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Reframing Childhood Disability: Pushing Boundaries in the **Rehabilitation Sciences**

Emily J. Cox, The University of Western Ontario

Supervisor: Teachman, Gail, The University of Western Ontario A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Health and Rehabilitation Sciences © Emily J. Cox 2022

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Abstract

The purpose of this study was to critically examine the ways that dominant discourses surrounding childhood disability, as constructed in the neoliberal context, shape knowledge and practice in children's rehabilitation. I carried out a critical discourse analysis of text within the rehabilitation sciences, including peer-reviewed research, websites, and qualitative interview transcripts. Drawing on disability studies scholarship as well as my Foucauldian conceptual framework, I called attention to complex interactions between discourse, power, and knowledge that shape thought and action in the rehabilitation sciences. My findings suggest that despite a growing recognition of the harms associated with deficit-based understandings of disability, reformulation will require a considerable disruption of the durable neoliberal assumptions which ground contemporary Western society. This work adds to a growing body of literature which advocates for alternative, affirmative understandings of childhood disability through interdisciplinary collaboration, particularly between disability studies and the rehabilitation sciences.

Keywords: childhood, disability, children's rehabilitation, Foucault, critical discourse analysis, occupational possibilities, occupation

Summary for Lay Audience

In this study I critically examined the ways that dominant discourses, or pervasive ways of thinking and acting, surrounding childhood disability shape knowledge and practice in children's rehabilitation. To this end, I carried out a critical discourse analysis of text within the rehabilitation sciences by examining peer-reviewed research articles, websites of children's rehabilitation institutions, as well as qualitative interview transcripts. In this study I drew on disability studies scholarship as well as a conceptual framework informed by social theorist Michel Foucault to better understand the ways that power, discourse, and knowledge interact, shaping thought and action within children's rehabilitation. My findings suggest that there is a growing recognition of the harms associated with dominant deficit-based discourses of childhood disability which position disabled children as lacking in some capacity. With that said, current conceptualizations of childhood disability remain entrenched in neoliberal assumptions which value independence, self-sufficiency, and normalcy, and which inadvertently frame disabled children as 'in need'. This work contributes to a growing body of literature which calls for interdisciplinary collaboration between disability studies and the rehabilitation sciences, as well as for the promotion of alternative, affirmative understandings of childhood disability.

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Chapter 1

1 Introduction

Within a Western context, childhood disability has been long understood as a personal deficit and familial tragedy. In line with this framing, child health care, and more specifically children's rehabilitation, is focused on alleviating the so-called burden disability places on disabled children and their families (Gibson et al., 2016). Alternative conceptualizations of childhood disability have been proposed by disability studies scholars, wherein the 'problem' of disability is located in disabling social relations and conditions rather than in the individual (Shakespeare et al., 2018). In contemporary Western society, biomedicine wields privileged power in determining how disability is understood and acted on, thus reinforcing dominant deficit-based discourses (patterned ways of thinking and acting) surrounding childhood disability (Stiker, 2019). Such discourses risk contributing to negative internalized identities and other harms for young people who are labelled as disabled (Gibson et al., 2016; Hamdani & Gibson, 2019).

In this study I sought to problematize dominant deficit-based understandings of childhood disability by engaging in a critical discourse analysis of text (e.g., interview transcripts, published research, and websites) in the rehabilitation sciences. Throughout this study, I situate my data and analyses within broader neoliberal discourses that operate within contemporary Western society and which value ideals of normalcy, productivity, and self sufficiency (Goodley & Lawthom, 2019; Lupton, 2003). Here I define neoliberalism as the ideology which operates throughout contemporary Western society and values governable, productive citizens who contribute to society, often in the form of paid work (Berghs, 2015; Fadyl et al., 2019).

Deficit-based discourses surrounding childhood disability are engrained within neoliberal society, and thus children's rehabilitation, creating particular subject positions for disabled children and making others difficult to imagine. In this thesis I problematize the prevailing discourses within rehabilitation that construct childhood disability as a problem to be 'fixed'. Throughout, I draw on critiques provided by disability studies scholars to help ground my analysis. This work is a necessary first step in reframing childhood disability discourses within

the field of children's rehabilitation in order to influence changes in practice because, for Foucault:

"As soon as one can no longer think things as one formerly thought them, transformation becomes both very urgent, very difficult and quite possible"

(Foucault 1988 as cited in Moss, Dillon, & Statham, 2000, p. 237).

1.1 Research aims and purpose

The central aim of this study was to better understand the ways that dominant discourses surrounding childhood disability shape knowledge and practice within the rehabilitation sciences. In pursuing this aim, my intent has been to open space for the advancement of an alternative conceptualization of childhood disability that accounts for the potential harms disabled children and their families may experience. This study builds on prior work which has investigated discourses surrounding disability in rehabilitation texts (Mosleh & Gibson, 2022; Phelan et al., 2014), by speaking directly with children's rehabilitation practitioners during qualitative interviews and analyzing this data alongside other text samples. This type of research helps build a foundation toward continuing the redirection of child focused disability policy, programs, and supports towards practices that reduce harms that unintentionally marginalize disabled children and youth.

1.2 Situating the study

This critical qualitative study is situated within a larger project led by Dr. Gail Teachman, my master's research supervisor. The aim of this larger project is to better understand conceptualizations of childhood disability in two central fields: children's rehabilitation and disability studies. In doing so, the larger project intends to bridge political and disciplinary divides and work toward a more affirmative conceptualization of childhood disability which is cognizant of some of the potential harms to disabled children and their families when disability is viewed primarily through a deficit-based lens. In this thesis, I report on my work using critical discourse analysis to interrogate dominant discourses in the field of children's rehabilitation represented through data from three sources:

- 1. peer-reviewed literature in the field of children's rehabilitation
- 2. children's rehabilitation institution websites
- 3. interviews with children's rehabilitation practitioners ¹

Engaging in this process of "carving out" my own study from this larger project required continual reflection as well as ongoing discussions with the members of the larger project's team.

1.3 Situating myself

I approach this research as a novice critical qualitative researcher who is an outsider to both the clinical rehabilitation and disability experiences. Through personal experiences in my early life as well as professional experiences as a support worker and camp counsellor for disabled children and adults I developed an understanding of disability which I did not see represented in media nor my early encounters with academia. I began to recognize the dominance of deficit-based views which position disability as inherently tragic and something to be overcome. It was not until I began taking disability studies courses during my undergraduate degree that I was able to put my critiques into words and begin questioning my taken-for-granted beliefs. Even still, I was often left defeated, wondering what could be done to shift such engrained ideas about childhood disability. I also found myself questioning whether I, being non-disabled, ought to speak on these issues in the first place. It was through this journey that I arrived at my ever-changing positionality as a critical qualitative researcher, recognizing the complex interactions between knowledge and power which shape all thought and action. In this role I aim to open space for ways of knowing otherwise, and to commit to being a lifelong learner who is always ready to listen to her peers, both disabled and non-disabled, and be continually reflexive.

I also incorporate in this research an occupational perspective, defined by Njelesani and colleagues (2014) as "a way of looking at or thinking about human doing" (p. 233). In this study I have drawn on the concept of occupational possibilities, which recognizes that occupational choices may be shaped through social and neoliberal rationalities which frame certain

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¹ For my purposes, 'practitioner' includes both clinicians and researchers.

occupations as attainable given an individual or group's circumstances (Laliberte Rudman, 2005; 2010). That is, certain ways of doing or being in the world may be privileged or seen as possible, leaving others difficult to imagine.

1.4 Structure of the thesis

In **Chapter 2,** I situate my work within the current neoliberal social landscape and discuss some of the predominantly medicalized discourses of childhood disability operating within Western societies. In doing so, I define some of the current harms experienced by disabled children, namely occupational limits placed on their lives due to prevailing thought on what disabled children should and should not do.

In **Chapter 3,** I describe my conceptual framework, encompassing my critical paradigmatic positioning and attention to Foucauldian conceptualizations of discourse, knowledge, and power. Here I demonstrate that current dominant ideas about childhood disability are the result of complex interactions between notions of discourse, knowledge, and power.

In **Chapter 4,** I attend to the methodology adopted within this study, critical discourse analysis, and describe the specific methods employed. Here I describe the study design, and procedures related to ethics, sampling, interviewing, and analysis.

In **Chapter 5**, I present my results. I begin by describing my dataset, made up of published research articles, children's rehabilitation institution websites, as well as qualitative interview transcripts. I then go on to describe the results of my critical discourse analysis of these texts.

In **Chapter 6**, I contextualize the results of my analysis within my conceptual framework and situate the study results in terms of my stated aim and purpose. Here I also speak to the important contributions of this work, future research suggested by these results, and I address the limitations and implications of this research before closing with some final remarks.

Chapter 2

2 Background and literature review

2.1 Introduction

In this chapter, I provide the necessary background to situate my study. I begin by describing the way I am defining discourse and situate my critique within broader neoliberal discourses before further elaborating on intersecting discourses surrounding childhood disability that operate in the global north today. I then set out the ways that childhood disability is framed when viewed with a predominantly medical gaze and point out key discourses that influence these framings, namely, normalcy, independence, and individualization.

Integrated in this chapter, I discuss critiques of medicalized discourses of disability, rehabilitation, and childhood contributed by disability studies and other critical scholars. In doing so, I explore prevailing discourses concerning childhood disability, describing the ways that they have influenced children's rehabilitative practice, both historically and presently. I conclude by further situating my research question within this larger body of literature.

2.2 Dominant disability discourses

In this thesis, discourse is understood as inescapable ways of thinking and doing which all members of society are subjected to (Hook, 2001; Lupton, 1992). Importantly, though all persons are subject to these discourses in that they shape human thinking and action, those same persons play an important role in the dynamic shaping of discourses. That is, the ways people think and act, while shaped by discourse, also shape discourses.

The assumptions which ground children's rehabilitation that will be explored in this chapter can be understood as representing different discourses surrounding childhood disability (Hook, 2001). Rather than understanding discourse in its mere linguistic sense, I instead conceptualize it as a system of thinking and doing which directly impacts the lived experience of individuals and groups (Grue, 2011). This research draws on disability studies and takes a Foucauldian informed approach to critical discourse analysis, attempting to uncover the ways that discourses are

reproduced, resisted, or modified within children's rehabilitation. Using such an approach allows me to account for the complex interactions between power and knowledge, and the ways that both circulate through individuals and institutions, serving to maintain certain discourses as 'true'. Understanding the discursive constructions of rehabilitative practice is a necessary first step in opening space for the reconceptualization of childhood disability and addressing some of the current harms experienced by disabled children and their families.

Neoliberalism can be understood as the latest stage of capitalism and is most often characterized through appeal to its grounding assumptions; these assumptions include the prioritization of goals directed at work readiness, independence or self-sufficiency, and productivity (Goodley & Lawthom 2019). Further, "neoliberalism is driven by material well-being and profit accumulation, even in those areas which can't emerge profit, such as social services, health care, and education" (Romstein, 2015, p. 327-328). That is, neoliberal entrenchment spans wider than occupations centered around economic and monetary growth. Individuals are expected to perform and progress in a linear fashion in most all areas of their lives, including for many, rehabilitation (Moseleh & Gibson, 2022). When we view neoliberalism as entrenched within its grounding assumptions, its importance for both children's rehabilitation and disabled children becomes clear in that it suggests a certain idealized subject position of the independent, self-sufficient citizen.

Some have argued that this neoliberal climate is "sustained by identifying the responsible compliant citizens – 'us' – and those who fail to live up to the neoliberal ideal type – 'them' (Runswick-Cole, 2014, p. 1118). Those who are conceptualized as failing to live up to the neoliberal ideal type include the elderly, young children, disabled children, and those who are otherwise seen as not meeting standards of productive citizenship. With a central tenet of neoliberal ideology being self-sufficient productivity, or productive citizenship, rehabilitation has evolved into a mediator of independence and productivity (Fadyl et al., 2019). Within children's rehabilitation specifically, there is a focus on skill development, grounded in the goal of a seamless transition into a productive adulthood (Mosleh & Gibson, 2022). This is problematic because it leaves no room for alternative ways to be and to become, and restrictions are placed on the occupational lives of disabled children (Slater, 2013).

2.2.1 Disability as constructed by medical discourses

In contemporary Western societies, it is largely uncontested that the medical community holds a privileged position of authority in defining disability and deciding how to act on it (Haegele & Hodge, 2016). More specifically, the authority to determine how, when, and to what degree rehabilitation professionals should treat disability, is ascribed to the broad field of medicine and those deemed to hold specialized knowledge of the body. Historically, scientific knowledge related to health and illness was developed out of the medical field, and medical professionals were thus placed in their position as the 'cognitive authority' on disability (Haegele & Hodge, 2016). The term cognitive authority, first conceptualized by Patrick Wilson (1983), refers to the central ways in which people construct knowledge. In those instances where an individual does not have firsthand knowledge or experience, they rely on established cognitive authorities, or those people generally accepted as having credible knowledge in that area. In the field of childhood disability, this has led to a privileging of medical understandings of disability as a deficit that should be 'fixed', and a lack of regard to other ways of understanding disability, such as those proposed by disability studies theorists and disabled people themselves (Phelan et al., 2014).

Medicalized conceptualizations of disability are becoming increasingly critiqued by disability studies scholars who point to the harms that they may reproduce for disabled children and their families (Bingham et al, 2013; Humpage, 2007). The idealized conception of the 'normal child' is produced through scientific discourse and importantly, has the potential to do harm in the everyday lives of disabled children (Cooper, 2013). This is not to say that rehabilitative practices do not have real benefits for disabled children and their families, but that there is a potential for harm when practices and assumptions are not questioned or made explicit. Assumptions relating to outcome measures, independence, and quality of life all ground rehabilitative practices, tools, and measures (Gibson et al., 2009). If rehabilitation is to best serve disabled children and their families, these central assumptions must be deconstructed and questioned.

Originally proposed as existing in direct contrast to medicalized understandings of disability, the social model understands disability as rooted in society, rather than individual bodies (Kattari et al., 2017). Proponents of the social model of disability recognize the ways in which

understandings of disability are inevitability wrapped up in power relations and systems of oppression which privilege non-disabled bodies (Oliver, 2013; Owens, 2015). Since its inception, the social model of disability has undergone scrutiny stemming from its failure to account for specific elements of the lived experience of disabled people, namely their experience of particular impairments (Haegele & Hodge, 2016; Bingham et al., 2013). Even still, the social model of disability prompts important questions in the area of children's rehabilitation.

According to some disability studies theorists, diminished quality and satisfaction with life is largely associated with social, environmental or occupational inequities rather than physical impairments (Whalley Hammell, 2015). That is, environmental barriers, such as limited access to free play (to be discussed), contribute to lower reports of quality of life than impairments themselves.

Discourses surrounding normality not only exist within medicine but are also pervasive throughout all levels of society and have particular implications for disabled people.

Expectations of normalcy contend that there are defined ways to 'do' and 'be' that fit neatly with societal expectations (Cooper, 2013; Waldschmidt, 2015). As an indicator of the magnitude of such discourses, entire disciplines such as rehabilitation were initially grounded in an intent to restore normality amongst patients, utilizing assessments to determine individual levels of normality and function (Waldschmidt, 2015). Expectations of normalcy can be understood as rooted in and held together by neoliberal ideologies which privilege individualism, productivity, and self-governance. Though rehabilitation can be understood as a site in which discourses of normality are produced and maintained, this process occurs throughout society, including microlevel everyday interactions. Such discourses and grounding assumptions of normality are valueladen, begging the question of how people come to think about those who do not fit within socially dominant ideas of normal. Despite more recent moves towards 'flexible normalization', essentialist discourses remain pervasive (Waldschmidt, 2015).

