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Beyond inclusion: collective social spaces of safety, communion, and recognition

Além da inclusão: espaços sociais coletivos de segurança, comunhão e reconhecimento

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Abstract

This paper unsettles taken-for-granted understandings of social inclusion in the field of occupational therapy and links with the concept of radical inclusion developed in social occupational therapy. It traces the ways that, over time, inclusion has been reduced to a position within the inclusion/exclusion binary. Pierre Bourdieu's reflexive theory of practice is introduced to expand understandings of how the negative value accorded to disability is reproduced through exclusionary social conditions and relations. Drawing on the results of a qualitative study that examined the everyday lives, practices and occupations of 13 Canadian youth who used augmentative and alternative communication (AAC) modes as a result of physical impairments, three elements of more inclusive social spaces – safety, communion, and recognition – are presented alongside implications of each for occupational therapy. These alternative approaches for thinking beyond inclusion are grounded by narratives illustrating elements of social spaces that can foster a sense of belonging and connection. The perspectives shared by youth in the study add complex insights into how they made 'practical sense' of prevailing calls for social inclusion. Their stories show how even as they struggled for inclusion, they were subject to and internalized negative valuations of disability. Importantly, the paper highlights strategies employed by youth to reformulate inclusion on their own terms. These reformulations go beyond over-simplified conceptions of inclusion and hold potential to inform the ways that occupational therapists work alongside individuals and collectives to improve life chances, expand occupational possibilities, and support flourishing for disabled children and youth.

Keywords: Social Inclusion, Communication disability, Youth, Occupational Therapy, Social Theories.

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Resumo

Este artigo desestabiliza os entendimentos aceitos sobre a inclusão social no campo da terapia ocupacional e relaciona-os com o conceito de inclusão radical desenvolvido na terapia ocupacional social. Traça as maneiras pelas quais, ao longo do tempo, a inclusão foi reduzida a uma posição simplificada dentro do binário inclusão/exclusão. A teoria reflexiva da prática de Pierre Bourdieu é introduzida para expandir a compreensão de como o valor negativo atribuído à deficiência é reproduzido por meio de condições e relações sociais excludentes. Com base nos resultados de um estudo qualitativo que examinou a vida cotidiana, práticas e ocupações de 13 jovens canadenses que usam modos de comunicação aumentativa e alternativa (AAC), em decorrência de suas deficiências físicas, três elementos de espaços sociais mais inclusivos são apresentados juntamente com as suas implicações para a terapia ocupacional: segurança, comunhão e reconhecimento. Essas abordagens para pensar além da inclusão são fundamentadas em narrativas que ilustram elementos dos espaços sociais que podem promover um sentimento de pertencimento e conexão. As perspectivas compartilhadas pelos jovens acrescentam percepções complexas sobre como eles deram "sentido prático" aos apelos predominantes por inclusão social. Suas histórias mostram como, mesmo enquanto lutavam pela inclusão, foram submetidos e internalizaram avaliações negativas sobre a deficiência. Importante ressaltar as estratégias empregadas pelos jovens para reformular a inclusão em seus próprios termos, que vão além de concepções simplificadas de inclusão e têm potencial para informar as maneiras pelas quais os terapeutas ocupacionais trabalham com indivíduos e coletivos para melhorar as oportunidades de vida, expandir a ocupação.

Palavras-chave: Inclusão Social, Transtornos de Comunicação, Juventude, Terapia, Ocupacional, Teorias Sociais.

Introduction

The goal of fully including disabled people in society has been enshrined in international documents and legislation (UN General Assembly, 2006; World Health Organization, 2021), 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 global climate, there is little room to question the authority or morality of calls for inclusion. Yet, knowledge of what actually constitutes inclusion and how it can be realized remains elusive and the perspectives of groups categorized as 'in need of inclusion' are largely missing from policies aimed toward mitigating social exclusion. 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 which were seen as closely aligned with the values of occupational therapy, called for *segregation*, *normalization*, and *integration* of disabled persons. Each movement, situated in temporal and socio-political contexts has, in turn, purported to offer solutions to the 'problem' of disability and experiences of social exclusion. Yet, each has largely fallen out of favor and given way to inclusion-directed mandates.

