inclusion/exclusion. In so far as Bourdieu’s notion of habitus largely accounts for the position-takings adopted by disabled youth, it is possible to examine how, even as they might creatively resist and reshape their social worlds, disabled youth also unwittingly reproduce the social order (Bourdieu, 1985, 1989). In what follows, I unpack these ideas to show how elements of Bourdieu’s approach oriented the conceptual framework of the study. I begin by outlining Bourdieu’s reflexive theory of practice, defining key concepts to show how Bourdieu envisioned their use as relational analytic tools. I then discuss how these ideas align with the study aims, and specify Bourdieu’s approach for the exploration of ‘inclusion’ with youth who use AAC.

3.2 Bourdieu’s reflexive theory of practice

Bourdieu rejected dichotomies, such as structure and agency, subject and object, or micro- and macro-analysis, which dominated sociological debates in his time (Bourdieu & Wacquant, 1992, p. 5). He re-conceptualized ‘individuals’ and ‘society’ as continually co-constituted through complex systems of dynamic, yet surprisingly durable, hierarchical relations. This necessarily involved a rejection of the notion of individuals as autonomous, primarily biological bodies acting with ‘free will’. Instead, Bourdieu conceptualized persons as agents co-constituted through their relationship with social worlds. As social bodies, agents act within the limits of a practical rationality (habitus) that is structured by and in turn structures their social worlds. Likewise, Bourdieu re-conceptualized society as social space made up of multiple, relatively autonomous fields of interest. Within this view, habitus and field are inextricably linked and interact in a continuous dialectical relation that varies according to the amount and type of power (capital) available to agents. Bourdieu posited that the relations among these three master
concepts of field, habitus and capital will vary across fields, according to the tacit rules and norms that order specific fields, to produce a *logic of practice* (Bourdieu, 1977b).

For Bourdieu, practices are observable behaviours, beliefs, preferences or tastes that occur in real time and exhibit a logic that seems natural, and makes “practical sense” (Bourdieu & Wacquant, 1992, p. 21) because of the relationship between persons’ daily subjective interactions and the broader social structures in which they are immersed (Bourdieu, 1990b). Thus, practices are the mostly pre-reflexive ways that people navigate everyday life, including the strategies they employ to conserve or improve their positions in and across fields. Strategies, following Bourdieu, are not purposeful, consciously planned pursuits or premeditated goals; rather, they are objectively oriented patterned behaviours and actions that occur over time and conform to what is ‘think-able’ or ‘do-able’ (Bourdieu & Wacquant, 1992; Swartz, 1997). Practices reflect “adaptation to the constraints of social arrangements and social conditions” of persons’ lives (McDonough, 2006, p. 633). They are shaped (but not determined) by the relations among agents’ habitus (incorporated dispositions), their capital (the field-specific resources they possess or are able to access) and the multiple fields (multiple, relatively autonomous domains) they occupy as they go about their lives. I move now to describe field, habitus and capital in more depth.

### 3.2.1 Field

A field is “a structured space of positions, a *force field* that imposes its specific determinations upon all those who enter it.” (Wacquant, 2008, p. 268) Social space is comprised of a number of relatively autonomous, interlocking fields which can be thought of as arenas, networks or configurations of objective relations organized around particular institutions or interests. For example, the family, the healthcare field, the education field, and the religious field (Bourdieu & Wacquant, 1992) are social configurations with their own logic(s) which operate in their own patterned system of objective (yet mostly invisible) forces. These objective forces include implicit rules, tacit truths, values, ideals and beliefs (*doxa*) and regulatory principles, all of which delimit the structure of the field and the practices of agents in a field (Grenfell, 2008, p. 70). Importantly, these objective forces concomitantly dictate how a field is differentiated in relation to other fields. While agents may consciously reflect on their behaviour to make rational decisions and choices within the particular context of their lives, their actions and decisions are
also bounded by habitus, their pre-reflective sense of what is logical, practical or possible for them from their position within a social field. This logic of practice works to reproduce the divisions and classifications that position agents in particular hierarchical locations within a field.

For Bourdieu, fields incorporate situated histories that reflect the development of the field, and contribute to the field structure and its relations with other fields. As such, fields dynamically evolve and are always sites of struggle and competition between social agents. Notably, fields are differentiated by the particular forms of capital (resources) valued in the field. For example, whereas physical prowess might be highly valued in the field of sport, it is likely to be less valued or even negatively valued in the field of theoretical physics. Although fields have their own particular logic, Bourdieu pointed out that the various fields incorporated in social space tend to be homologous in structure, reproducing similar distributions of more or less dominant agents or groups of agents who compete for control of the structure and boundaries of a field (Bourdieu & Wacquant, 1992). Power can be traced in fields as capital, which is accrued, exchanged, and leveraged strategically by agents to secure or improve their (dominant or dominated) position in a field. More capital equates to more power, more advantages, and a more favourable position in a field. It follows then that capital largely determines agents’ positions in a field. There is a reciprocal linkage between habitus and field, such that an agent’s position in a field shapes their dispositions (habitus) toward patterned position-takings (practices), which in turn, shape the field.

As persons move about in the course of their everyday lives, they can also be seen as agents traversing a series of fields. Following Bourdieu, space can be viewed as both physical and social since “as a body and a biological individual, I am situated in a place; I occupy a position in physical space and [italics added] social space” (Bourdieu, 2000, p. 131). These two types of space do not map directly onto one another, although they correspond to a greater or lesser degree. For example, an undergraduate student might be situated in close proximity to her professor in a classroom; yet, they are separated by considerable social distance in the hierarchy

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8 I employ Bourdieu’s terminology as quoted here to refer to ‘physical space’ on the one hand, and ‘social space’ on the other. ‘Place’ describes a position either in physical space or within a field in social space. This usage differs from conventional notions of space and place in academic geography (see for example Kitchin, 1998).
of the field of education. Thus, while physical spatial relations are not discounted by Bourdieu, his conceptualization of social space adds a critical view of the differential social arrangements and conditions that shape people’s lives:

The notion of space contains, in itself, the principle of a relational understanding of the social world. It affirms that every "reality" it designates resides in the mutual exteriority of its composite elements. Apparent, directly visible beings, whether individuals or groups, exist and subsist in and through difference; that is, they occupy relative positions in a space of relations which, although invisible and always difficult to show empirically, is the most real reality.” (Bourdieu, 1998, p. 31)

Thus, a Bourdieusian orientation to social space affords a kind of analytic ‘double vision’ where individuals, as social agents, are located geographically in physical spaces where life ‘takes place’, and are positioned ‘in their place’ within the relational hierarchies that order social space. “Social distances are inscribed in bodies or, more precisely, into the relation to the body, to language and to time.” (Bourdieu, 1989, p. 17)

3.2.2 Habitus

Bourdieu centred his unified theory of practice on the socialized body, which is produced by and produces the structure of social relations (Swartz, 1997). Habitus, in Bourdieu’s formulation, is the corporeal embodiment of social structures which operates pre-reflexively as a sense-making device to orient persons’ actions. It functions as an interpretive scheme for understanding and acting in the world. In Bourdieu’s words:

Of course people are structured by society. … I developed the concept of ‘habitus' to incorporate the objective structures of society and the subjective role of agents within it. The habitus is a set of dispositions, reflexes and forms of behaviour people acquire through acting in society. It reflects the different positions people have in society, for example, whether they are brought up in a middle class environment or in a working class suburb. It is part of how society reproduces itself. But there is also change. Conflict is built into society. People can find that their expectations and ways of living are suddenly out of step with the new social position they find themselves in. (Bourdieu, 2000, p. 19)
Habitus is formed through repeated exposure to particular sets of conditions and positions across fields. Over time, these conditions and positions are bodily inscribed as natural, logical and realistic ways of understanding the social world and knowing one’s ‘place’ in the world. A person “feels at home in the world because the world is also in him (sic), in the form of habitus…” (Bourdieu, 2000, p. 143). As a generative set of principles, habitus regulates agents’ actions as improvisations on a theme through what appears as a “spontaneous interpretation of statistics” (Bourdieu, 1977b, p. 77). The ‘statistics’ Bourdieu referred to represent a person’s accumulated experiences in and across particular fields, especially early childhood experiences where families socialize children’s bodies to behave in ways that reflect their place in the family, and in the wider world. This early inculcation of social structures in children’s bodies, which Bourdieu termed primary habitus, explains the durable nature of habitus which has a propensity to privilege early experiences (1977b). Secondary habitus are acquired through subsequent exposure to a multitude of fields in the course of everyday life as children move beyond their family into a wider range of social settings. The combination of these experiences give habitus its durable and transposable nature. Habitus “is constantly subjected to experiences, and therefore constantly affected by them in a way that either reinforces or modifies its structures. It is durable but not eternal!” (Bourdieu & Wacquant, 1992, p. 133)

As “a system of durable, transposable dispositions, structured structures predisposed to function as structuring structures” habitus shapes agents’ aspirations and actions in alignment with their position in a particular field “without presupposing a conscious aiming at ends or an express mastery of the operations necessary in order to attain them” (Bourdieu, 1990b, p. 53). This has the effect of excluding certain trajectories and practices without consideration; they are simply unthinkable. Habitus provides an “unquestioning apprehension of the social world which, by definition, does not reflect on itself and excludes the question of the conditions of its own possibility.” (Bourdieu, 1977b, p. 3) The structured systems of classification that order fields are embodied in habitus as ‘principles of vision’, or schemes of perception which frame particular ways of understanding social life, and obscure other possible understandings. These principles of vision operate ‘under the surface’ of the day-to-day business of ‘getting on’ with life. Once inculcated, these principles appear natural and are tacitly accepted as ‘the way of the world’ (Bourdieu, 1989). Bourdieu referred to this process as a “twofold social genesis” (1989, p. 14), reflecting, on the one hand, embodied schemes of perception through which individuals
subjectively experience the world, and on the other hand, the distribution of material resources and social positionings that structure their social worlds. Thus, habitus accounts for agents’ perceptions of the positions that are realistic and possible for them to aspire toward in their social worlds.

Bourdieu used a number of analogies to illustrate how habitus shapes observable behaviours. Very often, he likened social relations to games, where a field is envisioned as a playing field or arena. Players (agents) take up their positions in the game according to the ranking system previously established to determine which skills or attributes are most highly valued in that game. Having acquired habitus as a ‘feel for the game’, the players conform to the rules of the game and are at ease in their positions on the field. Players are likely to accept their position as natural, sensing they are not ‘fit’ for other positions, but this does not preclude them from jostling to attain a position that they perceive as more desirable. Their shared investment in the game and their belief in the value of what is at stake are what Bourdieu termed *illusio*. At other times, Bourdieu compared the work of habitus in generating practice to a jazz orchestra playing in perfect harmony without a score. In this analogy, the musicians appear to simply ‘know the score’. Yet, their regulated improvisations draw on embodied musical principles that set out the key, tempo, role, and style of their ‘part’ in the composition. Although each agent has a unique habitus constructed in relation to their own historical and structural contexts, they may share many common elements of habitus with other agents within a field, just as the trumpet players in an orchestra share similar roles in a musical performance.

Much of Bourdieu’s work focused on social reproduction, but as noted earlier, he acknowledged “there is also change” (Bourdieu, 2000, p. 19). Incremental adjustments mean that “habitus change constantly in response to new experiences” (Bourdieu, 2000, p. 161). Thus, revisions to habitus are the result of minute adjustments made over relatively long periods of time, analogous to the slow steady processes of erosion or sedimentation. When fields are rapidly transformed during situations of crisis (e.g. wars, political upheaval, or major social reform), or when agents move rapidly into new positions in social space, Bourdieu posited that some habitus may be more disposed to embrace the opportunities that these events present and, therefore, more likely to modify practices accordingly (Bourdieu, 2000). The adaptability of habitus, in Bourdieu’s view, corresponds to variations in individuals’ flexibility and rigidity.
Habitus has taken the brunt of critiques of the interrelated concepts in Bourdieu’s theory of practice. It has been accused of carrying too heavy an explanatory load, and of standing in for the agency of agents (see Crossley, 2001). Bourdieu adamantly refuted these critiques, suggesting they represented misreadings of his work (Bourdieu & Wacquant, 1992). He did concede that while habitus provides a useful way of explaining patterns of behavioral conduct, some practices can also be explained as products of explicit and highly codified or ritualized social situations (Swartz, 1997). Habitus, in this study, provides a way to link youths’ dispositions and practices with their imposed positions in social space, without eliminating their agency.

3.2.3 Capital

Capital can be understood as the ‘energy’ that drives the development of a field through time. (Grenfell, 2008, p. 105)

Bourdieu by used the term ‘capital’ as a metaphor for power, or accumulated labour, that accounts for the historical structure and functioning of the social world. Capital, in Bourdieu’s formulation appears in either its objectified institutional or material forms, or its incorporated embodied forms. Capital plays a key role in Bourdieu’s theory because it reflects social inequalities that create conditions where “everything is not equally possible or impossible” (Bourdieu, 1986, p. 241). Contrary to views of society where “at each moment anyone can become anything” (p. 241), Bourdieu asserted that, while social interactions can be seen as games, they are not simple games of chance. Instead, examinations of the (unequal) distribution and composition of capital within and across fields yield analyses of the power relations in play. Bourdieu conceptualized three fundamental forms of capital - economic capital, cultural capital and social capital, each of which functions as symbolic capital in particular fields. Forms of capital can be exchanged or converted by agents, but always with associated costs or effort. I describe each of these forms of capital below.

Economic capital is comprised of material assets that are “immediately and directly convertible into money, and may be institutionalized in the forms of property rights” (Bourdieu, 1986, p. 242). Economic capital can be thought of as the root of all capital and the form most readily visible. The other forms are disguised, in the sense that their role in social relations is most often obscured by taken-for-granted assumptions about how the world works. For example, Bourdieu drew on the interplay between economic capital and institutionalized cultural capital in empirical
studies that helped to explain the unequal scholastic achievement of children from different social classes. His results ran contrary to dominant assumptions linking academic success or failure with ‘natural’ aptitude (Bourdieu & Passeron, 1977). Prevailing beliefs that suggested intelligence naturally leads to academic success were shown to mask the important role of middle class families’ investments in transmitting cultural capital to their children to assure academic achievement. This failure to recognise the interplay of economic capital with cultural capital and instead, sustain belief in an egalitarian system where talent and aptitude ‘win out’, is what Bourdieu termed misrecognition, where the arbitrary character of the exercise of power is perceived as legitimate and just (Swartz, 1997).

Cultural capital exists in three forms as described by Bourdieu: embodied as comportment, sense of style, aesthetic tastes or manners of speaking; objectified in material cultural goods such as artworks, smart phones, or couture fashion; and institutionalized as educational qualifications and professional titles. Returning to the notion of capital as accumulated labour, Bourdieu pointed out that it takes time to accumulate embodied cultural capital and it “cannot be done second hand” (Bourdieu, 1986, p.244). Further, since ‘time is money’, families with greater access to economic capital can afford to invest more time in the labour of transmitting cultural capital to their children who gain a ‘head start’ in accumulating embodied cultural capital. In work related to the field of sport, Bourdieu referred to physical capital as an alternate term for embodied cultural capital (Bourdieu, 1988, 1978). Elsewhere, he wrote extensively about another form of embodied cultural capital – namely, linguistic capital - which describes a person’s capacity to communicate in ways that command attention and are recognised as legitimate (Bourdieu, 1991, 1977a, 1986). These two forms of capital are particularly salient in this study. In the second section of this chapter, I specify the relevance of physical and linguistic capital for youth who use AAC.

Bourdieu suggested that a third form of capital, social capital, backs up cultural capital. Social capital is made up of social connections or networks that can be leveraged to support conditions that expand agents’ opportunities to accumulate and exchange cultural capital. This relation is exemplified in the case of executives who leverage social connections to gain entry to prestigious private clubs, or health professionals who draw on strategically-positioned social connections to jump the queue to access specialized health services. Bourdieu described social capital as the “possession of a durable network of more or less institutionalized relationships of mutual
acquaintance and recognition – in other words, to membership in a group” (Bourdieu, 1986, p.248). Being a member of the group means agents can access credit through “the backing of the [groups’] collectively-owned capital” (p. 248). Social capital can be instituted through the application of a common name (a family, class, or school name) and is formed through relations that presuppose proximity in both physical and social space. An agent’s volume of social capital corresponds to the size of the network of connections they are able to mobilize and on the volume of all types of capital possessed by each agent in the network (Bourdieu, 1986).

As noted, each of the three forms of capital described above can act as symbolic capital, which Bourdieu defined as any form of capital associated in a particular field with the power of domination through legitimation. All forms of capital become symbolic capital in a field when habitus incorporate the (mis)recognition of its value (Bourdieu, 1986). Cultural capital is particularly predisposed to functioning as symbolic capital because the means of its transmission and acquisition are so often misrecognised. Symbolic capital “is not perceived as power but as legitimate demands for recognition, deference, obedience, or the services of others.” (Swartz, 1997, p. 90). Bourdieu cited the practice of philanthropy and increased investments in prestigious forms of higher education as examples of the conversion of economic capital to symbolic capital in order to legitimate particular economic interests. Both of these conversions work to secure esteem in public opinion for dominant groups (Swartz, 1997). Closely linked with symbolic capital, is Bourdieu’s notion of symbolic violence - a “gentle violence, usually imperceptible and invisible, even to its victims” (Bourdieu, 2001, p.1). Through the exercise of symbolic power, disadvantaged groups are ‘put in their place’ and accept this positioning as natural or necessary. This subtle but powerful form of oppression “is exercised upon a social agent with his or her complicity” (Bourdieu & Wacquant, 1992, p. 167) (italics in original).

Here, Bourdieu stressed the key role of misrecognition since agents are unintentionally complicit in their own domination to the extent that they, like all other agents engaged in the field, accept it (they misrecognise it) as a natural part of the world. Symbolic capital and symbolic violence, as I discuss later, have particular significance in this examination of how youth who use AAC locate their place in the world.

Critical to Bourdieu’s view of social relations as competitive struggles are the mechanisms whereby the most dominant groups in a field control ‘what counts’ as valued capital. This is the symbolic power to represent as natural and legitimate, the historically
imposed and arbitrary systems of ranking and classification that order a field. This power reproduces relatively stable groups or classes of persons according to “the principles of division which, at a given moment, determine the vision of the world (rich/poor, white/black, national/foreign)” (Bourdieu, 2000, p. 186). Bourdieu’s interests cohered around empirical analyses of the reproduction of social classes, as exemplified in his celebrated study “Distinction” (Bourdieu, 1984). There, he elucidated the mostly invisible, resilient systems of social division and classification that reproduced hierarchical social classes by showing how classes or groups with the greatest wealth and privilege maintained their relatively high social position by cultivating dispositions and tastes aligned with their ‘distinctive’ social position. From these more dominant positions, they acted as the ‘legitimate’ arbiters of good/bad taste. As I will show, principles of division that are especially pertinent to this study include, but are not limited to, normal/impaired, articulate/inarticulate, able/disabled, and independent/dependent. While these classification systems can be contested, Bourdieu suggested that changes in the doxa ordering fields occur incrementally over long periods of time. He pointed to times of social crisis and transition as exceptions, noting these upheavals can surface the arbitrary systems ordering social life, bringing the taken-for-granted social order into question and potentially catalysing field transformation (Bourdieu, 2000).

Bourdieu stressed that the originality and value of his body of work would not be realized through taking up his concepts in isolation. He stressed that his key concepts were developed to be used in relation to one another and would lose analytic strength if taken up in isolation. As Bourdieu and Wacquant argued, “such notions as habitus, field, and capital can be defined, but only within the theoretical system they constitute, not in isolation.” (1992, p. 96) Bourdieu posited that his systematic approach was more sociological method than theory; that it suggested a manner of posing problems:

Sociology is the art of thinking phenomenally different things as similar in their structure and functioning and of transferring that which has been established about a constructed object, say the religious field, to a whole series of new objects, the artistic or political field and so on. (1990a, p. 40-41)
However, he cautioned against interpreting his work as methodological prescription. Rather, Bourdieu suggested that his conceptual toolbox was to be taken up and used as a set of inextricably related thinking tools.

In summary, Bourdieu’s theory of practice provides a set of conceptual tools for examining social relations as struggles for recognition. Social struggles arise as individuals and groups within competitive hierarchies jostle for relative status, and, unwittingly, reproduce structured systems of social inequities. Individuals take up the positions imposed on them by the relative rankings of the capital they possess in the fields that constitute their lives. From these positions, they develop a set of dispositions – habitus – that incorporate the beliefs, norms, and systems of categorization that structure particular fields. Habitus shapes persons’ sense of ‘the rules of the game’, that is, how various social worlds work, what is expected of them and what is reasonable to expect. Practices are sets of patterned behaviours and attitudes that arise from the interrelationships between habitus, various forms of capital, and particular fields. Although most practices function to reproduce the distinctions that afford relative dis/advantages to certain groups, agents are also able to resist the valuations imposed on them in important ways that, over time, contribute to gradual transformations in the social order. I move now from this overview, to specify Bourdieu’s theory of practice as an orienting framework for understanding links between dominant calls for ‘inclusion’ and the everyday practices of youth who use AAC. I show how Bourdieu’s conception of practices, fields, habitus and capital can be brought into conversation with the foci specific to this study.

3.3 Adjusting Bourdieu’s theory of practice to study ‘inclusion’ with youth who use AAC

Applying Bourdieu’s theory of practice, disabled youth can be viewed as agents who occupy positions in social space across multiple fields. Like all individuals, over time and with the accumulation of experiences, disabled youth internalize the systems of classification, unquestionable ruling presuppositions (doxa), and the social hierarchies that objectively structure those fields. They come to make sense of the world through a process of inculcating the principles of valuation and classification that contribute to their positioning in and across fields. Through these processes, they develop a sense of who they are, where they belong, what they are
'made for' and what is expected of them (Bourdieu, 1981). However, Bourdieu’s conceptualization of the mechanisms producing social relations is largely premised on assumptions about agents’ possessing ‘normal’ bodies. For example, Bourdieu frequently drew on his notion of bodily hexis (observable manners, gestures, postures, or ways of moving the body) as a reflection of a person’s pre-reflexive sense of their place in the social order (Bourdieu, 1984). Missing is any consideration of how bodily impairment might alter or obscure the ways the social world is embodied and reproduced as practices. Thus, the particularities of the relations among field, habitus and capital for youth who use AAC may differ, but have not been studied.

To account for these potential particularities I made necessary adjustments to Bourdieu’s conceptual framework. Whereas Bourdieu focused extensively on the ensemble of symbolic distinctions and categories of difference that constitute and reproduce social classes, I am interested in examining how arbitrary but deeply ingrained assumptions about ‘normal’ bodies/impaired bodies contribute to classification systems where bodies are sorted along moral hierarchies. While I acknowledge the intersection of mediators, including gender, age, or class, in shaping social relations for disabled persons, my research is focused on examining the extent to which bodily difference acts as fundamental social division to produce conditions of relative disadvantage (disability) for persons with impairments. Because of this focus on how impaired bodies are valued and, thus, positioned in social space, certain forms of embodied cultural capital - namely physical and linguistic capital - feature prominently in my analysis. In what follows, I bring Bourdieu’s approach and concepts into alignment with the study aims and further specify the study framework.

3.3.1 Alignment with the study aims

Bourdieu’s conceptual framework aligns with the study aims as follows. First, the study aims to contribute knowledge about the subjective experiences, understandings and everyday practices of youth who use AAC, especially as these relate to the notion of inclusion. Data generated with participants describes the material conditions, relationships, routines and activities that constitute their everyday lives, along with their perceptions of inclusion. These data were analyzed to

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9 These processes are demonstrated in the study results which are discussed in Chapters 6 and 7.
illuminate how habitus functions in relation to the “rules of the game” encountered by youth who use AAC. Second, the study aims to understand youths’ practices in relation to doxa that incorporate dominant inclusion discourses. Bourdieu’s key conceptual tools, namely habitus, field and capital, afford analyses of practices, that is, the ways youth who use AAC identify and negotiate their social placement or imposed positions as they go about their everyday lives in and across fields.

To emphasize the relation between a person’s social positions and their practices, Bourdieu often referred to practices as ‘position-takings’. Accordingly, in the study, disabled youths’ perceptions and representations of being ‘in place’ or ‘out of place’ afford insights into how habitus shapes their sense of inclusion. Disabled youths’ practices reflect their points of view as socialized bodies in a world structured by systems that classify and evaluate impaired bodies as deficient and in need of inclusion. With the adjustments that I clarify below, Bourdieu’s relational theory provides a vantage point from which to interpret the ways youth who use AAC reproduce or resist the social order through practices as they negotiate daily life. From this perspective, I consider how, even as youth might unwittingly reproduce the very systems of classification that disadvantage persons with impairments, they might also perform seemingly mundane, everyday acts of resistance that highlight alternative valued ways of living in the world.

Bourdieu was most interested in studying the overall structure of particular fields (such as education, art, or healthcare) with a view to revealing mechanisms that contributed to the ongoing reproduction of inequalities and hierarchal social ordering within those fields. However, in “The Weight of the World” (1999), Bourdieu and his co-authors presented a collection of case stories, based on interviews, to document conditions under which particular groups in French society were being marginalized across fields and made to endure not only material deprivation, but “all kinds of ordinary suffering” (p. 4). The experience of occupying inferior and obscure social positions was described in that study as ‘positional suffering’, which goes beyond material visible suffering to articulate the ways in which persons are made to feel they should feel grateful for any space made available to them in and across fields.

Bourdieu’s notions of ‘social position’ and ‘positional suffering’ afford analyses that go beyond binary thinking about inclusion/exclusion to link with Bourdieu’s notions of symbolic violence
and misrecognition. I am interested in understanding how disabled youths’ perceptions of inclusion intertwine with embodied dominant values and norms that determine how impaired bodies are evaluated (and thus, how they are socially positioned). In other words, my application of Bourdieu’s theorizing examines youths’ perceptions of their emplacement or positioning across fields and how/whether they engage in struggles for ‘inclusion’. Two forms of embodied cultural capital have particular significance for youth who use AAC in relation to how they are socially positioned: physical capital and linguistic capital.

3.3.2 Implications of linguistic and physical capital for youth who use AAC

Some further discussion of certain of Bourdieu’s formulations of capital is necessary to clarify how capital figures in my analyses and why particular forms of capital resonate in the study of youth who use AAC. I begin with a discussion of linguistic capital, an objectified or embodied form of cultural capital that can be appropriated and invested “as a weapon and a stake in the struggles” (Bourdieu, 1986, p. 247). In fields, such as education, where linguistic capital acts as symbolic capital, language and forms of speech can be exercised as symbolic power (Bourdieu, 1977a). Communicative competence, following Bourdieu, incorporates a legitimate right to speak, where competence is a capacity to command the listener, and where “speakers lacking the legitimate competence are de facto excluded from the social domains in which this competence is required, or are condemned to silence.” (Bourdieu, 1991, p. 55) In the education field, fluent, precise and eloquent speech is recognised as authoritative. Dysarthric speech or speech mediated by a speech-generating device is likely to be accorded low or negative symbolic value. Accordingly, persons with limited or negative linguistic capital are not accorded a legitimate right to speak. Persons who communicate in ways other than speech struggle to be heard because their modes of communication do not conform to norms set out for legitimate language and speech forms (Teachman & Gibson, 2014). Normalization, the measurement and classification of bodies against an idealized ‘norm’, is a form of symbolic power that is ‘world making’ (Swartz, 1997) and thus, would be expected to figure prominently in shaping habitus for youth who use AAC.

Bourdieu posited that linguistic capital, along with other embodied forms of cultural capital, is acquired pre-reflexively and remains marked by its earliest conditions of acquisition (along with primary habitus). This contention is predicated on possession of a ‘normal’ body and a basic
ability to produce ‘natural’ oral speech. While habitus of youth who use AAC will incorporate
doxa that privilege particular forms of speech, their communication in practice differs from
‘legitimate’ modes of communication. To some extent, Bourdieu anticipated this type of
interruption in relations between habitus and practices. He suggested cultural capital “cannot be
accumulated beyond the appropriating capacities of an individual agent; it declines and dies with
its bearer” (Bourdieu, 1986, p. 245). Biology mediates the accumulation and maintenance of
cultural capital and is “linked in numerous ways to the person in his biological singularity” (p.
245) This is an important implication for youth who use AAC, who because of particular
neurological impairments, are required to invest extraordinary amount of time and effort toward
appropriating parallel forms of communicative competency, only to find that their alternative
modes of communication are not recognised as legitimate. Furthermore, the legitimation of some
forms of embodied cultural capital, in particular, the right and proper ‘upstanding’ body
(Shilling, 2012, p. 154), works to fuel the field of children’s rehabilitation, where concerns with
normalizing bodies lead disabled children and their families to make extraordinary investments
toward independent walking (Gibson & Teachman, 2012; Gibson et al., 2012). This point leads
into discussion of the second form of capital I wish to expand on: physical capital.

Shilling (2012) argued that although Bourdieu succeeded in overcoming the subject/object
dualism by locating both within the body as habitus, he failed to examine the material aspects of
the body. Bodies accumulate capital, but bodies are also assigned value in and of themselves as
physical capital. They are commodified according to prevailing distinctions that assign prestige
and status to particular bodies and negatively value others. Since physical capital is bound with
all other capital to shape aggregate capital, the disadvantages (negative value) accrued through
bodily impairment can potentially reduce overall capital. For example, in a school setting, this
could occur for youth who use AAC if negative valuations ascribed to impaired bodies bring into
question the legitimacy of alternative modes of communication. Similarly, slow or difficult to
interpret speech may mask positively valued competencies that would otherwise accrue value in
educational settings (Simmons & Watson, 2015). Where impaired bodies are socially defined
and categorized as deficient, disabled people’s experiences of these negative valuations become
embodied (Edwards & Imrie, 2003; Gibson, Young, Upshur, & McKeever, 2007; Holt, 2010).
Thus, disabled youths’ perceptions of inclusion are likely to reflect, in one way or another, their
embodied sense of what counts as a legitimate body, where bodies with impairments are ‘placed’, and what trajectories are possible from those positions in particular fields.

Bourdieu’s conceptual tools were developed to describe and explain the enduring and reproductive power of social divisions, and elucidate people’s ongoing struggles to maintain or improve their position in social space. Thus, his relational concepts illuminate struggles over ‘inclusion’ as struggles for recognition and contests to determine the value of particular bodies and their ‘proper’ place in the social order.

3.4 Conclusion

In this chapter, I have outlined how Bourdieu’s key conceptual tools - namely habitus, field and capital - afford analyses of the ways disabled youth identify and negotiate their placement or ‘position’ in and across various fields as they go about their everyday lives. Through the interrelations between field, habitus and capital, youth who use AAC are exposed to and internalize norms that privilege ‘normal’ bodies over impaired bodies. Their perceptions of being ‘in place’ or ‘out of place’ (sense of inclusion or exclusion) are likely to reflect their points of view as socialized bodies in a world where bodily impairment is equated with burden. I have provisionally sketched out the significance of linguistic and physical capital in social evaluations of disabled youths’ capital ‘worth’. I have also conceptualized inclusion as a symbolic struggle over the power to legitimate which bodies belong in particular places, who is in need of ‘inclusion’ and therefore, who is excluded.

In addition to examining youths’ positions and position-takings in relation to social space, Bourdieu’s notion of analytic double-vision necessarily allows for consideration of the physical spaces occupied by youth who use AAC and the material conditions of their everyday lives. In line with the study questions and aims, I have adjusted and applied Bourdieu’s lens to focus on the taken-for-granted (yet arbitrary) systems of classification that privilege ‘normal’ bodies and (re)produce divisions, such as disabled/non-disabled, in and across fields. Because these systems are so often misrecognized, youth who use AAC are subject to what Bourdieu termed ‘positional suffering’ and other forms of symbolic violence. With the adjustments I have specified, Bourdieu’s relational theory offers a uniquely well-suited vantage point from which to interpret the ways disabled youth make sense of inclusion as they strive to find ways of living satisfying and valued lives. In the next two chapters, I describe the methodology and methods I developed
to overcome the particular challenges involved in executing the research with youth who communicate primarily in ways other than speech. I begin with a brief preface.
Preface to Chapters 4 and 5

In order to frame methods for co-constructing and interpreting data in my study, it was necessary to theorize communication impairment toward a shift away from conventional interview approaches that privilege ‘natural’ speech. In line with the critical conceptual framework and aims of the study, I wanted to unpack prevalent assumptions in research about what types of participants can provide ‘valid’ accounts and which types of communication are granted authority. Although Bourdieu wrote extensively about language, his interest lay less with speech acts as communication, and more with the relations among language, power, and politics. As noted in Chapter 3, Bourdieu’s theorizing of embodiment was predicated for the most part on assumptions about ‘normal’ bodies, including tacit understandings of how oral speech and language are acquired and articulated in everyday life. He understood utterances as the product of ‘linguistic habitus’ and described how individuals enlist language resources (capital), adapting their speech to suit particular ‘linguistic markets’ (Bourdieu, 1991). Though these ways of critically examining language as power were relevant to the research overall, they were less helpful in considering how mediated modes of communication have been deemed ‘inauthentic’ or ‘invalid’, and how I might overcome these judgments to support alternative interview methods.

The critical work of Mikhail Bakhtin is congruent with Bourdieu’s, and provides an evocative lens for acknowledging all forms of speech utterances as dialogical and always already multi-voiced. I elaborated on Bakhtin’s dialogism to develop a critical dialogical methodology for overcoming methodological challenges that arise in doing research with youth who use AAC. In Chapter 4, I present a manuscript that breaks new ground by outlining the critical dialogical methodology that I developed. In Chapter 5, I describe how I applied the methodology in a manuscript that discusses the study methods and execution in detail. Because the two manuscripts have been prepared to stand-alone for publication, there is a small amount of repetition across the two chapters. Together, the two chapters contribute a much-needed, innovative, and theoretically-informed alternative methodology, and integrated methods to guide interview-based research with people who communicate in ways other than speech.
Chapter 4
4 Interviews with youth who use AAC: A critical dialogical methodology

Manuscript Abstract

In this paper, I present a theoretical examination of communication difference in the context of a critical qualitative study that explored ‘inclusion’ with disabled youth. The study participants, who had little or no speech, used alternative and augmentative communication (AAC). Drawing on and extending Mikhail Bakhtin’s dialogism, I articulate a novel critical dialogical methodology that was developed to support the study interview methods by rethinking issues related to voice, authenticity and the ‘autonomous’ participant in interviews. I share a case example from the study to illustrate how the methodology helped generate data that recognized and represented the agency of youth who use AAC as they worked to make sense of inclusion and locate their ‘place in the world’. Through discussion, I illuminate the potential of this theoretical approach to more explicitly surface discursive power relations and normative value judgments that tacitly deem some kinds of interview ‘talk’ more valid than others. In concluding the paper, I argue that by adopting a critical dialogical methodology for research with people who use AAC, researchers will be prompted to reconsider conceptualizations of ‘voice’ and the ethics underpinning interview-based research more generally.

10 This manuscript has been prepared for submission to the journal “Qualitative Health Research”. QHR reaches an audience of international, interdisciplinary researchers and academics in the health and social service professions, including graduates who seek examples of qualitative methods. One of the aims of QHR is to further the development and understanding of qualitative research in health-care settings. This manuscript is sole-authored.
4.1 Introduction

Until recently, the experiences and perspectives of youth who use augmentative and alternative communication (AAC) were absent from research about childhood disability (Morris, 2003). Reasons for this were at least two-fold: researchers assumed youth who use AAC would not be capable of ‘speaking for themselves’, and researchers lacked access to well-described methods to guide them in designing studies and generating rich data with participants who had little or no speech. While some progress has been made toward mitigating these barriers (Lloyd, Gatherer, & Kalsy, 2006; Nind, 2009), there is still relatively limited information that explicitly describes strategies and procedures for involving people with communication impairments in research that directly affects them. Even less literature outlines methodological approaches for interpreting data generated with participants who have little or no speech.

This paper contributes to emergent knowledge and methodological debates about the authenticity and validity of alternative or mediated modes of communication by outlining a novel critical dialogical methodology. This approach draws on the work of Mikhail Bakhtin (1981, 1994) to contest the ways that particular types of oral speech are tacitly privileged in interview research while other forms of talk are deemed inauthentic or indecipherable. Drawing on his experience with people who had neurological conditions, Oliver Sacks observed:

It is all too easy to take language, one’s own language, for granted – one may need to encounter another language, or rather another mode of language, in order to be astonished, to be pushed into wonder again. (Sacks, 1989, p.9)

I suggest that undertaking studies with people who communicate differently opens space for reflexively reconsidering normative assumptions about what makes a ‘good’ interview and who is the ideal interview subject.

I developed the methodology for a study that examined the notion of ‘inclusion’ with youth who used AAC. Research advocating for the social inclusion of disabled persons has suggested that youth who have both physical and communication impairments experience high levels of social exclusion (Morris, 2001; Morris, 2003; Smith, 2005; Whitehouse, Watt, Line, & Bishop, 2009) yet, to my knowledge, there has been no research that explored inclusion and exclusion with youth who use AAC in relation to pervasive inclusion discourses in which they are immersed.
Complicating this lack of knowledge is the broader problem of how ‘inclusion’ and ‘exclusion’ are conceptualized in research and policy (Ravaud & Stiker, 2001). Dominant binary notions of inclusion/exclusion, where inclusion is understood as a universal ‘good’, risk effecting unintended harms and have rarely been informed by perspectives from disabled persons (Graham & Slee, 2008; Holt, 2003; Spencer-Cavaliere & Watkinson, 2010). I explored these issues in a critical qualitative study with 13 Canadian youth who use AAC. Participants had little or no speech because of neurological conditions, such as cerebral palsy, that caused motor impairments that interfered with speech production. More detailed descriptions of the study methods, and the substantive study results are discussed elsewhere (Chapters 5-7/Teachman et al., forthcoming). Here, my focus is on presenting a theoretical examination of communication difference, and describing the critical dialogical methodology that I developed to optimize data generation with youth who use AAC.

Following an introductory discussion of communication impairment and related terminology, I briefly summarize and critique the scant literature informing research methods with people who have little or no speech. Having provided a contextual frame for thinking about talk in research interviews, I introduce Bakhtin’s dialogism and use it to theorize communication difference. Then, following a brief outline of the study context, methods and procedures, I use examples from my research to illuminate ways that a critical dialogical methodology was ‘good to think with’. I show how this theoretical stance disturbed traditional conceptualizations of ‘the research participant’ and ‘voice’, and problematized tacit understandings of autonomy and authenticity in the co-construction of research data. I conclude the paper by highlighting the benefits of adopting a critical dialogical methodology in research interviews with individuals with communication impairments, and suggesting the insights gleaned through my theorizing might usefully inform thinking about issues of ‘voice’ and interview-based research more generally.