2.2.2 Impairment and disability terminologies

In most mainstream discursive spaces, the terms 'disability' and 'impairment' are conflated and understood as interchangeable. Social constructionist views of disability first emerged through activist efforts and were later taken up by scholars beginning in the 1980s (Beaudry, 2016).

These views emerged in stark contrast to indoctrinated medicalized understandings of disability as inherently problematic (Donoghue, 2003). A foundational tenet of social constructionist views of disability is the separation of or distinction between disability and impairment (Anastasiou & Kauffman, 2013). At first glance appearing as a linguistic formality, this distinction proves to be a foundational element of more progressive, critical thought on disability. Disability studies scholars identifying with social constructionist views assert that, to get at this thing that is disability, it is not sufficient to study impairment in isolation. Impairments are often understood as being measurable, identifiable, and individualized, and as a functional difference, whether it be physical, cognitive, or sensory. In contrast, disability studies scholars identifying with social constructionist views have conceptualized disability as existing in the social sphere (Andrews et al., 2019). That is, an individual becomes disabled through oppressive and exclusionary social practices which limit their occupational opportunities or possibilities.

Discussions surrounding language permeate the disability sphere. I have chosen to adopt what is labelled identity first language, which is taken up by some disability self-advocates and disability studies scholars. Identity first language is associated with a rejection of medicalized notions of an individual 'having' a disability. For some, disability is better understood as being at the core of their identity (Andrews et al., 2019; Botha et al., 2022). Throughout this study I use the term 'disabled person' intentionally to reflect my awareness of disability as realized through social relations, rather than as a condition or set of symptoms possessed or acquired by an individual.

2.3 Childhood and disability

2.3.1 What is childhood?

In the contemporary Western world, childhood is commonly conceptualized as a time for play, exploration, and many will argue most importantly, development (Samuelsson & Carlsson, 2008). The more recent emergence of a new sociology of childhood has begun to disrupt this dominant discourse, creating space for alternative ways to understand childhood (Prout, 2011). Does a boundary exist between childhood and adulthood? Legislative and procedural writings would indicate so. But does this boundary exist in the real world? Children are embedded in a number of social systems and institutions which, in many ways, contribute toward shaping them

into 'normal', functioning adults through a process labelled development, which goes well beyond biological growth. Most would agree that at some point in time, children transition into adulthood, whether that be when they turn 18 years of age, become financially independent, or reach a certain stage of cognitive capacity. Though often concealed, these lines of thought construct children, in their present state, as lacking agency and capacity. Scholars in the fields of childhood studies and childhood ethics have begun questioning the ways that these dominant discourses of childhood, as well as their grounding assumptions, impact the moral experiences of children (Carnevale et al., 2015; Prout, 2011)

2.3.2 What is childhood disability, and what should be done about?

When childhood is viewed primarily through a developmental lens, childhood disability is understood as disrupting the path of 'normal' development. Given the privileged power held within the medical field to decide how we act on disability, dominant deficit-based discourses surrounding childhood disability are continually reproduced (Stiker, 2019). As noted, these medicalized discourses risk contributing to negative identities and other harms for young people who are labelled as disabled (Gibson et al., 2016; Hamdani & Gibson, 2019). When childhood disability is framed in these terms, child health care, and more specifically children's rehabilitation, operate with the aim of alleviating the so-called 'burden' placed on disabled children and their families through a focus on capacity development (Gibson et al., 2016; Phelan et al., 2014). Such lines of thought pervade society relatively unquestioned, ignorant of the possibility that childhood disability is not a deviation from developmental norms, nor a natural tragedy, but rather is constructed as such through dominant patterns of thought and action, or discourses.

Medicalized conceptualizations of disability often rest on the central notion that disability, as an individualized trait, is something to be fixed or overcome (Haegele & Hodge, 2016; Mackelprang & Salsgiver, 2015; Phelan, 2011). Following standard models of child development, early intervention is consistently framed as being of the utmost importance for young children who have been, or are suspected of being, diagnosed with a disability. Early identification and intervention on disability is understood in the medical sphere as being crucial in mitigating different elements of impairment (Unicef, 2012). Contemporary practices in rehabilitative early intervention seek to promote participation and inclusion through the use of

evidence-based interventions, therapies, and other rehabilitative practices (Guralinick, 2005). Apart from formal therapeutic settings, occupations such as leisure activities and play are often framed as opportunities for rehabilitation for disabled children. That is, play and leisure are often seen as sites for development and rehabilitative work for disabled children (Hodge & Runswick-Cole, 2013). The underlying assumption here is that disabled children must put in the work, in most all areas of their lives, to emulate some, often undefined, standard of normalcy.

2.3.2.1 Occupation and the myth of the 'normal' child

Individuals make occupational choices every day, but these 'choices' are shaped through temporal and structural contexts that determine which occupations are or are not possible (Laliberte Rudman, 2005; 2010). This shaping of occupational possibilities is not within an individual's immediate control, often going unnoticed (Gerlach et al., 2018). That is, occupational possibilities are shaped through a variety of macro-level factors including the political and social climate, which shape and/or constrain individual choice. When applied in the context of childhood disability, assumptions regarding the value of approximating normal may lead to some childhood occupations being presented as inherently valuable.

In Western societies, play is commonly conceptualized as being the primary occupation of childhood, and useful beyond mere entertainment. Engaging in play has also come to be associated with cognitive, social, and motor development (Frost et al., 2012). In more recent years, free play, or play which is child motivated and led, has become largely regulated through appeals to health promotion and risk management, leading to potential harms to child well-being (Alexander et al., 2014). While understandings of play for development over mere entertainment do extend to disabled children, there is increased pressure to frame disabled children's play as being a path to achieving normalcy and independence. As such, there is an increased intensity and urgency associated with play for disabled children (Hodge & Runswick-Cole, 2013, p.313). Further, play is often used as a tool in assessment, diagnosis, and intervention for disabled children, limiting their time for free play (Frost et al., 2012; Hodge & Runswick-Cole, 2013).

Ideas surrounding play for therapeutic purposes and development in childhood disability are widespread and relatively unquestioned, placing value on the production of independence and normalcy. But what does a normal childhood, or normal development look like? Most children's

rehabilitative practice is grounded in value-laden assumptions of linear, normal development (Gibson et al., 2015). The concept of the 'normal child' is constructed through medicalized discourses which frame disabled children as lacking in some capacity (Cooper, 2013). This medicalized construction of the 'normal child' implies a problem to be fixed within children labelled as disabled or those whose course of development and engagement in so-called 'normal' occupations of childhood may be seen as abnormal. According to some disability studies theorists, diminished quality and satisfaction with life is largely associated with environmental or occupational inequities rather than physical impairments (Whalley Hammell, 2015). That is, environmental barriers, such as limited access to free play, contribute to lower reports of quality of life than impairments themselves. As such, interventions which target functional capacity may be less effective in improving well-being amongst disabled children.

2.4 Conclusion

The central purpose of this study is to better understand the ways that dominant discourses surrounding childhood disability are reproduced, resisted, or maintained within children's rehabilitation. In doing so, this critical discourse analysis aims to uncover the technologies which shape the subject positions of both disabled children, and children's rehabilitation practitioners with the ultimate goal of better understanding interactions of power, discourse, knowledge, and practice. Illuminating these interactions is critical to the eventual development of alternative conceptualizations of childhood and childhood disability which may help inform future practices in children's rehabilitation.

In this chapter I have begun to unpack some key discourses that pervade children's rehabilitation, and which are rooted in larger systems of thought such as neoliberalism. Having unpacked these dominant discourses surrounding childhood disability I will now turn to explore the ways in which they are taken up in rehabilitative practice. In this work, I am continually guided by my research question: how do dominant discourses surrounding childhood disability shape rehabilitative practice?

In the next chapter I will describe my conceptual framework. In doing so, I emphasize that the ideas I have described in this chapter pertaining to discourses of childhood disability in

children's rehabilitation, are not the 'fault' of individual practitioners. Rather, I will demonstrate, through appeal to Michel Foucault's post structuralist thinking on power, knowledge, and discourse, that individuals are often constrained in their thinking. Practitioners are subjected to ways of thinking, or discourses, through technologies of power and the logics which underpin children's rehabilitation specifically and our neoliberal society more broadly. The ways of thinking about childhood disability described in this chapter emerged over time and through structural conditions and interactions between knowledge and power which render some ways of thinking about childhood disability possible and others unthinkable.

Chapter 3

3 Conceptual Framework

3.1 Introduction

"People often know what they do; they frequently know why they do what they do; but what they don't know is what what they do does" (Foucault, in Dreyfus & Rabinow, 1983, p. 187).

Michel Foucault (1926-1984) was a French philosopher and social theorist whose work began gaining attention beginning in the 1970s and has remained useful in informing many types of socially oriented research (Fadyl et al., 2012). What do the things we do, do? According to Foucault's work, the things we do and say are wrapped up in larger societal discourses which are inextricably linked with power and knowledge (Behrent, 2013). Importantly, the things that we do and say also then contribute to the maintenance of these systems in a cyclical, seemingly inescapable loop (Mills, 2004; Olssen, 2014). In order to better grasp the ways that these systems of discourse, knowledge, and power operate in the childhood disability space I have engaged in a critical discourse analysis of talk and text in the rehabilitation sciences.

In this chapter, I further explicate my approach to critical discourse analysis by describing the conceptual framework of this study. First, I further position myself within a critical framework which draws on Foucauldian notions of power, knowledge, and discourse. I will describe the particular connections between these concepts before connecting this framework with childhood disability discourse to further complicate some of the questions raised in Chapter 2.

3.2 Critical orientation

In chapter one, I briefly introduced my critical paradigmatic positioning, describing some of the ways it has informed this study. Here I expand on this positioning to detail the ways that it has informed my conceptual framework. Notably, all stages of my approach to research have been informed by my critical paradigmatic positioning. A paradigm can be understood as a set of beliefs or a lens through which researchers view the world encompassing ontology, epistemology, and methodology (Guba & Lincoln 1994; Ponterotto, 2005). Together, the

paradigmatic stance a researcher takes on these concepts reflects a particular view on the nature of reality (ontology), knowledge (epistemology), and knowledge creation (methodology). It should be noted that the notion that paradigms have clear boundaries has been contested and that paradigms, instead, should be viewed more fluidly, as a continuum, and as continually emerging (Kivunka & Kuyini, 2017). For the purpose of this study however, I have conceptualized a researcher's positioning in regard to ontology, epistemology, and methodology as constituting their paradigmatic positioning.

Critical qualitative inquiry is an approach to research that seeks to deconstruct, disrupt, or uncover (Cohen et al., 2000). Within a critical paradigm, 'facts' about the world, or what has widely come to be taken as truth, are understood to be shaped through a variety of sociohistorical factors (Guba & Lincoln 1994; Ponterotto 2005). This view of historical realism can be understood as a critical ontological stance. I have taken up this critical realist ontology within this research given my understanding of reality as constructed but bearing effects. That is, though taking 'facts' about the social world as constructed, I recognize the real effects they have. With regard to epistemology, or the nature of knowledge creation, those operating within a critical paradigm recognize the complex interactions between the subject and the object of research, and the ways that all instances of knowledge creation are infused with value judgements from both the subject, the object, and the broader social contexts in which they are situated. Such epistemological assumptions are in stark contrast to those held within the positivist paradigm, wherein knowledge is regarded as value-neutral, and researchers are positioned as objective and bias-free. Within a critical epistemology, what comes to be known or taken as 'true' is understood as an effect of dominant discourses given that such discourse permeates the social world (Lincoln et al., 2011).

Critical researchers acknowledge that research is always value laden. In contrast to a positivist research approach where 'bias' is viewed as a limitation, critical approaches embrace interrogation of the values at play in research as a means to enrich analyses (Asghar, 2013). That is, critical researchers take an active role in the construction of knowledge in the research setting, rather than attempting to mitigate or eliminate their involvement. From a methodological standpoint, a critical paradigm is reconcilable with most qualitative methodologies or approaches to research. A critical positioning is largely concerned with the questions being asked and the

approach to analysis, rather than the specific methods by which you approach research, though some have suggested that it is more appropriate for use with qualitative methods (Hussain et al., 2013).

Researchers employing critical qualitative methodologies often locate their work within a theoretical framework to guide their thinking and add depth to their research (Levitt et al., 2021). I have engaged the work of Foucault to further inform my inquiry into childhood disability discourse. Although the primary focus of his work changed throughout his career, Foucault's work can be characterized by a focus on either the identification or deconstruction of dominant discourses (Dreyfus & Rabinow, 1983). In my own research, I have taken up Foucault's work to aid first in identifying the dominant discourses surrounding childhood disability within the rehabilitation sciences and to later begin deconstructing them. My paradigmatic positioning and theoretical orientation have informed all stages of this work, beginning from question development to data analysis and discussion.

3.3 A note on 'Foucauldian thought'

It is important to acknowledge that, in many ways, my account of 'Foucauldian thought' represents a purposive, specified framework which aligns with Foucault's theorization of discourse on a relatively broad level. This framework is not intended to provide an in-depth account of Foucauldian thought for use in research generally. Importantly, many scholars have argued that Foucault himself would be largely dismissive of any attempt to offer a prescriptive approach for taking up his work (Rabinow & Rose, 2003). This sort of work instead calls for deep critical reflection which is complexified and otherwise cultivated through a set of core Foucauldian concepts. In this study, those core concepts are knowledge, power, and discourse.

3.4 Knowledge, power, and discourse

Discourse, as conceptualized by Foucault, can be understood as encompassing language, both spoken and written, as well as the patterns which underlie certain ways of thinking and doing (Hook, 2001). That is, discourse can be understood as patterned ways of thinking and doing, often framed as mediated through power, and having the potential to produce oppressive effects (Hook, 2001). To further explicate the Foucauldian definition of discourse, Hall (1997) writes:

It is about language *and* practice. It attempts to overcome the traditional distinction between what one *says* (language) and what one *does* (practice). [...] It defines and produces the objects of our knowledge. It governs the way that a topic can be meaningfully talked about and reasoned about. (p. 44)

Foucault's conceptualization of discourse draws out a particular connection between thought, language, and action. I have chosen the above quote to demonstrate the productive nature of discourse. Rather than acting primarily in a repressive manner, discourse instead produces knowledge, power, and subject positions.

Power is commonly understood as operating in a repressive manner, flowing from the top-down. This conceptualization can be largely attributed to Marxist theorizations of power, wherein power is enacted upon the proletariat, or working class (Crotty, 1998). In contrast, Foucault conceptualizes power as circulating throughout all levels of society, with no clear source or point or origin, and in often concealed and subtle ways (Behrent, 2013). Foucault also conceptualizes power as a productive force, in that it always produces an effect, for example on the production of discourse, knowledge, or subjectivity. Importantly, Foucault believed knowledge and power to be inextricably linked, believing power to operate through the production of expert knowledges (Dreyfus & Rabinow, 1983). Under this view power not only exists within knowledge, but also contributes to its production and maintenance. In the context of childhood disability discourse, expert voices, or those of children's rehabilitation practitioners, are subjected to power in the form of discourse, and also, even unintentionally, contribute to its reproduction.

Foucault used the term 'technologies' (e.g., of power, of government) to refer to the mechanisms by which subject positions are created, dominant discourses are reproduced, and power is enacted (Behrent 2013; Foucault 1988). Subject positions are constructed through discourse, denominating particular ways to 'be' (Fadyl et al., 2012). For example, medicalized discourses have constructed particular conceptualizations of disabled children as subjects of medical study and intervention (Grue, 2011). Foucault's expanded conceptualization of technologies of power and government attends to the concealed nature of enactments of power. For example, certain ways of acting, thinking and being are privileged throughout society in often concealed ways, such that they become taken-for-granted as the only or right ways to act, think, and be. These

ideas have particular relevance when thinking about children, the project of rehabilitation, and childhood occupations and are discussed in more detail in Chapter 6.