In this paper, I aim to unsettle taken-for-granted understandings of social inclusion in the field of occupational therapy, query the ways inclusion has been reduced to a simplified position within the inclusion/exclusion binary, and propose alternative approaches for thinking about what fosters a sense of belonging and connection for individuals and collectives. To this end, I draw on the results of a qualitative study that examined the everyday lives, practices and occupations of thirteen Canadian youth who used augmentative and alternative communication (AAC) modes as a result of physical impairments (Teachman et al., 2020). The study focused on advancing understandings of how disabled young people made 'practical sense' of prevailing calls for social inclusion. Oriented by Pierre Bourdieu's reflexive theory of practice (Bourdieu, 1981; Bourdieu & Wacquant, 1992) the results illuminated ways in which disabled youth struggled for inclusion, internalized negative valuations of disability, and reformulated inclusion on their own terms. Here, I focus on these latter *reformulations of inclusion* which, I argue, have tremendous potential to inform the ways that occupational therapists can work alongside individuals and collectives to improve life chances, expand occupational possibilities (Rudman, 2010) and support flourishing for disabled children and youth.

Unsettling Inclusion

To help contextualize the ways that youth in the aforementioned study reformulated inclusion, I move next to 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, p. 428) depictions of inclusion, positing it as "something that looks quite different depending on the viewpoint of the observer". I then consider samplings from empirical research exploring perceptions of inclusion generated with diverse groups of people identified as excluded.

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 and specifically in Canada where this research was conducted, 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 social spaces. 'Integration' became a byword for equality and was a precursor to the inclusion movement (Weber & Bennett, 2004). In Canada, 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 statutes and common law (Tardif-Williams et al., 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-Williams et al., 2009). It is beyond the scope of this paper to consider how calls for inclusion evolved over time in Brazil, but it is worth noting that similar legislation came into effect in 2016 in Brazil with the new law for inclusion of persons with disability (law no.13,146/2015, Brasil, 2015).

Such developments have implications for disabled children, especially in relation to inclusion in the context of education. As recently as 40 years ago, disabled children and youth in Ontario, Canada 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. This standard was formalized into law in the United States through the Individuals with Disabilities Education Act of 1990. Canadian approaches to inclusive education were, and remain, 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 educational 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 and in society more broadly.

In occupational therapy, it is generally accepted that inclusion is an overarching and desirable goal for disabled persons. 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). This is not surprising when considering the predominant focus on the individual that continues to characterize occupational therapy theories, models and practices (Gerlach et al., 2018). 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 et al., 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'.

In a compelling critique of shifts in disability and employment policy in England, 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.

As noted earlier, calls for inclusion of disabled persons originated in social change movements with intents to decrease oppression and exploitation, and improve life conditions and opportunities (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-liberal discourses of equality and humanitarianism, understandings of inclusion veered away from beliefs in the inherent dignity and interdependence of all human life that had been promoted by disability activists (Prince, 2009; Roulstone, 2010; Vanier, 1998). The notion of integration that preceded the rise of inclusion discourses was premised on conformity and alignment with dominant norms by disadvantaged groups (Ravaud & Stiker, 2001). Inclusion, thus, has been understood and enacted according to shifting meanings that tend to align with concerns of relatively more advantaged social groups. It can signal being a part of a social space 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). Occupational therapy and rehabilitation more broadly have been implicated in what Ravaud & Stiker (2001 p. 508) described as a subtle "passion for assimilation through normalization at all cost". Blinded by this passion, it is all too easy to assume that inclusion goals will be enabled through extraordinary investments toward approximating 'normal' bodies and participating in 'normal' occupations (Njelesani et al., 2015). However, Ravaud and Stiker point out that the classification processes inherent to biomedical framings of rehabilitation are difficult to reconcile with the social cohesion implied by inclusion (Ravaud & Stiker, 2001). When occupational therapy is constrained within such biomedical framings, then a focus on individual difference is reproduced through practices designed to evaluate, categorize, rank and label persons in order to align them with the services, interventions, programs and funding supports that are deemed appropriate. Such framings risk neglecting altogether the importance and complexity of the social contexts of persons' everyday lives and obscures the very real material effects of oppressive social structures and conditions.

In a particularly salient sociological review of inclusion, Allman (2013, p. 1) posited that "architectures of inclusion" benefit those already included, as much or more than those 'in need of inclusion'. Like Prince (2009), Allman (2013, p. 11) 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.

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. An example comes from Hargie et al. (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. These results are strikingly similar to research with Brazilian youth experiencing poverty who incorporated and reproduced the stigma associated with life in favelas in spite of the ways that such stigma limited their opportunities for wider social participation (Gonçalves & Malfitano, 2020). 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).

