

IN PURSUIT OF INCLUSIVE EARLY LEARNING AND CHILDCARE IN NOVA SCOTIA:
THE INVISIBLE WORK OF MOTHERS OF YOUNG CHILDREN
EXPERIENCING DISABILITY

by

Colleen M. Diggins

Submitted in partial fulfilment of the requirements
for the degree of Master of Science

at

Dalhousie University
Halifax, Nova Scotia
August 2023

Dalhousie University is located in Mi'kma'ki, the
ancestral and unceded territory of the Mi'kmaq.
We are all Treaty people.

© Copyright by Colleen M. Diggins, 2023

DEDICATION PAGE

This thesis is dedicated to the mothers of children experiencing disability in recognition of all the work they do for their children and to my parents, Mona Diggins and the late Earl Diggins, for all the work they have done for me and the love they have given over the years.

TABLE OF CONTENTS

LIST OF TABLES	vi
LIST OF FIGURES	vii
ABSTRACT.....	viii
LIST OF ABBREVIATIONS USED	ix
ACKNOWLEDGEMENTS.....	x
Chapter 1 Introduction	1
1.1 Summary of the Research Problem	1
1.2 Purpose of the Study	3
1.3 Locating the Researcher and the Research	3
1.4 Thesis Overview	8
Chapter 2 Literature Review	9
2.1 Background and Context	9
2.2 Disability.....	10
2.3 Exclusion, Discrimination, Ableism and Disablism.....	11
2.4 Inclusion.....	12
2.5 Early Learning and Childcare in Canada.....	15
2.6 Early Learning and Childcare in Nova Scotia	17
2.6.1 Nova Scotia Canada-Wide Early Learning and Child Care Agreement.....	20
2.7 Some Factors Impacting Access to Inclusive Early Learning and Childcare.....	23
2.7.1 Affordability and Economic Factors.....	23
2.7.2 Paid Labour in the Workforce.....	25
2.7.3 Government and Social Policies	26
2.7.4 Human Resources	27
2.7.5 Specialized Services.....	28
2.7.6 Time	28
2.8 Invisible Work	29
2.9 Summary.....	35
Chapter 3 Methodology.....	37
3.1 Methodological Approach	37

3.1.1 Secondary Analysis.....	37
3.2 Theoretical Perspectives	39
3.2.1 Critical Feminist Theory	39
3.2.2 Occupational Perspective.....	40
3.2.3 Invisible Work as Occupation.....	42
3.2.4 Good Mothering/Bad Mothering Dichotomy	43
3.3 Background: Larger Study.....	46
3.3.1 Participants.....	48
3.4 Data Collection	50
3.5 Data Analysis.....	50
3.5.1 Reflexive Thematic Analysis.....	51
3.6 Quality and Rigour	53
3.7 Ethics and Ethical Considerations	55
Chapter 4 Findings	58
4.1 The Navigator	58
4.2 The Quilter.....	63
4.3 The Fighter.....	68
4.4 The Juggler	72
4.5 The Keeper.....	77
4.6 Sociocultural Factors	84
4.6.1 Childcare Space Availability and Waitlists	84
4.6.2 Affordability of Early Learning and Childcare.....	86
4.6.3 Childcare Location and Transportation	91
4.6.4 Staff Availability, Training, Experience and Continuity	92
4.6.5 Staff to Child Ratios.....	95
4.6.6 Professional Support	96
4.6.7 Employment Support	97
4.6.8 Social Support.....	99
4.6.9 The COVID-19 Pandemic and Public Health Restrictions.....	99
4.6.10 Inclusion, Exclusion, Discrimination and Ableism	100
Chapter 5 Discussion.....	107
5.1 Mothers and Invisible Work	107

5.2 Influence of the “Good Mother”	111
5.3 Influence of Ableism and Disablism	115
5.4 Research Significance and Implications	122
5.4.1 Implications for Occupational Science	122
5.4.2 Implications for Policy.....	127
5.4.3 Implications for Occupational Therapy and other Health Professionals ..	132
5.5 Study Strengths.....	133
5.6 Limitations.....	134
5.7 Future Directions	136
Chapter 6 Conclusion.....	137
6.1 Reflections	137
6.2 Conclusion.....	140
Bibliography	143
Appendix A Dalhousie University Research Board Ethics (REB) Approval Letter	157
Appendix B Interview Guide with Demographic Questions for Parents	158
Appendix C Demographic Information of the Participant Sample of Mothers.....	165
Appendix D Thematic Mapping Example	167
Appendix E Visual Mapping Example of Mother’s Childcare Journey.....	168
Appendix F Eight “Big-Tent” Criteria for Excellent Qualitative Research.....	169
Appendix G 15-Point Checklist for Good Reflexive Thematic Analysis.....	170

LIST OF TABLES

Table C1	Demographic Information of the Participant Sample of Mothers.....	165
Table F2	Eight “Big-Tent” Criteria for Excellent Qualitative Research..... -adapted from Tracy (2010).	169
Table G3	Braun and Clarke’s 15-Point Checklist for Good Reflexive TA..... –version 2022 adapted from Braun and Clarke (2022, p. 269).	170

LIST OF FIGURES

Figure D1	Initial thematic map of patterns across this study’s dataset based.....167 on Braun and Clarke (2022).
Figure D2	Initial thematic map for the theme of ‘the Fighter’ based on.....167 Braun and Clarke. (2022)
Figure E3	Visual Map Example of Kiana’s Childcare Journey.....168

ABSTRACT

Mothers of children experiencing disability do invisible work to access inclusive early learning and childcare. This extensive work is not paid or valued, but crucial for children to attend inclusive early learning and childcare settings and to keep family life running. **Purpose:** This research aims to illuminate the invisible work mothers of pre-school aged children experiencing disability do in pursuit of inclusive early learning and childcare in Nova Scotia, and to understand how sociocultural factors may shape this invisible work. **Method:** Using an occupational perspective, drawing on theoretical constructs of invisible work and the good mother, this interpretive secondary analysis explored the questions: 1/ What kinds of invisible work do mothers of children who experience disability do in pursuit of inclusive early learning and childcare in Nova Scotia? and 2/ How do sociocultural factors shape the invisible work mothers of children who experience disability do in Nova Scotia? Semi-structured interviews of 16 Nova Scotian mothers pursuing inclusive early learning and childcare for their children experiencing disability were analyzed using Braun and Clarke's (2022) method of thematic analysis. **Results:** Data analysis resulted in the development of five themes: 1/ the Navigator, 2/ the Quilter, 3/ the Fighter, 4/ the Juggler, and 5/ the Keeper. Sociocultural barriers and facilitators that shaped the invisible work mothers engaged in to access inclusive early learning and childcare were identified. They included: childcare space availability and waitlists, affordability of early learning and childcare, childcare location and transportation, staff availability, training, experience and continuity, ratios of teachers to children, professional support, employment support, social support, the Covid-19 pandemic and public health restrictions, and inclusion, exclusion, discrimination and ableism. Sociocultural factors were examined for how they influenced this gendered, invisible work. Two key influences that shaped the mothers' invisible work, and the occupational roles demanded of them, were the 'good mother' ideology and systemic ableism. Mothers in this study attempted to adhere to the 'good mother' discourse but were often at odds with being a good mother in their work to access inclusive early learning and childcare. A societal misunderstanding of inclusion and discrimination rooted in ableism also presented a pervasive barrier. **Conclusion:** Mothers do an enormous amount of invisible work to access inclusive early learning and childcare for their children experiencing disability. To mitigate this work, a fundamental, and perhaps radical, system change for early learning and childcare is needed to make it inclusive and easily accessible for all. As universal childcare is being implemented provincially and nationally, the findings from this study have the potential to inform emerging policies and the development of an inclusion framework for the early learning and childcare sector in order to enact system change.

Keywords: Invisible work, mothers, disability, childcare, early learning, inclusion, reflexive thematic analysis, qualitative

LIST OF ABBREVIATIONS USED

CanMOP	Canadian Model of Occupational Participation
CCDI	Canadian Centre for Diversity and Inclusion
CRRU	Childcare Resource and Research Unit
CSAP	Conseil Scolaire Acadien Provincial
DEC	Division for Early Childhood
EECD	Department of Education and Early Childhood Development
ECE	Early Childhood Educator
EIBI	Early Intensive Behavioural Intervention
ELCC	Early Learning and Childcare
G-tube	Gastrostomy tube
HRM	Halifax Regional Municipality
HRCE	Halifax Regional Centre for Education
ISG	Inclusion Support Grant
MLA	Member of the Legislative Assembly
NAEYC	National Association for the Education of Young Children
NSECDIS	Nova Scotia Early Childhood Development Intervention Services
QIG	Quality Investment Grant
RCEs	Regional Centres for Education
REB	Dalhousie University Research Ethics Board
RTA	Reflexive Thematic Analysis
SCCG	Supported Child Care Grant
SLP	Speech Language Pathology
UN	United Nations
UNICEF	United Nations International Children's Emergency Fund
WHO	World Health Organization

ACKNOWLEDGEMENTS

I would like to express my gratitude and appreciation to my thesis supervisor Dr. Shanon Phelan for her mentorship and ongoing feedback in this Masters journey. She fostered my ability to think deeply about my research and evolve my thoughts on inclusion, invisible work, disability, and ableism. Her passion for the topic of inclusion has inspired me to continue studies in this area and continue to advance my skills in qualitative research. I would also like to thank the members of my supervisory committee, Dr. Brenda Beagan and Dr. Sarah Moore. I appreciate Dr. Beagan's guidance and always thoughtful comments for this thesis, as well as twenty years ago when I was an occupational therapy student. Her dedication to occupation is steadfast. I would like to thank Dr. Moore for her insights and evident dedication for helping children experiencing disability. I also acknowledge funding support from the Social Sciences and Humanities Research Council of Canada, Employment and Social Development Canada, Canadian Occupational Therapy Foundation and Dalhousie School of Occupational Therapy.

I graciously acknowledge the mothers interviewed for this study and the tremendous work they do everyday for their children and families. They are awe-inspiring and have valuable stories to tell and learn from. I would like to thank my family for their love and support during my Masters program and completing this thesis. Without them, I could not have accomplished this or so many other things. To my husband, Mark, thank you for helping to shoulder the work of our lives together these past two years. To my son Cameron, thank you for understanding my goal to complete this thesis. Being your mother is my most important role. To my mother, Mona, thank you for instilling a love for pursuing ongoing education, and to my late father, Earl, thank you for always believing in me. Lastly, thank you to my dog, Cabot, who kept my feet warm many nights while writing this thesis.

1.1 Summary of the Research Problem

Families of children experiencing disability¹ pursue inclusive childcare and early education opportunities because there is a strong link between high-quality inclusive early learning and childcare and better health and developmental outcomes (Barton & Smith, 2015; Odom et al., 2011). The United Nations Conventions on the Rights of the Child (UN, 1989) and the Rights of Persons with Disabilities (UN, 2007) advocate for children's rights to inclusive play and education. Being denied access to inclusive early learning or childcare not only violates children's Human Rights, but it can also negatively affect the social, behavioural, cognitive, and physical development of children experiencing disability (Irwin & Lero, 2021).

Over my occupational therapy career, families have described many contextual barriers to inclusion in early learning and childcare that impact the child's occupational engagement and their therapy. For decades, families of children experiencing disability have faced inequitable access to inclusive early learning and childcare due to financial, political, social, cultural, and discriminatory barriers (Eilers, 2020; van Rhijn et al., 2021). Children experiencing disability often experience exclusion by frequently being denied opportunities to engage in occupations, such as play and learning, in early learning and childcare settings, at home, and within the larger community context (Benjamin-Thomas et al., 2021). To date, children experiencing disability

¹ I intentionally use the terminology 'children experiencing disability' to bring attention to the ways disability is shaped by inaccessible and exclusionary spaces, medicalization, systemic constraints, discriminatory policies, and ableist attitudes. In this way, disability is a social, cultural, and relational experience rather than a diagnosis manifested within the individual (Brett, 2002; Oliver & Barnes, 2012, Phelan & Reeves, 2022). Peers and her colleagues (2014) stated "the phrase *person who experiences disability* is designed to acknowledge the wide variety of embodied sensations, social structures, cultural understandings, and identities that may be related to someone's disability experience" (p. 275).

can be, and often are, turned away from childcare and early education sites in Nova Scotia due to lack of policy, resources, funding, and/or discriminatory practices (Irwin & Lero, 2021; Phelan et al., 2022). The province of Nova Scotia has yet to mandate an inclusion policy for early learning and childcare settings. This has resulted in a theory to practice gap as it relates to conceptualizations of inclusion and how inclusion is enacted (Phelan & Reeves, 2022). This gap significantly impacts the occupational engagement of children and families; children experiencing disability have limited opportunities to engage in childhood occupations with their peers. Therefore, families, particularly mothers, are taking on invisible work in order to create such opportunities for their children.

Mothers are far more likely than fathers to be directly involved in maintaining routines and facilitating activities for their children (Green, 2007). Finding and securing early learning and childcare in Nova Scotia has long been the responsibility of individual families, typically mothers (Odom et al., 2011). Regarding childcare, it is typically mothers who are responsible for problem-solving challenges, designing the plan, and adapting “best-laid” plans (Breitkreuz et al., 2021), in what can be considered invisible work, meaning women’s unpaid work which is “physically out of sight, ignored or overlooked, socially marginalized, economically and/or culturally devalued...or some combination thereof” (Hatton, 2017, p. 337). Mothers of young children experiencing disability do a significant amount of invisible work advocating for their children, attempting to find, access and maintain fully inclusive childcare, and applying for funding for various supports, even more so than mothers with typically developing children (Grace et al., 2008). Understanding invisible work, and the conditions that necessitate it for mothers in pursuit of inclusive early learning and childcare for their children experiencing disability is necessary if we are to reimagine access and inclusion in ways that support families.

1.2 Purpose of the Study

The purpose of this research study was two-fold:

- 1) to identify the invisible work that mothers of young children experiencing disability do in pursuit of inclusive early learning and childcare, and
- 2) to explore how contextual factors create the conditions that necessitate this invisible work.

This research is timely considering Canada's commitment to creating an inclusive, barrier free-society (Accessible Canada Act, 2019) and recent provincial and federal universal childcare policies coming into effect (EECD, 2022b). Consideration of the knowledge and viewpoints held by families with children experiencing disability is critical to inform an inclusive, universal national childcare system designed for all children and their families (van Rhijn et al., 2021).

1.3 Locating the Researcher and the Research

Reflexivity is an essential ongoing process in qualitative research. It involves the researcher critically reflecting on their role as the researcher as well as how knowledge is generated and constructed through the research process (Braun and Clarke, 2022; Guillemin & Gillam, 2004). From a critical perspective, reflexivity tasks the researcher to examine current ideologies and to enact and champion change (Phelan, 2011). To be reflexive, it is important to acknowledge my positionality forms my world views, values, and beliefs as a researcher, and will also influence the entire research process. Darwin Holmes (2020) stated positionality "acknowledges and recognizes that researchers are part of the social world they are researching, and that this world has already been interpreted by existing social actors" (p. 3). Using Savin-Baden and Major's (2013, as cited in Holmes, 2020) three ways to identify and develop positionality, I locate myself about the subject, the participants, and the process and context.

As an “existing social actor” (Darwin Holmes, 2020, p. 3), I am a white, married, heterosexual, educated, middle-class, seventh generation Canadian and Nova Scotian. I come from a largely Irish and German background and was a practicing Catholic until the last decade. I identify as a female, mother, wife, daughter, occupational therapist, and scholar. I am a mother to an elementary school-aged son who does not experience disability. He attended daycare and later pre-school, both of which were labelled as inclusive. Through my work as an occupational therapist in pediatrics and my volunteer work as a co-chair of the Student Advisory Council at my son’s school, I recognize the difficulty families in Nova Scotia have had for many years when trying to access childcare and I bring that lens to this research. I have spoken to families, both with and without children experiencing disability, who have been denied childcare on multiple occasions or have not been able to afford it. I have taken part in conversations and witnessed these families’ stress regarding how to ensure their child’s safety, social development, and well-being while they attempted to work and make money for their family.

I personally spent time performing invisible work so my son could attend a daycare and pre-school of our choice. I put him on childcare waitlists prior to his birth. I valued choice as a mother, and I acknowledge that I am privileged to have made this choice based on my experience of working with children and networking with those knowledgeable in the childcare field. The work of getting my son on waitlists and calling periodically to see where he was on the waitlist took effort and work, as did researching centres that had programs in line with our family values and had good reviews. I have reflected on that process as I wrote this thesis and initially felt I needed to be conscious that it did not overly influence my view of accessing childcare. However, upon being more reflexive, I recognized my post positivist tendencies, in assuming that bias does not have a place in this qualitative research as is the expectation in quantitative

research. Therefore, rather than making false attempts to rid myself of bias, or have no affect on the research, I locate myself about the research and attempt to understand what influence I may have on the research process, and in what ways my experiences may offer unique insight into the understanding of mothers' stories in this research.

As a practicing occupational therapist in pediatrics for eight years before I had my son, I had the privilege to form an opinion of what I wanted in a childcare setting. I knew the questions to ask to help me determine if a setting was acceptable to our family, I knew what inclusion could be and that it takes many forms. I knew how to advocate for what I wanted and was able to avail of my first choice in an inclusive daycare. I did not have to piece childcare together like many mothers, but it did take invisible work. When mothers in this study spoke of settings where they would never send their child because it was dirty, had too many children, was physically not accessible, or children weren't being engaged, I could picture childcare settings with all of these scenarios from my own experiences. From my perspective, I would agree with them but could also empathize with their need for childcare to be able to return to work. It is a tough decision.

To further understand my position in this research, I had to be reflexive about my own childhood experiences and how I was parented. My parents were older when I was born and parented in what may now be considered a very traditional way in a nuclear, Catholic family. My father was born in 1922 to a "very" Catholic family and had a very traditional view of husband and wife roles, particularly that mothers cared for the home and children. Those views are not my views and I watched him evolve his thinking about gender roles with age. However, as a Canadian fighting in World War II where men volunteered to fight for their country and women most often stayed home to look after children and the home, I recognize he was a product of his society. As a person who greatly looked up to my father it was difficult as a child to not

believe his beliefs particularly around traditional gender roles and nuclear families. These views were also impressed upon me every Saturday evening at Catholic Mass. Later on, I could confront my father in a witty manner but still convey my evolving thoughts on gender roles to him. I personally did not attend early childcare as a child but do have some memories of friends going to Busy Bee Nursery School two days a week and wondering why I could not go. My mother, a Registered Nurse and Director of Nursing, left her well-paying career, in which she made more income than my father, to parent me full time. She was forty years old when she became pregnant and was told by her physician it was best to abort the pregnancy, meaning me, to avoid having a child with Down Syndrome. She told me she never considered that suggestion and did not tell my father. This shaped my view of disability, and although it is demonstrative of how society has viewed disability and impairments, it was more influential for me that my mother rejected this view. As my father worked “on the road” as a salesman from Monday to Friday, my mother was my primary parental caregiver. My recollection is that she welcomed this stay-at-home experience and will still say she values her choice to stay at home. I, however, reflect on my experience differently as I am a full-time working mom who paid for childcare; at times I felt guilty for having my son in childcare while I was working with other children. I know my mother never felt guilt for choosing to stay home with me. Knowing guilt might come up in these interviews, I also knew I would be compassionate toward these mothers. I do value that my son made friends in childcare that he continues to play with today, and in some cases our families have also become friends. I do value these socialization opportunities and experiences. I value that my mother would have raised and loved me whether I had Down Syndrome or not.

To locate myself amongst the participants and about the research context and process, I have lived and worked in various parts of Nova Scotia, the province where the research is

situated, for my entire life and am proud of this. It is important to me to focus on Nova Scotian mothers as I feel invested in this province and its citizens. I have worked as an occupational therapist with school-aged children experiencing disability, their families, teachers, and other school staff for over 20 years. I have largely worked in the Halifax Regional Municipality but have also worked with children in the Valley and South Shore areas and to a lesser degree in the entire province when I was employed as an occupational therapist specializing in Alternative and Augmentative Communication in a tertiary role. Therefore, I feel I have some perspective on rural and urban childcare experiences. I have worked with young children experiencing disability and their families in various settings, including in childcare environments, and these experiences informed the lens I used in this research. I have been privileged to have had many experiences shared with me from families with children experiencing disability. I have seen a spectrum of parenting styles and abilities to advocate.

I acknowledge I have become critical of the discourses in government programs for children experiencing disability and their families and am becoming increasingly aware of ableism. I also acknowledge that I often work with educators who say they are providing inclusive care, but when considering the definition of inclusion and the various sociocultural and socio-political factors they are not. This is often frustrating, and these experiences and frustrations will likely affect my perceptions of how inclusion is implemented in relation to what the participants say. As I have experienced working in a variety of childcare settings with children experiencing disability in my career, I have witnessed many ways in which inclusion has been enacted. These experiences informed my thoughts and opinions of how inclusion could be and should be enacted but is usually not. I observed childcare centres that were enacting many aspects of inclusion in a way in which children were able to participate in activities together

which I considered more desirable and beneficial for all children. I also witnessed children in some settings that were often segregated from peers or were said to be included when they were physically placed in a room with peers, but no meaningful participation was occurring. I do not recall ever meeting a childcare worker that did not want to practice in an inclusive manner, but these workers ranged in how they thought about and defined inclusion and definitely in how they enacted inclusion. I also recognize I have great empathy for children experiencing disability and their families, as over the years I have observed and heard about many families' experiences, both positive and those that were unjust. This undoubtedly influenced how I analyzed and interpreted the data as I am sensitized to these stories. I see this as a strength that I brought to this work. This sensitivity also served as a motivator for me to make sure I represented these mothers' lived experiences.

1.4 Thesis Overview

This thesis is comprised of six chapters. Chapter One includes an introduction to this thesis topic and a reflexive account of how the researcher and the research is positioned. Chapter Two offers an extensive review of the literature relevant to this thesis and frames the theoretical approaches of this study. Chapter Three details the methodology and methods used. Chapter Four contains the study's finding. Chapter Five offers a discussion and potential implications as well as strengths, limitations and future directions of this study. Chapter Six offers reflections and the study's conclusion.

Chapter 2 Literature Review

2.1 Background and Context

Over 1 billion people (WHO, 2021) and more than 240 million children globally, aged infant to 17 years, experience disability (UNICEF, 2021). That translates to a rate of one in ten children experiencing a disability worldwide (UNICEF, 2021). These numbers continue to increase globally (Halfon et al., 2012). Older data indicated more than 200,000 Canadian children, aged infant–14 years, experienced disability, and this number was increasing (Statistics Canada, 2007). Nova Scotia has the highest rate of disability in Canada; 30% of Nova Scotians aged 15 years and older have at least one disability diagnosis compared to the national average of 22.3% (Statistics Canada, 2018). In Nova Scotia, there is little data for young children experiencing disability and their families (Department of Pediatrics and Healthy Populations Institute, 2022; Friendly et al., 2020) and current information on children under 15 years of age is not available (Statistics Canada, 2018). What little is known suggests that Nova Scotia's number of children experiencing disability is proportionately higher than the national average and the province has the highest percentage of people experiencing disability of all ages when compared to all other provinces (Statistics Canada, 2018). Among Nova Scotians between the ages of 15 and 24 years, 21% experience disability (Statistics Canada, 2018). As the global and national numbers of children experiencing disability is increasing (Halfon et al., 2012; Statistics Canada, 2007), one may consider that the number of children experiencing disability in Nova Scotia is on an increasing trajectory too. Thus, a deeper understanding of disability, as a social, cultural, relational, and political experience, is a pressing issue provincially, nationally, and globally. This is reflected in both Canada's commitment (Accessible Canada Act, 2019) and

Nova Scotia's commitment (Accessibility Act, 2017) to creating an inclusive, barrier-free society.

2.2 Disability

Disability is both diverse and complex and definitions continue to evolve with much scholarly debate (Halfon et al., 2012). Disability has commonly been understood as something to be avoided, even feared, and therefore intervention prioritizes normalization or normalcy (Phelan, 2011). Dominant disability narratives describe children experiencing disability as 'atypically developing' (Asbjørnslett et al., 2015), 'having special health care needs' (Munambah et al., 2020), and 'having special needs' (Case-Smith & O'Brien, 2015), descriptors that all serve to medicalize the disability experience and have othering effects (Reeves et al., 2020). The medical model of disability has largely located disability within the person and focuses on finding a cure for deficits (Oliver & Barnes, 2012). Some definitions attend to sociocultural aspects but still medicalize or allude to the medicalization of disability. The World Health Organization (WHO) defines disability as the interaction between a person with a *health condition* and personal and environmental factors (WHO, 2021). Disability scholars have disrupted the individualistic focus on deficits to acknowledge different capacities of individuals and locate disability in environments that are exclusionary and not designed for the participation of everyone (Goodley & Runswick-Cole, 2010; Hughes & Paterson, 1997, Oliver & Barnes, 2012). This involves an interaction between the individual and aspects of their environment such as available resources, social support, and surrounding attitudes (Race et al., 2005). Critical disability theories acknowledge that medical and disease characteristics only contribute partially to disability as an experience entangled with multiple forms of oppression and discrimination (Goodley, 2013; Phelan, 2011). Phelan and Reeves (2022) noted "disability is culturally

constructed through inaccessible spaces, medicalization, systemic constraints, discriminatory policies, stigma, and ableist attitudes. The effects of deficit-oriented discourses *disable* children and their childhoods, limiting full participation and inclusion in cultural life” (p. 77). For this thesis, I understand disability as a socially, culturally, relationally, and politically constructed process involving an interaction between the person and their environment (Oliver & Barnes, 2012). Disability and health are not one and the same; while an individual experiencing disability may have a health issue, disability itself is a social and relational experience and not a health condition (Brett, 2002; Goodley, 2013; Oliver & Barnes, 2012). In this thesis, I gave consideration to the ways in which the sociocultural and sociopolitical context disables children and their families.

2.3 Exclusion, Discrimination, Ableism and Disablism

People experiencing disability in the Western world, including children and their families, have been historically excluded and marginalized (Oliver & Barnes, 2012). Discrimination from society on the basis of disability has presented great barriers to inclusion and social participation (Hughes & Paterson, 1997). Discrimination on the basis of disability is defined by the Convention on the Rights of Persons with Disabilities (UN, 2007, article 2) to mean “any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation”. Practices of exclusion are rooted in ableism (Goodwin & Ebert, 2018), considered “the contemporary ideals on which the able, autonomous, productive citizen is modelled” (Goodley, 2014 as cited in Tyler, 2015, p. 660). Families of children experiencing

disability often face judgment by others rooted in ableist societal beliefs about their child's impairment and what their child can or cannot do (Goodwin & Ebert, 2018). Disablism, defined as "the social, political, cultural and psycho-emotional exclusion of people with physical, sensory and/or cognitive impairments" (Goodley, 2014 as cited in Tyler, 2015, p. 659-660), is the direct effect of ableism.

2.4 Inclusion

Inclusion is considered best practice for all children (Barton & Smith, 2015; Irwin & Lero, 2021) and the inclusion of children experiencing disability in education, including early learning, is becoming a priority across the globe (Dalkilic & Vadeboncoeur, 2016). This is supported by the United Nations Conventions on the Rights of the Child (UN, 1989) and the Rights of Persons with Disabilities (UN, 2007) commitments to all children having a fundamental right to engage fully in childhood occupations, such as inclusive play and learning in their daily settings. Like the language around disability, inclusion also has different scholarly meanings. The Canadian Centre for Diversity and Inclusion (CCDI) states that inclusion "is about creating a culture that strives for equity and embraces, respects, accepts and values difference" (2022, para. 4). According to the National Association for the Education of Young Children (NAEYC) and the Division for Early Childhood (DEC) in the United States, inclusion in early learning and childcare refers to "values, policies, and practices that support the right of every infant and young child and his or her family, regardless of ability, to participate in a broad range of activities and contexts as full members of families, communities, and society" (NAEYC-DEC, 2009, p. 2) including childcare environments. A more robust definition situated in Canadian literature states that inclusion "means that individual children are involved in activities and social structures in a way that is meaningful to their own unique experience. It

means that they truly belong, have community, and are equal participants in that community” (Hanvey, 2002).

Inclusion is valued; important goals of early learning and childcare include social inclusion, parental employment, and positive outcomes for all children in behavioural, cognitive, social, and physical development (Irwin & Lero, 2021). Many parents with children experiencing disability want them to be in inclusive settings (Barton & Smith, 2015; Odom et al., 2011): “factors that influenced families’ decisions about childcare for their children experiencing disability mirror those factors that support inclusion” (Weglarz-Ward & Santos, 2018, p. 140). Families of children experiencing disability pursue inclusive early learning and childcare opportunities because of the strong link between high-quality inclusive early learning and childcare and family well-being and better health and developmental outcomes (Barton & Smith, 2015; Odom et al., 2011). It has been reported that children experiencing disability significantly benefit from better cognitive and social outcomes when they attend quality inclusive programs with peers, appropriate resources, and supports as opposed to children experiencing disability who do not attend inclusive programs (Halfon & Friendly, 2013; Odom et al., 2011). Inclusion in early learning and childcare benefits more than children experiencing disability and their families, it benefits communities and society as a whole. For example, by including children in early learning and childcare and supporting their families, issues such as poverty and unemployment can be positively affected (Halfon & Friendly, 2013).

Although inclusion is best practice, it is often not practiced or accessible (Barton & Smith, 2015; Irwin & Lero, 2021). Historically, there has been inequitable access to inclusive early learning and childcare across Canada, including in Nova Scotia, for all children including those experiencing disability due to financial, political, social, cultural, and discriminatory barriers

(Eilers, 2020; Irwin & Lero 2021). Inclusion is also still not mandated in early learning and childcare in Canada (van Rhijn et al., 2021). Despite the well-documented positive relationship between child development and inclusive childcare (Barton & Smith, 2015), a vital gap occurs between how inclusion is theorized and how it is implemented and experienced (Odom et al., 2011; Phelan & Reeves, 2022). Hanvey (2002) discussed that actual inclusion does not put the onus on a child, instead it tasks society to provide a meaningful context for all. Inclusion is about the collective, it is about putting the responsibility on society to create a culture of inclusion and not individuals (CCDI, 2022; Hanvey, 2002). Odom and colleagues (2011) discussed that a slow shift in thinking regarding inclusion is starting to examine how larger social, physical, cultural, academic, community, and societal systems affect the inclusion of children experiencing disability and how they belong. Despite this shift, this knowledge is still not often translated to action (Whitley & Hollweck, 2020).

Implementing high quality inclusion in early learning and childcare is necessary, but it is not easy and is often illusive (Barton & Smith, 2015). Inclusion is often erroneously synonymous only with the physical placement of children experiencing disability in the same setting as children not experiencing disability (Odom et al., 2011). Inclusion is more than this, it is the development and valuing of a child's identity within their community that has social, cultural, and spiritual contexts (Frankel et al., 2019). Even if a setting is labelled as inclusive it does not mean children experiencing disability feel included or that the setting is aware of the children's felt experiences or feelings of exclusion (Reeves et al., 2020). Despite a child's right to inclusion, children experiencing disability often experience exclusion by frequently being denied services (Halfon & Friendly, 2013) and opportunities to engage in the occupation of play in school or childcare, home, and larger community contexts (Benjamin-Thomas et al., 2021). Children can be excluded from childcare due to inadequate

human, professional, and financial resources (Irwin & Lero, 2021; Killoran et al., 2007). Thus, systemic discriminatory practices are at play in early learning and childcare settings (van Rhijn et al., 2021).