The origins of discourses surrounding childhood disability are not the central concern of this study. While acknowledging that these discourses can be traced historically, within the scope of this study I focus on how they have presented themselves in the context of children's rehabilitation, as well as their implications within a contemporary context. Identifying discourses as historically and contextually constructed helps demonstrate that ways of knowing and becoming in the world could have been different, or otherwise. Everyday practices are shaped by discourse and importantly, also contribute to the shaping of discourses. In this way, 'knowledge' comes to be understood as arbitrary in that, rather than comprising some essential truth, it is understood as sets of statements rooted in power (Miller, 1990). It becomes apparent that the power to determine idealized childhood occupations exists not exclusively as a top-down process, but rather as enacted in everyday practices and interactions at all levels of society.

In this chapter I have set out my conceptual framework through appeal to both my critical paradigmatic positioning and Foucauldian theoretical lens. In the next chapter, I describe the overall methodology of my study, critical discourse analysis, and outline the more procedural aspects of my approach to demonstrate the ways that this conceptual framework has informed my specific methods.

Chapter 4

4 Methodology

This study employed a critical discourse analysis (CDA) methodology to explore the ways that discourses surrounding childhood disability shape practices and knowledge in children's rehabilitation. In Chapter 3, I described my conceptual framework through appeal to both my critical paradigmatic positioning and attention to Foucauldian concepts of knowledge, power, and discourse. In this chapter, I draw on this conceptual framework to describe my study design and study procedures, namely recruitment, data generation, and analysis.

4.1 Critical discourse analysis

Approaches to discourse analysis investigate more than language, including also "the manner in which individuals and institutions communicate through written texts and spoken interaction" (Lupton, 1992, p. 145). In this study, I have sought to identify dominant discourses surrounding childhood disability, to begin to understand the ways they shape children's rehabilitation. Approaching my analysis in this way allowed me to go beyond the analysis of linguistics, to attend to enactments of power through discourse and the production of subject positions (e.g., the disabled child, the developing child).

Recall, the larger question which guides the present research: how do dominant discourses surrounding childhood disability shape rehabilitative practice? This work is explicitly concerned with understanding what dominant discourses of childhood disability *do*, and how they constitute disabled children as subjects of a preferred way of being. The results of my analysis, described in Chapter 5, speak to the productive nature of these discourses, the voices that are being privileged by such discourses, and the voices that are left out, among other related questions.

Critical discourse analysis, when named as a methodology, can be understood to encompass specific methods, while also attending to positionality, paradigmatic location and theoretical underpinnings, all contributing to the general approach to research (Mackenzie & Knipe, 2006). This type of methodology aims to explicitly interrogate and problematize discourses and the systems of power which sustain particular patterns of thought and action (Lupton, 1992; Fadyl et al., 2012).

4.2 Study Design

As described, the approach to critical discourse analysis I have utilized in this study goes beyond inquiry into language, "to the manner in which individuals and institutions communicate through written texts and spoken interaction" (Lupton, 1992, p.145). This approach to discourse analysis differs from others in that it focuses on both saying and doing. This focus on language and practice is evidenced in the current study through the analysis of both written text within the rehabilitation sciences, including peer review research articles and websites, and data generated in qualitative interviews with rehabilitation practitioners. Beyond the identification of discourses, this study was also designed with the end goal of deconstructing them (Laliberte Rudman & Dennhardt, 2014). This project of deconstruction begins at the outset of data collection and continues iteratively throughout the study processes.

This study followed a phased approach. The first phase of this study involved sampling and analyzing texts using an analytic guide (Appendix F). As this analysis progressed, I began the second phase of the study, wherein I conducted semi-structured qualitative interviews with rehabilitation practitioners. A process of iterative preliminary analysis continued until all interviews were completed, at which point both text and interview data and analyses were integrated. This analytic process is described in more detail in section 4.4.

Recall from Chapter 3 that no prescriptive method for a 'Foucauldian critical discourse analysis' has been set out that would be endorsed by Foucault himself (Fadyl et al., 2012). Instead, Foucauldian conceptualizations of power, knowledge and discourse have influenced how I have approached all stages of my research project, informing the specific decisions I have made regarding study procedures.

4.3 Procedures

4.3.1 Establishing research quality

In keeping with my paradigmatic positioning, quality was established for this study through careful attention to criteria suited toward critical qualitative research. Within qualitative research, there are paradigm specific approaches to establishing research quality or rigor, which account for the complexities of different paradigmatic approaches to research (Ravenek & Laliberte-

Rudman, 2013). Even still, approaches to ensuring research quality which define specific sets of criteria for each paradigm, focusing on the adequacy of measures and techniques, have been called into question (Eakin & Mykhalovskiy, 2003). In ensuring quality for this study, I took a substantive approach as follows. In presenting my results (Chapter 5) I ground my interpretations of the data by providing empirical examples. Providing this information to my reader is important not only in that it demonstrates the way that I have approached my data, but also because it continues to guide my reader through the 'story' of the research I am presenting, an approaching described most eloquently by Eakin and Mykhalovskiy (2003) who, when differentiating between procedural and substantive approaches to quality, write:

A substantive approach would instead try to enhance the readers' capacity to 'feel' the texture of the account being put forward, to understand the conceptual development and foundations of the analysis and thereby, ultimately to better apprehend the leaps of imagination and creative thinking that constitute (arguably) the most valuable feature of all research, qualitative or otherwise. (p. 191-192)

In keeping with this substantive approach, I have committed to practicing reflexivity throughout the research process, recognizing the role that I play in the co-construction of knowledge. One way I have practiced reflexivity is through my writing. I have come to view writing as a reflexive process (Eakin & Gladstone, 2020) wherein the act of putting my thoughts into words has helped me to not only elaborate my understanding of my data and analyses, but also consider how my personal experiences and taken-for-granted assumptions have guided my thinking. In other words, through my writing, I have come to see the multiple ways I am implicated in my research. Importantly, from within my critical paradigm, I do not view this as bias that I should work to eliminate, but as a standpoint contributing to and enriching my research (Eakin & Mykhalovskiy, 2003; Lincoln et al., 2011). As just one example, the post interviews summaries (Appendix E) that I completed following each qualitative interview (described in section 4.4.2), provided me an opportunity to explore and reflect on my taken-for-granted assumptions regarding childhood disability and children's rehabilitation, and how these might have informed the data generated, as well as my interpretation of that data. In sitting down to write these summaries, I came to realize all the ways that medicalized discourses surrounding childhood disability have shaped my own thinking, and how some of this thinking made its way into the interviews, helping me better

appreciate the durable nature of the very ideas I had set out to problematize. This realization reinvigorated my motivations for exploring this topic and reinforced my confidence in the value added by taking up my critical theoretical approach.

4.3.2 Ethics

Ethical considerations in research can be broken down into two categories: procedural, and practical (Guillemin & Gillam, 2004). Procedural ethics involves gaining approval from an institutional research ethics board to ensure that all study related plans (i.e. recruitment, consent, data security, etc.) meet the relevant normative standards or codes. Ethics approval for the current study was granted by the Western University Health Sciences Research Ethics Board (HSREB) in August of 2021. This application was concerned only with the interviewing portion of the study, as ethical approval is generally not required for text analyses alone. During this process of procedural ethics, a letter of information (Appendix A) and consent form (Appendix B) were created and later approved by the HSREB. Following principles of informed consent, these documents were used to ensure that participants were aware of any risks, benefits, and confidentiality concerns prior to consenting to participate. During this process, it was also important that participants were given multiple opportunities to ask questions both prior to consenting to participate, and after. Following interviews, I took great attention to maintaining my participants anonymity by removing all identifying information and changing incidental facts that may identify a participant. This process was especially important in this study given its more local context.

Guillemin and Gillam (2004) refer to practical ethics, or "ethics in practice" (p. 262), as those ethical dilemmas which come up during the research process, requiring the researcher to make a quick decision regarding how to proceed. Guillemin and Gillam (2004) call these instances "ethically important moments" (p. 262), referring to those times where a researcher must weigh the ethical advantages and disadvantages in a given situation and decide how they will proceed. During the planning stages of the current study, these moments were anticipated to come up during the qualitative interviews. Though not allowing me to predict or avoid them, this anticipation allowed me to better handle these moments as needed during the interviews.

Remaining reflexive, or actively recognizing both my positionality and that of my participants was crucial in navigating these ethical considerations as they came up during interviews.

During my interviews with rehabilitation practitioners, there were certain instances where I needed to make decisions regarding my tone and language. Coming into interviews, participants were aware of the study aims and objectives, and likely had an idea of our teams critical positioning based on their knowledge of Dr. Teachman's program of research. As such, it was important that I carefully navigate the questions and discussions in each interview to ensure that the questions were not coming off as accusatory or condescending regarding their position as a rehabilitation practitioner. In some instances, I quickly chose to frame questions around larger disciplines rather than personal stance. That is, asking "within your field, what might be some agreed upon ideas about how we should act – or what needs to be done – in order to support children and families experiencing disability?", rather than "what do *you* think needs to be done in order to support children and families experiencing disability?". Framing some key questions in this way allowed me to depersonalize them and avoid any discomfort, while still getting at these important ideas. Remaining reflexive throughout each interview ensured that I was able to recognize and address these and other "ethically important moments" as they arose.

4.3.3 Text sampling

A purposive sampling strategy was used to identify relevant texts from the rehabilitation sciences. During sampling, I aimed to produce a set of texts which could begin to construct the central and peripheral discourses that have contributed to contemporary, dominant conceptualizations of childhood disability in the global north (here, defined as contexts where the fields of children's rehabilitation and disability studies are established and have the potential to influence children's lives). To narrow the scope and optimize the feasibility of my study, I elected to sample texts primarily within a Canadian context. The larger project in which this study is situated sampled and analyzed texts from children's rehabilitation published in the global north between 1990-2022. Within my more limited study, I focused on contemporary texts published during or after 2012. This allowed me to focus on more recent conceptualizations of childhood disability within the rehabilitation sciences, and necessarily precluded tracking the

evolution of these ideas. This type of archaeological method (Dreyfus & Rabinow, 1983) is important, but beyond the scope of my study.

I approached sampling with an awareness that, due to the constraining nature of dominant discourses, there is only so much that can be said about a topic such as childhood disability within a particular discipline (Fadyl et al., 2012). For this reason, text sampling was not completed with the end of producing a representative sample, with such 'representativeness' assumed to be tied to achieving a predetermined number of texts. Instead, I was concerned with sampling information rich texts. Sampling ended once I began finding similarities and common patterns within the discourses identified because, within my critical paradigm, I did not set out to reach 'data saturation'.

I searched the Western University Library Database using key words "childhood disability" and "children's rehabilitation" to scan for information rich texts. Some of the texts chosen were taken as specific examples of rehabilitative practices or measures specific to childhood disability, while others were deemed commentaries or discussions surrounding rehabilitative understandings of childhood disability. I chose to select from both types of texts in order to produce a sample which might illuminate not only what was said about childhood disability in the rehabilitation sciences, but also what rehabilitation leaders were reporting as being done about childhood disability. Websites were sampled based on my understanding of various local institutions doing work in the area of childhood disability who are perceived as having reaching impact and information rich webpages to analyze.

4.3.4 Interview sampling and recruitment

I employed a purposive sampling strategy to identify 5 practitioners with specialized knowledge and prolonged experience in the area of childhood rehabilitation and disability who could be invited as potential participants. This determination of specialized knowledge and prolonged experience was supported by members of the larger team, including the study's principal investigator, Dr. Gail Teachman. Within qualitative study designs, purposive sampling is often used as a tool to select participants believed to be "information-rich cases" representing a homogenous group (Patton, 1990). For the purposes of this study, I chose to invite participants whose insights and descriptions of practices might aid in determining dominant or central

discourses about childhood disability in parallel with those I had begun identifying in my text analysis. I made this decision with consideration of what seemed feasible given the limited size and scope of the current study, and consideration of the limitations on data generation imposed by the COVID-19 pandemic which constrained research processes at the time of this research.

4.4 Data generation

4.4.1 Qualitative interviews

Individual semi-structured qualitative interviews lasted between 60-90 minutes and were conducted remotely using Zoom video conferencing software. The aim of my qualitative interviewing process was to better understand the ways that rehabilitation practitioners conceptualize childhood disability, as well as their role in supporting disabled children and their families. Each interview followed an interview guide (Appendix C). In keeping with my iterative research process, this guide was revised throughout the study, based on my post interview summaries and reflections during and after each interview. I describe this process in more detail in section 4.4.2. Throughout the interviewing processes I maintained a flexible approach allowing me to shift my focus and strategy as data was generated and my own understandings and interpretations progressed (Manderson et al., 2006). Apart from the changes I made to the interview guide, I adopted a reflexive attitude going into each interview to ensure that I was integrating learnings from previous interviews. During each interview, I shared a selection of preliminary results from the ongoing text analyses with participants to preface a discussion surrounding some of the discursive threads that I had begun thinking about.

All interviews were audio recorded with the participants' permission and later transcribed. I transcribed the first interview independently to gain an understanding of the transcription process, including what can be lost during transcription. All subsequent transcriptions were completed by a professional transcriptionist. Depending on the approach to transcription, nuances such as pauses, smiles, and laughter can be lost during the transcription process. For this reason, among others, I found it important to create post-interview summaries following each interview to capture some of what might have been lost.

4.4.2 Post-interview summaries

To add rigor and promote my own critical reflexivity, I completed post-interview summaries and memos following each interview (Appendix G). These summaries helped to capture non-verbal aspects of the interviews, nuances such as pauses, smiles, and laughter that, as mentioned, can be lost during the transcription process. This process further enabled me to reflect on my initial impressions and interpretations from the interviews, as well as more procedural concerns with the interviewing process and interview guide. It was important that I be continually reflexive regarding the interviewing process itself, including considerations of which questions or prompts might need to be changed or removed before future interviews. For example, the following question and set of prompts appeared in my initial interview guide (Appendix C):

4. When discussing childhood disability in particular, there is often a focus on preparation for the future, or what some might call 'outcomes'. Do you see that in your field?

[Prompts]

Do you think your answer aligns with that shared by society generally?

Thinking back to your description of you everyday practices at work, how do you hope to influence disabled children's futures?

If you had the power to change minds about childhood disability, what would you want everyone to know?

Following completion of my first interview and post-interview summary, I decided to remove all three of these prompts as I found them to be either not relevant to my research question or asked in a way that was not effective in eliciting further discussion. In my revised interview guide (Appendix D), I chose instead to probe more into my participants knowledge of the general rehabilitative focus on preparing children for the future by asking slightly different questions. For example, asking my participants to describe what an 'outcome' is in their field of specialization, or whether they have ever thought about what an 'optimal outcome' might look like for their clients. Engaging in this exercise of reflexivity following each session allowed me to strengthen my interviewing skills and make adjustments before the next interview.

These summaries were also meant to capture an important element of all qualitative interviews: what was not said. While it is important to reflect on that which might not be captured in the later produced transcripts while it is still top-of-mind following each interview, it is also important to reflect on what was not sayable or thinkable. For example, due to my participants positions within the rehabilitation sciences and their understanding of this study's critical orientation, I anticipated there to be some avoidance of certain topics. For example, some practitioners may have been inclined to alter their language surrounding childhood disability based in their understanding of critiques in this area from disability studies and other critical scholars. Conversely, I anticipated that some participants would be hesitant to comment on critical perspectives surrounding childhood disability because they felt they lacked knowledge in that area. The post-interview summaries in part served to capture these nuances which will be discussed at more depth in Chapters 5 and 6.