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 occupational therapy, 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 et al., 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). 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).

By explicitly unsettling and problematizing taken-for-granted understandings of inclusion, space is opened to question assumptions about the positive value of being included in the center of mainstream spaces (Graham & Slee, 2008), and more nuanced attention can be paid to the interrelations among a person's positioning within social hierarchies and their internalized perceptual schemas (the ways they come to understand the world). The research shared above 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, it might be more productive to de-center inclusion acknowledging 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 center from which exclusion processes are derived, where the normative is naturalized, and the Other is named and excluded (Graham & Slee, 2008; Swain & Cook, 2001). In the Brazilian context of social occupational therapy and education, Lopes & de Oliveira Borba (2022) have forwarded the notion of 'radical inclusion' wherein the entire project of education is problematized and reimagined in order to radically and inclusively reformulate learning for all. Surfacing the assumptions that underpin dominant understandings of inclusion is crucial for occupational therapists to advance better understandings of how the 'social' in social inclusion is linked with collective values and beliefs and therefore indivisible from the individual.

In summary, at the outset, this research adopted the following provisional 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, the research explored how social relations unfold to produce disabled youths' sense of inclusion (and/or exclusion) in particular spaces. In what follows, I briefly outline the theoretical framework of the study before expanding on how youth resisted negative valuations of disability to reformate inclusion on their own terms. I outline three elements of more inclusive social spaces – safety, communion and recognition - as described by study participants and ground these by sharing excerpts from one youth's narratives. Implications for occupational therapy are linked with considerations of how youth in the study made practical sense of inclusion and how they resisted oversimplified, binary conceptions to reformulate inclusion on their own terms.

Drawing on Social Theory to Re-think Inclusion

As noted above, the study was focused on youth living with communication and physical impairments. Disability advocates and researchers have suggested they experience high levels of social exclusion (Morris, 2001; Smith, 2005, 2014; Whitehouse et al., 2009). Yet at the time of the study, no research with these young people had explicitly explored their perspectives on inclusion or exclusion in relation to the social contexts in which they were positioned. Accordingly, in line with scholars in "disabled children's childhood studies" (Curran & Runswick-Cole, 2013, p. 9), the critical approach of this study interrelated 'private troubles' with public issues and adopted the stance that impairment is not (only) an *individual* problem, but instead, is irreducibly linked with the *social*. Critical approaches to research in occupational therapy and occupational science add value to research results by insisting that the personal and the social are always intertwined (Eakin et al., 1996). It was vital to attend closely to the accounts of youth, acknowledging their role in co-producing and co-analyzing data for this research. However, it was equally important to go beyond 'giving voice' (Facca et al., 2020) to interpret how youths' presentations of their lives and their understandings of inclusion were shaped by their social positions, and by the values, norms and beliefs that underpin calls for inclusion. Bourdieu's theory of practice seemed well-suited to examine 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.

Bourdieu's social theory has considerable potential for discerning the social contexts in which occupations are situated (Galheigo, 2011). For example, Galvaan (2015) drew on Bourdieu's theorizing in a study about marginalized youth in South Africa and the situated nature of occupational choice. The study results illustrated how patterned engagement in occupations reflected the social environment, and the collective and contextual histories in which the youth were immersed (Galvaan, 2015). This example is a reminder that occupations, as key components of everyday life are a component of what, in social theory, is termed practices. There are a wide range of social theories that can help advance understandings of how occupation is situated within social contexts. My aim in this section is to briefly discuss how and why Bourdieu's theory added value to the research about inclusion described here.

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 natural because of the relationship between persons' daily subjective interactions and the broader social structures in which they are immersed (Bourdieu, 1990). Society (reconfigured as social space by Bourdieu) is made up of interlocking fields (e.g., family, sport, education, or rehabilitation), each with a patterned system of tacit rules and unquestioned beliefs that define its functioning (McDonough, 2006). A person's positions in a given field, or 'who belongs where', vary according to the field-specific resources or capital at their disposal. This socio-spatial aspect of Bourdieu's work held promise as a way to help think in more complex and nuanced ways about how youth understood inclusion, how they might work toward achieving inclusion, and what effects inclusion-oriented policies and programs might have on their lives.