Families have important voices and insights to share related to inclusive early learning and childcare; this is also their Right as advocated for by the United Nations Conventions on the Rights of the Child (UN, 1989) and Rights of Persons with Disabilities (UN, 2007). Consideration of the knowledge and viewpoints held by families with children experiencing disability is critical to inform an inclusive, universal national childcare system designed for all children and their families (van Rhijn et al., 2021).

2.5 Early Learning and Childcare in Canada

The Canadian early learning and childcare system has been based largely on a market model with a patchwork of not-for-profit and profitable services, high fees, and varying degrees of access to childcare dependent on geographic location among other things (Prentice & White, 2020). The number of childcare spaces does not meet the demand in Canada, and this gap between demand and supply continues to expand (MacDonald, 2018). Approximately one in five young children had a regulated childcare space in most provinces in 2018 (Friendly et al., 2018). In 2022, the Survey on Early Learning and Child Care Arrangements depicted that slightly more than half (52%) of Canadian children younger than six years were in licensed or unlicensed childcare in early 2022. Data for this survey was collected only in provinces and not in the Canadian territories (Statistics Canada, 2022b). Approximately two in five parents who were using childcare in early 2022 reported having had difficulty finding childcare, which was a similar rate to late 2020 (Statistics Canada, 2022b). Other research indicated almost one-third of Canadian parents live in what has been labelled a “childcare

desert”. This term refers to communities where there are more than 50 young children with less than one childcare space for every three children of that same age (MacDonald, 2018; Young et al., 2020).

A fundamental right for all children is to fully engage in inclusive play and learning in their daily settings, as advocated for by the United Nations Conventions on the Rights of the Child (UN, 1989) and Rights of Persons with Disabilities (UN, 2007). Canada has signed both Conventions thus agreeing to their contents, including the right to inclusion and the right to access service free from discrimination. For Canadian children experiencing disability and their families, inclusion and access to supports, services, and opportunities to fully participate in everyday activities, have been identified as ongoing critical gaps across Canada (Clark et. al, 2009). Barriers within and between systems when implementing inclusion include poor understanding of what inclusion really is, lack of evaluation of inclusive programs, and not acknowledging issues within current settings such as a lack of staff training or physical inaccessibility (Irwin & Lero, 2021). A recent study by Irwin and Lero (2021) evaluated program quality and inclusion quality in a sample of inclusive early learning and childcare programs across five provinces: British Columbia, Manitoba, Ontario, New Brunswick, and Nova Scotia. Nova Scotia was an exception and had a significantly lower SpecialLink Early Childhood Inclusion Quality Scale score² (Irwin, 2009) compared to the other provinces in the study, which all yielded much more favourable results (Irwin & Lero, 2021).

For more than fifty years, a goal of the Government of Canada has been to create universal, affordable, and inclusive childcare (Prentice & White, 2020). However, there was little success reaching this goal until recently. Lack of success of this endeavour has often been attributed to a

² The SpecialLink Early Childhood Inclusion Quality Scale (SECIQS) (Irwin, 2009) consists of two subscales designed to assess inclusion quality. The Inclusion Principles subscale assesses the degree to which a childcare centre has committed to inclusion in practice and policy. The Inclusion Practices subscale assesses the quality of resources, environment and practices used to support inclusion in particular childcare rooms. The SECIQS is available from www.speciallinkcanada.org along with a video, training manual, and scoring sheets.

disconnected system in which the federal government controls various social programs across Canada but the provincial and territorial governments are responsible for the actual implementation of these programs (Prentice & White, 2020). Recently the Government of Canada committed to improving equitable access to childcare and early learning by implementing a national universal childcare policy in which daycare spots would be created for ten dollars per day (Trudeau, 2020). However, a plan has not been well articulated and little attention has been given to coordinating other systems that affect early childhood services when planning a national universal childcare program inclusive of children experiencing disability (van Rhijn et al., 2021).

2.6 Early Learning and Childcare in Nova Scotia

In Nova Scotia, as in most other Canadian provinces and territories, there are several forms of childcare options including licensed childcare centres or daycares, licensed and unlicensed family dayhomes, Pre-primary Programs³, and non-regulated childcare providers. In Nova Scotia, the Early Years Branch at the provincial government's Department of Education and Early Childhood Development (EECD) is responsible for licensing and monitoring childcare centers and Pre-primary and grade primary programs as well as administering childcare subsidies (CRRU, 2016). Last reported in 2021, there were 334 licensed childcare centers and 14 licensed Family Home Child Care Agencies in Nova Scotia (EECD, 2021). In September 2017, the province began rolling out a free, universal Pre-primary Program for four-year-old children. It was fully implemented across Nova Scotia in September of the 2020-2021 school year. Pre-primary is available to all 4-year-old children in their catchment areas, but it is not a mandatory program (CRRU, 2016); parents can still choose to enroll their children in other programs or keep them home. The Pre-primary program is stated to be an inclusive program

³ The Pre-primary Program is a free program provided by Nova Scotia's Department of Education and Early Childhood Development for four-year-olds (and some three-year-olds) in the province. It is a child-centered, play based program for children the year before they start school. Its' purpose is to help these children transition into the school system and provide experiences that give children the best start to succeed in school and life.

(EECD, 2023). In 2021, the Report of the Auditor General to the Nova Scotia House of Assembly released a performance report on the Planning and Implementation of the Pre-primary Program. Findings of the audit included that the initial implementation of the Pre-primary Program was not adequately planned, and they made nine recommendations to improve the functioning of the program and to develop an evaluation measure to determine the program's outcomes with four-year-old children. However, the audit did not mention children experiencing disability or inclusion. The province also rolled out a three-year-old Early Learning Program in select schools in the fall of 2022. Priority access to this program is given to three-year-old children whose families identify as members of equity seeking groups and/or from vulnerable families (EECD, 2023; Government of Canada, 2022).

Two potential facilitators of inclusion in Nova Scotia for young children in early learning and childcare may be the Act Respecting Accessibility in Nova Scotia and the Inclusion Support Grant (ISG). The Early Years Branch offers the ISG which can be considered a contextual facilitator for inclusion and occupational participation as its intention is to facilitate the participation of all children in their community (Nova Scotia Government, n.d.). The goal of the ISG is to assist all regulated childcare centres in creating and sustaining inclusive programs for young children focusing on diversity, equity, and quality (Nova Scotia Government, n.d.). Funding is given to licensed childcare centres “in their commitment to build capacity to provide inclusive programming for children with complex needs and from diverse cultural backgrounds” (Government of Canada, 2022, para. Annex 2). Another Government of Canada (2023, Priority 3) source stated that the ISG is provided to “regulated child care centres to provide inclusive programming for children with complex needs. Funding supports centre investments in the acquisition of resources and additional staffing to support developmental, social, and physical inclusion for children who require specialized supports”. Funding is not designated for specific children (Nova Scotia Government, n.d.). ISG funding can be used for

specialized training and professional development for Early Childhood Educators (ECEs), additional staff to enhance ratios for the delivery of a facility's inclusive program, and to purchase education and resource materials directly related to inclusive programs (Nova Scotia Government, n.d.). Data from 2019 indicated 254 childcare centres in Nova Scotia were receiving the ISG (Friendly et al., 2020). The ISG replaced the Supported Child Care Grant (SCCG) in 2018 which is noteworthy as data from 2016 indicates that 226 centres were in receipt of the SCCG, and these centres reported that in total there were 883 children with special needs (Friendly et al., 2018). These centres included children from infant age to twelve years old but may give a slight glimpse into the number of children experiencing disability in childcare that year.

Finding and securing inclusive early learning and childcare in Nova Scotia has long been an individual family's responsibility. Alarming, children experiencing disability in Nova Scotia are often denied entry to childcare due to their needs and abilities, and even if they are accepted, they may not be included (Irwin & Lero, 2021). They often experience exclusion by being denied opportunities to engage in occupations such as play in childcare or in childcare itself (Benjamin-Thomas et al., 2021). This is in violation of their Rights (U.N. 1989, 2007). In the Nova Scotia Licensee's Manual for Regulated Child Care Settings, inclusion is rarely mentioned but it does state that "[i]nclusion supports the right of all children, regardless of their diverse abilities, to participate actively in natural settings within their communities. A natural setting is one in which the child would spend time if he or she did not have a disability (NAEYC/DEC, 2009)" (Government of N.S., 2021, p. F2). By referring to this inclusion only briefly but not offering strategies on how to support inclusion, the Nova Scotia government is failing children, families, and early educators.

2.6.1 Nova Scotia Canada-Wide Early Learning and Child Care Agreement

In July 2021 the Government of Canada and the Province of Nova Scotia jointly signed the Nova Scotia Canada-Wide Early Learning and Child Care Agreement signalling the start of a shift in Nova Scotia's Early Learning and Child Care (ELCC) environment (EECD, 2021) and indicating early learning and childcare are priorities in Canada and Nova Scotia. Via this Agreement, Nova Scotia will receive \$604.9 million in funding from the federal government and will also invest \$40 million from the years 2021-2022 to 2025-2026. At the start of the 2023 fiscal year, Nova Scotia released their Agreement Accountability Action Plan for universal childcare. The plan included future tracking of the number of children under the age of six who experience disability, the number of children needing enhanced or individual supports that are in regulated Early Learning and Childcare spaces, and the number or proportion of childcare service providers who provide services that are adapted to the needs of children experiencing disability and children needing enhanced or individual supports (Government of Canada, 2022, sect. 5.1.1).

This Agreement (EECD, 2022b) is welcomed in many respects, as is the promise of an action plan around inclusion. It is of concern that it is unknown how inclusion will be directly addressed or if parents will be or have been consulted regarding their knowledge of how children experiencing disability can be included in early learning and childcare. It is also of concern that data for children experiencing disability in Nova Scotia is very minimal (Department of Pediatrics and Healthy Populations Institute, 2022; Friendly et al., 2020) and cannot inform planning. The Nova Scotia Canada-Wide Early Learning and Child Care Agreement (EECD, 2022b) is also committed to creating new spaces in early learning and childcare in the province (EECD, 2022a). However, there has been little mention of who will qualify for these spots, how that qualification will be determined, or if there will be enough spaces for all children. There has not been discussion of whether children experiencing disability are given priority with specifically designated spots or if they can still be turned away from

childcare settings that receive provincial funding. It is also unknown if the spaces created will be in settings that are using an effective inclusion model. Interestingly, some childcare settings have actually closed due to the Agreement (EECD, 2021) being signed (Willick, 2022). Highlights of the provincial objectives of the Agreement include:

2.6.1.1 Affordability. The EECD (2022b) stated that as a result of this investment the province significantly reduced costs for families beginning with a 25% decrease in April 2022 and by December 2022 there was an additional 25% decrease in fees. The Agreement projects that by 2026 families will pay \$10 per day per child in all licensed childcare centers that opted to sign the 2022-23 Quality Investment Grant (QIG) Funding Agreement with the EECD. All licensed childcare operators were offered to opt into this funding Agreement, with some operators choosing not to do this. Government subsidies can still be accessed by families.

2.6.1.2 Accessibility. In 2022, later updated to be by the end of 2023, 1500 more early learning and childcare spaces were to open in Nova Scotia (EECD, 2022b). Nova Scotia committed to use federal funds to increase the net number of regulated childcare spaces for children under the age of six to reach a coverage rate of approximately 59% by March 2026, it is projected that 9500 new spaces will have been created (EECD, 2022b; Government of Canada, 2022, sect. 2.1.1).

2.6.1.3 Wage increases for ECEs. The *Nova Scotia Excellence in Early Childhood Education Workforce Strategy* is being implemented with the goal of increasing wages for ECEs; with wages being between 14 - 43% higher dependent on classification level and experience. The announcement of these wage increases was made in October 2022, with wage increases being retroactive to July 2022. This Strategy also addresses the further professionalization of ECEs and benefits. This Strategy does not cover Pre-primary ECEs as they have collective agreements

negotiated with their employers, the Regional Centres for Education (RCEs) and Conseil Scolaire Acadien Provincial (CSAP), but wages are reportedly comparable. From May 10 to June 19, 2023, all ECEs in Pre-primary in the Halifax area were on a labour strike. They were not working at this time but were picketing and receiving strike pay only. Also, during this time all children in Pre-primary in Halifax were not attending.

2.6.1.4 Inclusion. Under the province’s inclusion plan, in addition to the aforementioned implementation of the ISG, there is the availability of Nova Scotia Early Childhood Development Intervention Services (NSECDIS). The NSECDIS is service offered by the Early Years Branch; it provides specialized services to families of young children (birth to school entry), who either have a biological risk for or a diagnosis of developmental delay. Nova Scotia will also use the Pyramid Model for Promoting Social Emotional Competence in Infants and Young Children (Pyramid Model) which provides a framework of evidence-based practices for promoting social emotional and behavioural development (Government of Canada, 2022).

2.6.1.5 Before and After School care. For 3–5-year-old children, before and after care school options, also known as ‘wrap-around care’, will be expanded to provide a “seamless day of before and after school wraparound care” (EECD, 2022b) although details were not readily available.

2.6.1.6 Government Oversight. Nova Scotia committed to developing a new provincial organization responsible for all regulated childcare in the province. It will “be responsible for ensuring that children experiencing disability and children needing enhanced or individual supports are welcome, accepted and supported” (Government of Canada, 2022, Annex 2).

2.6.1.7 Data Sharing and Reporting. Nova Scotia commits to track and share administrative and financial data with respect to inclusion and diversity needed to monitor progress (Government of Canada, 2022).

2.7 Some Factors Impacting Access to Inclusive Early Learning and Childcare

As Nova Scotia does not have current policies or a framework to guide the implementation of full inclusion in early learning and childcare, families are often left to do the work for championing inclusion on their own. It is unknown what families, particularly mothers, who have children experiencing disability “do” to try to secure inclusive childcare. Existing literature has alluded to factors that shape this form of invisible work:

2.7.1 Affordability and Economic Factors

Economic barriers exist for many families in Nova Scotia where the child poverty rate is the fourth highest in Canada and the highest in Atlantic Canada (Campaign 2000, 2022). Almost one in four children in Nova Scotia were living below the poverty line in 2019 (Frank et al., 2021). In 2020, the child poverty rate decreased in Nova Scotia by 24.3%, which is the most significant reduction in a single year on record (Frank & Saulnier, 2023). Government benefits related to the Covid-19 pandemic response reduced child poverty by 55.9% in Nova Scotia in 2020, lifting 26,810 children aged infant to 17 years old out of poverty in the province. Without those government benefits, the child poverty rate would have been 41.4%. In 2020, there were still 31,370 children living in low-income families (18.4%), or more than one in six children in Nova Scotia (Frank & Saulnier, 2023). It must also be considered that people experiencing disability experience disproportionately high rates of poverty (Frank & Saulnier, 2023), and Nova Scotia has the highest rate of disability in Canada (Statistics Canada, 2018). Children

experiencing disability are twice as likely to live in families living in poverty and using social assistance (Frank & Saulnier, 2023)

Childcare plays a role in supporting low-income families (Campaign 2000, 2022), but as the cost of childcare is significant, many families cannot afford early learning and childcare. These families must prioritize their basic needs. The Nova Scotia Canada-Wide Early Learning and Child Care Agreement (EECD, 2022b) is attempting to address these economic inequities by including commitments to decreasing family costs and reimbursing childcare operators who signed the Agreement. It still remains to be seen exactly how this will be done.

In Nova Scotia tax credits for children experiencing disability and children in childcare exist as facilitators, as do some subsidies, which can reduce economic barriers for families who receive one or both. Nova Scotia's Child Care Subsidy Program (Government of N.S., n.d.) helps eligible families, with children 12 years and under, pay for a portion of childcare fees at licensed childcare facilities and regulated family home day care agencies if they are eligible based on their income and finances.

Another cost related barrier is the lack of both subsidized and non-subsidized spaces for children experiencing disability in early childhood settings. Many settings cannot keep up with the demand for childcare (Irwin & Lero, 2021). Some settings have long waitlists, and settings are often able to pick and choose who they take into their care. This may lead to discriminatory or exclusionary practices as children experiencing disability may be passed over for reasons such as childcare staff not having the proper training to work with children experiencing disability or that the child needed more attention and support than the staff could give (Irwin & Lero, 2021). This is likely related to a lack of government funding with few funds being allocated to have enough trained staff or enough subsidies to make it affordable (van Rhijn et al., 2021). Mitigation of financial barriers is important to facilitate inclusion and ensure the rights of children to education (UN, 1989). It remains to be seen how the Nova

Scotia Canada-Wide Early Learning and Child Care Agreement will address spaces for children experiencing disability, although they commit to it in a proposed action plan (EECD, 2022b). As the wording of the Agreement (EECD, 2022b) does not explicitly support this, it is worrisome that finding childcare spaces for children experiencing disability continues to be a barrier.

Economic facilitators and barriers also exist for the purchase of often expensive equipment for the child by the family and/or early childhood settings (Halfon & Friendly, 2013). Some provincial and federal government programs assist families with full or partial funding for equipment such as walkers, wheelchairs, and standers, if the family and child meet eligibility criteria. However, families do not always qualify for funding and there are many resources that only have partial coverage or none, such as communication devices. If a source of financial coverage or at least contribution to coverage is not found, children are at risk for not having the resources they require to do the occupations they want and need to do (Irwin & Lero, 2021).

Some parents may actually find it is more financially feasible to remain out of the workforce as the cost of early learning and childcare, along with equipment and transportation costs, may exceed what the parent(s) earn in income. When this is the case, they in essence would be paying to work. These types of barriers can also lead to families using more social assistance systems and facing more barriers to be able to be financially independent of these systems.

2.7.2 Paid Labour in the Workforce

Government social and economic policy aims to encourage parents to work, and childcare is one resource reflective of this aim (Van Rhijn et al., 2021). Mothers with children experiencing disability, who want or need to work, are less likely to engage in paid employment than other mothers (Lewis et al., 2000). Care responsibilities and a lack of childcare shapes the employment decisions of mothers; they are more likely to work part-time or casually if they work at all (Lewis et al., 2000;

Rosenzweig et al., 2008). Maternal employment may be hindered by the time it takes and the barriers they face when looking for and maintaining childcare, particularly for a child who experiences disability (Irwin & Lero, 2021). The ability to work is further lessened for single mothers of children experiencing disability who do not have a partner in the home with whom to alternate care, household activities, or paid employment responsibilities (Powers, 2003).

To manage responsibilities, mothers also often require flexibility and accommodations at work (Breitkreuz et al., 2021). Mothers who can outsource household duties, including childcare, have been shown to have higher paying jobs and more time with their children (Seedat & Rondon, 2021). Many critical life decisions families make are based on available adequate and sufficient childcare (Lewis et al., 2000; McConnell et al., 2016). Therefore, childcare is considered a crucial resource for mothers to organize and balance a sustainable family routine and attain/maintain employment (Bianchi & Milkie, 2010).

2.7.3 Government and Social Policies

For Canadian children experiencing disability, access to supports and services in early childcare have been identified as critical gaps in all provinces (Clark et. al, 2009). As mentioned previously, children experiencing disability can be, and have been, turned away from early learning and childcare in Nova Scotia due to lack of policy, resources, and funding, violating their Rights (Killoran et al., 2007; van Rhijn et al., 2021). There is a need for inclusion and economic policies regarding early child learning and childcare that not only uphold rights but also attend to the relational aspects of inclusion and belonging for children and families (Phelan et al. 2022; Phelan & Reeves, 2022; van Rhijn et al., 2021).

2.7.4 Human Resources

There is a shortage of qualified ECEs in Nova Scotia, often related to low rates of pay deterring people from entering the ECE profession (Irwin & Lero, 2021). This also affects the ability to find childcare as a lack of staff correlates with a lack of available childcare spaces. If childcare workers were recognized and compensated at a rate commensurate to their value, staffing may improve. The Nova Scotia government is trying to decrease and/or remove this barrier by introducing a workforce strategy called “Excellence in ECE” with incoming financial support from the Government of Canada (EECD, 2022b). Funding sources, often national and provincial governments, for early childcare settings need to be stable and adequate to recruit and retain trained and experienced workers (van Rhijn et al., 2021).

Ratio of staff to children as set by government regulations are lower for staff working with children experiencing disability, particularly when a child has a complex disability requiring constant and consistent supervision and assistance to do most or all activities (Irwin & Lero, 2021). This means that by enrolling a child or children experiencing disability, more staff will most likely be needed, which creates issues as staff may already be difficult to find. It could also mean that the child experiencing disability is turned away (Killoran et al., 2007).

Specialized training focusing on the unique needs of children experiencing disability is another vital factor for inclusion (Odom et al., 2011). Childcare settings may exclude children experiencing disability due to lack of staff confidence or training in inclusion and care, or if there are inadequate human, financial, or professional resources to ensure the setting is prepared to include all children (Killoran et al., 2007). Obtaining training is often hindered because it is expensive, optional, difficult to access, and there is limited incentive to do so (Irwin & Lero, 2021). Not having ECEs with the necessary education to work with children experiencing disability can make it difficult to be inclusive and help children fully engage in occupations such as play and learning. To better facilitate inclusion,

staff positions to support and consult on issues related to access and inclusion could be created (i.e., inclusion consultants). However, these positions are contingent on government funding or high fees paid by families (Irwin & Lero, 2021).

2.7.5 Specialized Services

The NSECDIS provides specialized services to families with children who are either at risk for or have a diagnosis of developmental delay who are between birth and school entry. Along with other services, NSECDIS supports developmental outcomes for children through information sharing, support, consultation, and services to help both the child and their family (Nova Scotia Government, n.d.). The Department of Health and Wellness of Nova Scotia also support children experiencing disability and their families through services such as occupational therapy, physiotherapy, recreation therapy, and psychology.

However, access to all these services is dependent on where the family lives and how in demand the service is (EECD, 2022b; Nova Scotia Government, n.d.). A barrier may also be poor coordination of services such as not having the information from health professionals or from previous settings to help inform the child's inclusive programming of daily activities (Irwin & Lero, 2021).

2.7.6 Time

The amount of time parents, mainly mothers, spend on unpaid work related to childcare, housework, or organizing and managing others can be considered as “committed time” (As, 1978). This also includes time to problem solve and address barriers and facilitators. Time, social capital, and human capital are all resources used to meet a person's responsibilities and needs. Childcare is one of those responsibilities whether it is provided by a parent or acquired directly with financial means or resources (Zilanawala, 2016). Time is considered a crucial resource for families with children experiencing disability to find and maintain childcare (DeVore & Bowers,

2006). Parents, but especially mothers, are socially expected to invest time in their children (Schmidt et al., 2023). The additional work that mothers of children experiencing disability do in relation to disability for all services their children need requires additional time.

2.8 Invisible Work

Society has shaped what defines work and ‘not work’; work is often seen as paid and public whereas ‘not work’ may be considered private work (Daniels, 1987; Kaplan et al., 2020). Daniels (1987) coined the term ‘invisible work’ in the mid-1980s to describe types of women’s unpaid work, particularly housework, volunteer labour, and emotion work, which were not valued economically or culturally. The idea of invisible work arose during a time when social justice was being continually examined and invisible work was advanced as a means of highlighting women’s unpaid work and bringing it more to the forefront to be ‘seen’ (DeVault, 2014). Many scholars extended Daniels’ (1987) invisible work concept to “characterize various types of feminized reproductive labour, including paid domestic work (Cox, 1997; Rollins, 1996), breastfeeding (Stearns, 2009), emotional labour and care work (Glenn, 2000; Macdonald, 1998; Macdonald and Merrill, 2002; Rutman, 1996)” (as cited in Hatton, 2017, p. 336). The definition of invisible work has been used liberally and thus its definition is often unclear, confusing, or varied in meaning (Hatton, 2017). Invisible work has often been defined as unpaid domestic work activities and home care responsibilities, including personal care and housework, that are performed to sustain the family and/or household (Blackburn, 1999; Seedat & Rondon, 2021). Historically, mothers have performed a disproportionate amount of the unpaid domestic and home care responsibilities whether they are single or partnered (Seedat & Rondon, 2021), in what is considered a gender inequity. This labour division is influenced by established gender ideologies and power dynamics between partners (Wada et al., 2010). Over time, the literature

has differentiated this gendered invisible work between housework and care work. Housework has been identified as cleaning, cooking, laundering, shopping, managing the household budget and paying bills, distributing resources to various needs, and caring for family members (Kaplan et al., 2020). Care work or caregiving have largely been associated with caring for children but includes care for other family members as well (Bianchi & Milkie, 2010).

Invisible work is a complex concept with many dimensions. To define invisible work, Kaplan and colleagues (2020) identified four interconnected and “socially constructed binary conceptual axes: work vs. not work, paid vs. unpaid labor, formal vs. informal labor, and the private vs. the public spheres” (p. 1527) that are all informed by capitalist culture. Kaplan and colleagues (2020) defined them as follows: 1/ Work vs. ‘not work’: capitalist societies have made a clear differentiation between activities considered both culturally and socially to be work and those activities that are not (Daniels, 1987). 2/ Paid vs. unpaid labor: in capital societies, a vital feature of work is that it involves monetary compensation (Daniels, 1987), thus activities, or labour, that is paid for is considered work (Kaplan et al., 2020). If monetary compensation is not involved, it is not considered work and may be devalued or rendered invisible (Hatton, 2017). This is irrespective of whether the activity took a lot of time or skill (Kaplan et al., 2020). Through a capitalist lens, work and ‘not work’ is judged by the consideration of monetary compensation, public or private environments where the work occurs, and gender role differentiation (Daniels, 1987; Kaplan et al., 2020). The notion of women’s work and the distinction between paid labor and unpaid labor have become entrenched in both feminist and sociological research (Kaplan et al., 2020). 3/Formal vs. informal labour: researchers put forth that social construction creates formal and informal labour, and usually involves the market economy and institutional settings. The differentiation between labour types can vary over time,

across countries and among contexts (Kaplan et al., 2020). 4/ The private vs. the public sphere: Based on the logic of the three previously mentioned dimensions of work, all work practices carried out in the home are defined as ‘non-work’, thus omitting many activities from the concept of work at home, creating the concept of invisible work (Hatton, 2017).

Emotion work⁴ is considered invisible (Daniels, 1987), has feminist origins, and involves the management and expression of emotions as an enduring part of daily life (Hochschild, 1983, 2012). The theory of emotion work proposes that sociocultural rules govern how emotions are constructed and managed as challenging the assumption that one’s emotions are indicators of individual psychological issues (Clarke, 2006; Hochschild, 1983, 2012). Emotion work “involves attempts to suppress unwanted emotions while evoking desirable emotions that are suitable for social situations” (Findling et al., 2022, p.2), thus people adapt and manage their experienced emotions as directed by social expectations (Findling et al., 2022; Hochschild, 1983, 2012). Caregiving work, often invisible and unpaid work done by women, involves a great deal of difficult emotion work (Clarke, 2006). When a child has extra caregiving needs, such as a child experiencing disability or illness, mothers do the emotion work for them in addition to the emotion work they do for themselves, and for their spouses and other children (Clarke, 2006; Findling et al., 2022; Hochschild, 1983, 2012). Findling and colleagues (2022) related parental burnout to emotion work and found mothers of children experiencing disability reported significantly higher parental burnout, deeper emotion work and a higher perceived level of care than mothers of children who do not experience disability.

⁴ The term ‘emotion work’ is sometimes used synonymously with the term ‘emotional labour’. They are both categorized as invisible, but Hochschild (1983, 2012) differentiates them between private and public domains respectively. She defined emotional labour as “the management of feeling to create a publicly observable facial and bodily display; emotional labor is sold for a wage and therefore has exchange value” (2012, p. 7). She used the term emotion work to describe “these same acts done in a private context where they have use value” (2012, p. 7), but are not compensated monetarily. Thus, the term ‘emotion work’ fits the work the mothers in this study do more so than ‘emotional labour’ and will be used going forward.

Across many disciplines, invisibility is a common scholarly theme regarding work that is disability related (DeVault, 2014). Parents of children experiencing disability typically have a more traditional division of household work than parents with children not experiencing disability, with mothers playing a larger role as primary caregivers (Kagan et al., 1999). This occurs whether the mother is employed in paid work or not (Kagan et al., 1999). The time mothers dedicate to unpaid care work increases with the presence of children in the house, particularly when children are under five and/or have a disability (Irwin & Lero, 2021). Mothers attempting to sustain family routines with young children, carry the responsibilities of caring for the family, employment, and other commitments for all family members; this requires ongoing flexibility related to organization and planning (Breitkreuz et al., 2021). Mothers face ongoing challenges to plan, organize and manage their families' daily lives and routines (Bianchi & Milkie, 2010; Breitkreuz et al., 2021; McConnell et al., 2016;) and may need to make many accommodations to make these routines work (Breitkreuz et al., 2021). It is often very challenging for families to find childcare. The process to find, procure, and manage childcare has been found to be “gendered, often invisible, and require[s] substantial accommodations and flexibility by mothers” (Breitkreuz et al., 2021; p. 436). This could all be considered invisible work as informed by Daniels' (1987) and Hatton's (2017) research. Barriers regarding access include few available spaces, long waitlists often with no follow-up from childcare settings, inaccessible physical environments (Van Rhijn et al., 2021), and challenges accessing specialized services. These barriers all necessitate the substantial unpaid advocacy work of mothers to obtain childcare and these services (Lewis et al., 2000). This invisible work is not often valued economically or socially (Matthews et al., 2021).

Mothers of young children experiencing disability often do a significant amount of invisible work advocating for their child. This may include attempting to find, access and maintain truly inclusive childcare and applying for funding for various needs, even more so than mothers with typically developing children (Grace et al., 2008; Irwin & Lero, 2021; Odom et al., 2011). They dedicate considerable amounts of energy “to meet cultural and environmental constraints in support of the inclusion of their children” (Goodwin & Ebert, 2018, p. 13). Mothers must navigate a number of barriers in their pursuit of inclusive early childcare (Irwin & Lero, 2021).

As the number of children experiencing disability increases in our society there are increasing demands, and less available space, for care (Lewis et al., 2000). “[P]arents of disabled children are operating within a very narrow and often inflexible system of benefits, allowances and access to various resources” (Ryan & Runswick-Cole, 2008, p. 206), thus affecting all the work they do to help their child and family. Mothers of children experiencing disability may spend a considerable amount of time and energy doing the work to build relationships, educating staff who are with their child, and developing coping strategies when facing non-conscious ableism related to their child (Goodwin & Ebert, 2018). They become well versed in navigating the health care and social service delivery systems (Green, 2007). They manage family resources in order for their child experiencing disability to participate in activities alongside their peers (Goodwin & Ebert, 2018), such as childcare and early learning. The support of parents is considered essential for children experiencing disability to participate and be included (Goodwin & Ebert, 2018). When parents do the work of finding and obtaining resources to achieve supports required for family life, such as attending medical appointments or securing childcare, it takes considerable planning and effort (Goodwin & Ebert, 2018). Accommodations pertaining to

issues arising with early learning and childcare may include adjusting routines and commitments to fit with inflexible childcare, parental employment changes to accommodate childcare needs, turning to family or friends to assist with childcare, or leaving employment entirely due to lack of childcare (Breitkreuz et al., 2021). When considering the previously discussed factors impacting access to inclusive childcare and early education, it is usually mothers who take on this care work and navigate systems.