4.5 Analysis

Qualitative analysis broadly, and critical discourse analysis specifically are iterative processes which can hardly be described through appeal to a linear set of steps (Laliberte Rudman & Dennhardt, 2014). For reasons of comprehension and clarity, I outline my analytic process sequentially in this section, but it should be noted that this process involved many instances of circling back to initial analyses, jumping ahead to cross text analysis, and continuously returning to my research question, aim, and conceptual framework. Throughout my analytic process, I continually reflected on my positionality in regard to the data, recognizing my 'creative presence' in the process of analysis (Eakin & Gladstone, 2020).

Data analysis began in parallel with data generation stage and continued into the later writing stages of this study where I found that I made many realizations about my data and analysis. Written expression has come to be viewed as a form of analysis (Eakin & Gladstone, 2020), where my careful choice of words and structure helped illuminate my own positionality in relation to my data and ongoing analysis.

4.5.1 Within-text analysis

The first phase of analysis involved critically examining individual texts using an analytic guide (Appendix F). All texts, including peer-reviewed research articles, websites, and interview transcripts were analyzed following the same procedure. This guide was developed in collaboration with the principal investigator of the larger study to help guide analysis and was informed by my conceptual framework and understanding of current thinking in the area of childhood disability discourse. Developing and utilizing an analytic guide can aid in incorporating theory into a critical discourse analysis and helps facilitate cross text analysis (Laliberte Rudman & Dennhardt, 2014). The analytic guide produced for this study included questions such as:

- 1. What is assumed by the text's positioning of disability, childhood, and/or childhood disability?
- 2. Who benefits from these conceptualizations?
- 3. Are tensions apparent in the text?
- 4. Does this text's conceptualization (implicitly or explicitly) suppress competing discourses?
- 5. What does this text 'do' in relation to conceptions of childhood disability (e.g. reproduce, contribute, challenge, reformulate understandings)?
- 6. Whose perspectives are authorized or represented as legitimate, and which are discounted, silenced, or left out?

The analytic process involved a cycle of reading and re-reading each text, paying specific attention to how the discourses I was beginning to identify fit with the larger context of neoliberalism and medicalized conceptualizations of childhood disability of which I was aware and have described in some detail in Chapter 2. In this way, I was able to understand the way the texts themselves and my analyses of them fit within my larger sociocultural plane of interest (Crowe, 2005; Fairclough & Wodak, 1997). Additionally, prior to analysis I recognized that medicalized discourses may render certain ways of thinking about childhood disability hard to imagine. As such, it was also important that I pay particular attention to what was not said in the

sampled texts in order to shed light on that which certain discourses may render unsayable (Laliberte Rudman & Dennhardt, 2014).

In accordance with the protocols for the larger project, sampled research articles and websites were critically examined by two study team members using the analytic guide. In the case of texts derived through interviews, I completed primary analyses of transcripts and then engaged in a group analysis session where members of the larger team contributed their perspectives on excerpts form the data. This approach was chosen not to confirm or deny the primary analyses, but rather with the aim of producing a richer analysis and critical understanding of the sampled texts. In the current study, I included any analyses of texts in children's rehabilitation completed by members of the team as of June 2022 for two reasons. First, because I believe it allows for a richer analysis and discussion, but also because I have been immersed in the thoughts and critiques of this team since the beginning stages of the larger project, making it clear that my own thinking was inextricably linked with contributions over time from the larger team.

4.5.2 Analyzing across texts

After completing the within-text analysis described above, I began analyzing across my sampled texts, including peer-review research articles, websites, and interview transcripts. This across-analysis involved an iterative process of reading and re-reading the sampled texts and their associated analytic notes for common threads, contradictions, and contrasts (Laliberte Rudman & Dennhardt, 2014), rather than searching for themes. Following this preliminary analysis across texts, I inputted each text's associated analytic notes into NVivo qualitative data analysis computer software to aid in my analysis. There I carried out a form of coding in order to produce reports on some key threads identified in my preliminary analysis which will be described in more detail in Chapter 5. It was important that I not organize my data in this way until the very final stage of analysis, so that I was familiar with each text before taking it out of its primary context. With my data analyzed in this way, I was in a place to further the process of reading within my theoretical lens and identifying discourse and subjectivity. During this final process of analysis, I asked specific questions of the data such as "how is childhood disability being conceptualized here?", and "what assumptions ground this conceptualization?" This process allowed me to contextualize my data, linking it together until it began to produce an emerging

'story' (Eakin & Gladstone, 2020). In Chapter 5, I will describe my final sample in more detail, as well as the results of my iterative analytic process.

Chapter 5

5 Results

In this chapter I first describe my study sample in more detail, made up of peer-reviewed research articles, websites, and qualitative interview transcripts. I then go on to describe the results of my analysis which I present as four interrelated discursive threads that align with my critically oriented analytic questions.

5.1 The sample

The search strategy described in section 4.2.1., as well as the qualitative interviews conducted, yielded a final sample of 17 texts (**Table 1**). The sample included:

Peer reviewed research articles (10): published between 2012-2021 and which are explicitly concerned with childhood disability and children's rehabilitation;

Children's rehabilitation institution websites (2): Holland Bloorview Kid's Rehabilitation Hospital, and CanChild Research Centre at McMaster University;

Qualitative interview transcripts (5): from semi-structured qualitative interviews with practitioners who had prolonged engagement with children's rehabilitation practice and/or research.

Table 1: Study sample

Type of Text	Text
Peer reviewed research articles	Adair, B., Ullenhag, A., Rosenbaum, P. L., Granlund, M., Keen, D., & Imms, C. (2018). Measures used to quantify participation in childhood disability and their alignment with the family or participation-related constructs: a systematic review. <i>Developmental Medicine and Child Neurology</i> , 60(11), 1101-1116.
	Fawcett, B. (2016). Children and disability: Constructions, implications and change. <i>International Social Work, 59</i> (2), 224-234. doi:10.1177/0020872813515011

Interview transcript	Participant ID01 Participant ID02
	Holland Bloorview Kid's Rehabilitation Hospital. (n.d.). https://hollandbloorview.ca
	https://www.canchild.ca
Website	CanChild McMaster University Research Centre. (n.d).
XX 7 . 1	doi:10.1080/09638288.2020.1862925
	disability. Disability and Rehabilitation, 43(7), 1022-1028.
	'normal'! Lessons from COVID for professionals working in childhood
	Rosenbaum, P. L., Silva, M., & Camden, C. (2021). Let's not go back to
	Development, 28(4), 457-463. doi:10.1111/j.1365-2214.2011.01338.x
	disability: I swear this is how we should think! Child: Care, Health and
	Rosenbaum, P. L., & Gorter, J. W. (2011). The 'F-words' in childhood
	doi:10.3389/fresc.2021.710580
	research and practice. Frontiers in Rehabilitation, 2, 1-6.
	Reconceptualizing the family to improve inclusion in childhood disability
	Phoenix, M., Reitzel, M., Martens, R., & Lebsack, J. (2021).
	10.1097/PEP.0b013e31823e06d1
	therapy. <i>Pediatric Physical Therapy</i> , 24(1), 31-37. doi:
	(2012). Autism spectrum disorder: an emerging opportunity for physical
	Mieres, A. C., Kirby, R. S., Armstrong, K. H., Murphy, T. K., & Grossman, L.
	Medicine & Child Neurology, 59(1), 16-25. doi:10.1111/dmcn.13237
	analysis of processes and outcomes in childhood disability. <i>Developmental</i>
	Imms, C., Gandlund, M., Wilson, P. H., Steenbergen, B., Rosenbaum, P. L., & Gordon, A. M. (2016). Participation, both a means and an end: a conceptual
	An Interdisciplinary Approach, 13(2), 161-167. doi:10.3233/PRM-190618
	in pediatric rehabilitation care. Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach, 13(2), 161, 167, doi:10.3233/PPM 100618
	Roebroeck, M. E. (2020). Focus on autonomy: Using 'Skills for Growing Up'
	Hilberink, S. R., Grootoonk, A., Ketelaar, M., Vos, I., Cornet, L., &
	BMC Health Sevices Research, 16(680), 1-11. doi:10.1186/s12913-016-1926-
	childhood disability: a qualitative study of carers' interface with services.
	P. M., & DiGiacomo, M. (2016). Navigating the journey of Aboriginal
	Green, A., Abbott, P., Delaney, P., Patradoon-Ho, P., Delaney, J., Davidson,
	122-127. doi:10.1097/PEP.00000000000575
	response to unpredictability important? Pediatric Physical Therapy, 31(1),
	Maximizing participation during walking in children with disabilities: is
l	Gosselin, D., Wright, A., Sole, G., Girolami, G., & Baxter, D. (2019).

Participant ID03
Participant ID04
Participant ID05

5.1.1 The interviews

A total of five qualitative interviews were conducted with children's rehabilitation practitioners and/or researchers and were later transcribed. The interview sample included 1 physiotherapist, 1 audiologist, 1 social worker, and 2 occupational therapists. Each of these participants had prolonged engagement (at least 10 years) with children's rehabilitation, whether within private practice or in the public sector in a Canadian context. Each of these practitioners also held research or teaching appointments at Canadian universities. Each interview lasted approximately one hour and focused on the participant's understandings of childhood disability, their experiences in the field of children's rehabilitation generally, as well as their field of specialization more specifically. The transcripts produced from these interviews are hereafter treated as 'texts' in the same manner as those texts coming from peer-review research articles and websites.

5.1.2 Other text sources

Ten peer-reviewed research articles were sampled using the purposive strategy described in section 4.3.3. Texts were sampled that, upon preliminary review, appeared to align with dominant medical discourses of childhood disability, and others which appeared as aiming to shift such discourses. Half of the texts were written by at least one Canadian author; the remainder were produced by authors working in other countries in the global north.

Two websites were sampled, both of Canadian rehabilitation institutions which are perceived as highly influential, nationally and internationally. These institutions, Holland-Bloorview Kid's Rehabilitation Hospital, and CanChild Research Centre at McMaster University are generally regarded as leaders in the creation of knowledge related to childhood disability.

5.2 Results of analysis

In this section I present the results of my analysis which I have divided into four discursive threads. Here, I define discursive threads as repeated elements of the discourse, or logics that surfaced through my analytic questions. Though I will present each thread sequentially, it should be noted that they are all interconnected in ways that will be elaborated upon in Chapter 6. Generally, I saw a pattern of shifts in the texts away from deficit-based language, however childhood disability was continually framed as an individual difference and problem in need of some solution. Across texts, there was evidence of a conceptual shift away from models focused purely on fixing the disabled child, though the assumption remained that something should be done to address the 'problem' of disability. Using my Foucauldian lens, I began to recognize just how difficult it can be to speak and act outside of the dominant deficit-based discourse surrounding childhood disability, even in cases where practitioners recognize the harms associated with such framings. Below I provide a brief summary of the four discursive threads, and then I expand on each in the sections that follow.

Childhood disability. In this thread I discuss how childhood, disability, and childhood disability were conceptualized across texts. With childhood being conceptualized primarily as a developmental period, childhood disability was most frequently framed as a disruption or barrier to typical development. Though there was a recognition of functional *and* social elements, childhood disability was most often conceptualized as a difference within the individual disabled child.

Problems and solutions. Whether framed in biological, functional, social or participatory terms, childhood disability was conceptualized across texts as a *problem* within the child. Regardless of specific discursive framing, there remains an ingrained assumption that some action must be taken with the child and their family to address childhood disability. In this section I discuss different framings of the 'problem' of disability, as well as actions suggested to address the problem.

Tensions. In this thread I discuss two related tensions which surfaced through my data analysis. First, the tension between traditional approaches to children's rehabilitation which aimed to 'fix' disabled children, and emerging alternative approaches which attempt to emphasize social

connection and life skills. I also discuss how, through my analysis, I came to question whether approaches framed as 'alternative' differ from traditional interventions in any meaningful way. The second tension discussed relates to the structural constraints faced by children's rehabilitation practitioners. This tension was evidenced through the interviews with practitioners where participants described the structural constraints (outcome measures, systemic requirements) that, in some cases, required them to focus more on 'fixing' and less on intangible skills such as social connection and life skills.

What does the text 'do'? In this thread I describe the effects of the texts analyzed. Across texts, dominant deficit-based discourses of childhood disability were reproduced, despite, in some cases, being framed as reformulated, alternative definitions. Given the Foucauldian conceptualization of discourse adopted in this work, this tendency to reproduce deficit-based notions of childhood disability can be attributed to the durability and dominance of the discourses being described. That is, even as practitioners describe becoming increasingly aware of the problems that surround deficit-based views that prioritize 'fixing' disabled children, it is challenging to act outside of this dominant discourse or to alter the course of its effects.

5.2.1 Childhood disability

In my analysis, I found it important to break down 'childhood disability' into its constitutive parts: childhood and disability. Though my interest lies primarily with their intersection, I found it important to tease out conceptualization of both childhood and disability to ensure attended to the nuances of both concepts, while still recognizing that they are hardly dissociable. Across the sample, childhood was variably conceptualized as a time for exploration, active participation, and play. However, most frequently, it was conceptualized as a time of development (Adair et al., 2018; CanChild; Fawcett, 2016; Green et al., 2016; Hilberink et al., 2020; Imms et al., 2016; Phoenix et al., 2021; Rosenbaum & Gorter, 2012). For example, Participant 03 explained that "childhood is really characterized by a period of significant growth and significant development, of engaging in your environment, and starting to create a foundation of capacity for kind of whatever comes next in our lives."

The texts analyzed refer to childhood as bound up within family and school contexts where children engage in occupations deemed necessary to the cultivation of skills required for capacity

development. Notably, the overwhelming consensus across the data regarding childhood, was that only children who are *not* labelled as disabled progress unproblematically along this milestone-oriented developmental path toward adulthood, a notion that is evident in Fawcett's (2016) reflection:

Although significant changes have occurred, expectations relating to disabled children still differ markedly from those applied to children generally. Accordingly, most children are expected to grow, develop, become increasingly autonomous, benefit from education and social experiences and broaden their horizons. (p. 225)

My analysis revealed frequent invocations of a linear developmental framing of childhood. However, there was also evidence of the beginnings of a conceptual shift away from this dominant mode of understanding childhood as a primarily developmental period in which children grow into their future adult selves. The authors of one sampled text explicitly aim to shift away from a "traditional notion that child development should be marked by the achievement of a set of normative 'milestones', and a belief that there is some standard or normal timing and quality of functioning" (Rosenbaum et al., 2021, p. 1023). Instead, these authors advocate a shift in focus toward adaptability, family development, and functioning to whatever capacity best serves the child:

The authors strongly believe that our focus, going forward, should be on child and family development, and on helping children to build on their best 'capacity' so that everyday 'performance' reflects those abilities. (Rosenbaum et al., 2021, p. 1028)

While conceptualizations of childhood as a life stage characterized by progression along a 'normal' developmental timeline were relatively stable across texts, conceptualizations of disability were slightly more varied. However, disability was continually framed in terms of difference, whether it be biological, functional, or social. Some texts referred to disability as a functional limitation or barrier to participation, characterized by a set of symptoms and associated diagnosis (Adair et al., 2018; CanChild; Gosselin et al., 2018; Green et al., 2016; Holland Bloorview; Mieres et al., 2012). These texts further stipulate that disability, as an individual biological or functional difference, can be intervened upon in order to increase and/or

improve participation. For example, Gosselin and colleagues (2018) comment on a perceived connection between gait performance and improved participation:

We propose that a better understanding of how children respond to unpredictability may foster the development of innovative interventions to improve a child's gait performance in real-life walking environments, potentially resulting in improved levels of participation and quality of life. (p. 122)

Other texts make appeals to more socially oriented understandings of disability, noting connections between individual functional differences, and environmental, contextual, and societal reactions or outcomes (Fawcett, 2016; Imms et al., 2016; Rosenbaum et al., 2021). To illustrate, Participant 04 described disability as a "difference in function which, if visible, creates a social response." That is, a difference which is not normalized in our society and thus provokes a social response. Participant 02 explained: "this [disability] is something that's different about you, and it affects you in different ways depending on what you're tying to do or where you're trying to do it." While still focusing in and around difference, this comment suggests a more relational or context-based conceptualization of disability.