Bourdieu's notion of capital also offered a way to 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, 1977, 1986, 1991) – had particular relevance for youth in the study who communicated in ways that tended to be accorded less value than so-called normal speech, and who experienced physical impairments that resulted in their bodies being "understood, symbolically, only insofar as they deviate from a prescribed set of norms" (Edwards & Imrie, 2003, p. 244). Because of these differences, disabled persons who use AAC are likely in many social contexts to be accorded little or negative linguistic capital.

The last concept in Bourdieu's toolbox, habitus, represents the ways that 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).

With a provisional stance on inclusion that incorporated views from groups labelled marginalized or 'in need of inclusion' and with the help of Bourdieu's toolbox to serve as an analytic guide, it was time to design the other elements of the study. More detailed descriptions of the study methodology and results have been set out elsewhere (Teachman & Gibson, 2018; Teachman et al., 2018, 2020). In brief, a total of 13 disabled young people aged 15-24 years (7 young women and six young men) participated in the study; all used AAC, lived with family; and had cerebral palsy with associated communication and mobility impairments. The methods combined face-to-face interviews with participant-generated photographs, a graphic elicitation technique termed Belonging Circles (McKeever et al., 2015), and observations (for a more detailed account of the methodology see Teachman & Gibson, 2018). The combined data set included 27.5 hours of video-taped interviews, 951 photos and 80 Belonging Circles (McKeever et al., 2015) which participants used. This combination of methods helped optimize the data generated and supported analyses of participants' understandings of their social worlds alongside rich data that reflected the social, cultural, and material contexts that shaped their views (Bourdieu & Wacquant, 1992; Green & Thorogood, 2018; Shuttleworth, 2012). All data were analyzed as instances of situated social relations using a flexible analytic guide consistent with the study aims and conceptual framework and following recommended procedures to ensure rigor (Miles & Huberman, 1994; Sandelowski, 1995). Narrative case summaries integrated each participant's account with their photos, Belonging Circles, and related researcher observations to assemble a sense of each participant's sense of inclusion. Multiple cycles of iterative team analysis identified three interrelated set of practices which illuminated understandings of inclusion and how it might be achieved.

I move now to sharing selected study results in order to highlight socio-material conditions that youth identified as elements of their sense of inclusion. These were broadly characterized as social spaces imbued with a sense of safety, communion, and recognition. After expanding on these aspects of what youth described as inclusive social spaces, I will share one brief narrative to help illustrate the ways that youth's perspectives on inclusion were situated within broader collective understandings and social contexts.

Reformulating Inclusion

Elements of a sense of safety, communion and recognition were important to youth's sense of inclusion; however, these factors were *intermingled* across stories of inclusion and could be present alongside other factors that produced a simultaneous sense of exclusion. Each of these elements can be considered in light of their potential implications for occupational therapy.

Safety

Youth in the study experienced mainstream environments (e.g., community settings such as a shopping mall, integrated school 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 desired and enjoyable but could also be scary and uncomfortable. Likewise, some youth expressed feeling anxious and uncomfortable with their educational or care attendants, especially in relation to providing personal care (e.g., toileting, bathing) and they struggled to communicate their feelings 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 occupational therapists can act on this information is to invite more open discussions with youth and their families about their fears, anxieties, and the challenges they experience. Occupational therapists are often socialized in their training to focus on the positive and this might inadvertently lead to 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. Occupational therapists can more adequately promote a sense of inclusion by explicitly giving permission for disabled youth to discuss social situations that cause them to feel anxious or unsafe. Youth may feel uncomfortable acknowledging these feelings, or, having incorporated the negative social value assigned to disability, they may assume that they must accept these conditions.

Communion

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. Continuity 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, and arguably disabled youth in general, to form a sense of 'communion' with new people. Participants reported feeling less included when they had to continually help others learn about their physical differences or how to communicate with them. Continuity of personnel, including teachers, attendants, or health care professionals, built familiarity and supported interactions where youth felt they could express themselves and be listened to. Occupational therapists should consider the ways that a sense of inclusion might flourish through community-based programs that allow youth with impairments to congregate with other disabled youth as well as non-disabled peers. Drawing on knowledge produced in the field of disability studies, occupational therapists can contribute to the promotion of more positive disability identities.