4.2 Terminology

Persons might experience a range of types of communication impairments. In this paper, I refer to a level of impairment where a person has significantly reduced or absent ability to produce oral speech. They might be able to vocalize (e.g. audibly laugh, or call out) but have reduced control over the more complex and differentiated motor tasks that produce speech. With considerable effort, some might produce dysarthric speech (i.e. ‘slurred’, often very slow speech)
that is understood by familiar communication partners, for example, family members. Modes of augmentative and alternative communication (AAC) can include multiple systems of gestures, non-speech vocalizations, facial expressions, personal communication books, human communication partners, and computer technologies such as speech-generating devices. These modes of communication are used in varying combinations in different environments to substitute for or augment speech. Communication assistant is a term used to describe a person who acts as an intermediary between a person using AAC and communication partners who are not familiar with AAC modes (Collier, McGhie-Richmond, & Self, 2010). However, the term ‘assistant’ implies a relation that is inconsistent with the dialogical view of communication interactions that is argued in this paper, so I have elected to use the more neutral communication partner. Acknowledging there is no one, correct way to describe youth who have physical and communication impairments, I use the language youth who use AAC or disabled youth because these terms are aligned with my critical methodology and represent youth as active communicators who are disabled not by an individuated condition as implied by person-first language (e.g. youth with disabilities), but by social conditions where disability is made more or less apparent (Goodley, 2011; Schillmeier, 2008).

4.3 Emergent methods for research with persons who use AAC

A growing number of researchers have recognized the importance and benefits of incorporating the perspectives of people with communication impairments (Lloyd et al., 2006). A complementary body of literature has emerged that describes related methodological issues and insights. In this section of the paper, I briefly synthesize and critique methods and strategies for doing research with persons who use AAC that are described in extant literature. I discuss queries raised in the literature concerning the authenticity or ‘validity’ of data generated through various alternative, mediated modes of communication, adding my own stance to the discussion. This sets the stage for a move toward thinking differently about communication difference, where I draw on dialogical perspectives to (re)conceptualize speech and ‘voice’ in interviews.

A number of techniques and processes for improving data quality in research with persons who use AAC have been suggested in the literature. These include becoming familiar with participants’ preferred communication modes prior to data generation (Boggis, 2011; Morris, 2003), increasing researchers’ comfort and ‘fluency’ with various AAC modes (Lloyd et al.,
2006; Low, 2006), selecting a quiet interview location, and anticipating the potential need to conduct a series of shorter interviews due to participant and/or researcher fatigue (Boggis, 2011; Carlsson, Paterson, Scott-Findlay, Ehnfors, & Ehrenberg, 2007; Morris, 2003; Teachman et al., 2014). Fatigue issues have been ameliorated through study designs that incorporate electronic interviews with subsequent face-to-face interviews (Appendix 12/Teachman et al., 2014) or provide participants with interview questions in advance of interviews. These strategies allow participants to prepare, at their own pace, by composing some responses and ensuring their communication system contains vocabulary to support conversation about the research topic (Morris, Dudgeon, & Yorkston, 2013; Philpin et al., 2005). More generally, it has been recommended that researchers adopt methods for generating data with persons who use AAC that are open, flexible and readily adapted to best suit individual participants; or what Boggis (2011) has termed ‘bespoke’ methods.

Concerns about the credibility or authenticity of participants’ accounts have been raised by some scholars. For example, in advocating for the development of methods for research with children who use AAC, Boggis (2011) queried the authenticity of communication mediated by a speech-generating device because these devices were programmed by another person. Though she framed the young participants in her study as competent social actors, Boggis raised concerns about whether the children were being “lent” voices, and reflexively questioned whether, through interpretations of their nonverbal gestures or facial expressions, she could adequately or justifiably speak about or for them. Because of these concerns, Boggis submitted that what she termed ‘inarticulate’ voices might be difficult to authenticate. Validity concerns have been raised by other scholars (Philpin et al., 2005), who point out the variety of unanticipated (and unsolicited) ways in which spouses or caregivers supplemented or expanded on participants’ responses during interviews. These interjections simultaneously prompted researchers’ concerns about bringing proxy perspectives into their research, and illuminated the shared nature of the experiences being discussed. Ultimately, Philpin and her colleagues concluded that while the spouse or caregiver contributions added important perspectives and insights, the data could not be considered as part of so-called valid patient accounts.

I posit that these types of concerns reproduce conventional positivist notions of autonomous speakers whose individual ‘voices’ and views are faithfully ‘captured’ through the research process. They expose broader, pervasive and, most often, unacknowledged assumptions about
‘who’ is able to participate in research and ‘how’ they are able to participate, as well as ‘what’ researchers listen to and ‘how’ they listen (Simmons & Watson, 2015). Queries about ‘whose voice’ is being elicited reveal assumptions about voice as a personal attribute or property that can be possessed. Doubts about the quality or depth of interviews that might be conducted with persons who use AAC, surface dominant understandings of the types of talk that produce ‘good’ data in interviews. Contra these views, Lloyd and her co-authors (2006) suggested that all qualitative research, by its very nature, is less concerned with ‘truth-telling’ than on the ways participants ascribe meanings and tell particular stories, all of which are co-constructed through the research process. Thus, the interpretation and analysis of accounts from people with communication impairments are no more infused with the researchers’ views and perspectives than any other qualitative research.

I have engaged with and problematized these normative understandings because, left unexamined, researchers unwittingly risk reproducing the very constraints that have excluded people who communicate differently from participating in research. To be clear, my work owes a debt to the creative and committed work of scholars who developed the emergent methods reviewed here. However, moving forward in my own research with persons who use AAC, I was interested in developing methods for generating and analyzing data flexible enough to build on participants’ abilities as opposed to attending to deficits. Accordingly, I looked for perspectives and theories that could help understand communication difference and build on emergent methodological scholarship in this area. In the next section, I draw on the work of Mikhail Bakhtin (1981, 1994) and Bakhtinian scholarship (Baxter, 2011; Frank, 2005; Holquist, 2002; Tanggaard, 2009; Linell, 2009) to problematize and complicate conceptualizations of ‘voice’ in research.

4.4 Bakhtin’s dialogism

Bakhtin was a Russian philosopher and linguist whose aim was to reveal the relational and situated nature of all dialogue. Bakhtin’s theory of dialogism (Bakhtin, 1981, 1994) is made up of a set of concepts and theoretical principles that can be used to analyze language, not in the conceptual terms of linguists, but in relation to the active, creative capacity of utterances, and the actualized meanings of communication interactions. It is worth noting that some scholars, when discussing research interviews, use the term ‘dialogic’ to refer directly to Bakhtin’s work
(Tanggaard, 2009); others (misguidedly) use the term to frame research interviews as caring conversations between “egalitarian partners” (Kvale, 2006, p. 483). Here, I use the terms ‘dialogism’ and ‘dialogical’ as I extend Bakhtin’s work to theorize ‘talk’ that doesn’t conform to normative expectations for individuated ‘voice’, speech, and utterances contained in and emerging from a ‘talking body’. Although Bakhtin lived with physical impairments (at age 43 his right leg was amputated subsequent to osteomyelitis) he did not write about speech or language in relation to communication impairments. Nonetheless, his work is ‘good to think with’ when contemplating how to interview, and interpret the accounts of persons who use AAC in ways that highlight the legitimacy of their accounts.

I have synthesized two key propositions that run through Bakhtin’s dialogism and provide a lens for thinking differently about talk with youth who use AAC. The first proposition highlights Bakhtin’s insistence that taken-for-granted assumptions about the ‘individual, autonomous speaker’ are illusions. The second deals with how meanings are actualized through dialogue. Bakhtin’s first proposition provides a way to problematize dominant understandings of ‘voice’, which attribute talk in research interviews to ‘individual bodies’ that produce autonomous utterances in response to an interviewer’s probes. Instead, dialogism locates voice in the space between speakers where “no one person’s voice is ever even his or her own….each voice is always permeated with the voices of others” (Frank, 2005, p. 968). In other words, all utterances are multi-voiced in the sense that they are inextricably linked to what has been said before, and anticipate what will be said next. Accordingly, we are all limited and enabled in our talk by what has already been said, by the language we have available, and by our anticipation of what will be said, and ‘should’ be said ‘next’.

Bakhtin was more interested in the interplay of power among various social discourses, than in power relations at the level of individuals or groups engaged in talk (Holquist, 2002). While it remains important to consider power relations at the level of researcher/participant throughout the research process, a dialogical approach considers broader social power relations at play that shape what persons are able to say, to whom, and in what contexts. Some utterances, such as swearing, act as powerful discursive strategies to draw attention, or to delineate a particular identity. Wickenden (2011c) provided an evocative example of power relations at a discursive level that drew from her research with youth who use AAC. She described how two study participants shared that they wanted swear words programmed into their device, but this was
prohibited by the people on whom the youth relied to program vocabulary into their devices. Thus the youths’ lack of access to these types of words had the effect of ‘regulating’ their talk. This example elicits reflection on the limits and enablers of all speech which are made material and visible in the context of use of speech-generating devices or other modes of AAC.

Bakhtin used the term ‘monologic’ to describe dominant discourses involving truth claims, where alternative perspectives or explanations are ‘ruled out’ or even inconceivable (Holquist, 2002). Monologic discourses about ‘voice’ as something one possesses, make it difficult to conceive voice as a social rather than individual construct. In research that involved young children, some of whom had communication impairments, Komulainen (2007) critiqued understandings of children’s voice as “a relatively straightforward mental, verbal and rational property of the individual” (p. 13). With Bakhtin, she argued voice is always a multidimensional social construction and that determinations of what is ‘true’ and ‘real’ are always therefore unresolvable. Describing discourses on communication as essentially moral, Komulainen pointed out that a focus on articulating the ‘voices’ of inarticulate children presumes to bring them into line with notions about ‘good’ and normal communication. The notion of ‘giving voice’ presumes a pre-existing voice or utterance that has been subjugated or muted, whereas a dialogical view posits that voice only exists in the relation between two or more speakers in the context of talk. Thus, voice is not an individual property that researchers can retrieve, enable and possess through interviews.

Similarly, Erevelles (2002) argued that persons who rely on human communication partners and/or various AAC devices challenge normative notions of autonomy and subjectivity by blurring the boundaries between human beings and machines. Powerful social discourses construct the ‘human’ in ways that idealize independence, ability and autonomy. In the face of the rational, coherent and autonomous ideal human subject, the value of the speaker who uses AAC is brought into question. People with communication impairments are positioned according to their differences whereby they must prove the authenticity of their ‘voice’ and reclaim agency that is denied them by virtue of having little or no speech. Yet, the independence and authorship of the ‘normal’ speaker whose real-time verbal communication is augmented by machines, such as cell phones or computers, is tacitly accepted. A dialogical approach insists that all communication is interdependent and a mediated co-production between persons, and in some instances, technologies. As observed by Linell (2009), a preeminent Bakhtinian scholar,
“nowhere it seems easier to demonstrate the relevance of dialogical theory …than in communication with persons with disabilities. You can immediately see the interdependencies with others, or for that matter, dependencies on the other.” (p. 25) Thus, it is possible in research with persons who use AAC to recognize their agency without invoking hegemonic notions of communication as a morally requisite independent competency.

Bakhtin’s (1994) second proposition can be distilled from his assertions that meaning is dynamic, relational, and always uncertain. From this perspective, “communication is a dialogic struggle, and out of this struggle identities are shaped.” (Baxter, 2011, p. 11) Here, struggles are over meanings: whose meanings count, how meanings are ascribed value, how meanings can change, and how life is made meaningful through relationships. ‘Struggle’ seems a fitting term to describe the work of people who use AAC against dominant stereotypes that assume people with communication impairments have little to say. In the dominant hierarchy of forms of talk, persons who use AAC are too often judged incoherent, unintelligent, and ‘simple’. However, Bakhtin insisted that verbal communication is not self-sufficient (1994); rather, “verbal discourse directly engages an event in life and merges with that event, forming an indissoluble unity.” (p.162) Thus, meanings are always situated. Utterances, following Bakhtin, are not only spoken words but also ‘signs’ such as gestures or facial expressions. They are situated in the extraverbal context that is shared by the speakers, almost like “passwords” (p. 164) known only to those who belong in the same social space.

To comprehend an utterance does not mean to grasp its general meaning, as we grasp the meaning of a ‘dictionary word’. To understand an utterance means to understand it in its contemporary context and our own, if they do not coincide. It is necessary to understand the meaning of the utterance, the content of the act and its historical reality. … Without such an understanding, meaning is dead, having become some dictionary meaning of no necessity. (Bakhtin, 1994, p.157)

This view of utterances as creative or generative suggests that meaning is situated in time and place, and can evolve to de-centre dominant ‘true’ meanings such as those in a dictionary. As noted earlier, Bakhtin termed these latter types of utterances monologic. In the context of conversations, Bakhtin specified that speech is made up of a mix of utterances, some which are more monologic and others that are more dialogical. In other words, in my speech I both
conform to normative meanings, and I resist other meanings by creatively (dialogically) infusing new situated and relational meanings. Applying these ideas, Bakhtin’s work suggests research interviews, as dialogues, are never completely monologic. Instead, interview ‘talk’ is made more or less monologic or dialogic through researchers’ interpretations of participants’ meanings.

Meaning, for Bakhtin, is constructed within the “unity of the real conditions of life that generate a community of value judgments - the speakers’ belonging to the same family, profession, class, or other social group” (p.163). This relational understanding of value and the link to practice echoes Pierre Bourdieu’s concept of habitus (1977b). A readily apparent example of this is found in the idiosyncratic communication modes that accumulate between people who use AAC and their familiar communication partners. Over time, and in the context of shared experiences, an upward gaze combined with a distinctive non-speech vocalization by the person using AAC might convey a range of shared meanings. This dialogical view of meaning has implications for researchers who are immersed in traditions where participants’ perspectives are represented as if they were ‘real’ and ‘true’ accounts that capture some pre-existing knowable position, perspective or account. Drawing on Bakhtin, Frank (2005) suggests that a more ethical relation seeks to understand participants’ accounts “as one move in a continuing dialogue through which those participants will continue to form themselves, as they continue to become who they might yet be” (p. 967). In this way, researcher and participant come together and through their dialogue they are both changed.

Contra views of communication impairment as a barrier to research, I propose that a critical dialogical methodology opens fertile space in which to (re)conceptualize communication difference. I do this by shifting away from monologic approaches that valorize some types of speech and discount others. The critical dialogical methodology I propose seeks to interpret talk as generative, creating opportunities for multiple potential interpretations and resisting calls for any single authoritative interpretation. It aims to legitimate speech mediated by AAC by recognizing that all language and dialogue, including putatively ‘natural’ speech is multi-voiced and frequently technologically mediated. Monologic discourses are those that ‘speak truth’ and finalize, as might occur when researchers feel obliged to query the autonomy and authenticity of speech mediated by AAC. In the absence of dialogical methodologies, researchers who intend to ‘give voice’ risk unwittingly shutting down dialogue even as they strive for recognition and legitimacy on behalf of people who use AAC. Having sketched out the principles that underlie
this methodology, I move now to share applied examples from my research with youth who used AAC.

4.5 Implementing a critical dialogical methodology

4.5.1 Study overview

As introduced earlier, I developed a critical dialogical methodology in the context of a multi-centre qualitative study that explored the notion of ‘inclusion’ with 13 youth who use AAC. The study purposes were to: 1) contribute detailed descriptions of the daily activities, social networks, personal geographies, and material environments of youth who use AAC with a particular focus on their perceptions of ‘inclusion’; and 2) interpret the ways youth who use AAC accommodated, resisted or reformulated dominant social inclusion discourses to position themselves in the various social worlds they inhabited. Interview, photo, and visual methods were combined to generate multiple, complementary types of data. I drew on Bourdieu’s theory of practice to examine the ways that dominant inclusion/exclusion discourses were taken up and manifested by youth who use AAC through their talk and practices. Critical approaches, including Bourdieu’s, posit that individuals are not able to fully reflect on the sources of their own marginalization or their everyday practices in relation to broader social structures (Kincheloe & McLaren, 2005). For this reason, non-discursive visual methods (photo and graphic elicitation) were used along with observations to generate complementary data about participants’ social worlds that might not be elicited through interviews alone (regardless of participants’ communication modes). These ethnographic methods were particularly well-suited to the research since AAC strategies frequently incorporate visual symbols, photographs or images to scaffold and augment other communication modes.

Each youth participated in two interviews (ranging from 30 - 150 minutes) at her/his home conducted by this author. The first interview focused on getting to know the participant, their communication modes, and details about their everyday lives. The second interview integrated the photo-elicitation (Drew & Guillemin, 2014; Gibson et al., 2013) and graphic elicitation methods (Bagnoli, 2009). Participant-generated photographs were reviewed with participants to foster discussion of their understanding and experiences related to inclusion and exclusion. Graphic elicitation refers to methods whereby participants were asked to indicate their sense of belonging to places depicted in the photographs by selecting a location on a graphic diagram of
two-dimensional concentric circles termed Belonging Circles\textsuperscript{11}. All interviews were video-recorded and analyzed directly. I used a variety of AAC clarification strategies to optimize understanding during the conversation (see Appendix 12/Teachman et al., 2014 for examples), and intentionally encouraged participants to use all of their preferred modes of communication during the interviews, including use of a familiar communication partner. All of 13 participants elected to include a communication partner (12 were participants’ mothers or female guardian, one was a sibling).

4.5.2 Dialogue with Jamila

I illustrate the dialogical methodology and Bakhtin’s propositions, by providing examples drawn from interviews with Jamila, one of the study participants (all names are pseudonyms). Focusing on this single case, allows me to explore the context and interactions in depth. Jamila was a 17-year-old young woman with cerebral palsy and multiple, complex medical conditions that made her reliant on a number of life-sustaining and assistive technologies, including tube feeding, mechanical ventilation, wheelchair and AAC. She lived with her legal guardian, Rebecca, and a menagerie of animals.

To reiterate, in the first proposition, Bakhtin insists that assumptions about the ‘individual, autonomous speaker’ are illusions. Instead, all utterances are multi-voiced in the sense that they are inextricably linked to what has been said before, and anticipate what will be said next. The second proposition argues that meanings are actualized through situated dialogue. I begin by providing examples from the interviews with Jamila to illustrate the first proposition. When a person communicates using AAC, Bakhtin’s dialogism is materialized in remarkably illustrative ways. AAC is nearly always multi-modal, that is, a whole range of non-verbal gestures and expressions might be combined with a speech-generating device, a symbol-based communication

\textsuperscript{11} Belonging Circles were developed by Nicole Yantzi and Nancy Young for School, Home and Neighbourhood Accessibility: Physically Disabled Children’s Assessments (The ScHaN Project), Co-Principal Investigators Patricia McKeever and Susan Ruddick, funded by the Canadian Institutes of Health Research (funding #86653) and The Bloorview Kids Foundation Chair in Childhood Disability Studies. Used with permission.
book, or the spoken interpretation of a familiar communication partner. For example, when using a speech-generating device (or any material system such as a communication book or symbol display), utterances can only be constructed using symbols, letters, words or phrases that are already in the system. In most cases, these have been programmed or added to an AAC user’s system by a family member, a caregiver or a paid professional (e.g. a teacher, a clinician) with or without the AAC user’s collaboration. Illusions about generating ‘individual, autonomous’ speech through using an AAC device are dispelled when considering that all possible utterances that can be constructed by the AAC user will be made up of the assembled language or symbol set which incorporates multiple person’s input, including foundational input installed by the device manufacturer. In order to program a device, the ‘programmer’ must first consider what language will be needed, in which contexts, and with which types of communication partners. Thus, talk with youth who use a speech-generating device was already dialogical at one level because their utterances relied on the language that had already been programmed into the device. The relation between the AAC user, the programmer and the device provides both a material and a relational example of the interplay of multiple voices in Bakhtin’s dialogism.

One trait of putatively authentic speech is the novelty of the utterance. Authenticity comes into question when listeners suspect a speaker of using another person’s words. As discussed earlier, when a person who uses AAC has depended on another person to program the utterances stored in their communication device (which is most often the case) they are called on to defend themselves as authors of authentic speech. Toward the close of the second interview, Jamila used her device to comment on her inclusion/exclusion experiences using a series of pre-programmed statements (a series of related utterances):

“Most people assume that just because my muscles and lungs and stomach do not work the way theirs do, that my brain and heart and soul are disabled too. …I am a real and whole human being…. I want them to know that it is not OK to treat me like I am invisible, or talk about me like I do not exist…. I am not the puppet of my [speech-generating device]. I am the puppeteer.

Here, Jamila was ‘reusing’ phrases and paragraphs that had been programmed for past communication interactions. Jamila reproduced (re-uttered) a series of personal reflections and stories in the context of the interview with different intentions, ordering and emphasis, to share
feelings of being left out and/or stigmatized because of her bodily differences and her use of a speech device. In a monologic view of dialogue, this reuse of past utterances might raise concerns about the authenticity of Jamila’s talk and its ‘proper’ place in relation to the research interview. But seen dialogically, it is clear that “ultimately, virtually all sense-making depends on prior or present, actual or imagined contexts and interactions” (Linell, 2009, p. 26).

Jamila’s case can also be drawn on to illustrate the second of Bakhtin’s propositions – namely that meanings are dynamic, relational, and always uncertain. They are situated so that, between those who share the same purview, utterances can be like ‘passwords’. Dialogues with participants were dialogical in the ways that meanings were generated, not only through a process of clarification, but also through the rich, shared past that was brought into the interview context through the relations between participants and their communication partners. Bakhtin asserted: “To be means to communicate. ...A person has no sovereign territory, he is wholly and always on the boundary; looking inside himself, he looks into the eyes of another or with the eyes of another” (Bakhtin, 1984, p. 287). In describing her communication with Rebecca, Jamila expressed a remarkably similar sentiment: “I love being able to cuddle on the couch and just look at each other and laugh or cry and know what we are thinking without using words.”

People who use AAC often use very short utterances that might not be grammatically complete or ‘correct’ in order to save time and energy (Wickenden, 2011c). This strategy, sometimes termed telegraphic speech, is akin to the style of text messages. For example, in talking about her favourite television shows, Jamila used her speech-generating device to say “hope”, but I was unable to clarify her meaning. As Jamila gazed over to Rebecca, the two suddenly broke out into laughter. Rebecca explained that Jamila was talking about a new show called “Saving Hope”. The inside joke was that, although Rebecca had programmed that title into Jamila’s device, the two had recently reorganized the system for storing vocabulary. Neither could recall where the words were stored in the complex language software that is used to organize thousands of words and phrases. The utterance was meaningful in the context of their past shared language relations, so that Rebecca was able to clarify Jamila’s meaning without the necessity of additional language.

The form of the interview dialogue shifted across the course of the two interviews. At the first interview, Jamila worked hard to present herself as a competent independent communicator. She
made extraordinary efforts to construct grammatically correct utterances using her speech-generating device, perhaps anticipating I would be more likely to value her contributions to the research if she demonstrated this competency. The process was very slow and arduous (3-4 minutes to compose a short sentence). As she became more comfortable and settled in the interview, and to avoid becoming overly fatigued, Jamila began to shorten her responses and more often indicated that she wanted Rebecca to provide details or clarification. Rebecca and I took care to clarify Jamila’s utterances, seeking understanding and recognizing the dynamic and relational nature of the interview interaction. Jamila and Rebecca drew on their past shared experiences as well as anticipation of what I, as the interviewer, might want to ‘hear’. Each of these influences shaped the co-construction of Jamila’s account. Thus, the meaning of the interview talk was relational, situated, dynamic and always uncertain. However, with Bakhtin, I argue these meanings were uncertain only in as much as this can be said of all dialogue.

By adopting a critical dialogical lens, the interview process generated data that illuminate the ways that participants co-constructed a version of themselves in the relational ‘communication space’ between the researcher, communication partner, communication device and the participant. This ‘in between’ space contains more than just the utterances of the interviewer and interviewee, but also those that have gone before and those that are anticipated. As Bakhtin (1986) reminds us:

> Our speech…is filled with others’ words, varying degrees of otherness or varying degrees of “my-own-ness”, varying degrees of awareness and detachment. These words of others carry with them their own expression, their own evaluative tones, which I assimilate, rework and re-accentuate. (p.89)

### 4.6 Conclusion

In this paper, I have outlined a novel critical dialogical methodology that extends Bakhtin’s dialogism to provide a framework for interview research with people who have communication impairments. The methodology helps make visible the normative assumptions that uphold traditional notions of ‘voice’, authenticity and autonomy in the context of qualitative research. I propose that the value of a critical dialogical methodology is that it opens space for a reconsideration of the ethics that shape interview-based research, not only in relation to communication difference, but in research more broadly.
A critical dialogical methodology has potential to ethically represent research accounts from people who use AAC by more fully acknowledging all of the ways they communicate as legitimate and valuable. I have shared a conceptualization of communication difference that is able to overcome the limitations of more positivist framings of research interviews that risk systematically excluding people who communicate in ways other than speech. It opens space to query whether there is such a thing as single ‘voice’ and whether any dialogue is ‘authentic’.

Consistent with interpretive and critical epistemologies, a critical dialogical methodology sets aside monologic assertions that research participants autonomously and independently provide ‘true’ accounts and extends this discussion to those who communicate differently. Moving forward, I anticipate developing the approach further in continued research with children and youth who use AAC. I have shared here what might be thought of as a provisional sketch of the methodology that will benefit from ongoing refinement and revision through continued applications.

In summary, Bakhtin asserted that every individual is able to resist and confront imposed meanings, and generate personal meanings through social exchange. In dialogism, consensus or ‘shared meanings’ are not necessarily a preferred outcome – instead meaning is always relational, embracing difference and uncertainty. A critical dialogical methodology, as outlined here, views utterances and language as never finalized and therefore never ‘authenticated’. The researcher engages in dialogues with participants where their utterances are inextricably linked. Neither is a sole author, and the individual autonomous speaker is recognized as an illusion. Their relationship is constructed through their dialogue. Communication impairment, rather than limiting a person’s involvement in research, provides an opportunity to reconsider and expand the ways we think about talk in interviews and how social relations are formed in the dialogical relation that is all of our communication.
Chapter 5
5 Integrating visual methods with dialogical interviews in research with youth who use AAC

Manuscript Abstract

Scant information is available to guide the selection and modification of methods for doing research with people who use augmentative and alternative communication (AAC). In this paper, I describe and illustrate a novel combination of methods that were used to optimize data generation in a critical qualitative study with 13 disabled youth who had communication impairments. Using a critical qualitative inquiry approach, the study explored relations between disabled youths’ positions in and across physical and social spaces and their position-takings on ‘inclusion.’ Building on emergent literature, I selected and integrated three complementary methods that were aligned with AAC strategies familiar to participants. Photo-elicitation and a graphic elicitation method termed ‘Belonging Circles’ were combined with interviews using a critical dialogical methodology developed for the study. The interview methods were modified to accommodate all of the AAC modes used by participants, and to acknowledge the relational, situated and thus, dialogical nature of all communication in interviews. Each method is described, and rationales for their selection and modification are discussed. Then, the processes for combining them to generate and analyze data are discussed and illustrated using a case example from the study. Taken together, the data illuminated the everyday lives and practices of youth who use AAC, and the strategies they used to position themselves as more or less included across the social spaces that they traversed. The paper concludes with reflections on the methods and future directions for development of the methodology in ongoing research with disabled children and youth.

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5.1 Introduction

Augmentative and alternative communication or AAC describes a range of modes of communication used by persons with communication impairments to substitute for or augment speech (e.g. non-speech vocalizations, facial expressions, personal communication books, human assistants, and computer technologies such as speech-generating devices). Until recently, there has been very little research on the lives of youth who use ACC, partly because investigators have lacked methods for eliciting their perspectives and gatekeepers judged them as incapable of contributing to research (Morris, 2003). In the last decade or so, however, there has been an increase in knowledge and awareness of methods for doing research with people who use AAC (Boggis, 2011; Lloyd et al., 2006; Low, 2006; Morris, 2003; Morris et al., 2013; Philpin et al., 2005; Teachman et al., 2014; Wickenden, 2011b) and a small body of work that examines substantive issues with youth who use AAC has emerged (Bennett, 2011; Mitchell, 2010; Gibson, King et al., 2014; King et al., 2014; Raghavendra et al., 2012; Wickenden, 2011a, 2011b).

Despite acknowledging the importance of involving people who use ACC in research (Lloyd et al., 2006; Morris, 2003), there remains a relative lack of information to guide the selection and modification of methods. Furthermore, little attention has been paid to how ‘voice’ is conceptualized in AAC research, or to the potential effects of normative judgements about the validity and authenticity of research accounts from persons who communicate in ways other than speech. Left unexamined, assumptions about capturing a person’s ‘own voice’ undermine the involvement of people who use AAC in research interviews. For example, the process of independently generating text-based responses using a speech-generating device or spelling board is likely to be associated with extraordinary exertion and fatigue on the part of the person using AAC (Boggis, 2011; Morris, 2003; Teachman et al., 2014). As a result, the quality and quantity of data generated in a standard qualitative interview might be reduced. Persons who use AAC have reported that they are able to say more, and with less fatigue, when supported by a familiar communication partner (Collier et al., 2010). Yet, in the context of research with people who use AAC, queries have been raised about the validity of researchers’ interpretations of alternative communication modes (Boggis, 2011) and about ‘whose voice’ is being represented when another person attempts to mediate communication between a participant and interviewer (Philpin et al., 2005).
In designing research that critically explored the notion of ‘inclusion’ with youth who use AAC, I determined first to build on emergent methods by explicitly surfacing and addressing concerns about the authenticity of accounts generated with persons who use AAC. To address this goal, I looked to Mikhail Bakhtin’s dialogism (1981, 1994) to help theorize communication difference, and to argue that talk generated using mediated communication modes is no more or less authentic than any other interview data. I reframed ‘voice’ in interviews, and communication more generally, as always multiple and relational by developing a critical dialogical methodology which I have described in more detail elsewhere (Chapter 4/Teachman et al., forthcoming). Here, my focus is on showing how I combined interviews that involved mediated communication with visual methods to elicit high quality, multifaceted data with youth who use AAC as they described their everyday lives and perceptions of ‘inclusion’.

In what follows, I begin with an overview of the study and a brief description of how I theorized communication difference to overcome validity concerns and frame the interview methods that are described herein. Next, I introduce the study methods. After providing descriptions and rationales for each of the visual methods selected, I review the specific study processes used to integrate the visual methods with interviews. Using examples from the study, I illustrate how the novel combination of methods generated complementary data that allowed interpretations that considered multiple perspectives on inclusion. I conclude by reflecting on the methods and directions for their ongoing development in future research.

5.2 Study overview

5.2.1 Study context and aims

Disability advocates and researchers have suggested that youth with physical and communication impairments experience high levels of social exclusion (Morris, 2001; Morris, 2003; Smith, 2005, 2014; Whitehouse et al., 2009). Yet, to my knowledge, there has been no research with these youth that explores their perspectives on inclusion or exclusion in relation to the social contexts in which they are positioned. Complicating this lack of knowledge is the broader problem of how ‘inclusion’ and ‘exclusion’ are conceptualized in research and policy (Ravaud & Stiker, 2001). Dominant social inclusion discourses assume a predetermined normative centre that constructs people as either insiders or outsiders along a moral hierarchy that privileges so-called ‘normal’ bodies and abilities (Edwards & Imrie, 2003; Gibson & Teachman, 2012;
Graham & Slee, 2008). I might well ask, however, into what are disabled persons to be included; what exclusions might this entail; and, whose interests are served through inclusion practices?

These gaps and issues informed the development of this critical qualitative study which aimed to: 1) contribute detailed descriptions of the daily activities, social networks, personal geographies, and material environments of youth who use AAC, and their perceptions of inclusion; and 2) interpret the ways youth who use AAC accommodated, resisted or reformulated dominant social inclusion discourses to position themselves in and across various social fields. I used a multi-centre design that combined face-to-face interviews with participant-generated photographs, a graphic elicitation technique termed Belonging Circles, and observations (in the form of extensive field notes – see Appendix 9). The study design combined these methods in order to support analyses of participants’ understandings of their social worlds alongside data that reflected the social, cultural and material contexts that shaped their views (Bourdieu & Wacquant, 1992; Green & Thorogood, 2013; Shuttleworth, 2012). Drawing on Bourdieu’s (1990b, 2000) theory of practice (Chapter 3), I analyzed the reciprocal relations between participants’ ‘emplacement’ in disadvantaged positions within socio-spatial topographies (what Bourdieu termed ‘fields’), their dispositions, and their practices (the mostly pre-reflexive ways they navigated their everyday lives within and across fields) to understand how they made sense of dominant notions of inclusion.

5.2.2 Study participants

Thirteen Canadian youth who use AAC (aged 15-24 years, 6 young men) participated in the study. To maximize diversity across the sample in relation to participants’ age, gender, socioeconomic status, and geographic location (rural, urban), and thereby optimize data quality, depth and variation (Sandelowski, 1995a), I combined purposive and convenience sampling strategies13. Participants were recruited from three regional children’s treatment centres encompassing urban and rural communities that ranged in size and density. Institutional ethics approval was obtained from each treatment centre’s Research Ethics Board (see Appendices 1 –

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13 Initial convenience sampling involved inviting all eligible participants who expressed interest in the study. As recruitment progressed, I worked in partnership with each children’s treatment centre to maximize variation across the sample in relation to socioeconomic status and urban vs. rural location (see Appendix 1).
5 for study forms/recruitment details). All participants had cerebral palsy with associated communication and mobility impairments, three had cortical vision limitations and two had a concurrent chronic disease. Youth in the study were in high school or had completed high school within the past year, and all lived in southern Ontario.

This group of young people was the target of the study for a number of reasons. In the Ontario school system, disabled students who require curriculum modification or adaptation may remain in high school longer than their same-aged peers, which accounts for the age range across participants. I anticipated high-school-aged youth who used AAC were more likely than their younger peers to have developed the requisite communication skills to support participation in the study (e.g., a consistent yes/no, ability to compose a simple message using text). Finally, adolescence is a time when youth who use AAC confront rapidly changing social and communicative expectations (Smith, 2005, 2014) which might potentially ‘widen the gap’ (the social distance) separating them from their ‘typically-developing’ peers. Thus, I expected participants would have experienced and been able to reflect upon shifts in their everyday social worlds and their perceptions of inclusion.

The substantive study results are discussed elsewhere (Chapters 6 & 7/Teachman et al., forthcoming). As noted earlier, my focus here is on describing the study methods and explicating how they were combined to optimize data generation with youth who use AAC. In the section that follows, I introduce each method individually, providing a brief description and rationales for their selection. Following this overview of the study methods, I describe the study processes in greater detail to share how the study unfolded as I worked to integrate the methods and data analyses.

5.3 Study methods

5.3.1 Dialogical interviews

In setting out to develop interview methods to optimize data generation with youth who use AAC, I first considered how to optimize the quantity and quality of data generated while attending to the need for an interview approach that would be less onerous for participants. Use of a communication device to produce words or sentences that approximate speech has several advantages in that it is generally clear and readily understood across environments. However, the
process is often extraordinarily arduous and fatiguing for the person using the device. In the intimate and routinized context of the home, persons who use AAC might use communication devices much less than in other spaces. In part, this occurs because AAC devices cannot be physically accessed during a variety of activities. It also happens that, over time, families might develop idiosyncratic, situated systems of communication that are more reliant on non-verbal gestures, facial expressions, dysarthric speech, and non-speech vocalizations. Given these considerations, I elected to conduct the interviews in participants’ homes and encourage use of any and all preferred modes of communication, including mediation by familiar communication partners which had the potential to greatly reduce participant fatigue.

Second, I reflexively queried tacit assumptions held in positivist research traditions. In these traditions, participants’ utterances during interviews are idealized as ‘authentic’ and ‘autonomous’ voices that can be captured and ascribed verifiable ‘true’ meanings (Kvale, 2007). These types of assumptions have the effect of judging mediated communication as inauthentic. Particularly in cases where a communication partner might be involved, the autonomy of the participant using AAC may be brought into question. Researchers may assume that participants possess singular a priori views and responses (their ‘own’ voice) and that these are simply ‘translated’ by a communication partner and captured by the researcher. In the face of these notions of ‘voice’, it seems logical to question whose perspectives are being expressed: those of the person using AAC or those of the communication partner.

To contest notions about ‘authentic’ voice as singular and autonomous, I drew on the work of Mikhail Bakhtin (1981, 1994) who argued the nature of all dialogue is relational and situated. He examined power relations between language framed as dogmatic, authoritative truth claims (which he termed monologic) and dialogical communication where meanings are temporal, constructed in the space between listeners and speakers, and open to multiple interpretations (Frank, 2005). For Bakhtin, each utterance and each voice is always already permeated with those that went before, so that no one person’s voice is ever his or her own; rather, it is the product of the interaction between speakers and the broader social context in which the utterance emerges (Bakhtin, 1994). Although Bakhtin did not specifically address effects of communication impairments, his work explicitly attended to normative value judgments that deem some forms of ‘talk’ more valid than others, so that some social groups are silenced or subjugated while the status quo is maintained and reproduced. Whereas a focus on
‘independently’ generated speech valorizes the notion that persons possess a singular, unique ‘voice’, I adopted a more dialogical approach to the interview conversations – a critical dialogical methodology - which I have described in more detail elsewhere (Chapter 4/Teachman et al., forthcoming). Using this approach, participants, communication partners, communication devices, and the interviewer were seen as engaged in relations where each played a role in co-constructing participants’ accounts.

5.3.2 Visual methods

Dialogical interviews were augmented by two visual methods: photo-elicitation and a graphic elicitation technique termed Belonging Circles. These were selected, in part, because they offered the added value of being aligned with what are termed ‘visual strategies’ in AAC (Beukelman & Mirenda, 2012) where graphic symbols, line drawings or photographs are used to support conversations. Visual information can set a topic, provide details, or clarify an utterance. Photographs or items, such as a concert program or a movie ticket, might be kept in a communication book to support sharing news, or telling a favourite story.

Photo-elicitation is a method where photographs are used primarily to scaffold, contextualize and enrich interview discussions in order to add complexity and depth to research results (Allen, 2012; Smith, Gidlow, & Steel, 2012). Photo-elicitation can involve images generated by participants within the context of the study, self-selected from their personal or family photograph collections, or introduced by the researcher. I elected to include both participant-generated and self-selected photographs to provide choices about how participants might show and talk about their perceptions of inclusion. Participant-generated photo-elicitation has been used in research with disabled youth to examine topics including self-perceptions of impaired bodies (McLaughlin & Coleman-Fountain, 2014), resilience and micro-mobilities (Porcelli, Ungar, Liebenberg, & Trépanier, 2014) identities and masculinities (Gibson, Mistry, et al., 2014) and optimal activity settings (Gibson, King, et al., 2014; King et al., 2014).