Childcare and employment of the mother are often correlated, as one societal reason for childcare has been to maintain the workforce, particularly the maternal labour workforce (Powers, 2003). A primary deciding factor in a mother's ability to enter and remain in paid employment relies on invisible work (Seedat & Rondon, 2021), including searching for and accessing childcare. This is significant as the number of mothers in the workforce has increased steadily. In 1976, 40.5% of mothers were in the workforce whereas in 2021, 76.5 % of mothers were employed (Statistics Canada, 2022a). Therefore, childcare may be considered a crucial resource in organizing a sustainable family routine (Bianchi & Milkie, 2010), including paid work. Many critical decisions that mothers make, including entering and remaining in the workforce, are actually based on childcare availability (Lewis et al., 2000). Childcare has been conceptualized by some as a business issue even more so than a family issue as it affects why, when, and how people work and economic productivity (Modestino et al., 2021). Mothers spend an unknown amount of unpaid time and invisible work accessing childcare for their young children, a task with more complexities when a child experiences disability. Not having available childcare can cause stress and conflict when parents want or need to join the paid workforce (Bianchi & Milkie, 2010), thus affecting parental well-being. Compared to other parents, mothers of children experiencing disability are less likely to be employed in paid work (Lewis et

al., 2000; Statistics Canada, 2022a). If they are employed, it is more probable they have casual or part-time work due to not being able to secure appropriate childcare (Lewis et al., 2000). A recent Norwegian study found that mothers' participation in the labour market, earnings, and hours of work are all less if they are caring for a child experiencing disability as compared to mothers caring for a child who does not experience disability (Wondemu et al., 2022). They also found that the more complex the child's disability experience was the more likely mothers were to decrease hours worked or stop working altogether. Wondemu and colleagues (2022) also concluded that the earnings of fathers who had children experiencing disability were not significantly impacted unless their child was considered to have a severe disability.

Sometimes families secure childcare to meet the parents need to work, however they are dissatisfied with the arrangement for a variety of reasons including quality of inclusive care (Scott et al., 2005). This dissatisfaction necessitates continued work to find a better option for childcare that is more satisfactory. Families that generally do better managing their day-to-day lives are families with resources to develop and maintain a meaningful, daily routine; one such resource is having childcare that is considered satisfactory and sufficient by the family (McConnell et al., 2016).

2.9 Summary

The literature speaks to the uneven distribution of care work, particularly invisible work, that mothers do in supporting their children who experience disability (Grace et al., 2008; Irwin & Lero, 2021; Odom et al., 2011). I argue that searching for, accessing, and maintaining inclusive early learning and childcare for children experiencing disability in Nova Scotia contributes to the invisible work mothers do, as it is unpaid, informal care labour and takes time, effort, energy, and skill. Although it is known that mothers consider quality of care, inclusion,

availability, affordability, and the need for specific interventions when looking for childcare for their child experiencing disability (DeVore & Bowers, 2006), the actual invisible work they do and the conditions that necessitate this invisible work have not been explored in the Nova Scotian context. In this research I sought to understand the kinds of invisible work mothers identify that they do to research, locate, access, secure, and maintain childcare for their child experiencing disability. This research is relevant as Nova Scotia rolls out the Universal Childcare program without an existing inclusion framework. Consideration of the knowledge and viewpoints held by families with children experiencing disability is critical to inform an inclusive, universal national childcare system designed for all children and their families (van Rhijn et al., 2021).

Chapter 3 Methodology

3.1 Methodological Approach

This study extends a branch of inquiry from a larger interpretive qualitative study that explored the questions: 1) What are the barriers and facilitators to accessing childcare and/or early education settings for families of pre-school aged children (birth to 5 years) who experience disability?; and 2) How do sociocultural factors shape opportunities for inclusion in childcare and/or early education settings for families of pre-school aged children (birth to 5 years) who experience disability through an ecocultural perspective (Weisner, 2002). During analysis of the larger study, the invisible work of mothers in pursuit of inclusion was identified as a branch worthy of further inquiry. Thus, using theoretical constructs of invisible work (Hatton, 2017) and the *good mother* (Goodwin & Huppertz, 2010; Hays, 1996), this interpretive study employed a secondary analysis to explore the questions:

1/ What kinds of invisible work do mothers of children who experience disability do in pursuit of inclusive early learning and childcare in Nova Scotia?

2/ How do sociocultural factors shape this invisible work mothers with children who experience disability do in Nova Scotia?

3.1.1 Secondary Analysis

Secondary data analysis “allows for the development, extension, and exploration of a phenomenon in a flexible and unobtrusive way” (Sherif, 2018, para. 35). It entails maximizing data from a previous study to answer new research questions and illuminate findings that were not explored when the primary dataset was analyzed (Hinds et al., 1997). The data analyzed from that first study may focus more on one theme that was only partly addressed in that study’s analysis (Watters et al., 2018), as is the case for this study. Secondary data analysis may also

include analyzing data from a larger study using different approaches (Ruggiano & Perry, 2019). Hinds et al. (1997) further detailed four types of secondary data analysis approaches: (1) investigating a different unit of analysis from units in the larger study; (2) analyzing themes from a sub-set of data of the larger study in a more in-depth and focused manner; (3) analyses of data from the parent study that seemed important, but was not adequately focused on in the larger study analysis; and (4) using the dataset from a larger study as one source of data but also collecting newer data to refine the larger study's purpose, research questions, or process of data collection (Hinds et al., 1997). Akin to type two and three, the theme of invisible work that mothers do in pursuit of inclusive early learning and childcare was taken from the larger study and analyzed in more depth in this secondary analysis using an interpretive approach (Braun & Clarke, 2022). A different theoretical lens was also used for this secondary analysis.

Successful secondary analysis of qualitative data is “most effective when used with high-quality, relevant, rich, and complex datasets” (Sherif, 2018, para. 36), which this study's dataset provides. There are both strengths and limitations of qualitative secondary analyses (Sherif, 2018). The prospect that a researcher using secondary analysis may uncover new evidence or derive novel findings from archived research data using new research questions, and perhaps a new theoretical approach, is an intriguing benefit. This is perceived a benefit because the data is already collected, it is a cost-effective way to do research, and the researcher can still become immersed in rich data (Ruggiano & Perry, 2019; Sherif, 2018). Another benefit of secondary analysis is that participants of vulnerable or difficult to access populations are not asked to retell sensitive information (Chatfield, 2020; Ruggiano & Perry, 2019). There are methodological concerns to secondary data analysis (Hinds et al., 1997; Sherif, 2018). There is a risk that the original study may not have sufficient data regarding the phenomenon of study in

the secondary analysis or that the original study and the secondary analysis differ too much to make new findings (Chatfield, 2020; Hinds et al., 1997). Researchers need to weigh the limitations and benefits of doing a secondary data analysis before embarking on such a study (Chatfield, 2020). The benefits and limitations of secondary data analyses are addressed further in relation to this secondary analysis in the Ethical Considerations (section 3.7), Quality and Rigour (section 3.6), Strengths (section 5.5), and Limitations (sections 5.6) sections of this thesis.

3.2 Theoretical Perspectives

An occupational perspective (Njelesani et al., 2012), informed by the constructs of invisible work (Hatton, 2017) and good mothering, also referred to as intensive mothering (Hays, 1996; Goodwin & Huppertz, 2010), was used to inform this interpretive qualitative research study (Braun & Clarke, 2022). Both invisible work and good mothering were understood through a critical feminist lens. The combination of perspectives draws attention to the work and invisible work, family life and routines, and felt experiences of inclusion, belonging, and well-being of mothers with young children experiencing disability.

3.2.1 *Critical Feminist Theory*

A critical feminist lens offers an opportunity to make the familiar strange and the strange familiar (Greene, 2000). In this case, it allowed me to critically examine mothers' everyday experiences of pursuing inclusion in early learning and childcare in order to illuminate the invisible work that is involved and the conditions that create the need for this work. Critical feminist theory draws from both the roots of critical theory and feminism to recognize and disrupt the established hegemonic systems of power and privilege and challenge and deconstruct oppressive patriarchy (Lindbom-Cho et al., 2014). A critical feminist lens can be used to

“critically [examine] themes of social power and oppression while attending to gender equity as it intersects with other aspects of identity, such as class, race, ethnicity, ability, sexual orientation, body size, age, immigration status, geographic location, and more.” (Kuri & Fierheller, 2022, p. 8). Gender is understood as being socially produced and is inextricably linked to the social circumstances that constructs it (Rhode, 1989). Critical feminist theory can be used to focus on how people's experiences, interpretations, and settings intersect meaningfully in relation to gender; it can also be used to explore, scrutinize, and challenge traditional gender conceptions such as beliefs regarding mothers and mothering (Kuri & Fierheller, 2022; Lindbom-Cho et al., 2014). Feminist scholars developed the concept of "invisible work" to highlight women's unpaid, unacknowledged, and devalued labour (Daniels, 1987; DeVault, 2014; Kaplan et al., 2020). Thus, critical feminist theory offers generative possibilities when examining the invisible, gendered, work mothers do for their children experiencing disability.

3.2.2 Occupational Perspective

Occupation is a difficult construct to operationalize (Baker et al., 2003) and can be defined differently by people at different times (Hammell, 2009). Occupations may be considered the activities that people do every day to occupy time and bring meaning and purpose to life (WFOT, 2021). Polatajko and her colleagues (2013) defined occupation as one or more activities performed with some regularity and consistency that provides structure and is given meaning and value by individuals and cultures. Occupations are performed by individuals, within families, and within communities, and include all the activities that people need to do, want to do, and are expected to do (WFOT, 2021; Wilcock, 2006). “People place occupations within the framework of their lives” (Clark, 1993, p. 1076) and one can express who they are and what they want to become through occupation (Wilcock, 2006). Well-being and occupational balance are

shaped by the degree of congruence between occupations and one's need of doing, being and becoming (Wada et al., 2010; Wilcock, 2006). Occupations may also be considered a social construct and their situation in people's lives has been embedded in occupational therapy and occupational science literature for a long time (Nyman & Isaksson, 2021). The concepts of occupation or knowledge about occupation have largely been developed with privileged socio-economic groups mostly in the Western world (Kantartzis & Molineux, 2011), and may not be as relevant globally (Hammell, 2009). Occupations may be affected, and possibly constrained, by class, gender, race, religions, education, sexual orientation, poverty, culture, age, power, politics, a person's mood, the people present and by context (Hammell, 2009; Reed et al., 2013). It is important to note that occupation is often socially and culturally defined and sanctioned, thus indicating that different cultural groups will have their own unique understanding of occupation (Reed et al., 2013). Clark (1993, p. 1076) stated that "each civilization invented culturally specific occupations as solutions to their issues of lifestyle and survival," thus placing occupations in the everyday lives of members of a society for a long time. Childcare, whether done by a mother or outsourced by a mother, is an occupation (Arnold et al., 2018).

Context is important for understanding occupation, including the knowledge and understanding of how people's occupations are situated in the social, political (Prodinger et al., 2015) and cultural contexts (Munambah et al., 2020). Prodinger and colleagues (2015) defined "occupation as situated" to illuminate the ways that occupation is shaped within, and influences the shaping of, the cultural, political, economic, social, and other, contextual factors. This may be considered a transactional view of occupation as the person and context are linked through action to form a dynamic relationship (Dickie, Cutchin, & Humphry, 2006).

Both occupational therapists and occupational scientists use an occupational perspective to understand people's lives "as consisting of a complex, interconnected web of occupations" (Laliberte Rudman et al., 2022, p. 13). An occupational perspective has been defined as a way of looking at or thinking about human "doing" (Njelesani et al., 2012). What people do is affected by internal and external influences, as well as their own effort to shape what they do through initiating and maintaining change (Townsend, 1998). An occupational perspective has several underlying assumptions, including "a connection to doing that contributes to being, becoming, and belonging; a relationship with health and well-being; containing form, function, and meaning from individual to societal levels; and a transactional relationship with the context" (Njelesani et al., 2012, p. 234). It enables us to see daily occupations as integral to all individuals and contexts (Asbjørnslett et al., 2015) and consider occupational participation. Occupational participation within the new Canadian Model of Occupational Participation (CanMOP) is defined as "having access to, initiating, and sustaining valued occupations within meaningful relationships and contexts" (Egan & Restall, 2022b, p. 76). This all suggests there are benefits to researching and understanding the daily lives of children experiencing disability and their families, in this case, the role of mothers, as well as their participation in all occupations considered to be significant in their context and community (Asbjørnslett et al., 2015), including the invisible work of organizing and planning for childcare.

3.2.3 Invisible Work as Occupation

Parents of children experiencing disability face challenges accessing specialized services, necessitating their substantial unpaid advocacy work to obtain these services (Matthews et al., 2021), in this case inclusive early learning and childcare. As previously discussed, this work is not often valued socially or economically (Matthews et al., 2021) and may be considered as

invisible. The literature depicts mothers as, most often, the primary caregiver who performs unpaid, invisible care work (Bianchi & Milkie, 2010; McConnell et al., 2016; Seedat & Rondon, 2021). As care work has historically been considered feminized, unpaid, undervalued, unrecognized, and invisible, this familial division of labour can be considered a gender inequity (DeVault, 2014; Hatton, 2017; Matthews et al., 2021). The global COVID-19 pandemic and public health response disrupted the invisible work of childcare and accessing childcare. This served to illuminate the reasons we need childcare, gender inequities in the workplace, disproportionate and gendered provision of childcare, and the many systemic inequities in childcare (Petts et al., 2021).

For this study, an occupational perspective was bolstered by the incorporation of feminist conceptualizations of invisible work; invisible work is occupation. Invisible work was used as a sensitizing concept to illuminate how the daily lives of mothers are shaped by systems of power related to both gender and disability (You & McGraw, 2011).

3.2.4 Good Mothering/Bad Mothering Dichotomy

The sociocultural construct of the caring “good mother” (Goodwin & Huppatz, 2010; Hays, 1996) looms large in society and was used as another sensitizing concept in this study as it is assumed that this discourse influences mothers’ engagement in invisible work in pursuit of inclusion for their children who experience disability. Good mothers are characterized by intense maternal devotion to their children in which they are morally responsible for their own children’s development and how they participate in society as adults (Hays, 1996). There is a social expectation that mothers invest a large amount of time, emotional labour, money, and effort into caring for their children; they are also then held accountable for the social-emotional development, care, and education of their children (Hays, 1996; Muthukrishna & Ebrahim,

2014). Goodwin and Huppertz (2010) purported that “the good mother is known as that formidable social construct placing pressure on women to conform to particular standards and ideals, against which they are judged and judge themselves” (p. 1-2). Thus, being a “good mother” is very often a social ideology and a social obligation for mothers that seems to take precedence over their own needs and shape their daily lives (Goodwin & Huppertz, 2010, Guendouzi, 2006; Hughes-Miller et al., 2017). Good mothering operates beyond the beliefs and choices of individual mothers, rather this concept is institutionalized socially and acts as a form of social regulation powerfully influencing the sociocultural standing of mothers (Goodwin & Huppertz, 2010; Muthukrishna & Ebrahim, 2014).

As there is the concept of a good mother, there is also the cultural concept of a bad mother and if thought of superficially one may perceive them to be in direct contrast with one another. Bad mothers are often too simply characterized by the harm they do to their children which may be in the form of abuse, abandonment, neglect, or murder (Hughes-Miller et al., 2017). However, bad mothering goes beyond this in its construction. Bad mothers may be labelled as such if they are unemployed, poor, on welfare, disabled, too busy, too stressed, too young, too old, or too tired, as well as if they work too much, drink alcohol, smoke, or do drugs (Goodwin & Huppertz, 2010; Hughes-Miller et al., 2017). This list goes on. Bad mothering is also a social ideology and punitive (Hughes-Miller et al., 2017) and, like ‘good mothering’ is shaped by sociocultural context (You & McGraw, 2011). In the cultural discourses of the Western world, mothers are often blamed for their children’s problems, including diagnoses and disability (Hughes-Miller et al., 2017). Mothers have unjustly “served as a scapegoat for social and economic disadvantage” (Hughes-Miller et al., 2017, p.192).

Mothers of children experiencing disability engage in significant work to raise their children (McKeever & Miller, 2004), even more so than mothers of children not experiencing disability (Ryan & Runswick-Cole, 2008). These mothers are affected by the sociocultural narratives of the good mother, and this influences how they perceive and represent themselves (Knight, 2013). Dominant maternal discourses promote that children experiencing disability should be cared for by mothers at home regardless of circumstance; mothers raising a child experiencing disability “clearly feel oppressed, disempowered and under physical and emotional stress” (Brett, 2002, p.840). Mothers of children experiencing disability have been found to be under immense pressure to adopt and embody a persona of selflessness and advocacy and conform to what society views as the best care for their children (Brett, 2002; McKeever & Miller, 2004). These views of selflessness and caring for their child often conflict with their work in paid employment external to the home, causing them additional stress and feeling like they are not a good mother (Brett, 2002). More recent literature has examined intensive mothering related to employment ideals. Working mothers are starting to construct the ideology that good mothering can be “more delegatory than hands-on” (Christopher, 2012, p. 91); a good mother can responsibly outsource childcare to external care providers while they engage in paid work (Christopher, 2012; Schmidt et al., 2023). However, their strategies of delegating childcare “reflect their ultimate responsibility for their child’s well-being” (Schmidt et al., 2023, p. 64). Mothers are redefining what it means to be a ‘good mother’ including both being responsible for finding childcare that contributes to their child’s wellbeing, when they cannot directly care for their child, and contributing to their child’s well-being by earning income to benefit their family (Christopher, 2012).

The normative discourses of ‘good mothering’ may be a reason mothers do the work of pursuing inclusive childcare for their children experiencing disability, and thus was used as a sensitizing concept to illuminate how this work may be shaped. In much of the Western world, a gender ideology also exists where mothers are considered as the pivotal person in the family who shoulders the responsibility of providing primary care for children and ensuring their needs, including safety, are met (Guendouzi, 2006). Thus, theories of gender inequities and feminism are strongly linked to the good mother ideology (Goodwin & Huppatz, 2010), and were once again incorporated in this study when examining how a good mothering/bad mothering perspective may affect the invisible work of mothers with a child experiencing disability.

Viewed through an occupational lens (Njelesani et al., 2012), mothering and the invisible work done by mothers is affected by internal and external factors and mother’s own efforts to make change (Townsend, 1998). Gendered divisions of household labour and caregiving has positioned women as primary caregivers (Seedat & Rondon, 2021), and define women's worth and successful embodiment of womanhood by their fulfilment of the dictates of 'good mothering'. Good mothering demands women's engagement in the invisible work of providing or seeking optimal childcare for their children. Thus, for this study, an occupational perspective comprised of sensitizing concepts of invisible work and good mothering was used to examine how mothers access inclusive early learning and childcare for their children experiencing disability and identify what sociocultural factors affect these efforts.

3.3 Background: Larger Study

The larger study received ethical approval from Dalhousie University’s Research ethics board: REB# 2022-6054 (Appendix A). Maximum variation sampling was used in the larger study to allow for diverse representation and multiple perspectives to yield rich data (Creswell &

Poth, 2018). Maximum variation sampling helped the researchers “explore the common and unique manifestations of a target phenomenon across a broad range of phenomenally and/or demographically varied cases” (Sandelowski, 2000, p. 337-338). Inclusion criteria for the larger study included:

- Living in Nova Scotia
- Able to participate in an interview in English
- Identify with having at least one child with a disability between the ages of 0 and 5 years who has not begun formal schooling
- Identify with at least one of the following experiences as related to early childcare and early education:
 - 1/ attempted but were unable to access early childcare,
 - 2/ are in the process of trying to access early childcare,
 - 3/ are currently accessing early childcare, or
 - 4/ previously accessed childcare but are not currently.

Participants were recruited through disability related organizations via 1/ social media; 2/ email lists; 3/ newsletters, 4/ display. Seventeen parents were recruited into the larger study.

Semi-structured interviews were used in the larger study as the primary method of data collection (Brinkmann, 2013). See Appendix B for the Interview Guide that was developed for the larger study by Phelan and Diggins. The sample included 16 mothers and one father, thus the number of mothers who responded to be interviewed was far greater than fathers. Eight interviews of mothers and one interview of a father were conducted by C. Diggins and eight interviews of mothers were conducted by Dr. S. Phelan as part of the larger research study. Interviews with each mother were 60-90 minutes in length and conducted in a medium indicated

by the participant. In-person interviews were conducted using the participants' preferred mode of communication (virtual via Microsoft Teams, in-person, or by phone). All participants were compensated \$50 for their time. All interviews were recorded with participant consent; recordings were transcribed verbatim, checked for accuracy, and deidentified.

Participants were asked to complete brief demographic questions at the end of their interview (Appendix B). Demographic questions asked of mothers included: age of child, education level, employment, household income range, location in province, ethnicity or identification with cultural groups, gender, partnered or unpartnered, age range of participant, etc. See Table 1 in Appendix C for a detailed description of the sample. All participants were given pseudonyms.

3.3.1 Participants

Focussing on mothers, participants for the secondary analysis were identified through the larger study. For this study, a mother was defined as a child's biological or adoptive legal parent or guardian of any gender or age who identified as a mother. An infant was considered a child younger than 18 months old, a toddler was considered a child between 18-35 months old, and a pre-school child was considered a child who was 36 months old or older not attending school (with the exception of a pre-primary program) (N.S. Early Learning and Child Care Regulations, 2020). It is acknowledged that these terms can vary between provinces, countries, and cultures. For the purpose of this research, the terms "early childhood" and "young children" encompassed children from birth to five years (from the start of infancy to the start of formal schooling). As mentioned previously, mothers were identified as a focus because the literature review widely indicated that mothers are typically the primary parent caregiver who performs unpaid, invisible care work (Bianchi & Milkie, 2010; McConnell et al., 2016; Seedat & Rondon, 2021) and do a

significant amount of invisible work searching for and accessing early childcare for their children experiencing disability (Grace et al., 2008; Odom et al., 2011).

There were 16 mothers of children who experience disability included in the secondary analysis. The mothers all identified as female. Diversity was represented in the sample in many respects. Mothers ranged in age from 25-49 years old. Their children who experienced disability ranged in age between 18 months and 5 years old at the time of the interview. Of the 16 mothers, 11 were married, 3 were common-law and 2 were single. Two married couples elected to participate, one couple were married mothers (Jennifer and Andrea) and one couple was a married mother (Pamela) and father; they all interviewed separately. The one participant who identified as a father in the larger study was excluded as this study focussed on the lived experiences of mothers of children experiencing disability as it pertains to the research questions. While he can comment on the experiences of his wife doing invisible work, the father did not directly engage in this invisible work as a mother and thus cannot comment on the lived experience of a mother from a mother's perspective.

Mothers were interviewed from across Nova Scotia with seven mothers living outside of Halifax Regional Municipality (HRM). Geographically, mothers were interviewed from Shelburne to Glace Bay, with many other regions represented. Mothers of English, European, American, and French Acadian cultural backgrounds were represented as were mothers that identified as Caucasian, Indigenous and Black. One mother also identified as having a disability. In relation to education, 11 mothers identified as graduating from university with a Bachelor or Master's degree, 2 mothers graduated from Community College, one mother had completed grade 12, and 2 mothers were currently in Community College. There were 3 mothers who identified as being "stay-at-home" mothers, and 13 mothers were employed in various capacities.

Household incomes ranged between \$25 000 and \$175 000 per year, with two participants not knowing their yearly income.

3.4 Data Collection

The data included all 16 verbatim interview transcripts from interviews conducted with mothers in the larger study. This generated approximately 1500 minutes of dialogue between interviewers and participants. Refer to Section 3.3.1 for participant demographic information.

3.5 Data Analysis

This secondary data analysis was guided by the research questions and informed by the theoretical perspectives described above. Notions of invisible work and the good mother/bad mother dichotomy were used as sensitizing concepts. Sensitizing concepts are used to “provide a general sense of direction and reference for a study” (Schwandt, 2011, p. 274) and enable researchers to “notice and name aspects of phenomena they might otherwise have overlooked” (Gilgun, 2019, p. 111). Invisible work as a sensitizing concept allowed for the identification and description of the work done by mothers in pursuit of inclusive education to further explore the sociocultural factors that create and mitigate this work. The normative discourses of good mother/bad mother were also used as a sensitizing concept to illuminate how this work of mothers may be shaped.

Data for analysis included interview transcripts, demographic questionnaires, and reflexive researcher notes from each interview. Quirkos 2.5.3, a qualitative data analysis software program, was used for data management, coding, and to support the generation of themes in this secondary analysis.

3.5.1 Reflexive Thematic Analysis

With an aim to capture the nuances of invisible work that mothers of children experiencing disability do in pursuit of inclusive early learning and childcare, Braun and Clarke's (2006, 2022) reflexive thematic analysis (RTA) was used to explore, examine, and describe relevant patterns of meaning in this data set. RTA is an interpretive approach to analysis and is theoretically flexible (Braun & Clarke, 2022), and thus was chosen so the analysis could focus on patterns of meaning related to invisible work. RTA emphasizes that researchers have active roles in the production of knowledge (Braun & Clarke, 2022). Analysis was guided by both semantic (inductive, open) and latent (theoretically informed) coding (Braun & Clarke, 2022)

RTA involves a process of six phases which can assist with identifying and focusing on the important aspects of the thematic analysis (Braun & Clarke, 2022). Although the six phases are organized in a linear fashion, the process of RTA does not progress this way; rather, researchers go back and forth between phases (Braun & Clarke, 2022). When engaged in RTA, I did go back and forth between phases often and, as Braun and Clarke suggested (2022), this helped me further immerse myself in the data to make more connections and interpretations of the data.

1/ Familiarizing yourself with the data: The first phase involved my deep familiarization and immersion with the content of the dataset, as well being critically engaged. I listened to all recorded interviews. This helped me to capture the nuances and I believe the emotions of the participants. I also read and re-read all transcripts that had been transcribed during the first study. There were some recorded interviews and transcripts I had to check, and at times further transcribe, to better capture missing information in the interview and ensure accuracy. For example, some sentences were not sensible in some transcripts or were labelled as

“unintelligible”, but by listening to the interviews again and sometimes playing the interviews on slower speeds, I was able to identify what was said and add it to the transcription. As I was more familiar with the interviews I had done for the larger study, I was cognizant to listen to the interviews I did not do and read their transcripts on numerous occasions to ensure I was as familiar with that data. As I did this, I documented thoughts or insights I may have related to the analysis of the data as a whole as well as for each data point.

2/ **Coding:** according to Braun and Clarke (2021, 2022), codes are considered the building blocks for the researcher to develop themes in reflexive thematic analysis. *Coding* is the evolving and open iterative systematic process of using codes and code labels to capture relevant meanings in the data in relation to the research questions (Braun & Clarke, 2022; Braun et al., 2019). Phase two for my study involved systematic and thorough coding initially at a semantic level (Braun & Clarke, 2022), where I explored explicit, or surface level, meanings. I then advanced toward coding for more latent or implicit meanings (Braun & Clarke, 2022), drawing more specifically on my theoretical perspectives and sensitizing concepts. For transparency purposes, it is important to note that I was on the primary research team for the larger study and participated in coding data using the qualitative analysis software program Quirkos 2.5.3. I again used Quirkos 2.5.3 for coding this data. I was the only coder for this study, which is considered good practice for RTA (Braun & Clarke, 2022) and coded all transcripts anew.

3/ **Generating initial themes:** In phase three I identified shared patterned meaning across the data set by clustering codes and generating themes as they related to the purpose of the research while considering nuances based on gender, disability, race, place of residence, socioeconomic status, and intersections of these identities. In this phase, as discussed by Braun and Clarke

(2022), I started to write my formal analysis referring to my more informal journalling and notes that I have taken since the start of this study.

4/ Developing and reviewing themes: In phase four I assessed the themes by going back to the dataset as a whole to determine if the themes highlight the most important patterns of meaning across the dataset. Once I had become quite familiar with the data, and had coded all transcripts at least twice, hand-drawn visual thematic mapping (Appendix D) was done. This technique was used to aid in theme generation, to explore how codes and potential themes may be linked to one another, and if any patterns across the dataset were evident visually (Braun & Clarke, 2022). This process was reflexive and iterative. Visual mapping (refer to an example in Appendix E, Figure E3) was also used to map the sequence of each mother's individual journeys when pursuing childcare. This mapping was helpful to look for nuances across participants but to also look for patterns of meaning across participants.

5/ Refining, defining and naming themes: Phase five involved the refinement and definition of themes. I also engaged in reflexive dialogue with my supervisor throughout the process of coding and generating themes to establish resonance.

6/ Writing up: The sixth phase involved writing up the analysis in preparation for dissemination.

3.6 Quality and Rigour

To address quality and rigour, the elements of this study's design was attended to diligently. Tracy's (2010) Eight-Point Conceptualization of Key Markers of Quality in Qualitative Research (Appendix F) were considered throughout this study, particularly the criteria: sincerity, credibility, and meaningful coherence. Yardley's (2000) essential qualities of good qualitative research: sensitivity to context, commitment and rigor, transparency and coherence, and impact and importance were also considered throughout this study. To help

ensure quality in the thematic analysis, Braun and Clarke's (2022) 15-point Checklist For Good Reflexive TA (p. 269) (Appendix G) was consulted.

Rigour is judged by the care with which data is collected, analyzed, and interpreted (Tracy, 2010). To enhance rigour for qualitative research Milne and Oberle (2005) put forth strategies to use including sampling flexibly yet systematically, ensuring that transcription of interviews is accurate, ensuring that coding is data driven, and giving attention to context on a continuing basis. As this was a secondary analysis and the sampling was already completed in the larger study, the sampling could not be overly flexible. However, it was flexible in that only mothers' interviews were used. The coding was data driven and continual attention was given to context in this study.

With regard to secondary analyses with qualitative data, a main concern involving rigor and ethics (Ruggiano & Perry, 2019) is the currency of the dataset (Hinds et. al., 1997). As qualitative data involves both the collection and interpretation of data at a certain time, it can be shaped by the political, cultural, and social context of that time. Should primary data be analyzed too far from that time-period, context and norms can change (Ruggiano & Perry, 2019) and thus the data or analysis is not current. This is one concern I continually and carefully considered throughout the entire secondary analysis as the childcare and early learning landscape is changing very quickly in Nova Scotia. The importance of being reflexive about the data in relation to this changing context was recognized and addressed on an ongoing basis. The interviews were done in the summer of 2022 and were less than a year old when this secondary analysis was done.

My aim was to be *sincere* in this research by being honest, self-reflexive, transparent about the entire research process, and by auditing the data (Tracy, 2010; Yardley, 2000)

which I did. To achieve *credibility, meaningful coherence* (Tracy, 2010) and *internal consistency* (Lincoln & Guba, 2000), I located myself in the research and was consistent with my approach of inquiry and what I hoped to know from the research questions. My aim was to produce “a meaningfully coherent piece [that] makes use of the concepts that fit [my] paradigm and research goals” (Tracy, 2020, p. 848), and I feel this was accomplished.