Recognition

Youth in the study struggled to achieve recognition for aspects of their personhood beyond their devalued bodies. A sense of being valued arose from being 'expected' in a space, rather than feeling like an intruder who didn't 'fit'. Youth also shared that 'being known' contributed to a sense of inclusion. This involved being a part of social interactions where, over time, they had a chance to get to know other people and those people got to know them. The research results can also challenge occupational therapists to reconsider the ways in which people's engagement in occupations has come to be valued in ways that reproduce assumptions about the value of 'normal' ways of doing. For example, one youth described the pleasure he took in weekly piano lessons, but this young man was not able to reach out with his arms or use his hands to physically play the piano keys. His family and his music teacher recognized his talent and passion for music. Their recognition serves as a catalyst for asking '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 occupational therapy that delimit the types and nature of disabled children and youths' engagement with the world within tacit understandings of what is expected, 'typical', and 'developmentally appropriate'. Recognition is a concept that inherently implies some type of socially produced attribution of value. Youths' appeals for recognition reinforce calls for occupational therapists to move beyond a focus on individuals toward more collectivist approaches where the transformative power of occupation has potential to fuel social change (Malfitano et al., 2021).

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 disabled youth can take up valued roles and be recognized and valued *as they are*. In particular, key tenets of social occupational therapy (Lopes & Malfitano, 2021; Malfitano & Lopes, 2018) provide a way forward toward fostering and showcasing a broader range of possibilities for disabled youth to live lives that they and others within collectives ascribe value. For example, social occupational therapy places an emphasis on sociological analyses that are able to account for power relations and the inequitable distribution of resources that contribute to oppression of some social groups (Galheigo, 2011). This type of analysis highlights the political nature of occupation and the ways that individuals' occupations and daily lives cannot be separated from the collective dimensions of shared social spaces. In line with Bourdieu's theorization of social spaces and positionings, social occupational therapy attends to the real material conditions of people's lives, highlighting the situatedness of occupation within specific delimited 'territories' or collective settings (Barros et al., 2011). Certainly, for occupational therapists to act on social issues in ways that contribute to aspects of inclusion – namely safety, communion, and recognition – it is imperative that they vision practices that extend beyond a primary focus on individuals (Gerlach et al., 2018) and transcend the confines of healthcare settings and funding systems (Malfitano et al., 2014).

Jamila's narrative

To add further context to the ways youth in the study came to understand their place in the world, and how they worked to reformulated inclusion on their own terms, I share the following excerpted narrative, illustrated by a sample of the photos and belonging circles that one participant generated to contribute data to the study. This narrative provides a glimpse into how youth internalized and drew 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 took 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. Names used here are pseudonyms.

Jamila, aged 17 at the time of the study, lived with her adoptive guardian, a single woman named Rebecca and had very little contact with her birth mother. She communicated using a speech-generating device, a communication book, picture symbols on her 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, she had experienced increasing levels of physical impairment. 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: 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. For example, she shared:

> *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.*

Jamila and Rebecca lived in a tiny, rented 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. Inside, every available space was organized to accommodate Jamila's medical and personal care. In a series of photographs (two are shown in Figure 1 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*".

Figure 1. Jamila depicts aspects of her home and her sense of inclusion at home.

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 where she was able to move about on her own by crawling, in a stadium seat, and reclining in a favorite hammock. Sometimes, she used a walker or a stander, explaining she found that when she was standing up, people treated her more "like a human being" and less as if she was a little child.

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. She said she felt more included in her special education class that was equipped with a mechanical lift and raised plinth used to assist in Jamila's personal care. She marked the center of a Belonging Circle to correspond to her sense of inclusion in her "home room" at school. 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.

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 just 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 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.*

Across Jamila's account, she made frequent appeals for recognition as a "whole human being" and there is evidence even in this short excerpt of the ways that a sense of safety and communion contributed to feeling included in some social spaces, even as so many of her experiences were marked by exclusionary social relations.

Concluding Remarks

To summarize, the research described here demonstrated that from their social positions in various fields, disabled youth, like all persons, developed 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). This sense of one's place shared a close correspondence with study participants' senses of inclusion. Youth had incorporated broader social systems and values that tend to categorize and devalue disabled people, but they also resisted those mechanisms to reformulate inclusion on their own terms, and *as they are*.