Photo-elicitation methods afforded at least five advantages in this study with youth who use AAC. First, the collaborative interaction between researcher and participant in preparing to take the photographs, viewing the photographs, and talking together about the photographs is a key strength of the photo-elicitation method. Participants sharing their reasons for taking particular photographs and interpreting the meaning of their images provides for “a situation of co-
analysis” (Gibson et al., 2013, p. 387). Second, photographs can reveal “embodied and material manifestations” of phenomena that might be difficult for youth to articulate (Allen, 2011, p. 488). Third, photographs taken by participants in the course of their everyday lives can introduce topics potentially unknown to the researcher, and reveal aspects of participants’ lives beyond their own perceptions and descriptions (Croghan, Griffin, Hunter, & Phoenix, 2008; Drew & Guillemin, 2014; Drew, Duncan, & Sawyer, 2010; Gibson, 2005; Meo, 2010). Fourth, photographs can aid with rapport and lessen potential awkwardness by providing a point of focus that supports communication (Drew et al., 2010; Meo, 2010; White, Bushin, Carpena-Méndez, & Ni Laoire, 2010). Finally, participants might be asked to add captions to their photographs to suggest meanings they ascribed to the images (Packard, Ellison, & Sequenzia, 2004). The feasibility of using this method was established in my previous research with disabled youth who used AAC (Gibson, King, et al., 2014; Teachman & Gibson, 2013; Teachman et al., 2014); I built on that learning in the methods described here.

Like photographs, graphics can be used in interviews to enhance participants’ reflexivity, elicit discussion about abstract concepts, and generate data in ways that are non-linguistic (Bagnoli, 2009). Graphic elicitation methods can involve graphics brought into the study by the researcher or those generated by participants within the study. In the first approach, the researcher introduces participants to a diagram representing concepts or relationships that are integral to the research focus and might be difficult to express in words alone. Participants’ responses to the diagram “may clarify vaguely understood concepts and hint at previously unconsidered ones” (Crilly, Blackwell, & Clarkson, 2006, p. 305). The latter approach, where graphics are generated by participants, refers to drawing methods, which are well-established, particularly in research with children (Bagnoli, 2009; Punch, 2002). In research with young adults, participant-generated drawings termed ‘diagrammatic maps’ have elicited information about complex or ‘difficult to discuss’ phenomena, for example, migration and identities (Bagnoli, 2009), or social settings of drug use (Ravn & Duff, 2015). However, since drawing tasks are often challenging for disabled youth, and because graphic symbols are a familiar and commonly used AAC strategy, I elected
to incorporate a researcher-generated diagram called a Belonging Circle\textsuperscript{14} to elicit discussions about inclusion.

Belonging Circles is a graphic elicitation method where participants are asked to indicate their sense of belonging or inclusion by selecting a location on a simple schematic diagram of three concentric circles (see Figure 3 below for an image of a completed Belonging Circle). I used the Belonging Circles graphic to help elicit dialogue about youths’ perceptions of inclusion in relation to the places and events recorded in their photographs. The completed Belonging Circles contributed non-linguistic data about participants’ perceptions of being more or less included in the socio-material spaces represented by their photographs.

\textbf{5.4 Study processes: Integrating visual methods with interviews}

In research with people who use AAC, it is crucial to modify consent processes that rely on written text and oral speech (Cameron & Murphy, 2007; Carlsson et al., 2007; Lloyd et al., 2006; Nind, 2009). Consent was obtained from each participant and a parent or guardian prior to the onset of the first interview, using a ‘visual consent framework’ developed by this author where visual pictures, communication symbols and AAC strategies are used to support the process (see Appendix 6 and Appendix 12: Teachman et al., 2014). An ‘ethics-as-process’ approach (Cutcliffe & Ramcharan, 2002) was used to confirm participants’ ongoing consent through frequent interviewer-initiated checks and reminders that participants could stop the interview, refuse to answer any questions, or withdraw from the study at any time.

Two interviews (ranging from 30-150 minutes) were conducted at home with each participant and were videotaped to record participants’ non-verbal communication, their audible responses, and responses generated with human or technological assistance. In ethnographic interviews, researcher observations complement and contextualize interview data (Green & Thorogood, ---

\begin{figure}[h]
\centering
\includegraphics[width=0.3\textwidth]{belonging_circle.png}
\caption{Completed Belonging Circle diagram.}
\label{fig:belonging}
\end{figure}

\textsuperscript{14} Belonging Circles were developed by Nicole Yantzi and Nancy Young for School, Home and Neighbourhood Accessibility: Physically Disabled Children's Assessments (The ScHaN Project), Co-Principal Investigators Patricia McKeever and Susan Ruddick, funded by the Canadian Institutes of Health Research (funding #86653) and The Bloorview Kids Foundation Chair in Childhood Disability Studies. Used with permission.
2013). I conducted all of the interviews and recorded extensive notes after each. These notes included descriptions of: participants’ appearance, communication preferences and overall presentation (e.g. impressions of their comfort level and their engagement with the research topic); descriptions of other people present and their role(s) in the interview; the interview setting; interactions over the course of the interview; and any initial analytic impressions. These observational data helped contextualize analytic case narratives which integrated data from the interviews, photographs, and Belonging Circles.

Participants used multiple modes of communication during the interviews. All communicated non-verbally using idiosyncratic gestures, facial expressions or movements such as eye-gaze or pointing. Ten used a speech-generating device and seven had limited dysarthric speech that was understood by their familiar communication partners. All youth in the study elected to include a communication partner in the interviews. In one case, the partner was an older sibling (aged 17 years); in all other cases, participants’ mothers (or female guardian) took on this role. In four instances, other family members asked if they could join the interview briefly to learn more about the research. In those cases, clarification of participants’ responses was more fluid as the role was shared among family members who were present. A number of ongoing strategies were used to clarify participants’ meaning and intent. For example, I used verbal rephrasing to confirm understanding of non-verbal communication and checked with participants when a communication partner interpreted their responses (for a more complete description of strategies to support interviews with people who use AAC see Appendix 12: Teachman et al., 2014). I had an extensive clinical background working with young people who used AAC and was comfortable with various strategies I could use to confirm and clarify shared meanings.

5.4.1 Interview one

The first interview established rapport and built familiarity with participants’ modes of communication through discussions of everyday routines, activities and social settings (e.g. Tell me about yourself, Who is in your family? What types of things do you like to do? Describe a typical day) (see Appendix 7). A one-page questionnaire was used to collect demographic information (e.g. participant diagnosis, education level of parents, family cultural identity, family income range) and was completed by a parent or guardian at the onset of the interview (see Appendix 10). This information was used to describe the study sample and guide purposive
sampling. At completion of the interview, procedures for taking photographs were reviewed, and time was spent selecting from a range of switches and wheelchair mounting equipment that could be loaned along with a switch-adapted camera for a two-week interval. A written reference sheet was provided, outlining “Suggestions for Taking Photos” (summarized in Figure 1 below, a complete version is shown in Appendix 8). Participants were advised they could also select existing photographs from personal albums if they wished to use these to show and talk about their experiences related to inclusion/exclusion. Finally, the discussion topics and activities of the second interview were discussed, including the completion of Belonging Circles and captioning of participants’ photographs. Examples of each were shared with participants.

### Figure 1 Suggestions for taking photographs

- You can take the photos or ask someone else to take them for you. But you should decide what photos to take. You can be the director and put yourself in the photos!
  - Take pictures that tell important things about YOU: your daily routines, the places and people that are part of your everyday life.
  - Think about taking 10-20 photos.
  - There is no right or wrong. Anything is welcome.

### 5.4.2 Interview two

After a two-week loan period, the camera was retrieved. This enabled previewing of participants’ photographs to individualize the interview guide for their second interview, which occurred three to four weeks after the first. At this interview, discussions were elicited by jointly viewing the photographs on a laptop computer and prompting participants to assign captions and/or complete Belonging Circles to correspond with their photographs. Topics included: a) participants’ intentions and decisions to take or select photographs for the research; b) what aspects of everyday life were depicted and their significance; c) whether/how particular images represented participants’ understandings of inclusion/exclusion; and d) important activities or environments not represented in the photographs (see Figure 2 below: Sample questions for interview two). For each event or setting represented in the photographs, participants were invited to complete a corresponding Belonging Circle to visually indicate their recall of feelings of inclusion and/or
exclusion. The process was adapted to suit each participant’s abilities; some marked an ‘x’ or pointed to one or more spots on the printed graphic to show their perception of being included, while others used an AAC technique known as partner-assisted scanning, where the interviewer pointed or described the concentric circles and the participant signaled where they wanted to place a mark.

- You took a lot of pictures when you went to the mall. Tell me what is happening here? Who are these people? Do you often do things with them? How were you feeling when you took this photo?
- What are some good things about the place, group or activity in the photo? What are some ‘not so good’ things? Are there things in these photos that you wish you could change?
- Here’s a photo of you having lunch in your classroom with your educational assistant. How would you caption this photo? (alternative probe) Imagine the day when this photo was taken. Now, try completing this sentence: When I had lunch with my educational assistant in the classroom, I was feeling...
- Since my first interview, did you do things or go places where you didn’t take photos? …maybe you didn’t get permission, or perhaps you thought “No, I don’t want to take a photo here.”
- How do these photos help to tell about where and how you feel included (like you are part of things), or maybe sometimes excluded (a little or a lot left out)?
- Are there ideas in these photos that you want to share with other people? What are the most important things that these photos tell about?

Figure 2 Sample questions for interview two

All youth in the study expressed excitement about the novelty of portraying their lives through taking and talking about photographs. Participants took between 10 and 100+ photographs. Though I had suggested upper and lower limits (20 and 10 photographs, respectively) as a guide (Gibson et al., 2013), all but one participant exceeded the upper limit. The three youth who had cortical vision impairments engaged with varying levels of support in taking photographs: one needed occasional assistance to frame the images she wanted to capture; the other two directed another person to take their photographs. In five cases, photographs were included from a personal collection to tell about vacations or special memories. Each participant’s set of photographs sketched out the places or events that were regularly incorporated into their
everyday lives. When it was not possible to discuss all of the photographs taken or submitted, interview discussions focused on one or two photographs from each activity/event represented across the photograph set. Relatively independent use of a switch-adapted camera was new for nine of the 13 participants. There was variation across and within participants’ approaches to taking photographs: 10 opted to take some photographs on their own and to direct another person for other photographs; three had limited or no reliable switch-use so directed others to take all of their photographs.

The following field note excerpt illustrates the integration of the visual methods with the interviews. This was the second interview with Chloe (all names are pseudonyms), an 18-year-old with cerebral palsy and cortical vision limitations. Chloe had taken 74 photographs (many were repeats) depicting her home life with family and personal support workers, her school classroom, activities at her local community centre, and at a children’s treatment centre:

Chloe primarily communicated using very dysarthric speech. I understood only a few words, usually her one-word responses but her mom understood and repeated Chloe’s utterances. A few times I needed to interrupt to ask for clarification if Chloe’s mom forgot to repeat what Chloe had said. Chloe’s mom suggested … she could make adjustments in the photograph size and position of the screen to help ensure that Chloe could see the photos. ... After setting up, we proceeded to talk about the pictures. Both mom and I provided verbal description of the photos while Chloe leaned in close to look at them. It took a few minutes for Chloe to process the visual information before responding. Chloe used her [speech-generating device] to provide information that her mom wasn’t able to clarify. She was excited to look at her photos, but didn’t seem to relate to the captioning activity. She more readily responded to the Belonging Circles and showed a lot of enthusiasm for this way of sharing her feelings about a place. … Chloe was keeping us ‘on track’ by correcting [my interpretations] … I could quite clearly make out her comment: “Boring!”, as I looked at photos from an appointment at her local children’s treatment centre. She couldn’t point fast enough to an outer location on a Belonging Circle for that photograph, explaining that she felt left out of the adults’ discussions.
Having reviewed the methods and processes used to combine them, I next describe the approach used for integrating and analyzing the data generated.

5.4.3 Integrated data analyses

Data collection and analysis were conducted concurrently to allow for new information to be investigated as the study proceeded (Green & Thorogood, 2013). Interviews were video-recorded to ensure that rich non-verbal interactions, which would be largely diminished through transcription, could be viewed and reviewed in all their complexity (Gravois, Rosenfield, & Greenberg, 1992). I elected not to produce transcripts to represent the interview interactions. Although methods to guide transcription in research with people who use AAC have been developed (Soto & Hartmann, 2006; Von Tetzchner & Basil, 2011), they tend to reproduce the very issues I aimed to overcome with my critical dialogical approach. Utterances are attributed, interpreted and legitimated through the work of transcription, which unavoidably reduces and simplifies multimodal communication. The process of producing written transcripts is, in itself, an analytic process wherein only a small fraction of the non-verbal communication is interpreted and represented (Poland, 1995).

In interviews with persons who use AAC, the implications of missing non-verbal communication are magnified so that the quality of the data generated might be greatly diminished. Accordingly, all interview video recordings, observational field notes, captions and photograph data were entered into Atlas.ti v.7 software, which allowed direct coding and memoing of the interview video data. Later, following multiple iterative stages of data analysis, representative interactions were recorded as text and extracted to support written representations of the study results.

Analysis followed recommended procedures and techniques for ensuring the quality of qualitative research (Kvale, 1996; Miles & Huberman, 1994; Sandelowski, 1995b; Sandelowski & Barroso, 2002). I conducted all aspects of the study analyses, in close consultation with my supervisors, to interrogate, refine and confirm conceptual categories and interpretations of patterns across the data. An analytic guide (see Appendix 11), consistent with the study questions, aims and conceptual framework, was developed and revised during inductive and deductive cycles of analysis. Initially, multiple viewings of each participant’s interviews - with the related field notes, photographs and Belonging Circles kept close at hand - helped make it possible to get a sense of the whole (Sandelowski, 1995b). Memos were recorded at this stage.
and throughout the analyses to make links with related literature, and to theorize the data according to the Bourdieusian conceptual framework of the study (e.g. asking questions including ‘What tacit assumptions (doxa) structure participants’ imposed positions and their embodied dispositions (habitus) in particular fields? What strategies (practices/position-takings) reproduce or counter negative valuations of disability (negative capital) and/or the low ranking positions imposed by these valuation? What objective conditions (in and across particular fields) are linked with subjective perceptions of inclusion?).

Next, ‘facts’ were extracted for later use in contextualizing participants’ accounts. Facts are “those elements of data that are least subject to errors of inference” (Sandelowski, 1995b, p. 374), for example, assistive devices used by participants and places that were part of participants’ daily routines. At this stage, and before moving to analyze across participants’ accounts, narrative case summaries were drafted (Miles & Huberman, 1994; Sandelowski, 1995b). The case summaries integrated the data generated with each participant (interviews, photographs, captions, Belonging Circles and field notes) and addressed the first study aim which was to describe each participant’s everyday activities, social networks, personal geographies and material contexts, and their perceptions of inclusion.

To maximize the value of the study results and bring together data that reflected multiple perspectives, the analysis engaged a process of ‘crystallization’ (Ellingson, 2009; Richardson, 2000; Richardson & St. Pierre, 2005) where the complexity of the views afforded by each type of data is retained to produce layered multidimensional interpretations. Crystallization involves researchers reflexively “embracing knowledge as situated, partial, constructed, multiple, embodied, and enmeshed in power relations.” (Ellingson, 2009, p. 10) Multiple iterative cycles of analysis followed where data were compared and contrasted to discern patterns and ambiguities. It was evident that the photographs, Belonging Circles and field notes complemented and illuminated the interview data, revealing contradictions, complexity and insights in ways that interviews alone would not.

Analyses of the photographs, captions and Belonging Circles were linked with meanings described by participants while remaining open to “multiple meanings that may change over time” (Drew & Guillemin, 2014, p. 56). While the photographs contributed data (e.g. about participants’ material environments and preferences), they were not analyzed on their own, nor
were they viewed as representative of particular ‘truths’. Rather, the photographs were interpreted in relation to: 1) the objective conditions in which they were taken, 2) participants’ expressed intentions in making or selecting the images, and 3) the meanings participants ascribed to the photographs during the process of co-analysis afforded during the interviews (Jenkins, Woodward & Winter, 2008; Gibson et al., 2013; Drew & Guillemin, 2014). In short, they were made meaningful through participants’ talk and the role they played in generating particular topics or stories.

5.5 Case examples

I move now to examples drawn from data generated with one of the study participants to illustrate the types of data produced and how they were complementary and integrated during analyses. Figures 3 and 4 present data generated in the second interview with Jack, a 21-year-old participant. Each includes an interview excerpt, corresponding photograph(s), a caption and a completed Belonging Circle. During the first interview, Jack’s communication modes included: a speech-generating device, head nods, gestures and facial expressions, and a communication partner (his mother). For his second interview, Jack had pre-programmed some messages in his device, anticipating some of what he wanted to share about the photographs he had taken. Because the interview was structured around viewing and discussing the photographs, more of the conversation was augmented by the information in the photographs and Jack asked for less support from his mother. Occasionally he turned to her to indicate he wanted her to provide background information which would otherwise require considerable time and effort to compose using his speech-generating device. Meanings were negotiated in real-time and arose out of the interactions among Jack, the interviewer, his mother, and his communication device.

Jack had completed high school in the previous year and had a part-time job at the time of the research. Jack’s set of photographs included portrayals of himself participating in a number of sport-related activities, as well as a few images taken at home, work, and synagogue. Included, were several images conveying his experiences during try-outs for a power wheelchair hockey league. Jack was especially keen to talk about the hockey photographs, stating that when he played hockey he felt like “a free bird”. Figure 3 displays multiple types of data generated with Jack around this topic.
“Hockey – I felt included right away when I joined power wheelchair hockey but the speed bumps came. No matter how good a person gets trained on the different kinds of disabilities, they are still missing some key factors on their way to speaking to a non-speaking individual. … Most people talk to me… as if they were talking to a little child who has done something wrong. They don’t take into consideration that I am all together up there. … I feel most included in my synagogue, but hockey has gotten me new friends and a new outlook on life meaning. I felt welcome.” (Jack, age 19, text generated via speech-generating device)

Jack’s caption: “I was the fourth line. It sucks!”

Figure 3 Jack and wheelchair hockey

Jack’s talk emphasized that he felt “included right away” and described the “new friends” and “new outlook on life” that were benefits of his involvement with the micro-field of power wheelchair hockey (in the broader field of sport). Yet, he described feeling stigmatised by the way people spoke to him as if he were a misbehaved child or assumed that he was intellectually disabled. As well, the photograph captioning technique elicited a rather candid “It sucks!” in reference to being assigned to “the fourth line” (the lowest ranked players) because of the relative severity of his physical impairments. Furthermore, on a Belonging Circle, Jack indicated that the outer ring of the graphic corresponded to his sense of inclusion. Taken together, the interrelated data about hockey point to a dynamic and layered interplay where Jack’s perception of being included (he had taken up a position in the field of sport) co-existed with experiences of feeling devalued and marginalized (he was positioned at the bottom of the social hierarchy of players) because of his physical and communication impairments.
Later in the same interview, in reference to a group of photographs taken at his part-time job, Jack proudly declared, “I’m a working man now!” As with the hockey photographs, much of the discussion while reviewing the work photographs was focused on Jack’s positive sense of inclusion in the field of paid work. The visual methods provided opportunities for Jack to show and talk about aspects of his work experiences that might have been difficult to discuss otherwise. One photograph (in Figure 4 with related data) showed a set of stairs that led to the office he was initially assigned. Because this office was wheelchair inaccessible, Jack booked temporary workstations when he was in the building, some of which he portrayed in photographs. Through a caption, Jack employed humour to defuse what otherwise might seem like an affront and unacceptable workplace accommodations.

Figure 4 Jack at work

Photographs of smiling co-workers elicited a conversational shift, returning to Jack’s sense of achievement in having challenged disability stereotypes by securing a job. Though he marked a position outside of the centre on the corresponding Belonging Circle (Figure 4), Jack explained this aligned with how he wanted to be included because it required extraordinary effort and much of his “free time” to work on his speech-generating device, programming phrases and chunks of information that he needed to be able to readily communicate at work. At that point, Jack gestured to another photograph of a large whiteboard that showed an intense schedule of work,
attendant care, travel arrangements, assistive technology service appointments, and structured leisure/sport activities.

The integrated data afford what Bourdieu termed a kind of analytic ‘double vision’ (1989) where it is possible to consider not only disabled youths’ subjective perceptions of inclusion, but also the mostly invisible objective structures that shape their perceptions and their pre-reflexive sense of who they can be and where they belong. For example, in this snapshot from data generated with Jack, he presented himself as a masculine, sport-loving and productive young adult, while minimizing his impairments and the effects of exclusionary interactions. His participation in sport (especially hockey, an iconic Canadian sport, culturally symbolic of masculinity and prestige), and his extraordinary efforts to pursue paid work, were interpreted as practical manoeuvres as he struggled to gain symbolic capital and improve his social position in and across fields. The study results (Chapters 6 and 7/Teachman et al., forthcoming) illuminated the social conditions and arrangements in which the participants, over time and with repeated exposure, internalized judgements about the ‘natural’ limitations associated with physical and communication impairments and drew on these to make ‘practical sense’ of inclusion.

The contrast between Jack’s declaration that he “felt included right away” at hockey, and his Belonging Circle and caption: “It sucks”, is representative of instances across the study data where the Belonging Circles and captioning technique elicited responses that differed in spontaneity and tone from the mostly positive ways that participants presented themselves and their lives in the research. Since the terms ‘inclusion’ and ‘exclusion’ are discursively charged with positive and negative values, I anticipated it might be troubling for participants to think and talk about ‘exclusion’ or to name social settings where they felt unwelcome, stigmatized or less valued. As other researchers have noted (Bagnoli, 2009; Gibson et al., 2013), visual methods can provide an alternative means to access topics that are relatively difficult to broach and express using language alone. Through the combination of methods, rich data were generated and made more meaningful through the co-analyses that emerged during the interview interactions. In the next section of the paper, I reflect on the methods and processes used in the study.

5.6 Reflections on a method

The integrated methods approach had three strengths. First, I found there was considerable value in designing the study with two interviews for each participant. The first interview yielded
important data that sketched participants’ daily routines and personal geographies (the places and journeys that were part of their daily lives). It also provided crucial opportunities to establish trust and rapport, clarify the purpose of the research, and importantly, build familiarity on the part of the interviewer with participants’ modes of communication. Discussions at the first interview prompted youth to reflect on how or where they felt included (or not) and begin to creatively plan portraying their lives through photographs. It helped participants focus on taking or selecting photographs that portrayed not only how they wanted to present themselves in the research, but what they imagined I wanted to learn as an ‘absent but present’ researcher (Gibson, 2005).

Second, I found that encouraging youth in the study to use their preferred modes of communication, which could include a communication partner, was less taxing than if I had privileged ‘independently generated’ responses. This observation was based on previous research with youth who used AAC (Gibson, King, et al., 2014; King et al., 2014) where participants’ interview responses, generated primarily using speech-generating devices, were very brief and lacking in detail. The critical dialogical interview methodology allowed participants, with their communication partners and other preferred AAC modes, to narrate their accounts with relatively greater ease and comfort, which produced more and better quality data.

As a result of explicitly encouraging youth to use their preferred communication modes during the interviews, I gained a surprising insider’s view of the unique and intimate ways that participants communicated with other family members, especially their mothers. As noted above, all of the young people elected to include a communication partner during the interviews. Under these conditions, seven of 13 putatively ‘non-speaking’ participants (i.e. the term is often used to describe persons who use AAC) used quite a lot of speech that, while not understood by myself as the interviewer, was mostly understood by their communication partner. Thus I learned that within the home and supported by the shared history among family members, some youth clearly self-identified as being a person with speech. This insight highlights a likely disjuncture between the practiced ease and intimacy of communication interactions among family/familiar communication partners, and those outside of familiar relations.

A third strength is that the combination of methods made it easier to readily adjust my interview approach for each participant. While the overall study procedures were consistently
implemented, the individual methods were deployed using a flexible approach to suit participants’ abilities, strengths and preferences. For example, although the captioning technique evoked emotional responses from some participants, others interpreted this more as a descriptive or labelling activity (e.g. “This is me with my sister”) which provided less insight into their intentions in taking photographs and the meanings they ascribed to them. Most participants (11 of 13) readily embraced the graphic elicitation activity and completed between five to 10 Belonging Circles. But, two participants indicated they didn’t understand the abstract graphic and preferred not to respond using this method. As I noticed variations in how participants responded to the visual methods, I was able to immediately adjust to focus on those which seemed most engaging or the best ‘fit’ for that young person.

Next I discuss two potential limitations of these combined methods and my approach to mitigating each. First, contextual factors, such as policies governing photography or gaining access to a space, mediated the range and types of photographs youth generated. In some settings or with some people, permission to take photographs was not granted. This prompted one parent to comment on her new insights into her son’s experiences of inclusion. In some situations, youth described feeling pressured to include certain people in posed group ‘selfies’. These interactions illuminated ways that people in the environment appeared motivated to present themselves and the setting as inclusive through the research. Rather than view these factors as problematic, I used their occurrence to prompt considerations of how contextual mediators made certain photographs possible, while others were not permitted or even ‘unthinkable’ (Gibson et al., 2013).

Second, the Belonging Circles provided a means to elicit youths’ recall of emotions, impressions and sensations associated with particular times and spaces in ways that were less bound by the discursive constraints of language, but not free from discursive effects. I considered how the graphic might ‘prime’ respondents (Crilly et al., 2006) since, on one hand, the concentric circles of the Belonging Circle diagram reproduced dominant centric inclusion discourses that idealize a middle ‘belonging’ position. This potential influence could have been mitigated by asking participants to generate their own conceptual drawings (Crilly et al., 2006); however, because I anticipated most of my participants would have difficulty drawing, I did not consider this option. On the other hand, the concentric rings of the diagram afforded a number of options for youth to
indicate their perceived positions in social spaces along a gradation either within or outside of the graphic.

Before concluding these reflections, I suggest my learning supports a few practical summary recommendations for research with this population. Researchers contemplating studies that will include people with communication impairments will benefit from training to increase their competence in communicating with persons who use AAC. They may wish to incorporate visual methods, such as photo/graphic elicitation, which can help scaffold interview discussions as well as add alternative means for participants to express their views. Crucially, researchers must be prepared for AAC-mediated interviews to proceed at a slower pace than oral interviews, requiring considerable physical and mental effort on the part of participants, but also extra efforts from the interviewer who actively works to clarify understandings (Carlsson et al., 2007; Morris, 2003; Teachman et al., 2014). In planning a study that integrates participant-generated photo-elicitation methods, researchers should allow for the additional time and expenses that may be accrued. Attention should be paid to ensure that potential participants are supported to access information about the study and provide consent using familiar communication modes that optimize their understanding and engagement. Last, interviewers should incorporate frequent checks and breaks to help accommodate for potential participant fatigue.

5.7 Conclusion

In this paper, I have outlined a novel methodological approach that combined participant-generated photography, a graphic elicitation method termed Belonging Circles and dialogical interviews to generate data in a study examining the notion of ‘inclusion’ with youth who had communication impairments. I was interested in learning how participants’ everyday lives and their perceptions of inclusion were shaped by broader social values, beliefs and assumptions that structured the various socio-material spaces they occupied. To achieve the study aims, I modified and integrated visual and interview methods, enabling participants to direct some aspects of data generation outside of the interview context, and reflect on their experiences of inclusion. These innovative visual methods are relatively new in health research. To my knowledge, this study is the first to combine them in interviews with youth who use AAC. The combination of methods opened multiple, alternative means for youth to express themselves, generating in-depth, multifaceted and frequently contrasting data that illuminated the lives and practices of youth who use
AAC. This study is the first that I know of to report on the use of direct video analysis of interviews with augmented speakers. I suggest this analytic method merits further development in order to extend methods for research with people who use AAC.

My approach to modifying and combining methods developed in tandem with a novel critical dialogical methodology for interviews with people who use AAC, informed by Bakhtin’s dialogism. I extended Bakhtin’s work to propose a shift away from thinking about ‘valid’ participant accounts as those that represent an individual’s ‘own’ independent voice, toward a stance where participants’ accounts were viewed as interdependent, relational and open to multiple interpretations; that is, they were dialogical. With this move, interview dialogue mediated through technologies or another person (as a communication partner) was judged no more or less valuable or valid than dialogue generated entirely through putatively ‘natural’ speech. With significant modifications to ‘traditional’ interview methods, it is possible to ensure that youth (and people of all ages) who use AAC are able to actively contribute to research that is about them, and that has the potential to affect their lives. I look forward to developing these methods and this methodological approach further in ongoing research with children and youth who use AAC.
Chapter 6
6 The space of points of view

6.1 Overview

The results of the study are shared in the next two chapters. Following a brief summary of group-level data, this chapter is made up of a series of case narratives that embed each participant’s perceptions of inclusion with their presentations of their daily activities, social networks, personal geographies, and material environments. The case narratives serve two purposes. First, the narratives address the first study aim which was: to contribute detailed descriptions of the lives and practices of youth who use AAC with a focus on their subjective experiences of inclusion. Second, the narrative format situates participants’ perceptions of inclusion in the context of rich details about their lives and the circumstances that shaped their perceptions. The chapter title, ‘The space of points of view’, borrows from Bourdieu (1999) in “The Weight of the World” in which he argued the merits of bringing together participants’ points of view through “simple juxtaposition” (p.5) to demonstrate how each is founded in social reason. In Chapter 7, which follows, I draw on Bourdieu’s theory of practice to more explicitly illuminate the interrelations among participants’ conditions of existence, social positions, dispositions and position-takings.

I begin with a summary description of the group of participants before moving to the illustrated case narratives which make up the remainder of this chapter. Youth who use AAC are a relatively small fraction of disabled youth living in the study area, which increases the chances that clusters of facts might reveal a participant’s identity. To protect the youths’ anonymity, detailed information about their family circumstances, socioeconomic background, physical function, personal care and appearance is presented at a group level. As well, some facts (e.g. whether a participant lived with one or two parents, number or gender of their siblings) have been altered or omitted in most of the narratives, but are preserved in cases where these relations were crucial to understanding a participant’s practices (Saunders, Kitzinger, & Kitzinger, 2015). All names are pseudonyms selected to reflect (but not directly align with) the range of ethnicities across the group (Saunders et al. 2015). Where participants’ photographs might contribute to identifying them, features, including faces, signs or specific objects, have been pixelated or cropped. All photographs included in this dissertation are used with the consent of the young people who recorded the images.
The primarily descriptive results set out in this chapter integrate participants’ accounts with their photographs, captions and Belonging Circles, and my observations as recorded in interview field notes. The observational and visual data add depth and dimension to the youths’ portrayals of themselves and the various physical and social spaces in which they were situated. I have endeavoured to remain close to the participants’ points of view and their presentations of their lives and practices. Nevertheless, the research is a co-production where my influence and interpretations are woven into the narratives through the processes of listening, observing, selecting and reassembling the data\(^{15}\). The goal of the chapter is to compile and illustrate the youths’ presentations of their lives and their understandings of inclusion. However, the narratives are not simply about the young people who participated in the study. Rather, they reveal the wider social, structural and cultural factors that shape disabled youths’ lives. As Goodley, Lawthom, Clough & Moore (2004) noted: “Stories are more than individual tales. They are the products of complicated research relationships. They are imbued with theory, with practice and policy implications and with humanity.” (p. 195) The results presented in this chapter extend knowledge of the conditions of existence experienced by youth who use AAC, and how they respond to dominant calls for inclusion. Before presenting the individual case narratives, I provide aggregate descriptions of the study sample.

6.2 Group-level descriptions of participants

Thirteen Canadian youth who used AAC (aged 15-24 years, 7 young women) participated in the study. In total, the aggregate data generated with participants included: 27.5 hours of videotaped interviews, 951 photographs and 80 Belonging Circles. Additional demographic information was elicited though a questionnaire (see Appendix 10) completed during each first interview.

\(^{15}\) It is also important to note that I had a past clinical relationship with two participants which altered the context through which I interpreted their accounts. It also influenced data generation (e.g. when participants’ comments imply a desire to provide updates about their circumstances).
Table 1: Aggregate participant demographics (n=13)

<table>
<thead>
<tr>
<th>Reported ethnicity</th>
<th>Family income</th>
<th>Home location</th>
<th>Parents’ education level (n=25)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canadian only</td>
<td>$15-44,999</td>
<td>Major urban</td>
<td>High school</td>
</tr>
<tr>
<td></td>
<td>$45-90,000</td>
<td>Suburban</td>
<td>College/baccalaureate</td>
</tr>
<tr>
<td>Additional ethnicity</td>
<td>$90+</td>
<td>Small town</td>
<td>Postgraduate</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Rural</td>
<td></td>
</tr>
</tbody>
</table>

Social class and family background: Based on their housing arrangements, parent(s)’ level of education and family income, three participants appeared to be from working or lower class backgrounds, four from middle class, and six from upper-middle class. All of the young people in the study lived at home with at least one parent. Two participants’ parents were divorced – each of those young people spent time in their father’s home but lived primarily with their mother.

Physical function: All youth reported a diagnosis of cerebral palsy, and three had cortical vision impairments. One participant had a concurrent degenerative neurological disease; another had a concurrent seizure disorder and respiratory disease. Nine of 13 youth experienced fluctuating involuntary, sometimes painful, muscle spasticity throughout their bodies. For this reason, they used various types of restraints (e.g. arm and/or leg straps), attached to their wheelchairs, to secure their bodies during certain activities. Four participants received nutrition wholly, or in part, via a gastric tube.

Participants varied with respect to their control over body movements. Of 13 participants, one was able to walk short distances indoors without a mobility device, and used a walker or manual wheelchair for long distances; three crawled at home or when visiting extended family; seven used a manual wheelchair and required human assistance to move about; and five used a power wheelchair, both indoors and out. Six youth had impairments that limited nearly all use of their arms and hands; five experienced hand impairments but used a hand switch or a joystick to

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16 These categorizations are based on observations and reported information about housing, home type and location, family income and parents’ education levels.
control assistive technologies; two had enough hand and arm control to, for example, point or type on a keyboard.

Appearance: In spite of age, gender and class differences across the sample, there was remarkably little difference in youths’ clothing styles. One participant distinguished herself with rainbow-dyed streaks in her hair. Otherwise, for all of the interviews, each youth was neatly groomed and dressed casually in jeans or sweatpants, with a loosely-fitting knitted top and sneakers or slippers. Less ‘ordinary’ were the visible joint contractures, asymmetries, or unusual body postures that distinguished each youth’s appearance in one way or another. Eight of 13 participants experienced swallowing impairments which caused uncontrolled drooling, especially during effortful activities. I include this information to acknowledge the highly visible bodily differences which contribute so significantly to the nature of social relations for many disabled people.

Personal care routines and assistance: All participants required assistance with personal care, though the level of assistance varied. One youth, Audrey needed only occasional assistance with some grooming or dressing activities; the remaining 12 were largely dependent on others to assist them with washing, dressing, toileting, grooming and most aspects of feeding. For these young people, care routines typically took up to four hours each day (not including additional personal care provided in school settings). Ten of 13 youth needed assistance throughout the day and night to change their body position. I did not routinely ask participants to report specifics about who assisted with their personal care; however, most described basic information about the extent to which they relied on attendant care. There were no patterns across the data to suggest links between use of attendant care and participant’s level of impairment or their families’ financial resources.

I move now to the case narratives, beginning with participants who were younger and earlier in their high school careers, and ending with those who were within a year of completing high school. This ordering supports a reading that evokes the youths’ progression through high school toward future-oriented trajectories. Each case begins with a photograph summary and then proceeds according to the home, school, and community spaces (e.g. recreation centres, religious gatherings, shopping malls) described in the participants’ presentations of their lives. In line with the Bourdieusian orientation of the study, my organization of information in the narratives is
intended to help prompt consideration of the interlocking fields youth inhabited (including the fields of family, medicine and rehabilitation, education, and the public sphere) and how the dominant logics of those fields structured youths’ habitus. As mentioned earlier, illustrating these descriptions are selected sets of photographs, captions and Belonging Circles17, as well as observational data drawn from my field notes. The narratives vary in length and in the depth or breadth of descriptions provided, according to the data generated with each participant. Some youth were more forthcoming than others. Their levels of reflection on the topic of inclusion varied, as did their engagement with the visual methods. I begin with one of the younger participants, Emma, who requested that her older brother (aged 17) act as her communication partner for the interviews. In all other cases, participants elected for their mother to take on this role.

6.3 Case narratives

6.3.1 Emma

Emma took 16 photographs: 7 at school, 9 at home

Emma was aged 15 at the time of the research. At home, her primary mode of communication was dysarthric speech – she could approximate single words and phrases but it was difficult for her to say more than a few words at one time. She also had a tablet with a commercially-available speech-generating app that she used mostly at school.

*Home:* Emma lived with her parents and three siblings in a new custom built home in a rural area. This relative isolation was *not* something Emma appreciated – she marked the outer ring of a Belonging Circle to correspond with her feelings about her home’s location. A number of relatives lived nearby, but, she reported, didn’t visit often.

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17 I have selected and grouped key photographs, captions and Belonging Circles from the data produced with each participant to illustrate the ways they presented themselves through the research. When describing youths’ responses to a Belonging Circle in words, as opposed to displaying the graphic, I refer to the ‘centre’, ‘second’, or ‘outer’ concentric rings of the circle.
During the week, Emma had no scheduled after-school activities or lessons. She described herself as a hockey fan, saying she filled her time at home out of school by watching almost all televised games, and checking scores. Most weekends revolved around attending her siblings’ hockey games and practices. Aside from hockey, Emma enjoyed travelling with her family. She had often been on airplanes and laughed about being able to board before other passengers. Occasionally, a long-time attendant, whom Emma described as her friend, took her out to attend a movie or similar activity. This attendant also accompanied the family on vacations. Otherwise, Emma said she had no friends and was happy in the company of her family. Emma’s family owned two vacation homes in addition to their main residence. She spoke quite negatively about one of these, noting it had a very steep, scary drive and the interior was not accessible. Emma preferred not to go there, feeling it wasn’t worth all of the effort. In addition, she felt the people who were part of the social circle in that environment treated her “like a baby”.

To portray her overall sense of inclusion at home, Emma included photographs (above) of herself and a brother as he was driving an ATV outside their home. She said she enjoyed watching from the garage, and wouldn’t want to ride on the ATV because it might be scary and uncomfortable, especially as she didn’t like spinning.

School: Emma attended a segregated classroom in the special education ‘Life Skills’ stream\textsuperscript{18} at her local high school. Emma’s school photographs were focused on physical accessibility.

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\textsuperscript{18} Streaming (also known as ‘setting’ or ‘tracking’) is a controversial but common educational practice where students are categorized and grouped over the course of their schooling according to school achievement and intellectual, physical, or behavioural assessments. Categories vary across school systems and might include streams identified as: ‘gifted’, ‘life skills’, ‘applied’, and ‘academic’.
For example, the computer lab (above left) was inaccessible and, she said, made her feel excluded, whereas the school elevator and an adjustable height desk in her classroom (above right) portrayed her sense of inclusion in these spaces. Emma also took a photograph of the school cafeteria, and explained she liked to go there but couldn’t eat at school because the staff was afraid to feed her. She marked the second ring of a Belonging Circle to show her feelings about this. Emma had two educational assistants that she could communicate with while at school and whom she described as “fun, silly people”. She said she hadn’t thought about what she might want to do after high school.