Braun and Clarke’s (2022) 15-point Checklist for Good Reflexive TA (p. 269) Appendix G along with “thoughtful engagement and understanding” (p. 268) were helpful for me to be reflexive in the analytic process. The reflexive journaling, I did throughout the data analysis phase and the entire research process, helped me reflect on my ideas over time and document how my ideas about the data evolved and were integrated in a reflexive manner. Journaling also helped me be reflexive about my own role, assumptions, and values. For example, I used the checklist to prompt me to thoroughly recheck the transcriptions (Braun & Clarke, 2022, no. 1 of the criteria for good thematic analysis) from the larger study against the original interview recordings to ensure accuracy. I also analyzed and interpreted my data to tell a coherent story of my research (Braun & Clark, 2022, No.7 and 9). I allowed ample time to complete all six phases of the thematic analysis so I could spend time with the data to fully and actively develop internally coherent and consistent themes (Braun & Clarke, 2022, No. 11). I also was an active researcher in the research process of this study when developing well-defined and distinctive themes and frequently referred back to the research questions (Braun & Clarke, 2022, No. 6 and 15).

3.7 Ethics and Ethical Considerations

Procedural ethics involves seeking approval from a relevant ethics committee to undertake research involving humans (Guillemin & Gillam, 2004). Although there were no

anticipated risks in this study, this did not mean that risk was not present. I assisted in completing the application for the Dalhousie University Research Ethics Board (REB) with regard to the larger study, I was reflexive about the ethical considerations throughout that process and study, as well as with the secondary analysis. The REB for the larger study was approved and this ethics approval extends to the secondary analysis. Please refer to Appendix A for the REB approval letter for the larger study. Informed consent was gathered at the time of interview for the participant's information to be used in further data analysis as related to their interview answers. Data and documents were securely stored with pseudonym identifiers only. I ensured the privacy and confidentiality of all participants, their children and spouses/partners, throughout all of the secondary analysis. Childcare settings were not named in the study and were referred to only as a childcare setting for privacy and confidentiality purposes. Data and notes stored electronically had encrypted password protection. Paper data was stored in a locked cabinet in my office, and I was the only person with a key.

A strength of secondary analysis of qualitative data is that it eases the burden and time needed of research participants and community partners to collaborate with researchers and participate in the study (Ruggiano & Perry, 2019). It should be noted that I was on the primary research team and participated in collecting and coding data for the larger study. In some cases when doing secondary analysis, access to primary data and the primary study team as well as decisions around authorship can be difficult (Hinds et. al., 1997). For this smaller study, these issues were all discussed with a plan for access and authorship. Hinds and colleagues (1997) also noted that another challenge in secondary analysis can be that the secondary researcher is not able to assess the quality and nature of the primary data set, defined as formally determining the primary data set's qualities and characteristics including

gaining an overall impression of the data. As a primary researcher in the initial study, I felt I was better able to determine the nature and quality of the data set in relation to this secondary analysis. As a primary researcher, however, I must also acknowledge my closeness to the data, which affords advantages and disadvantages that are important to acknowledge. Closeness benefitted me as I knew the context of the primary data well, however I needed to be intentional about not having fixed ideas or making preliminary assumptions about the data in the secondary analysis (Hinds et. al., 1997).

Chapter 4 Findings

These findings are based on the interview narratives of mothers of children experiencing disability. They are organized in response to this study's two research questions. The first section on the invisible work mothers do in pursuit of inclusive early learning and childcare provides a detailed description based on data analysis of the occupational roles mothers take on to perform invisible work. The second section addresses the sociocultural factors that affect mothers' engagement in invisible work as a form of occupation.

Question One: What kinds of invisible work do mothers of children who experience disability do in pursuit of inclusive early learning and childcare in Nova Scotia?

The invisible work mothers of young children experiencing disability do in pursuit of inclusive early learning and childcare was reflected in five themes identified from the data using reflexive thematic analysis (Braun and Clarke, 2006, 2022): The Navigator, The Quilter, The Fighter, The Juggler, and The Keeper. Each theme represented an occupational role mothers engaged in to perform the invisible work to pursue inclusion in early learning and childcare.

4.1 The Navigator

This theme illuminates how mothers of children experiencing disability navigate various systems to access inclusive early learning and childcare. All mothers noted that navigation was difficult, and many labelled it as work. Erica described it as “a little mini job, trying to figure out where we were going to put our son.” She added, “knowing where to look, how to look, [and] having the patience to look” were all important for successful navigation. However, no job description, map, decision tree or guidelines existed to do this navigator job. Most mothers indicated they had to ‘learn on the job’ and actively seek information, not knowing where to

start. Samantha acknowledged that this navigation was a steep and ongoing learning curve involving many systems; she did not always know who to contact or what to ask, and information changed often. She discussed difficulty finding out about “local resources and just what’s out there and how people are navigating these ridiculous systems...to advocate for your kid”, and that you never really know if you have connected with all the right people and places.

In preparation for navigating childcare access, mothers worked to understand their family needs and wants. Most mothers had mental or written lists to track this information. Wish lists typically included a safe, clean place, close in proximity, with low teacher-to-child ratios, and where their child would have support and would be included in all activities with peers. Transportation methods, hours of childcare operation, hours of maternal work, and when to pick up other children typically influenced childcare searches and location needs. As childcare offerings rarely met mothers' wants or needs, they had to be flexible, alter expectations, and continue navigating to find inclusive early learning and childcare.

Mothers reported navigation work started with a lot of ‘research’. Bridget labeled it “self-directed research”, reflecting how independent and directionless the process was. Mothers often began navigating by openly searching the internet or social media, asking others, or scouting community daycares. They sought reviews and feedback to evaluate suitability of childcare options. Mothers formed opinions about inclusive childcare through this ‘research’ including discussions with childcare settings and other parents, consideration of reviews, and performing site visits. Teresa shared:

We did a lot, a lot of research and kind of digging around. I became a little obsessive over kind of checking out reviews. So, looking at the photos told me a lot about the facilities,

especially the day care centers. So, I would do a lot of review checking and looking at the photos and seeing if they offered any inclusion support.

Mothers indicated this research process required work skills; they had to organize and problem-solve. They spent time and effort on navigation work, often administrative in nature, finding childcare provider names, writing and reading emails, seeking and tracking childcare setting reviews, making phone calls and follow-up calls, filling out daycare application forms, putting their child on waitlists, arranging meetings and site visits, visiting and appraising childcare settings, and meeting with providers to discuss their child's specific needs and overall accessibility of the childcare setting. Mothers formulated lists of questions to ask settings about accepting children who experience disability, waitlists, wait times, programming details, inclusion, staff training, support types and amounts, staff-to-child ratios, and more. Mothers tracked who they contacted, the waitlists their child was on, the settings that rejected their child, fees, and other details.

Application information required by childcare settings varied; sometimes mothers submitted a child's name and phone number only, while other times they completed paper or electronic applications that ranged in length and asked about things like their child's disability, diagnosis, and interests. Navigating waitlists created a lot of work for mothers; they often called childcare settings to check on their child's waitlist status and remind them they were still waiting. Kiana highlighted how this necessitated more work: "I had to call, like I basically called them all the time, asking like, I just wanna know where he is on the list." Mothers were often discouraged since their child's name remained on waitlists with sites never contacting them. Mothers also explained that the time spent navigating took away from other meaningful occupations. Teresa said she "spent a lot of the later months of maternity leave, scrolling the internet researching and

finding ways that would be best to help Liam," decreasing time actually spent with her son. This time-consuming navigation work often was unsuccessful, requiring them to start anew.

Once they accessed childcare, mothers were often considered responsible for providing training to childcare staff for such things as positioning and feeding. This involved work; some mothers gathered teaching materials, called health providers for advice, made information binders, and/or made their own presentations for staff. It was often mothers' jobs to not only train caregivers, but at times do some tasks their children needed at childcare if caregivers were not allowed or trained to do it. In relation to her son's gastrostomy tube (G-tube) for feeding, Bridget shared:

My son has a feeding tube now. So, if the feeding tube comes out, um, they wouldn't put it back in 'cause that's deemed medical. So, they have to call me and then I have to go, and I have to put it back in. And if I can't get there in a certain amount of time, 'cause the hole will start to close up, then they have to take him to the [children's hospital] and call me and I have to go to the [children's hospital] ... So that is to them deemed medical.

Interestingly, an everyday occupation of mothering for Bridget was considered a medical intervention by others.

Mothers navigated childcare costs and finances by budgeting and doing the work to search and locate potential financial resources. Some mothers discussed that not knowing about financial aid and having to search for it prolonged their navigation work, such as researching government programs and subsidies and their various criteria. Many mothers did the work to navigate these resources to learn they did not qualify for subsidies as their income was considered too high. They were then left to find other resources. Regarding the work to complete a subsidy application, Cara stated, "I don't remember it being overly complicated, but you need

to bring them a copy of your pay, and just fill out everything about you, and your child, and all the money that you bring in and stuff.” She stated it was a “long” wait to receive it. After filling out the application for her own child, Kiana helped other mothers do the same to ease their burden.

Navigation work for a few mothers was related to attempting to find part-time inclusive childcare. Due to economic barriers, these mothers could not afford full-time care but wanted their children to have some opportunity to socialize with other children in a childcare setting. Thus, they searched for a form of part-time childcare. Childcare settings that were flexible and offered part-time care were seemingly more difficult to find than settings offering full-time care. However, mothers did not give reasons for why part-time care may be more difficult to secure. With some navigation, Teresa was able to secure part-time childcare for her son for two and a half hours each morning, which was what she wanted. In contrast, Kiana, who was searching for full time childcare, initially could only find childcare in a centre on a part-time basis for two days per week. She had to patch together childcare and wait months before she could access a daycare centre where her child could attend for five days per week.

Mothers shared examples of work they did in addition to the usual occupations of mothering. Work included navigating diagnosis processes, deciphering the meaning of medical information, building the child’s health team, supporting therapies in home and childcare, and attending appointments. This excerpt from Lena illustrated the work she did to understand her child’s diagnosis so she could best help her daughter:

LENA: “our first appointment with her pediatrician, when she was diagnosed globally delayed ...was when I asked him about the genetic blood tests. He got it done that day...a few months later I got her results back, it was so difficult...I had to ask them for the

paper... and that paper...had a lot of confusing phrases...It was, it gave me her exact chromosomes... she has, um, a deletion in one of her chromosomes, and a duplication in another chromosome. So, it took me quite a while to figure out what those meant.

INTERVIEWER: Were you kind of left on your own to figure that out?

LENA: “Oh yeah. I went to all of her support workers, and none of them knew anything about it. They didn’t know anything about, um, chromosomes. I’m the one that actually even taught them a few [things] because I was doing a lot of research.

The Navigator role entailed constant engagement – and preoccupation – with new and unknown tasks related to disability and childcare.

4.2 The Quilter

All mothers took up the role of the Quilter, planning, designing and crafting childcare by patching and piecemealing it together for their children experiencing disability until they made it work. This patching and piecemealing process usually involved multiple childcare providers and limited options. Their patchwork may have not been their desired childcare plan or goal, but it had to work until they could patch together something they considered better. Bridget noted, “we just kind of piecemealed childcare as needed until he was accepted” into daycare. Mothers quilted childcare in pursuit of availability, affordability, accessibility, inclusion, and socialization for their child, as well as to accommodate for mothers’ employment or education obligations.

Mothers would patch and change childcare arrangements if it meant accessing a more inclusive environment. They would then continue the work of searching for childcare they considered more desirable. Kiana shared:

That first actual daycare that I put him in is, like, not the best daycare, but I had no choice... I don’t think they were really qualified to work with disabled children, but I was,

you know what I mean? I had no choice. And even when they send you home notes that they're frustrated because he's cranky and threw a toy, there's nothing you can do. You have to keep sending him there because you have no other choice for better childcare.

The childcare options mothers researched, and attempted to procure, came in many forms. They also weighed the cost-benefit of mothers, or in one case a father, staying home in lieu of external childcare. Care was often required for before- and after-school and summers for Pre-primary children.

Dayhomes were often the first option mothers could access. Some mothers with children in dayhomes were told their child was too difficult or disruptive to manage, often in the first few days of attending. With no alternative childcare, mothers need to start their search over. After those encounters, if they had not already, mothers expanded their search beyond dayhomes. Some mothers never considered dayhomes, as they did not think they were accommodating. Samantha explained her thoughts and rationale for choosing a daycare centre by addressing:

The differentiation between the center avenue and...the less formal home day care options ... personally I barely even thought about it...We needed to know we had care every day, you know there was no summer vacation or whatever, but that being said in my opinion a home set-up or a smaller center is not even an option for a kid with extra needs. Because then you're looking at if a child had mobility issues, is the house going to be accessible to them? You are thinking about ratio – if they have one person, maybe they could have 6 four-year-olds or however many it is but if you add my kid to the mix, they can probably only have 2. That is another limitation to families with additional needs children...the pool for childcare resources is that much more limited because I

think probably for most of us, we are looking at bigger centers who are able to accommodate our kids.

Even when accessing a larger centre, mothers shared that those centres were not necessarily inclusive, accommodating, physically accessible, affordable or had trained staff. This led some to continue their searches, while other mothers did find childcare, they were content with, such as Erica, who said her son “is where he is supposed to be and he’s enjoying it and we’re very happy.”

Pre-primary programs administered by the RCEs or CSAP are tax-funded and made available to students one, and occasionally two, years prior to their entry into formal education. Mothers need only register their child to attend. However, they were responsible for the work of planning and designing, patching and piecemealing childcare around the Pre-primary school day. They discussed how the need for summer and before- and after-school care created work, as Pre-primary only ran the length of the school day and not in summer. Some mothers accessed or attempted to access before- and after-school childcare programs including programs like Excel in RCEs or Petit Voilier at CSAP. Often, before- and after-school childcare programs were full, with long waitlists. When these options were not available, mothers investigated community alternatives. Many mothers tried to bridge Pre-primary and formal schooling with summer camps, but it was often difficult to find inclusive camps with trained workers. Thus, Pam, a mother who could not find inclusive childcare for her son with a week left before summer, was forced to take an abrupt leave from work.

Needing to patch together childcare affected life decisions, including workforce participation. A lot of work went into trying to make childcare and the paid work of mothers congruent. Visually mapping the processes of each mother’s childcare journey depicted that

quilting childcare took a substantial amount of time, effort and creativity and sometimes numerous patches. Kiana shared an example of this (see Appendix E, Figure E3); after the owner of the dayhome her son had just started attending told her he could no longer attend there, she had to determine a new childcare plan and make it fit her work hours:

I was due back to work the day after his first birthday so I took him [to the dayhome] a few days before while I was still on maternity leave to try to drop him off for like an hour for him to get used to it and literally the first day she was like, I dropped him off,...I was only gonna leave him for like an hour or 2, and then she's like texting me like he won't stop crying, I don't know what to do. And then the next day I brought him there again and then literally she texts me, she's like yeah, he's like freaking out. He hates me. And when I went there, she's like yeah I don't think it's going to work out because like he's having a really hard time. So literally I was due back to work like the next day and had no childcare. So, I started like calling all the daycares that I already had him on the list for but there's only a handful in Cape Breton that take 12 months [of age], most don't take until 18 [months]. So that was 4 years ago, so my mother, my mother took a stroke like a year and a half ago so she was actually in decent health then and she was working herself. So, I work 8:30 to 4:30 and she works 3:30 then 'til 8:30 so she's like I can watch him in the day but like I get off at 3:30. I don't get off 'til like 4:30. So I had to get another um, I found another woman and I had to pay her to watch him from 3:30 to 4:30.

Kiana spent a lot of time organizing the logistics of this childcare patching job as there were several hurdles to work through to ensure she could be employed, and her child was cared for.

One difficult obstacle was her son needed to be transported from her mother's home to the

caregiver's home. Kiana recruited her younger brother to walk her son between homes, and Kiana picked her son up after work. This continued for 8 months.

In another example, Teresa made a significant life change and resorted to creating childcare by opening her own dayhome, when she could not find an inclusive option for her young son, Liam. She quit her job to care for him, but as she required income and a means for Liam to socialize, she needed to make it work. She stated:

When I found out Liam had a disability when he was 6 months old, uh, we started looking for daycares. At the time, we really thought a dayhome would be more beneficial given his challenges. Um, but we did look at daycare centers too. And I actually ended up quitting a career and...opened a dayhome because we just couldn't find somewhere that would provide the support that he needed. So, um, I quit my, my job and opened a dayhome which was never something I wanted to do, nor was ambitious about, but I knew it was what I needed to do to get through.

In this instance, the impact on paid work was dramatic, causing a mother to make an abrupt and unwanted career shift.

Chelsea also could not find childcare in a centre for her son experiencing disability and posted an advertisement in a "Childcare Needs Facebook group" to search for someone to look after her children in her home while she tried to work. Three applicants were interested, and Chelsea then formulated interview questions and scheduled interviews. One applicant did not show up for the interview, one had no experience with children, and the successful applicant had years of daycare experience. Once hired, Chelsea had to arrange remuneration, teach the new caregiver about the needs of her son experiencing disability and train her how to manage his

Gastrostomy tube (G-tube) for feeding. She noted she was still in the house trying to work when the caregiver was there, so was never far in case something went wrong:

I will get up and come out if Connor is really upset...I will leave her to try and calm him for a while. Sometimes he doesn't calm. Then the feeding. I have been working on training her on how to feed him with his G tube. Just because of timing, she was here for about a week straight and starting to get it, then Connor got sick, so she was off for an entire week. Now she is not fully remembering what she is supposed to do again. So, I am back out helping her still. Most of the time because once he hooks up to the G tube, he can sit in his highchair, and she doesn't have to do anything except watch him and be nearby— and I will go back to work at that point.

She discussed how this hindered her work productivity and caused a lot of household tension and stress, as her husband often worked away, and the care was mainly her responsibility.

4.3 The Fighter

“The Fighter” theme highlights mothers’ engagement in advocacy-related occupations for their children experiencing disability. Almost all mothers used language of conflict, likening their advocacy efforts to a “fight” or “battle”. For example, Teresa stated it is a “constant fight of advocating for your child with a disability” and Bridget discussed she had “to constantly battle”. The term ‘constant’ was often associated with advocacy to illustrate relentlessness throughout the navigation and quilting of inclusive childcare. Mothers anticipated their fight would continue into their child’s school years; this work would not end. Kiana noted, “sometimes it is frustrating ‘cause no matter where he is, I’m gonna have to like, you know, advocate for him”.

Mothers reflected on the work of advocacy describing necessary advocacy skills, the need to be persistent, and the amount of emotion work involved. Kiana noted advocacy work

was “not easy. You have to learn to do it actually. If you’re always like, I don’t want to ruffle feathers and piss people off..”, she then shrugged. When discussing advocacy, Samantha stated, “you need to be a pain in the ass really. It is a lot of work.” Bridget reflected on her own abilities: “I guess there’s a little bit more... confidence I guess is the word for that, to just not take the *status quo* as what it is and fight for what I think he needs. Um, it’s a lot of advocacy.” Quality communication with childcare staff was identified by mothers as integral to advocating for childcare; poor communication created a lot more work. Kiana stated, “You have to ask all the time [for others] to make accommodations for your child.” A few mothers discussed needing to come out of their comfort zones to advocate for their child. Andrea expressed this uniquely:

We’re resourceful and we’re capable and, you know, I know that not every family has the ability to put as much time and effort...into advocating for their children. Like it’s, it’s a fight, like it really is a fight. And I am a very, um, passive, quiet, figure-things-out-myself kinda person and, you know, having a child with special needs was a real rapture in me, in that I had to get real comfortable, real fast with making other people uncomfortable to ensure that my child didn’t get special treatment, but got what he needed. You know, it’s not, it’s not about special treatment, it’s, it’s about basic rights, basic needs.

Mothers continually fought to get what they wanted or as close to what they wanted as they could for their children experiencing disability and their families. Mothers were fighting for the safety, inclusion, and acceptance of their children, free from discrimination, that satisfied their children’s basic human rights. They were fighting for equitable and accessible early learning and childcare. When their children were accepted into childcare, mothers fought for inclusion to be enacted, good communication and relationships with childcare workers, workers to understand

their children's needs, and to have supportive teams for their children. Mothers did the hard work of advocacy, with Samantha advising "if [childcare settings] are not doing what you need them to do, fight and get it".

The "fights" mothers engaged in when pursuing, and even when attending, inclusive childcare were broad and varied. For example, Tiffany discussed her fight to have her son accepted into childcare and how he "was actually denied into two daycares, and almost denied this one he is in now until [she] fought tooth and nail for him." Andrea "had to fight to have the background radio, the music that the teacher liked to have on in the classroom, we had to fight to have them understand that that made, um, Aaron's comprehension and speech development harder", a significant need for her child. Teresa had to fight for childcare employees to "see" her child and not be dismissive of his needs or think he would be easy to work with. She feared settings would accept him initially, but when the time came for him to be given a space, they would not be able to support him. Thus, the family would again be looking for a spot for him to be cared for. She shared:

We called and viewed at least four dayhomes and all of them made promises that I knew from my experience was impossible. They just really had no idea of what they were getting into. The daycare centres... I think I emailed everyone in [my local area] and if they did reply they would be very dismissive of Liam's needs and basically [say] we can manage... And because Liam to look at might not scream 'child with disability'... and, at that point, he wasn't in a wheelchair, so we often had to really advocate for his needs. People at the dayhome level just had no idea of the supports he would need. He was very much being classed a typically developing child by other dayhomes, um, which wasn't the case, um, and so we didn't really feel like...we could trust anyone with him.

While all mothers may engage in advocacy, the mothers in this study were advocating to meet the poorly understood and complex needs of their children.

Mothers were also fighting for their own ability to be employed to earn money, go to school for an education, or have a break. If mothers did not have childcare, their ability to go to work or school was threatened, as all mothers put the care of their children above work and school. Tiffany stated that without childcare she “wouldn’t be able to work, wouldn’t be able to go to school”. This was stressful for mothers as working outside of the home or going to school was often required to provide financially for their family.

In addition to stress, many mothers discussed that advocating continually was tiring.

Bridget stated:

Other families that I speak to are just tired of the advocating that gets us nowhere. Um, so just keep, keep doing it because that’s the only way that change is going to happen for the next kid and the next kid and the next kid. But it’s hard. And it’s exhausting...So, my advice is to just advocate for what you believe in for your kid and what they need but [pause] it’s easy to wanna stop.

Knowing the need to fight will persist, some mothers were teaching their children to self-advocate. Pamela reflected on working to teach her son his own self-advocacy skills and its’ importance: “Even at school, like I said, he will tell them, like, I need to go in a quiet space or something’s too loud. So, he’s doing that and he’s advocating for himself too.” A few mothers believed their persistent advocacy had the potential to help not only their own children but also other children experiencing disability and their families.

When asked for advice about advocating for their children experiencing disability, many mothers shared the need to keep fighting. Lena stated:

Never stop fighting for your child, keep looking for what is...what you feel is best for them, and even if you can't find it, even if you can't find it like I couldn't find it...I fought for our school [Pre-primary] to be able to help my daughter. I fought my community to be able to help my daughter. So just to never stop fighting for your child. Because you are the voice for your child.

4.4 The Juggler

The theme of the Juggler was identified as all mothers of children experiencing disability tried to juggle maternal duties, family, social roles and expectations, competing demands and multiple work responsibilities, both visible and invisible. Mothers described the work of trying to simultaneously perform many tasks such as household activities, including cleaning and meal preparation, caring for their children, and working in the workforce. This was apparent even when mothers were engaged in the interviews while simultaneously helping their child with activities such as feeding or wiping their nose. When asked how the inability to access childcare outside of the home affected her family, Chelsea gave a detailed example of her invisible work and the many activities she tries to juggle:

I have no time for the family life... I do 5 hours [of paid work] during the day. So, I get up with Nicole and get her off to school. If I do any appointments with Connor, I try (child babbling in background)...to put them in the morning, that doesn't always work, but I try to put them before noon, so that I don't have to interrupt the workday anymore. So, we run around to appointments all week in the morning. Then in the afternoon I will work my 5 hours, so Nicole will come home and play with the babysitter. At 5PM when the babysitter is leaving, [Nicole] wants to play and do stuff, but I don't always have time because I have to cook supper and I don't have a big window [of time] because the kids

go to bed at 7. So, between 5-7 I have to get supper cooked, get them fed, get them bathed if they are having a bath that night, stories read, and all that stuff done. Get them to bed. Teeth brushed, whatever, and off to bed. [Connor] usually takes longer at 7, he's probably not down until about 7:30-7:45. At that time I put him in his crib, and that's if I am lucky ...because lately he wakes up screaming when you lay him in the crib. So, it can take a few tries. On a good night we can get him down between 7:30/7:45 when my husband will come home and he will be trying to eat supper, and I will be trying to clean up the house as much as I can. Then, I will go to work, my husband will be out here doing whatever he does. And I'll be working. By the time I am done, there is no time left for anything except getting the house cleaned up and prepared for tomorrow and go to bed. Since surgery, my son has been sleeping in our bed with us, because he seems petrified of his crib. And the weekends are spent, you know, groceries, lawn mowing, clean up the house, get stuff done you can't do all week. It's hard to find time.

Her description illustrates not only the multitude of occupations surrounding othering a child who experiences disability, but also the complexity of keeping all the balls in the air, in a carefully choreographed performance with little room for interruption or improvisation.

Bridget also spoke about juggling her son's health and childcare needs and coordinating his appointments with her own schedule.

Appointments that we go to, it's nice now that we have the daycare that they can happen without me when I need it to, but it's a lot. It's probably a full-time administrative job to manage all of his support people and when they're seeing him and where and if I have to be there or if I don't have to be there and what they need before it happens. I would say it's a lot...all that extra administrative work is extra.

Juggling so many activities was complex and emotionally draining. Maria said, “As a working parent at the same time as a mom to this child and two other children...it is very difficult to balance everything, and we find it overwhelming.” Mothers had to prioritize what they attended to and what must wait. Cara stated this juggling “is a lot. And it does take a toll on me... I will have a day where I’m like, I can’t go to work. I’m too tired. I need to catch up on housework.”

Some mothers in the study alluded to the work of navigating, quilting, and juggling childcare as being gendered and reported doing most or all the work compared to a partner. This inequitable, gendered work included researching, planning, and the bulk of the caring. When Kiana was asked if her husband was able to help with accessing childcare, she laughed and replied, “No. I feel like he just felt like you have a kid, and then you go back to work, and just call a daycare and say ‘hey, can you take my kid’? It wasn’t like that.” Cara noted she was going away overnight and hired paid caregivers to come into their home to help with her twin sons with autism so her husband could “have a break” and get them to bed and daycare. A few mothers discussed they juggled work with their partners, although the balance may not be equal. Teresa discussed the balance struck with her spouse:

[We] have a good balance. I don’t think I could work; I couldn’t work full time while having a child with a disability. I don’t know how any parent does it! So, I’m fortunate that my husband takes on a lot of the financial burden and works a lot of hours during the week while I do the other side of the family stuff, which is a little bit of work and then taking Liam to most of his appointments.

All mothers in this study had varying degrees of involvement from fathers. Chelsea, who works at home in the day and then again when her children go to bed, discussed how gender expectations have affected their family life:

My husband was supposed to get it set up at work that he would be home by 8 every night. But he works for some people who are very old school, and the men are not supposed to do anything with the kids, the women are. So...he's not usually home, like I said he is away now for a few days. If the kids get up after 8, when I have to work, then I have to go deal with the kids and get back to work later. So, it can be 2AM and I am still working some nights and then get back up again.

Not only does the role of the Juggler fall primarily to mothers, but (when done well) it is rendered invisible.

Some mothers noted that pursuing inclusive childcare for children experiencing disability entailed more work, more barriers and required juggling more activities, compared with accessing inclusive childcare for typically developing children (with some mothers having experience with accessing both). Bridget, who is self-employed, shared that when looking for inclusive childcare for her son experiencing a disability, she juggled a lot:

It's just not as easy. Like it's just, I felt there was only two options where other parents would have multiple options. The two options were nowhere near my home. So, I had to be willing to take on the extra travel time and the impact that that would have on my ability as a self-employed person to accept or not accept work. Um...Like meetings or opportunities for me to be at the center to do education pieces is time that I have to take off, you know, possibly making my income...So there are lots of like lost income opportunities and I guess personal sacrifices, which everyone will do as best they can because that's what you do for your kids.

Juggling for these mothers was difficult, extra work and some things had to be dropped. When her son started childcare, Sandra shared:

It was more of an ask when he was starting than others, more preparation, transition meetings and even when we had started...we had 2 transition meetings leading up to him even going...I am glad they want to, but it is more. It is more.

These extra meetings did not occur for children not experiencing disability who were entering childcare. Kiana reflected, "If most people have a child, their life changes but like if you have a child with a disability like your world literally flips upside down. It doesn't just change."

Mothers discussed the work of pursuing childcare affecting their entire lives, including paid employment, where they lived, and how they spent their money and time. Andrea expressed:

Here, again, is another way that having a child with special needs is, and I'm not saying that it's for better or for worse by any – not making any judgment about it at all, it could be the most wonderful thing, um [pause] but it's influencing in a bigger way the decisions that, you know, our family will make about the career that the working adults have, um, and about even making decisions about where we live. You know like [pause]. We might like to move to another city, to another part of the country, to another part of the province, um, and we would have to do a lot of research into whether or not Aaron would be supported and that the resources we need would be there. So, you know, there's, there's impact in a much bigger way when you have a child with special needs.

This is illustrative of how mothers of children experiencing disability and their families are continually cognizant of how the construct of disability affects their lives, occupations, and contexts.

4.5 The Keeper

Mothers in this study all spoke about the complex emotion work related to their pursuit of inclusive early learning and childcare for their children experiencing disability. They were the keepers of their own emotions and of their family's emotions. The job of a keeper is to preserve and maintain, to watch over and defend, take care of and tend, and offer support (Merriam-Webster, 2023). Mothers discussed keeping and managing various emotions, primarily negative in nature, including "guilt", "stress", "worry", "panic", "anger", "frustration", "anxiety", "exhausti[on]", "disappointment" and "defeat". Feelings of shame were linked to guilt and the perceived inability to adequately fulfill mothering duties. Mothers discussed these emotions as constant and overwhelming in all aspects of their work to access inclusive early learning and childcare, including when children were refused childcare or were attending for the first time. Andrea directly labelled emotion work and differentiated it from practical work. She stated, "so there's like the practical work of, like, problem solving and then there's the emotional work of, you know, like having the conversation with the first day camp that prides themselves on their inclusivity...and feeling so defeated" on discovery they were not inclusive. Emotion work and practical work frequently overlapped, however. For example, when mothers faced and felt 'defeat', it often meant continuing the practical work of patching together better childcare solutions.