With Kinsella & Whiteford (2009), this examination of inclusion was informed by Bourdieu & Wacquant's (1992) notion of epistemic reflexivity and adds to their call for ongoing critical reflection on the assumptions that underpin occupational therapy as well as the social conditions under which those assumptions came into being. It is important to ask the seemingly simple question: "How did we in this discipline come to think in these ways" when it comes to foundational concepts such as inclusion and disability. It can be argued that, in spite of emerging new approaches such as practices aligned with social occupational therapy for example, occupational therapy has not moved all that far from a biomedical focus on enabling individuals with impairments, illness or chronic conditions to engage in occupations that approximate expected and 'normal' ways of doing. This is not surprising given that the positive social value accorded to normalcy is durably embedded, not only in the logics of occupational therapy, but in the broader social fabric. Thus individuals and groups working with occupational therapists are equally influenced by these value systems. The arbitrary nature of social hierarchies and categorizations has long since slipped from view so that they appear as natural, legitimate and fixed categories of difference. Yet, instead of perpetuating beliefs and values that reinforce the negative value accorded to difference and disability, occupational therapy as a field could play an important part in exposing the effects of unwitting allegiance to idealized and oversimplified notions of inclusion. As more researchers and clinicians reflexively challenge their own assumptions and those embedded within the profession, gradual changes can occur. Occupational therapists can challenge the status quo by partnering with communities, educators and local civic organizations to redress the foreclosure of future possibilities imposed on disabled youth by ableist socio-spatial-temporal systems and structures.

Occupational therapists can join and be leaders in moving beyond oversimplified conceptions of inclusion. The rich perspectives shared by youth in the study support calls for occupational therapy to move past a restrictive focus on individuals and attend more closely to the 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' directed toward achieving inclusion and even 'radical inclusion' are conceptualized and might be enacted in the context of more collective approaches where safety, communion and recognition might be best fostered. In closing, I draw a final time on Bourdieu's (2000, p. 237-238) 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.

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References

Allman, D. (2013). The sociology of social inclusion. *SAGE Open*, *3*(1), 1-16.

Barros, D. D., Ghirardi, M. I. G., Lopes, R. E., & Galheigo, S. M. (2011). Brazilian experiences in social occupational therapy. In F. Kronenberg, N. Pollard, & D. Sakellariou (Eds.), *Occupational therapy without borders* (Vol. 2: Towards an ecology of occupation-based practices, pp. 209-215). Edinburgh: Elsevier.

Bourdieu, P. (1977). The economics of linguistic exchanges. *Social Sciences Information. Information Sur les Sciences Sociales*, *16*(6), 645-668.

Bourdieu, P. (1978). Sport and social class. *Social Sciences Information. Information Sur les Sciences Sociales*, *17*(6), 819-840.

Bourdieu, P. (1981). Men and machines. In A. V. Cicourel & K. D. Knorr-Cetina (Eds.), *Advances in social theory and methodology: toward an integration of micro-and macro-sociologies* (pp. 304-317). London: Routledge & Keegan Paul.

Bourdieu, P. (1986). The forms of capital. In J. Richardson (Ed.), *Handbook of theory and research for the sociology of education* (pp. 241-258). New York: Greenwood.

Bourdieu, P. (1988). Program for a sociology of sport. *Sociology of Sport Journal*, *5*(2), 153-161.

Bourdieu, P. (1990). *The logic of practice.* California: Stanford University Press.

Bourdieu, P. (1991). *Language and symbolic power.* Cambridge: Polity Press.

Bourdieu, P. (2000). *Pascalian meditations.* California: Stanford University Press.

Bourdieu, P., & Wacquant, L. J. D. (1992). *An invitation to reflexive sociology.* Chicago: University of Chicago.

Brasil. (2015, 7 de julho). Lei nº 13.146, de 6 de julho de 2015. Institui a Lei Brasileira de Inclusão da Pessoa com Deficiência (Estatuto da Pessoa com Deficiência). *Diário Oficial [da] República Federativa do Brasil*, Brasília. Retrieved in 2023, February 28, from http://planalto.gov.br/ccivil_03/_Ato2015-2018/2015/Lei/L13146.htm

Curran, T., & Runswick-Cole, K. (2013). *Disabled children's childhood studies: critical approaches in a global context.* Basingstoke: Palgrave Macmillan.

Eakin, J., Robertson, A., Poland, B., Coburn, D., & Edwards, R. (1996). Towards a critical social science perspective on health promotion research. *Health Promotion International*, *11*(2), 157-165.

Edwards, C., & Imrie, R. (2003). Disability and bodies as bearers of value. *Sociology*, *37*(2), 239-256.

Facca, D., Gladstone, B., & Teachman, G. (2020). Working the limits of "Giving Voice" to children: a critical conceptual review. *International Journal of Qualitative Methods*, 19(4):160940692093339.