In regard to childhood disability specifically, many texts reproduce dominant conceptualizations of childhood as a unique point in time during which problematic 'characteristics' associated with different disabilities can be effectively targeted in order to facilitate development (CanChild; Gosselin et al., 2019; Hilberink et al., 2020; Holland Bloorview; Imms et al., 2016; Mieres et al., 2012). For example, Participant 02 shared the following: "they [disabled children] come with this like resilience and this ability to make change. And even some of the most severe disabilities in childhood still have a pretty nice critical window where you can make specific gains".

This claim is not surprising given the common conceptualization of childhood as a time for development of skill and capacity, particularly in the case of childhood disability where children are assumed to require more support to achieve certain developmental milestones (Adair et al., 2018; CanChild; Fawcett, 2016; Green et al., 2016; Hilberink et al., 2020; Imms et al., 2016; Phoenix et al., 2021; Rosenbaum & Gorter, 2012).

Some texts drew quite heavily on the World Health Organizations International Classification of Functioning, Disability and Health (ICF) in their conceptualization of childhood disability (Phoenix et al., 2021; Rosenbaum & Gorter, 2012; Rosenbaum et al., 2021). These texts appealed to a biopsychosocial model, integrated in the ICF, which explicitly attends to environmental and social barriers that disabled children might experience. This model incorporates assumptions that in order to effectively treat disability we must attend to environmental and social factors rather than only to individual impairments. Phoenix and colleagues (2021) note the ways this model counters traditional approaches to intervention:

Application of a biopsychosocial model in the World Health Organization's International Classification of Functioning, Disability and Health (ICF) shifted thinking to a contextual view of the child, recognizing that children's function is impacted by both children's health conditions and their social environments. (p. 2)

Even still, the analyzed texts remain focused at the level of the individual. That is, they advocate for social and environmental interventions for the treatment or rehabilitation of a particular child. A notable exception (Fawcett, 2016) went beyond references to environmental factors, to discuss the particular harms children labelled as disabled may experience. The text describes that even in the case of 'successful' individualized intervention, harms are likely to persist given restrictions identified at the systemic level:

For many disabled children, expectations are limited, and social and education opportunities are restricted. Indeed, disabled children often have to contend with their childhood status being significantly prolonged, with questions continually posed about their capacity and capability." (Fawcett, 2016, p.225)

5.2.2 Problems and solutions

Across the sampled texts, childhood disability is constructed as a difference or problem. In the previous section, I showed that the problem of childhood disability is constructed in a number of ways, whether it be biological, social, an issue of function, or of participation. Regardless of specific construction, childhood disability is conceptualized as a problem in need of a solution. The assumption that disabled children are in need of tools and supports in order to engage in

their daily lives is found operating in the background of many of the texts sampled, implicitly indicating the there is a problem within the child (CanChild; Green et al., 2016; Hilberink et al., 2020; Imms et al., 2016; Mieres et al., 2012; Rosenbaum & Gorter., 2012; Rosenbaum et al., 2021).

Adair and colleagues (2018) took a more occupational approach, focused specifically on lack of activity engagement and competence in disabled children, indicating that in order to act on or address disability and improve competence, participation must be specifically targeted by rehabilitation practitioners as well as parents. Similarly, Gosselin and colleagues (2019) sought to improve participation and social interaction amongst disabled children through specific interventions aimed at improving their individual mobility skills and response to environmental unpredictability. A focus on aiming to achieve independence and autonomy for disabled children was also prevalent across the texts:

To support the development of autonomy and life-skills, interventions should not aim at problems or negative outcomes, but rather target the development and competencies, social connection and self confidence to improve the self-determination of youth. In this way, youth can gradually take over responsibilities of their caregivers to manage their health condition and its implications in daily life. (Hilberink et al., 2020, p.162)

In this quotation there is an emphasis on intangible skills such as social connection, however these are framed in the context of individualized intervention.

Some texts presented a model termed the F-Words of childhood disability which builds on the ICF (CanChild; Rosenbaum & Gorter., 2012; Rosenbaum et al., 2021). This model aims to shift the focus of children's rehabilitation away from 'fixing', towards optimizing function, family, fitness, fun, friends, and future. This shift in focus was also reflected in many of the interview transcripts where participants described a shift in practices away from viewing the child as an individual in need of 'fixing', toward considering the child within their family context and in relation to activities deemed meaningful to that child:

Our goal used to be to fix the kids. Fix the kids and fix the families and then our job is done. [...] And now its more around understanding the values and beliefs of the family

and the context and the culture, what's important to them you know its all those kinds of things. Its much more collaborative. (Participant 01)

In this type of approach, collaboration with the family and attention to environmental factors are understood as being critical to any rehabilitative efforts. It does seem, however, that there remains an assumption that something should be done about childhood disability, a responsibility which falls on the disabled child and their family.

5.2.3 Tensions

Across texts, there are alternative approaches to childhood disability being advanced in research and practice, but do they differ from the traditional, deficit-focused approaches focus in any meaningful way? In many ways, it seems as though attempts at reformulating the standard approach to rehabilitation are focused on the end goal of 'normality' and place the responsibility for change on the disabled child and their family, despite presenting means which may be interpreted as being alternative or even progressive. For example, Hilberink and colleagues (2020) claim that "to support the development of autonomy and life-skills, interventions should not aim at problems or negative outcomes, but rather target the development of competencies, social connections and confidence to improve the self determination of youth" (p. 162). Throughout the study, however, is a commitment to promoting independence through a set of predetermined goals related to domains such as activities of daily living, transportation, and work. This tension, between accepting disabled children as they are and encouraging an approximation of normal was evidenced in Rosenbaum and Gorter's (2012) study where it is argued that "it is important to encourage the development and practice of function without regard to how 'nicely' it is achieved" (p. 460), while maintaining that there is a natural, ideal standard of 'normality': "the idea that normality (what most people do) can be used to guide function but it certainly need not be the *only* way things are done" (p. 459).

There is also a tension between what children's rehabilitation practitioners are expected to do and what they might like to do with their clients (Adair, 2018; Rosenbaum et al., 2021). Though related, this tension is more concerned with the recurrent focus on measurement and outcomes within rehabilitation which is sustained through systems and structures that reflect dominant medicalized discourses of disability. Most clinical practice settings are heavily regulated and

surveilled, requiring practitioners to make use of standardized measures and meet certain requirements:

Unless they are addressing "assessment" and "fixing" problems, many developmental therapists risk not being paid. This results in a significant focus on diagnostic labels, testing with standardized measures, and professionally defined outcomes – driven and perpetuated by services that are only funded when these boxes are ticked – rather than focusing on modern ideas about health and striving to bring function to the fore in a useful way [...]. (Rosenbaum et al., 2021, p. 1023)

There is an evident emphasis within children's rehabilitation on measuring individual function, rather than accounting for more subjective and intangible factors such as social connection and life skills. Most interview participants cited this tension as their reasoning for entering private practice, explaining that making this move allowed them to work on things that were truly meaningful to their clients:

I think historically it's very much about here's a problem, here's the solution I'm applying to fix it, here's how I'm measuring that I have that change. In my private practice, that's not an issue. So families pay me for my services. And so I can really work within a model that makes sense to the family. (Participant 03)

This structural tension was also offered as a reason why the rehabilitation community has been slow to move away from the standard "fixing" model:

So that's where the community in rehab is at, is still at fixing. And they're moving away from it, but it's a hard thing to do because that's what the government wants to do, right. The government wants to show that we can fix kids. (Participant 02).

As such, interview participants conveyed that dominant deficit-based discourses which center around 'fixing' childhood disability are entrenched at the systemic level, making alternative models difficult to advance in practice.

5.2.4 What does the text 'do'

Across texts, dominant, deficit-based discourses surrounding childhood disability were often reproduced, though at times framed as reformulations or shifts away from deficit-based thinking. Even as practitioners become aware that 'fixing' can be a problematic way of thinking about disability, it is very difficult, according to Foucault, to actually transform the dominant discourse and its effects. As noted above, there is a recurrent focus on individualized intervention (Adair et al., 2018; Gosselin et al., 2019; Holland Bloorview; Mieres et al., 2012), and ensuring that disabled children be able to engage in occupations deemed 'normal' for their age (Hilberink et al., 2020). As noted, a number of other texts implicitly represent their work as constituting a novel reformulation of childhood disability, for example, by prioritizing environmental and contextual elements of disability (CanChild; Imms et al., 2016; Phoenix et al., 2021; Rosenbaum & Gorter, 2012; Rosenbaum et al., 2021). In these texts there is a consistent push to move beyond 'fixing' disability or the disabled child, by framing the child within their familial and environmental contexts. Even so, many of these texts reproduce the assumption that disability is inherently something to be "acted-on" by some means. In spite of a shift beyond 'fixing', the problem of disability is still located within the disabled child and their family in that they bear the responsibility for change. In this section I present two ways that these discourses were reproduced in my sample: representation of practitioner voices positioned as 'experts', and the construction of a narrow subject position of the disabled child.

In some texts I saw the voices and perspectives of researchers and rehabilitation practitioners being represented, with far less focus on other voices such as those of families and disabled children themselves (Adair et al., 2018; Gosselin et al., 2019; Hilberink et al., 2020; Mieres et al., 2012). Some texts emphasize the need to engage families and caregiver voices, albeit in ways that are mediated through tools and systems created by either researchers or practitioners (Adair, 2018; Green, 2016; Hilberink et al., 2020). In a notable exception, Green and colleagues (2016) wrote the following with regard to their interviews with Aboriginal caregivers of disabled children: "carers play a central role as navigators of their child's care thus, exploring the experiences of carers is imperative in understanding service access for children with a disability" (p. 2). In describing their particular methods, however, I saw that this elicitation of caregiver voices was mediated by non-Aboriginal practitioners positioned as 'experts'. Whether

intentionally or not, explicit framings of practitioner interviewers as 'experts' overshadows the meaningful effort to elicit caregiver voices.

There was, however, a noticeable push to meaningfully engage caregiver voices by involving them in research (Phoenix et al., 2021), or consulting them in the development of assessment tools (CanChild). Rosenbaum and Gorter (2012) noted that "services have traditionally been very paternalistic, and professionals have not explored families' issues and realities" (p. 460), suggesting a move towards a new approach to research and practice which meaningfully engages parent and caregiver voices. While acknowledging that the views of families and disabled children are important and should be elicited to a greater degree, most texts still prioritize practitioner authority, thereby legitimizing medicalized discourses of childhood disability.

A wide range of disabilities were represented in the sample texts, with multiple texts focusing explicitly on cerebral palsy (Adair et al., 2018; CanChild; Gosselin et al., 2019; Hilberink et al., 2020; Holland Bloorview; Rosenbaum & Gorter, 2012; Rosenbaum et al., 2021) and autism spectrum disorder (Adair et al., 2018; CanChild; Holland Bloorview; Mieres et al., 2012; Rosenbaum & Gorter, 2012; Rosenbaum et al., 2021). Other texts spoke of childhood disability in general terms with little mention of specific diagnoses. Notably, there was a consistent explicit focus on those children who might be seen as progressing in some regard due to active engagement with rehabilitation. That is, they suggest a particular type of subject position, one of the disabled child who is malleable and able to progress in observable, measurable ways:

In childhood rehab, I worked in a clinic out in X Province in my postdoc where we saw lots of kids that were very medically complex, and they don't change, right. And so if they weren't making progress towards their goals, you discharged. [...] And maybe they're not making progress in a way that we can objectively measure it, but they're still children. They still need support to be the best person they can be, regardless of what their function might be. (Participant 02)

This sentiment, of the explicit focus on children seen as progressing, was common across interviews with practitioners but was not explicitly mentioned in any of the published research articles or websites sampled.

There was less attention paid within the sampled texts to discussions of the life circumstances of disabled children, beyond functional limitations, that may impact participation. As such, these texts make invisible the range of factors that may impact participation or perceived progress. Some interview participants noted that it was not uncommon for disabled children who have families that are not English speaking to be left out of conversations or have poor experiences with rehabilitation:

It's also the families who do not speak English. Almost all our tests and measures are for English speaking families and English-speaking kids. And all our resources or most of our resource materials are in English, some of them might be in French, but you're not going to find a lot of them in Spanish or in any of the other languages that are so common in our urban environments today and so the families that do not speak English really don't get a lot of resources. Or are expected to do the test measures in English, which affects their performance. (Participant 01)

A similar observation was shared regarding low-income families of disabled children:

"The families who cannot afford, so even though the early hearing detection and intervention program is free for families, so they get hearing tests, they still have to pay for ear molds and hearing aids. So there is some government funding, like through the disabilities program, but it doesn't pay for all of it. So, its the financially strapped families that get left out too" (Participant 01)

Conversations had with practitioners during the interviews helped to shed light on some of the families and children who seem to be left out of the discursive construction of childhood disability in the context of children's rehabilitation. Other sampled texts made no explicit mention to these different life circumstances, instead broadly grouping disabled children without consideration of the ways in which they differ. These groupings have an effect in that they can inadvertently construct specific subject positions of disabled children who are worthy of rehabilitation, or who are disabled but able to be 'fixed', and also mark out those who are not worthy. These implications will be discussed in more detail in Chapter 6.

In this chapter I have described both my sample and the results of my analysis in four key areas: childhood disability, problems and solutions, tensions, and discursive implications. In Chapter 6 I return to my own positionality and conceptual framework to situate these results and their implications within broader literatures and discussions.

Chapter 6

6 Discussion

In this final chapter I first contextualize the findings presented in Chapter 5 within my research question, aims, and conceptual framework. I then go on to discuss the limitations and implications of this research, as well as plans for future research before providing some final remarks to close out this thesis.

6.1 Childhood disability discourse in a neoliberal society

The results of this study described in Chapter 5 demonstrate the extent to which dominant deficit-based views on childhood disability shape children's rehabilitation knowledge and practice in often concealed, taken for granted ways. My conceptual framework has directly influenced my analysis and in this section, I will draw out these connections more explicitly and situate my results within neoliberalism.

Across texts, childhood disability was invariably constructed as a difference. Though texts varied in how they constructed this difference (i.e., biological, functional, social, participatory), each framed disability as individualized and inherently different from the norm. Some of these framings of childhood disability, namely those alluding to social or participatory differences, were framed as progressive or alternative to dominant deficit-based understandings of childhood disability and the associated goal of 'fixing'. It is important, however, to note that these 'alternative' framings continue to reproduce a very particular subject position, of the disabled child as deficient and in need of support. In problematizing these discourses, I do not suggest that disabled children are not worthy of support and rehabilitation services. Rather, I suggest that there may be alternative ways to think about childhood disability, ways that do not frame the disabled child as inherently in need of support or treatment. I suggest that this focus on the support and rehabilitation of disabled children is not reflective of inherent or natural deficits in disabled children, but of prevailing neoliberal discourses.

Recall from Chapter 2, that neoliberalism, as the prominent political ideology and system of thought in contemporary western society (Lupton, 2003), places inherent value on traits related to productivity, work readiness, and self-sufficiency (Goodley & Lawthom, 2019). Notably,

these traits are most commonly conceptualized as requiring some degree of independence. Within contemporary neoliberal societies, the independent and productive worker is constituted as the ideal subject, valued for their contribution to society (both economic and through labour). In contrast, disabled children, within neoliberal society, are constituted as subjects 'in need' (e.g., of rehabilitation services, additional supports), in order to meet these neoliberal ideals.