Responses mothers received from childcare settings directly affected their emotion work and the type of emotions felt. Children denied childcare, sitting on their own and not included when mothers went to pick them up, or labelled as 'difficult to handle' were all situations exacerbating negative emotions. Mothers spoke of the stress and anxiety they felt, or feelings of depression when they did not know if and when they would have childcare and how they would

juggle it with all of the other demands in their lives. A few mothers discussed how this stress was compounded because they never had breaks or external support. Lena shared her experience:

I was very depressed...I was crying almost every day. Every time I'd talk to my friends about it, I would cry because I didn't know what I was supposed to be doing for providing for them. And because welfare is not a lot of money and I know I have a lot of bills to pay...like almost half of welfare would have gone towards my car payment and then I have my phone bill, then for gas, for taking my kids to their appointments, like...It was very hard. And then my mom got sick during that time...she was feeling um weak for a few months. And so I was trying to figure out um what I can do for another job, if I could get an evening job and I was trying to figure out who I would be able to get for childcare. I don't trust many people with my kids, so that was even harder. And my mom even told me that she wouldn't be able to take care of both of them and so that put even more stress on me, so I was just like, for months, I was just crying.

Bridget described how challenging emotions did not go away even when childcare was found.

She commented that when she left her son at daycare her emotions were also difficult to manage:

It's stressful. It's definitely, like it causes me distress...I'm anxious about it a lot...I don't always trust when I leave him there that he's going to be okay, but I don't see another option. That's hard to deal with...I know it's probably the best place for him in terms of childcare settings, but it still doesn't feel like it's as good as it should be.

She also mentioned the work mothers did for their children could be repetitive and not effective, adding to their stress and fatigue, and sometimes feelings of defeat. She commented this was often related to systemic requirements, which can be onerous and discriminatory:

Again, around the systems, it was just another series of hoops to jump through in order to get something that we needed so, like the mental strain and the exhaustion from like, going through another system, 'cause there's just a lot of applications and a lot of paperwork and a lot of proving disability [laugh] that can be really exhausting.

Some mothers discussed that advocating for their child was exhausting. Bridget touched on the mental load required to process what needed to be done to advocate but acknowledged she needed to be ready to do that work:

When I seek care for him or when I, you know, there's something that he needs, but I honestly can't wrap my brain around writing an email and so it'll just sit and wait for 2 weeks until like, my brain is ready for that but that's 2 weeks that he could have had something that he needed, um, so I have to constantly battle, battle and balance that, as in not giving all of that all of my attention all the time; it's impossible.

Although, she did not mention it directly, Bridget implied that there was guilt involved when her capacities to juggle everything were exceeded.

Mothers often discussed feeling judged by others or that their child was being judged by others, or both. Some mothers tried their best to control this judgement with their actions. An example of this was when Kiana reflected on her thought process around when to tell daycares she was applying to that her son had autism. She stated, "I didn't want to tell them but, because I felt like then he'd be judged before he even got in the door...I also don't want to not tell them and then...not have enough support that he needs."

With judgement, often came guilt and self-criticism about whether they were adequately meeting the needs of their children. Guilt frequently stemmed from the belief they could have done more for their child or been a 'better mother'. Pamela detailed a range of emotions: "I get

angry, and I get sad and then I feel guilty because I'm feeling like maybe I'm not advocating enough for my kid." Guilt was expressed by mothers immersed in finding inclusive childcare; some felt they were neglecting other children, relationships, and work. Some reflected they were constantly living in an unpredictable environment without routine, trying to fulfil all their roles. Pamela discussed the various reasons emotion work is created and touched on a wide array of emotions:

After school when I pick him up and come home to work, he's really tired...if he is losing his mind when he gets home, we kind of have to, okay, we spend some time to kind of decompress and bring that in and okay we get you your snack and set you up with maybe your tablet for 2 hours or an hour and a half before anybody else comes home. Is it ideal? No. Is it teaching him anything? Nope. Maybe he's just in front of the TV, he does need his downtime, but I'm not parenting. I'm just kind of propping him with some stuff and there he is, like I'm not engaging. And I'm also stressed out because I'm not giving either the proper attention. I'm not giving work the proper attention; I'm not giving him the proper attention. And yeah, so my doctor has given me a note to put me off on stress leave, got some medication that I need to pick up and a referral to the psychologist. There's a lot going on, not just this and the pressures of work and there's some outside things at work that, you know...I'm gonna crack, I'm pretty upbeat, I'm like let's do the things, you know, but I love my job. That's the other thing, I don't know, it's crazy but I've always loved to work. And I do work too much and when I'm trying to avoid other things, I will focus on the work because I can control part of this. I can be good at this when I'm not good at that.

Emotional well-being and the need to care for oneself came secondary for mothers in relation to all the other work they did. In relation to advocacy work, Bridget asserted it was important to “figure out a way to avoid the burnout.” Pamela’s need to go on stress leave illustrated that her need to manage her emotion work, paid and unpaid work including parenting, and well-being had become overwhelming, affecting her health. However, her stress leave had not started before she had to stop working because her son had no summer care, adding to her stress.

Several mothers disclosed they frequently cried, particularly when they felt their child was being discriminated against. When Lena was waiting to know if she secured childcare for her daughter, she discussed the childcare setting “kept telling us we have to see who’s going to be coming, we have to see if we have enough workers, and so it was all that that we were waiting on and so I was almost crying almost every day.” Some mothers expressed often experiencing dynamic and sometimes contradictory emotions. Lena felt happiness when her daughter learned something new in childcare, but also guilt and sadness she was not there to experience it with her. Mothers spoke about the difficulty of managing their emotions with others, and at times they could not control them. Cara discussed after a rough day she may “end up having, like, an emotional outburst at [my husband] because I’m like, feel like my mental load is way greater than his.”

Although many emotions mothers identified were negative, some mothers identified positive emotions such as happiness, gratitude, joy, and relief, often in relation to their children accessing inclusive childcare. Through tears, Erica described her range of emotions:

He loves it and that makes me so happy as a parent. I know the first couple days was not like that. I mean he cried, I cried and literally it was just days and like the second week in he was just like yeah, here I go... I’m so thankful that he is where he is.

Responses from childcare settings deemed favourable to mothers often alleviated stress and anxiety providing a felt sense of relief. Sources of relief included having their child accessing childcare they perceived to meet their needs, flexibility, good and consistent communication with the childcare setting, and the financial relief offered by the new universal childcare program.

Emotion work by mothers was not isolated to themselves, they also did the emotion work for their children and partners. They recognized their children had many emotions to manage and did not have the skills to do so. Some mothers wanted their children to be able to self-regulate their emotions and perhaps ironically this was a source of stress and worry for these mothers, thus adding to their emotion work. Lorraine was looking for childcare and therapy that offered their child “relaxation strategies, stress management to reduce the anxiety...stress is very hard to manage in our child”. When reflecting on marital relationships when raising a child experiencing disability, Teresa talked about the difficulties and related emotion work:

So many parents break up if they have a child with a disability and I can totally see that because we are thrown so many unnecessary hurdles and challenges. But really it doesn't have to do with the child, it is society that just cannot figure it out and be inclusive and educated. Um, so it's a very stressful point in our relationship mostly because I have the education, I have the ability to advocate, my husband does not. So, he hasn't really been around disability...it causes a lot of tension because we have different views and it ends up falling on, on myself and that seems kind of the norm across this world, that unfortunately that we are living in, as parents with children experiencing disability.

(breathes in)

Maintaining relationships can be difficult and requires a lot of emotion work from both partners on an ongoing basis.

In summary, The Navigator, The Quilter, The Fighter, The Juggler, and The Keeper are all occupational roles that mothers of children experiencing disability attempt to fulfill in their pursuit of inclusive early learning and childcare for their children. The pursuit usually starts with the mother as a navigator of systems who quickly becomes a quilter to design and patch together early learning and childcare. As a Navigator and Quilter, she simultaneously must take on the occupational role of the Fighter to advocate for her child and family, sometimes in an adversarial way, through the navigation and quilting work. She also occupies the role of the Juggler throughout these other work roles, attempting to juggle the many activities expected of her when navigating, quilting, and fighting in addition to her other daily routines and occupations. The role of the Keeper is described last, but this work is threaded throughout the mother's pursuit of inclusive childcare and in every other occupation she performs for herself or her family. These roles are not mutually exclusive. They often overlap and are dependent on one another, with the invisible work sometimes becoming blurred across more than one role as mothers pursue inclusive early and childcare.

As mothers engage in these five occupational roles, they face sociocultural factors that shape their invisible work. These factors can be facilitators, barriers and at times both. It is important to examine these sociocultural factors further to determine how they influence the invisible work and occupational roles of mothers when pursuing inclusive early learning and childcare for their young children experiencing disability. Thus, these factors will be examined next in Question Two.

Question Two: How do sociocultural factors shape the invisible work mothers with children who experience disability do in Nova Scotia?

4.6 Sociocultural Factors

The navigation, quilting, advocacy, juggling, and emotion work mothers engaged in to access inclusive early learning and childcare for their children experiencing disability was shaped by many sociocultural factors, including: childcare space availability and waitlists, affordability of early learning and childcare, childcare location and transportation, staff availability, training, experience and continuity, ratios of teachers to children, professional support, employment support, social support, the Covid-19 pandemic and public health restrictions, and inclusion, exclusion, discrimination and ableism. These factors shaped the invisible work illuminated across the themes above and may have functioned as barriers, facilitators, or both, depending on circumstances. I have expanded upon each of these factors below.

4.6.1 Childcare Space Availability and Waitlists

Mothers discussed there are not enough childcare spaces to meet demand in Nova Scotia, and even less so for children experiencing disability. Infant spaces were challenging to secure compared to spaces for 18-month-olds to 5-year-olds, which were also difficult to find. Several mothers shared they put their children on multiple waiting lists when they were pregnant or when their child was very young, often not yet knowing of their child's disability diagnosis. In some cases where a disability diagnosis was not yet known, mothers had placed their children on waitlists without thinking about inclusion, so when it came time for their child to attend, the childcare setting was unable to accommodate them. Kiana stated when her son "was pretty much born, I put him on like every list and, um, it was actually a nightmare" trying to navigate it all.

The number of waitlists that mothers put their child on ranged from 1 to over 20 waitlists. Cara reflected on the challenge of finding two spaces for her twin boys with autism, at the same time. She was grateful, although surprised, she found a place quickly:

Right now, the waitlist for that daycare is I believe in the 70s. Um, at the time that I called them, there was...we freakishly got right in. I think we waited 2 weeks, um, and then both my boys got in, and they've been there ever since.

Despite Pre-primary being free for families, it too was difficult to navigate. Finding wrap-around care for Pre-primary children was also a challenge for some mothers, often impacting work lives and leading to several mothers deciding their child would remain another year in a daycare they pay for before entering school directly. Teresa expressed her son "will go straight to primary. I did not have a good experience trying to navigate Pre-primary and basically just gave up." Pamela shared that she had decided to keep paying for her son's full-time spot at his previous dayhome although they were sending him to Pre-primary. They quilted this arrangement to have a back-up plan in case Pre-primary did not work out for him. This childcare plan ended up being worthwhile as they ended up taking Aiden out of Pre-primary for a few months and sending him back to the dayhome, due to both COVID-19 related restrictions and because they felt he regressed while attending Early Intensive Behavioural Intervention (EIBI) in Pre-primary.

Some mothers shared that securing a space was sometimes easier if they had an older child attending a daycare or who had attended previously, as siblings generally get moved to the top of waitlists. This was true for Andrea and Jennifer, spouses who were interviewed separately. However, Chelsea reflected that while her son, Connor, was able to go to the daycare her older daughter Nicole attended she still put him on other waitlists for settings that offered inclusion as

Nicole's daycare did not. Cara, who found care almost immediately, felt she was facilitated by phoning at the "right time" when the place she called had designated spots for children experiencing disability.

4.6.2 Affordability of Early Learning and Childcare

Some mothers noted the cost of childcare, along with all the other needs of the child experiencing disability, presented barriers. Teresa articulated:

We have to navigate a lot of extra financial strains, even down to do we pay for a private assessment for Liam that is \$5000, or do we wait on the [local children's hospital] waitlist for 2 years? And...he falls all the time, so he needs clothes more often. Um his wheelchair, we use our cars a lot more because we are driving back and forth from the hospital. And unfortunately, because my husband makes what is deemed a high income, we don't get much financial support.

Erica suggested higher daycare costs have traditionally meant better quality daycare, which for these parents usually meant inclusion: "I mean we do have good careers, but we spend a lot of money in daycare because we want the best, but it would be nicer if it wasn't so expensive." Teresa also believed the quality of trained staff and service given was correlated with the cost of childcare: "I do find a lot of the daycares that have the education, and the accessibility, are much more expensive. And the daycares that I did really like were extortionately priced." Lorraine felt the cost of childcare was expensive and still her child "will not get the care she needs".

When Chelsea was waiting for a daycare to accept her son, she hired someone to care for her children in her home while she tried to work. She noted this option was much more expensive than daycare:

Going the route we are right now until he gets into the daycare, where we have someone coming into our house, it is absolutely ridiculous. We can't afford it in any way, shape, or form, but we are making it work to the best of our abilities.

Her preference was to keep the in-home caregiver, but this option was unaffordable. Pamela needed summer care for her son just finishing Pre-primary and cost was prohibitive:

We were looking at people coming into the house and we did find a couple of potentials, \$24 to \$26 an hour which sounds, listen, they're worth every penny, I just can't afford it. If I made 20 to 30 thousand dollars more I could do it and I would do it if somebody would come into my home and take care of him and take him places...The least expensive I found was \$15. I have no idea what this person was like, [I] did the quick math and went no, I'm still paying more than what I bring home...affordability-wise [he] needs to be in a center.

Unfortunately, at the time of the interview, Pamela felt she would be forced to take a work leave due to not being able to find affordable summer childcare. This involved lost income and was quite stressful for her.

To manage childcare costs some mothers reported needing to find external support. Some mothers described receiving financial assistance from family members. While childcare subsidies were available, some families were either aided or hindered by the eligibility requirements, particularly the required income level. Mothers who met criteria and qualified were able to receive subsidies. If household income levels were categorized as too high, subsidies would not be granted. Information on subsidies and how to apply was helpful, but finding and accessing that information was a barrier and increased mothers' work. Cara stated daycares should have to

share this information as many people do not know about available funding for childcare for children experiencing disability. She shared that even with subsidies, childcare is expensive:

Since day one, well no, not since day one. I didn't know about...the provincial childcare subsidy. I didn't know about that until about [pause] the better half of a year into daycare. And so, when I found out, I was pretty annoyed ...I didn't know. And so I applied for that, and we were approved for some, some relief, some financial assistance. But, um, it was like, my boys' daycare is still about \$1,000 a month...for both. Yeah. So, um, we get a little bit from childcare subsidy, but it's still a big chunk of a monthly cost.

On the suggestion of her childcare setting, Lena, an Indigenous mother of two children, was able to access support through Jordan's Principle. This government program aims to address the needs of First Nations children by ensuring there are no gaps in government services to them, including early learning and childcare. When Lena was asked about the affordability of childcare, she discussed that Jordan's Principle was very helpful and without it she would have had concerns about trying to pay for daycare. She reported, "Jordan's Principle will pay for their daycare...and for Carly to have her own [education assistant]...to give her more one-on-one and help."

Some mothers thought childcare was too costly to justify being in the workforce, particularly full-time. Some mothers sought part-time care, despite its lack of availability, so they could afford to give their child at least some opportunity to socialize. Bridget shared her son initially went to childcare 3 days per week, "so having even the option to be part time as part of an ease on financial strain was really lovely, um, and it made it possible for us to go." Part-time childcare was harder to find than full-time. The financial futility of paid employment just to pay for childcare arose in a few interviews as a barrier. For example, Anna was sending her child to

pre-school two half-days per week; she stated, “if I was looking at daycare [everyday], that is the number one reason why I am not returning to work because it makes no financial sense, I’d be paying somebody so I could go to work. I’d be giving them my paycheque.” Lena and other mothers also expressed how expensive it was to pay for early learning and childcare for multiple children. She stated, “because I’m paying daycare for my son [not experiencing disability] right now and I’m paying around \$500 a month, which is not bad, but paying \$1,000 [a month] for two? I wouldn’t be able to do that... That would be a whole paycheque for me.” Sandra was an employed teacher and although she had childcare for her children, she did not feel her son Levi was receiving what he needed for her to remain in the workforce as a teacher. She shared:

The support Levi was getting in the daycare facility was not what I was hoping he would get at the time. I did not want to continue. I didn’t want to work all day and not earn income that was going to contribute [to] anything at that point but daycare bills and him not be getting support he needed during the day when I could be doing that at home. We made the choice for me to stay home.

This situation demonstrated how the occupations of mothers and children are intertwined and affect them both as occupational beings.

One facilitator slightly offsetting childcare costs for families was identified as a sibling rate, if two or more children attended together. Pre-primary being free was also helpful, although high costs were associated with before and after school and summer care needed for Pre-primary children. One summer care program told one mother their child could come to the camp if the family paid for a full-time support worker.

Another facilitator discussed by mothers was universal childcare. Its promised decreases in childcare costs have been marketed as the solution for affordable childcare, though parents

still need to find an available spot. With its recent introduction and initial implementation, not all mothers knew about universal childcare. Others mentioned that universal childcare, funded both provincially and federally, has already helped them with affordability. Sandra expressed that “it was great honestly. The reduction in cost was a huge savings.” A few mothers also shared that by the end of the year (2022), there would be an additional cost decrease. Tiffany, whose son Peter has a provisional diagnosis of autism, shared her thoughts on cost and affordability of childcare in Nova Scotia with universal childcare:

Right now, it is a lot better for sure. Before the rates changed, I found it very expensive even with subsidy – I do have subsidy. Um, before the rates changed, um, for someone who does not have a lot of money, I was paying \$200-300 a month with subsidy. Um, thankfully right now I am only paying \$36 a month. Way better now.

Anna noted with universal childcare and more affordable care, she may be able to send her child to pre-school more than on a part-time basis, depending on the price of gas.

Universal childcare works for those with a childcare spot. On the other hand, one mother, Chelsea, noted that universal childcare may actually be decreasing the number of spaces available because it is now cheaper, and more people can afford it:

Parents of kids that would have never gone to daycare are being sent to daycare and not necessarily because the parents are going to work, but so the parents can have a break.

Which I understand but it does limit it for people that are trying to go to work.

This sentiment was not voiced by other mothers but is an interesting lens to use as universal childcare unfolds.

4.6.3 Childcare Location and Transportation

Many mothers wanted childcare in their local communities, with Bridget saying, “proximity to home, it matters”. Time constraints and picking up other children typically influenced this. Due to the inability of childcare staff to re-insert a feeding tube, two mothers required childcare near their workplace to ensure they could reinsert it if necessary. Chelsea elaborated on this:

With Connor, part of the importance for location is his G-tube. If it comes out it has to be reinserted within 10 minutes, otherwise it starts to kind of close in on itself and he could potentially need another surgery to put it back in. And daycares, from everybody I have spoken to, no daycare will touch it if it comes out, they won’t put it back in. So, I have to be able to get there quickly. Mothers often cited that location of the childcare setting was important, but for these two mothers it was a critical factor in the health of their children.

Several mothers mentioned reliable transportation was important to consider as it could limit locations where their children could attend. Maria noted “the distance to where the care is and...because we have one car, at times it can be challenging.” Some mothers were willing to travel for childcare and able to do so. Having dependable transportation allowed some mothers to travel longer distances to enroll their child in what they deemed quality childcare. Public transportation was noted by a few mothers to not be conducive to getting their child to childcare and was not really an option. Kiana addressed this access issue: “I know a lot of young moms and single moms who don’t drive, so they...rely on buses. The bus system here [rural Nova Scotia] sucks...it’s really hard to access.” A few mothers cited the price of gas as another determining factor when choosing childcare location.

4.6.4 Staff Availability, Training, Experience and Continuity

Mothers who found childcare settings with trained staff who could implement inclusionary practices found it very favourable. Cara discussed that workers at her sons' daycare "have university degrees and/or [are] studying childcare development at university." She continued to say it was "reassuring that they...want a career working with kids." Some mothers reflected that when staff had training and relevant experience in inclusion, childcare was much more beneficial for their child and family because their child was included with their peers in all activities. Lena discussed that her daughter Carly never wanted to be around her peers but her trained ECE was able to facilitate her inclusion in activities to eventually play with peers:

Her, um, worker would, whenever they had story time they would sit in a circle, and so her [caregiver] would sit on the floor and have my daughter sit on her lap. And so that's what they always did. And then towards the end of the year she started sitting down at the circle on her own...And then she would sit beside her peers, which I thought that was amazing because she never liked being around her peers. So, she used to sit next to them, she started playing with them a little bit, and I was just amazed because I was like that wasn't like her before.

However, mothers often encountered childcare workers not trained in inclusion or who did not understand the needs of their child. Many mothers expressed all childcare staff should have explicit training in inclusion and care for children experiencing disability. Unfortunately, ECEs trained in providing inclusionary practices were often difficult to find, particularly as spaces were already limited. Settings offering what mothers deemed more satisfactory inclusion had even fewer available spaces because they were seemingly in higher demand.

Throughout many of the interviews, mothers discussed that Nova Scotia currently has a shortage of ECEs and it is difficult for childcare settings to find not only trained staff but *any*

ECEs, even substitutes. Pamela, who works in the employment service field and addresses shortages of ECEs, commented, “good luck finding an ECE”. Many attributed the scarcity of trained childcare professionals to poor remuneration. When asked about what she perceived the biggest barriers to accessing inclusive childcare was, Cara responded it is a “lack of financial resources to pay for qualified people and to keep them.” She continued “so we need more staff, we need qualified staff, and they need to be earning a living that will keep them in that position.” Jennifer echoed the same sentiment regarding ECEs “I feel so bad for them. They have really hard jobs, and they love their jobs and work really hard to...mold our kids and they are paid nothing.” Some mothers intimated that many of the trained ECEs in Nova Scotia moved to Pre-primary to receive better pay and benefits, whilst leaving other childcare settings short of workers because they were unable to compensate them equally. Poor compensation and not enough support were also speculated as reasons for high turnover of childcare workers. Mothers with children in childcare appreciated the ECEs working with their children and empathized with them. Pamela articulated ECEs doing childcare work need better pay and support:

The care and the wanting is there...they're stretched to the max themselves and I think that they don't have enough support. They don't have enough people to call in. They're getting sick or they're getting injured and there's a lot heaped on them. It's not fair to them either. Like I can see why people don't want to go into that profession. So, they get paid better at [Pre-primary], I get that. But that's not it...they need to be paid better, but they also need the supports...Nobody has enough...and there's more kids who have needs.

She also touched on the increasing number of children experiencing disability and made the link that more staff and staff training will be needed.

A few mothers discussed that staff continuity, in addition to training, were facilitators of inclusion, and that high staff turnover was a barrier to inclusive childcare. Mothers also stated that when turnover did happen, it was important to have a planned handover of care between providers. Andrea discussed the support her son received from trained early education staff was excellent, but with a few staff turnovers and poor transition of care, the practice of inclusion was lost. She discussed that the “holistic, integrated feel of the support he had at daycare started to change and, um, that actually helped make our decision about transitioning Aaron into Pre-primary instead of keeping him at the daycare centre, which had originally been our plan.”

The lack of training and lack of supports, resources, and infrastructure to provide caregivers with training, meant mothers trained staff. In relation to her son’s gastrostomy tube (G-tube) for feeding, Bridget commented: “I do wish that they had some more specialized training so that it wasn’t all on the parents to make sure that they have what they need”. She continued:

I would hope and expect a center that gears towards these children... have First Aid training and to have, um, you know epilepsy training or tracheotomy training or tube-feed training. Like the types of things that they’re probably going to see a lot more frequently. I would like their staff to be prepared better than just relying on a parent because sometimes parents learn things [laugh] from medical staff under [pause] very stressful situations and have limited time to absorb it all. And then now it’s my job now to teach someone else how to do it and it feels like, I don’t, I don’t know if I’m teaching them right. I have no idea.

Complexity of care made staff training and continuity even more important.

4.6.5 Staff to Child Ratios

Low ratio of staff-to-children was considered important, as mothers correlated it with support children received. Sandra spoke about ratios in the after-school EXCEL program at RCEs and how she perceived it in relation to her son Levi's needs and safety:

EXCEL is not necessarily structured in a way where I feel he would be safe for a year, having worked in it. I know the program and it is great for kids that can hold their own and play on the playground and it is not designed for a child who is so far developmentally behind. Would they accommodate? Most likely in the sense of an extra person. The waitlist at our school is astronomically large so he wouldn't get in and there isn't a ton of after school programs in this area other than [dayhomes], but those are one staff member to a ratio of eight kids after school. That is not going to work for him when he needs an extra person. That is just something they can't do; they are a day home. They provide...1:8 after school and that is fine. For my older child that would be great, but not for [Levi]. So, these things I find limiting us in our options.

Cara linked low teacher-to-child ratios to financial resources and felt improved ratios led to improved child development:

[We need] to have the financial resources allocated for inclusive programs so that the ratios will benefit the child. Um 'cause you'll, the child will get lost in the mix if the ratios are off, and you see, you see growth, and you see skill development growth, and growth in all areas when the child has more access to one-on-one support or two-on-one support.

She thereby linked the provision of inclusive childcare to better child development and that having the financial resources to afford low teacher to child ratio was critical.

4.6.6 Professional Support

Some participants identified human resources as helpful, including Developmental Interventionists, and members of their child's healthcare team, such as Occupational Therapists or Clinic Nurses. Mothers identified that the members of their children's health teams need to be readily available to see children experiencing disability. Many mothers also reported it to be easier if the child's team members could see them at their childcare setting, decreasing time mothers had to take from work for these appointments. Pamela may have summarized it best when she stated people looking for childcare need "one stop shopping, one good resource, a navigator". For Pamela that person was their Developmental Interventionist:

I can't say enough about her, as a navigator and a sounding board. She's there for us, she's not working there for other people. She's like oh you want me to ask the hard questions, I'm gonna ask, if you don't want to ask them, I'm like yeah that'd be great.

Although inclusion coordinators were not present at every childcare setting, mothers whose children had access to this resource found their assistance very beneficial. Erica stated:

I'm very thankful he's at a place where there's an inclusion coordinator. She is the one person we connect to...She attends all our team meetings, she updates us on how Justin's doing with his interventions in school, I'm so thankful that she is there now, now that this is our journey.

Sandra further discussed this, describing helpful activities her child's inclusion coordinator did:

The inclusion coordinator helps us... she sits in all of our SLP [speech language pathology] meetings. She facilitates OT [occupational therapy] and physiotherapy coming in. Help work and facilitate goals in the center. SLP had a picture communication program they were implementing with concrete images and not just the PEC [Picture Exchange Communication] board images but pictures of those things. She helped

document them, laminate them, put them on loops. Getting all that going for him in the center and making sure it was being facilitated in the classrooms.

Without inclusion coordinators, mothers would be left to do this work as some in this study were. Sandra identified Direct Family Support for Children (DFSC), a provincial program that enables families to support children with a disability at home, was very helpful. It enabled them to have respite care in their home and alleviate some of the care tasks needing to be done. Other resources that facilitated information gathering, such as parent support groups, the internet, social media, access to reliable transportation were important to mothers.

4.6.7 Employment Support

Mothers identified employer flexibility, support and understanding of their child's needs and childcare situations as important factors. The flexibility of employers afforded mothers the ability to look after their children's often unpredictable childcare needs. Mothers praised flexible employers, expressing gratitude as flexibility eased their work, stress and anxiety, and their need to juggle everything at once. Samantha expressed, "I am just fortunate I have flexibility with work because with transition meetings and follow ups and monthly meetings at the daycare...and every specialist that goes in, you kind of need to go in to support and make those connections". Benefits such as sick days or family days were important. However, even if employers offered them, they were sometimes not enough. Sandra's son's frequent illnesses were causing her to go "through sick time at work faster than [she] could accumulate it" which was one reason, along with her son's lack of inclusion in childcare, she left the workforce and stayed home full-time.

Even with flexible employers, mothers understood they had to make up any lost time and perform their work activities somehow which could impact well-being. It also did not mean these mothers did not feel guilt related to the need for their employers to be flexible. Mothers tried to

give their employers as much notice as possible and be as accommodating as they could. Kiana discussed guilt around her needing to juggle between caring for her child and work:

I do feel guilty all the time because I feel like...I'm the one that's always like well my kid's got an appointment, well my kid's sick, the daycare called, I have to leave. But they are really flexible and good, I am very lucky that way. Because if I worked like at a bank or something, I'd probably be fired.

Mothers without employer flexibility were worried about job security or left the workforce to meet childcare needs. Even if underpaid and unfulfilled, mothers like Pamela and Teresa stayed in jobs to maintain employer flexibility for childcare. This generated emotion work as mothers were not pursuing or meeting career goals. For Teresa, this meant anger, resentment, and grief:

I gave my whole career up because I had a child with a disability, and I haven't been able to get my career back since I have had Liam. Umm, I still cannot get my career back. I work 20 hours a week, umm, as a support worker for disabled adults, ah which is fine, but the money is a lot less. Uhhh. It's not as...it's not the level of work that I would like to do, given my education. Umm, but because of our childcare situation I don't see me being able to get that back, because... even when Liam goes to school, umm, I think that's just going to be another hurdle we have to jump through because there's no way he could go to before...and then after school care.

Several mothers also noted their partners usually did not have jobs that were as flexible in nature, and that it was often their male spouses that made more money and could advance in their careers but did not provide as much care or invisible work resulting in familial gender inequity.

4.6.8 Social Support

The importance of a supportive family and social network came up often as facilitators to finding inclusive childcare. If relatives and friends lived far away or grandparents were elderly and unable to help, the lack of such supports was a barrier to childcare and daily life, including relationships. Mothers who had supportive networks expressed the benefit of social and emotional support. Teresa stated “some of my closest friends, now, have children experiencing disability because they are the only people that really, truly get the challenges and exhaustion that comes with the constant fight of advocating for your child with a disability.” Several mothers, such as Pamela, spoke about the importance of having a “community” or a “village” to support them, and that not having this was difficult. A strategy for Lena to deal with her emotions included weekly chats with her best friend, “[s]he tells me about her stresses, I tell her about mine, and then we feel a bit better afterwards.”

4.6.9 The COVID-19 Pandemic and Public Health Restrictions

COVID-19 was declared a global pandemic beginning in Canada on March 11, 2020. Public health restrictions related to the COVID-19 pandemic affected accessing childcare in some manner for most mothers in this study. Mothers noted COVID-19 was a large disruptor in their child’s development, childcare routines and in the routines of others. Childcare settings were closed as mandated in Nova Scotia for parts of 2020 (Government of Nova Scotia, 2020), when almost all mothers in the study were accessing or trying to access childcare. When public health restrictions loosened, and childcare settings re-opened, some restrictions remained in place making it difficult to meet childcare providers in-person or view environments, affecting the family’s navigation efforts. When children were allowed to return to childcare, many of the staff they knew were gone. Anna recounted:

I noticed that a lot of things that [my daughter] was doing, after COVID came, she regressed a lot. She went from eating everything to eating next to nothing. So, we ended up having to, I ended up having to you know navigate this system that I did, I knew nothing about, by myself because I didn't have my person from Public Health 'cause she got pulled to do other things and she was going to help me do all of this.