Galheigo, S. M. (2011). Occupational therapy in the social field: concepts and critical considerations. In F. Kronenberg, N. Pollard & D. Sakellariou (Eds.), *Occupational therapies without borders* (Vol. 2: Towards an ecology of occupation-based practices, pp. 47-56). Edinburgh: Elsevier.

Galvaan, R. (2015). The contextually situated nature of occupational choice: marginalised young adolescents' experiences in South Africa. *Journal of Occupational Science*, *22*(1), 39-53.

Gerlach, A. J., Teachman, G., Laliberte-Rudman, D., Aldrich, R. M., & Huot, S. (2018). Expanding beyond individualism: engaging critical perspectives on occupation. *Scandinavian Journal of Occupational Therapy*, *25*(1), 35-43.

Gibson, B. E., Darrah, J., Cameron, D., Hashemi, G., Kingsnorth, S., Lepage, C., Martini, R., Mandich, A., & Menna-Dack, D. (2009). Revisiting therapy assumptions in children's rehabilitation: clinical and research implications. *Disability and Rehabilitation*, *31*(17), 1446-1453.

Gibson, B. E., Young, N. L., Upshur, R. E., & McKeever, P. (2007). Men on the margin: a Bourdieusian examination of living into adulthood with muscular dystrophy. *Social Science & Medicine*, *65*(3), 505-517.

Gonçalves, M. V., & Malfitano, A. P. S. (2020). Brazilian youth experiencing poverty: everyday life in the favela. *Journal of Occupational Science*, *27*(3), 311-326.

Graham, L. J., & Slee, R. (2008). An illusory interiority: interrogating the discourse/s of inclusion. *Educational Philosophy and Theory*, *40*(2), 277-293.

Green, J., & Thorogood, N. (2018). *Qualitative methods for health research* (4th ed.). Los Angeles: Sage.

Hall, E. (2010). Spaces of social inclusion and belonging for people with intellectual disabilities. *Journal of Intellectual Disability Research*, *54*(Suppl. 1), 48-57.

Hargie, O., O'Donnell, A., & McMullan, C. (2011). Constructions of social exclusion among young people from interface areas of Northern Ireland. *Youth & Society*, *43*(3), 873-899.

Holt, L. (2003). (Dis)abling children in primary school micro-spaces: geographies of inclusion and exclusion. *Health & Place*, *9*(2), 119-128.

Kinsella, E. A., & Whiteford, G. E. (2009). Knowledge generation and utilisation in occupational therapy: towards epistemic reflexivity. *Australian Occupational Therapy Journal*, *56*(4), 249-258.

Lopes, R. E., & de Oliveira Borba, P. L. (2022). A inclusão radical como diretriz para terapeutas ocupacionais na educação. *Revista Ocupación Humana*, *22*(2), 202-227.

Lopes, R. E., & Malfitano, A. P. (2021). *Social occupational therapy: theoretical and practical designs.* Philadelphia: Elsevier.

Malfitano, A. P. S., & Lopes, R. E. (2018). Social occupational therapy: committing to social change. *New Zealand Journal of Occupational Therapy*, *65*(1), 20-26.

Malfitano, A. P. S., Lopes, R. E., Magalhães, L., & Townsend, E. A. (2014). Social occupational therapy: conversations about a Brazilian experience. *Canadian Journal of Occupational Therapy*, *81*(5), 298-307.

Malfitano, A. P. S., Whiteford, G., & Molineux, M. (2021). Transcending the individual: the promise and potential of collectivist approaches in occupational therapy. *Scandinavian Journal of Occupational Therapy*, *28*(3), 188-200.

McDonough, P. (2006). Habitus and the practice of public service. *Work, Employment and Society*, *20*(4), 629-647.

McKeever, P., Dunn, J., Yantzi, N., Aslam, H., Doherty, S., Ruddick, S., Young, N. L. & Scott, H. (2015). Developing an ethnography-based accessibility survey with and for disabled children. *Journal of Ethnographic and Qualitative Research*, *10*(2), 69-86.

Miles, M. B., & Huberman, A. M. (Eds.). (1994). *Qualitative data analysis: An expanded sourcebook.* California: Sage.

Milner, P., & Kelly, B. (2009). Community participation and inclusion: people with disabilities defining their place. *Disability & Society*, *24*(1), 47-62.

Morris, J. (2001). Social exclusion and young disabled people with high levels of support needs. *Critical Social Policy*, *21*(2), 161-183.