Community spaces: Emma said she wasn’t interested in trying out “special camps” or other programs for disabled youth. She shared that she preferred to spend weekends and vacations with her family. She felt she was “just like other teens”, citing a number of recreation activities that she had participated in with her family. These included: skiing, baseball, horseback riding, go-karting and tubing. But, she qualified that these activities had all been scary or uncomfortable and she didn’t wish to pursue them. Emma avoided shopping because “people stare too much”.

6.3.2 Hadia

Hadia took 252 photographs for the study: 97 at home, 9 at her high school, 103 at a waterpark resort, and 43 at a family birthday party.

Hadia, aged 15, communicated with gestures and facial expressions as well as a speech-generating device. She had no speech, but could call out if she was in distress, and occasionally shared an infectious giggle.
Home: Hadia lived with her parents and several siblings in a newly-built detached home on the perimeter of a large metropolitan area. In addition to a large number of ‘selfies’ (one appears below), she prepared what amounted to a virtual tour of her home, where she emphasized areas that were inaccessible. For example, she recorded photographs of a staircase leading to the upper level. Photographs of her bedroom (below left), showed a hospital bed with rails and a mechanical lift suspended from the ceiling to help transfer her in and out of bed. Other photographs featured “Hadia’s bathroom” (below right) which was renovated to include a large raised plinth used to assist with her personal care.

Much of her time at home was taken up with attendants who, in addition to providing personal care, carried out a daily home therapy program that involved exercises, stretching, and time spent in a stander. Hadia said she did not like using the stander: “It is too tiring, it hurts, and it’s boring to stand.” Aside from these activities, Hadia spent nearly all of her time at home watching television or listening to music. As we reviewed Hadia’s photographs of various attendants (one is pictured below), she explained that she wanted to talk about how she felt unsafe with certain attendants and didn’t look forward to working with them. For example, she felt “cold” and “frightened” during showers, especially because a shower chair had once broken while she was
seated in it. For Hadia, attendants were not her friends. She said she wished her family could assist with more of her personal care.

_School:_ Hadia was in her second year of high school. She spent part of her time in a special education class where she described participating in therapy activities such as stretching and standing. She said she didn’t have any friends in her special education class and commented “they are all independent”. With an educational assistant, she attended two mainstream courses. Hadia said she felt very happy and included at school.

_Community:_ Hadia’s community-based outings involved excursions to visit extended family or attending activities organized by a charitable organization that supported families with disabled children. A large number of photographs were taken during an overnight trip to one of these events, but portrayed only Hadia and her family. She said she enjoyed attending mosque, visiting fast food restaurants, and swimming though she didn’t often get to do the latter. Her mother explained that they needed at least three people to help take Hadia into the pool. She had tried adapted skating but didn’t like the cold, and had attended a summer camp for disabled youth but found it “frightening”. Hadia said she’d rather stay at home all summer than go to camps for disabled youth.

### 6.3.3 Stewart

Stewart took 97 photographs: 45 at home, 7 at school, 5 at church, 25 at a local activity centre for disabled children, and 15 depicting either his school bus or public transportation.

Stewart, aged 15, communicated with his family using facial expressions, a few word approximations (e.g. ‘eh’ for “Yes”), and a mix of iconic and idiosyncratic gestures (e.g. thumbs
up for ‘yes’, pointing to his forehead indicated “I have a question”). He also used a speech-generating device to express short phrases or single words.

**Home:** Stewart lived with his parents in a detached home in a cosmopolitan urban neighbourhood. One older brother was away at university. The home had been renovated to make it easier to navigate with a wheelchair, and was fitted with an elevator so that Stewart could access all three floors. A wheelchair ramp led from the street to the front door, discreetly camouflaged by garden landscaping.

Weekday routines after school revolved around television viewing (a photograph of his favourite sport is below) and tutoring to improve Stewart’s use of his speech-generating device. In the evenings, Stewart was often quite tired and went to bed early (7-8 p.m.) after spending time cuddled together with both parents. Stewart can be seen in a photograph (below left) with his parents at bedtime as they chatted on a speaker phone to his older brother, and reviewed the next day’s routine. (In the foreground, Stewart can be seen activating the green camera switch). Stewart explained that he tended to feel concerned and anxious about what the next day might bring, so his family spent considerable time reviewing the next day’s activities and routines. He talked about a number of other fears. For example, he emphatically disliked “surprises” of any kind. New people, new places, sudden sounds including sirens and large crowds – all made Stewart very agitated and sometimes caused him to “melt down”.

A large number of Stewart’s photographs portrayed various adult family gatherings at his home. These get-togethers were highlights for Stewart, when he said he enjoyed playing the role of family “joker”. In the summer, his family spent time at their family cottage where, Stewart said, he enjoyed getting out on the lake on a pontoon boat which he could access while remaining in his wheelchair. In the winter, the family was involved in a ski club where there was a disabled
skiers program. Stewart participated in this program with an attendant whom he described as “a worker and friend”.

School: Stewart said he considered time spent on his school bus as “the best part of the day” (a photograph taken during the ride to school appears below on the left). He was in his second year at his local high school where he attended a segregated special education program. He described his class as “self-contained”. Photographs showed a large space with two accessible washrooms, a dining/kitchen area, and a more traditional classroom section with tables and an interactive white board. Stewart reported he had almost no interaction with other students at the school. He indicated he enjoyed yoga, art, music and swimming, and disliked math. He reported having very little homework. Stewart and his classmates remained in the classroom for lunch. One photograph (below right) featured a classmate that Stewart said was his current “crush”.

Community spaces: Stewart regularly went swimming with his family at a local children’s treatment centre where the water was warm and the pool had ramp access. He took photographs at church (below right) where he said he especially enjoyed the choir and organ music.

Many weekends, Stewart attended a parent-led alternative therapy program (a long ramped entryway is pictured on the left above), where, with other disabled children and youth, he worked on stretching and standing. He had attended a church-based family camp, but said he felt
frightened and anxious about being in a new place with so many new people. Similarly, though he was a basketball fan, when he had attended a game in person, he felt quite ambivalent; he indicated it was fun but much too loud and overwhelming.

6.3.4 Bernard

Bernard was aged 16 at the time of the study. He said he found using his speech-generating device extremely labour-intensive and he seldom used it at home. With familiar people (his bus driver, school teachers and family) Bernard communicated using dysarthric speech, though this was also quite tiring for him.

Home: Bernard lived with his parents and younger sister in a large home in a wealthy neighbourhood of a large urban centre. The entry opened into a large atrium pristinely decorated with expensive-looking art objects. To the side, there was an elevator that Bernard could use to access the upper and lower floors of the house.

During the week, Bernard had a number of scheduled afterschool activities; all took place at home. These included: tutoring two or three times a week, physical therapy sessions, and piano lessons that involved watching and listening while his teacher played the piano. He described a special bond with his male physical therapist. Although he said the sessions were strenuous, he looked forward to them and described his workouts with a ‘macho’ sense of accomplishment. Occasionally, Bernard had a friend from his class at school come for a visit. Each evening, Bernard spent time with his younger sister reading books, playing games or watching television. He said he was proud of his role as an older brother. On weekends, Bernard most often went shopping with his father, while his mother took his sister to lessons or activities. Once a month, he attended a day respite program associated with his local children’s treatment centre. He also attended an integrated camp program there each summer.

School: Bernard was the only study participant who attended a completely segregated high school for students with ‘exceptionalities’ (e.g. physical and/or intellectual impairments, low school achievement, behavioural issues). He attended the physical disabilities stream and said he
“loved it!” He was in his third year at the school, and would be allowed to stay another four years. Classrooms for students with physical impairments were in one area of the school; students with developmental disabilities were in a different designated area. The remainder of the school housed classrooms for students pursuing technical courses in an applied versus academic stream. Bernard ate lunch in his classroom, but shared that if he finished quickly enough, he was allowed to roam the school in his power wheelchair. Bernard took pleasure in this privilege, noting it was not extended to other students in his class. He described a good friend, Jon, who sat beside him in class and helped “translate” his speech.

A photograph (below) taken in the classroom showed a large interactive white board that was touch enabled. Bernard explained he was the only student allowed to use the board during class ‘free time’. He browsed the web and sometimes did homework by directing his educational assistant to control the interactive whiteboard, and had helped his teacher troubleshoot the system. With a mix of discomfort and excitement, Bernard explained he was “smarter than the other kids” in his class. On a Belonging Circle, he marked the centre ring to tell how he felt when in his classroom.

However, Bernard’s feelings differed in relation to the school at large. He referred to himself as one of the “PD” (physically disabled) students, whereas, other students at the school were either the “DD” students (those in the developmental disabilities stream) or the “normal” students (non-disabled students in the applied stream). He explained the ‘normal’ students wouldn’t move aside to allow him to navigate the halls if he ventured into shared spaces, such as the cafeteria or the assembly hall, specifying this didn’t necessarily bother him, but “it is not safe”. In general, Bernard said he had very little interaction with these students, and wasn’t particularly interested in mixing with the “normal kids”. He said he felt intimidated and “out of place” when he was in
what he termed the “integrated” spaces of the school. To show this on a Belonging Circle, Bernard indicated a spot outside of the circle graphic, nearly off the page.

Similarly, Bernard explained that he didn’t feel he fit in with the “DD” students. When he had elected to stay back from class field trips, he spent the day in the developmental delay classroom. He disliked this experience, explaining the students “do nothing” in that class, “they don’t talk”, and “they just hang out”. On a Belonging Circle, Bernard again indicated a space outside the perimeter of the circle graphic to correspond with these feelings.

Bernard spoke about several class field trips, and took photographs to represent some of these. He especially enjoyed a trip for adapted bowling (pictured below). During a fieldtrip to a theme park, Bernard could not go on any rides. He found this maddening, saying he “couldn’t understand why they [his class] keep going back” since the rides were not accessible for him, but he didn’t bother complaining because “they wouldn’t listen to me”. He shared that he had decided to stay home on days when he didn’t like a particular field trip location, because his only other option was to spend the day with the “DD” students at school. I return to this example in Chapter 7 in discussions about how participants positioned themselves within the social order of structured school spaces.

Community spaces: For Bernard, time spent in public spaces was limited to school fieldtrips, excursions with his family, or visits to the children’s treatment centre. He included a photograph of himself with his mother and younger sister at a local museum, with this caption: “I couldn’t access any of the interactive activities. It was boring. I won’t go… again”. This corresponded with a mark on the outer ring of a Belonging Circle. As a rule, Bernard explained, “In community spaces I don’t feel safe”. Probed about whether he had experienced people staring, Bernard said “Yes”, but clarified this wasn’t something that bothered him. Another photograph
told about a family excursion to a drive-through safari park. Bernard showed off his sense of humour by electing to represent this trip with a photograph of a monkey’s backside. He said he had loved the trip largely because he had been able to stay inside the family van, and indicated the centre ring on a Belonging Circle to correspond to his sense of inclusion at the safari park.

Toward the end of the second interview, we talked about the future. Bernard said he thought he’d like to go to a day program, but clarified that he had no idea what this might involve. Alternatively, he thought he’d like to volunteer at his local children’s treatment centre. When I probed about potentially attending college, Bernard repeated that he thought he’d enjoy volunteering. He spoke a little more about how “frustrating” and “tiring” it was to talk with strangers, but said he felt people were “doing their best”. He then asked to complete a Belonging Circle and marked a spot on the outer ring to indicate how he felt during interactions with strangers.

6.3.5 Stephen

Stephen took 48 photographs: 16 at home, 17 at a grocery store, 11 at school, and 4 at a community-based youth centre

Aged 16, Stephen communicated primarily using dysarthric speech and was able to express full sentences with minimal exertion. He had a computer tablet with speech-generating software that he sometimes used at school, but he reported that his teacher (for the past three years) understood most of his speech. Stephen enjoyed telling stories but became shy and reticent when asked to discuss his feelings, or reflect on the stories he told. He completed just one Belonging Circle.

Home: Stephen lived with his parents and three siblings in a two-storey detached home on a quiet suburban cul-de-sac. The home was immaculate and comfortably decorated in a family-friendly style. There was an electronic lift in the garage that Stephen used to exit the house in his wheelchair. Otherwise, there were no obvious renovations to make the home more accessible. Stephen’s bedroom was just off the kitchen on the main level of the home and was decorated to feature his interest in cars. Stephen enjoyed sharing how his father woke him each morning with hugs or play fights. He was less enthusiastic about time spent with the attendant who came each weekday morning to help him get up, dressed, fed and ready for school: “My helper comes to bathe me, but I don’t like that”. Stephen said he felt “happy and safe” at home. A number of
times during the second interview, he said: “I want to talk about home” and redirected the
discussion to re-view photographs he had taken at his home or with extended family. These
included images of Stephen in his wheelchair at family birthday dinner (below), and seated on
the living room couch beside his father and a close family friend as they were watching hockey
(also below).

Stephen said that some evenings, he was carried downstairs to the basement where there were
soft exercise mats set up for him to play or engage in therapy activities on the floor. Both
Stephen and his parents seemed reluctant to expand on these activities and none of his
photographs portrayed this space. In addition to frequent visits to the homes of extended family,
Stephen reported that he often went to his grandparents’ cottage where, with assistance from his
father, he enjoyed snowmobiling, skating, go-karting, and swimming. He proudly told how one
of his sisters had learned to skate by pushing his wheelchair around the ice while he wore hockey
skates.

School: Stephen was in his third year of high school. He attended a segregated special education
program. With his classmates, he went to other areas in the school, including the business lab,
the auto shop, and the cooking classroom. Stephen described just one student who was able to
communicate with him – the others in his class either didn’t understand him, or didn’t
communicate in ways that he could understand. He ate lunch with his class at a group of tables within the main school cafeteria but said he didn’t interact with the non-disabled students. Stephen said he really enjoyed school and felt very happy there, though he sometimes was frustrated that there were so few people he could talk with. He took photographs of himself eating lunch in the cafeteria, eating a snack in his classroom, and working on a typing assignment in the business class within the school.

Instead of participating in physical education class, Stephen stayed in his classroom to participate in therapeutic activities, such as standing in a standing frame, riding an adapted bicycle, or doing stretching exercises, with an educational assistant. He disliked standing because: “It hurts my knees” and “I can’t move when I’m in there”, but added, “It is good for me”. Stephen’s homework was limited to occasional reading assignments.

Community spaces: Asked about evening and weekend routines or activities, Stephen said: “I want to go out and do something”. He reported that he often headed out into the community accompanied by an attendant. He said that, for the most part, he chose which activities they would do together. On weekends, Stephen enjoyed going to the library, swimming, or grocery shopping (he took several photographs to document one of these trips). One evening each week, he and an attendant met up with two other boys that Stephen had befriended at a camp for disabled youth. He said they usually went bowling but sometimes headed out to the movies or another activity. Stephen’s family had arranged this regular social activity to foster the boys’ ongoing friendship. Whereas the attendant who helped with his personal care each morning was employed through a professional attendant care service, those who took Stephen on outings in the community were young women recruited through a local university. Stephen referred to these
attendants as his friends. The image below shows Stephen in his bedroom with one of the teen boys and an attendant as they are getting ready to go out for the evening.

Another evening each week, Stephen attended a program for disabled youth, held at a local community recreation centre. This was a relatively new activity for Stephen. He took a number of photographs of himself at the program, in a room with billiards and air-hockey tables, and said he really enjoyed the program and felt a sense of inclusion. He shared that he had been comfortable enough to initiate conversations with the new people he met (something he said he rarely did elsewhere), and felt they made an effort to understand his speech.

Stephen mentioned a number of fears that influenced his comfort in some public spaces. For example, he was frightened of all animals. He felt anxious about trips that involved doctors, therapy or other medical appointments. With a sense of relief, he said: “I do my therapy at home”. As discussion shifted to queries about life after high school, Stephen responded primarily with “I don’t know”. His mother interjected at one point, saying: “Maybe you’ll get a job”, to which Stephen, quite confidently, responded “No” but didn’t wish to elaborate.

6.3.6 Audrey

Audrey, aged 17, communicated using dysarthric speech (in single words or short phrases), gestures, hand signs, and a speech-generating device. She rarely used the device with her family, who understood her speech and were fluent using modified hand signing. Audrey explained that no one at school understood her speech or signs so she used her speech-generating device there.
Audrey differed from the other study participants in that she could walk short distances indoors using furniture or walls for support. For longer distances, Audrey used a walker or manual wheelchair.

Home: Audrey lived with her mother, and her older brother in a rented two-storey clapboard home on the outskirts of a small town. The home was crowded but clean and tidy. Audrey’s mother had two jobs - one at a factory, another in a restaurant. Audrey mentioned one of her mother’s friends was “like family” and often stayed with Audrey when her mother was at work, so that she wouldn’t be alone for long periods. Audrey said she felt she could be left on her own, and pointed out she was “17 almost 18!” but, she then conceded that she needed supervision because she experienced “panic attacks” and had a history of seizures. Audrey took photographs at home that depicted various family members. In one, she posed before heading off to school for Valentine’s Day dressed up with heart-shaped earrings and heart tattoos on her cheek. She said that most days after school, she liked listening to music or watching television. Laughing, she explained she didn’t have much homework and was pleased about that. When I asked Audrey to show how she felt when at home, she pointed enthusiastically to the centre ring of a Belonging Circle.

School: Audrey was in her fourth year of high school and said she planned to continue until she reached age 21. She was placed in a segregated special education stream. She stressed that although she took a bus to school, it was “a regular bus, not one for wheelchairs!” Audrey took a photograph of herself, with her classmates, as they worked on an art project. She explained that she really enjoyed school, and said she had very little interaction with non-disabled students at the school. Her class ate lunch in the hall outside their classroom instead of in the cafeteria. Audrey reasoned this must be because the cafeteria was “far away” from her class. Audrey stated that when she was in her class, she felt included and pointed to the centre ring of a Belonging Circle. But, she also marked the outer circle to describe how she felt unsafe and sometimes threatened when outside of her class. She told how she had been bullied by a boy at school: “He used to bully me but then he got to know me. Now he’s my friend and he helps look out for me.” After Audrey shared this information, her mother commented: ‘Small town people are more ignorant about those things”.
Community spaces: Audrey attended a social group for disabled youth at her local children’s treatment centre. They met every two weeks to attend movies, dine out, or socialize at the centre.

Audrey’s photographs depicted the group eating pizza and playing board games. She marked the centre of a Belonging Circle to tell how she felt with the youth group. Audrey said she hadn’t attended local summer camps because her mother couldn’t afford to pay for the full-time assistant that each camp required for disabled campers. Instead, with her mother, Audrey attended a camp for disabled youth for a week each summer. At the time of the research, she said she was looking forward to acting as an ambassador in a telethon to help raise money for the camp.

Audrey included photographs taken with family during a trip to the shopping mall. In the photographs, she looks happy and at ease, but Audrey explained that she was not as comfortable as she appeared: “I feel bad and just want to leave”. She explained that in places like the mall, people stared at her or made derogatory comments. Her corresponding Belonging Circle shows the contradictory feelings she experienced.

Toward the end of the second interview, we talked a bit about the future. Laughing, she said that more than anything else, she’d like to work in a restaurant just like her mother, and ideally with her mother. However, she ruled out future possibilities, such as learning to drive or going to college, as “too hard and too scary”.

6.3.7 Jamila

Jamila took 228 photographs for the study: 64 at home, 45 at her high school (all taken after hours), 21 at her grandmothers’ home, 17 at a local children’s treatment centre, 15 at her afterschool program, 15 at music therapy, 14 inside her wheelchair-accessible van, 10 at a hockey game, 6 at an orthotics clinic, 4 taken while outdoors in the rain, and 1 at church. She included 16 photographs from a personal album.

Jamila, aged 17, lived with her adoptive parent/guardian, a single woman named Rebecca. She communicated using a speech-generating device, a communication book, picture symbols on her

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19 Chapter 4 discussed additional data generated with Jamila which is not revisited here.
wheelchair tray, gestures, and facial expressions along with dysarthric, slow and very quiet speech. Sometimes she ‘mouthed’ words but lacked the breath control to project an audible voice. In addition to cerebral palsy, Jamila had a number of complex medical conditions that made her reliant on medical technologies for breathing and nutritional support. Over the course of her teen years, Jamila had experienced increasing levels of physical impairment.

Jamila shared a number of reflections on her experiences living with communication impairments and using AAC:

I am so thankful that I have a couple of people in my life who really and truly understand me as a real and whole person both with and without AAC. AAC is hard work and it takes a long time to use, so it is good to have people who know me well enough to take the time to really talk and some who actually understand me.

Outside of home, she said most people didn’t understand her speech, so she used her speech-generating device:

I would love to be able to control my muscles and my voice and my words and not need AAC at all. But that is not my reality. I need AAC and I think I will still be getting used to it for my whole life.

Jamila noted that people treated her differently depending on how she communicated. She worried that her speech-generating device prevented people from seeing her capabilities: “My speech-generating device is a tool that I use to help me live my best life.” She said she had learned that complex sentences and large vocabularies were more highly valued than simple language, and she would be judged in part by her verbal facility:

Sometimes without my speech-generating device, I get so tired and frustrated when I try to talk with my voice that I talk with really simple words even though my heart and brain think in dictionary words…. My device helps other people see me as a smart and whole human being too.

Home: Jamila and Rebecca lived in a tiny bungalow in an older, slightly run-down subdivision. A rambunctious patch of flower garden growing out of control along the walkway to the front step offset the general disrepair and clutter. A large wheelchair van sat in the single drive. Jamila explained that raising funds to secure the van had been a long, exhausting struggle that involved “a lot of begging and pleading”. Inside, every available space was organized to
accommodate Jamila’s medical and personal care. In a series of photographs (two are shown below), Jamila recorded the multiple medical and assistive technologies that dominated much of the space, including a ceiling lift, a ventilator, bins of medical supplies stacked in Jamila’s bedroom, and various standing or therapy devices.

Jamila explained that she and Rebecca had rejected the traditional terms ‘mother’ and ‘daughter’, preferring to use first names when addressing each other. Turning to look at Rebecca during the first interview, Jamila explained: “You’re my person, and I’m yours”. Many of the photographs Jamila submitted were taken when she was not using her wheelchair. For example, she recorded images of herself sitting on a couch, on the floor, in a stadium seat, and reclining in a favourite hammock. Sometimes, she used a walker or a stander, explaining she found that when she was standing up, people treated her “like a human being” and less as if she was a little child. Below are photographs of her favourite “hang-out spot” at home, and at a family get-together.

On the rare occasions when Rebecca was out of the home, she arranged home care nurses and/or attendants to stay with Jamila. Persons who spent time alone with Jamila needed to be intensively trained to provide care and emergency intervention. Jamila explained she always needed another person close at hand:

Jamila: “I can be by myself, if someone else is nearby in another room”
GT: So, you wouldn’t stay home alone?  
Jamila: “Oh no!”

Because Rebecca worked full-time and Jamila could not be home alone, Jamila was bused to an after-school care program for younger children (aged between 5 and 10) after the regular school-day. Jamila and Rebecca explained that a long administrative struggle had been necessary before Jamila was granted a space in the program on “compassionate grounds”. Once home, Jamila said she participated in physiotherapy activities with Rebecca, or spent time resting. She explained she rarely had much homework so evenings were spent watching TV, movies or playing games with Rebecca before beginning her extensive evening care routines.

School: Jamila attended her neighborhood high school, where she spent part of the day in mainstream academic classes, but had very little interaction with the non-disabled students. The remainder of the school day was spent in a special education resource room where an area had been equipped to help manage Jamila’s personal care while at school. She received assistance throughout the day from a nurse and a rotation of educational assistants. Jamila said she found it very scary and intimidating when she moved about the school to attend various classes because when the hallways were full of students bustling between classes, all she could see were “bums and bodies” and she couldn’t see where the hallway stopped and dropped off into a staircase (Jamila took a photograph of the hallway, below right, though it was empty at the time). She said she felt more included in her special education class, shown in a photograph (below left) that features a mechanical lift and raised plinth used to assist in Jamila’s personal care. She marked the centre of a Belonging Circle to correspond to her sense of inclusion in her “home room”, and the second ring to describe how she felt as she navigated other parts of the school.
Jamila spent the lunch hour with other disabled students in a program termed “The Snack Pack” which was located away from the school cafeteria. Jamila said she didn’t mind this and tried to be friendly, but she qualified that these were not students she would have chosen to spend time with. Across her school activities, Jamila said she felt most included in her drama program. She included images showing a circle of chairs in the drama studio where a space was left for her wheelchair (below left), and another taken before going onstage in her stander (below right).

Community spaces: Rebecca supplemented her income by providing occasional weekend respite in her home for another disabled teen, so Jamila necessarily stayed at home during those times. Otherwise, Jamila and Rebecca spent weekends doing shopping or errands. Occasionally, Jamila visited with her birth mother, saying: “When she wants to see me, we drive to her place and she comes out to see me in the van”.

Cold, hot or rainy weather limited activities outside of the home for Jamila. Being out in the rain could be a real hazard since Jamila relied on various electronic medical and assistive devices which were attached to her wheelchair. In hot weather, Jamila became dangerously overheated. Sometimes, in the summer, she and Rebecca set up a tent and their sleeping bags indoors because, although Jamila had enjoyed camping in the past, it was no longer feasible given all of the medical technologies that she relied on for survival. Jamila selected a number of “favourite memory pictures” to show times and spaces outside of her home where she had felt included. These depicted her with Rebecca while being carried ‘piggyback’ through a cornfield, roughhousing and crawling on the grass, being held in shallow waves at a beach, and roasting marshmallows at a campground.
Jamila explained that it was a lot of work to get to know new people, and to help them get to
know her. She said she had one “best friend”. The girls met in elementary school and Rebecca
tried to ensure they had chances to get together, at least occasionally. At various times, Jamila
spoke about feeling invisible or ‘not human’ when she was in public spaces:

Most people assume that just because my muscles and lungs and stomach do not work the way
their do, that my brain and heart and soul are disabled too. …I am a real and whole human
being. I think, I feel, I believe, I see, I hear. I feel things. I like textures and touching things to
learn more about them even though my muscles and my body doesn’t work…I am still a real and
whole human being.

To illustrate her point, Jamila described being in pain while in hospital and struggling to tell a
nurse what was happening. She recounted how the nurse, who couldn’t understand Jamila’s
speech, “patted my head like I was a dog and said ‘That’s nice’ ”. It turned out that a needle
dropped into the bedding was sticking into Jamila’s back. She finished the story by saying:

People treat me like what I have to say does not exist….I want them to know that it is not OK to
treat me like I am invisible, or talk about me like I do not exist. I do not do that to them and they
should not do that to me… Living with a disability like mine can be really, really, really, really hard
and I would not want anyone else to suffer like I do sometimes. I sometimes feel so trapped and
anxious and invisible. …It takes a lot of courage and ‘stick-to-it-ness’ to be me and deal with the
frustrations of life….Being an AAC user is hard and lonely and tiring and slow but it beats the
heck out of the options.

Across Jamila’s account, she made frequent appeals for recognition as a “whole human being” –
I consider the implications of this in Chapter 7.

6.3.8 Chloe

Chloe took 62 photographs: 11 at home, 2 getting on the school bus, 34 at her school, 4 at a clinic
appointment, and 11 at community centre.

Chloe, aged 18, experienced visual as well as physical and communication impairments. She
spoke with very slow and laboured dysarthric speech but loved telling stories and giggling at her
own bad jokes. She relied on her speech as her primary mode of communication at home, but
also used a speech-generating device at school.
*Home:* Chloe lived with her parents and siblings in a modest, newly built home in a busy suburban area. The rooms on the main level of the house were sparsely furnished to accommodate Chloe, who preferred not to use her wheelchair indoors. She crawled on the floor and was able to scoot up or down the stairs on her own. She included photographs to show how she moved about the house (one is below).

In general, Chloe said she felt a sense of inclusion at home, but she took a photograph of family mealtimes (below) to point out that this was a time that she felt less included. She explained that mealtimes were one of the few times that her family was all together. She said she wanted this to be a time when she could tell stories and chat, but felt her family didn’t slow down enough for her: “My family don’t always listen to me. You should wait and listen to me”. Chloe’s mother said this revelation “was a real eye-opener”, and commented:

> Chloe has such a good nature. I didn’t think there would be too many places where you wouldn’t feel included, and I was surprised there were places, even here at home with the people you most rely on, where you didn’t feel included.

Following the interview as I was preparing to leave, Chloe’s mother referred back to this exchange saying:
Of course, we pretty much arrange our lives around doing things and going places where it will be a positive experience for her… but then I realize the place she most wants to feel included is at home with her family…and we had no idea that she was feeling this way.

As Chloe noted, weekdays at home were busy times when her siblings were involved in various sport or extracurricular activities. Chloe didn’t participate in these types of afterschool activities – her time was dominated by personal care routines, rest periods, and frequent medical appointments. Chloe took a couple of photographs during a clinic visit, but hastened to say she did not feel included and found this type of appointment “boring!” Some evenings, Chloe had homework which she enjoyed doing independently: “I can do my homework myself!” She loved audio books, and said she’d go to bed earlier if this meant she could spend more time listening to books. On weekends, Chloe enjoyed frequent visits with extended family, many of whom lived close by. One attendant spent extra time with Chloe on weekends. Aside from personal care activities, this person helped Chloe with therapy activities, such as standing or stretching, but integrated these with games. Chloe enjoyed this relationship (portrayed above right). Laughing, she said this was because “she plays games and lets me win!”

School: Chloe was in her fifth year of high school. She attended a segregated classroom and reported she spent nearly all of her time at school inside her classroom. In lieu of attending physical education with the rest of her class, Chloe worked on therapy activities with an educational assistant - she practiced using her walker or stood in her stander. She said she enjoyed using the interactive white board in her class (below left) because she felt it helped her demonstrate her abilities to her classmates. In another photograph taken at school (below right), Chloe can be seen dancing with a classmate at a Halloween party. Chloe said she enjoyed eating with her class instead of in the cafeteria. She felt: “It works really well” because there was time for her classmates to listen to her.
Chloe described having a few friends in her class. She had also been matched with a non-disabled student volunteer as part of the ‘Best Buddy’ initiative at her high school. The aim of the program was to provide opportunities for disabled youth to “have experiences that most people take for granted”\textsuperscript{20}. Interestingly, non-disabled youth volunteered for the program, whereas Chloe said that all of the students in her class were required to participate.

Community spaces: Chloe attended a weekend program for disabled youth at a local community recreation centre where she was free to explore on her own. She said she especially enjoyed taking advantage of the library (pictured left) where there was a large collection of books on tape. Some weekends, Chloe went shopping or attended movies with paid attendants recruited from a local college by her family. She described these young women as girlfriends she could “get out with”. Stressing that her mother was “banned” from these excursions, Chloe described feeling proud that she spent these times away from her family.

6.3.9 Bobby

Bobby took 28 photographs: all at home.

At the time of the study, Bobby had just turned 18. He had very little movement control, cortical visual impairments, and a small number of communication modes. However, during both

\textsuperscript{20} Description extracted from the national program website: \url{http://bestbuddies.ca/program-overview/}
interviews, he was engaged and persistent. To indicate agreement, he looked up with his eyes, or raised one arm slightly. With tremendous effort, he could produce a soft, breathy ‘yeh’. He moved his head from side to side to respond in the negative. Bobby had a communication book which was used only at school.

**Home:** Bobby lived in a detached home in an older suburban area with his parents and a number of siblings. Both of his parents worked long hours – they employed a number of attendants and other household staff to mind the children and assist with Bobby’s personal care. The home was quite chaotic during both interviews, with Bobby’s siblings, their friends, pets, and attendants coming and going constantly.

Aside from attending school, Bobby spent nearly all of his time at home. He took two photographs (below) to convey the sense of relief he felt when, at the end of the school day, he was assisted out of his wheelchair onto a couch in the family room at home.

He also recorded a series of photographs that showed him “standing straight and tall” in his stander, pictured to the right. He said he enjoyed listening to music, or watching as his siblings did their homework nearby. Sometimes, extended family came to visit – these were highlights for Bobby. Most evenings, he was carried upstairs and helped in to bed by an attendant. Each night, he said he would call out from his bedroom until his mother came to say goodnight. Though his mother explained that she felt this was a routine that Bobby found reassuring, she said his siblings found it difficult, and told Bobby to stop being so loud.
School: For four years, Bobby had attended a segregated special education classroom at his local high school. He would attend the school for another three years. Bobby’s mother said the classroom staff was constantly changing so that it was difficult for Bobby to get to know them or communicate with them. There were just three other students in his class, along with a full-time nurse, two teachers, and several education assistants. Bobby said he had very little interaction with his classmates, who his mother described as “medically fragile”, or any other students at school. In the past, Bobby had been in a larger special education class where, he said, he had a friend and where “there was always something happening”. In his new class, he said it was very quiet and “not much happens”.

Community spaces: Though he had almost no speech, Bobby’s mother reported he could vocalize one phrase quite clearly: “I go out”. He tried to demonstrate this during the second interview, but was not feeling well and found vocalizing was too tiring. His mother stated that some days he repeated this phrase “like a broken record” – Bobby nodded emphatically in agreement. But, excursions with his family were quite limited. His mother explained that during the week, they found getting out with Bobby was impractical. On weekends when the family went out as a group they occasionally took Bobby, but more often he stayed at home with an attendant. If they went away for a weekend, Bobby stayed at a respite facility. He became extremely upset at these times but, his mother explained, they felt it wasn’t an option to bring him along. As the discussion turned to descriptions of places Bobby had visited, he became very animated. He indicated he loved any activities that involved being outdoors in the fresh air – regardless of the weather. Sometimes Bobby’s mother took him to the mall with her, but he said he found the larger stores scary and too crowded. Still, his mother rationalized, “it’s an outing”. Bobby said he loved taking the dog for a walk with his mother or an attendant. This usually involved a brief stop for lunch at a local coffee shop where Bobby ordered his favourite foods. When he was younger, he had attended a summer camp for disabled youth but, his mother reported, he felt extremely anxious and couldn’t sleep. At the time of the research, he had grown too old for these camps, and spent the summer at home, listening to music, going for occasional walks with his mother, or just “hanging out” with his family and attendants.
Peter was 21 years of age at the time of the research and communicated using head nodding, vocalizations (e.g. ‘Ah’ paired with head nodding for ‘yes’), facial expressions and a speech-generating device. Because he had visual impairments, Peter used a complex system that involved first listening to a series of word or phrase options via a tiny speaker in his wheelchair headrest, before selecting the one that he wanted to ‘speak’ via his device. Though his device was programmed in English, Peter was bilingual – he understood English as well as his family’s Slavic native language. In spite of the considerable cognitive load involved in using his speech-generating device, Peter said he was used to people thinking he was “not smart”. He reasoned “this is just the way it is”.

Home: Peter lived in newer home on a main thoroughfare in an urban area. Steep concrete stairs led to the front door of the home. Inside, the home was decorated in a continental style which reflected the family’s European heritage. Stairs led to the upper and lower levels of the home. Peter lived with his parents and one sibling who attended the same high school as Peter. For part of each year, his grandparents came from Europe to stay with the family. During vacations, Peter’s family often returned to “the old country” to visit relatives for weeks or even months at a time. Peter said he enjoyed these trips, though many places were not wheelchair accessible. His family coped with this by carrying him whenever necessary. Peter explained he didn’t usually take his speech-generating device on these extended trips mostly because it was programmed only in English, and he could only use it when seated in his wheelchair.

By the time Peter arrived home from school on weekdays, he said he was exhausted and looked forward to getting out of his wheelchair for a rest. He reported that he especially enjoyed spending time with his grandfather who engaged in long chats with him. They also shared the same taste in music. With the help of an attendant, Peter said he enjoyed going out for walks or listening to books on tape during weekday evenings. He took a photograph with one of his attendants (below left). Though he accepted attendant care “was necessary”, he didn’t feel “a fit” with his attendants and wished his family could assist with all of his personal care. He had taken
a photograph of his feet (below right) to prompt discussion about the problems he experienced with attendant care. Peter had joint contractures in his feet, which made donning and doffing shoes a challenge. He said that sometimes attendants “jammed” his feet into his shoes causing him intense pain, but they didn’t understand Peter’s attempts to explain what was upsetting him. At times, he explained, he had endured this pain until he could get the attention of someone who was more familiar with his communication.

School: Peter was in his seventh and last year of high school. He attended a segregated special education ‘centre’ made up of four classes. Several photographs taken at school depicted a food preparation lesson which, for Peter, involved watching an educational assistant prepare sandwiches (below). He said he felt this was a “ridiculous” activity since he would not ever be able to make sandwiches. For him, these types of lessons were “a waste” of his time.

Still, Peter shared he didn’t want to leave school and felt “a bit scared” about what might happen after. He said he wanted to explore programs he could attend after high school, such as those organized by community living groups, because: “I don’t want to stay home all day!”

At high school, Peter had developed what he described as friendships with some of his teachers and felt they understood him. However, he said his classmates didn’t communicate with him and
he felt he didn’t really know them. Though one of Peter’s non-disabled siblings attended the same school, he said they rarely interacted during the school day. Peter stated, in general, he preferred to interact with adults because they were more patient and more likely to wait while he responded to questions. He said he avoided the hallways at school because he found them much too busy, and preferred the quiet environment in the special education centre.

*Community spaces:* Nearly every weekend, Peter accompanied his family to one of his siblings’ sporting events. He said he knew all of the other families - they all came up to talk to him and made him feel very special. At these events (one pictured below), he said, he felt a strong sense of inclusion. He was intensely proud that he had been awarded medals to recognize his consistent support at team events.

Peter disliked shopping malls - he said he felt that people, especially young children, stared and asked too many questions. He disliked the way people would lean on his wheelchair or touch him without asking permission. Periodically, Peter attended medical appointments where he received multiple injections to reduce the muscle spasticity in his upper body (a photograph taken in the clinic appears below). The injections were particularly painful but Peter said he tried to “take it without a fuss, and be brave”. Though he’d prefer not to have these injections, he said he went along with the treatments to please his parents.
6.3.11 Jack

Jack took 53 photographs: 19 during try-outs for a wheelchair hockey team, 10 at a fitness centre, 2 at a therapy supplies store, 9 at home, 9 at work, 4 at church and 3 from a personal album.

At the time of the research Jack was aged 22, had completed high school in the previous year, and had a part-time job. He used a speech-generating device, which was mounted on his power wheelchair, as his primary mode of communication. In fact, he said he used it “24/7”. With tremendous effort, Jack was able to vocalize, approximating some words that his mother understood. He used a combination of facial expressions and head movements to indicate “yes” and “no”.

Home: Jack lived in a working-class industrial town with his parents and siblings. His home was among a long row of older semi-detached townhouses. The front door opened into a hallway, with Jack’s bedroom and an accessible washroom immediately to one side. This area was originally a living room but had been renovated so that Jack no longer needed to be carried upstairs. The kitchen and dining area opened out at the back of the main floor of the house. Jack said he rarely went upstairs to spend time in the relocated family room.