For some mothers, the threat of their child getting COVID-19 was also a reason to keep their child out of childcare, even when children were allowed back, particularly as many of their children were immunocompromised. Erica appreciated the flexibility and understanding of the childcare facility they were pursuing for her son; they arranged to be distanced to meet and “were very accommodating and very clear in what they could offer and what they did.”

4.6.10 Inclusion, Exclusion, Discrimination and Ableism

The biggest barriers to having their child experiencing disability in a truly inclusive environment were often systemic in nature including misunderstandings of inclusion and discrimination. These two barriers often intersected.

Inclusion was highly sought after when looking for childcare, as many mothers voiced it was the best model for their child to learn and develop. The point that inclusion is not normative and is still an exception was brought up by several mothers. Teresa stated, “[i]nclusion is very important; I think every child deserves the right to be included. I don't think it should be a question, or a challenge or a hurdle, it should just be the norm.” Mothers wanting inclusion had to navigate what inclusion really meant to them and to the settings their children may attend. This involved work as their views of inclusion often did not align with the inclusion offered by childcare settings.

Discrimination was often a large sociocultural barrier for mothers accessing inclusive childcare. Tiffany spoke about her son, Peter, experiencing “[p]eople not just wanting to give him a chance”, alluding to the discrimination mothers and their children experiencing disability face routinely. The fight against discrimination began very early in the pursuit of early learning and childcare for some mothers. When her son was quite young, Sandra encountered discrimination regarding childcare:

It was a bit of a struggle. I remember when he was 6 months old, I had just been talking to a few people to get him on some lists. Just some comments we got were...will normal daycares take a child like him? And, at that point I said, they have to. Legally they have to accommodate. When we actually started looking into it, it was different.

Most participants shared examples of discrimination, some quite outright and shocking, in their “fight” to obtain inclusive childcare. Children being denied childcare because of their disabilities was most common in dayhomes, but also in childcare centres, before- and after-school programs, and summer care. When asked if she contacted anyone that said they do not accept children experiencing disability, Teresa stated “I contacted two day-homes that said they wouldn’t be able to take a child with disabilities.” Sandra shared her experience of touring a childcare setting who said they had upcoming availability: “They saw Levi had Down Syndrome, and [on] a piece of paper with big bold letters wrote Down Syndrome. We never got a call back from the daycare.”

The concepts of systemic discrimination and ableism increasing the invisible work of navigating childcare was raised by some mothers. They noted advocating was difficult despite privilege, knowledge, and resources. A few mothers commented on the variability of people’s capacity to garner resources, and they did not know how people with less resources or in marginalized groups were able to advocate, as it was so difficult and time consuming. Jennifer

summed this up saying, “I know that people struggle more than we do. At the same time, we struggle too.” She speculated on the additional challenges potentially faced by those who are less privileged:

[Those who are] not white, do not have good jobs with salaries, vacation and extra personal days, flexibility we have at our jobs, don’t have the same education to know to pick up the phone to call a program to confirm ‘it says this on your website, what does it mean?’ We know to do that because of our experiences, maybe they don’t. I don’t know what those families would do. It is sad, I don’t know how to help those people. I want the government to wake the hell up.

Cara shared a similar sentiment, highlighting systemic issues and social judgement as barriers for members of marginalized groups trying to advocate:

I am...an educated white woman, and I generally don’t get judged when I try to advocate for myself or in like, you know, communicating with these professionals. That is not the case for, you know, a young mom who’s a Black young mom or a like a newcomer to Canada who needs a translator...they do get judged. And it’s really ironic when it’s, you know, they’re getting judged by people who work in social services. Yeah. Um, or you know, they are drug users...and they don’t get taken seriously. And they get ignored and they get turned down. Like I see it all the time. So, I think there’s a need for like, diversity and equity and inclusion in people's training. Like it should be mandatory.

Her comments highlighted how being a member of a marginalized group could affect the ability to access childcare.

The advocacy work mothers in this study engaged in and systemic barriers they faced impacted their pursuit to access childcare and maintain it. One example includes the requirement

of a diagnosis to be able to apply for some funding and support services. Not qualifying for funding, usually due to income, was often a barrier. Mothers fight systems often. Chelsea shared:

We were told we didn't qualify for [funding]. I was hoping to get that to help with the cost of the girl that comes in every day. Because that's expensive. I was told that if I wanted to really fight that, I could through like the [Member of the Legislative Assembly (MLA)] and see if they could fight for us to get it. In the group I am in, on Facebook for medically complex children, everybody... it doesn't seem to matter what disability the child has, they get rejected. I have seen...children that [have] severe cerebral palsy, and quadriplegia and all sorts... and they all get rejected too and they end up needing to go through the [MLA] and get the [MLA] to fight for them, because they get rejected every time.

It appears 'support' systems are designed to block access to necessary supports.

Some rules and processes set by childcare settings could also be barriers. Andrea shared when trying to get her Pre-primary child on the list for a summer camp, the program told her to register her son in the youngest group for his developmental needs regardless of his age, but she was hindered by the application process as it would not allow her to enter his birthdate and select the program she was told to select. When she tried lying about his birthdate, she could select the correct program, but it was full. She shared, "I missed my opportunity because their system wouldn't let me do what I needed to do and there was no way around it."

Samantha's daughter Faye's childcare experience was quite inclusive until daycare policy dictated she had to move to the next age group and room due to her age. However, this room was not physically accessible as it had many stairs to enter it which Samantha felt her daughter could

not safely climb. She fought this, going to the director, Board of Directors, and the Department of Early Childhood Education:

At first I thought they were going to help me, but upon their discussions with the center, they were told that the reason they can't help families like ours and allow for a defer year [was] because we weren't the only ones who were told no. Faye has two little friends both in wheelchairs in her current room and they couldn't offer them the next room because the building is not accessible.

Samantha ended up going through the process to find another childcare setting for Faye due to discriminatory policies.

Some mothers discussed the short-sightedness and restriction of some policies and sometimes a lack of guidelines necessitating the work of advocacy. Andrea reflected, "then I had a kid with special needs, and I started encountering the restrictiveness of these policies that are meant to be, you know, what's best for him." Mothers often looked toward government policies and lack of funding as systemic barriers to securing childcare. Samantha stated, "we take care of certain segments of society, why are we still struggling to provide appropriate spaces for children experiencing disability? It is not like they haven't been around forever. It is heartbreaking."

From a social services perspective, Cara addressed how many mothers get stuck in the cycle of working to barely pay for daycare and necessities:

I hear stories that you know I'm working just so my kids can go to daycare. Or I'm working and all, like my paycheques pay my bills and that's it. Or I can't afford to send all of my kids to daycare, just one of them. So, with my line of work, I work with a lot of folks, um, in the poverty range and who are on social assistance, income assistance and that, um, that in and of itself does not consider, you know, equitable

access to resources. So, um, very often parents, like if you're a single mom and you are on income assistance, you hit, like you're in this cycle that you cannot get out of. So...if they want to get out of income assistance and start working, typically they're going to start at a minimum-wage job and that's not a livable wage whatsoever... then they don't have access to, income assistance, um, anymore, which offers only \$400 a month towards childcare and, um, and that's only for one kid, I think. So, if you have two kids then you still have to pay full price for one of them, um, but then also apply for the provincial childcare subsidy, which will make up some of it, but it's still not affordable, not affordable for these folks. So, they're stuck, they're stuck at home until all their kids go to the public school system and then if they find a job, still likely not livable wages, and have to finagle their work schedule so that it doesn't interfere with after-school care. It's just not a good situation.

This cycle of low-income, and perhaps poverty in some cases, demonstrates how government policy can dictate how families live and engage in occupations.

Fighting for systemic awareness of disability was discussed often; mothers had to be vocal to encourage more education and proper training for early childcare workers. Andrea suggested the need to advocate is created by systemic social oppression and discrimination:

I don't want to be thinking about how do I advocate for my son to have access to basic needs that he has, um. So yeah, like I- I-, part of me wants to just figure it out and, and deal with it. But then there's this other part of me that wants to stand on a mountain and scream about how unjust it is.

Fighting for disability awareness goes beyond childcare, with Teresa stating, “there is so little training and awareness around disability in Nova Scotia”, “kids with disabilities are not a priority.”

In summary, the experiences of the mothers in this study illuminated important sociocultural factors that impacted access to inclusive early learning and childcare for young children experiencing disability in Nova Scotia. These sociocultural factors, organized from a micro to macro perspective, shaped facilitators and barriers to access and inclusion in early learning and childcare and contributed to creating the conditions for invisible work, mainly the responsibility of mothers. Mothers’ invisible work has a cascade of effects on families’ daily roles, routines, occupations, and well-being. The demands of this invisible work necessitated the need for new occupational roles. Mothers responded by creating and taking on occupational roles as the Navigator, the Quilter, the Fighter, the Juggler, and the Keeper.

Chapter 5 Discussion

5.1 Mothers and Invisible Work

The findings of this study illuminated the experiences of 16 mothers of children experiencing disability across Nova Scotia, the occupational roles they had to take on, and the invisible work they did in pursuit of inclusive early learning and childcare. As DeVault (2014) has argued, “bringing invisible work into view may help to advance projects of social justice and inclusion” (p. 775), including making access to inclusive childcare easier for families. By exploring these mothers’ pursuit of inclusive childcare and how contextual factors create the conditions that necessitate this invisible work, this study also contributes to the body of knowledge needed to mitigate barriers and reimagine access and inclusion in ways that support families and society. The detailed examination of mothers’ invisible work in this secondary analysis illuminates the occupational roles mothers of children experiencing disability fill. The invisible work these mothers did is captured in the roles of the Navigator, the Quilter, the Fighter, the Juggler, and the Keeper.

All mothers in the study were **Navigators**, mapping the way for themselves and their children in an unknown landscape when pursuing inclusive childcare. Navigating childcare took a lot of organization and problem solving beyond the usual experience that finding childcare requires “a great deal of planning, management, and the ability to accommodate changing situations” (Breitkreuz et al., 2021, p. 449). Matthews and colleagues (2021) suggest that to access information, secure services, find funding, and coordinate care for their child experiencing disability, parents have to be skilled navigators. Parents of children experiencing disability have also previously been identified as the “bridge [to] disconnected and disparate services” due to systemic disorganization and other inadequacies such as poor funding

(Matthews et al., 2021). This study supported these findings that navigating access to inclusive early learning and childcare requires mothers to be skilled in their occupational role as Navigators.

As **Quilters**, an occupation usually performed by women (Dickie, 2003), all mothers in the study attempted to organize the occupations of their family life and work life by piecing and patching childcare together the best they could. Results of this study supports scholars' analogy of a constant pattern of patches or a "patchwork quilt" to illuminate the work mothers do to organize childcare (Breitkreuz et al., 2021; Scott et al., 2005). Supporting findings in this current study, Breitkreuz and colleagues (2021) found that mothers arranged childcare in a number of ways, that often are not optimal, with a variety of informal and formal care, and a mixture of the two. They likened the ways mothers organized their childcare to a "patchwork" (p. 346) necessitated by a fragmented and underfunded Canadian childcare system. The findings of this study demonstrate that this holds true for mothers of children experiencing disability as well. They also form patchworks of care, including quilting combinations of formal daycare, in-home caregivers, dayhomes, and family and friends, in an effort to make something work. In this study, the mothers' first attempts at 'making a quilt' to organize childcare may not have been the most desired inclusive childcare situation, or the most beautiful quilt, but it still sufficed to meet some of the needs of the mother, child, and family. Most mothers in this study continued to craft and patch their childcare quilt in pursuit of inclusion.

All the mothers in this study were **Fighters** in their advocacy efforts, with most indicating these efforts were often adversarial in nature. This research bolstered previous findings that mothers' advocacy roles were significantly enhanced as a result of challenges faced to obtain what they needed for their children experiencing disability (Ryan & Quinlan, 2018;

Ryan & Rumswick-Cole, 2009). All mothers in this study faced barriers rooted in continuous systemic oppression and discrimination and fought against them. This supported previous findings that these barriers necessitate the substantial unpaid advocacy work mothers have to do to access early learning and childcare (Lewis et al., 2000). The advocacy work of parents with children experiencing disability is dynamic as they “face uncertainty, seek help, acquire services, and promote awareness” (Smith-Young et al., 2022, p. 9). Mothers in this study support those findings as they conveyed fighting for their children was dynamic and unpredictable. In addition, a few mothers were hopeful their fight would not only benefit their children but other children and families in the future.

All mothers occupied the role of **Juggler** as they attempted to manage all of their responsibilities at home, work and in the community. Participants in this study, as in previous studies (Guendouzi, 2006), juggled their social roles as mothers, professionals, partners and more. They also juggled all of the roles related to their invisible work identified in this study. Others have found that organizing childcare while managing a multitude of competing responsibilities, demands, and needs requires significant work and planning – work that is invisible and gendered (Breitkreuz et al., 2021). The same results were seen in this study, only this time with mothers of children experiencing disability. McConnell and colleagues (2016) noted that every family faces the difficult task of establishing and maintaining a daily routine that integrates diverse family activities in a meaningful way. They went on to say that facing this task may be especially difficult for families raising children experiencing disability. The current study supports those findings as families needed to juggle family and work obligations with the additional demands and stress that is associated with caring for a child experiencing disability (McConnell et al., 2016). As in previous studies (e.g., Grace et al., 2008; Irwin & Lero, 2021;

Odom et al., 2011; Ryan & Runswick-Cole, 2008, 2009), these mothers discussed that they did more complex invisible work, juggled more activities, and faced more difficult barriers when accessing inclusive early learning and childcare compared to mothers who had children not experiencing disability. All mothers looking for early learning and childcare face barriers, however the barriers and work are magnified for mothers with children experiencing disability.

All mothers also occupied the role of **Keeper** as they managed their child's, families, and their own emotions in this study. Their emotion work was noted to be significant, supporting previous findings that emotion work is invisible gendered, care work (Clarke, 2006). Mothers often brought up their range of emotions, particularly stress, guilt, and anxiety. This supported previous research that found the difficulty in finding and accessing childcare for a child experiencing disability is a significant cause of emotion work with mothers trying to manage stress and guilt (Grace et al., 2008; Kagan et al., 1999). Many of the invisible

work roles these mothers occupied created emotion work, in an example of how themes intersected. Navigation of the childcare system, advocating for their children and quilting childcare by piecing together multiple caregivers all led to stress in this study and others (Breitkreuz et al., 2021; Matthews et al., 2021). This invisible work was found to be isolating and overwhelming, supporting the findings of Matthews and colleagues (2021). One mother discussed her emotion work at length and that the risk of "burn-out" in her pursuit of childcare had been a real possibility. Findling and colleagues (2022) also suggested that mothers of children experiencing disability demonstrated deeper emotion work and higher parental burn-out compared to mothers of children not experiencing disability.

Two key factors that shaped the invisible work of these mothers, and the occupational roles demanded of them, were the influences of the gendered ‘good mother’ ideology and the influences of ableism and disablism.

5.2 Influence of the “Good Mother”

Mothers of children experiencing disability represent themselves based on the sociocultural narratives of “the good mother” ideology (Knight, 2013). The dichotomy of good mother/bad mother has power, perpetuating beliefs in families and society of gender roles that position mothers as carers (Goodwin & Huppatz, 2010; Hays, 1996). This ideology was threaded throughout this research and the invisible work of these mothers. Within this study, all mothers wanted to, and felt obligated to, do all they could to help their children, putting their children’s needs over their own including their mental health, personal goals, and employment. This finding is supported by previous research (Brett, 2002; Goodwin & Huppatz, 2010; Guendouzi, 2006; Hays, 1996; Miller et al., 2017) suggesting that the good mother social ideology plays a role in mothers’ invisible work and that mothers took on the pressures of being the ‘good mother’ and sacrificed their own needs for the needs of their children. Demonstrative of this may be when some mothers in the study decided not to send their child to free Pre-primary in favour of paying to keep their child in childcare they considered more inclusive or ‘best’ for their child despite the financial stresses this entailed. This also highlights societal inequities as some mothers may have wanted to do this but could not afford to, thus facing potential guilt for being ‘bad mothers’.

To do what was best for their child, mothers in this study had to be flexible, accommodating, and adaptable in response to the barriers presented when accessing inclusive childcare. As in other research (Knight, 2013), they were flexible to meet the needs of their children and family often at their own expense including getting less sleep, having less social and

personal time, and sacrificing their work goals or employment in general. Thus, the normative discourses of “good mothering” shaped all of the invisible work these mothers did in pursuit of inclusive childcare for their children experiencing disability. The juggling mother aligned with the good mother ideology in many respects, as mothers juggled all their duties in an attempt to be a good mother. In some cases, these unpaid, invisible work duties may have included providing training to paid childcare workers for things such as medical procedures. Advocacy was another means for mothers to be a selfless “good mother” and fight for what they wanted in this study supporting Ryan and Runswick-Cole’s (2009) work supporting that “activism allows mothers to ask for help while at the same time managing their image as the ‘selfless carer’” (p. 51). Good mothering was also influential to mothers as fighters as advocacy was often adversarial. Mothers fought societal opinions and beliefs created by more powerful systems, such as early learning and medical systems, to get what their children needed. Mothers also assumed the good mother stance on a more societal level and wanted to do the invisible work now to advocate for the next child and ideally change the systems to ease the burden of mothers that will follow.

Emotion work and care work are gendered (Hochschild, 1983, 2012; Seedat & Rondon, 2021) and invisible (Daniels, 1987) and both are central to the kinds of work roles mothers engaged in. The findings echo previous research, in that mothers continue to strive to meet the societal expectations of the good mother, but these standards are unrealistic and seemingly not truly attainable (Collins, 2021; Hays, 1996; Schmidt et al., 2023), yet are the basis for internal and external judgement regarding a woman’s ‘adequacy’ in the mother role. This leads to deep rooted feelings of guilt, stress, anxiety, shame, and sometimes depression linking the good mothering/bad mothering discourses to the emotion work mothers did trying to access inclusive early learning and childcare in this study. Guilt is especially prevalent when a mother endeavours

to balance motherhood, her child's needs, her family's needs, her individual needs, and the needs of her workplace (Guendouzi, 2006; Schmidt et al., 2023), and this was evident in the various shared experiences in this study. Mothers in this study attempted to keep it all together and adhere to the 'good mother' discourse, but nonetheless felt guilt. This supports findings that "guilt serves as a regulating force in mothers' lives" (Collins, 2021, p. 22-23) as they assume responsibility for the health, development, and well-being of their children (Collins, 2021; Schmidt et al., 2023). The gendered, sociocultural expectation that mothers are the primary caregivers for their children caused tension and anxiety, and even shame when mothers worried they were not providing their children enough individual attention or that their children are not participating in inclusive childcare. The guilt the mothers in this study also felt trying to continually fight for their children experiencing disability, and what they perceived as failing, amidst the numerous sociocultural barriers, was pervasive whether they stated it explicitly or not. Mothers who found and enrolled their child in childcare that they did not consider to be inclusive or in line with what they wanted, but what they needed in order to work in the labour force, felt guilt and shame. A few mothers apologized at times in their interviews such as when discussing the need to fight hard for their child, finding it difficult to deal with all of the work and emotions, and on two occasions when visibly crying. This is demonstrative of what they may perceive as being found wanting under the ideology of the good mother, moving into the territory of the bad mother causing them to feel guilt and shame for not being "good" enough.

A goal for many mothers of children experiencing disability was to be in the workforce because they wanted to be or needed to be. However, ultimately, they did not prioritize this as highly as the goals of being a good mother and doing all that they could for their children, which meant ensuring their child was well cared for and ideally accessing inclusive childcare before

working. This study also supports findings (Modestino et al., 2021; Powers, 2003) that childcare and labour market participation for mothers with children experiencing disability are correlated. Without childcare, mothers can't juggle work too, their ability to work is greatly diminished. Mothers' responses reflected that accessibility, including affordability, of childcare affects the economic system and gender equity in the workforce. For mothers whose childcare costs are as much as they earn in the labour force, paid employment is often impossible and may be viewed as pointless. As employers and politicians want more people in the workforce to bolster the economy, boosting the maternal workforce is also a goal (Modestino et al., 2021; Powers, 2003), thus it is important for them to ensure inclusive childcare options that are in the best interest of children and families. Now, and historically, as fewer mothers than fathers are employed (Statistics Canada, 2022a), gender inequities in the workforce exist.

Mothers of children experiencing disability feel oppressed and disempowered (Brett, 2002) and experienced a power differential when trying to access childcare in this study. Institutions and systems hold power (van Rhijn et al., 2021). The good mother ideology is oppressive, as mothers are expected to be silent (Knight, 2013; Ryan & Runswick-Cole, 2008). Although mothers were often proud of their persistent advocacy work in this study, their fights were incongruent with this expectation of silence and often left them as an uncomfortable antagonist of ableism, exclusion, and the 'good mother'. Collectively, mothers of children experiencing disability are often oppressed and not heard, regardless of their individual efforts to advocate (Knight, 2013), which again is shaped by gender inequities (Ryan & Runswick-Cole, 2008). Mothers wanted to engage positively, but when it often produced no results, mothers resorted to the bad mother role by "ruffling feathers" or "pissing people off" in an attempt to achieve what they needed for their child, as with Ryan and Quinlan's (2018) research with

mothers of children diagnosed with autism. Most mothers in the current study expected this to happen, and referred to it as a constant battle or fight.

5.3 Influence of Ableism and Disablism

Ableism and disablism were found to be infused in the early learning and childcare system in Nova Scotia, violating the Human Rights (UN, 1989, 2007) of children experiencing disability and their families. When looking at the invisible work mothers in this study did, ableism and its discriminatory effects were threaded across all interviews and all themes. Seemingly, just being a mother of a child experiencing disability was not socially normative and these mothers were othered by systems and, at times, individuals. All families faced some form of discrimination and almost all mothers experienced exclusion for their child when attempting to access childcare and/or when accessing childcare, highlighting a social justice concern and pervasive discriminatory practices in early learning and childcare. Discrimination and the social oppression of children experiencing disability was pervasive, with Mothers in this study illuminating numerous examples at micro, meso, and macro levels. It greatly increased the invisible work the mothers in this study did. Systemic discriminatory exclusionary practices were evident throughout the navigation, quilting, and accessing of inclusive childcare in this study, and often rooted in systemic ableism. In their role as Navigator, mothers' invisible work included navigating ableist belief systems. This finding was supported by the work of Goodwin and Ebert (2018) who outlined four themes of parental hidden work related to ableism and their children experiencing disability. These included (a) inclusion is immensely effortful; (b) children are judged by their impairments, not their possibilities; (c) ongoing education is needed to open doors and sustain participation; and (d) the guilt of staying home and not having their child included. They also related their work to how parents emotionally experienced these themes,

which bolstered this study's findings that mothers' emotion work in their roles as Keepers was also often rooted in ableist and discriminatory practices and the attitudes of others.

Many mothers started their journey to access inclusive early learning and childcare thinking their child experiencing disability had to, by law, be included and accommodated. They also thought they had a choice of where their child could attend, and that ableism or disablism were not determining factors. Through their navigation process, they realized these were not 'truths,' and instead presented as sociocultural barriers. Findings in this study support other scholarly findings that children may be denied childcare based on disability (Irwin & Lero, 2021; Killoran et al., 2007; van Rhijn et al., 2021) and that inclusion is often illusive (Halfon & Friendly, 2013; van Rhijn et al, 2021) or a paradox (Dalkilic & Vadeboncoeur, 2016). Messages that society values all abilities, and all are included, were not usually what mothers in this study encountered in reality. Children were denied rights based on their impairments and abilities, and although inclusion was often advertised, it was seldomly realized, supporting many previous findings (Eilers, 2020; Halfon & Friendly, 2013; Odom et al., 2011; Reeves et al., 2020). Mothers shared stories in which their children experiencing disability were directly denied childcare for a multitude of reasons, but on examination, it was always due to disability and rooted in systemic ableism. This supports other Canadian research that found across all centres in their sample, including centres in Nova Scotia, children with special needs who could have benefitted from attending an early learning/childcare program were turned away" (Irwin & Lero, 2021, p. 47-48), for various reasons. The current study also supports findings from another Canadian study in which 80% of parents reported their children experiencing disability were excluded from early learning services (van Rhijn et al, 2021).

Full inclusion in early learning and childcare was difficult if not almost impossible to find, which was a major factor in necessitating the invisible work of mothers. The dissonance

between how inclusion is defined and understood *versus* how inclusion is actually enacted and experienced in many childcare settings was real for the mothers in this study and their children. This needs to be acknowledged and actively improved if universal childcare is going to be inclusive and uphold children's and families' human rights. Mothers made it clear that the definition of inclusion needs to encompass inclusion of people experiencing disability. The dissonance is created by systemic ableism, although usually not intentionally. Ableism, disablism, discrimination, and exclusion are all shaped by policies and guidelines, underpinned by sociocultural beliefs. Symptoms of these larger issues are evident in early learning and childcare when considering a lack of trained ECEs, resources and available childcare spaces, as well as the presence of exclusionary practices (van Rhijn et al., 2021). The idea that higher cost equates to better, more inclusive childcare is one more example of dissonance and social inequity.

Society has tasked mothers of children experiencing disability with work they inequitably need to be doing to pursue inclusion. This is also contrary to Hanvey's (2002) recommendation that implementing actual inclusion is the responsibility of society and the onus should not fall on individuals such as mothers, family members, and children themselves. Unfortunately, the findings in this study suggest that we are indeed tasking mothers of individual children experiencing disability to make inclusion work, while society is seemingly relieved of this. We are relying on mothers' unpaid invisible work to enact inclusion, to train paid childcare workers in activities that policy has deemed these workers cannot do, and to access childcare in hopes they will then enter the workforce to contribute to the economy. The invisible work required of mothers of children experiencing disability to attain and ensure inclusion is simply too much.

By illustrating the work mothers in this study did to patch and piecemeal childcare together in an attempt to find a childcare solution makes it evident that systems are incongruent. Systemic policies and guidelines, and even laws, are often made to help and protect members of the public and most likely intended to be inclusionary. However, at times policies can be in direct conflict with one another as seen in this study and may serve to exclude children (van Rhijn et al., 2021). In fact, one systemic requirement is often contingent on a policy or guideline in another system, unknown to both systems. This is often a result of various government departments working independent of each other and not coordinating social services for families. One example in this study included children not receiving respite care or subsidies if they do not have a diagnosis given by the medical system, which was also found by van Rhijn and colleagues (2021). The process of diagnosis can be difficult and long, not only because there is a need to be thorough but because there may be many specialists involved, many tests, and long waitlists in healthcare. Also, within the healthcare system, other systemic policy conflicts exist, for example, Early Intensive Behavioural Intervention EIBI is only offered to children with autism prior to school entry. Therefore, some families may choose to retain their child in early learning and childcare for another year in order to avail themselves of EIBI. This results in pressures on both systems, but even more so on families. Another example in this study was when mothers pay for an extra year of childcare *versus* enrolling their child in the provincially funded Pre-primary program, as was evident in this study. Several mothers discussed that school staff have suggested children experiencing disability go directly to grade primary instead of the Pre-primary program, because supports are less in Pre-primary. This speaks to inclusion not being enacted in Pre-primary as people perceive it should be. This choice to pay is not an affordable option for all parents, thereby increasing inequities. This example is supported by the

need for Pre-primary to still roll out a detailed inclusion policy, even years after the program commenced, in addition to the limited information regarding inclusive practices on their website (EECD, 2023).

One more example of systemic issues and discriminatory practices is that from May 10 to June 19, 2023, a labour strike occurred in the Halifax region of Nova Scotia in which all Pre-primary ECEs and other groups were on strike for increased wages; Pre-primary was closed. Thus, all Pre-primary children in this region were home and their parents were scrambling for childcare, doing the invisible work to try to find it while often still trying to work or needing to take a leave from the labour force. In many cases, leaves or work flexibility may not be options, and people end up leaving their jobs completely. Without childcare, mothers cannot work. Even with childcare, if the employer is not flexible, the mother may still not be able to work or has to work fewer hours. This all disrupts the economic system, the family routine, as well as early learning and childcare, and illustrates that reliable childcare is crucial to keep family life running.

On a more meso level, policies within actual childcare settings can also contradict each other and reinforce ableism and exclusion. As seen with Samantha and her daughter Faye, childcare setting policies dictated that at a certain age children graduate to the next childcare room. For Faye, it was not physically accessible, so after much advocacy work by the family to put her in an accessible room they ended up withdrawing her and putting her in another childcare setting after yet again having to search for inclusive childcare. This served to affect Faye and her family the most and uncovered systemic discoordination.

Systemic ableism intersects with systems not communicating, collaborating, or coordinating together. Mothers of children experiencing disability are working within systems that are not flexible or coordinated with regard to funding, benefits and resources (Ryan &

Runswick-Cole, 2008). These system inadequacies enforce “perceptions of disability as negative and undesired, which in turn mirrors the dominant views of disability within society as a whole” (Ryan & Runswick-Cole, 2008, p. 206). Without the appropriate social funding, inclusive and discrimination-free early learning and childcare will not exist. Lack of adequate funding, supportive policies or an inclusion framework can also create dissonance which seems to be at least partly the case in Nova Scotia with the minimally available information related to inclusion in universal childcare. Without offering inclusion, free of discrimination, in childcare, let alone publicly and parent funded childcare, we are doing a disservice to all children, not just children experiencing disability, their families and our wider communities. Inclusion in early learning and childcare needs to be normative, not an exception, and systems must collaboratively design their programs as such. Lack of childcare spaces and long waitlists are resultant of poor funding and planning, as well as a lack of data of children experiencing disability in the younger years in Nova Scotia. Lack of inclusive training of ECEs is again related to the lack of appropriate funding of professional learning and development and liveable wages. This has also been tied to the shortage of ECEs. It must be acknowledged that ECEs generally want what is best for children and want to provide inclusive learning and care; failures of the system cannot be pinned on individual childcare providers. They are victims of systemic ableism too.

With the introduction of universal childcare, movement has been made by the provincial, territorial, and federal governments toward improving childcare funding, expanding childcare settings to create more spaces, and training more ECEs (EECD, 2022b). This is a big step in the right direction for Nova Scotia and all of Canada. However, it also will require a commitment to create a robust inclusion framework that moves beyond rights and prioritizes relational dimensions of inclusion and provides equitable access to inclusive early learning and childcare

for all (Phelan & Reeves, 2022). Policy makers and stakeholders need to understand the type of invisible work mothers do in pursuit of accessible and inclusive early learning and childcare for their children experiencing disability to inform the development of a universal inclusive early learning and childcare system that mitigates the conditions that create invisible work and associated inequities. Employers and policy makers need to understand the patching and piecemealing done by mothers, particularly mothers of children experiencing disability, and how uncertain it can be. Without this understanding, we risk universal childcare being built on an exclusionary and unstable foundation. To alleviate gendered invisible work and support more women in the workforce, inclusion also has to be tasked to society and safe, accessible and affordable inclusive childcare needs to be available to all.

Mothers are experts on their own experiences, as seen in this study. Consideration of the knowledge and viewpoints held by families with children experiencing disability is critical to inform an inclusive, universal national childcare system designed for all children and their families (van Rhijn et al., 2021). As Canada has committed to creating an inclusive, barrier free-society (Accessible Canada Act, 2019) and with the signing of the *Canada-Nova Scotia Canada-Wide Early Learning and Child Care Agreement* (EECD, 2022b) indicating that early learning and childcare are priorities in Canada and Nova Scotia, there is a great opportunity for decision-makers and policy makers to listen to and act on the experiences of mothers of children experiencing disability to realize equitable childcare. By understanding the work these mothers do and how sociocultural factors shape this work, Nova Scotia's universal childcare can be built to include all children and lessen the burden on mothers.