Njelesani, J., Teachman, G., Durocher, E., Hamdani, Y., & Phelan, S. K. (2015). Thinking critically about client-centred practice and occupational possibilities across the life-span. *Scandinavian Journal of Occupational Therapy*, *22*(4), 252-259.

Paterson, K., & Hughes, B. (1999). Disability studies and phenomenology: the carnal politics of everyday life. *Disability & Society*, *14*(5), 597-610.

Ponic, P., & Frisby, W. (2010). Unpacking assumptions about inclusion in community-based health promotion: perspectives of women living in poverty. *Qualitative Health Research*, *20*(11), 1519-1531.

Prince, M. J. (2004). Canadian disability studies policy: still a hit-and-miss affair. *Canadian Journal of Sociology*, *29*(1), 59-82.

Prince, M. J. (2009). *Absent citizens: Disability politics and policy in Canada.* Toronto: University of Toronto Press.

Ravaud, J., & Stiker, H. (2001). Inclusion/exclusion: an analysis of historical and cultural meanings. In G. Albrecht, K. Seelman & M. Bury (Eds.), *Handbook of disability studies* (pp. 490-512). Thousand Oaks: Sage.

Roulstone, A. (2010). Disability, dependency and the new deal for disabled people. *Disability & Society*, *15*(3), 427-443.

Rudman, D. L. (2010). Occupational terminology: occupational possibilities. *Journal of Occupational Science*, *17*(1), 55-59.

Sandelowski, M. (1995). Qualitative analysis: what it is and how to begin. *Research in Nursing & Health*, *18*(4), 371-375.

Shuttleworth, R. (2012). *Bridging theory and experience: a critical-interpretive ethnography*. Durham: Duke University Press.

Smith, M. M. (2005). The dual challenges of aided communication and adolescence. *Augmentative and Alternative Communication*, *21*(1), 67-79.

Smith, M. M. (2014). Adolescence and AAC: Intervention challenges and possible solutions. *Communication Disorders Quarterly, 36*, 112-118.

Spencer-Cavaliere, N., & Watkinson, E. J. (2010). Inclusion understood from the perspectives of children with disability. *Adapted Physical Activity Quarterly*, *27*(4), 275-293.

Swain, J., & Cook, T. (2001). In the name of inclusion: 'We all, at the end of the day, have the needs of the children at heart'. *Critical Social Policy*, *21*(2), 185-207.

Tardif-Williams, C. Y., Trent-Kratz, M., & Donato, K. (2009). In F. A. Owen & D. M. Griffiths (Eds.), *Challenges to the human rights of people with intellectual disabilities* (pp. 240-262). London: Jessica Kingsley Publishers.

Teachman, G., & Gibson, B. E. (2018). Integrating visual methods with dialogical interviews in research with youth who use augmentative and alternative communication. *International Journal of Qualitative Methods*, *17*(1).

Teachman, G., McDonough, P., Macarthur, C., & Gibson, B. E. (2018). A critical dialogical methodology for conducting research with disabled youth who use augmentative and alternative communication. *Qualitative Inquiry*, *24*(1), 35-44.

Teachman, G., McDonough, P., Macarthur, C., & Gibson, B. E. (2020). Interrogating inclusion with youths who use augmentative and alternative communication. *Sociology of Health & Illness*, *42*(5), 1108-1122.

Titchkosky, T. (2011). *The question of access: disability, space, meaning.* Toronto: University of Toronto Press.

UN General Assembly. (2006). *Convention on the rights of persons with disabilities*. Retrieved in 2023, February 28, from http://www.un.org/disabilities/default.asp?navid=15&pid=150

Vanier, J. (1998). *Becoming Human.* Toronto: House of Anansi Press.

Weber, K., & Bennett, S. (2004). *Special education in Ontario schools.* Thornhill: Highland Press.

Whitehouse, A. J., Watt, H. J., Line, E. A., & Bishop, D. V. (2009). Adult psychosocial outcomes of children with specific language impairment, pragmatic language impairment and autism. *International Journal of Language & Communication Disorders*, *44*(4), 511-528.

World Health Organization – WHO. (2021). *WHO policy on disability*. Geneva: WHO.

Wright, F. V., Rosenbaum, P. L., Goldsmith, C. H., Law, M., & Fehlings, D. L. (2008). How do changes in body functions and structures, activity, and participation relate in children with cerebral palsy? *Developmental Medicine and Child Neurology*, *50*(4), 283-289.

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