Jack referred to all of his attendants as “friends”. He explained that most days, a female, middle-aged attendant assisted with his personal care. He described how a series of younger male attendants, about his own age, accompanied him when he wanted to go out, played video games with him, and helped with aspects of his work. Jack described these young men as his “best friends”. Jack had participated in an independent-living training program organized by a children’s rehabilitation centre. As part of the program, he stayed for a week, with attendant supports, in a college residence. Jack described this as an important experience: “I found myself finally…and I stayed on budget” He said he hoped to live on his own in the future, and noted: “My parents are not going to be around forever!”

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21 Chapter 5 discussed additional data generated with Jack which is not revisited here.
Overall, Jack reported he felt somewhat left out when he was at home (which he said corresponded with the middle ring of a Belonging Circle), but he was reluctant to explain this further.

**School/Work:** Jack had attended his local high school and graduated with a diploma at age 21. It took him a full year to complete courses that were typically scheduled for one term. Jack described his time in high school as emotionally and physically painful, but he said he was also immensely proud of this accomplishment. In his final year of school, he was elected by his peers as ‘Prom King’, a fact Jack proudly shared, implying he interpreted this as a symbol of his status as a person who had overcome disability. Building on experience he gained through a high school co-op course, Jack had secured a part-time job as a disability advocate for a local school board. Early in the first interview, he announced: “I’m a working man now!”

Jack included photographs about his job that showed a van dropping him off at a speaking event (below left) and a white board where he organized various speaking engagements and appointments. He explained that he was able to do some of his work from home. Other times he went in to the school board, where, because he had been assigned an inaccessible office, he booked temporary desk space.

He explained that his work was primarily focused on sharing his own experiences and encouraging parents to support their disabled children to follow his example. Jack spoke passionately about his mission, saying: “they [disabled kids] need to know they have a place in this world”; “disabled kids have the right to be included in all aspects of normal activities that contribute to the regular life that non-disabled kids take for granted”; and “it takes perseverance to get there”. Although Jack was eager to share these views through the research, he explained that when employers asked him to provide hard copies of his speeches, he had refused. He said
he felt strongly that his words should not be disseminated in his absence. His message and the particular way he communicated were a package and he had no desire to be “giving away” the information. In Chapter 7, I interpret the implications of Jack’s comments in relation to Bourdieu’s conceptualization of linguistic capital.

*Community spaces:* Jack took a number of photographs to portray his sense of inclusion when he was in the community. He said he felt right at home at his local therapy supplies store (pictured below) because “they’ve known me for as long as I can remember”. In fact, during the second interview at Jack’s home, a mechanic from the therapy store arrived early for a wheelchair service appointment. The repair was a priority for Jack so the interview paused while the mechanic went about his work. With a special lift, he raised the power chair, while Jack was seated in it, to attend to the wheel bearings. A lot of ‘manly’ chatter ensued between the mechanic and Jack as they discussed the minutiae of wheelchair maintenance.

On weekends, Jack was very involved at his synagogue where he was active on the youth council. He marked the centre ring of a Belonging Circle to express how he felt about “my temple family”. However, he stated that recently, the youth group had been relocated to a space in the basement that was not accessible. Jack said he wrote a letter to the rabbi explaining that this meant he could no longer attend, but received no response. Jack described this as just one more instance where “people just don’t get it”.

Jack felt activity helped his cerebral palsy and relaxed his body. His photographs (two are below) included a large number of images of Jack engaging in body-work or in sport activities. He said that a couple of times each month, one of his attendants accompanied him to a local community centre. Together, the young men used the weight machines and did floor exercises for core strength.
Jack told how he had also started to handle his own finances and went regularly to the bank, noting: “Yeah – they know me!” I asked about other social pursuits that he might have tried, for example, going to bars. Jack responded: “Drinking and me doesn’t work. But, I went on a date. I paid, of course. I was grown-up in a sense”. His said his date drove and they went to a movie, but Jack felt it just didn’t work out, and he didn’t think he’d ask that person out again.

6.3.12  Sarah

Sarah took 23 photographs: 9 at home, 6 during a trip to visit a friend, 4 at volunteering activities, 2 while out shopping, and 2 in relation to a college open house.

Sarah, aged 19, had completed high school in the previous year. Though she had been diagnosed with cerebral palsy as an infant, she had experienced progressive losses in strength and physical function. She began to have difficulty speaking around age 5. By her early teens, few people could understand Sarah’s speech, but she had refused to use a speech-generating device because it made her look “too different”. She explained: “I feel stupid using a voice generating device…it is just not a good fit. It’s not me”. Sarah felt that using a letter display to spell out words showed that she was “normal” and “smart enough to spell”. During the interviews, Sarah communicated using a letter board, facial expressions, gestures and head nodding to supplement her speech. Her mother could detect the slight modulations in Sarah’s barely audible speech. She commented: “I know the words that might be coming because we’re around each other more often”.

*Home:* Sarah lived with her parents in a spacious bungalow on a large working farm about 30 minutes from the nearest town. The home had a lower level with a large family room, but Sarah needed to be carried downstairs, so didn’t spend much time there. One bathroom had been
extensively renovated to make it easier for her parents to assist with Sarah’s personal care, and the main level had been opened up to allow space for Sarah to navigate in her wheelchair. Sarah’s father had also constructed an extensive system of paved pathways outdoors that led to the various farm outbuildings.

Sarah said she felt safe and happy at home, though she found life in a rural location was isolating and she dreamed about one day living in a city. A number of her photographs portrayed her using a tablet computer (below left) or watching television as she relaxed on a couch at home (below right). Sarah was not able to hold her tablet and needed a stable surface to support it during use, but said she found most wheelchair trays were too “medical and institutional”. Instead, she had asked her father to make her a lap board using scraps of wood.

When extended family and friends came over to the house, Sarah said she didn’t “fit in” because people treated her “like a baby” and didn’t spend time trying to talk with her. She marked the outer ring on a Belonging Circle to show how she felt as she struggled to be part of social interactions at those times. Sarah was able to be at home on her own for brief periods when her mother went out, though she said she found it a bit frightening to be on her own in the evenings. She could text her father if she needed help - he worked long hours but was usually close by in one of the farm outbuildings.

School: When she had attended high school, Sarah had been placed in mainstream academic classes with an educational assistant, earned a high school diploma, and in her final year, had been elected ‘Prom Queen’. Sarah was very proud of these accomplishments and said she had always felt “very included” at school. Yet, as she continued to talk about school, it was clear that completing high school had been exceedingly difficult. Sarah described the extraordinary effort it had taken for her to keep up with homework demands. She described feeling utterly exhausted
by the end of the school week. But, she likened this to the “hard work” she regularly did to try to keep up her muscle strength. She said she strongly believed “if you don’t use it, you lose it”.

Sarah explained that it had been a bit scary to navigate the hallways – there were nearly 2500 students at her high school. She said she had been allowed to leave classes a few minutes early, but refused this offer because she disliked being treated as if she were “special”. Although getting around in the busy halls was frightening, Sarah reasoned “that’s just the way it is” and reported she had never been teased or bullied. She said she had developed one close friend who understood her speech and tried to sit near Sarah for most of their classes. Sarah said she had worked hard to avoid appearing “different”. For example, throughout her years in high school, she ate lunch in a classroom with other disabled students because she didn’t want the non-disabled students to see that she needed assistance. Aside from the lunch hour, Sarah said she had almost no interaction with the other disabled students: “I didn’t belong there”. She explained she felt she was much smarter than the students in the special education stream. Incredibly, Sarah shared that she had never used the washroom at school because she didn’t want her mainstream peers to know that she was “different” and needed assistance. She simply waited until she got home. Sarah said that early in her teen years, she had been quite distressed about her inability to control drooling, so had elected to undergo surgery to address the issue.

At the time of the study, Sarah was beginning to look into a college program that accommodated disabled students. She explained, “You have to have a purpose in life” and expressed she’d like to work in a job helping older persons, in part, because she felt she could relate to the losses in function that some older persons experienced. For example, she empathized with her grandmother’s hearing loss. But, when Sarah and her mother attended an open house to learn more about the college program, she was told she would have to use a speech-generating device and work on a number of independence goals before she could be admitted to the program. At the time of the research, she had not decided whether to explore college further.

*Community spaces:* Sarah said she was finding it difficult to fill her days since finishing high school. She explained she stopped looking at Facebook because it made her feel “down” when she read about other people her age were doing. During the interval when Sarah was taking photographs for the research, she visited her school friend who had gone away to college. Sarah
Sarah had started to volunteer at a local cat shelter (above right) and collected money in a local mall for a charity because “It’s something to do”. She said she enjoyed going to local baseball games, but insisted that her mother carry her up to sit in the bleachers. If she had to sit in the designated wheelchair spot, she explained: “I’d rather not go”. Sarah talked about hating the way that so many people in public spaces “embarrassed” her by patting her head, talking as if she were a baby, and even offered her candy. She avoided all occasions when she might need to eat in public, because she found it “humiliating” to be seen being fed by her mother.

6.3.13 Meg

Meg took 45 photographs: 17 at her day program, 13 at a restaurant, 3 at a hospital, and 12 at home.

Meg had just turned 24 at the time of the research and had completed high school in the previous academic year. Meg’s communication modes included a speech-generating device, eye gaze, gestures and facial expressions. She was able to laugh and could call out, but did not attempt to approximate words. She could moderate the tone of her vocalizations in ways that were discreet and understood by her family. For example, she consistently produced a particular sound to indicate agreement. Meg felt her older brother was her “best” communication partner, followed by her mother and father. She indicated that extended family members didn’t try to talk with her, even when she used her speech-generating device.

Home: Meg lived with her parents, her brother and his partner in a detached home in an older, suburban area. On the main level of the home, renovations had been undertaken to open up the
space so that it was easier to move about in a wheelchair. Meg’s room was on this level in what might have otherwise been a dining-room. It was a large room with double doors where, aside from a ceiling lift, there were few signs of medical or rehabilitation equipment. The walls and ceiling were plastered in ‘boy band’ posters. Meg said her favourite place to be was a large, overstuffed recliner where she could spend time out of her wheelchair and in front of the TV.

Meg shared that her family were very close. They spent nearly all weekends and vacations together. Her mother volunteered that she and her husband had recently spent their first night away from Meg. Most of the time, Meg and her family entertained friends at their home rather than go out. She had gone to a few sports events with her family, but said she disliked that they couldn’t sit together - only one person was allowed to sit with Meg in the wheelchair access areas. At a recent event, when there was ample space remaining in the section set aside for wheelchairs, Meg said that she and her family had asked if they could stay together, but the stadium security guards had forbidden their request, citing their need to abide by “the rules”.

Meg described herself as quite shy and fearful around strangers, but “a good friend” to people she knew well. With her mother’s assistance, she stayed in touch and maintained friendships with several past attendants and many of her past teachers. She said she struggled to adjust to changes in her routines or when new attendants became involved in her care. The photographs Meg took at home documented a large gathering of family and friends. Meg also took photographs that pictured her being helped by an attendant to prepare for the event. She marked the centre ring of a Belonging Circle to correspond with these home-themed images, and explained that one reason she felt included during these types of gatherings was that she always had a designated job. She monitored guests’ alcohol intake and was the ‘keeper’ of their car keys. Meg explained that this had been her role at family parties for a number of years and she took it very seriously.

Day program/School: When in high school, Meg had been placed in a segregated special education classroom. When she completed school, she was granted a “certificate of completion”, but did not receive a high school graduation diploma. At the time of the study, Meg still volunteered at her school, with an attendant, for a half day each week. With her former teacher and classmates, she visited all of the school classrooms to collect and sort materials to be recycled. The other four days of the week, Meg attended a day program for disabled youth and
young adults. The program was located in a warehouse within a nearby industrial park and consisted of educational and therapeutic activities, group fieldtrips and some paid group employment projects. Meg said she didn’t mind the program; her mother interjected to say it was “really the only choice”. Meg indicated she felt she fit in at her day program, primarily because she was a “helper” and not because she was like the other clients. She said she had tried to learn sign language so that she could understand one of the other clients, but that most of her interactions at the program were with the staff.

Meg was very engaged as she described her role as a valued helper at the day program. She saw herself as a “minder” who helped watch out for clients who might do things that were unsafe. She said she felt her peers in the program were the younger staff members. For example, she told how one young worker, described as “a best bud”, liked to “gossip behind the scenes” with Meg. Another young man who worked at the program would mimic Meg’s bodily postures (she had a number of joint contractures). She thought this was very funny and said she liked that he spent time talking with her. During the interview, Meg shared a number of stories about “silly” things some of the other clients did, including one incident where a young man forgot to pull up his pants. Meg said she didn’t feel she was like the other clients because she was smarter and “knew better” how to behave. She took pictures of the overall program space (below left), various staff members, and one of the clients that she “watched out for” (below right).

Though Meg considered the younger staff to be friends, she said she was less comfortable with the supervisors in charge of the program. She felt they didn’t support the way she identified as a helper in the program, and seemed wary of the ‘friendly’ relationship that she felt with the younger staff. In several photographs (one appears below), these senior staff members had posed, smiling and embracing Meg’s chair. But, Meg explained she hadn’t wanted to take those pictures. She made a great effort to compose the following explanation using her speech-
generating device: “These people felt they should be allowed in the pictures even though I did not want any with them. I took pictures with them only because I thought they would be mad if I didn’t”.

Community spaces: Meg said she intended to take photographs during a hospital visit, but then decided that taking pictures for the research might conflict with the appointment, so she only took photographs of the outside of the hospital (below left). She said she felt that during medical appointments, she didn’t have much to contribute and was happy to have her mother assist with communication in these situations. In discussing the photographs of the hospital, Meg was reminded of an incident in the past that had been quite traumatic for her. She shared how she had appealed for permission to have her mother join her in the recovery room since she couldn’t speak. She recalled that she had been feeling panicked about the potential problems she might encounter after the surgery. Both Meg and her mom said they had been affronted when the surgeon refused to accommodate this request.

As we discussed a photograph taken in a restaurant (above right) at a celebration with Meg’s grandparents, Meg stated that she felt extremely uncomfortable in this type of setting because strangers stared at her. She explained that if she conceded to go, her family tried to make
reservations at times when few other people would be dining. Meg said that occasionally, she went with her family or an attendant to the shopping mall or bowling alley but, she said, she also avoided these places because she felt uncomfortable with the way people stared. Meg preferred not to use her speech-generating device when she went out “in public” because, she said, she thought it made her look “too different” and drew additional unwanted attention.

6.4 Conclusion

This chapter has addressed the first study aim - to contribute detailed descriptions of the lives and practices of youth who use AAC with a focus on their subjective experiences of inclusion – by presenting a series of case narratives that retain a focus on the quotidian and resist summarily reducing the lives of youth in the study to decontextualized generalizations of the group. Youth articulated their points of view in ways that differed and were not necessarily reconcilable. For example, in relation to their experiences of school-life, ‘the space of points of view’ set out across the youths’ accounts incorporates, on one hand, Bernard’s desire to avoid mingling with the ‘normal kids’, and on the other, Sarah’s insistence that she doesn’t ‘belong’ with the group of disabled students at her school. Both practices, as I will show in Chapter 7, are founded in social reason; the varying points of view articulated by participants correspond with their social positions (Bourdieu et al., 1999). Nevertheless, there were also points of convergence. Despite the variability across participants’ socioeconomic status, living conditions and family situation, their stories illustrate common experiences in relation to growing up with physical and communication impairments and patterned responses that reflect those experiences as follows.

To summarize, participants’ lives unfolded under conditions and constraints that would be considered intolerable for most non-disabled persons. Day-to-day life revolved closely around family and home where care and management of their bodies dominated the youths’ routines. In school, the participants were almost exclusively positioned at a distance from non-disabled students. In some instances, this social separation corresponded with physical separation, as for example in segregated classrooms. However, even when youth were in close physical proximity to non-disabled persons (e.g. in the hallways at school, in the shopping mall, in mainstream classrooms), their social interactions were delimited by the effects of negative social valuations and inhospitable material arrangements. Following Bourdieu, these shared experiences and circumstances contributed to the structure of participants’ habitus. Individuals come to
understand their place, and what is expected of them through a gradual process of embodiment whereby the personal and the social interpenetrate inextricably. In setting out descriptions of participants’ lives, I have sketched the social conditions and arrangements that, as I will argue in the following chapter, were embodied to durably structure their habitus and shape their perceptions of inclusion and their struggles to position themselves as ‘included’.
Preface to Chapter 7

In Chapter 7 (a third manuscript), oriented by my specification of Bourdieu’s theory of practice, I address the second aim of the study which was: to interpret the interrelations among position-takings of youth who use AAC (how they accommodate, resist or reformulate inclusion in their lives) and their social positions in and across the social spaces they inhabit. In the manuscript, I posit that from the points of view made possible to them, youths’ practices represent logical and practical strategies for claiming inclusion that, paradoxically, reproduce and resist the systems of categorization that relegate them to disadvantaged social positions. The interpreted results which follow, demonstrate how, following Bourdieu, the dialectical relationship between structure and human agency is expressed as logical practice that arises from practical logic.
Chapter 7

Manuscript Abstract\textsuperscript{22}

This article draws on a Canadian qualitative study that examined the lives and practices of thirteen disabled youth who use augmentative and alternative communication (AAC) to better understand how they made ‘practical sense’ of discourses of inclusion. Drawing on Bourdieu’s theory of practice, I first suggest that participants’ narratives reveal habitus – a socially constituted set of dispositions - that predisposed them to accommodate the devalued social positions and constricted conditions of existence imposed on them. From the points of view made possible to them, the youths’ practices represent logical and practical strategies for claiming inclusion that, paradoxically, reproduced and resisted the systems of categorization that marginalized them. Second, I assert that some forms of ‘inclusion’ perpetuate symbolic violence, as youth who use AAC misrecognized the arbitrary nature of dominant social norms and values that privilege ‘normal’ bodies. All study participants claimed inclusion but under constricted conditions of possibility that were not of their choosing. Finally, I argue that although their practices primarily reproduced the status quo, youth in the study also worked at the margins to create locally produced forms of inclusion that attempted to transform the ‘rules of the game’. These results suggest a need for systemic shifts past reified notions of inclusion toward fostering social spaces where alternative ways of being in the world are positively valued.

\textsuperscript{22} This manuscript has been prepared for submission to the journal “Sociology of Health & Illness”. This is an international journal which publishes sociological articles on all aspects of health, illness, medicine and health care. One of the aims of the journal is to identify and contribute to new areas of debate and research. This manuscript is sole-authored.
7 Articulating ‘inclusion’ with youth who use AAC

7.1 Introduction

In the last three decades, the development of augmentative and alternative (AAC) systems and technologies, such as speech-generating devices and communication symbol sets, has increased the options available for youth with physical and communication impairments to engage in social and communicative interactions. In children’s rehabilitation, the notion of inclusion is a foundational construct and an over-arching goal. Yet, despite expanded communication options and interventions aimed to promote social inclusion, disabled youth who have little or no speech continue to lead narrowly circumscribed lives. The small amount of research that has examined the lives of children and youth who use AAC suggests they struggle for recognition outside of the family sphere and experience social isolation which increases with age (Batorowicz et al., 2014; Clarke et al., 2012; Raghavendra et al., 2012; Wickenden, 2011a). During adolescence, youth who use AAC confront rapidly changing social and communicative expectations (Smith, 2005, 2014) and a widening of the gap that separates them from their non-disabled peers (Clarke et al., 2012).

Understanding how youth who use AAC respond to dominant calls for inclusion is important because when inclusion is constructed as a unidirectional journey by disabled people toward mainstream contexts, the onus is on the individual to do the work of ‘fitting in’, exposing them to stigmatization and unintended harms (Hall, 2010; Holt, 2003; Milner & Kelly, 2009). For disabled youth, rehabilitation interpenetrates education as both fields endeavour to categorize and manage bodies deemed ‘exceptional’. In the field of education, competing conceptualizations of inclusion have implications for how disabled students, including youth who use AAC, are ‘placed’ in schools and the educational outcomes available to them (Tardif-Williams et al., 2009; Weber & Bennett, 2004). In the context of rehabilitation, conceptualizations of inclusion remain largely unexamined (Hall, 2010), which is problematic since dominant biomedical discourses tend to frame disability as an individual problem, unrelated to discriminatory social practices (Titchkosky, 2011). Rehabilitation has been implicated in what Ravaud and Stiker (2001) described as a subtle “passion for assimilation through normalization at all cost” (p.508) based on tacit assumptions that social inclusion is enabled through extraordinary investments toward approximating ‘normal’ bodies. Accordingly,
in children’s rehabilitation, calls for inclusion tend to be unreflectively envisioned as individual struggles by children with impairments to ‘overcome’ disability. Little is known about how prevailing calls for inclusion affect the lives of youth who use AAC. Nor is there information to help understand their practices in relation to dominant understandings of inclusion. These knowledge gaps are significant limiting factors in designing programs and services that aim to promote social participation and improve life-opportunities for youth who communicate in ways other than speech.

In the current climate, there is little room to question the authority of calls for inclusion (Edwards, Armstrong, & Miller, 2001; Roulstone, 2010). Yet, disability scholars and activists suggest there is an urgent need to critically examine gaps between the rhetoric and the reality of policies founded on ideals such as inclusion (Prince, 2012; Ravaud & Stiker, 2001; Roulstone, 2010). For example, little is known about the potential negative effects of inclusion-focused social policies and practices on persons deemed ‘in need of inclusion’ (Edwards et al., 2001). The limited research that has critically examined inclusion from the perspectives of groups identified as excluded, suggests inclusion is neither neutral nor universally desirable (Ponic & Frisby, 2010; Welsby & Horsfall, 2011). Nor should it be reduced to objective observations of being ‘in’ a particular space or social interaction (Spencer-Cavaliere & Watkinson, 2010; Holt, 2003). Rather, these studies suggest that inclusion is relational and perspectival. Meanings of inclusion vary with one’s social background, educational level, and “worldview” (Hargie et al., 2011, p. 895), and thus, are multifaceted, situated and open to interpretation. Building on the idea that a person’s sense of inclusion is influenced by their social position, I looked to sociologist Pierre Bourdieu’s theory of the logic of practice and its key concepts - namely field, capital and habitus - as heuristic tools for thinking about youth who use AAC as agents ‘emplaced’ within social hierarchies in positions of relative advantage or disadvantage (Bourdieu, 1989; Bourdieu & Wacquant, 1992). I argue Bourdieu’s theorizing affords a nuanced approach for elucidating the social relations implicated in the enduring social divisions and ongoing struggles between persons and groups to maintain or improve their positions in social space.

Oriented by Bourdieu’s theory of practice, this paper draws on a qualitative study that examined the lives and practices of thirteen Canadian youth who use AAC to better understand how they made ‘practical sense’ of discourses of inclusion. My objective was to illuminate the extent to which the constraints of social arrangements and conditions delimited the social interactions of
youth who use AAC and shaped their sense of inclusion. The results make three contributions to existing research on disabled children’s lives and children’s rehabilitation. First, I posit that youths’ narratives reflect habitus - socially constituted sets of dispositions - that predispose them to accommodate the devalued social positions and constricted conditions of existence imposed on them. From the points of view made possible to them, youths’ practices represent logical and practical strategies for claiming inclusion that, paradoxically, reproduce and resist the systems of categorization that relegate them to disadvantaged social positions. Second, I argue that some forms of inclusion perpetuate symbolic violence, as youth misrecognize the arbitrary nature of dominant social norms and values that privilege ‘normal’ bodies. All study participants claimed inclusion but under constricted conditions of possibility that were not of their choosing. Finally, I assert that although youths’ practices primarily reproduce the status quo, they also work at the margins to curate locally produced forms of inclusion that attempt to transform the ‘rules of the game’ and valorize their preferred forms of capital. The research illuminates the mostly invisible mechanisms that contribute toward perpetuating significant social inequities that constrain youth who use AAC. The results suggest a need for systemic shifts past reified notions of inclusion toward promoting social spaces where alternative ways of being in the world are positively valued.

The paper begins with a brief sketch of Bourdieu’s theory of practice where I specify how his conceptual toolbox oriented my analyses. I then describe the study and present data that illustrate the nature of disabled youths’ struggles for inclusion. The paper concludes with a call to reconsider inclusion-focused policies and practices that unreflectively aim disabled youth toward idealized inclusion in mainstream social spaces. In so doing, it points to alternative ways for children’s rehabilitation to play a role in advocating for and assembling social spaces that foster safety, communion and recognition for youth who use AAC.

7.2 Bourdieu’s theory of practice: A socio-logical23 approach to examining inclusion

For Bourdieu, practices are observable, patterned, yet creative, sets of behaviours, beliefs, perceptions or preferences that occur in real time and exhibit a logic that seems practical or

23 Bourdieu’s word-play (1981, p. 309)
natural because of the relationship between persons’ daily subjective interactions and the broader social structures in which they are immersed (Bourdieu, 1990b). According to Bourdieu, all practices work to reproduce or transform the social order in one way or another. Society (reconfigured as social space by Bourdieu) is made up of interlocking fields (e.g., family, education, sport, or rehabilitation), each with a patterned system of objective forces in the form of tacit rules and unquestioned givens (doxa) that define its functioning (McDonough, 2006). Agents’ positions in a given field, or ‘who belongs where’, vary according to the field-specific resources or capital at their disposal. Fields are always sites of struggle as agents compete over the available capital and ultimately over power to dominate a field.

Bourdieu’s notion of capital can help illuminate social relations that tend to reproduce ‘disability’ as a marginalized and devalued social position. Capital, for Bourdieu, is any resource that is valued in a given field and can be accrued and exchanged to improve or maintain one’s social position. The main forms of capital outlined by Bourdieu (1986) are economic, cultural (knowledge, credentials, forms of speech, physical attractiveness), social (connections, membership in a group) and symbolic (the power of legitimation or recognized value). Two forms of embodied cultural capital – physical capital (Bourdieu, 1988, 1978) and linguistic capital (Bourdieu, 1977a, 1986, 1991) – have particular relevance for youth who use AAC.

Dominant notions of desirable physical attributes and abilities account for the ways that impaired bodies “are usually understood, symbolically, only insofar as they deviate from a prescribed set of norms” (Edwards & Imrie, 2003, p. 244). Likewise, a person’s capacity to communicate in ways that command attention and are recognised as legitimate determines their field-specific linguistic capital (Bourdieu, 1991). Because communication norms tend to privilege ‘natural’ speech in nearly all fields, persons who use AAC are likely to be accorded little or negative linguistic capital.

Through habitus, a set of inculcated dispositions reflecting dominant social structures, persons internalize the meanings and values that order their social worlds, including those that privilege ‘normal’ bodies and speech over impaired bodies and ‘disordered’ speech (Edwards & Imrie, 2003; Gibson et al., 2007; Paterson & Hughes, 1999). Habitus accounts for the pre-reflective, embodied nature of practices as people act within the limits of what appears logical and reasonable in a given social situation. Likening social relations to games, Bourdieu described habitus as ‘a feel for the game’ whereby players conform to the rules of the game and feel at ease
in their positions in the field of play. In other words, “each agent has a practical, bodily knowledge of her present and potential position in social space, a ‘sense of one’s place’….It is this practical knowledge that orients interventions in the symbolic struggle of everyday life.” (Bourdieu, 2000, p. 184)

Determinations of which bodies are legitimated and which are discounted are made by groups in dominant positions of power within a field (Swartz, 1997). Incorporated as doxa, these determinations operate pre-reflectively to organize systems of social classification and division which appear natural and logical. Disabled bodies, in most fields, are symbolically coded by negative valuations that contribute to the perpetuation of the marginalized social position of people with impairments (Gibson et al., 2007). In the education field, fluent, precise and eloquent speech is recognised as authoritative. Embodied norms of communication act to exclude and discriminate against people with communication impairments (Paterson and Hughes, 1999). Competence (as physical and linguistic capital) “is bestowed on bodies that perform to the ‘gold-standard’ norms of speech, timing and movement, and withheld from those which do not” (Paterson & Hughes, 1999, p. 607). This type of domination, where disabled persons are ‘put in their place’ and accept this positioning as logical or even preferred, is what Bourdieu described as symbolic violence, a “gentle violence, usually imperceptible and invisible even to its victims” (Bourdieu, 2001, p.1). Misrecognition plays a key role in reproducing disability as a marginalized or excluded social position since, following Bourdieu, agents are unintentionally complicit in their own domination to the extent that they, like all other agents engaged in the field, accept it (they misrecognise it) as a natural part of the world.

To summarize, from their social positions in various fields, all persons develop a sense of how the world works, who they are meant to be and their “socio-logical” place in the world (Bourdieu, 1981, p. 309). As I will show, this sense of one’s place shares a close correspondence with study participants’ senses of inclusion. Youth who use AAC incorporate as habitus, doxa that categorizes and devalues impaired bodies. This shapes their ‘practical sense’ of inclusion, and the strategies they employ to position themselves as included.
7.3 The study

Using a critical qualitative design, data were generated with 13 youth who use AAC (aged 15-24 years\textsuperscript{24}, 7 young women) by combining two visual methods with interviews and observations. The visual methods used were participant-generated photographs and a graphic elicitation technique termed Belonging Circles. The combined methods produced data from multiple perspectives to support analyses of relations between participants’ subjective experiences of inclusion and the objective social positions and conditions that shaped their practices (Bourdieu & Wacquant, 1992; Green & Thorogood, 2013; Shuttleworth, 2012). To participate in the study, youth needed to: be in high school or have completed high school in the previous year; be able to understand the interview questions and purpose of the research; and have developed the requisite communication skills to support participation in the study (e.g., a consistent yes/no, ability to compose a simple message using text in English). To maximize diversity across the sample in relation to participants’ ages, gender, socioeconomic status, and rural vs. urban location, and thereby optimize data quality, depth and variation (Sandelowski, 1995a), initial convenience sampling was followed by purposive sampling. Participants were recruited, following institutional ethics approval, through collaborations with three regional children’s treatment centres. All photos are used with the consent of the young people who recorded the images. A demographic summary of the group of participants appears in Table 1 below.

Table 1: Aggregate participant demographics (n=13)

<table>
<thead>
<tr>
<th>Reported ethnicity</th>
<th>Family income</th>
<th>Home location</th>
<th>Parents’ education level (n=25)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canadian only</td>
<td>$15-44,999</td>
<td>Major urban</td>
<td>High school</td>
</tr>
<tr>
<td></td>
<td>$45-90,000</td>
<td>Suburban</td>
<td>College/baccalaureate</td>
</tr>
<tr>
<td></td>
<td>$90+</td>
<td>Small town</td>
<td>Postgraduate</td>
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<tr>
<td>Additional ethnicity</td>
<td></td>
<td>Rural</td>
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To optimize data quality and counter queries about the putative ‘authenticity’ of accounts generated through mediated communication modes, I developed a critical dialogical \footnote{\textsuperscript{24} In the province where the study was conducted, disabled students are afforded the option of remaining in high school longer than their same-aged peers, which accounts for the age range across participants.}
methodology (see Chapter 4/Teachman et al., forthcoming) that draws on Bakhtin’s (1981, 1994) dialogism to reframe ‘voice’ in interviews, and communication more generally, as always already multiple and relational, thus, dialogical. Accordingly, participants communicated using their preferred communication modes, including use of a communication partner. Two interviews (ranging from 30-150 minutes) were conducted with each participant. An initial in-depth interview was used to elicit descriptions of youths’ day-to-day lives, that is, their everyday routines, activities and the social settings they traversed. Following the initial interview, participants were provided switch-adapted cameras and asked to record (or select from a personal album) images that represented their sense of inclusion (and/or exclusion) over a two-week period. In a second interview, the researcher and participant collaboratively reviewed and discussed the meanings youth ascribed to their photos, and their reasons for taking particular photos. In some instances, participants captioned their photos (Packard et al., 2004) to more explicitly articulate their intent in recording the image. Thus, the photo-elicitation method added complexity and depth to the data (Allen, 2012; Smith et al., 2012) and provided for “a situation of co-analysis” with participants (Gibson et al., 2013, p. 387).

Like photographs, graphics can be used in interviews to enhance participants’ reflexivity, elicit discussion about abstract concepts, and generate data in ways that are non-linguistic (Bagnoli, 2009). As the photos were discussed, youth were invited to indicate their corresponding sense of inclusion by selecting a location on a Belonging Circle. This simple schematic graphic of three concentric circles allowed participants to show and talk about relative degrees of inclusion. In the presentation of the data below, selected Belonging Circles display youths’ responses in blue shading and are placed adjacent to the corresponding photos. Both visual methods helped optimize the quality of data because they were well aligned with what are termed ‘visual strategies’ in AAC where graphic symbols, line drawings or photos are used to support conversations (Beukelman & Mirenda, 2012).

In total, the data generated with participants included: 27.5 hours of videotaped interviews, 951 photos and 80 Belonging Circles. Interviews were video-recorded to ensure that rich non-verbal interactions, which would be largely diminished through transcription, could be reviewed in all their complexity (Gravois et al., 1992). Accordingly, all interview video recordings, observational field notes, captions and photo data were entered into Atlas.ti v.7 software, which allows for direct coding and memoing of video data. Analysis followed recommended
procedures and techniques for ensuring the quality of qualitative research (Kvale, 1996; Miles & Huberman, 1994; Sandelowski, 1995b; Sandelowski & Barroso, 2002). Briefly, all data for each participant was analyzed following a flexible analytic guide consistent with the study aims and Bourdieusian conceptual framework. Narrative case summaries were prepared by integrating participants’ accounts, photos, Belonging Circles and my observations to develop a sense of the whole (Sandelowski, 1995b) for each participant before moving to analyze across accounts. A more in-depth discussion of the study methods and methodology has been reported elsewhere (Chapter 5/Teachman et al, forthcoming).

7.4 Results and interpretations

The study results indicate that negative valuations of their bodies and communication abilities were deeply inscribed and embodied by the participants. My analysis draws on Bourdieu’s relational concepts to consider the interplay among physical and communication impairments, bodies, and socio-material environments in mediating the practices and ‘practical sense’ of inclusion of youth who use AAC. In their photos and Belonging Circles, as well as in their talk, the youths’ practices (which Bourdieu has termed position-takings) reflected the separate, constricted and marginalized positions imposed on them, and the coding of their bodies as burdensome, incoherent and lacking value. However, their practices also resisted these categorizations in important ways. In this section, I present the study results in two parts. First, to ground my interpretation of youths’ practices, I provide a descriptive summary of the group of participants and sketch out the social positions and conditions of existence that characterized their lives and structured their habitus. Then, drawing on Bourdieu’s theory of practice, I outline a theoretically-informed analysis of three interrelated sets of practices adopted by youth as they worked to be included.

All youth in the study lived at home with at least one parent, and all had cerebral palsy with associated communication and mobility impairments. Twelve participants used a wheelchair as their primary mode of mobility, one walked short distances indoors, and three crawled within their home. Three had cortical vision limitations and two had a concurrent chronic disease. Ten youth were in high school at the time of the research; three had completed high school in the previous year (one worked part-time, one attended a day program four days per week, and the other spent most days at home).
Eleven participants experienced levels of physical impairment that, in medical parlance, would be termed ‘severe’; two had more ‘moderate’ impairments. Twelve were largely dependent on others to assist them with washing, dressing, toileting, grooming and aspects of feeding (four received nutrition wholly, or in part, via a gastric tube); the remaining participant, Audrey (all names are pseudonyms), required assistance with some aspects of dressing and grooming. Nine experienced involuntary, and sometimes painful, spastic body movements; eight had swallowing impairments which caused uncontrolled drooling. All communicated using a range of AAC systems. In addition to modes including eye gaze, gestures, facial expressions and non-verbal vocalizations, seven participants were able to produce dysarthric speech which was largely understood by their family, but not by unfamiliar listeners. As well, 11 used a speech-generating device; one a communication book and one, a spelling board. These technologies were primarily used to communicate with less familiar listeners, in school or community settings; only three of 13 participants reported using their speech-generating device to augment communication at home. Below, I sketch out and illustrate the social arrangements and conditions of existence that characterized day-to-day life for youth in the study and contributed to structuring their habitus.

7.4.1 Social positions and conditions of existence: Structuring habitus

Though participants differed in socioeconomic status, geographic location and family situation, they shared experiences in relation to growing up with physical and communication impairments. Their accounts revealed that living with impairments involved daily confrontations with physical pain, physical and emotional discomfort and/or fatigue, all of which were compounded by communication difficulties. For participants and their families, the ‘ordinary’ demands of everyday life required extraordinary investments of time and energy. Because of these day-to-day embodied experiences of impairment, youth were obliged to have a heightened awareness of their bodies, including how others judged them as disordered or abject:

Living with a disability like mine can be really, really, really, really hard and I would not want anyone else to suffer like I do sometimes. I sometimes feel so trapped and anxious and invisible. …It takes a lot of courage and ‘stick-to-it-ness’ to be me and deal with the frustrations of life.

What frustrates me most of all is communication stuff. Everyday someone asks me a question and then walks away before I have time to answer them. It sometimes makes me want to not even bother trying to make an answer.

Most people assume that just because my muscles and lungs and stomach do not work the way theirs do, that my brain and heart and soul are disabled too. (Jamila)
The youths’ physical and communication impairments and their concomitant dependencies meant they were rarely alone. Participants reported that the crowds, noise, unpredictability, derogatory comments, and unwanted stares of strangers combined to elicit feelings of fear, anxiety, frustration and embarrassment that were only somewhat offset by the reassuring presence of the person(s) accompanying them.

All of the participants had developed idiosyncratic systems of communicating with family members. Although a number of youth reported that their siblings were sometimes best at understanding them, it was their mothers who spent the most time with them in and out of the home, a finding that is consistent with research that examined mothering disabled children (McKeever & Miller, 2004). At school or in other public spaces, participants’ alternative communication modes were most often discounted as inarticulate, out of sync, and illegitimate. As Jack observed:

No matter how good a person gets trained on the different kinds of disabilities, they are still missing some key factors on their way to speaking to a non-speaking individual. … Most people talk to me… as if they were talking to a little child who has done something wrong. They don’t take into consideration that I am all together up there.

Nearly all of the youth described spending some amount of time each day, both at home and school, involved in activities to promote standing, walking, strengthening or stretching. Youth generally viewed these activities, even when painful, as necessary and beneficial. With the exception of Sarah, who rejected communication technologies, all of the youth and their families were involved in ongoing training, programming and maintenance of these devices for use at school or in other social spaces.

During the week, life revolved around home and school for nearly all participants, with little time for activities outside of home. As one mother commented: “It’s just not doable.” Physical barriers resulted in some youth being confined to particular spaces at home and isolated from some aspects of family life. As they grew larger and heavier with age, it was more difficult for families to assist their children to access all of the spaces in their home. Regardless of their school placement, youth in the study reported almost no little interaction with their non-disabled peers and few, if any, school-based friendships. Within their school, the youths’ movements were circumscribed by a variety of safety rules and the in/accessibility of the physical space.
Nearly all of the youth recorded images to comment on their school’s accessibility (two appear in Figure 5 below) and its contribution to their sense of inclusion or exclusion.