5.4 Research Significance and Implications

Federal, provincial, and territorial governments have committed to positive change for the early learning and childcare sector, starting with the universal childcare program (EECD, 2022b). What is missing is a commitment to inclusion. The findings of this study have the potential to inform the planning, developing, and implementation of an *inclusive* universal childcare program, both nationally and provincially, that meet the needs of all children and their families. This research illuminated the invisible, unpaid work mothers of children experiencing disability do when pursuing inclusive childcare, what barriers they typically face, and what facilitators may assist them. Understanding how the various sociocultural factors shape and create the conditions necessitating this invisible work can support decision-makers in transforming and creating policies, processes, and practices that mitigate the need for such work and actually support families. The findings from this study demonstrate the influences of gendered and ableist discourses and the ways that these discourses generate discriminatory and exclusionary practices that shape families' abilities to access inclusive early learning and childcare. Notably, mothers shared that their children experiencing disability can be, and often are, turned away from early learning and childcare in Nova Scotia due to lack of policy, resources, and funding. This violates children's rights (UN 1989; UN, 2007) and is arguably a human rights concern for fields, policies and practices concerned with children's and families' well-being.

5.4.1 Implications for Occupational Science

Occupational science is the scholarly field devoted to the study of human occupation (Hocking, 2009) being all the activities that people need to do, want to do, and are expected to do (WFOT, 2021; Wilcock, 2006). An occupational perspective (Njelesani et al., 2012) was used

throughout the research process with the intention of illuminating how occupations, particularly the invisible work mothers do pursuing inclusive childcare, are contextually affected and situated. Also, of importance, according to Hocking (2009), is knowing ways in which occupation affects those who participate in them, which in this study was largely the mothers but on a more macro level, also society. This research has implications for occupational science because understanding how both social inequities and invisible work shape everyday experiences of occupations related to keeping a family running may help movement toward greater social justice, in this case through informing steps toward inclusive universal childcare. Understanding the occupations and invisible work of mothers of children experiencing disability, and how those occupations and invisible work are related to and shaped by both ableism and gender ideologies, is potentially of interest to occupational scientists doing scholarly work in ableism, childhood occupations, occupations of mothers, inclusion, belonging, co-occupation of mothers and children, occupational possibilities, occupational rights, and occupational justice.

Childcare itself is an important occupation for mothers, whether it is done in the home or outsourced to another setting (Arnold et al., 2018). Wilcock (2006) suggests that well-being and occupational balance are shaped by the degree of congruence between occupations and one's needs for doing, being, and becoming (Hitch & Pepin, 2021; Wilcock, 1998). For the purposes of this paper, the dimensions will be assigned operational definitions as informed by both Wilcock's (1999) and Hitch and Pepin's (2021) work. **Doing** is defined as active participation or engagement in an occupation (Hitch & Pepin, 2021), allowing people to interact socially as well as grow in society (Wilcock, 1999). **Being** is defined as the person and includes identity, personal abilities, roles, creativity, consciousness and personal meaning (Hitch and Pepin, 2021). Wilcock (1999) suggested "being" requires people to have the time to discover themselves by

thinking, reflecting, and existing. Wilcock (1999) asserted there is a balance between doing and being in that one must not do too much occupation without allowing balanced time to “be”.

Becoming is defined transformatively as the doer endeavors to develop, change, grow, and ultimately be better (Lyons et al., 2002). It encompasses development over the lifespan, including development of competencies and aspirations (Hitch & Pepin, 2021). Mothers of children experiencing disability engage in *doing* the invisible work and all its encompassing activities to access inclusive early learning and childcare for their child. They are also *being* a mother and working on *becoming* who they want to be, while facilitating the optimal becoming of their child (Wada et al., 2010; Wilcock, 2006). In this study, being a mother of a child experiencing disability meant doing the invisible work of accessing childcare by being a navigator, a quilter, a fighter, a juggler, and a keeper and meeting the expectations of a good mother, a student, and/or an employee.

Hocking (2009) purported it is important for occupational scientists to study how context shapes occupation, which is why sociocultural factors were examined in this study. Context can affect how opportunities for children and families to engage in occupations are shaped (Benjamin-Thomas et al., 2021) and is vital for understanding how people’s occupations are situated in the social, political (Prodinger et al., 2015) and cultural contexts (Munambah et al., 2020). Thus, it is important to understand from this study how mothers’ invisible work related to accessing inclusive childcare shapes, and is shaped by, family, inclusion, and the social, cultural, political, economic, and physical contexts. Knowing this context enables occupational scientists and other stakeholders to understand the current landscape of inclusive childcare, and what barriers must be addressed to make a fully inclusive and universal childcare system work. Findings will also contribute to how mothering occupations and the invisible work mothers do in

relation to accessing early learning and childcare for their children experiencing disability have come to be understood and represented. By knowing and examining this work, we can better understand the occupational participation of these mothers, their children, and families.

Occupational scientists have an ethical responsibility to address occupational justice and “research occupations of people who are marginalized, deprived, invisible, and disabled” (Hocking, 2009, p. 147). Illuminating details of the invisible work done by mothers for their children experiencing disability in the current childcare context serves to attend to occupational justice issues. It highlights how gender inequity and powerful, oppressive social systems presenting many sociocultural barriers affect the occupational participation of mothers trying to do what is best for their children. Occupational justice depicts an ideal situation in which everyone has the chance to participate in occupations that match their routines, wants, beliefs, values, needs, abilities, and responsibilities (Egan & Restall, 2022a; Wilcock & Townsend, 2000). It unites two complex concepts: 1/ the wide-ranging beliefs created by considering occupation as everything people do to organize and achieve everyday life and 2/ “the ethical and political ideas of equity like justice, empowerment, civic society” (Wilcock & Townsend, 2000, p. 85). Occupational justice is connected to inclusion and diversity, and “in an occupationally just society no one would be denied participation in occupations that he or she needed or wanted to do” (Townsend & Wilcock, 2004, p. 261). In contrast, occupational injustice is not having these opportunities. It can be considered the “violation of human and occupational rights⁵” (Hammell & Beagan, 2017, p. 66). Mothers in this study and their children have largely experienced occupational injustice as their occupations have been drastically negatively affected. Their rights have been violated through discrimination in accessing inclusive learning and

⁵ Occupational rights are considered “individual legal, social, or ethical entitlements related to occupation” (Egan & Restall, 2022a, p. 311)

childcare and their efforts have been oppressed and largely ignored by society. Mothers in this study all identified as the critical person in their families to provide care and do the invisible work, including accessing safe and inclusive childcare, for their child experiencing disability. These findings bolster previous findings of Seedat and Rondon (2021) and Guendouzi (2006) and highlight gender and systemic inequities. As long as gender inequities exist in the workplace, and in familial divisions of labour, as long as disproportionate and gendered provision of childcare continues and the many systemic inequities in inclusive childcare occurs (Petts et al., 2021), mothers of children experiencing disability will experience occupational injustice.

The invisible work and identified contextual facilitators and barriers related to the invisible work of mothers pursuing inclusive childcare for their children experiencing disability is significant to the field of occupational science. It helps to understand occupations of both the mothers, the children, and the families better. This research has the potential to inform the ways we envision and enact inclusion in policies and practices and how systems can affect inclusion and the work these mothers do, as well as right the occupational injustices. In addition to occupational justice, these findings may have implications for occupational possibilities, occupational choices, and do address children and mothers as occupational beings, as well. Furthering people's understanding of inclusion in early education and childcare is imperative for occupational scientists who are committed to furthering our understanding of childhood occupations, occupational identities, occupational possibilities, inclusion, and the co-occupation of mothers and their children experiencing disability.

Currently, there is also a scholarly restructuring of the concept of work. A "major reorganization of work which expands and depends on many kinds of activities that are occurring out of sight" (p. 777) is occurring in the sociology field (DeVault, 2014). With this work

reconceptualization, the field of occupational science could potentially illuminate mothers' invisible work in a whole new light. Defining "invisible work" using an occupational lens will hopefully lead to more social recognition and value of this work as we understand it in relation to occupation and occupational participation. An occupational perspective on the invisible work of mothers pursuing inclusive childcare and early education can illustrate its effects on families' roles, routines, relationships, and occupations. Identifying the barriers and facilitators could benefit families looking for childcare. It may also contribute to fields such as early childcare education, occupational science, social work, and occupational therapy who are all concerned with inclusion in childcare. With this understanding, those who work with families with young children experiencing disability will be better equipped to support families in navigating systems in ways that mitigate the burden of invisible work and lead to equitable access to inclusive childcare and early education. This will ideally lead to more meaningful occupational participation, occupational engagement, health, and well-being for children experiencing disability and their families.

5.4.2 Implications for Policy

Policy and how it is written is important for families to access inclusive childcare (Barton & Smith, 2015). "The pandemic, government response and significant reduction in poverty rates demonstrated that child poverty is a policy choice, not an economic inevitability" (Campaign 2000, 2022, p. 7) and this could be said of childcare as well. It is important to listen to the lived experiences of families and children to inform an inclusive, universal national childcare system (van Rhijn et al., 2021). As such, it is important to offer suggestions for an inclusive framework to be developed and enacted based on the experiences of mothers and their invisible work in this study. To start the process of alleviating the invisible work mothers of children experiencing

disability do to pursue inclusive early learning and childcare, several policies and practices may need to be considered.

For the universal childcare strategy to be truly inclusive and effective, it must be acknowledged that many systems intersect to influence inclusive childcare accessibility and need to be addressed. For this reason, it is pertinent to review all existing policies and consider any conflicts or contraindications that may exist due to inaccurate or differing terminology or wording that could affect the reader's interpretation (Barton & Smith, 2015). Policy change may need to occur. The following recommendations are based on the findings from this study:

1/ Rights Based Policies

- Recognize the full breadth of rights outlined in the United Nations Review policies and consider that conflicts might be due to differing terminology or inaccurate interpretations of wording Convention on the Rights of Persons with Disabilities (U.N., 2007); equal access to ELCC is a human right for all children. All Canadians have the right to access services free from discrimination, including inclusive childcare services as per the United Nations (1989);
- Adhere to the Accessibility Act (2017) and the Nova Scotia Act Respecting Accessibility. In 2017, Nova Scotia passed the Act Respecting Accessibility in Nova Scotia. This Accessibility Act aims to make Nova Scotia inclusive and barrier-free by 2030;
- Directly address “children experiencing disability” and “inclusion” in universal childcare agreements, amend those signed (Irwin & Lero, 2021);
- Ensure universal childcare has universal access, make it mandatory that all childcare settings accept and include children regardless if they experience disability or not;

- Integrate and coordinate services and systems for universal access to childcare and services associated with disability and development (Van Rhijn et al., 2021);
- Increase licensed early learning and childcare spaces and enhance ratios (Irwin & Lero, 2021);
- Develop literature and a clear process for families to start the access process for childcare, make this information readily available;
- Inclusive universal childcare needs an education roll-out plan to the public with supporting documentation in many languages.

2/ Economic Policies – for a childcare strategy in Nova Scotia to economically support families with children experiencing disability, the following suggestions are grounded in Mothers’ experiences:

- Provide public funding for disability services and equitable universal access through childcare and family support programs;
- Make inclusive childcare part of the business infrastructure to improve access to childcare and thus improve access to economic productivity (Modestino et al., 2021);
- Recognize the value of the invisible work mothers do and recognize the monetary, relational, and temporal contributions of families with no penalty for those unemployed;
- Create support structures for women at work (Modestino et al., 2021) – Enhance gender-responsive employment policies and legislate employers to offer all parents of children experiencing disability specific care benefits including leaves of absences, family time, job security, flexible work schedules, childcare subsidies and/or the provision of onsite or affiliated childcare supervision and spaces. Labour unions should prioritize this. Creating this for all parents may lessen the work that mothers do. Incentivize this for employers.

Employers may consider offering their own childcare or partner with a childcare setting to offer easy to access inclusive childcare for children of employees, close to work;

- Implement priority mechanisms for families and children who have not been participating fully in the childcare system to do so (Van Rhijn et al., 2021);
- Childcare settings should be responsible to give families information on financial aid.

3/ Access and Inclusion Policies – inclusion needs to be normative, not an exception, exclusion needs to be eliminated.

- The meaning of inclusion needs to be well defined and the theory to practice gap for the enactment of inclusion needs to be filled;
- Ensure early learning and childcare is conceptualized as part of a complex service group that includes family support, healthcare, early intervention, social services, and other family services (Van Rhijn et al., 2021);
- Address staffing shortages;
- Invest in education of ECEs in inclusion training (Wuart et al., 2014). Educate ECEs and meet their diverse needs as learners, including method of education delivery (eg/ virtual learning to reach rural and urban areas), style of teaching and follow-up mentoring and coaching once in practice (Weglarz-Ward & Santos, 2018);
- Ensure each setting has the resources they need to offer full inclusion (Wuart et al., 2014);
- All necessary services should be implemented when a child is first born or diagnosed with a disability (Matthews et al., 2021), including a plan for inclusive childcare.
- All services and providers be accessed through a single entry-point with a central facility and facilitator (Matthews et al., 2021).

- Consider extending formal public early learning education to include children younger than three and four years old for families who want it;
- Re-evaluate inclusion in provincial Pre-primary programs as the mothers in this study largely agreed that inclusion and the support their children need is not occurring;
- All children in Pre-primary care should have wrap-around care if required, consider extending the day or offering wrap-around care that matches the hours of a workday. Create and fund the position of an Early Childcare Inclusion Consultant/Navigator/Advocate for primary caregivers to work with directly to help them find an inclusive childcare space for their child. These positions should be contingent on government funding and not high fees paid by families (Irwin & Lero, 2021) and could help for consistent access to childcare (Ryan & Quinlan, 2018);
- All children who experience disability in childcare settings should have access to publicly funded healthcare team members across the province to help implement inclusion (Barton & Smith, 2015; Irwin & Lero, 2021). Children in childcare need access to the right health professionals at the right time (e.g/ occupational therapists and physiotherapists for training lifting and transferring; nurses for training on the use of G-tubes, etc.)
- Each childcare setting should have access to an inclusion coordinator with the accompanying funding (Grace et al., 2008);
- Help create oversight into the quality of care and inclusion; Early Childcare Inclusion Consultant/Navigator/Advocate could also be trained and consult to early learning and childcare settings on inclusion planning and implementation (Matthews et al., 2021; Wiart et al., 2014);

- All early learning and childcare settings should be physically accessible (Wuart et al., 2014);
- Identify and use an evidence-based tool to measure inclusion, have a schedule for re-evaluation (Odom et al., 2011).

4/ Collect Data - Commit to capture current provincial level data of children experiencing disability in Nova Scotia aged birth to 14 years (Department of Pediatrics and Healthy Populations Institute, 2022; Friendly et al., 2020; Irwin & Lero, 2021). This data is urgently needed to inform a Provincial Inclusive Childcare Strategy framework and various policies for early childcare including for children experiencing disability. Ideally data would be collected for their parents as well to inform needed services and resources and workplace strategy.

5.4.3 Implications for Occupational Therapy and other Health Professionals

Implications identified for occupational science will have significance for occupational therapy and other health professions as well, as occupation frames and conceptualizes the profession of occupational therapy (Reed et al, 2013). This study highlighted the value mothers place on members of their child's healthcare team seeing their child at childcare, as opposed to parents taking their child to them. This information is important for all healthcare professionals, including occupational therapists, to consider. Health team members working with children at their childcare setting not only helps with working on occupational participation in their realistic environmental settings but also eliminates the need for mothers to have to take time away from work or school to take children to appointments. Healthcare providers and their employers realizing this could help decrease systemic incongruencies and help children and families with all their occupational participation. In turn, it is important for all healthcare providers to include

parents in the therapy process and decision making and encourage their advocacy (Smith-Young et al., 2022).

Occupational therapists and other healthcare professionals have a responsibility to highlight ableist acts they witness, and advocate for inclusion for all. For occupational therapists, and other professions, this is often outlined in their professional competencies. Thus, findings from this study can support the work occupational therapists do with young children, their families, and childcare staff, as well as how they advocate for social justice, inclusion, and change.

On a micro level, as an occupational therapist whose clinical practice is with children experiencing disability including working on the goal of toilet training, I realize how far reaching achieving this goal can be. However, on a macro level, it is important for all health professionals to join families in identifying ableist and exclusionary practices, such as denying a child childcare if they are not toilet trained. Once identified, health care professionals can turn this back onto society and advocate for supports to be in place so the child can attend.

5.5 Study Strengths

The participant sample size was substantial for a qualitative study (Hennink & Kaiser, 2022) capturing broad perspectives and insights. The sample was diverse, with mothers representing many parts of Nova Scotia and different education levels, household incomes, and cultural backgrounds. The age of mothers varied as did the number, age, and diagnoses of their children. A few mothers had multiple children experiencing disability of different ages that enabled them to bring a lens to compare their experiences when pursuing childcare. I believe it was a strength that, although this was a secondary analysis, I was a part of the larger study and performed 8 of the 16 interviews. As Hinds and colleagues (1997) suggested, my closeness to the

data and being immersed in the data for a long time was helpful in understanding context and having time to develop my analysis and think about the nuances of the findings. In terms of depth and relevance of my knowledge and understanding of the data, I am confident that it fits with the focus of this secondary analysis. My familiarity with the primary study's data facilitated the use of this data by informing the secondary study's design. Also, a strength of secondary analysis was that it reduced the potential burden on participants; the mothers in this study did not have to be interviewed again, potentially exposing vulnerabilities by retelling sensitive stories (Chatfield, 2020; Ruggiano & Perry, 2019).

5.6 Limitations

It is acknowledged this study has limitations. As this is a secondary analysis, findings may not totally reflect the range of experiences of mothers' invisible work when pursuing inclusive childcare as these mothers were not recruited specifically to investigate invisible work. Thus, there could be a methodological issue with the "fit" between the primary study questions and the secondary study questions (Watters et al., 2018). However, interview questions did touch on the concept of invisible work and there were a lot of rich data on this topic, so this limitation may be minimal, if it is a limitation at all. Also, although it is a large cross-province sample for a qualitative study, those who participated may have had a heightened interest in participating compared with those people who did not respond to recruitment strategies. There also were geographical areas not represented. Another limitation was the demographic questionnaire did not capture more information about participants such as if they were a newcomer. As the interviews were only performed in English, this could be considered a limitation as there is a large newcomer population that do not speak English as their first language, and we may have missed out on their perspectives. Also, although this study was designed for the Western world,

particularly Canada and its province of Nova Scotia, it must be acknowledged that this research is done in a largely white and privileged area of the Western world that has been heavily influenced by colonialism. As with any qualitative research, the theoretical insights may be transferable and resonate with others across contexts (Tracy, 2010).

A further limitation could be myself and perhaps not recognizing some of my beliefs that are embedded in dominant life discourses, and then using this potentially biased lens to analyze the data. Another potential limitation was that follow-up interviews were not done to gather richer information, however due to time constraints associated with the Masters program milestones, this was not an option for me.

The landscape of early learning and childcare was changing dramatically in Nova Scotia and Canada throughout the writing of this thesis. Some of the information presented by mothers in their interviews may not be as accurate or detailed as it was at the time the interviews were completed, such as the number of childcare spaces now available or the information shared by the government at the time of interviews regarding universal childcare. This rapidly changing landscape may be considered a limitation as it could be a difficult task at times to keep up with the ongoing updates, and there is a possibility I missed information. However, it could also be considered a strength of the study; by keeping up to date, I feel the information in this thesis has been contextualized, the analysis happened in real time and was responsive to the changes in early learning and childcare. An example of this was the aforementioned labour strike in Halifax that occurred for Pre-primary workers starting in May 2023. The rhetoric around this enabled me to enrich my analysis by considering aspects of how systemic inequities oppress children experiencing disability and their families, I may not have previous to the strike.

5.7 Future Directions

As universal childcare is in its infancy in most of Canada, by no means inclusive, and remains seemingly ableist and discriminatory, it would be interesting to perform a study like this in a few years time to examine if the invisible work of mothers has changed, if and how inclusion is enacted, and to query if discriminatory practices still exist. Future research is needed regarding the construction of the good mothering ideology and mothers of children experiencing disability in order to identify the discourses oppressing these mothers and help to reconstruct mothering of children experiencing disability. Examining the occupational roles of fathers of children experiencing disability would also be interesting to examine when considering what socially deconstructing and then reconstructing what parenting of children experiencing disability could look like. There are also a number of themes in this study that are worthy for more in-depth exploration, including the good mother ideology and the juggling mothers of children experiencing disability have to do, as it relates to the constructs of gender, emotion work, privilege, capitalism, choice, and being partnered or unpartnered. Looking further at the emotion work but also the mental load of mothers trying to do this work would be of benefit. Working directly with children to study how they are included in various childcare settings would also be of interest.

Also, as there is minimal research in occupational justice (Hammell & Beagan, 2017), using an occupational perspective (Njelesani et al., 2012) with occupational justice as a sensitizing concept to further study the everyday occupations of mothers of children experiencing disability and access to childcare would be informative. The goal would be to advance the concept of occupational justice in the literature with this population.

Chapter 6 Conclusion

6.1 Reflections

Throughout this research I have tried to reflect on my known assumptions and uncover what my unknown assumptions may be. It was daunting at times to shine a critical lens back on myself to examine what dominant discourses affected my life and my views. I do know I personally often identify with the good mother/bad mother dichotomy, and I know many of my friends do as well. I often feel guilt about the things I should be doing with or for my child but am not, or at least feel I am not doing well enough. The many hours writing this thesis contributed to this guilt and at times a feeling of selfishness that I was doing a graduate program instead of reading with my son or playing basketball with him. I certainly reflected that, as he ages, I won't have those opportunities as much. The emotion work for mothers is real and can be overwhelming.

I certainly have reflected more on the invisible work that all mothers, including myself, do in their care work. I find myself acknowledging this work more with parents I work with now in my clinical practice. I felt honoured but also felt a responsibility to tell the stories of these mothers in this study accurately and convey not only their enduring struggles, but their emotions including their tears and their humour.

With a topic such as this, the ever-changing landscape of early learning and childcare affected my writing and shaped my analysis. Throughout the process, parts of universal childcare were being implemented by the provincial government, including making childcare more affordable and giving more money for childcare infrastructure thus creating more spaces. This helped families and all children. On the other hand, a labour strike in Halifax that occurred for Pre-primary ECEs and other members in their union, including school education program

assistants, started on May 10, 2023. Therefore, Pre-primary children, approximately 3000, in this region were not allowed to attend Pre-primary as ECEs were not there to teach and care for them. The strike also notably impacted families of children experiencing disability as these children were not allowed to attend school. As the strike progressed, some children experiencing disability could attend school for only short periods of time or could attend with parents present. School continued throughout all of this, with children experiencing disability feeling the effects of discrimination and exclusion. Parents' invisible work for all of these children increased, as many of them advocated for a return to early learning and childcare and formal school. Many parents' paid employment was also affected, some families took leaves from their jobs, some tried to juggle childcare and working from home and some tried to patch childcare together with friends and family. The rhetoric around this enabled me to think deeply about ableism and systemic oppression and enrich my analysis by considering aspects I may not have prior to the strike. I also further developed my analysis of the invisible work these mothers do in response to systemic oppression. This experience also made me realize just how far behind this province is in living in a culture of inclusion.

Yet another facet of my reflections were the unprecedented forest fires that occurred in various parts of Nova Scotia in May and June of 2023. In one area of Halifax alone, two large childcare centres were completely lost, and families lost their childcare. One of these settings shared that they lost 68 childcare spaces and access to an additional 104 childcare spaces until physical access to the site was allowed and power was restored. It was not known how long this would take, and certainly affected childcare for children and employment for the ECEs working there. It also highlights the intricate working of social systems again as municipal, provincial, and federal assistance was implemented to fight the fires and provide relief. Insurance will no

doubt play a role in this as well. Another factor in this situation is the kindness of community with various members and organizations offering furniture and toys to replace what was lost in these childcare centres.

I personally have concerns with the inclusion plan that EECD (2022b) currently has for universal inclusive childcare in Nova Scotia. While they address inclusion, it is very encompassing of many terms and does not address in detail how inclusion will be implemented specifically for children experiencing disability. The lack of this information is concerning as universal childcare is being implemented now. We risk implementing a similar approach to what we already have or adopting a “wait-and-see” approach making us responsive, but not informative, to the system.

I also reflected throughout this study on the gender inequities apparent in childcare and seeking childcare. Recruitment for the larger study yielded 17 participants, 16 of whom identified as mothers. Using a post-positivist lens, which I have been more familiar with in the past, one may purport that the sample was gender unbalanced. However, looking through a critical feminist lens I realize this serves to illuminate that gender inequities are strong and shape the invisible work done in pursuit of accessing inclusive early learning and childcare, and that it is typically mothers who do this work. It reinforces that a gender inequity exists; unpaid invisible work is primarily done by mothers to access inclusive early learning and childcare. I also was keenly aware of the “good mother” ideology in this research, but I did unknowingly turn this lens on my own life and realize I too am trying to live up to this ideology. It really is pervasive in Western society. To add that pressure onto a mother who is fighting against social oppression for their child experiencing disability is an incredible social burden.

I do reflect on what I hope this work has to offer. My hope is that this research informs positive change to universal childcare in Nova Scotia and perhaps other Canadian provinces. I would define positive change as inclusion being a social expectation and practiced in all early learning and childcare, and that exclusion rooted in ableism and disablism is a thing of the past. Positive change to me would also mean that mothers' invisible work is "seen" and acknowledged by society and that the system rightfully takes ownership of proper inclusive early learning and childcare and not rest this burden on mothers. A personal hope is that I continue to build on the knowledge gained in this work and increase my efforts based on research evidence to advocate for inclusion for all children experiencing disability and their families.

6.2 Conclusion

Mothers do an enormous amount of invisible work to get their children experiencing disability access to inclusive early learning and childcare. Their journeys are long and difficult and start well before their child enters the door of a childcare setting. This research has added to the current knowledge of what invisible work mothers across Nova Scotia do to access inclusive early learning and childcare for their children experiencing disability. It has identified the roles these mothers occupy, as Navigators, Quilters, Fighters, Jugglers, and Keepers, as well as what barriers they face, and what facilitators have helped them.

Identifying these mothers' invisible work and the challenges they face has illuminated that a fundamental, and perhaps radical, system change for early learning and childcare is needed to make it inclusive and easily accessible for all. This research indicates that "the current system should not be replicated using public funds to implement similar approaches. Any definition of inclusion must be disability inclusive and recognize both program-level inclusion and the role of childcare in creating inclusive communities" as universal childcare is implemented (van Rhijn et

al., p. 407). Change is needed at all levels and the provincial and federal governments need to work together to make this happen. Examining this invisible work in detail illustrates the information needed to task society with planning, developing, and implementing a high quality, inclusive national childcare system. To develop and implement a fully inclusive national childcare system in Canada, this research supports that the rights and insights of children experiencing disability and their families must be included “to ensure it is truly accessible to all in terms of availability, affordability, and ability to support the needs of all children and families (van Rhijn et al., p. 400).

This research has resulted in policy recommendations that can be used to inform such a system and actioned to make it inclusive and accessible. To be able “to locate, choose, and maintain childcare, families [need] specific resources to orchestrate their searches including time, adult support, and economic stability” (DeVore & Bowers, 2006, p. 210). Emphasis also needs to be placed on addressing childcare costs and increasing childcare spaces, as well training ECEs, in inclusive participation for all children and paying them fairly. Many early childhood support and services such as family support, developmental interventionists, and healthcare team members such as occupational therapists, nurses, and speech language pathologists, and most likely the creation of childcare navigators and a navigation process, are critical if children experiencing disability are to be fully included in childcare. On a more macro level, addressing ableism, disablism and discrimination is warranted if we are to become an inclusive society for all, including people experiencing disability and their families. Recognizing that there are gender inequities in the invisible work these mothers do, often to be the “good mother,” is also important on a societal level. Societal expectations that mothers continue with this invisible work and continue to participate in the workforce are not sustainable in reality without accessible

inclusive early learning and childcare. Once developed, this inclusive childcare system will require periodic re-evaluation to ensure it is meeting the needs of all children and families. A national universal childcare plan must address major access and equity issues, and the implementation of true inclusion for all.

Bibliography

- Accessibility Act. Government of Nova Scotia (2017, c. 2, s. 1.)
- Accessible Canada Act, Government of Canada, S.C. (2019, c. 10).
- Arnold, S., Mackenzie, L., James, C., & Millington, M. (2018). International perspective on factors influencing the performance of housework: A scoping review. *British Journal of Occupational Therapy, Vol. 81*(12) 687–699.
- As, D. (1978). Studies of time use: Problems and prospects. *Acta Sociologica, 21*, 125-141.
- Asbjørnslett, M., Engelsrud, G. H., & Helseth, S. (2015). How children with disabilities engage in occupations during a transitional phase. *Journal of Occupational Science, 22*(3), 320-333. <https://doi-org.ezproxy.library.dal.ca/10.1080/14427591.2014.952365>
- Baker, N.A., Jacobs, K., & Tickle-Degnen, L. (2003). A methodology for developing evidence about meaning in occupation: Exploring the meaning of working. *Occupational Therapy Journal of Research: Occupation, Participation and Health, 23*, 57 - 66.
- Barton, E. E., & Smith, B. J. (2015). Advancing high-quality preschool inclusion: A discussion and recommendations for the field. *Topics in Early Childhood Special Education, 35*(2), 69-78. <http://dx.doi.org/10.1177/0271121415583048>
- Benjamin-Thomas, T. E., Rudman, D. L., McGrath, C., Cameron, D., Abraham, V. J., Gunaseelan, J., & Vinothkumar, S. P. (2021). Situating occupational injustices experienced by children with disabilities in rural India within sociocultural, economic, and systemic conditions. *Journal of Occupational Science, 1-18*. [10.1080/14427591.2021.1899038](https://doi.org/10.1080/14427591.2021.1899038)
- Blackburn, R. M. (1999). Is housework unpaid work? *International Journal of Sociology and Social Policy, 19*(7/8), 1–20.
- Bianchi, S. M., & Milkie, M. A. (2010). Work and family research in the first decade of the 21st century. *Journal of Marriage and Family, 72*(3), 705–725. <https://www.jstor.org/stable/40732504>
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. doi:10.1191/1478088706qp063oa
- Braun, V., Clarke, V., Hayfield, N., & Terry, G. (2019). *Answers to frequently asked questions about thematic analysis*. <https://cdn.auckland.ac.nz/assets/psych/about/our-research/documents/Answers%20to%20frequently%20asked%20questions%20about%20thematic%20analysis%20April%202019.Pdf>

- Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology, 18*(3), 328–352. <https://doi.org/10.1080/14780887.2020.1769238>
- Braun, V. & Clarke, B. (2022). *Thematic analysis: A practical guide*. Sage Publications, Thousand Oaks, CA.
- Breitkreuz, R., Colen, K., & Horne, R. (2021). Producing the patchwork: The hidden work of mothers in organizing child care. *Journal of Family Studies, 27*(3), 436–459. <https://doi.org/10.1080/13229400.2019.1635038>
- Brett, J. (2002). The experience of disability from the perspective of parents of children with profound impairment: Is it time for an alternative model of disability? *Disability & Society, 17*(7), 825–843. <https://doi.org/10.1080/0968759022000039109>
- Brinkmann, S. (2013). *Qualitative interviewing*. Oxford University Press. <http://ukcatalogue.oup.com/product/9780199861392.do>
- Campaign 2000. (2022). *2022 report card on child and family poverty in Canada*. <https://campaign2000.ca/pandemic-lessons-ending-child-and-family-poverty-is-possible/>
- Canadian Centre for Diversity and Inclusion (CCDI) (2022). *Diversity defined*. <https://ccdi.ca/our-story/diversity-defined/>
- Case-Smith, J., & O'Brien, J. C. (2015). *Occupational therapy for children and adolescents* (Seventh ed., Objective Measurement: Theory into Practice). St. Louis, Missouri: Elsevier.
- Chatfield, S. L. (2020). Recommendations for secondary analysis of qualitative data. *The Qualitative Report, 25*(3), 833-842,833A.
- Childcare Resource and Research Unit (CRRU) (2016). *Finding quality child care: A guide for parents*. Toronto, ON. www.findingqualitychildcare.ca
- Christopher, K. (2012). Extensive mothering: Employed mothers' constructions of the good mother. *Gender & Society, 26*(1), 73–96. <https://doi.org/10.1177/0891243211427700>
- Clark, F. (1993). Occupation embedded in a real life: Interweaving occupational science and occupational therapy. 1993 Eleanor Clarke Slagle Lecture. *The American Journal of Occupational Therapy: Official Publication of the American Occupational Therapy Association, 47*(12).
- Clark, D., Clark, M. & Seel, K. (2009). *Disability policy in Alberta: An initial exploration of transition implications*. Mount Royal College. Institute for Nonprofit Studies.