In asking what discourses of disability as deficit 'do', my analyses indicate that the answer is nuanced. For example, the question of value becomes additionally complex at the intersection of disability and income, where some families are unable to access rehabilitation services beyond those in the public sector and thus are not seen as working towards neoliberal ideals. Similarly, my analysis revealed that children who are labelled as being 'complex cases' or who are not progressing within rehabilitation and meeting predetermined goals are inadvertently framed as incapable, or even less capable than 'other' disabled children of taking up the idealized neoliberal subject position of the independent, self-sufficient worker. That is, they may be constituted as subjects 'in *additional* need'. Inherent in this framing is the idea that these disabled children are not valued in neoliberal society, and that certain groups of disabled children (i.e., those with more complex needs, who are not progressing, who are from low-income families) are valued even less, or that they should be valued only as objects of charity. This finding is consistent with critiques forwarded by disability studies scholars who comment on the discursive framing of disabled people as failing to meet normative ideals and are resultantly seen as objects of pity or charity (Goodley et al., 2019).

Across texts within the rehabilitation sciences, there was some evidence of a growing awareness of the harms associated with dominant, deficit-based conceptualizations of childhood disability. For example, some texts recognized an emergent shift away from models which center around practices aimed at 'fixing' disabled children. Many texts purported to take up alternative views which do not reproduce such harmful discourses. My analysis revealed, however, that most texts inadvertently reproduced the very discourses they sought to problematize and/or resist. In keeping with the Foucauldian framing of this study, I have attributed this reproduction to the pervasiveness of discourses of disability as deficit in the rehabilitation sciences. Even as children's rehabilitation practitioners attempted to resist such deficit-based models, the rationalities which ground them, taken-for-granted as they are, are near impossible to shift. As a

result, the same subject positions are reproduced in the circulation of knowledge in rehabilitation, albeit inadvertently.

In producing a specific subject position of the disabled child as in development, and 'in need' of rehabilitation services and treatment, discourses of disability as deficit make assumptions regarding which occupations are inherently valuable for disabled children. That is, though occupational choices are made by disabled children and their families, they are shaped through structural contexts (Laliberte Rudman, 2005; 2010) and neoliberal discourses which frame certain occupations as possible and/or desirable. Recall the example of play as occupation from Chapter 2, where I described the current focus on play for development (Frost et al., 2012; Hodge & Runswick-Cole, 2013). Framed within neoliberal discourse there is an intensity and increased pressure associated with play for development for disabled children, in that it may be seen as a means to attaining or working towards the ideal neoliberal subject position of the independent, rehabilitated child.

Scholars have noted that disabled children may find meaning, pride, and belonging through the development of a positive disability identity (Dunn & Burcaw, 2013; Marsa-Sambola, 2017), however continued reproduction of discourses of disability as deficit risks contributing to negative internalized identity for disabled children. Now the question is raised: what can be done to truly challenge discourses surrounding childhood disability and create alternate subject positions for disabled children? Across the texts sampled in this study, I saw that practitioner authority was continually legitimized and prioritized. I also saw that there was a growing trend, calling for the inclusion of parent and child voices in research and rehabilitation. What I did not see, however, was an integration of perspectives from outside of the rehabilitation sciences, including those of disability studies scholars, disability self-advocates, other critically oriented scholars, and disabled children themselves. When practitioner authority is continually reinforced, the role of and need for children's rehabilitation is reaffirmed. Though often unintentionally, this affirmation has the effect of continuing to discount perspectives from disability studies and reinforcing the power and knowledge held within rehabilitation.

Though disability studies scholars have traditionally critiqued medicalized disability intervention (Curran & Runswick-Cole, 2014), there are growing interdisciplinary calls for the integration of

more critical understandings of disability into the rehabilitation sciences. (Burghardt et al., 2021; Magasi, 2008; Mosleh, 2019; Phelan, et al., 2014). For example, justifications have been made for utilizing disability studies critiques of idealized standards of normalcy and other taken-forgranted assumptions regarding disability found in the rehabilitation sciences (Phelan et al, 2014). I have drawn on perspectives emerging from the field of disability studies throughout this research. Importantly, in doing so, I have not aimed to offer alternative forms of intervention or support for disabled children and their families. Instead, I have engaged thinking from within disability studies to problematize the assumption that there is always some action required to support or intervene upon the 'problem' of disability.

Further, I have resisted the neoliberal framing of childhood disability as an inherent problem to be 'fixed'. This problematization has the potential to be transformative but requires an unprecedented disruption in prevailing neoliberal assumptions grounding contemporary society. In theorizing this transformation, I reflect on a question posed by Maria Karimiris (2020), a researcher working at the intersection of disability studies, post-colonial studies, and post-structural feminism: "how might we work with one another to create systems, structures and institutions that assure that life in all its varying embodiments not only survives but thrives? (p. 112)". The path forward is unclear but is sure to require continual reflection on and problematization of society's most taken for granted assumptions. I also propose that this way forward, toward thriving, requires meaningful interdisciplinary collaboration.

In order to better foster such interdisciplinary collaboration, some scholars have recommended integrating disability studies learnings into health professional education to better support new practitioners in understanding the complexities of a positive disability identity. Block and colleagues (2005) describe the integration of a disability studies course into an occupational therapy program at an American university. The course focused on deinstitutionalization and community life, provided students with reflective activities, and allowed them to meaningfully engage with a local independent living center. Other scholars have recommended integrating learnings from disability studies at the undergraduate level, finding that early exposure to alternative ways of thinking about disability can help motivate future practitioners to impact change in healthcare (McGoldrick et al., 2018). Within literature that falls at the intersection of the disability studies and medical spheres, there is a growing recognition of the value of

interdisciplinary collaboration, and an assertion that reframing knowledge surrounding disability begins with the recognition that these two fields are not necessarily opposed, but each have something to offer the other (Duane, 2014; Campbell, 2009; Mosleh, 2019; Phelan, 2011)

6.2 Limitations and future research

Based on my positionality as a critical qualitative researcher, I have no intention of minimizing my voice within my research or producing statistically generalizable results. Rather than attempting to minimize my 'bias' or the presence of my voice within the research, as one might when operating within a positivist paradigm, I instead recognize myself as necessarily implicated within this research (Finlay, 2002; Guba & Lincoln 1994; Ravenek & Laliberte Rudman, 2013). Rather than understanding these realizations as limitations of this research, I instead take them as inevitable (although often unacknowledged) aspects of all research endeavors. In this section I describe limitations that resulted out of *choices* I made during the research process, or pragmatic limitations resulting from the limited size and scope of a master's research project, rather than limitations of researcher bias or influence. In this section I also refer to work that is ongoing in the larger project in which this study is situated.

The first limitation of this study pertains to the interview participants. Though each of the participants had prolonged clinical experience in children's rehabilitation, they each also held research or teaching appointments. As such, it can be assumed that the participants interviewed may have had exposure to emerging critical thought on childhood disability. The participants interviewed each brought rich insight and drew heavily on clinical experience in their area of specialization, however their conceptualizations of childhood disability may be different in some regard to those practitioners whose experience is purely clinical and who might not have had any previous exposure to disability studies scholarship and emerging perspectives regarding childhood disability and rehabilitation.

This research was carried out during the COVID-19 pandemic which brought some limitations of feasibility, primarily related to sampling. Due to pandemic related circumstances at the time of recruitment, many potential participants had increased workloads and were less likely to take on additional time commitments. For this reason, I also decided to begin recruitment for interviews at the same time that preliminary analysis of peer-reviewed research articles and websites were

being completed. This approach strayed from my initial plan to complete a more strict phased approach, but did not impact the data collected in any meaningful way.

The limited size and scope of this project has some implications. For pragmatic reasons, I limited my text sample to only those texts published after 2012. In doing so, I was unable to comment on the historical evolution of rehabilitation practitioners' conceptualizations of childhood disability, or what Foucault might have termed the archeology of knowledge in this field (Dreyfus & Rabinow, 1983). Though this study could have been strengthened through a more in-depth historical contextualization, the findings presented are valuable in their own right as a snapshot of how childhood disability is currently conceptualized within the rehabilitation sciences. Within the larger project, ongoing work is underway to comment on the historical development of dominant discourses described in this study. There, a longer time period (1990-2022) is being used to trace thinking on childhood disability as it has evolved through this time period of rapid change.

Perhaps the most important limitation of this study is that I was unable to directly consult those with whom my work is explicitly concerned with, that is, disabled children and their families. Though an advisory panel was formed for ongoing consultation within the larger project, the size and scope of the current study limited me from engaging with their perspectives regarding my own work in any meaningful way. Claims of 'giving voice' to disabled children in research have been troubled, requiring alternative approaches to the representation of children's perspectives (Facca et al., 2020). Building on this research, next steps should involve direct collaboration and/or consultation with disabled children and their families, while attending to the complexities associated with 'giving voice', and also recognizing that disabled children and their families are also subjected to the durable, dominant discourses discussed in this study.

6.3 Final remarks

The findings of this study demonstrated the extent to which dominant discourses surrounding childhood disability, as constructed in the neoliberal context, shape children's rehabilitation knowledge and practice. Recall that according to Foucault, discourses and their effects are difficult to think and act outside of, meaning that true change will require a considerable disruption in the neoliberal assumptions which ground contemporary society, as well as

biomedical conceptualizations of deficits. In this chapter, I have suggested the need for an increase in interdisciplinary collaboration between disability studies and the rehabilitation sciences, as well as meaningful collaboration with disabled children and their families. These actions are necessary steps towards a critical reformulation of the taken-for-granted assumptions operating in contemporary society which shape knowledge and practice related to childhood disability.

References

- Adair, B., Ullenhag, A., Rosenbaum, P. L., Granlund, M., Keen, D., & Imms, C. (2018).

 Measures used to quantify participation in childhood disability and their alignment with the family or participation-related constructs: a systematic review. *Developmental Medicine and Child Neurology*, 60(11), 1101-1116. https://doi: 10.1111/dmcn.13959
- Alexander, S. A., Frohlich, K. L., & Fusco, C. (2014). Problematizing "Play-for-Health" Discourses Through Children's Photo-Elicited Narratives. *Qualitative Health Research*, 24(10), 1329–1341. https://doi.org/10.1177/1049732314546753
- Anastasiou, D., & Kauffman, J. M. (2013). The social model of disability: Dichotomy between impairment and disability. *Journal of Medicine and Philosophy*, 28(4), 441-459. https://doi:10.1093/jmp/jht026
- Andrews, E. E., Forber-Pratt, A. J., Mona, L. R., Lund, E. M., Pilarski, C. R., & Balter, R. (2019). #SaytheWord: A disability culture commentary on the erasure of "disability". *Rehabilitation psychology*, *64*(2), 111–118. https://doi.org/10.1037/rep0000258
- Asghar, J. (2013). Critical Paradigm: A preamble for novice researchers. *Life Science Journal*, 10(4), 3121-3127.
- Beaudry J. S. (2016). Beyond (Models of) Disability?. *The Journal of medicine and philosophy*, 41(2), 210–228. https://doi.org/10.1093/jmp/jhv063
- Behrent, M. C. (2013). Foucault and technology. *History and Technology*, 29(1), 54-104. https://doi.org/10.1080/07341512.2013.780351
- Berghs, M. (2015). Radicalising 'disability' in conflict and post-conflict situations. *Disability & Society*, 30(5), 743-758. https://doi.org/10.1080/09687599.2015.1052044
- Bingham, C., Clarke, L., Michielsens, E., & Meer, M. V. de. (2013). Towards a social model approach?: British and Dutch disability policies in the health sector compared. *Personnel Review*, 42(5), 613–637. https://doi.org/10.1108/PR-08-2011-0120
- Block, P., Ricafrente-Biazon., Russo, A., Ke Yun Chu., Suman, S., & Koerner, L. (2005). Introducing disability studies to occupational therapy students. *American Journal of Occupational Therapy*, *59*(5), 554-560. https://doi: 10.5014/ajot.59.5.554

- Botha, M., Dibb, B., & Frost, D. M. (2022). "Autism is me": an investigation of how autistic individuals make sense of autism and stigma, *Disability & Society*, *37*(3), 427-453. https://doi:10.1080/09687599.2020.1822782
- Burghardt, M., Edelist, T., Fudge Schormans, A., & Yoshida, K. (2021). Coming to Critical Disability Studies: Critical Reflections on Disability in Health and Social Work Professions. *Canadian Journal of Disability Studies*, *10*(1), 23–53. https://doi:10.15353/cjds.v10i1.743
- Campbell, F. (2009). Medical Education and Disability Studies. *Journal of Medical Humanities*, 30(4), 221-235. https://doi.org/10.1007/s10912-009-9088-2
- CanChild McMaster University Research Centre. (n.d). https://www.canchild.ca
- Carnevale, F. A., Campbell, A., Colin-Vézina, D., & Macdonald, M. E. (2015). Interdisciplinary studies of childhood ethics: developing a new field of inquiry. *Children & Society*, 29(6), 511-523. https://doi.org/10.1111/chso.12063
- Cohen, L., Manion, L. and Morrison, K. (2000). Research Methods in Education. 5th Edition, Routledge Falmer. http://dx.doi.org/10.4324/9780203224342
- Cooper, H. (2013). The oppressive power of normalzy in the lives of disabled children:

 Deploying history to denaturalize the notion of the 'normal child'. In T. Curran & K.

 Runswick-Cole (Eds.), *Disabled children's childhood studies: Critical approaches in a global context* (pp. 136-151). Palgrave Macmillan.
- Crotty, M. (1998). The foundations of social research: Meaning and perspective in the research process. Sage.
- Crowe, M. Discourse analysis towards an understanding of its place in nursing. *Journal of Advance Nursing*, 51(1). 55-63. doi:10.1111/j.1365-2648.2005.03461.x
- Curran, T. & Runswick-Cole, K. (2014). Disabled children's childhood studies: a distinct approach?, *Disability & Society*, 29(10), 1617-1630. doi: 10.1080/09687599.2014.966187
- Donoghue, C. (2003). Challenging the authority of the medical definition of disability: An analysis of the resistance to the social constructionist paradigm. *Disability & Society*, 18(2), 199-208. https://doi:10.1080/0968759032000052833
- Dreyfus, H. L. & Rabinow, P. (1983). *Michel Foucault: Beyond structuralism and hermeneutics*. Routledge.

- Duane, A. M. (2014). What's Best For Them: Teaching Disability Studies to Science Majors. *Journal of Inclusive Scholarship and Pedagogy*, 25(2), 175-178. https://doi.org/10.5325/trajincschped.25.2.0175
- Dunn, D. S., & Burcaw, S. (2013). Disability identity: Exploring narrative accounts of disability. *Rehabilitation Psychology*, 58(2), 148–157. https://doi.org/10.1037/a0031691
- Eakin, J. M., & Gladstone, B. (2020). "Value-adding" analysis: Doing more with qualitative data. *International Journal of Qualitative Methods*, *19*(1), 1-13. https://doi.org/10.1177/1609406920949333
- Eakin, J. M., & Mykhalovskiy, E. (2003). Reframing the evaluation of qualitative health research: Reflections on a review of appraisal guidelines in the health sciences. *Journal of Evaluation in Clinical Practice*, 9(2), 187–194. https://doi.org/10.1046/j.1365-2753.2003.00392.x
- 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(1), 1-10. https://doi:10.1177/1609406920933391
- Fadyl, J. K., Nicholls, D. A., & McPherson, K. M. (2012). Interrogating discourse: The Application of Foucault's methodological discussion to specific inquiry. *Health*, *17*(5), 478-494. https://doi.org/10.1177/1363459312464073
- Fadyl, J. K., Teachman, G., & Hamdani, Y. (2020). Problematizing 'productive citizenship' within rehabilitation services: insights from three studies. *Disability and rehabilitation*, 42(20), 2959–2966. https://doi.org/10.1080/09638288.2019.1573935
- Fairclough, N. L., & Wodak, R. (1997). Critical Discourse Analysis. In T. A. van Dijk (Ed.), Discourse Studies: A Multidisciplinary Introduction (pp. 258-284). London: Sage.
- Fawcett, B. (2016). Children and disability: Constructions, implications and change. *International Social Work*, 59(2), 224-234. https://doi:10.1177/0020872813515011
- Finlay, L. (2002). "Outing" the researcher: The provenance, process and practice of reflexivity.