**Figure 5**

In summary, participants’ lives unfolded under conditions and constraints that would be considered intolerable for most non-disabled persons. Day-to-day life revolved closely around family and home where care and management of their bodies dominated their routines. In school, youth were almost exclusively positioned at a distance from non-disabled students. In some instances, this social separation corresponded with physical separation, often in the form of segregated classrooms. However, even when youth were in close physical proximity to non-disabled persons (e.g. in the hallways at school, in the shopping mall, in mainstream classrooms), their social interactions were delimited by the effects of negative social valuations and inhospitable physical arrangements. Following Bourdieu, these common experiences and circumstances - these social relations of disability - contributed to the structure of the participants’ habitus. In what follows, I interpret the interrelations among participants’ life conditions and social positions, their structured habitus, and their practices to help understand how they made ‘practical sense’ of the notion of inclusion.

**7.4.2 Positions, dispositions and position-takings: Articulating inclusion**

My analyses identified three interrelated sets of practices adopted by youth as they made ‘practical sense’ of the notion of inclusion. The first, most prevalent across the data, reflects dispositions of accommodation, that is, a sense that their marginalized position in the social order was reasonable and necessary. Misrecognizing the arbitrary systems that excluded or marginalized them, youth expressed a preference for the enclosed and ‘special’ positions they
inhabited. Following this practical logic, inclusion was perceived as something for others. In the second set of practices, youth actively struggled for inclusion as they understood it. This was manifest in their resistance to socially-imposed negative valuations and in the extraordinary investments they made toward ‘overcoming disability’ and approximating ‘normal’. A third set of practices involved position-takings where youth, with their families, reformulated notions of family, friends, and community to create positive micro-spaces of inclusion on their own terms. In so doing, they resisted dominant ways of ascribing value and meaning to lives. Reformulating inclusion involved shaping it along the lines of their own abilities, preferences, and strengths (Gerschick & Miller, 1995). Although the second and third sets of practices were less prominent across the data, they represent important variations for understanding how youth made ‘practical sense’ of inclusion. It is worth noting that none of these practices can be characterized as entirely reproduction, resistance or reformulation. Practices that can be interpreted, from one perspective, as resistance to the dominant order of things, can also be seen, in other ways, as reproduction. In what follows, I elaborate on each of these three sets of practices.

7.4.2.1 Accommodation: a ‘special’ sense of inclusion

Amongst the nine youth placed in segregated classrooms, it was largely taken for granted that segregation within special education spaces was necessary and reasonable. Over years of repeated exposure to systems of classification that judged them unqualified for mainstream education, the youths’ habitus incorporated this classification as special, deficient, and/or dependent. The broader high school environment was experienced as inhospitable and intimidating, and youth had developed a practical preference for enclosed and segregated spaces where the low expectations placed on them seemed reasonable and logical. For example, Bernard, who attended a fully segregated high school, referred to himself as one of the “PD” (physically disabled) students. He explained that “normal” students wouldn’t move aside to allow him to navigate communal spaces such as the cafeteria or the assembly hall. He said he felt intimidated, unsafe, and “out of place” when he was in the “integrated” spaces of the school, but reasoned this didn’t bother him much because he wasn’t interested in mixing with the “normal kids”. To show this on a Belonging Circle, Bernard indicated a spot outside of the circle graphic, nearly off the page.
For Jamila and Hadia, who attended some mainstream classes, the relative safety of the special education classroom offered a type of respite. Jamila said she felt it was not safe to drive her wheelchair through hallways packed full of bustling students, pointing out that her view of obstacles (such as the staircase in Figure 6) was blocked, and all she could see were “bums and bodies”. She felt more included in her special education class, and illustrated this through images of a mechanical lift and raised plinth (Figure 6). Jamila was accustomed to and relied on these physical arrangements. She marked the centre of a Belonging Circle to correspond to her sense of inclusion in her “home room”, and the second ring to describe how she felt as she navigated other parts of the school.

**Figure 6**

The data suggest that, irrespective of their abilities, youth who use AAC were ‘placed’ in the school system primarily according to their impairments, and learned to judge themselves and adjust their expectations accordingly. For example, Bernard described helping his teacher trouble-shoot computer technologies in his classroom. In the micro-field of his segregated classroom, Bernard’s knowledge of computer systems and relatively higher capacity to demonstrate his academic skills were recognized as cultural capital that accorded him certain privileges denied to his classmates. In another example, Peter, who had visual impairments as well as communication and physical impairments, had mastered use of a complex auditory scanning system to access his speech-generating device. Yet, opportunities for Peter to accrue valued cultural (academic) capital were foreclosed by his emplacement in special education classrooms where he was exposed to a ‘life skills’ curriculum focused on teaching skills for independent living. Several photos taken at school depicted a food preparation lesson which, for Peter, involved watching an educational assistant prepare sandwiches (Figure 7 below).
Peter said he felt this was a ‘ridiculous’ activity and a waste of time since he would never be able physically to make sandwiches. Yet, he stated he felt most included in the quiet, familiar and safe environment of the special education centre at his school. Having internalized the social arrangements and conditions of segregated education spaces, he had adjusted his expectations and preferences accordingly. The perceived advantages of the low expectations at school were echoed by Stewart, Stephen, Audrey, Jamila and Bobby who happily declared that their lack of homework was an advantage of being ‘special’. They gave no signs of perceiving this as an indication of negative evaluations of their educational potential.

The youths’ strategies reflect the dispositions developed through immersion in the school and other social spaces. Habitus, following Bourdieu (1984) provides a sense-making schema that makes a virtue of necessity. Disabled youth, having grown accustomed to conditions that circumscribe their participation, incorporate those conditions as preferences. As Fawcett (2014) observed:

For the disabled child or young person, if they are viewed or positioned in a certain way and have no access to other perspectives or ways of operating, then disabling processes become internalized...Similarly, …targeting or focusing on the ‘special needs’ of disabled children can perpetuate exclusion and marginalization rather than the valuation of difference and diversity within the mainstream. (p.6)

The participants’ accounts suggest special education ‘makes’ special students. Stigmatizing and sometimes frightening experiences outside of protective and segregated positions continually reinforced the youths’ embodied beliefs about the necessity of possessing a ‘normal’ body outside the confines of segregated ‘special’ spaces. Thus, their position-takings can be interpreted as sensible, practical strategies to avoid the hostile ableist conditions that they encountered in mainstream classrooms.
Connor and Ferri (2007) suggested that, while the catchword ‘special’ in the context of education connotes “a safe haven from an unwelcoming general education system” (p. 67), it also obscures the oppressive conditions imposed on those categorized as ‘special’:

> Used as a euphemism, ‘special’ serves as a gauze curtain behind which the word ‘disabled’ resides – perhaps too painful to be confronted as is. Sadly, more often than not ‘special’ (i.e. disability) becomes synonymous with exclusion, segregation and marginalization. (p. 64)

Agents’ subjective expectations and aspirations, through the dispositions of habitus, are adjusted to their objective conditions of possibility (Bourdieu, 2000). As Bourdieu explained, “early and lasting insertion into a condition defined by a particular degree of power, tends through experience of the possibilities offered or denied by that condition, to institute durably in the body dispositions-to-be.” (p. 217) The youths’ accounts suggest their aspirations were shaped by the constraints placed on them by an educational system that denied them the credentials (a high school diploma) necessary for entry into college or university. Those in segregated classrooms infrequently had homework, and the curricula they described were skewed toward life skills training with little expectation that they would reach academic goalposts. Queries about future aspirations were mostly avoided or deflected with an abrupt “I don’t know”. With probing, Bernard shared that he might volunteer at a children’s rehabilitation centre. Peter felt “a bit scared” about life after high school, but emphatically stated: “I don’t want to stay home all day!” He suggested he might look into day programs for disabled adults. Only Audrey envisioned having a job in the future; she imagined working in a restaurant, just as her mother did. However, she ruled out future possibilities, such as learning to drive or going to college, as “too hard and too scary”.

Most of the examples I have cited in describing this set of practices involve position-takings in the field of education where participants spent the majority of their time when not at home. However, similar practices were observed across the data as youth described their experiences in public spaces. With the exception of Jack, all of the participants related numerous examples where, in shopping malls, public streets, restaurants, or other mainstream social spaces, strangers’ stares and rude behaviours served as reminders of the negative ways their bodies and their alternative communication were coded. The youth reported varying approaches to these experiences – from avoiding these spaces altogether or attempting to minimize unwanted attention, to ensuring they were in the company of a familiar communication partner who acted
as an interlocutor. Bernard found it “frustrating” and “tiring” to talk with strangers who seldom took the time to listen. Still, he said people were “doing their best”. This was associated with concerns for his personal safety: “In community spaces, I don’t feel safe”. Accordingly, for Bernard, the logical and practical course of action was to avoid public spaces whenever possible. Emma reported she stayed clear of shopping malls altogether because people stared too much. Audrey described similar experiences, saying: “I feel bad and just want to leave”. Meg preferred not to use her speech-generating device when she went out “in public” because it made her look “too different” and drew additional unwanted attention. Both Sarah and Meg said they avoided eating out in restaurants because it was ‘humiliating’ to be fed in public. In general, youth navigated these spaces by drawing on the social capital they were able to access through family or paid attendants. Without this, public spaces were uncomfortable, frightening and unsafe for them.

This first set of practices demonstrates the processes by which the youths’ formulations of inclusion were delimited by the constraints of the social arrangements and conditions imposed on them. Following Bourdieu, “habitus is this ‘can be’ which tends to produce practices objectively adjusted to …the perceptions and evaluation of the possibilities inscribed in the present situation.” (Bourdieu, 2000, p. 217) Thus, individuals have a practical, embodied sense of their present and potential position in the social order (Bourdieu, 2000). As a result of the negative social value accorded to impaired bodies and communication, the youths’ social positions at school and in other public spaces were characterised by marginalization and disadvantage. From these positions, opportunities to develop cultural capital in the form of educational credentials, or social capital in the form of social networks, were severely constrained. The youth, their families, and educators all invested extraordinary time and energy in ongoing body-work. These investments reflect logical responses to dominant assumptions linking improvements in a person’s physical or communication functions with improvements in their life conditions, or in Bourdieusian terms, the conditions of possibility open to them. However, the data generated with the three youth who had completed high school suggests their worlds became further constrained as options to take up positions in fields outside the family were further delimited. This is reflected in Meg’s mother comments in reference to the day care program that Meg attended: “It was really the only choice”.

While the data suggest that the youth adjusted their practices to their social positions and conditions of existence, they also drew on their available capital to claim power and improve their position within the constrained spaces they occupied. For example, among the group of physically disabled students with whom he was placed at school, Bernard ranked himself “the smartest” in his class and enjoyed the privileges this accorded him (e.g. he was allowed to use the interactive whiteboard, and was allowed to leave his classroom to roam the school on his own). He expressed a strong aversion to all interactions with the ‘DD’ (developmentally delayed) students. He disliked spending any time with them, saying: “they do nothing”, “they don’t talk”, and “they just hang out”. Here, Bernard’s comments suggest he strongly resists any association with students whom he perceives as having even less physical and/or linguistic capital than him.

It is important to point out that this interpretation in no way suggests that Bernard’s position-takings represent a reflective, or conscious, intent to demean his fellow students. Rather, they demonstrate his embodied understanding of “the rules of the game” in relation to education. Through habitus, he pre-reflectively makes sense of the world in ways that are logical and reasonable because he has taken up these systems of classification and misrecognizes their arbitrary and oppressive nature. Similar self-rankings were apparent in other youths’ position-takings. Meg, who attended a day program for young disabled adults after she graduated from high school, reported she was the only client who “knew how to behave”. She struggled to improve her social position by aligning herself with the younger staff at the program and identifying herself as a “minder” who kept other clients out of trouble. Jack’s comment: “They don’t take into consideration that I am all together up there”, also suggests that he unwittingly leverages dominant valuations of intellectual capital in order to assert his social position as superior to persons with intellectual disabilities. Thus, within the marginalized social space of special education, social hierarchies were reproduced, structured by the doxa of the field of education but with relative adjustments to the type of capital at stake. This jostling for a relatively improved position can also help explain how youth tacitly came to know their place. Through the perceptual schema provided by their habitus, nearly all of the youth pre-reflectively calculated that they were unlikely to be successful in mainstream education spaces, or feel safe and valued in the public sphere. Accordingly, they developed a ‘practical sense’ of inclusion in enclosed, protective, ‘special’ social spaces where they were more likely to distinguish themselves by highlighting their relative strengths. As Bourdieu pointed out, “every
reproduction strategy is at the same time a legitimation strategy.” (1986, p. 254) Next, I explore the second set of practices aimed toward claiming inclusion.

7.4.2.2 The struggle for inclusion: assimilating the dominant ideal

Bourdieu postulated that persons in dominated social positions have two options: accommodation, where one makes a virtue of conditions of necessity, or investments in “individual effort[s] to assimilate the dominant ideal” (1984, p. 384). The second set of practices aligns with the latter option and involved resistance to the imposition of social categorizations through extraordinary individual investments toward approximating dominant ideals of ‘normal’. Across the data, these practices were most evident in the accounts of Sarah, Jack and Jamila, though all of the participants were invested in normalizing activities of one type or another. Unlike their counterparts who experienced education in segregated social spaces, Sarah and Jack were placed almost exclusively in mainstream classes throughout their education. Thus, it would be expected that their habitus adjusted over the years of their schooling in ways that reflected this ‘normal’ social emplacement. Both Sarah and Jack evidenced dispositions that rejected the constraints of being categorized ‘disabled’. Having incorporated the negative coding of impaired bodies, both worked to maintain their precarious social positions in mainstream educational spaces by ‘overcoming’ or minimizing their impairments and avoiding interactions with other disabled students at their schools. For them, ‘inclusion’ involved arduous and ongoing struggles to meet the standards ‘normally’ expected of their non-disabled peers, regardless of the personal costs. Although their individual circumstances and strategies differed, both fought to maintain or increase their overall capital and thus, avoid being categorized as tragic, unfortunate, or, in short, disabled.

Sarah had completed high school in the year prior to the research. She went to great lengths to present herself as ‘normal’, independent and capable. She used a power wheelchair but resisted other assistive technologies, suggesting they didn’t fit with her self-identity: “I feel stupid using a speech-generating device…it is just not a good fit. It’s not me”. She felt that using a letter display to spell out words showed that she was “normal” and “smart enough to spell”. In most of her photos, Sarah arranged the setting and her own comportment in ways that conveyed her identity as a ‘typical’ young woman. For example, on the left in Figure 8 below, Sarah (in red) presents herself seated on a couch beside her one girlfriend. On the right, she portrays herself
using a tablet computer. She is seated in her power wheelchair, but the chair is obscured by the board that supports Sarah’s tablet. Sarah explained that she had asked her father to fashion the wooden tray to fit onto her wheelchair because she felt most wheelchair trays were too “medical and institutional” in appearance. For both photos, Sarah completed a Belonging Circle indicating these photos portrayed aspects of feeling included.

![Figure 8](image)

Sarah’s account suggests she was acutely aware that in most fields, assistive technologies signal dependencies and detract from the user’s legitimacy as a ‘normal’ or non-disabled person. Her rejection of speech-generating technologies can be interpreted as a strategy to preserve some measure of linguistic capital. To use a device would be to acknowledge and make visible her communication impairments. The tradeoff was that her communication interactions were constrained by the availability of a familiar interlocutor which greatly reduced opportunities for her to acquire social capital; although Sarah said she was well known at school, she described having just one friend. At home, she was almost always in the company of her mother, and when at school, Sarah’s educational assistant and her one friend were the only people who understood her speech. She had earned a high school diploma, and had been elected prom queen - a distinction that she suggested was recognition of her persistence in ‘overcoming’ disability.

But as Sarah spoke about her pride at these accomplishments, she gradually revealed more information about the extraordinary efforts she had invested toward masking her differences. For example, she confessed that in five years of school, she had never used the toilets because she didn’t want the non-disabled students to know that she needed assistance for toileting. She simply waited until she was at home. Sarah needed assistance with feeding, so she ate lunch with the disabled students in the special education area of the school where her need for help would go unnoticed by the non-disabled students. Nevertheless, she said she had no interaction with the
other special education students because: “I didn’t belong there”. Early in her teen years, Sarah had been quite distressed about her inability to control drooling, so she had elected to undergo surgery to address the issue. She found it scary to navigate the hallways in a school of over 2500 students, but she rejected the notion of leaving her classes ahead of the other students because, as she explained: “I hated being treated as if I was special”. Instead she had opted to brave the crowded hallways in her power wheelchair and explained: “That’s just how it is”.

Sarah’s efforts to appear ‘normal’ by strategically deploying her store of physical and linguistic capital carried forward into other fields. For example, when she attended local baseball games, she stated that it was important that her mother help her out of her wheelchair and carry her up into the stands. When asked how she felt about sitting in the area designated for people who use wheelchairs, she responded: “I’d rather not go”. Long-term exposure to mainstream school spaces predisposed Sarah to maintain inclusion through practices requiring perseverance and hard work. She put it this way: “You know the saying – if you don’t use it, you lose it”. Furthermore, when Sarah stated “That’s just how it is” she signaled her adjustment to the harsh and inequitable demands placed on her as she took on the work of ‘fitting in’ to mainstream social spaces.

Sarah’s actions are representative of practices shaped by habitus where inclusion is envisioned as an individual struggle to assimilate the dominant ideal and resist being categorized ‘disabled.’ However, Sarah described feeling isolated, confined and uncertain about her future within a few months after completing high school. She stated that she had stopped using Facebook, a social networking website, because it was too distressing to read about her school peers who had “moved on,” while she now spent nearly all of her time at home with her mother. She had looked into attending a college program for students with disabilities, but had been informed that she would be required to use a speech-generating device and would have to become “more independent”. Both of these impositions would disturb Sarah’s embodied resistance to adopting assistive technologies. Sarah described her situation as a dilemma. On one hand, she desperately wanted to meet social expectations that she become a productive young adult – she thought perhaps she might work with elderly people in some capacity. On the other hand, acquiescence to the college’s demands represented a challenge to her sense of herself and her place ‘on the margins of normal’ - a place she had fought hard to maintain through logical and practical strategies aimed at locating herself as among those who are socially included.
Jack’s account, while mirroring that of Sarah, provides further insights into participants’ struggles for inclusion. Like Sarah, Jack had been positioned primarily in mainstream high school classes and graduated with a diploma after seven years. Across his account, Jack presented himself as a masculine, sport-loving and productive young adult, while minimizing his impairments and the effects of exclusionary interactions. Jack’s photos, taken to portray his sense of inclusion, predominantly featured his participation in sport and in his part-time job as a speaker and disability advocate for a local school board. Early in the first interview, Jack announced: “I’m a working man now!” Figure 9, below, includes two of Jack’s photos, his captions, and his sense of inclusion as indicated using the Belonging Circle method, which was the same for both photos. The photo on the left shows Jack using his upright adapted cycle. On the right is an image Jack recorded to show his heavily booked speaking schedule.

Figure 9

While Jack’s ‘practical sense’ of inclusion, like Sarah’s, formulated inclusion as an individual struggle to overcome negative social valuations of impaired bodies, his strategic practices differed. Whereas Sarah primarily worked to mask her impairments in an effort to avoid discrediting her physical and linguistic capital, Jack embraced the doxa of the rehabilitation field in which he had been immersed since birth. With the ongoing support of his mother, he developed a mastery of speech-generating technologies. Among the study participants, Jack was alone in reporting he used his device “24/7”. Jack shared that he had refused to provide written copies of his advocacy presentations, reasoning that they would lose their power if reduced to words on a page, insisting: “they are my words”. Here, Jack suggested he implicitly understood that his competence in approximating embodied norms of communication was a source of increased linguistic capital that allowed him to command an audience, claiming symbolic power
as a player in the field of paid work. This is a particularly striking example of Bourdieu’s conceptualization of social relations as irreducibly linked with contests to improve one’s position by acquiring capital. Likewise, Jack’s engagement in ongoing body-work and active sports, such as wheelchair hockey, weightlifting, and cycling, can be interpreted as practical maneuvers to gain physical capital and improve his social position in and across fields.

As noted, the strategic patterns of practices revealed across the data were apparent in one way or another for all of the participants. My intention in describing the cases of Sarah and Jack in more depth is to elucidate the interrelations among participants’ social positions as persons with disabilities and their dispositions and practices in order to understand the differing ways that youth in the study made ‘practical sense’ of inclusion. Participants’ position-takings on inclusion varied, but all engaged in practices that resisted their devalued social positions by engaging in various types of body-work or embracing assistive technologies to increase physical and cultural capital. Given the social value accorded to independent, upright, talking bodies, these practices make ‘practical sense’ and they are rigorously reinforced in the fields of rehabilitation and education (Gibson & Teachman, 2012).

A final and particularly poignant variation of the struggle for inclusion was apparent across Jamila’s account as she repeatedly appealed for recognition as a human being. Jamila repeatedly articulated a sense that she was judged as less human or invisible:

> Most people assume that just because my muscles and lungs and stomach do not work the way theirs do, that my brain and heart and soul are disabled too. …I am a real and whole human being. I think, I feel, I believe, I see, I hear. I feel things. I like textures and touching things to learn more about them even though my muscles and my body doesn’t work…I am still a real and whole human being.

> People treat me like what I have to say does not exist….I want them to know that it is not OK to treat me like I am invisible, or talk about me like I do not exist. I do not do that to them and they should not do that to me….Being an AAC user is hard and lonely and tiring and slow but it beats the heck out of the options.

In other conversations, Jamila said she noticed that, “other people see me as more human when I’m in my stander”. Referring to her speech-generating device, she noted: “my device helps other people see me as a smart and whole human being”. Jamila’s comments suggest her ‘practical sense’ of inclusion was, at least in part, envisioned as a struggle to position herself in what might be called the ‘field of humanity’, that is, a field inclusive of all persons by virtue of being
persons. Jamila had been abandoned by her birth mother, and had secondary health conditions that caused her to be dependent on highly visible life-sustaining medical technologies (e.g. she used a ventilator and multiple alarm systems). I suggest the combination of these circumstances may account for her acute awareness of the negative coding of her body. Her comments resonate with Goffman’s (1963) account of how stigmatization constructs some groups as “not quite human” (p. 5) because their ‘impaired’ bodies fail to meet dominant standards for what might 'naturally' and 'legitimately' be considered a human body. Thus, they are excluded from or, at best, marginalized across nearly all fields. Of course, disabled and non-disabled people are mostly unaware that they are implicated in perpetuating dominant notions of what counts as a ‘human body’. As Hughes (2007) argued:

The invulnerable self is a fantasy and form of self-deception associated with carnal ‘normalcy’. It is widely used by non-disabled people to create and sustain social distance between disabled and non-disabled people….Ironically, the ontological insecurity of non-disabled identity is the original sin that pushes disabled people to the margins of the human community” (p.681)

By denying their humanity, some people with impairments are made to feel they have no place in the human community. That is, they are capital-less across all fields of practice – essentially lacking personhood. I next set out the third set of practices which, I argue, represent creative strategies for producing alternative formulations of inclusion outside of a priori societal definitions.

7.4.2.3 Reformulating Inclusion

The third set of practices is evidenced across the data as activities undertaken to create positive micro-spaces of inclusion. These practices were characterized by the interplay of strategies of reproduction and resistance as youth, with their families, struggled at the margins of fields to ‘make’ inclusion on their own terms. They did so through attempts to adjust the forms of capital that are valued in particular social spaces, and subvert the oppressive social conditions and arrangements that constrained youths’ opportunities to accumulate capital. These practices are important because they begin to suggest ways to move past impoverished and potentially, harmful, notions of inclusion.

I begin by describing how within the field of family, parents, youth and other family members made adjustments to promote youths’ sense of inclusion. Overwhelmingly, participants indicated they felt most included within the familiar and protective social space of family. Jack was the
only participant to indicate that he felt somewhat excluded when he was at home, but he did not elaborate. Apart from this exception, there were numerous examples where families ‘opted out’ of social pressures for a ‘normal’ family life; instead, they invested in creating alternative lifestyles that incorporated social settings where their child was valued and adapted the physical environment to ‘fit’ with their child’s capacities. Chloe’s mother commented: “We pretty much arrange our lives around doing things and going places where it will be a positive experience for her”. This view is representative of those of a number of parents in conversations that preceded or followed the interviews. In their accounts, nearly all of the youth cited get-togethers with extended family as among their favourite activities, and these events featured prominently in the photos that they associated with feelings of inclusion. Grandparents, aunts, cousins, and family friends that were “like family”; all were described as important people in the youths’ lives who took the time to communicate and share in activities where youth experienced a sense of safety and success. For example, Sarah’s photos featured scenes with her aunt at a cat shelter where they regularly volunteered together. Hadia photographed a favourite uncle who delighted her by programming ‘secret’ messages and jokes into her speech-generating device.

Participants’ presentations of family relations suggest that, over time, and with personal exposure to impairment, their family members made adjustments that blurred distinctions between disabled and non-disabled divisions, re-valuing youths’ alternative communication modes and their impaired bodies. This is not to ignore that participants, with their parents, engaged in ongoing practices aimed to approximate more ‘normal’ bodies and more legitimized modes of communication. But it is important to point out these practices were intertwined with efforts to resist the devalued positions imposed on youth who use AAC. My analysis suggests that what youth valued most was the time invested by others to slow down and communicate at a pace that accommodated their alternative communication modes. These strategies also demonstrate how youth drew on cumulative family social capital to claim inclusion in spaces where their capacities were recognized to a greater extent than in other fields.

Participants reported having few friends at school, and limited friendships outside of school, a finding described elsewhere (Batorowicz et al., 2014; Clarke et al., 2012; Raghavendra et al., 2012; Wickenden, 2011a). However, my analysis revealed two categories of valued friendships that were described by 10 of the 13 participants - friendships nurtured through paid attendant care and those built through associations with other disabled youth. Relationships with attendants
were promoted by parents, whether intentionally or not, through hiring similarly-aged attendants to accompany their child on community outings. Although these alliances were precarious because of their monetary component, they appeared to contribute to youths’ stock of social capital. For example, Chloe described the young attendants who took her shopping or out to movies as girlfriends she could “get out with,” proudly stressing that her mother was “banned” from these excursions. These relationships afforded opportunities for her to feel valued and recognized, and to navigate the hostile environment of mainstream spaces within the ‘margin of safety’ afforded by the presence of her attendants.

The second category of friendships describes those that youth developed with other disabled young people, both within and outside of the confines of segregated social spaces. Stephen, Audrey, Stewart and Chloe participated regularly in group activities with other disabled youth in bowling alleys, community centres, camp programs, and ski clubs, to name just a few of those portrayed in youths’ photos. Figure 10 shows two images with captions and a Belonging Circle that represents two youths’ responses when asked to record their sense of inclusion during the events they depicted. On the left, Stephen is getting ready to go bowling with friends whom he met at a camp for disabled youth. They were accompanied by a paid attendant. On the right, Bernard is bowling with one of his classmates during a school fieldtrip.

Figure 10

When they were with a group of disabled youth in these mainstream social spaces, participants reported they were less anxious and felt included. The youths’ accounts suggest their perception of being valued in these spaces was linked with social relations where they were acknowledged
and known as a person, instead of ‘unknowable’. In research on social inclusion with people with intellectual disabilities, Weisel and Bigby (2014) posited that ‘being recognised’ and ‘becoming known’ are important conditions for developing social capital, and for opening the possibility for more meaningful relationships. This sense of the importance of ‘becoming known’ was repeated across youths’ accounts:

- He used to bully me but then he got to know me. Now he’s my friend and he helps look out for me. (Audrey)
- Yeah, they know me! (Jack, describing how he is managing his own bank finances)
- I am so thankful that I have a couple of people in my life who really and truly understand me as a real and whole person ….It is good to have people who know me well enough to take the time to really talk and some who actually understand me. (Jamila)

In other examples, both Peter and Emma described themselves as enthusiastic spectators at all of their siblings’ sporting events. Peter had attended and cheered on his brother’s basketball team for several years, and reported that all of the other families and fans knew him and took the time to acknowledge his presence at the games. The league had recognized Peter’s participation by awarding him a medal. For Peter, this distinction held great value. Conferring the medal posed no threat to the positions of the players, and could be interpreted as a token gesture. However, it might also signal that, as Peter became known to more agents in this field, his ardent support of his brother and the team became valued.

Similarly, Jamila stated that, across her school activities, she felt most included in her drama program. She recorded an image (Figure 11) showing a circle of chairs in the drama studio where a space was left for her wheelchair. Her caption: “My chair fills the gap”, suggests her ‘practical sense’ of inclusion was, in part, the result of material and social conditions where she was ‘expected’ and a place was made for her.
As Bourdieu observed, acts of recognition - to be known and recognized - "literally make the person." (Bourdieu, 2000, p. 242) This notion of ‘becoming known’ as a strategy to build one’s social capital also resonates with an observation made by Kittay (2006), who is both a philosopher and a parent of a disabled child:

The desire for normality is importantly tied to the desire to be recognized as who we are and what we want ourselves to be recognized as. …Yet to the extent that we come to be identified with the anomaly, we simply are identified as someone who lacks value and even intelligibility. (p. 106)

To summarize, study participants engaged in three types of creative practices to make ‘practical sense’ of inclusion: accommodation, assimilation of the dominant ideal, and reformulating inclusion. Through their practices, participants both resisted the doxa ordering fields and reproduced the distinctions that afford relative dis/advantages to certain groups. However, by reformulating notions of inclusion, youth and their families purposefully created inclusive spaces of recognition, communion and safety. Seen in this light, their practices represent creative strategies for producing alternative formulations of inclusion that disrupt a dominant ‘vision of divisions’ by valuing alternative ways of being in the world.

7.5 Discussion

Drawing on Bourdieu’s theory of practice, my analysis of participants’ accounts makes three contributions to existing research on inclusion in relation to disabled children’s lives and children’s rehabilitation. First, drawing on an understanding of the interrelations among field, habitus, and capital, my analysis illuminates ‘social relations of disability’ through which youth who use AAC develop a ‘practical sense’ of inclusion. This sense of their place in the social order is shaped by, and reflects, the social positions and conditions imposed on youth who use AAC across fields where impaired bodies and ‘incoherent’ or mediated communication are
negatively valued. Even as the youth struggled to “incarnate the linguistic norm” (Bourdieu, 1977a, p. 659) through, for example, speech-generating devices, their accounts suggest that outside of home, most people were not patient enough to listen, or pre-judged the potential value of what youth had to say in accordance with their devalued bodies. This result further confirms that “disabled people’s bodies are subjected to the values of a society that renders them ‘less than valuable’ and inferior to those considered the embodiment of ‘normality’.” (Edwards & Imrie, 2003, p. 252) As a perceptual schema or a sense-making structure, each participant’s habitus provided a pre-reflective knowledge of what is logical or practical, and delimited their sense of who they ought to be and what was expected of them.

Youth who use AAC develop a practical understanding of the world in the only ways possible from the points of view afforded from their social position as disabled persons. Thus, they come to an understanding of inclusion that reflects their adjustment to the conditions of possibility that characterize their existence and, like all agents, misrecognize the arbitrary nature of the systems of classification that devalue and dehumanize them (Bourdieu, 2000). While participants’ dispositions differed, comments, such as “They are doing their best” (Bernard) or “That’s just the way it is” (Sarah), exemplify their internalized understandings of, and resignation to, the way their bodies were coded as deficient and dysfunctional. Bourdieu (1977a) posited that “speech always owes a major part of its value to the value of the person who utters it” (p. 652). Having incorporated negative valuations of their bodies and their communication, the youths’ practices reflected a sense that, in certain conditions, it was most practical to acquiesce and be silent.

Given the hostile social conditions that youth who use AAC encounter in a world constructed for ‘able’ bodies, it is unsurprising that they come to view themselves as ‘misfits’ in mainstream social spaces, and prefer to avoid exposure to stigmatizing and frightening situations. They have little choice but to accommodate the devalued social positions assigned to them, although this does not preclude them from engaging in struggles to improve their ranking in the social ordering of bodies. They make sense of inclusion in the only ways possible.

A second contribution concerns the ways in which unquestioned formulations of inclusion, and the programs and policies premised on these, can act to perpetuate symbolic violence. In this research, two dominant forms of inclusion had effects for the participants: inclusion as presence ‘in’ a space, and inclusion as the achievement of ‘fitting in’ to ‘normal’ spaces. In the first, inclusion is conceptualized as being merely present in a particular space such as a neighbourhood
school. This formulation risks reproducing the exclusionary conditions it was intended to overcome, for example, by placing students in local schools that arbitrarily separate disabled persons and keep them in their place. Indeed, Bourdieu (1986) suggested that schools have become the most influential social spaces of reproduction of social divisions and hierarchies. Not only are youth in many segregated school spaces denied valued credentials, they are made to feel that this is a result of their own ‘natural’ incapacities and impairments. This constitutes a type of symbolic violence that is “all the more powerful because it is, for the most part, exercised invisibly and insidiously through familiarization with a symbolically structured physical world and through early and prolonged experience of interactions informed by the structures of domination” (Bourdieu, 2000, p. 169).

Possessing little of the physical or linguistic capital deemed necessary for mainstream education, all but two study participants were placed within segregated school spaces. These spaces provided a modicum of protection against the realities of an educational system that was not designed for them, but simultaneously exposed them to conditions where they had few opportunities to acquire cultural capital (in the form of academic credentials, knowledge and skills) or social capital (as would be afforded through a social network of friends). I concur with scholars who have suggested that the shift away from ‘schools for the disabled’ toward locating special education classrooms within local schools creates an illusion of inclusion (Graham & Slee, 2008; Swain & Cook, 2001). Furthermore, my results point out the extent to which these institutional practices foreclose trajectories and delimit disabled youths’ embodied sense of ‘realistic’ aspirations. Believing they are not capable or ‘smart enough’, study participants who were placed in ‘special’ education developed a practical acceptance of “the inevitably limited spatial horizons of the impaired body” (Allen, 2004, p. 502).

The second formulation of inclusion, which had effects for youth in the study, is premised on taken for granted assumptions about the positive value of being included in idealized ‘normal’ spaces. Policies and practices framed by this understanding of inclusion unreflectively aim disabled youth toward mainstream social spaces. Dominant medical and rehabilitation discourses perpetuate understandings of the impaired body as ‘unfinished’ and in need of constant ‘fixing’ to approximate normality (McLaughlin & Cole-Fountain, 2014). Likewise, tacit valuations of impaired bodies as deficient, dependent, and burdensome are rigorously, if unintentionally, reinforced. In the case of children born with impairments, the fields of family and education are
interpenetrated by the fields of medicine and rehabilitation from an early age. Distinctions, such as normal/disordered speech and normal/impaired bodies, are thus, likely to be deeply inscribed in the socialized bodies of children with physical and communication impairments. Sarah and Jack’s arduous and sustained efforts to strategically represent themselves as ‘normal’ and minimize their differences reflect their internalization of the logics of rehabilitation. These practices, reported elsewhere (Wickenden, 2011a, 2011b), reveal the complexity of their struggles to ‘overcome’ disability. While their achievements earned them some social recognition, I suggest that it is vitally important to question the costs of those achievements, and the potentially devastating effects of engaging in such exhaustive struggles.

Finally, my research begins to illuminate the mostly invisible mechanisms that contribute toward reproducing the significant social inequities which constrain youth who use AAC. These results suggest a need for systemic shifts past reified notions of inclusion toward promoting social spaces where alternative ways of being in the world are positively valued. Although participants’ practices primarily reproduced the status quo, they also worked at the margins to create locally produced forms of inclusion that attempted to transform the ‘rules of the game’ and valorize their forms of capital (e.g. alternative communication modes, alternative constructions of friendship, knowledge about living with impairments). All the youth in the study were ‘making inclusion,’ although not under conditions of their choosing. As individual struggles, their practices amount to what Cresswell (1996) described as “desperate responses to the power-laden imposition of norms and boundaries that they did not create.” (p. 166). As much as their acts of resistance might inform understandings of how youth, with their families, ‘make’ more inclusive spaces, this is not work that youth and families should have to do on their own. Nor are their efforts likely to reduce the symbolic violence that so disadvantages disabled persons. It is important to recognize that Bourdieu’s work emphasized the enduring logics of reproduction that characterize fields: “while fields are sites of resistance as well as domination...they seldom become sites of social transformation” (Schwartz, 1997, p. 121). Fields are transformed gradually over long periods of time; however, the effects of symbolic violence imposed by the wide-spread privileging of ‘normal’ bodies and ‘normal’ communication modes, can only begin to be addressed by first making them explicit and visible. Thus, by revealing the mechanisms whereby dominant visions of divisions are internalized and perpetuate disabled youths’ marginalization, my research contributes towards addressing these inequities.
Its specific contributions aside, this study provides a starting point on which to build future research that examines inclusion from a wider range of perspectives within the social hierarchies in which disabled youth are positioned. Position-takings of parents, siblings and extended family members in the field of family would enrich the interpretations offered in my research. Likewise, in the fields of education and rehabilitation, points of view from agents in more dominant social positions, for example educators, clinicians and policy-makers, would be important to consider because these groups are relatively more powerful than disabled youth and are likely to be invested, in one way or another, in maintaining the ‘rules of the game’. Examinations of their position-takings would be essential for a more comprehensive understanding of the dynamics of struggles over inclusion.

7.6 Conclusion

In this paper, I have applied a particular specification of Bourdieu’s theory of practice to examine the lives and practices of youth who use AAC in relation to inclusion. The advantage afforded by adopting a critical stance is what Bourdieu termed a kind of analytic ‘double vision’ (1989) where it is possible to consider not only the youths’ subjective perceptions of inclusion, but also the mostly invisible objective structures, and ‘social relations of disability’ that shape their perceptions and their pre-reflexive sense of where they belong. To date, very little research has been done with youth who use AAC; even less has focused on their everyday lives and, as far as I know, this is the first study to examine disabled youths’ position-takings in relation to dominant understandings of inclusion. Most research in the field of AAC has focused on technology development, anecdotal descriptions of language and literacy patterns among AAC users and their partners, or interventions directed toward the individual with communication impairments (Bedrosian, 1999; Light, 1999; McNaughton & Light, 2015). There is a need for more research that is focused on the broader material and social structures that directly influence the possibilities open to youth who use AAC throughout their childhoods and as they look forward to the future. By developing and implementing methods that helped optimize the quality of data generated, and interpreting youths’ accounts in relation to the social arrangements and conditions that shaped their perspectives, this research begins to address these gaps.

My research revealed that, for the most part, youth in the study identified themselves as ‘already included’ as opposed to ‘in need of inclusion’. From an early age, dominant medical and
rehabilitation deficit discourses are embodied by youth who use AAC, thereby predisposing them to accept, without question, conditions that would likely be considered intolerable by most people. The oppressive conditions imposed by the material structure of most social spaces (whether home, school, or community) make ‘mis-fits’ of persons with physical and communication impairments. Faced with these exclusions, youth came to prefer the private site of the family home, and the segregated protection of ‘special’ education placements, partly because these were the only places available to them. In other words, having internalized devalued and circumscribed social positions, participants’ habitus provided a schema for making a virtue of necessity.