 *Qualitative Health Research, 12(4), 531-545.

 https://doi.org/10.1177/104973202129120052
- Flynn, S. (2022). Critical disability studies and the affirmative non-tragedy model: presenting a theoretical frame for disability and child protection. *Disability & Society*, 1-22. https://doi.org/10.1080/09687599.2022.2070061

- Frost, J. L., Wortham, S. C., & Reifel, S. (2012). Play and Child Development (4th edition). Pearson.
- Foucault, M. (1988). Technologies of the self. In L. H. Martin, H. Gutman, & P. H. Hutton (Eds.), *Technologies of the Self: A Seminar with Michel Foucault* (pp. 16-49). Tavistock Publications.
- 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. https://doi.org/10.1080/11038128.2017.1327616
- 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. https://doi.org/10.1080/09638280802621390
- Gibson, B. E., Teachman, G., & Hamdani, Y. (2015). Rethinking "Normal Development" in Children's rehabilitation. In *Rethinking Rehabilitation: Theory and Practice*, K. McPherson, B. E. Gibson, A. Leplege (eds.). CRC Press.
- Gibson, B. E., Teachman, G., & Hamdani, Y. (2016). Development. In B. E. Gibson, *Rehabilitation: A Post-critical approach* (pp. 75-88). CRC Press.
- Goodley, D., & Lawthom, R. (2019). Critical disability studies, Brexit and Trump: a time of neoliberal-ableism. *Rethinking History*, 23(2), 233-251. https://doi: 10.1080/13642529.2019.1607476
- Goodley, D., Lawthom, R., Liddiard, K., & Runswick-Cole, K. (2019). Provocations for critical disability studies. *Disability & Society*, *34*(6), 972-997. https://doi.org/10.1080/09687599.2019.1566889
- Gosselin, D., Wright, A., Sole, G., Girolami, G., & Baxter, D. (2019). Maximizing participation during walking in children with disabilities: is response to unpredictability important?

 *Pediatric Physical Therapy, 31(1), 122-127. https://doi:10.1097/PEP.000000000000575
- Green, A., Abbott, P., Delaney, P., Patradoon-Ho, P., Delaney, J., Davidson, P. M., & DiGiacomo, M. (2016). Navigating the journey of Aboriginal childhood disability: a qualitative study of carers' interface with services. *BMC Health Sevices Research*, 16(680), 1-11. https://doi:10.1186/s12913-016-1926-0

- Grue, J. (2011). Discourse analysis and disability: Some topics and issues. *Discourse & Society*, 22(5), 532-546. https://doi.org/10.1177/0957926511405572
- Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and "Ethically Important Moments" in research. *Qualitative Inquiry*, 10(2), 261-280. https://doi.org/10.1177/1077800403262360
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (1st ed.) (pp. 105-117). Thousand Oaks, CA: SAGE.
- Guralnick, M. J. (2005). An overview of the developmental systems model for early intervention. *The developmental systems approach to early intervention*, *1*(1), 3-28.
- Haegele, J. A., & Hodge, S. (2016). Disability discourse: Overview and critiques of the medical And social models. *Quest*, 68(2), 193-206. https://doi:10.1080/00336297.2016.1143849
- Hall, S. (1997). The work of representation. In S. Hall (Eds.), *Representation: Cultural Representations and signifying practices* (pp. 44-64). London, UK: Sage Publications.
- Hamdani, Y., & Gibson, B. E. (2019). Challenging assumptions about 'normal' development in children's rehabilitation: The promise of critical qualitative research. In *Enhancing healthcare and rehabilitation: The impact of qualitative research* (pp. 209-21). CRC Press.
- Hodge, N., & Runswick-Cole, K. (2013). 'They never pass me the ball': exposing ableism through the leisure experiences of disabled children, young people and their families. *Children's Geographies*, 11(3), 311-325. https://doi:10.1080/14733285.2013.812275
- Hilberink, S. R., Grootoonk, A., Ketelaar, M., Vos, I., Cornet, L., & Roebroeck, M. E. (2020).
 Focus on autonomy: Using 'Skills for Growing Up' in pediatric rehabilitation care.
 Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach, 13(2), 161-167. https://doi:10.3233/PRM-190618
- Holland Bloorview Kid's Rehabilitation Hospital. (n.d.). https://hollandbloorview.ca
- Hook, D. (2001). Discourse, knowledge, materiality, history: Foucault and discourse analysis. *Theory & Psychology, 11*(4), 521-547. https://doi.org/10.1177/0959354301114006
- Humpage, L. (2007). Models of Disability, Work and Welfare in Australia. *Social Policy & Administration*, 41, 215-231. https://doi.org/10.1111/j.1467-95152007.00549.x
- Hussain, M. A., Elyes, T., & Naseef, O. A. (2013). Research paradigms: A slippery slope for fresh researchers. *Life Science Journal*, *10*(4), 2374-2381.

- Imms, C., Gandlund, M., Wilson, P. H., Steenbergen, B., Rosenbaum, P. L., & Gordon, A. M. (2016). Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability. *Developmental Medicine & Child Neurology*, 59(1), 16-25. https://doi:10.1111/dmcn.13237
- Karmiris, M. (2020). The Myth of Independence as Better: Transforming Curriculum Through Disability Studies and Decoloniality. *Canadian Journal of Disability Studies*, 9(5), 96–121. https://doi.org/10.15353/cjds.v9i5.692
- Kattari, S. K., Lavery, A., & Hasche, L. (2017) Applying a social model of disability across the life span, *Journal of Human Behavior in the Social Environment*, 27(8), 865-880. https://doi:10.1080/10911359.2017.1344175
- Kivunja, C. & Kuyini, A. B. (2017). Understanding and applying research paradigms in educational contexts. *International Journal of Higher Education*, *6*(5), 26-41. https://doi:10.5430/ijhe.v6n5p26
- Laliberte Rudman, D. (2005). Understanding political influences on occupational possibilities:

 An analysis of newspaper constructions of retirement. *Journal of Occupational Science*, 12(3), 149-160. https://doi:10.1080/14427591.2005.9686558
- Laliberte Rudman, D. (2010). Occupational Terminology: Occupational Possibilities. *Journal of Occupational Science*, 17(1), 55-59. https://doi:10.1080/14427591.2010.9686673
- Laliberte Rudman, D. & Dennhardt, S. (2015). Critical discourse analysis: opening possibilities through deconstruction. In S. Naya & M. Stanley (Eds.), *Qualitative research methodologies for occupational science and occupational therapy* (pp. 137-154). Routledge.
- Levitt, H. M., Morrill, Z., Collins, K. M., & Rizo, J. L. (2021). The methodological integrity of critical qualitative research: principles to support design and research review. *Journal of Counseling Psychology*, 68(3), 357-370. https://doi:10.1037/cou0000523
- Lincoln, Y.S., Lynham, S.A., & Guba, E.G. (2011). Paradigmatic controversies, contradictions, and emerging confluences, revisited. In *The SAGE handbook of qualitative research* (4th ed., pp. 97–128). SAGE Publications, Ltd.
- Lupton, D. (1992). Discourse analysis: a new methodology for understanding the ideologies of health and illness. *Australian Journal of Public Health*, *16*(2), 145-150. https://doi.org/10.1111/j.1753-6405.1992.tb00043.x

- Lupton, D. (2003). *Medicine as culture: Illness, disease and the body in Western societies*. Sage Publications.
- Mackelprang, R. W. (2010). Disability controversies: Past, present, and future. *Journal of Social Work in Disability & Rehabilitation*, 9(2), 87–98.

 https://doi.org/10.1080/1536710X.2010.493475
- Mackelprang, R. W. & Salsgiver, R. O. (2016). *Disability: A diversity model approach in human service practice*. Oxford University Press.
- Mackenzie, N. and Knipe, S. (2006) Research Dilemmas: Paradigms, Methods and Methodology. *Issues in Educational Research*, 16(1), 193-205.
- Magasi S. Infusing disability studies into the rehabilitation sciences. *Top Stroke Rehabilitation*. *15*(3), 283-287. https://doi: 10.1310/tsr1503-283.
- Manderson, L., Bennett, E., & Andajani-Sutjahjo, S. (2006). The Social Dynamics of the Interview: Age, Class, and Gender. *Qualitative Health Research*, *16*(10), 1317–1334. https://doi.org/10.1177/1049732306294512
- McGoldrick, K., Zelizer, D., & Ray, S. (2018). Shifting Perspectives: Enhancing Healthcare Professionals' Awareness Through Disability Studies Undergraduate Curriculum. *Canadian Journal of Disability Studies*, 7(1), 26-51. https://doi.org/10.15353/cjds.v7i1.401
- Mieres, A. C., Kirby, R. S., Armstrong, K. H., Murphy, T. K., & Grossman, L. (2012). Autism spectrum disorder: an emerging opportunity for physical therapy. *Pediatric Physical Therapy*, 24(1), 31-37. https://doi:10.1097/PEP.0b013e31823e06d1
- Mills, S. (2004). Discourse: A new critical idiom (2nd ed.). Routledge.
- Moss, P., Dillon, J., & Statham, J. (2000). The 'child in need' and 'the rich child': Discourses, constructions and practice. *Critical Social Policy*, 20(2), 233–254. https://doi.org/10.1177/026101830002000203
- Njelesani, J., Gibson, B. E., Nixon, S., Cameron, D., & Polatajko, H. J. (2013). Towards a critical occupational approach to research. *International Journal of Qualitative Methods*, 12(1), 207–220. https://doi.org/10.1177/160940691301200109
- Mosleh, D. (2019). Critical disability studies *with* rehabilitation: Re-thinking the human in rehabilitation research and practice. *The Journal of Humanities in Rehabilitation*, 1-12.
- Mosleh, D. & Gibson, B. E. (2022). Abnormal-Becoming-Normal: Conceptualizations of

- Childhood disability in children's rehabilitation textbooks. *Scandinavian Journal of Disability Research*, 24(1), 122-135. https://doi.org/10.16993/sjdr.877
- Oliver, M. (2013). The social model of disability: Thirty years on. *Disability & Society*, 28(7), 1024–1026. https://doi:10.1080/09687599.2013.818773
- Olssen, M. (2014). Discourse, complexity, normativity: Tracing the elaboration of Foucault's materialist concept of discourse. *Open Review of Educational Research*, 1(1), 28-55. https://doi:10.1080/23265507.2014.964296
- Owens, J. (2015). Exploring the critiques of the social model of disability: The transformative possibility of Arendt's notion of power. *Sociology of Health & Illness*, *37*(3), 385–403. https://doi:10.1111/1467-9566.12199
- Patton, M. (1990). Qualitative evaluation and research methods (pp. 169-186). Sage.
- Phelan, S. K. (2011). Constructions of disability: A call for critical reflexivity in occupational therapy. *Canadian Journal of Occupational Therapy*, 78(3), 164-172. https://doi.org/10.2182/cjot.2011.78.3.4
- Phelan, S. k., Wright, W., & Gibson, B. E. (2014). Representations of disability and normality in Rehabilitation technology promotional materials. *Disability and Rehabilitation*, *36*(24), 2072-2079. https://doi.org/10.3109/09638288.2014.891055
- Phoenix, M., Reitzel, M., Martens, R., & Lebsack, J. (2021). Reconceptualizing the family to improve inclusion in childhood disability research and practice. *Frontiers in Rehabilitation*, 2(1), 1-6. https://doi:10.3389/fresc.2021.710580
- Ponterotto, J. G. (2005). Qualitative research in counseling psychology: A primer on research paradigms and philosophy of science. *Journal of Counseling Psychology*, *52*(2), 126-136. https://doi:10.1037/0022-0167.52.2.126
- Prout, A. (2011). Taking a step away from modernity: Reconsidering the new sociology of childhood. *Global Studies of Childhood*, *I*(1), 4-14. http://dx.doi.org/10.2303/gsch.2011.1.1.4
- Rabinow, P., & Rose, N. (2003). Introduction: Foucault Today. In P. Rabinow & N. Rose (Eds.), The essential Foucault: Selections from the essential works of Foucault, 1954-1984 (pp. 1-30). New Press.

- Ravenek, M.J. & Laliberte Rudman, D. (2013). Bridging conceptions of quality in moments of qualitative research. *International Journal of Qualitative Methods*, 12, 436-456. https://doi:10.1177/160940691301200122
- Romstein, K. (2015). Neoliberal values and disability: critical approach to inclusive education. Bulgarian Comparative Education Society.
- Rosenbaum, P. L., & Gorter, J. W. (2011). The 'F-words' in childhood disability: I swear this is how we should think! *Child: Care, Health and Development*, 28(4), 457-463. https://doi:10.1111/j.1365-2214.2011.01338.x
- Rosenbaum, P. L., Silva, M., & Camden, C. (2021). Let's not go back to 'normal'! Lessons from COVID for professionals working in childhood disability. *Disability and Rehabilitation*, 43(7), 1022-1028. https://doi:10.1080/09638288.2020.1862925
- Runswick-Cole, K. (2014). 'Us' and 'them': the limits and possibilities of a 'politics of = neurodiversity' in neoliberal times. *Disability & Society*, 29(7), 1117-1129. https://doi:10.1080/09687599.2014.910107
- Samuelsson, I. P., & Carlsson, M. A. (2008). The playing learning child: Towards a pedagogy of early childhood. *Scandinavian Journal of Educational Research*, *52*(6), 623-641. https://doi:10.1080/00313830802497265
- Shakespeare, T., Cooper, H., Bezmez, D., & Poland, F. (2018) Rehabilitation as a disability equality issue: a conceptual shift for disability studies? *Social Inclusion*, *6*(1), 61-72. https://doi.org/10.17645/si.v6i1.1175
- Slater, J. (2013). Research with dis/abled youth: Taking a critical disability, 'critically young' positionality. In T. Curran & K. Runswick-Cole (Eds.), *Disabled children's childhood studies* (pp. 180-195). Palgrave Macmillan.
- Stiker, H. J. (2019). A history of disability. University of Michigan Press.
- Unicef (2012). Early childhood development and disability: discussion paper. *World Health Organization*. https://apps.who.int/iris/bitstream/handle/10665/75355/?sequence=1
- Waldschmidt, A. (2015). Who is normal? Who is deviant? "Normality" and "risk" in genetic Diagnostics and counseling. In S. Tremain (Eds.), *Foucault and the Government of Disability* (191-207). University of Michigan Press.
- Whalley Hammell, K. (2015). Quality of life, participation and occupational rights: A

capabilities perspective. *Australian Occupational Therapy Journal*, 62, 78-85. https://doi:10.1111/1440-1630.12183

Wilson, Patrick. (1983). Second-hand knowledge: an inquiry into cognitive authority. Greenwood Press.

Appendix A: Letter of Information



SSHRC = CRSH

Letter of Information and Consent

Reframing childhood disability: Bridging political and disciplinary boundaries to improve disabled children's lives.

Principal Investigator: Gail Teachman PhD, OT Reg. (Ont.) Western University.

Study Funder:

This study is funded by a SSHRC Insight Development Grant.