The results suggest there is a need for careful (re)consideration of programs that unreflectively aim disabled youth toward participation in mainstream roles and spaces where the playing field, the stakes, the rules and the pace of the game are all structured in ways that will marginalize and silence disabled youth. Likewise, there is a need to attend to the foreclosure of future possibilities that is imposed on youth when they are positioned as ‘included’ in segregated spaces. Potential roles for rehabilitation, and healthcare generally, might involve 1) working to expose the hostile and dehumanizing socio-material conditions that constrain and threaten disabled youth, and 2) promoting social spaces that open a broader range of possibilities for youth who use AAC to live valued lives.

While my work takes issue with unquestioned conceptualizations of inclusion, my intent in executing the research was to examine how the lives of youth who use AAC are affected by idealized notions of inclusion and the inclusion-directed programs and policies premised on those notions. My interest is not to question the inherent worth of efforts to improve the life conditions and opportunities afforded to disabled youth. Importantly, this research contributes insights into the mechanisms whereby some formulations of inclusion may be reproducing the very hierarchical structures and exclusionary practices they were designed to mitigate. The unquestioned aims of most inclusion-focused programs and policies are to assimilate children into ‘normal’ spaces and thus efface their differences. I suggest this equates to the imposition of inclusion. As an idealized notion, inclusion suggests a society without divisions and categories of difference that structure social life (Ravaud & Stiker, 2001). In its dominant incarnation, inclusion is a politically charged discourse that shifts attention from present inequalities and
struggles and focuses it toward an idealized future. A more fruitful way forward might involve moving on from the inclusion imaginary.
Chapter 8
8 Implications and conclusion

My goal in this dissertation was to provide a critical exploration of the notion of inclusion, applied to the ‘case’ of disabled youth who use AAC. The study results presented in Chapters 6 and 7 empirically addressed the aims that I set out in undertaking the research. To reiterate:

- The first study aim was to contribute detailed descriptions of the lives and practices of youth who use AAC with a focus on their subjective experiences of inclusion. The thirteen narratives that make up Chapter 6 addressed this aim by illustrating the lives of the participants and their perceptions of inclusion. The case narratives situated and linked the youths’ accounts with the broader socio-spatial, temporal and political structures that mediated their lives and practices.

- The second study aim was to interpret the interrelations among position-takings of youth who use AAC (i.e., how they accommodate, resist or reformulate inclusion) and their social positions in and across the social spaces they inhabited. Oriented by my specification of Bourdieu’s theory of practice, the interpretation of the participants’ accounts, which is presented in Chapter 7, addressed this second aim. In that chapter, my analysis illuminated the social relations implicated in structuring the youths’ ‘practical sense’ of inclusion and reproducing the enduring social structures that oppressed them.

In this final chapter, I first summarize the key contributions of my research. Then, I discuss the implications of the study for advancing theory, for rehabilitation, and methodology, and identify a few further contributions. Finally, before concluding the dissertation, I discuss the limitations of the study with suggestions for future research.

8.1 Summary of key contributions

This dissertation makes five key contributions to knowledge in the fields of AAC and in children’s rehabilitation more broadly. I have already set out the first three substantive contributions in Chapter 7. I briefly restate them here before elaborating on further two (one substantive, one methodological):
1. This research contributes new insights into how youth who use AAC respond to calls for inclusion and how their responses contribute to reproducing the status quo. The study results demonstrate that it is in and through the devalued social positions and constricted conditions of existence imposed on them, that youth who use AAC embody perceptual schemas that shape their ‘practical sense’ of inclusion. They make ‘practical sense’ of inclusion, and work to position their selves as included, in the only ways possible from the points of view open to them.

2. By illuminating the life circumstances and delimited life trajectories of youth in the study, my research vividly demonstrates that some forms of ‘inclusion’ perpetuate symbolic violence by keeping disabled youth ‘in their place’ through the oppressive effects of misrecognised social norms, beliefs and values that privilege ‘normal’ bodies.

3. This research also contributes practical information about material and social conditions that contributed toward creating a sense of inclusion in social spaces of recognition, safety, and communion – what I have termed ‘social spaces of possibility’ - for youth who use AAC.

4. In addition to the contributions outlined above, this study adds rich, in-depth descriptions of the nature of day-to-day life for youth who use AAC. This is an important contribution to knowledge because, as I noted in Chapter 2, only a handful of studies have examined the lives of youth who use AAC. In order to evaluate and improve programs and services focused on this group of disabled youth, it is vital to understand the circumstances of their lives.

5. Finally, my work builds on emergent methods for doing research with people who have communication impairments by adding an innovative, theoretically-informed methodological approach and a suite of complementary adapted methods. In order to execute the research and meet the study aims, I needed to overcome the challenges inherent in generating quality data with a population who communicate using multiple, mediated communication modes. I have addressed this challenge by drawing on the work of Mikhail Bakhtin to theorize communication impairment and develop a novel critical dialogical methodology (set out in Chapter 4). I also carefully selected and combined visual methods with interviews to optimize data generation with youth who use AAC (described in Chapter 5 and Appendix 12). While I look forward to refining the methodology and methods in future research, I
suggest they can be practically and immediately applied to improve the quality and quantity of research done with people who have communication impairments.

Having summarized these main contributions of this dissertation, I move to discussing the implications and some further contributions of the work.

8.2 Implications of the research

8.2.1 Theoretical implications

This research adds to critical scholarship on inclusion in relation to disability. It does so within the context of children’s rehabilitation – a field where idealized notions of inclusion remain largely unquestioned. To review, I began the study by synthesizing critiques of inclusion to develop the following provisional stance:

- inclusion should not be reduced to a universal ‘good’, nor is it neutral;
- inclusion is wholly dependent on the perspectives made possible by a person’s social position; and
- reducing inclusion to simply being ‘in’ a physical space is an impoverished conceptualization.

The research findings support and flesh out these claims by contextualizing inclusion in the lives of youth who AAC, but also adds an important caveat: Because inclusion is relational and perspectival, it is not a particularly useful concept in redressing social inequity. My reasoning in adding this statement is as follows. The results of this study highlight the insufficiency of merely asking a person whether they feel included (or not) and the necessity of interpreting how people come to perceive their experiences and impart meanings in particular ways. Critical social science approaches challenge the primacy that is often accorded to participants’ subjective experiences in the analysis of research data by highlighting the value added of situating and interpreting participants’ accounts in relation to the social contexts that shape them.

I am reminded of the work of Allen and Cloyes (2005), which drew on Bourdieu’s conceptualization of social relations to argue that “the language of experience does too much and too little…it misses history and social practice….Experience deserves a rest.” (p. 103) I would argue that inclusion too, deserves a rest. As a reified concept, it is asked to do too much. As an
oversimplified binary opposite of exclusion, it does too little. Finally, as I have demonstrated, when imposed unreflectively on disabled youth, it can do harm. Idealized notions of inclusion are “warm and inviting” (Edwards et al., 2001) but because they are future-oriented; they overlook the immediate, present social conditions that disadvantage disabled people. Thus, policies and practices perpetually aim toward inclusion, which has the effect of diminishing the necessity to attend to the present. In the case of children’s rehabilitation, and as revealed through this research, this ‘hoped for’ inclusion reinforces what are viewed as logical and productive investments in body-work that aims toward approximating ‘normal’. The effects of impoverished, binary notions of inclusion as a position ‘in’ a physical space were evident in the participants’ reported experiences of anxiety and discomfort that led them to feel excluded when they were ‘in’ the public sphere. Too little attention is paid to the ways that inclusion is framed as an ‘individual’ struggle and how this leads disabled youth to identify their selves as ‘the problem’ rather than inequitable, ableist social structures. Last, the potential harms of some formulations of inclusion were demonstrated as youth who use AAC were placed ‘in’ their local school, but, as shown across their accounts, largely segregated in social spaces where their chances to attain educational credentials and form social networks were severely diminished.

My work adds a creative approach for interrogating inclusion that was oriented by Bourdieu’s theory of practice to examine youth who use AAC as agents positioned within interconnected socio-spatial topographies. This extends Bourdieu’s work in a new direction by applying his relational concepts to illustrate the relational and perspectival aspects of inclusion. A key insight contributed by my research – namely the close correspondence between an individuals’ social position, their dispositions, and their subjective perceptions of inclusion – would not have been generated had I not elected to draw on Bourdieu’s conceptual arsenal. Bourdieu’s notion of social space captures the irreducible co-constituting relations between individuals and society. This allowed me to argue that inclusion should be analyzed in relation to both a person’s objective social positions in society, and their subjective position-takings on inclusion. My work provides a theoretically-informed framework for studying inclusion that, to my knowledge, is the first work to extend Bourdieu’s theory of practice in this direction.

While I have argued that this provisional framework for analyzing inclusion shows promise, further elaboration is needed in a number of areas. To begin, it will be helpful to more explicitly explore how the relations among field, habitus, and capital unfold for persons born with bodily
differences. There is a small amount of research that provides a point of departure for examining these interrelations (Allen, 2004; Edwards & Imrie, 2003; Gibson & Teachman, 2012).

Bourdieu’s conceptualization of the socialized body incorporates the biological, but he offers very little guidance in relation to how biological differences might alter or disrupt the ways that social relations unfold. Moreover, this work lends itself to a more thorough theorization of how habitus develops as a ‘structured and structuring structure’ in the case of biological impairments that might limit or alter the processes involved in social learning. In Chapter 7, I have suggested that Bourdieu’s notion of fields can be extended to consider the ‘field of humanity’ in order to theorize the mechanisms that deny some people claims to personhood. This application would benefit from elaboration in future research, but by taking Bourdieu’s theory in a direction that is particularly relevant in critical disability studies, this work shows promise for exploring how some bodies are constructed as human, while others are ‘not quite’ human. Finally, my specification of Bourdieu’s work could also be extended, as noted in Chapter 7, by expanding the research scope to elicit points of view on inclusion from a broader range of individuals and groups distributed across the social hierarchies that structure specific fields (e.g. education, employment, rehabilitation, or community-based recreation). This would involve identifying agents from a wide range of dominant and dominated social positions, identifying the types of capital they possess, and the ways they deploy that capital in relation to struggles over determination of ‘which types of bodies belong where’ in a specific field.

Last, this dissertation has implications for how communication impairment is theorized. This is an area where there has been very little research, even within disability studies. My theorization of communication impairment, which draws on Bakhtin’s dialogism, opposes dominant biomedical conceptualizations of communication differences as ‘disorders’. I have argued in Chapters 4 and 5 that mediated communication is no more or less ‘authentic’ than oral speech, and that embodied norms of communication have the effect of muting persons who communicate differently. This argument is supported by the study results and serves to counter research traditions that privilege idealized informants who ‘possess’ a singular, autonomous voice that can be captured by the researcher in order to re-articulate ‘authentic’ accounts. Certainly, there are many critics who have challenged the ways that ‘voice’ is conceptualized in research (see for example Jackson & Mazzei, 2009) but the critical project I have outlined in this dissertation breaks new ground by bringing those critiques into the context of AAC. I look forward to further
refining my theorization of communication impairment in future research with people who communicate using AAC.

### 8.2.2 Implications for rehabilitation

In this section, I discuss some of the implications of this study for rehabilitation research and clinical practice. First among these is a challenge for researchers and clinicians to leverage their positions of authority in order to expose and make public the hostile and dehumanizing socio-material conditions that constrain youth who use AAC. Rehabilitation is not a field where it is common to use terms such as ‘oppression’ in discussing disabled children. ‘Inclusion/exclusion’ is a notion that fits more comfortably within its purview. Research that incorporates critical social science perspectives can increase awareness of the broader social structures in which rehabilitation is embedded. This research takes an important step toward effecting change by making visible the social arrangements and conditions of everyday existence that constrain youth who use AAC. Only through making these underlying mechanisms visible can steps be taken toward shaping more humane societies (Bourdieu & Wacquant, 1992). In children’s rehabilitation, this suggests there is a need for increased awareness of, and engagement with, the macro-level social structures that influence disabled children’s lives.

With Kinsella and Whiteford (2009), this examination of inclusion draws on Bourdieu’s (1992) notion of epistemic reflexivity to call for ongoing critical reflection on the assumptions that underpin rehabilitation and the social conditions under which they came into being. At its core, children’s rehabilitation is focused on ‘enabling’ the impaired child to function in ways that approximate ‘normal’ because the positive value of the upright, walking, talking body is durably embedded, not only in the logics of rehabilitation, but in the broader social fabric. Thus the project of rehabilitation, with its emphasis on the evaluation and classification of impaired bodies, may be irreconcilable with idealized inclusion imaginaries where ‘differences’ are effaced. Rehabilitation, as a field, incorporates a history that involved populating categories of bodies along a moral hierarchy (Hughes, 1999; Stiker, 1999) where, for example, the upright walking body is deemed proper, the wheeling body is lesser, and the crawling body is abject. As doxa, the arbitrary nature of these categorizations had long since slipped from view so that they appear as natural, legitimate and fixed categories of difference. In contrast, dominant notions of inclusion are philosophically aimed toward an idealized society where those same boundaries
and categorizations are erased – that is, where differences are effaced. The mission of rehabilitation continues to draw moral import from the ‘personal tragedy’ model of disability where ‘success’ stories of children’s heroic victories in the face of disability fuel the philanthropic engine and fund the pursuit of new cures and treatments (Ignagni, 2011). Instead of perpetuating these tropes, rehabilitation could play an important part in exposing the effects of unwitting allegiance to enforcing normalcy. Admittedly, this is a somewhat grand proposition, but there are already currents within rehabilitation that are moving in this direction (see for example: http://www.criticalphysio.net/). As more researchers and clinicians reflexively challenge their own assumptions and those embedded within the professional doxa, gradual changes can occur.

This dissertation supports calls for rehabilitation to move past a restrictive focus on individual bodies and attend more closely to macro-level social structures that reproduce disability as a devalued and marginalized social position. A shift of this type has important implications for how the ‘problems’ of disability and exclusion are envisioned and how ‘solutions’ are conceptualized. I have argued that the disability/ability divide is durably inscribed as habitus in the bodies of youth who use AAC and articulated through their preferences, attitudes, perceptions and behaviours. This challenges any number of assumptions about the ‘personal problem’ of disability, but I point here to one example. Contemporary clinical reasoning in children’s rehabilitation tends to assume that part of the ‘problem’ of disability is that youth lack ‘opportunities to communicate’ and ‘opportunities to participate’. But, my work presents an interesting conundrum by pointing out the ways in which some participants were predisposed to avoid such opportunities. For example, Bernard’s declaration that he didn’t want to mingle with the ‘normal’ students at his school is representative of the group of youth who were placed in segregated classrooms. This suggests that the reported lack of social interactions between youth in the study and their non-disabled peers did not arise only because youth who use AAC were deprived of opportunities, but also because they made logical choices to avoid what they anticipated would be negative interactions. There is thus a need for more critical research that problematizes the ways that ‘opportunities’ and ‘choices’ are conceptualized in children’s rehabilitation.

This study suggests rehabilitation might challenge the status quo by partnering with educators to redress the foreclosure of future possibilities imposed on youth who use AAC in some special
education settings. One way forward is the ‘family groupings’ approach to school placement where teachers and groups of students of varying ages and abilities progress through the education system together. Through sustained relationships, the hope is that students develop interdependencies and connections that bridge their differences. The purpose of the school system, as argued by Bourdieu, is to sort children according to various trajectories such as universities, professional training, employment, or trade schools. He demonstrated that formal education reproduced the social order, where those who most benefit from education are those who already occupy positions of advantage and have ready access to capital resources (Bourdieu & Passeron, 1977). The results of my research demonstrate similar mechanisms through which disabled youth are further disadvantaged in education. On one hand, the placement of disabled youth ‘in’ their local school signals a shift toward more inclusive education. Yet, on the other hand, my work has shown that whether placed in mainstream or special education streams, youth who use AAC continue to confront socio-spatial-temporal structures made for and by ‘able’ bodies. In these social spaces, disabled youths’ chances of succeeding in the education ‘game’ are delimited, and importantly, as they incorporate and adjust to these limitations, they unwittingly help perpetuate the status quo.

Last, the research results provide information about the socio-material conditions that youth identified as conducive (or not) to creating a sense of inclusion. I discussed these, in Chapter 7, in relation to the ways they contributed to a sense of safety, communion and recognition; however, these factors were intermingled to support more inclusive social relations. Each of these factors has implications for rehabilitation as follows:

Safety: Rehabilitation practitioners should encourage youth who use AAC to discuss social situations that cause them to feel anxious or unsafe – youth may feel uncomfortable acknowledging these feelings, or may assume that they must accept these conditions. Youth who use AAC experienced mainstream environments (e.g., community settings, integrated classrooms) in different ways. Some were comfortable in these settings, but more often, participants reported feeling frightened and anxious which was not conducive to feeling included. Participation in ‘what non-disabled youth do’ was sometimes enjoyable, but could also be scary and uncomfortable for youth who use AAC. Likewise, some youth expressed feeling anxious and uncomfortable with their attendants, especially in relation to providing personal care (e.g., toileting, bathing) and struggled to communicate in these situations. ‘Feeling safe’ included
being in the company of a familiar communication partner who could act as an interlocutor when needed. One immediate way to act on this information is to invite more open discussions with youth and their families about their fears, anxieties, and the challenges they experience. There is a tendency to avoid discussing ‘negative’ topics and emotions with disabled children and youth, but, I suggest, this only reinforces messages about the need to ‘stay positive’ and ‘overcome disability’ without addressing disabled youths’ emotional needs.

Communion: *Rehabilitation or community-based programs that allow youth who use AAC to congregate with other disabled youth can promote positive disability identities.* Positive connections and communication interactions arise not only from the exchange of words, but also from a sense of feeling ‘understood’ and valued. Youth who participated in informal or formal interactions and programs with other disabled youth reported feeling included and valued in these social spaces. These are important spaces where the worth of disabled people is recognized and where impairments and differences are less stigmatized and may even be celebrated. In the broader social imaginary there is little movement to help disabled youth develop more positive disability identities. The assumption is this is an inferior identity. These can also be spaces where youth can develop more positive disability identities. *Continuity of care is especially important for youth with communication impairments who find it difficult to continually ‘train’ new people to be able to communicate with them.* It takes time for youth who use AAC to form a sense of ‘communion’ with new people. Participants reported feeling less included when they had to continually help others learn how to communicate with them. Continuity of personnel, including teachers, attendants, or health care professionals, built familiarity and supported interactions where youth who use AAC felt they could express themselves and be listened to.

Recognition: *Engaging in critical reflexivity can help clinicians, together with clients, embrace individual differences and envision possibilities for engaging in the social world that would be missed altogether in the pursuit of ‘normal’.* Youth in the study struggled to achieve recognition for aspects of their personhood beyond their devalued bodies. Some aspects of feeling valued arose simply from being ‘expected’ in a space, and the feeling of ‘being known’. Other examples from this research suggest the importance of ‘thinking outside the box’ to create alternatives for acquiring cultural capital that can be exchanged and recognised as valuable. Consider, for example, Bernard’s weekly piano lessons which can be interpreted as investments by his family in his development of cultural capital. But we could ask, ‘Why should a person necessarily
require the capacity to reach out and touch the piano keys in order to learn to appreciate the music, read the score, and develop a taste for and expertise in styles of music?’ This line of thinking could help disrupt ingrained patterns of thinking in rehabilitation that delimit the types and nature of disabled children’s engagement with the world within tacit understandings of what is expected, ‘typical’, and ‘developmentally appropriate’.

Future research is needed to explore, in more depth, the intersectionality of these elements – namely, safety, communion and recognition - towards creating more inclusive social spaces where youth who use AAC can take up valued roles and be recognised as persons as they are. Children’s rehabilitation is well-positioned to take a leading role in fostering and showcasing a broader range of possibilities for youth who use AAC to live lives that they and others value.

8.2.3 Methodological implications

The critical dialogical method forwarded through this research adds an approach to interviewing people who use AAC that respects their multiple modes of communication. As noted by Barnes and Oliver (1993), interviewers undertaking research with disabled persons should be mindful that the interview process becomes oppressive when it has the effect of “reinforcing into isolated individuals with impairments the idea that the problems they experience in everyday life are a direct outcome of subjective inadequacies or functional limitations and not the organization of society” (p. 7). My work owes a debt to the important methodological contributions already made by researchers in the field of AAC. What it adds is a dialogical approach that attempts to better support research participants with communication impairments as they engage in co-producing knowledge through interview-based methods. The following two extracts from my field notes illustrate the variety across the interview interactions:

Peter was relieved and pleased to have his mother join the interview as his communication partner. She took on the role in a somewhat formal way – initially asking permission to clarify Peter’s speech with each utterance – but relaxed as the first interview progressed. There were a number of times when Peter’s mother didn’t know what he was saying, but the two of them worked through it in a practiced manner – neither seemed frustrated. During these moments, she rose from her chair to see Peter’s face better, affectionately touching him and patiently working with him until she understood what he was trying to express.

Hadia, aged 15, communicated with gestures and facial expressions as well as a speech-generating device. She had no speech, but could call out if she was in distress, and occasionally
shared an infectious giggle. During the interviews, her mother sometimes attended to and interpreted minute changes in Hadia’s facial expression or eye movements. At other times, she responded to Hadia’s requests for help by directing Hadia to use her device. I tried, without success, to intercede by reminding Hadia and her mother that the interviews were not a test of Hadia’s independent communication skills. Both Hadia and her mother appeared to be very strong willed and it seemed likely that much of their communication involved similar struggles.

Without this methodology, the research would not have generated such a rich data set. More importantly, the participants would not have been supported to express their views to the same extent. The combination of a number of methodological innovations in this work (direct video analysis of interviews, combining graphic and photo elicitation with interviews to align with existing visual communication strategies in AAC, and the development of a dialogical analytic framework) is unique and could be built on in other research with youth who use AAC and disabled children generally. It could also be applied to help optimize data generation in research with a broad range of adult populations where communication is compromised, for example, after stroke, brain injury or the onset of dementia.

Under the broad ‘umbrella’ of methodological considerations, I turn to considering the importance of reflexivity in relation to research ethics – especially in relation to the recruitment process which, necessarily, involved making decisions to exclude certain disabled youth from research about ‘inclusion’. I endeavoured to be continually mindful of the potential effects of participation in research on youth and families. One interaction, which I will describe here, illustrates the importance of approaching research with humility and attention to researcher/participant relations. I made arrangements to meet and potentially enroll a participant whose mother had viewed a poster about the study. At the visit, the young girl became extremely agitated by the prospect of talking with a stranger (she used a speech-generating device but showed a high level of anxiety). Within a few minutes, as I tried to engage in discussion about the study, she began to engage in destructive, potentially harmful behaviours. The mother seemed desperate to involve her daughter in the study and I sensed this was largely because of the opportunity to use an adapted camera. But, the girl became increasingly anxious and was unable to engage in any conversation. I discussed my concerns with the mother, who eventually agreed that participation in the study seemed likely to cause undue distress to her daughter.
This interaction exemplifies what Guillemin and Gillam (2004) termed ‘ethically important moments’ that occur in the everyday practice of doing research. These ‘moments’ relate less to procedural ethics, or to any specific ethical dilemma, but rather, to the ethical responsibilities of researchers to interact with participants (and indeed, potential participants) in ways that are humane and non-exploitive, while reflexively attending to potential harms. My sense was that this single mother, who lived in barely furnished, dilapidated community housing, was desperate to access activities and supports for her daughter. I felt my presence in their home had resulted in a distressing intrusion for the girl, and worse, a rejection. For this mother, I was one more professional informing her that her daughter was not a ‘fit’. I later followed up to provide information about how to seek out other research studies and services which might be less stressful for her daughter, but the interaction served as a reminder that all research (at all stages) has effects for participants and for researchers, and leaves each individual changed through the process.

8.2.4 Limitations and implications for future research

In this section, I discuss study limitations with suggestions for future research. To begin, it is important to acknowledge that mine is one particular interpretation of the data generated with the youth in the study. While I have endeavored to produce a rigorous and plausible account of the data that adds new knowledge, like all research it is only one possible interpretation. Other researchers and other theoretical frameworks would have produced different interpretations. For example, a Deleuzian interpretation might have considered how youth who use AAC form, break and re-form assemblages of impaired bodies-able bodies-assistive technologies to ‘make’ inclusion. This approach would afford considerations of how particular assemblages are both enabling and disabling, and whether/how these interconnections are linked with perceptions of inclusion/exclusion. Alternately, following Thomas (2012), I might have drawn on Honneth’s work to conceptualize inclusion as a product of intersubjective ‘struggles for recognition’.

Thomas (2012) has argued it is “possible to analyse children’s place in society…to ask when, where and how they achieve reciprocal recognition (1) as love, (2) as respect and (3) as esteem.”

25 Aside from this instance, I use the term ‘recognition’ in line with Bourdieu’s theory of practice and his conceptualization of ‘struggles for recognition’ through possession of legitimated forms of capital and contests over determinations of the forms of capital valued in specific fields. Honneth’s (1995) theory also refers to ‘struggles for recognition’ but conceptualizes these differently.
Each of these approaches would also have had its limitations. The advantage of drawing on Bourdieu’s theory of practice was that it already accounts for socio-spatial topographies and the interplay between structure and agency. His conceptualization of the correspondence between embodied dispositions and social positions circumvents dualistic conceptions of disability as either a product of impairment or as the result of socio-political disadvantage (Edwards & Imrie, 2003).

This research is arguably limited by its in-depth focus on a relatively small, localized and particular population. Nevertheless, I would expect that the mechanisms through which youth who use AAC accommodate and resist their devalued social positioning would operate in similar ways across broader contexts. Youth who use AAC were the focus of this study, but the results have implications for broader populations of disabled children, particularly those who are deemed ‘severely’ disabled. This dissertation provides a starting point on which to build future research that examines inclusion from a wider range of perspectives in the social hierarchies in which disabled youth are positioned.

Finally, it is important to acknowledge how the researcher mediates all aspects of the study in ways that are both enhancing and constraining. Thus, I have imposed limitations on this work, as much as I have drawn on my particular background and strengths to imbue it with rigour and quality. Turning a reflexive lens on myself involved an ongoing, iterative process where I moved between what appeared ‘self-evident’, that is, my pre-reflective understandings of the research problem, concepts and data, and more critically reflexive considerations of how my positions as a researcher and my history as a clinician shaped my dispositions toward thinking about phenomena in particular ways. I drew on critical scholarship to rethink familiar concepts, such as ‘inclusion’, ‘impairment’, and ‘disability’, in ways that worked against the habitual and ingrained modes of sense-making acquired through my past position as an occupational therapist. That process has been rewarding and is ongoing.

Bourdieu posited limits to reflexivity. Individuals, he suggested, are never fully able to step outside of their subjective selves to analyze how their positions in social space shape their particular points of view. Habitus provides an “unquestioning apprehension of the social world which, by definition, does not reflect on itself and excludes the question of the conditions of its own possibility.” (Bourdieu, 1977b, p. 3) Thus, my own lens, as a researcher, cannot help but be
influenced by what might be termed my ‘clinical dispositions’, sedimented through my prolonged engagement as a health care professional. Exploring the limits of my own reflexivity has been both exciting and disquieting. My enthusiasm for the journey I have taken during my doctoral training has not lessened the inevitable discomfort and occasional dismay that accompanied my interrogation of the values, assumptions, and core concepts that underpin children’s rehabilitation. The change in my position from clinician to researcher has afforded me a new point of view. Nevertheless, while I have tried to make the familiar ‘strange’ in my analytic approach throughout this dissertation, I am mindful that my efforts to think ‘otherwise’ are necessarily partial and incomplete, but no more or less than any other researcher.

Before closing, there are a few more issues raised by this work that merit attention in future research. An important extension of this study would involve examining the lives and practices of young adults who use AAC (e.g. aged 25-35 years) to explore whether, as they age, youth might experience even more (or less) constrained conditions of possibility. A number of issues related to friendships and attendant care were raised that should be addressed in future studies (e.g. a critical exploration of how friendship is conceptualized and valued; research that examines how youth are affected by long-term attendant care arrangements and how families negotiate attendant care). There is a small amount of research examining friendships in the context of care relationships that could provide a starting point (Hughes, Redley, & Ring, 2011; Lafferty, McConkey, & Taggart, 2013). The prevalence of reports of anxiety and fear across participants’ accounts indicates this is an area that requires further study. Specific to the field of AAC, the study results point to the importance of investigating whether/the extent to which an emphasis on using speech-generating technologies might mute other communication modes in specific fields. Finally, my work could be extended by exploring parenting practices among families with children who use AAC. Parents of participants in this research were eager to share their perspectives in the intervals before and after the interviews. It was clear that they have important insights and had given the research topic considerable thought. The following exchange with Stephen’s mother (SM), at the close of the second interview with her son, is one that stands out:

SM: Can I ask you a dumb question?

GT: Of course, I’m sure it is not a dumb question.
SM: If all you ever knew was the way things have been for you as a special needs kid, then how would you necessarily think about wanting things to be different?

GT: I think that is a very insightful question!

SM: As a parent of an AAC kid, I want people to know that our kids have something to say...They matter.

8.3 Conclusion

This dissertation provides important information about the nature of disabled youths’ lives and struggles as they both resist and reproduce their devalued social positioning to claim ‘inclusion’. It was in and through their positions in home, school and community spaces that youth who use AAC developed and embodied habitus which shaped their perceptions, dispositions, and aspirations along with their ‘practical sense’ of inclusion. In particular, this work lays bare the inequitable nature of their struggles as they work to leverage what little capital they are able to access under severely restricted conditions of possibility. In social, material and temporal worlds that were not conceived for them, life for youth who use AAC involves either engaging in ‘arenas of play’ where the deck is stacked against them, or retreating to the relative safety of segregated and confined social spaces on the margins and, most often, out of sight.

Much more critical research is needed to better understand the lifeworlds of youth who use AAC and increase awareness of the social inequities they endure. I would like to close by drawing a final time on Bourdieu’s (2000) account of the enduring nature of struggles for recognition which, I believe, holds a vision for change at its heart.

What truly is the stake in this game, if not the question of *raison d'être*, the justification, not of human existence in its universality, but of a particular, singular existence, which finds itself called into question in its social being...? It is the question of the *legitimacy* of an existence, an individual’s right to *feel justified* in existing as *he* or *she* exists….The social world gives what is rarest, recognition, consideration, in other words, quite simply, reasons for being (pp. 237-40).
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Appendix 1: Recruitment Details and Poster

Assembling the study sample

A total of 13 youth who use AAC (aged 15-24 years, 6 male, mean age=18) participated in the study. Recruitment proceeded in two stages (between September 2013 and March 2014), with variations in the recruitment (as per REB directives) and sampling strategies for each of three children’s treatment centres in south-central Ontario. First, convenience sampling was used at the largest centre: a designated AAC clinician identified 54 youth who met the study inclusion criteria. Each received written information about the study and an invitation to participate. Of 54 invited, six responded and were included in the study. In partnership with the remaining two centres, a second stage of recruitment involved more theoretical sampling to maximize variation across the study sample. I identified particular traits or categories (i.e. sex, age, family income range) where I was seeking greater variation across the study sample. AAC clinicians contacted families of young people who met these criteria in addition to the inclusion criteria. With families’ permission, clinicians shared contact information for eight potential participants who had expressed interest. Of these, six young people agreed to participate. Two mothers, on hearing more about the study, felt their daughter/son would not be able to understand or contribute their views. An additional two participants were recruited via a poster (below)

[Poster below printed on Institution Letterhead]

**We are inviting YOUTH WHO USE AAC to help us learn about Inclusion**

**WHO:** Youth who communicate in ways other than speech and are in high-school (or who finished school in the past year) and who are able to participate in an interview using any type of AAC, including a familiar communication partner.

**WHAT:** Youth will participate in two interviews, each lasting about an hour AND will use an adapted camera for a period of 2 weeks to take pictures during daily life that help to tell about inclusion.

**WHY:** We want to learn about everyday life among youth who use AAC and the ways that they experience and think about inclusion. We are interested in knowing where and how they would like to be included. This information will help design programs for youth who use AAC.

**WHERE:** At your home or another location that you choose

**WHEN:** At a time convenient for you, weekdays or weekends

**HOW:** Contact Gail Teachman at 416-425-6220, ext. 3695 or gail.teachman@hollandbloorview.ca

(We will make every effort to correspond in ways that are easiest for you. Please be reminded that email correspondence is not secure and can involve risks related to loss of privacy.)
Appendix 2: Letter of Invitation

Dear (Date)

We are writing to invite you to consider participating in a research study with youth and young adults who use augmentative and alternative communication (AAC) to learn about their everyday lives and the ways they experience and think about inclusion. Information about the study is enclosed with this letter. This study is part of the requirements of a PhD program of study for Gail Teachman, who is a Clinical Associate with Holland Bloorview Kids Rehabilitation Hospital. Dr. Barbara Gibson is Principal Investigator for the study, and Senior Scientist at Bloorview Research Institute.

In this study, we want to learn more about everyday life for young people who are non-speaking. We are trying to better understand how they experience and think about inclusion. In particular we want to learn where and how they would like to be included. We are also studying the ways that beliefs, values and understandings of inclusion that are part of rehabilitation might affect youth who use AAC.

If you are interested in learning more about the study, please complete the form at the bottom of this letter and return it in the enclosed envelope to Gail Teachman. Remember to provide your contact information. By returning this form, you are only agreeing to learn more about the study. You do not need to agree to participate in the study.

On behalf of all the research team, thank you for thinking about participating in this study.
Sincerely,

Gail Teachman, PhD candidate

☐ Check the box if you would like to learn more about the study

Print your name: ________________________________

Print the name and contact information of a parent or caregiver. We will contact them to arrange a time to meet with you to tell you more about the study.

Parent or caregiver name: ________________________________

Phone or email contact: ________________________________

(*Please be reminded that email correspondence is not secure and can involve risks related to loss of privacy.)
Appendix 3: Determination of Capacity to Consent

Prior to seeking consent, the investigator (Gail Teachman) determined if the youth or young adult was capable of providing consent.

**Process**

- Review the information letter and study details in conversation with both the youth and a parent. Use the visual consent framework (see Appendix 12) for participants who communicate using a combination of pictures/picture symbols and text.
- Encourage and answer all questions and re-explain any information that is not clear.
- Through this conversation determine the youths’ capacity. Questions to help assess capacity may include:
  - Who can be a part of this study?
  - What will you do in the study? What else? Do you want to do all these things?
  - What if you start and decide you don’t want to do it anymore?
  - Who will know what you say?
  - Why do you think we are doing this study?
  - Will I use your name when I write a report?
  - Do you have to do this?
  - Will taking part hurt you in any way?
  - Who can tell you more if you have questions?

Note: an ‘incorrect’ answer will not necessarily be construed as incapacity but will serve as a cue to re-explain and reassess.
Appendix 4: Information about the Study

[Institution Letterhead]

Inclusion: What is it for youth who use augmentative and alternative communication (AAC)?

Principal Investigator:
Barbara Gibson, Senior Scientist, Bloorview Research Institute, 416-978-1819,
barbara.gibson@utoronto.ca

Co-Investigator and Primary Contact* for the study:
Gail Teachman, University of Toronto, 416-425-6220 ext. 3695,
Gail.teachman@hollandbloorview.ca
* This study is being done by Gail Teachman as part of her PhD. She is supervised by the three senior researchers who make up the research team.

Additional Co-Investigators:
Colin Macarthur, SickKids Research Institute
Peggy McDonough, Dalla Lana School of Public Health

What is this research study about?
This study will help us learn more about the everyday lives of young people who use augmentative and alternative communication (AAC). We are especially interested in how youth who use AAC think about and experience inclusion and exclusion, where they would like to be included, and the ways that they wish to be included. We need to learn more about these things so that we can design rehabilitation in ways that fit with young people’s opinions and wishes.

Ten to fifteen teens and young adults who use AAC and are in high-school (or finished within the past year) will take part in the study. About ten of these youth will be from Holland Bloorview. The others will be from two other treatment centres in Ontario (Erinoak Kids and 5 Counties Children’s Centre). We sent you this letter to invite you to take part in this research study.

How will you be involved in this study?
You will be involved in two interviews at your home, or another location that you choose AND you will borrow an adapted camera for two weeks so that you can take pictures to help you tell about inclusion. The interviews will last about one hour. During the interviews, you can communicate any way that you like. For example, you might use a smile, a nod or a shoulder shrug to tell some things. You might use your eyes to communicate other things. You might also use a communication book or a speech-generating device. You can invite a parent or other person who knows how you communicate to join the interview as your communication assistant. All of these ways of communication are fine. The interviewer, Gail Teachman, is familiar with augmentative and alternative ways of communicating.

Here is what you will do:
1. Gail will meet you in person to explain more about the study, let you ask questions, and then ask if you agree to be part of the study or not. You can choose not to be part of the study OR you can agree. If you agree, you can change your mind at any time and it is OK. If you agree, then Gail will ask you a few questions about your background (education, diagnosis, family income.) Then, we will go ahead and begin the first interview. You will be asked to talk about your everyday life - the places you go, the people in your life and the things you do. We will begin to make a ‘personal geographic map’. This is a map that shows where you live and other places that you go, for example: your school, a park, or the mall.

2. To help us talk about inclusion, we want you to take pictures that you think can help us understand more about inclusion, from your point of view. At the end of the first interview, we will loan you an adapted digital camera so that you take pictures on your own. You can also ask someone to take pictures for you if you prefer. The adapted camera could be mounted on your wheelchair - something like this:

Gail will show you how to use the camera and give you information to help you think about the pictures you want to take. We want you to take the camera with you as you go about your life for the following two weeks. The camera has a feature called ‘GPS tagging’ that will record the location where you took each picture. At the end of two weeks, we will ask you to return the camera and we will download your pictures for the study. (If you enjoyed using an adapted camera, we can provide information about adapting a camera of your own.)

3. At the second interview, you and Gail will look at the pictures you took. You will talk to her about how you were feeling when you took the pictures, and what they tell about you and inclusion. We will use the GPS tagging to mark on your personal geographic map the places where you took pictures.

At the end of the second interview, you will get to keep a copy of your personal geographic map and the pictures you took. This picture shows one type of personal geographic map.

Is it private?

All information we collect about you and your life will be kept private. Your name will not be used. We will remove the place names from your personal geographic map so that the map cannot identify you. Before taking pictures of people you must tell them about the study. Please ask their permission before taking their pictures. Only the research team will see the photos and the personal geographic maps. We will not make public anything that might identify you or your family unless legally required to do so. For example, we have to report any information that would lead us to suspect child abuse or neglect.

We will video record the interviews. These recordings will help us to record and review your communication during the interview. The video recording will be destroyed after we complete
the study analysis. Only the research team will see the video recordings and only they will know what you said. All the information that we collect will be kept safe on secured password protected computers or in locked cabinets in the Bloorview Research Institute. We will destroy all information seven years after the study ends.