Dear [inset name]:

Introduction: Dr. Gail Teachman and her team of researchers invite you to participate in a study that aims to understand the ways that childhood disability is understood and addressed. You are being invited to participate in this study because you have specialized knowledge of childhood disability stemming from either disability studies or children's rehabilitation. This study seeks to critically examine how childhood disability is currently conceptualized and acted on in two fields that impact disabled children and their families: disability studies and children's rehabilitation. How disability is understood in these fields has direct bearing on how people act in relation to disability. These differences have direct effects for disabled children and their families. Some of these effects might be beneficial but some might also be associated with potential harms. The goal of this research study is to use our analysis to develop a set of guiding principles (a new provisional conceptual framework) that has the potential to build stronger links across children's rehabilitation and disability studies in order to enact more affirmative and inclusive conceptualizations of childhood disability.

Study Procedures: If you agree to participate in this virtual study, you will be asked to participate in one virtual interview via Zoom. We will be recruiting 12-16 participants to engage in one individual interview with either Dr. Teachman or Emily Cox, Graduate Research Fellow. Each

interview will last approximately 60-90 minutes. The interview will be scheduled at a time that is convenient for you. During your interview, we will share what we learned in an earlier part of this study about how childhood disability is represented in the fields of disability studies and children's rehabilitation. We will discuss the ways that you think about and act on childhood disability in your everyday practices.

All interviews will be audio and video recorded to ensure an accurate recording of participant responses. The audio file will also be sent to a professional transcriptionist and used for our subsequent analysis.

Risks, Benefits and Confidentiality: All consent forms, research data, and personal identifiers (e.g., name, gender, profession, email address) will be stored on a password-protected, encrypted server at Western University. Any information collected during interviews that could reveal the identity of a participant will be altered or removed to ensure participation in the study remains anonymized and all appropriate methods will be employed to maintain confidentiality. Excerpts from interviews may be included in publications or presentations sharing the results of this research, however all quotations will be de-identified. We acknowledge there still exists a risk of breach of privacy. Only study personnel and the Western University Health Sciences Research Ethics Board (HSREB) will have access to the files. After seven years, in accordance with Western University policy, data will be destroyed following approved procedures.

There are no direct benefits to you as a result of your participation in the study. All participation in this study is voluntary and participants will not incur any related expenses. A \$50 gift card will be provided to you via email to acknowledge your contributions to this research. If you consent to participate you have the right to not answer individual questions and can withdraw from the study at any time prior to data analysis by notifying the Principal Investigator. If you elect to withdraw from the study after data analysis is complete, it will not be possible to fully remove data generated as a result of your participation. If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research. The HSREB is a group of people who oversee the ethical conduct of research studies. The HSREB is not a part of the study team. Everything you discuss will be kept confidential.

Next steps and Contact Information:

If you would like to participate, or if you want to learn more about this study, please contact our research assistant, Emily Cox, who will handle all administrative questions, collection of consent

forms and scheduling. We would be happy to follow-up with a phone call to discuss the study and any questions you have about participating. Alternately, we could address questions via email if that is your preference.

If, after discussing the study with Ms. Cox, you agree to participate in this study, we will request that you sign and return the consent form by email. We will follow up by scheduling an interview and sending you a fully executed copy of the consent form.

If you are not interested in participating in the study, no action is required on your part.

We will send one reminder email in two weeks if we don't hear back you. Thank you for considering this invitation to participate.

Sincerely,

Dr. Gail Teachman, PhD, OT Reg. (Ont.)

Western University, School of Occupational Therapy.

Appendix B: Consent Form



SSHRC **≡** CRSH

Reframing childhood disability: Bridging political and disciplinary boundaries to improve disabled children's lives.

Principal Investigator: Gail Teachman PhD, OT Reg. (Ont.) Western University,

CONSENT FORM

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by Gail Teachman of the School of Occupational Therapy at Western University. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.
Participant Name
(Please print full name)
Participant Signature
(Electronic signature is acceptable)
Date:
Person Obtaining Informed Consent
Signature of Person Obtaining Informed Consent

Appendix C: Interview Guide V1

PRELIMINARY INTERVIEW GUIDE

(Note: Specific probes may change or be added per developing analysis)

Project Title: Reframing childhood disability: Bridging political and disciplinary

boundaries to improve disabled children's lives.

Preliminary comments [including checks for ongoing consent]

I want to start by thanking you very much for agreeing to be part of this study and being willing to speak to your understanding of childhood disability. My name is **[Gail Teachman or Emily Cox]** and my pronouns are [insert interviewer pronouns]. Would you mind briefly introducing yourself and letting me know what pronouns I can use to address you?

I would like to remind you that your name will not be used in any study related reports – we will use pseudonyms/fictitious names when referring to all participants' comments from the interviews and we will remove or change any information that could reveal your identity. For example, removing place names, or the names of other people you mention.

Before we begin, I wanted to share with you some results from our document analysis. [insert brief summary of document analysis results].

Warm-up

As you know, in this study we are interested in understanding conceptualizations of children's disability stemming from both rehabilitation and activism/disability studies spaces. Before we get to that, would you mind telling me about yourself and your role as it relates to childhood disability?

As you might be aware, there are debates about how to talk about disability. Some prefer to use what is called person first language (i.e., "Person with a disability). Others prefer to use what is called identity first language (i.e., "Disabled person"), as they view disability as making up a piece of one's identity. With that said, do you have preferred language that you tend to use? Additionally, if you feel comfortable, would you be able to tell me whether you identify as disabled and/or as a member of a racialized or ethnic group?

Interview Questions

- 1. Do these results [document analysis] resonate with you?
- 2. To someone who was unaware or unsure, how would you describe disability? [prompts]

Can you tell me about how you came to formulate this definition? Influences? How do you think about disability in relation to non-disability? What about childhood disability? Do you think most people share your definition?

3. When discussing disability, there is often a lot of talk about what we should 'do about it'. Have you ever been a part of such a discussion? If yes, can you tell me about it?

[prompts]

Do you see a role for yourself in acting on childhood disability? What might your role be if any?

[if they answered yes and described their role...] can you tell me about a time you acted on this role?

Do you identify key values in your field that seem to indicate what should be done about childhood disability?

If so, do you have a specific example?

4. How do you think your definition of disability influences what you do every day? [prompts]

Can you tell me a bit about what you do every day at work?

Do you think your definition of disability influences your everyday practices at work?

Do you think others in your field share your definition of disability?

Do you feel supported to act within your definition at your current job?

5. I wonder if you have ever experienced tension between the ways that disability is understood – do you have any examples of that?

[prompts]

Have you ever found yourself in a disagreement about how to act on or think about disability?

Some people say there has been a shift in ways of thinking about childhood disability. Do you think things have changed since you have been working? How so?

How has your own understanding of disability evolved throughout your career?

6. When discussing childhood disability in particular, there is often a focus on the future, or what some might call 'outcomes'. What kind of future do you imagine for disabled children?

[prompts]

Do you think your answer aligns with that shared by society generally?

Thinking back to your description of your everyday practices at work, how do you hope to influence disabled children's futures?

If you had the power to change minds about childhood disability, what would you want everyone to know?

Is there anything we have not talked about today that you think we should know about?

Before we wrap up, do you have any questions?

Appendix D: Interview Guide V2

INTERVIEW GUIDE

(Note: Specific probes may change or be added per developing analysis)

Project Title: Reframing childhood disability: Bridging political and disciplinary

boundaries to improve disabled children's lives.

Preliminary comments [including checks for ongoing consent]

I want to start by thanking you very much for agreeing to be part of this study and being willing to speak to your understanding of childhood disability. My name is **[Gail Teachman or Emily Cox]** and my pronouns are [insert interviewer pronouns]. Would you mind briefly introducing yourself and letting me know what pronouns I can use to address you?

I would like to remind you that your name will not be used in any study related reports — we will use pseudonyms/fictitious names when referring to all participants' comments from the interviews and we will remove or change any information that could reveal your identity. For example, removing place names, or the names of other people you mention.

Before we begin, I wanted to share with you some results from our document analysis. [insert brief summary of document analysis results].

Warm-up

As you know, in this study we are interested in understanding conceptualizations of children's disability stemming from both rehabilitation and activism/disability studies spaces. Before we get to that, would you mind telling me about yourself and your role as it relates to childhood disability?

As you might be aware, there are debates about how to talk about disability. Some prefer to use what is called person first language (i.e., "Person with a disability). Others prefer to use what is called identity first language (i.e., "Disabled person"), as they view disability as making up a piece of one's identity. With that said, do you have preferred language that you tend to use? Additionally, if you feel comfortable, would you be able to tell me whether you identify as disabled and/or as a member of a racialized or ethnic group?

Extended warm-up

To get us started, could you please share a bit about yourself and your work in the area of _____.

[prompts]

How did you come to work in this area?

How long have you worked in this area?

Were you always interested in working with children [or studying/teaching/doing research that concerned children and/or disability]?

Do you recall any experiences that might have contributed to your interest in childhood disability?

Are there particular aspects of your work that you find rewarding – or that you feel especially passionate about?

At a broad level, what would you say is the key aim or aims of children's rehabilitation?

I noticed that you have used [person first OR identity first] terminology when talking about disability. As you might be aware, there are debates in this area. What are your views about the different approaches to talking about disability [expand here if needed e.g., "Some prefer to use what is called person first language, "person with a disability". Others prefer to use what is called identity first language, "disabled person", as they view disability as making up a piece of one's identity.]

Would you say that the terminology you tend to use is consistent with the ways disability is talked about in your field? What rationales support these choices, in your view?

Interview Questions

1. To someone who was unaware or unsure, how would you describe disability? [prompts]

Can you tell me about how you came to formulate this definition? Influences? How do you think about disability in relation to non-disability? What about childhood disability? Do you think most people share your definition?

2. When discussing disability, there is often a consideration of what to 'do about it'. In your field, are there some general agreements about how we should act – or what needs to be done – in order to support children and families experiencing disability?

[prompts]

Can you tell me more about your day-to-day in your role?

Before continuing with our interview, we wanted to share with some results from our document analysis. In this phase of the research, we have been looking at texts from both children's rehabilitation and disability studies to begin to examine the different discourses at play regarding childhood disability.

When we have looked at how childhood disability is written about, we are seeing that there is almost always a division drawn between children who are disabled vs. those who are non-disabled and where one of these groups is represented as the 'other'.... Do you think this system of categorization is common in your field or in your daily work?

We are also noticing a focus on children who are able to 'progress' in some regard. In children's rehab, this might look like a child who is able to progress along a developmental path toward young adulthood. Have you noticed this in your practice or research?

Have you ever encountered any of these ideas? Do these results resonate with you?

3. I wonder if you have ever experienced tension between the ways that disability is understood – do you have any examples of that?

[prompts]

Have you ever found yourself in a disagreement about how to act on or think about disability?

Some people say there has been a shift in ways of thinking about childhood disability. Do you think things have changed since you have been working? How so?

4. When discussing childhood disability in particular, there is often a focus on the future, or what some might call 'outcomes'. What kind of future do you imagine for disabled children?

[prompts]

What does an 'outcome' look like in your field of specialization? Have you ever thought about what an 'optimal outcome' might look like for your clients?

Is there anything we have not talked about today that you think we should know about?

Before we wrap up, do you have any questions?

Appendix E: Post-Interview Summary Template

Reframing childhood disability: Bridging political and disciplinary boundaries to improve disabled children's lives.

Participant ID:
Date of interview:
Length of Interview:
Who was present? (Describe in detail):
Observations/First thoughts:
What was not said?
Reflections on the dialogue, shared meanings, initial impressions and
interpretations:
interpretations:
Interpretations: Concerns/ Reflections on Interviewing Process:
Concerns/ Reflections on Interviewing Process:
Concerns/ Reflections on Interviewing Process:

Appendix F: Analytic Guide

<u>Analytic Guide – Reframing Childhood Disability</u>

I.	Citation (source or article title, authors, date, media source or journal):
II.	Topic (in brief):
III.	Type of Media or if paper, describe methodology or type (e.g., systematic review,
	phenomenology, editorial, commentary):
IV.	Field Positioning: children's rehabilitation (CR), disability studies (DS), or 'bridging' (B): * Bearing in mind stated positioning vs that which we perceive through analysis.
	* bearing in mind stated positioning vs that which we perceive through analysis.
V.	Main message:
L	
*Be sur	re to include any specific supporting quotations or texts (in the broad sense including images) with
page nu	umbers or other key to locating the text that support your analysis
1.	
1.	What is assumed by the papers positioning of disability, childhood, and/or childhood disability?
	What is assumed by the papers positioning of disability, childhood, and/or childhood disability? (Key ideas that underlie or inform these conceptualizations)
2.	(Key ideas that underlie or inform these conceptualizations)
2.	(Key ideas that underlie or inform these conceptualizations)
2.	(Key ideas that underlie or inform these conceptualizations) Bringing together 'childhood' and 'disability', how is childhood disability conceptualized in this
2.	(Key ideas that underlie or inform these conceptualizations) Bringing together 'childhood' and 'disability', how is childhood disability conceptualized in this
2.	(Key ideas that underlie or inform these conceptualizations) Bringing together 'childhood' and 'disability', how is childhood disability conceptualized in this text? (Implicit and/or explicit conceptualizations) a. What is the problem? Where is it located? What actions are implied or explicitly
2.	(Key ideas that underlie or inform these conceptualizations) Bringing together 'childhood' and 'disability', how is childhood disability conceptualized in this text? (Implicit and/or explicit conceptualizations)
2.	(Key ideas that underlie or inform these conceptualizations) Bringing together 'childhood' and 'disability', how is childhood disability conceptualized in this text? (Implicit and/or explicit conceptualizations) a. What is the problem? Where is it located? What actions are implied or explicitly
	(Key ideas that underlie or inform these conceptualizations) Bringing together 'childhood' and 'disability', how is childhood disability conceptualized in this text? (Implicit and/or explicit conceptualizations) a. What is the problem? Where is it located? What actions are implied or explicitly suggested to redress the problem?
3.	(Key ideas that underlie or inform these conceptualizations) Bringing together 'childhood' and 'disability', how is childhood disability conceptualized in this text? (Implicit and/or explicit conceptualizations) a. What is the problem? Where is it located? What actions are implied or explicitly suggested to redress the problem?
	(Key ideas that underlie or inform these conceptualizations) Bringing together 'childhood' and 'disability', how is childhood disability conceptualized in this text? (Implicit and/or explicit conceptualizations) a. What is the problem? Where is it located? What actions are implied or explicitly suggested to redress the problem?

a. What children are we talking about here? And who is left out?	
4. Are tensions apparent in/across the text? Are these acknowledged and discussed? What? How?	
5. Does this text's conceptualization (implicitly or explicitly) suppress competing discourses?	
6. What does this text 'do' in relation to conceptions of childhood disability e.g. reproduce,	
contribute, challenge, reformulate to understandings of childhood disability?	
7. Whose perspectives are authorized or represented as legitimate, and which are discounted,	
silenced, or left out? Are there tensions or contradictions?	
8. Any other analytic notes? (Links to other texts sampled?)	
Notes (include additions/changes to this template suggested by your analysis of this text?)	

Curriculum Vitae

Name: Emily Cox

Post-secondary Education and The University of Western Ontario

London, Ontario, Canada

Degrees: 2016-2020 B.A.

The University of Western Ontario

London, Ontario, Canada

2020-2022 M.Sc.

Honors and Awards:

The Western Scholarship of Excellence

2016-2017

Undergraduate Student Research Internship Award (USSRI)

2020

The Western Graduate Research Scholarship

2021-2022

Social Science and Humanities Research Council (SSHRC)

Canada Graduate Scholarship

2021-2022

McGill VOICE Student Stipend Award

2022

Related Work Experience:

Teaching Assistant

The University of Western Ontario

2020-2022

Graduate Research Fellow, Dr. Gail Teachman

2020-2022

Graduate Research Assistant, Dr. Sheila Moodie

2020-2022

Presentations:

Cox, E., & Teachman, G. (2022, May). Toward more affirmative conceptualizations of childhood disability (oral presentation). Presented at the Child Health Symposium, Western University, London, Ontario.