When the study is finished a summary of the results may be published or presented. Your identity will not be disclosed in any way without your permission.

**Do I have to do this?**

Participation in this study is voluntary. It is OK if you decide not to take part in this part of the study. You also have the right to change your mind and stop participating at any time. This will not affect the services you receive from the Holland Bloorview Kids Rehabilitation Hospital in any way. If you withdraw before the end of the study, we will delete all data about you. Anything you said will not be included in the study results.

**What are the risks?**

You do not have to answer any of Gail’s questions. If you become tired or uncomfortable during the interview, then you can take a break or stop the interview at any time you wish. There is a small chance you could become upset talking about inclusion or the challenges of using AAC instead of speaking. Time will be included in sessions to discuss any issues with you and the interview will be stopped if needed. If you become upset in the interview, Gail will stop the interview and ask one of your parents, or someone else you choose, to join us to talk about your feelings.

**What are the benefits?**

There are no direct benefits to you as a result of participating in this study. The study will provide information to help us understand more about inclusion and the everyday lives of young people who use AAC.

**What if I have questions?**

Gail will review this information with you at your first meeting. She will explain anything you don’t understand. If you use picture communication symbols to help communicate, then we can share information about the study in ways that include picture communication symbols. You will receive a one hundred dollar gift card as a token of our appreciation.

If you have any questions at any time, you or your family can call Gail Teachman at the Bloorview Research Institute, 416-425-6220 ext. 3695 or gail.teachman@hollandbloorview.ca

(Please be reminded that email correspondence is not secure and can involve risks related to loss of privacy.)

If you have any questions about your rights as a research participant please contact the Holland Bloorview Research Ethics Board Office at (416) 425-6220 ext. 3507. Thank you for thinking about helping us with this project.
Appendix 5: Consent Form

[Institutional Letterhead]

**Inclusion: What is it for youth who use augmentative and alternative communication?**

Please complete this form below:

A member of the research team has explained this study to me. I read the Information Letter dated [date] and understand what this study is about.

By signing this form, I agree that:

All my questions regarding the study have been answered.

I understand how I will be involved.

I understand that I may drop out of the study at any time.

Yes, I agree to participate in this study.

_________________________________  ___________________________  ____________
Participant’s Name (please print)  Signature  Date

I understand what this study is about. I support my child’s decision to take part in this study.

_________________________________  ___________________________  ____________
Parent’s Name (please print)  Signature  Date

_________________________________  ___________________________  ____________
Name of person obtaining consent  Signature  Date

(please print)
Appendix 6: Sample from Visual Consent Framework

Consent to participate in the study was confirmed through concrete co-construction of an agreement (or non-agreement) statement. If the potential participant chose the Picture Communication Symbol card that read “I don’t know”, the conversation returned to clarification of the information about the study, until the potential participant was ready to agree or disagree to participation in the study.
VISIT ONE: Interview Guide for a Sample Participant

Today, I’d like to get to know you a little bit and together, we’re going make a map while we talk that will show your home and some of the places you go.

Tell me about yourself
- Who is in your family? Also probe re: extended family and friends, pets, caregivers,
- What types of things do you really like to do?
- Do you have any hobbies or special interests?
- What are you really good at?

What is a typical day like for you? I have a map here, where I’ve marked your home already. Let’s find your school and mark it on the map. Ok, now let’s talk about what an average school day is like for you.
- Probe re getting up and ready for school, including timing, school location, transportation, social and communication networks at school, classroom type, assistance/support at school, fieldtrips, clubs or extracurricular activities, school peers/friends/helpers, favourite/least favourite subjects, general accessibility issues
- I would also like to mark on the map any other places that you go during the week. What do you usually do after school – typical evening routines and activities, with who, where in home, tightly structured care routines vs. variable and relaxed, time for leisure (again ask re timing)
- When you’re at home or with your family, is there someone who is your ‘best’ communication partner? What are the ways that you prefer to communicate when you’re with your family? What about when you’re at school, other places we’ve talked about.

Now let’s think about a typical week – are there variations between the days of the week?

What about weekends? Tell me about some of the things you do on the weekends. Let’s mark any other places you go on this map.

What about during a school break or in the summer; Are there seasonal differences in the things you do and the places you go?

Is there anything else you want to add to this map to show places you go, or things you do that are important to you in some way?

Let’s talk now about how you will be taking photos in some of these places to help with this research project. [Move to camera set-up and instruction, discussion about taking the pictures, what they are about, review of Appendix 6: Suggestions for taking pictures, review of what the study is about, review choice to include photos from a family album]

End with review of next session – what we will do, what we will talk about.
VISIT TWO: Interview Guide for a Sample Participant
[Individualized according to the photos generated by the participant]

You took a lot of pictures inside and outside of your home. Here’s a map that we can look at together. It shows all of the spots where you took photos in the last two weeks.

How did you choose which pictures to take inside of your home? Can you tell me about your home?

Can you tell me about the activity you did with your younger sister and her friend?
   Was there anyone else present? How do you communicate with the people here? Where would you put them on your social network chart?
   How often do you guys hang out?
   Did you feel included? (How did the activity make you feel?)
Can you show me on this Belonging Circle where you felt like you belonged, or how much you felt ‘included’ when the picture was taken. [Interviewer asks participant to point, or assists the participant to indicate a location on a belonging circle, which will be recorded by the interviewer]

When is it ‘OK’ to be outside of the middle of the circle (left out or not included)? When do you like to be ‘in the centre’ of things (I belong and I feel like I can be me).

Imagine being back with your sister. Think about what if felt like. What should the caption be for this photo? [Show participant Figure x Sample photo and caption]
   What are some good things about the place, group or activity in the photo? What are some ‘not so good’ things?
   Do you do other things together with these people? (What kinds of things and where)
   Is there someone who helps to make this part of your day ‘work’ for you? Can you/Do you do this with other people?

You had lunch at school in a classroom with your educational assistant. Can you tell me about these photos? What should the caption be for this one?
   What other things were part of your school day?
   Was there anyone else present?
   How often do you eat in the cafeteria/in the classroom?
   Did you feel included? (How did the activity make you feel?)
   Can you show me on the Belonging Circle?
   Imagine being back with your educational assistant at lunch.
   Think about what if felt like. Now complete this sentence:
   Having lunch in the classroom made me feel….
What are some good things about this activity? Bad things? How could it be better?
Do you do other things together with this person? (What kinds of things and where)

Probes regarding taking the photos:
   How did you find the process?
   Was this the first time you took pictures?
   Did it make you think of those people, places or activities differently?
   How did you decide to take the pictures you took?

Figure x Sample caption:
   Everyone stops to say Hi to Buster - my best friend forever
Did anyone help you? How?
Any times during the two weeks when you thought “No, I don’t want to take a picture of that?”
Did you do things or go places where you didn’t take pictures (outside of your home)? Let’s mark those places on your map so we can talk about them if you want. What were some of the reasons why you couldn’t/didn’t want to take some pictures?

General questions about the range of photos:
What is missing?
Do these photos tell a story about where and how you feel included (part of things), or maybe sometimes excluded (left out)?
Are there ideas in these photos that you would want to share with other people? What are the most important things that these photos tell about? How would you change the story told in your pictures to make it better for YOU?
Are there things in these pictures (or part of your life but not in the pictures) that you wish you could change? Can you tell me about that?
Is there anything else that we haven’t talked about today that you think we should know about?
Appendix 8: Suggestions for Taking Photos

What you’ll do for two weeks:

- Take pictures of the people, places and activities that are important or ‘regular’ parts of your everyday life and that tell something about how or when you feel included or excluded.
- You can also choose photos from your personal or family photo albums that tell important things about your life.
- We will look at your photos and talk about them in an interview. We will also make a map that shows where the photos were taken and we will mark the places that you go.
- I will compile your photos in a CD that you can keep.

What Photos should I take?

- You can take the photos or ask someone else to take them for you. But you should decide what photos to take. You can be the director and put yourself in the photos!
- There is no right or wrong. Anything is welcome.

Some suggestions:

- The people, activities and places in your home, other homes, your school or neighborhood that make you feel like you belong – or that make you feel you don’t belong.
- Sometimes both of these feelings can happen in the same place, so you can take photos that tell us about that.
- Photos that show how you are ‘included’ or ‘excluded’
- The main places that you go e.g. shopping, school, work, hanging out, visiting

How often should I take photos during the two weeks?

- Try to take photos at least once in each environment or setting that is part of your day. For example, if you are doing things at home, at school, and at a relative’s house, then try to bring the camera and take pictures in each those places.
- Take pictures that tell about your everyday life, but it is OK to also take photos that tell about people, places or activities that are less often part of your routine if you want.
- Take pictures that tell important things about YOU. A few photos that tell about you, your daily routines and the places and people in your life will be better than a hundred photos of everything you see.
- Think about taking 10 – 20 photos.

** IMPORTANT**

You NEED TO explain the study to anyone you want to include in your photographs and get their permission first.

You can tell them that you are participating in research to learn more about the everyday lives of young people who use AAC. If they don’t agree, DON’T include them in your photo.

CALL OR EMAIL ME IF YOU HAVE ANY QUESTIONS

Gail Teachman: (416) 425-6220 ext. 3695 / gail.teachman@hollandbloorview.ca

(Please be reminded that email correspondence is not secure and can involve risks related to loss of privacy.)
Appendix 9: Outline for Interview Field Notes

Study Pseudonym: ________            Date/Time: ___________________

Length of Interview:

Who was present?

Description of location and people:

Off tape Observations:

Summary (primary issues/ themes):

Reflections on Process and Content (what worked well and what didn’t, what was going on)

New Issues (e.g., change wording or order of questions, any other issues):

Other:
Appendix 10: Demographic Questionnaire

This questionnaire is designed to provide background information about you and your family. Your parents can help you complete the form. This information will help us describe the participants in this study in general terms. Your individual responses will not be identified in any way. Answers that you give will remain private and confidential. If you are not comfortable answering a question please leave it blank.

1. What grade or year are you at high-school? _____

2. What is your diagnosis? __________________________

FAMILY INFORMATION

The following questions are about YOUR parents’ education, employment, income and ethno-cultural background. Your responses to these questions are being gathered to enable the research team to describe the people who took part in the study in general terms. Your responses will be reported only as part of a summary of the entire study group.

In what size of community do you live? (Check ONE).

_____ Major urban (population over 100,000)
_____ Small urban (population from 3,000 to 99,999)
_____ Rural (population less than 3,000)

Reminder: If you are not comfortable answering a question please leave it blank.

3. What is the highest level of education that your parent(s) have completed? (Mark ‘M’ for mother, and ‘F’ for father in the corresponding rows)

Less than high school certificate or diploma

High school diploma

Apprenticeship or trades certificate or diploma

College or other non-university diploma

University Bachelor’s Degree

Graduate Degree (MSc, PhD)

4. Check the category which best describes your total family income last year before taxes.

_____ Less than $15,000

_____ $15,000 to $44,999

_____ $44,999 to $89,999

_____ More than $90,000

5. Please indicate the ethnic or cultural background(s) that you and your family members identify with:

_______________________________________________________________________

Thank you for taking the time to complete this questionnaire.
Appendix 11: Analytic Guide

WITHIN PARTICIPANT

1. Repeated viewing of the various data sources for each participant to get a sense of the whole, simultaneously coding directly to video within Atlas.ti
2. Concurrently record memos that might paraphrase sections of the data, make links to related literature, or aid in abstracting my thinking about the data (e.g. asking questions like: ‘What is going on here?’ or ‘What is this an instance of? What else is like this?’) Tag videos directly with corresponding analytic memos at this stage.
3. Extract the ‘facts’ across all data sources (from video interviews, field notes, demographic questionnaires, photos, and belonging circles) to construct case summaries describing each participant along with their everyday activities, social networks, personal geographies and material contexts
4. Critically analyze photo images, captions, and belonging circles; linking and comparing across data sets (within and eventually across participant accounts)

OVERALL GUIDING QUESTIONS

This list of questions, consistent with the study aims and conceptual framework will be ‘asked’ of the data during the coding and memoing processes of analysis. This iteration of the guide will continue to be revised as analysis proceeds from a focus primarily ‘within participant’ to ‘across participant’ in iterative cycles. The term ‘youth’ here refers to study participants.

DESCRIPTIVE ANALYSIS

Who is part of youths’ social networks, how often, in which settings?
What are the everyday routines of these youth?
Where do youth go, when and how often?
What are the material conditions of their everyday lives e.g. housing, assistive technologies, transportation, school placement, socioeconomic status
How do youth describe themselves? How do they relate to labels such as disabled, disordered, impaired, special needs?
How do they talk about inclusion/exclusion relation to their own lives and circumstances?
What ambiguities or contradictions are found in their accounts at a basic descriptive level?

* I understand Bourdieu’s concepts as relational, thus inextricably linked. For analytic purposes, it has been useful to group analytic questions according to the concepts of field, capital, habitus, and practices.

FIELD

Which fields are represented in participants’ lives?
Who occupies this field – how is it stratified? Who ‘belongs’ in the field?
How are youth and other agents positioned in/across the field (the advantage of Bourdieu is the provide complexity to the reductionist version of inclusion/exclusion with nothing in between)?

What’s the ‘name of the game’ – from youths’ position (point of view); from other positions in the field?

What is at stake, what are the stakes in the fields where youth are positioned/take up positions?

Are there fields that youth prefer to be excluded from? OR Included in?

What types of capital are valued or devalued in the field – how is it distributed, how transposable is it?

**HABITUS**

How does inclusion as a discourse structure habitus – how does it act as a structuring structure? Do youth accept some places are naturally not ‘open’ to them, or just ‘not where I belong’? not worth the effort?

What identities/positionings do youth reproduce, take up or resist? e.g. Same just different (normal), able/disabled/less disabled than others, part of which groups, outside of which groups; role model, best friend, good student, teenager, helper

What other discourses do they reproduce or resist (e.g. life goals and purposes, age based roles, “good person” good child/parent etc.)

How do primary habitus and family practices transfer (play-out) across other fields?

Are there examples of disruptions to family and ‘primary’ habitus as youth move into other fields?

**CAPITAL**

Which forms of capital do youth have (not have) and in what quantity? How do they leverage capital to improve or support their position in the field?

Is ‘inclusion’ recognised as capital? i.e. Does ‘inclusion’ (as a position-taking within a field, as membership in a social group in a field, or simply being in a field) have ‘legitimate’ symbolic value for youth, for other agents in the field?

How does family capital (all types) contribute to youths’ positioning/position-taking?

How/where is economic (material) capital leveraged - where is it valued, how does this vary across fields? How does it mediate access to other forms of capital, or access to particular fields? Consider finances, housing, assistive technologies, transportation, school placement, socioeconomic status within and across the fields where they are positioned?

How are impaired bodies (physical capital) valued within fields, how does this vary across fields? What are legitimate bodies, legitimate communication practices in the field?

How are bodies that speak/don’t speak (linguistic capital-a form of cultural capital) valued across fields?

How does negative physical capital and negative linguistic capital mediate youths’ positioning and position-taking (identities) in the field? (reformulations? resistance?)
How are particular technologies valued in/across particular fields? How are speech technologies vs. ‘bodily speech’ valued within/across settings? How are techno-bodies valued or devalued?
Which forms of capital do youth leverage to improve or support their position in the field? What strategies are in play?

PRACTICES

How do the everyday lives of youth reveal logical practices that reproduce, resist or reformulate inclusion as ‘best’ or ‘a good thing’?
How do some practices reflect a struggle to be positioned as included? How is this achieved? What does it look like – from the point of view of youth? How?
How are youths’ practices linked with family practices? school practices? ‘normal teen’ practices?
To what extent do everyday family practices reflect a struggle to achieve inclusion/avoid exclusion on behalf of youth who use AAC, and as well, for the family e.g. to be a ‘normal family’ participating in the ‘normal fields’ and ‘normal activities’ of childhood? What extraordinary efforts are expended to achieve this? (what capital is invested, divested, diverted)
Do youth take up ‘inclusion’ in ways that limit or support ‘living well in the moment’, opportunities to thrive, do their practices suggest alternative and potentially more fulfilling ways of being/doing and belonging in the world?

TIME - “practice unfolds in time” (Bourdieu)

Economy of time: being on time, speed and efficiency differences, taking too much time, running out of time, making time ‘right and proper’ time - developmental timelines, being ‘in time’ with others, being out-of-sync
What time/whose time must be invested toward the aim of ‘inclusion’?
How are ‘time logics’ implicated in understandings of inclusion and exclusion – e.g. is it only natural to be ‘left out’ because a person takes too much time, are there times to be included, or times where it is taken for granted to be left-out, ‘time-out’

INCLUSION/EXCLUSION

What multiple effects does ‘inclusion’ have in the everyday lives of youth who use AAC? Are there ways that inclusion (when understood as a move toward recognition as normal) is implicated in exclusionary, stigmatizing or marginalizing practices?
How are youth and their families complicit in these processes?
How do they resist or opt out?
How do youth reformulate marginalized or excluded positions in a field as optimal and included positions?
How do they make a “virtue of necessity”? How does a Bourdieusian analysis of the data disrupt the inclusion/exclusion binary to prompt thinking about inclusion in more complex ways? e.g. as dynamic, relational. Does ‘inclusion’ remain useful as a concept once disrupted in these ways? How is inclusion reproduced, reformulated, or resisted by participants?
Appendix 12: Sage Research Methods Case

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**Title: Doing Qualitative Research with People Who Have Communication Impairments**

Contributors: Gail Teachman & Bhavnita Mistry & Barbara E. Gibson

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**Links to the Research Output**


Abstract

In this case study, we trace the development and adaptation of methods for doing qualitative research with disabled young people who use augmentative and alternative communication. Persons with communication impairments are often excluded from research on the grounds that they cannot ‘speak for themselves’. Our aim is to bring our methods to life in a practical way, and thereby contribute to emerging literature that can guide the selection and implementation of methods for research with people who have communication impairments. Through the case study, we explicate our learning process within the context of a large, multi-methods project, where we combined ethnographic methods (observation, photo-elicitation) and interview methods (both face to face and electronic) to generate qualitative data with non-speaking youth about their activity participation experiences. Following an introductory discussion of terminology, and an overview of the research project and context, we follow one youth participant through the research process in order to illustrate our experiences and learning as we adapted and refined the study methods. We conclude by highlighting the merits of combining multiple, flexible methods for research with individuals with communication impairments, suggesting these lessons might inform both qualitative and quantitative researchers seeking to design more inclusive research approaches.

Learning Outcomes

By the end of the case, you should

• Have a better understanding of the methodological considerations involved in doing qualitative research, particularly interview-based research, with people who have communication impairments

• Be more familiar with the range of alternative communication modes employed by people with communication impairments and be familiar with various strategies that researchers can use to adapt their methods at various stages in a research study in order to promote participant–researcher understanding and optimize the data generated

• Be able to discuss the pros and cons of designing a study that employs multiple methods to collect various types of data when doing research with people who have communication impairments
Terminology

In this case, we use the terminology ‘people with communication impairments’ to describe people of all ages who communicate primarily in ways other than speech, because of developmental neurological conditions such as cerebral palsy or autism; acquired brain injuries, stroke or neurological degenerative diseases; or subsequent to illnesses where they may require tracheotomy, intubation or ventilation. Clearly, this is not a homogenous group, and we later elaborate on the necessity of individualizing research methods with each particular participant. We also occasionally refer to ‘non-speaking’ youth or youth who use augmentative and alternative communication (AAC) to describe the young participants in our research. The term ‘AAC’ is used in several ways: it can be used to describe a variety of non-speech communication systems and strategies that can include eye gaze, gestures, facial expressions or a human communication assistant. The term also encompasses an array of assistive communication technologies that range from simple alphabet boards, pictures and symbol-sets through to highly complex and costly speech-generating computer technologies. Finally, AAC is a term used to describe an interdisciplinary field. The first author of this case study has extensive experience in the field of AAC, which provided grounding for adapting our methods. We recommend researchers explore AAC literature to learn about interacting with individuals who have communication impairments. One introductory resource is an authoritative text authored by David Beukelman and Pat Mirenda, which provides an overview of AAC with children and adults.

People with communication impairments may or may not identify as disabled. We use the term ‘disabled youth’ as consistent with current usage in disability studies. This choice of terminology emphasizes a process whereby individuals are disabled by physical and social barriers in their environment, as opposed to ‘people first’ terminology where ‘youth with disabilities’ suggests disability is contained in the person and is a necessary effect of their impairments.

Project Overview and Context

Our research was part of a larger multi-team project, funded by a Canadian Institutes of Health Research Emerging Team Grant, to investigate multiple methods for studying disabled youths’ experiences of activity settings. The project was conducted from 2010 through 2012 at a regional children's rehabilitation hospital in Ontario, Canada. At least in part because of the lack of
research tools and methods, youth who communicate using AAC are often excluded from childhood disability research; however, evidence suggests that they are socially and physically marginalized. Little is known about how they experience and evaluate their everyday activity settings (i.e. places in which they ‘do things’). We were interested in learning how some activity settings might better facilitate opportunities to experience meaningful interactions, engage in challenging tasks, form social bonds or friendships or experience a sense of control or choice.

For the purposes of this case, we report only on the qualitative ‘arm’ of the research project that involved the cohort of youth who used AAC, where we combined ethnographic (observation, photo-elicitation) and interview (both face to face and electronic) methods. Our qualitative research team consisted of an interdisciplinary group of child health researchers. We discuss our overall project methodology in more depth in a recently published article (Gibson et al., 2013).

**Getting Started**

To illustrate our methods in action, we describe the research process with one participant, Andrew (a pseudonym), an 18-year-old AAC user. Andrew was a high school student with cerebral palsy, who communicated using eye gaze, non-speech vocalizations, facial expressions, gestures and body movements as well as a computerized speech-generating device and a laptop computer. Because he was unable to control his hand movements to access a keyboard or a mouse, he used an electronic head-controlled switch that was mounted on his wheelchair, to control these communication technologies as well as to drive his power wheelchair. (Many types and sizes of switches are used by people with movement limitations to control electronic devices.) Andrew lived at home with his parents and two siblings.

**‘AAC-User’ Collaboration in the Development of Methods**

In addition to agreeing to be a participant in our study, Andrew agreed to act as an expert consultant to our team, providing feedback as we piloted and refined our methods. His ‘insider’ perspectives were invaluable – we recommend researchers seek this type of collaboration early in the process wherever feasible.

**Flexible Contact Schedule**
Our first visit incorporated the study consent process with a short interview to learn about participants' daily activities, and their methods of and preferences for communicating. During this visit, we also prepared participants to engage with photo-elicitation (this method is described below), by completing an individualized camera set-up (e.g. stable camera mounted on a participant's wheelchair, along with switch access to camera controls). For most participants, we were able to complete this visit within 90–120 min, but in some instances, these research tasks were completed over several shorter contacts because of participant fatigue. All of these first contacts took place in a setting of the participant's choosing, most often at their home where a parent or caregiver was present to assist us in becoming familiar with the participant's communication repertoire.

In Andrew's case, the first ‘visit’ took place over two contacts at his home with his mother present. In general, it takes longer for people with communication impairments to respond to questions or participate in conversations. It is important to plan for this extra time and avoid making participants feel rushed. Andrew elected not to use his speech-generating device or his laptop computer on these occasions, preferring to use eye gaze, gestures or non-speech vocalizations, together with his mother acting as a communication assistant. In our experience, family members, and particularly mothers, of youth who use AAC reported these ‘low-tech’ communication strategies were most efficient for them – they know their child well and have had years of experience developing very specific, often idiosyncratic, ways of communicating together. Computers and speech-generating devices (often termed ‘high-tech AAC’) can facilitate much more precise, in-depth conversation; however, they can also be experienced as cumbersome and slow. People who use AAC, therefore, often prefer different modes of communication for different activities, in different settings and with different communication ‘partners’. Family members are ‘familiar communication partners’ (in AAC terms), whereas we were ‘unfamiliar’ with participants' communication styles. We also needed time to adjust our own communication to optimize our interaction. A parent's presence at these first visits was vital as we worked to adjust our approaches and methods to suit each participant's communication preferences.

**Supporting the Consent Process**
The use of visuals such as graphic symbols or photographs is a common augmentative communication strategy – simply put, visuals help all of us understand information more precisely, adding clarity where words alone might be confusing or easily misunderstood. In order to optimize potential participants' understanding of the study and involve them more actively in the consent process, we designed materials and a structured process that we've termed a ‘Visual Consent Framework’. With permission, we used Picture Communication Symbols (PCS©) along with photographs to augment the information about the study, as in Figure 1. More information about our development of a visual consent framework will be reported in a forthcoming publication. For a number of participants, this approach supported them to more readily ask questions, ensuring they understood the study before agreeing to participate. We suggest this approach could usefully augment the consent process for persons of any age who have communication impairments.

Figure 1. Sample page from visual consent framework.

Adapting and Combining Multiple Qualitative Methods

We report our experiences with Andrew in relation to each of the following methods (photo-elicitation, observations, electronic interviews and face-to-face interviews).
**Photo-Elicitation**

In photo-elicitation, participant-generated photographs or videos are used to enrich discussions in individual qualitative interviews. This approach can facilitate researcher–interviewee rapport and provide a point of focus to engage the interviewee. In our research with youth who use AAC, these images also served to augment conversation within the interviews; for example, the images helped to focus and clarify the topic of conversation, or an interviewer could point to an aspect of the image to confirm understanding about a particular comment made by a participant.

Most of our participants were very engaged by this method, commenting that they had never before had an opportunity to take photos independently. Adapting the camera so that it could be operated by one or two switches, and mounting the camera securely on the participant's wheelchair, provided a unique and potentially fun element to participation in the study. However, paradoxically, this sometimes detracted from generating the type of data we were hoping for. Understandably, many youth spent considerable time experimenting with the camera, and less time thinking about the actual images they were producing, or how those images could tell the research team about their experiences of activity settings. We developed a printed handout with suggestions and reminders for youth about why they were taking photos or video as part of the study, and we stressed the importance of thinking about what they were hoping to show through the images they recorded.

Andrew elected to participate in two activity settings for the research: playing video games and participating in a panel discussion. Both required that he use his head-switch to control his wheelchair and his laptop computer; thus, it wasn't feasible for him to control the camera at the same time. Instead, Andrew played the role of ‘director’ – selecting which images to record and directing another person to use the camera.

**Participant Observations**

We accompanied youth on two visits where they participated in their chosen activity settings. Each visit took between 1.5 and 3 h, with the average visit lasting 2 h. The researcher made observations and took field notes, engaged the youth in informal conversation and assisted them to take photos/videos reflecting their experiences.
In Qualitative Methods for Health Research, Judith Green and Nicki Thorogood pointed out that observational methods allow researchers to record the details of activity and interactions that may seem unremarkable to participants and that are unlikely to be shared in interviews. In our research, we found that although direct observation increased the overall time spent generating data in the study, it ‘paid off’ in terms of the rich data that were generated, and which we could build on as we probed within the subsequent electronic and face-to-face interviews. This was particularly important given the brief and succinct interview data that we anticipated due to participant's communication impairments.

The observation visits also afforded opportunities to ask questions while participants were immersed in the activity setting. For one of his visits, Andrew chose to play video games at home, in his room with a friend. They had worked out a system where they jointly controlled one game controller to play a game of hockey, and they were keen to ‘show off’ their techniques, explaining how the system worked as they progressed through the game. Andrew was seated in his wheelchair and used his forehead against the controller to direct the play, while his friend stood behind him and held the controller close to Andrew's head and hit the buttons according to Andrew's arm gestures. Only through direct observation would we have had an opportunity to observe how the two youth moved together in exhilarating, exuberant gaming. The session yielded some of the most illustrative observational data about ways that people, activities and environments interact, and what factors might mediate optimal environments for disabled youth. More examples of ways that participant observation helped to inform the other types of data being generated can be found in an article about our research findings (King et al., 2013).

**Electronic Interviews**

Electronic interviewing is increasingly used as part of a ‘toolbox’ of options in qualitative research. Because we anticipated that it would take a long time and a lot of effort for our participants to respond in face-to-face interviews, we incorporated electronic interviewing as one of our methods. We referred to emerging literature, particularly an article by Nicole Ison where she reported key benefits and potential limitations of using this method with people who have verbal communication impairments. After each activity setting observation, 8–10 written questions were emailed to participants, and their answers were returned prior to the final face-to-
face interview. Questions were both generic (e.g. ‘what would have made this activity perfect?’) and setting specific (e.g. ‘what were the good things about shopping at the mall?’). Participants were asked to return the email with their responses by a specific date (usually within a week) and were encouraged to complete their typed responses in whatever way was easiest for them: point form, having someone else type it out for them and so on. We asked participants to tell us how long it had taken them to respond – often they told us it took an hour to answer 8–10 questions, even though their responses were usually only a few words. The electronic interview data guided development of an individualized interview guide, allowing us to probe participants' electronic responses in greater depth within the final face-to-face interview. The following excerpt from one of Andrew's electronic interviews, illustrates our follow-up to the video game activity described above (questions in italics):

*What were the good things about doing this activity?*

Andrew (A): I got to hang out with my best friend and I was moving the players by myself.

*How did you feel when you were doing this activity?*

A: I felt excited when I was doing this activity.

*You said you ‘felt excited’ while doing the activity. What made you feel excited?*

A: What teenager doesn't like the game of hockey?

Here is another excerpt from the electronic interview that followed Andrew's participation at a public speaking event where, using his speech-generating device, he was a part of a panel discussion:

*What were the good things about doing this activity?*

(A): Meeting new people and sharing thoughts and feelings.

*How did you feel when you were presenting in public?*

(A): I felt scared.
How does it feel to present your ideas in front of a group of people?

(A): I liked it because it gave me a voice.

As mentioned, participants' responses in the electronic interviews suggested topics for further discussion or clarification in the final face-to-face interview. For example, when Gail later probed Andrew during the final interview about what made him feel scared (during the panel discussion), he shared that it wasn't because he felt any shyness or stage fright; it was because he was afraid that the speech-generating device might fail.

Face-to-Face Interviews

Semi-structured, face-to-face interviews were conducted at a location of the participant's choosing – in almost every case, participants chose their home setting. The interview guide consisted of generic and specific questions that were constructed for each participant and incorporated a variety of youth-friendly interview techniques that we have reported elsewhere (Teachman & Gibson, 2013). Data collected during the activities (i.e. participant-generated images, email responses and observational field notes) were used as points of discussion and prompts to elicit the participants' reflection on the two activities and their settings. For example, in Andrew's final interview, topics explored included physical sensations associated with enjoyment of activities like video-gaming; ways that specific activities like public speaking were associated with feelings of accomplishment, in/dependence or belonging; and factors that prevented him from doing activities as often as he would have liked.

During the face-to-face interviews, selections from the participant's self-generated photos and video were viewed on a laptop computer to elicit conversation. Most often, we asked youth what the images told about them, or what they wanted the research team to learn from the images. One youth, who used a power wheelchair, took many photos of doorways or tight, crowded spaces while participating in a shopping activity. During the final interview, these images facilitated discussion about her frustrations experiencing physical barriers in the environment. The average length of each face-to-face interview was 75 min.
Most interviews were conducted by the first author, Gail Teachman, who had extensive experience interacting with individuals who use AAC. This background allowed her to draw on a wide variety of general AAC strategies during the interviews. Key to our interviewing approach was the information we gathered at our first contact, where we explicitly focused on learning about a youth's individual communication preferences. If participants used a speech-generating device or laptop computer as part of their communication repertoire, we requested that they have this device available for use during the interview because we anticipated they could provide more detailed, in-depth responses using these tools. However, even using a device, most participants limited their responses to one or two words. It was very time-consuming and laborious for youth, particularly those who were using a switch, to construct responses. Like many people who use AAC devices, the youth in our study had learned to be quite succinct. This brevity can create opportunities for misunderstanding, so the interviewer frequently used repetition and rephrasing to clarify and confirm the participants' meaning. Participants needed frequent breaks, especially if they were using a device to communicate.

The following excerpts from our final interview with Andrew provide some sense of how our interviews unfolded, including examples of interviewer clarification strategies and noting the length of time for each excerpted conversation:

Interviewer (GT): Can you tell me a few things that you think are top of your list for really favourite activities?

[Long pause as Andrew composes his answer – almost 2 minutes pass as he composes his answer.]

Andrew (A): Playing NHL on the Xbox [via AAC device].

GT: So playing NHL on the Xbox, one of your favourite things to do. Is there anything else … your top favourite things, activities to do?

[Long pause as Andrew composes his answer. Andrew is heard breathing a bit heavily as he composes his answer due to the effort of repeatedly hitting his head switch to compose his answers. Almost a minute passes as he composes his answer.]

A: Riding my bike. [via AAC device]
GT: Riding my bike? [clarifying]

A: [non-speech vocalization and eyes up in agreement]

GT: Anything else? (Andrew nods ‘No’) That's it? Okay. So, what comes to mind about those activities that puts them high on your list?

[Long pause as Andrew composes his answer. He breathes heavily as he composes his answer. Just over a minute passes before his answer is heard via the communication device.]

A: Feeling excitement [via AAC device]

[9 minutes for this interaction]

Later on in the interview, Andrew talked about how he sometimes feels angry or frustrated because he can't engage in his favourite activities as often as he would like since he needs assistance. Here, Gail used a technique where, based on prior agreement from the AAC user, she watched as he composed a response and guessed how he might complete his response. This is a technique that can save energy on the part of the person using the AAC device but should only be used with prior agreement.

GT: So you're saying something stops you from doing your favourite activities as often as you want because you need a buddy to be doing it with you. So does that sometimes feel frustrating? (Andrew nods, eyes up for yes) Yeah? [interrogative tone] Are there any other words you would use for how that makes you feel?

[Pause as Andrew composes his answer]

GT: (reading the partial response and guessing) Sometimes angry?

A: mm-hmm (vocalizing an approximation of ‘uh-huh’)

GT: Yes? [interrogative tone – Andrew nods and gazes up for ‘yes’] Okay…What are the sorts of things or people … situations that make you angry?

[Long pause – Just over 3 minutes pass as Andrew composes his answer]
A: When people whine about taking me out. [via AAC device]

GT: Are you able to say who does that? (checking his comfort level in being more specific)

[6 minutes for this interaction]

Andrew went on to explain that his siblings sometimes tired of helping him. With Gail probing, he was able to clarify that he felt they were ‘burnt out’.

GT: Do you think they're just tired of it? Yeah? [interrogative tone – Andrew nods ‘yes’] It's not that it's too hard for them? (Andrew nods ‘no’) So, do you sometimes feel like maybe they're just a bit burnt out? [Andrew moves to indicate a very clear, dramatic nod for yes] Yeah, for sure? [affirmative tone] Okay, we got it on that one. Okay.

A: [multiple non-speech vocalizations – clearly indicating he has more to say]

GT: I'm just going to wait in case there is something more you want to say.

[Long pause – Just over 2 minutes pass as Andrew composes his answer]

A: I just want one day for them to have my body [via AAC device]

[5 minutes total for this interaction]

At several points during the interview, Gail rephrased Andrew's response in a summary statement so that he could confirm his responses. The next excerpt, which followed a series of probes about Andrew's activity preferences, illustrates this rephrasing technique:

GT: So I'm going to guess here, you can confirm. Playing video games is just a really super favourite activity, you don't really care too much who you play with or where it is, as long as you get to do it. That's what I'm hearing? [interrogative tone]

A: Hmmm [Andrew nods ‘yes’ and vocalizes]

GT: Yes. [affirmative tone] Okay.

[Long pause. 2 minutes pass as Andrew adds a qualifier to the statement]
A: So as long as the place has wheelchair access. [via AAC device]

[3 minutes total for this interaction]

Some participants elected to ask a parent to join the interview in the role of a communication assistant. In these instances, the parent's primary role was to confirm that the interviewer correctly interpreted the participant's responses, which was very helpful with some participants whose signals for ‘yes’ or ‘no’ were fleeting and difficult for a less familiar person to read. This excerpt, from a face-to-face interview with Jessica (another study participant) and her mother, illustrates how a communication assistant can act to support a person with communication impairments in an interview:

GT: What are some other activities that are things that you do a lot?

[long pause – 6 minute pass as Jessica works to compose letter-by-letter on her AAC device, but she seems to be frustrated, begins to sigh and is looking to her mother for assistance]

Mom: Do you want your board? [referring to a customized printed communication display that includes letters, words and short phrase for ‘quick communication’] This board? Your ‘Quick Board’? [Mom holds up one of the displays that she and Jessica had assembled prior to the interview] Okay?

J: [Jessica signals ‘yes’ to Mom using a very rapid, subtle shift in her eye gaze that is not easily discernible, then looks down at the display. Using eye gaze, she indicates to her mother a series of letters and key words to spell out her response. 3 more minutes pass as the pair co-construct Jessica's response]

Mom: Cards, she likes to play regular cards.

Interviewer: Okay.

[9 minutes total for this interaction]

The variety of idiosyncratic ways that Jessica used to communicate was very difficult for Gail to recognize and understand since she was not familiar with Jessica. Her mother's assistance during
the interview greatly increased the efficiency and clarity of the discussion, thereby maximizing Jessica's opportunity to share her perspectives. Our interview approach was quite unlike research where a parent or caregiver is asked to provide proxy responses on behalf of an individual with communication impairments. At times, participants asked a parent to expand on a particular question, especially when using a communication device would have taken considerably more time and effort. When this happened, the interviewer and parent took care to confirm with the youth that the parent was ‘getting it right’. Some researchers might express reservations about this approach to interviewing, querying parents’ influence or questioning whether we were ‘giving voice’ to the youth. However, our participants communicated in partnership with a friend, parent or caregiver for many/most of their activities. Many youth were accustomed to and valued having their parent act as a communication assistant. Interviewing them alone would have imposed a false and potentially uncomfortable separation that would not represent their ‘voice’ in the usual sense.

**Conclusion**

In this case study, we have outlined the process through which we developed and refined methods for doing qualitative research with youth who use AAC. This group is but one of many groups of individuals with communication impairments who are often excluded from research that directly affects them. We combined multiple methods that generated different types of data that informed one another and allowed for rich interpretations and deeper understanding of disabled youths' activity setting experiences. We have discussed practical lessons concerning our process and methods, using examples from one particular participant to illuminate our experiences. Further development of these methods is needed; however, we trust that by sharing our work, we have provided information that will prove useful not only for qualitative research designs but also for research in general.

**Exercises and Discussion Questions**

- Reflect on the differences between an interview with a ‘proxy’ respondent and an interview where a communication assistant supports a participant who has a communication impairment; discuss assumptions about participant ‘voice’ as they relate to this issue.
• Watch a video or television segment that involves a person talking but turn off the audio track. Make a note of the non-verbal communication, for example, gestures, facial expressions and so on that augment the speaker's voice. Use this exercise to reflect on the many types of communication that do not involve speech.

• In our case study, we combined four methods that were complimentary. Can you think of other methods that we might have included to help generate data with non-speaking participants?

• What might be strengths and weaknesses of our face-to-face interview approach?

Further Reading


Web Resource
https://www.isaac-online.org/english/home/

References