- Collins, C. (2021). Is maternal guilt a cross-national experience? *Qualitative Sociology*, 44(1), 1–29. <https://doi.org/10.1007/s11133-020-09451-2>
- Creswell, J. W., & Creswell, J. D. (2018). *Research design* (5th ed.). SAGE Publications.
- Creswell, J.W. and Poth, C.N. (2018). *Qualitative inquiry and research design choosing among five approaches*. 4th Edition, SAGE Publications, Inc., Thousand Oaks.
- Dalkilic, M., & Vadeboncoeur, J. A. (2016). Regulating the child in early childhood education: The paradox of inclusion. *Global Studies of Childhood*, 6(1), 17–30. <https://doi.org/10.1177/2043610615619982>
- Daniels A.K. (1987). Invisible work. *Social Problems*, 34(5): 403–15.
- Darwin Holmes, A. G. (2020). Researcher positionality—A consideration of its influence and place in qualitative research—A new researcher guide. *Shanlax International Journal of Education*, 8(4), 1–10. <https://doi.org/10.34293/education.v8i4.3232>
- Department of Pediatrics and Healthy Populations Institute (2022). *One chance to be a child: A data profile to inform a better future for child and youth well-being in Nova Scotia*. Full Report. Available from: www.onechancens.ca.
- DeVault, M. L. (2014). Mapping invisible work: Conceptual tools for social justice projects. *Sociological Forum*, 29(4), 775–790. <https://doi.org/10.1111/socf.12119>
- DeVore, S. & Bowers, B. (2006). Childcare for children with disabilities: Families search for specialized care and cooperative childcare partnerships. *Infants & Young Children: An Interdisciplinary Journal of Early Childhood Intervention*, 19(3), 203–212. <https://doi.org/10.1097/00001163-200607000-00005>
- Dickie, V. A. (2003). The role of learning in quilt making. *Journal of Occupational Science*, 10(3), 120-129.
- Dickie, V. A., Cutchin, M. P., & Humphry, R. (2006). Occupation as transactional experience: A critique of individualism in occupational science. *Journal of Occupational Science*, 13(1),83-93. doi:10.1080/14427591.2006.9686573
- Education and Early Childhood Development Nova Scotia (EECD) (2021). *The new Canada wide Child Care Agreement for Nova Scotia*. <https://www.ednet.ns.ca/childcare>
- Education and Early Childhood Development Nova Scotia (EECD) (2022a). *Child Care Transformation: Information for Families*. <https://www.ednet.ns.ca/childcare/information-for-families>
- Education and Early Childhood Development (EECD) (2022b). *The new Canada-wide Child Care Agreement for Nova Scotia*. <https://www.ednet.ns.ca/childcare>

- Education and Early Childhood Development (EECD) (2023). *Pre-primary FAQ Inclusion*.
<https://www.ednet.ns.ca/Pre-primary/faq-special-needs>
- Egan, M., & Restall, G. (2022a). *Promoting occupational participation: Collaborative relationship focused occupational therapy* (2nd ed., pp. 310). Canadian Association of Occupational Therapists.
- Egan, M., & Restall, G. (2022b). The Canadian Model of Occupational Participation. In M. Egan & G. Restall (Eds.), *Promoting occupational participation: Collaborative relationship focused occupational therapy* (2nd ed., pp. 73-95). Canadian Association of Occupational Therapists.
- Eilers, N. (2020). Critical disability studies and ‘inclusive’ early childhood education: The ongoing divide. *Journal of Disability Studies in Education*, 1(1–2), 64–89.
<https://doi.org/10.1163/25888803-00101004>
- Findling, Y., Barnoy, S., & Itzhaki, M. (2022). Burden of treatment, emotion work and parental burnout of mothers to children with or without special needs: A pilot study. *Current Psychology*. <https://doi.org/10.1007/s12144-022-03074-2>
- Frank, L., Fisher, L., & Saulnier, C. (2021, November). *2021 report card on child and family poverty in Nova Scotia - Worst provincial performance over 30 years*. Canadian Centre for Policy Alternatives (CCPA).
https://campaign2000.ca/wpcontent/uploads/2021/11/NovaScotia2021-RC-child_family_poverty-NS-Final-English.pdf
- Frank, L., & Saulnier, C. (2023, March 8). *2022 report card on child and family poverty in Nova Scotia: Kids Can't Wait*. <https://policyalternatives.ca/2022NSreportcard>
- Frankel, E.B., Chan, C. & Underwood, K. (2019). Inclusion is an experience, not a placement. *eceLINK Peer Reviewed Collection*, 2(2):25–34.
- Friendly, M., Larsen, E., & Feltham, L. (2018). *Early childhood education and care in Canada 2016*. <https://www.deslibris.ca/ID/10096600>
- Friendly, M., Feltham, L.E., Mohamed, S., Nguyen, N. T., Vickerson, R., & Forer, B. (2020). *Early childhood education and care in Canada 2019*. Toronto: Childcare Resource and Research Unit. https://childcarecanada.org/sites/default/files/ECEC-Canada-2019_full-publication-REV-12-2-21.pdf
- Goodley, D. (2013). Dis/entangling critical disability studies. *Disability & Society*, 28(5), 631–644. <https://doi.org/10.1080/09687599.2012.717884>
- Goodley, D., & Runswick-Cole, K. (2010). Emancipating play: Dis/abled children, development and deconstruction. *Disability & Society*, 25(4), 499–512.
<https://doi.org/10.1080/09687591003755914>

- Goodwin, D. L., & Ebert, A. (2018). Physical activity for disabled youth: Hidden parental labor. *Adapted Physical Activity Quarterly*, 35(4), 342–360. <https://doi.org/10.1123/apaq.2017-0110>
- Goodwin, S. & Huppatz, K. (2010). *The good mother in theory and research: an overview* (pp. 1–24). Sydney University Press.
- Government of Canada (2022, August 17). *Canada – Nova Scotia Canada-Wide Early Learning and Child Care Agreement – 2021 to 2026*. <https://www.canada.ca/en/early-learning-child-care-agreement/agreements-provinces-territories/nova-scotia-canada-wide-2021.html>
- Government of Canada (2023, March 20). *Nova Scotia’s action plan for fiscal year 2022 to 2023*. <https://www.canada.ca/en/early-learning-child-care-agreement/agreements-provinces-territories/nova-scotia-2021/action-plan-2022.html>
- Government of Nova Scotia (May, 2021). *Regulated child care settings: Licensee’s manual*.
- Government of Nova Scotia (2020, March 15). *First presumptive cases of COVID-19 in Nova Scotia; New prevention measures*. <https://novascotia.ca/news/release/?id=20200315002>
- Government of Nova Scotia (n.d). Child care subsidy. *Early Learning and Child Care (ELCC)*. <https://www.ednet.ns.ca/earlyyears/families/childcaresubsidy.shtml#:~:text=No%20Scotia's%20Child%20Care%20Subsidy,family%20home%20day%20care%20agencies>.
- Grace, R., Llewellyn, G., Wedgwood, N., Fenech, M., & McConnell, D. (2008). Far from ideal: Everyday experiences of mothers and early childhood professionals negotiating an inclusive early childhood experience in the Australian context. *Topics in Early Childhood Special Education*, 28(1), 18–30. <https://doi.org/10.1177/0271121407313525>
- Green, S. E. (2007). “We’re tired, not sad”: Benefits and burdens of mothering a child with a disability. *Social Science & Medicine*, 64(1), 150–163. <https://doi.org/10.1016/j.socscimed.2006.08.025>
- Greene, M. (2000). *Releasing the imagination: Essays on education, the arts, and social change*. John Wiley & Sons.
- Guendouzi, J. (2006). “The guilt thing”: Balancing domestic and professional roles. *Journal of Marriage and Family*, 68, 901–909. <https://doi.org/10.1111/j.1741-737.2006.00303.x>
- 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>
- Halfon, N., Houtrow, A., Larson, K., & Newacheck, P. W. (2012). The changing landscape of disability in childhood. *Future of Children*, 22(1), 13–42.

- Halfon, S., & Friendly, M. (2013). Inclusion of young children with disabilities in regulated childcare in Canada. A snapshot: Research, policy and practice. *Occasional Paper No. 27*.
- Hammell, W. H. (2009). Sacred texts: A sceptical exploration of the assumptions underpinning theories of occupation. *Canadian Journal of Occupational Therapy, 76*, 6–13. doi:10.1177/000841740907600105
- Hammell, K. R. W., & Beagan, B. (2017). Occupational injustice: A critique. *Canadian Journal of Occupational Therapy, 84*(1), 58–68. <https://doi.org/10.1177/0008417416638858>
- Hanvey, L. (2002). *Children with disabilities and their families in Canada: A discussion paper commissioned by the National Children's Alliance for the first national roundtable on children with disabilities*. <https://docplayer.net/21118942-Children-with-disabilities-and-their-families-in-canada-a-discussion-paper.html>
- Hatton, E. (2017). Mechanisms of invisibility: Rethinking the concept of invisible work. *Work, Employment and Society, 31*(2), 336–351. <https://doi.org/10.1177/0950017016674894>
- Hays, S. (1996). *The cultural contradictions of motherhood*. Yale University Press.
- Hennink, M., & Kaiser, B. N. (2022). Sample sizes for saturation in qualitative research: A systematic review of empirical tests. *Social Science & Medicine, 292*, 114523. <https://doi.org/10.1016/j.socscimed.2021.114523>
- Hinds, P. S., Vogel, R. J., & Clarke-Steffen, L. (1997). The possibilities and pitfalls of doing a secondary analysis of a qualitative data set. *Qualitative Health Research, 7*(3), 408–424. <https://doi.org/10.1177/104973239700700306>
- Hitch, D., & Pepin, G. (2021). Doing, being, becoming and belonging at the heart of occupational therapy: An analysis of theoretical ways of knowing. *Scandinavian Journal of Occupational Therapy, 28*(1), 13–25. <https://doi.org/10.1080/11038128.2020.1726454>
- Hochschild, A. R., (1983). *The managed heart: The commercialization of human feeling*. University of California Press.
- Hochschild, A. R., (2012). *The managed heart: Commercialization of human feeling: Vol. Updated, with a new preface*. University of California Press.
- Hocking, C. (2009). The challenge of occupation: Describing the things people do. *Journal of Occupational Science, 16*(3), 140–150. 10.1080/14427591.2009.9686655
- Hughes, B., & Paterson, K. (1997). The social model of disability and the disappearing body: Towards a sociology of impairment. *Disability & Society, 12*(3), 325–340. <https://doi.org/10.1080/09687599727209>

- Hughes-Miller, M., Hager, T. & Jaremko Bromwich, R. (2017). *Bad mothers: Regulations, representations, and resistance*. Demeter Press.
- Irwin, S. H. (2009). *SpecialLink Early Childhood Inclusion Quality Scale*. Wreck Cove, NS: Breton Books.
- Irwin, S. H. & Lero, D.S. (2021). *Inclusion quality: Children with disabilities in early learning & childcare in Canada*. Breton Books: A Speciallink publication.
<https://speciallinkcanada.org/resources/index.html>
- Kagan, C., Lewis, S., Heaton, P., & Cranshaw, M. (1999). Enabled or disabled? Working parents of disabled children and the provision of child-care. *Journal of Community & Applied Social Psychology*, 9(5), 369–381. [https://doi.org/10.1002/\(SICI\)1099-1298\(199909/10\)9:5<369::AID-CASP527>3.0.CO;2-H](https://doi.org/10.1002/(SICI)1099-1298(199909/10)9:5<369::AID-CASP527>3.0.CO;2-H)
- Kantartzis, S., & Molineux, M. (2011). The Influence of Western society’s construction of a healthy daily life on the conceptualisation of occupation. *Journal of Occupational Science*, 18(1), 62–80. [10.1080/14427591.2011.566917](https://doi.org/10.1080/14427591.2011.566917)
- Kaplan, A., Sabbah-Karkabi, M., & Herzog, H. (2020). “When I iron my son’s shirt, i feel my maternal role”: Making women’s invisible work visible. *Journal of Family Issues*, 41(9), 1525–1545. <https://doi.org/10.1177/0192513X19894351>
- Killoran, I., Tymon, D., & Frempong, G. (2007). Disabilities and inclusive practices within Toronto preschools. *International Journal of Inclusive Education*, 11(1), 81–95. <https://doi.org/10.1080/13603110500375473>
- Knight, K. (2013). The changing face of the ‘good mother’: Trends in research into families with a child with intellectual disability, and some concerns. *Disability & Society*, 28(5), 660–673. <https://doi.org/10.1080/09687599.2012.732540>
- Kuri, E., & Fierheller, D. (2022). Social work and mothering: Mapping the intersections of social work and matricentric feminism. *Journal of the Motherhood Initiative*, 13(1), 7-29.
- Laliberte Rudman, D., Aldrich R, & Kiepek, N. (2022). Evolving understandings of occupation. In M. Egan & G. Restall (Eds.), *Promoting occupational participation: Collaborative relationship focused occupational therapy* (2nd ed., pp. 9-30). Canadian Association of Occupational Therapists.
- Lewis, S., Kagan, C., & Heaton, P. (2000). Dual-earner parents with disabled children: Family patterns for working and caring. *Journal of Family Issues*, 21(8), 1031–1060. <https://doi.org/10.1177/019251300021008005>
- Lincoln, Y. S., & Guba, E. G. (2000). Paradigmatic controversies, contradictions, and emerging confluences. In N. K. Denzin & Y. S. Lincoln (Eds.), *The handbook of qualitative research* (2nd ed., pp. 163–188). Beverly Hills, CA: Sage.

- Lindbom-Cho, D. R., Edwards, K. T., Fasching-Varner, K. J., & Mitchell, R. W. (2014). Critical feminism in education. In S. Totten & J. E. Pedersen (Eds.), *Educating about social issues in the 20th and 21st centuries, Vol. 4: Critical pedagogues and their pedagogical theories*. (pp. 35–52). IAP Information Age Publishing.
- MacDonald, D. (2018). *Childcare deserts in Canada*. Ottawa: Canadian Centre for Policy Alternatives.
<https://www.policyalternatives.ca/sites/default/files/uploads/publications/National%20office/2018/06/Child%20Care%20Deserts.pdf>.
- Matthews, E. J., Gelech, J., Graumans, R., Desjardins, M., & Gélinas, I. (2021). Mediating a fragmented system: Partnership experiences of parents of children with neurodevelopmental and neuromuscular disabilities. *Journal of Developmental and Physical Disabilities*, 33(2), 311–330. <https://doi.org/10.1007/s10882-020-09750-0>
- McConnell, D., Savage, A., Breitzkreuz, R., & Sobsey, D. (2016). Sustainable family care for children with disabilities. *Journal of Child and Family Studies*, 25(2), 530-544.
<http://dx.doi.org/10.1007/s10826-015-0245-0>
- McKeever, P., & Miller, K.L. (2004). Mothering children who have disabilities: A Bourdieusian interpretation of maternal practices. *Social Science & Medicine*, 59(6), 1177–1191.
<https://doi.org/10.1016/j.socscimed.2003.12.023>
- Merriam-Webster (2023, May 24). Keeps. In *Merriam-Webster.com dictionary*
<https://www.merriamwebster.com/dictionary/keeps>
- Milne, J., & Oberle, K. (2005). Enhancing rigor in qualitative description. *Journal of Wound, Ostomy and Continence Nursing*, 32(6), 413–420. <https://doi.org/10.1097/00152192-200511000-00014>
- Modestino, A. S., Ladge, J. J., Swartz, A., & Lincoln, A. (2021, April 29). Childcare is a business issue. *Harvard Business Review*. <https://hbr.org/2021/04/childcare-is-a-business-issue>
- Munambah, N., Cordier, R., Speyer, R., Toto, S., & Ramugondo, E. L. (2020). A systematic review comparing the play profiles of children with special health care needs with typically developing children. *BioMed Research International*, 2020, 1–10.
<https://doi.org/10.1155/2020/9582795>
- Muthukrishna, N., & Ebrahim, H. (2014). Motherhood and the disabled child in contexts of early education and care. *Childhood*, 21(3), 369–384.
<https://doi.org/10.1177/0907568214524233>

- National Association for the Education of Young Children & Division of Early Childhood (NAEYC-DEC). (2009). *A joint position statement of the Division for Early Children (DEC) and the National Association for the Education of Young Children (NAEYC): Early childhood inclusion*. https://www.naeyc.org/sites/default/files/globally_shared/downloads/PDFs/resources/position-statements/ps_inclusion_dec_naeyc_ec.pdf
- Njelesani, J., Tang, A., Jonsson, H., & Polatajko, H. (2012). Articulating an occupational perspective. *Journal of Occupational Science*, 21(2), 226–235. <https://doi.org/10.1080/14427591.2012.717500>
- Nova Scotia (2017). *Accessibility Act*. 2017, c. 2, s. 1.
- Nova Scotia Early Learning and Child Care Act: Early Learning and Child Care Regulations. (2020). *Section A: Licensee Manual for Regulated Child Care Settings*. https://www.ednet.ns.ca/earlyyears/documents/ministerial_requirements/Section%20A%20Licensee%20Manual%20for%20Regulated%20Child%20Care%20Settings%20N.pdf
- Nova Scotia Government. (n.d.). *Early Learning and Child Care (ELCC)*. <https://www.ednet.ns.ca/earlyyears/index.shtml>
- Nyman, A., & Isaksson, G. (2021). Enacted togetherness – A concept to understand occupation as socio-culturally situated. *Scandinavian Journal of Occupational Therapy*, 28(1), 41-45, 10.1080/11038128.2020.1720283
- Odom, S. L., Buysse, V., & Soukakou, E. (2011). Inclusion for young children with disabilities: A quarter century of research perspectives. *Journal of Early Intervention*, 33(4), 344-356.
- Oliver, M., & Barnes, C. (2012). *The new politics of disablement: A sociological approach*, 2nd edition. London: Palgrave Macmillan.
- Peers, D., Spencer-Cavaliere, N., & Eales, L. (2014). Say What You Mean: Rethinking Disability Language in Adapted Physical Activity Quarterly. *Adapted Physical Activity Quarterly*, 31(3), 265–282. <https://doi.org/10.1123/apaq.2013-0091>
- Petts, R. J., Carlson, D. L., & Pepin, J. R. (2021). A gendered pandemic: Childcare, homeschooling, and parents' employment during COVID-19. *Gender, Work & Organization*, 28(S2), 515–534. <https://doi.org/10.1111/gwao.12614>
- 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., Diggins, C., Ausman, C., Vardy, L., McConnell, D., & Moore, S. (2022). *Equitable access to inclusive early learning and childcare for children with disabilities: The family experience* (p. 1-38). Submitted to Employment Social Development Canada, Government of Canada. Full Report.
- Phelan, S.K., & Reeves, P. (2022). (Re)Imagining inclusion in ways that foster belonging in the lives of disabled children and youth. *The Lancet Child & Adolescent Health*, 6(2), 77-78. doi: 10.1016/S2352-4642(21)00371-0.
- Polatajko, H. J., Davis, J., Stewart, D., Cantin, N., Amoroso, B., Purdie, L., & Zimmerman, D. (2013). Specifying the domain of concern: Occupation as core. In E. A. Townsend & H. J. Polatajko, *Enabling occupation II: Advancing an occupational therapy vision for health, well-being and justice through occupation* (2nd ed., pp. 13–36). Ottawa, ON: CAOT Publications ACE.
- Powers, E. T. (2003). Children’s health and maternal work activity: Estimates under alternative disability definitions. *Journal of Human Resources*, 38, 523-556.
- Prentice, S., & White, L.A. (2020). Childcare deserts and distributional disadvantages: The legacies of split childcare policies and programmes in Canada. *Journal of International and Comparative Social Policy* 35(1):59–74. <https://doi.org/10.1080/21699763.2018.1526700>.
- Proding, B., Laliberte Rudman, D., & Shaw, L. (2013). Institutional ethnography: Studying the situated nature of human occupation. *Journal of Occupational Science*, 22(1), 71-81. doi: 10.1080/14427591.2013.813429
- Quirkos 2.5.3 [Computer Software]. (2022). Retrieved from <https://www.quirkos.com>
- Race, D., K. Boxall, and I. Carson. (2005). Towards a dialogue for practice: reconciling social role valorization and the social model of disability. *Disability & Society* 20(5): 507-521. doi:10.1080/09687590500156196.
- Reed, K., Hocking, C., & Smythe, L. (2013). The meaning of occupation: Historical and contemporary connections between health and occupation: JNZAOT. *New Zealand Journal of Occupational Therapy*, 60(1), 38-44.
- Reeves, P., Ng, S. L., Harris, M., & Phelan, S. K. (2020). The exclusionary effects of inclusion today: (re)production of disability in inclusive education settings. *Disability & Society*, DOI: 10.1080/09687599.2020.1828042
- Rosenzweig, J. M., Brennan, E. M., Huffstutter, K., & Bradley, J. R. (2008). Child care and employed parents of children with emotional or behavioral disorders. *Journal of Emotional and Behavioral Disorders*, 16(2), 78–89. <https://doi.org/10.1177/1063426607312538>

- Ruggiano, N., & Perry, T. E. (2019). Conducting secondary analysis of qualitative data: Should we, can we, and how? *Qualitative Social Work, 18*(1), 81–97. <https://doi.org/10.1177/1473325017700701>
- Ryan, C., & Quinlan, E. (2018). Whoever shouts the loudest: Listening to parents of children with disabilities. *Journal of Applied Research in Intellectual Disabilities, 31*(S2), 203–214. <https://doi.org/10.1111/jar.12354>
- Ryan, S., & Runswick-Cole, K. (2008). Repositioning mothers: Mothers, disabled children and disability studies. *Disability & Society, 23*(3), 199–210. <https://doi.org/10.1080/09687590801953937>
- Ryan, S., & Runswick-Cole, K. R. (2009). From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum. *Journal of Applied Research in Intellectual Disabilities, 22*(1), 43–53. <https://doi.org/10.1111/j.1468-3148.2008.00438.x>
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health, 23*(4), 334–340. [https://doi.org/10.1002/1098-240X\(200008\)23:4<334::AID-NUR9>3.0.CO;2-G](https://doi.org/10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G)
- Schmidt, E.M., Décieux, F., Zartler, U., & Schnor, C. (2023). What makes a good mother? Two decades of research reflecting social norms of motherhood. *Journal of Family Theory & Review, 15*(1), 57–77. <https://doi.org/10.1111/jftr.12488>
- Scott, E. K., London, A. S., & Hurst, A. (2005). Instability in patchworks of child care when moving from welfare to work. *Journal of Marriage and Family, 67*(2), 370–386. <https://doi.org/10.1111/j.0022-2445.2005.00122.x>
- Seedat, S., & Rondon, M. (2021). Women’s wellbeing and the burden of unpaid work. *The BMJ, 374*, n1972. <https://doi.org/10.1136/bmj.n1972>
- Sherif, V. (2018). Evaluating preexisting qualitative research data for secondary analysis. *Qualitative Social Research, 19*(2). <https://doi-org.ezproxy.library.dal.ca/10.17169/fqs.19.2.2821>
- Statistics Canada. (2007). *Participation and Activity Limitation Survey 2006: Analytical report*. Ministry of Industry, Ottawa, ON: Statistics Canada. Catalogue no. 89-628-XIE
- Statistics Canada. (2018, November 18). *Canadian Survey on Disability*. <https://www150.statcan.gc.ca/n1/en/catalogue/89-654-X>
- Statistics Canada. (2022a, May 30). *Quality of Employment in Canada: Employment rate of mothers and fathers, 1976 to 2021*. <https://www150.statcan.gc.ca/n1/en/catalogue/14280001202000100012>

- Statistics Canada. (2022b, June 1). *Survey on Early Learning and Child Care Arrangements, 2022*. <https://www150.statcan.gc.ca/n1/daily-quotidien/220601/dq220601a-eng.htm>
- Townsend, E. (1998). *Good intentions overruled: A critique of empowerment in the routine organization of mental health services*. Toronto: University of Toronto Press.
- Townsend, E. & Wilcock, A. (2004). Occupational justice. In C. H. Christiansen & E. A. Townsend (Eds.), *Introduction to occupation. The art and science of living* (pp. 243-273). Upper Saddle River, NJ: Prentice Hall.
- Tracy, S. J. (2010). Qualitative quality: Eight “Big-Tent” criteria for excellent qualitative research. *Qualitative Inquiry, 16*(10), 837-851. <https://doi.org/10.1177/1077800410383121>
- Trudeau J. *Speech from the Throne*. (2020 Sept 23).
- Tyler, I. (2015). Dis/ability studies: Theorising disablism and ableism. *Disability & Society, 30*(4), 659–662. <https://doi.org/10.1080/09687599.2015.1014669>
- United Nations (U.N.) (1989). *Convention on the Rights of the Child*. Geneva: United Nations High Commissioner for Human Rights, 1–23. https://treaties.un.org/doc/Treaties/1990/09/19900902%2003-14%20AM/Ch_IV_11p.pdf
- United Nations (U.N.) General Assembly (2007). *Convention on the Rights of Persons with Disabilities: resolution /adopted by the General Assembly, 24 January 2007, A/RES/61/106*. https://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf
- United Nations Children’s Fund (UNICEF) (2019). *Equitable access to inclusive childcare early education for all children is a right and a priority across Canada*. <https://www.unicef.ca/en/discover/education>
- United Nations Children’s Fund (UNICEF) (2021, November 9). *Seen, counted, included: Using data to shed light on the well-being of children with disabilities - UNICEF DATA*. UNICEF DATA. <https://data.unicef.org/resources/children-with-disabilities-report-2021/>
- van Rhijn, T., Underwood, K., Frankel, E., Lero, D.S., Spalding, K., Janus, M., ... Haché, A. (2021). Role of child care in creating inclusive communities and access for all. *Canadian Public Policy 47*(3), 399-409. <https://www.muse.jhu.edu/article/807577>.
- Wada, M., Backman, C. L., & Forwell, S. J. (2010). Theoretical perspectives of balance and the influence of gender ideologies. *Journal of Occupational Science, 17*(2), 92–103. <https://doi.org/10.1080/14427591.2010.9686680>

- Watters, E. C., Cumming, S., & Caragata, L. (2018). The Lone Mother Resilience Project: A qualitative secondary analysis. *Forum: Qualitative Social Research, 19*(2). <https://doi.org/10.17169/fqs-19.2.2863>
- Weglarz-Ward, J. M., & Santos, R. M. (2018). Parent and professional perceptions of inclusion in childcare: A literature review. *Infants & Young Children, 31*(2), 128–143. <https://doi.org/10.1097/IYC.000000000000115>.
- Weisner, T. S. (2002). Ecocultural understanding of children’s developmental pathways. *Human Development, 45*(4), 275–281. <https://doi.org/10.1159/000064989>
- Whitley, J., & Hollweck, T. (2020). Inclusion and equity in education: Current policy reform in Nova Scotia, Canada. *PROSPECTS, 49*(3–4), 297–312. <https://doi.org/10.1007/s11125-020-09503-z>
- Wilcock, A.A. (1998). *An occupational perspective of health*. Thorofare (NJ): SLACK Incorporated; 1998.
- Wilcock, A.A. (1999). Reflections on doing, being and becoming. *Australian Occupational Therapy Journal, 46*: 1-11.
- Wilcock, A. (2006). *An occupational perspective of health*. 2nd Edition. New Jersey: SLACK Inc.
- Wilcock, A., & Townsend, E. (2000). Occupational terminology interactive dialogue: Occupational justice. *Journal of Occupational Science, 7*(2), 84-86.
- Willick, F. (2022, Mar. 11). *Halifax daycare closing due to government plans for sector, says owner*. CBC News. <https://www.cbc.ca/news/canada/nova-scotia/daycare-closing-government-child-care-plan-1.6378345>
- Wondemu, M. Y., Hermansen, Å., Joranger, P., & Brekke, I. (2022). Impact of child disability on parental employment and earnings: A quasi-experimental study of parents of children with disability in Norway [Preprint]. *In Review*. <https://doi.org/10.21203/rs.3.rs-1583177/v1>
- World Health Organization (WHO). (2021). *Disability and health*. <https://www.who.int/newsroom/fact-sheets/detail/disability-and-health>
- World Federation of Occupational Therapists (WFOT). (2021). *What is occupational therapy?* <https://wfot.org/about/about-occupational-therapy>
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health, 15*, 215-228.

- You, H.K. & McGraw, L. A. (2011). The intersection of motherhood and disability: Being a “Good” Korean mother to an “Imperfect” child. *Journal of Comparative Family Studies*, 42(4), 579–598.
<http://ezproxy.library.dal.ca/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=fmh&AN=64871931&site=ehost-live>
- Young, M., Montazer, S., & Singh, D. (2020). The consequences of living in childcare deserts: Evidence from Canada. *Canadian Review of Sociology/Revue Canadienne de Sociologie*, 57(4), 550–578. <https://doi.org/10.1111/cars.12316>
- Zilanawala, A. (2016). Women’s time poverty and family structure: Differences by parenthood and employment. *Journal of Family Issues*, 37(3), 369–392.
<https://doi.org/10.1177/0192513X14542432>

Appendix A Dalhousie University Research Board Ethics (REB) Approval Letter

Tuesday, April 26, 2022 at 15:23:20 Atlantic Daylight Time

Subject: REB # 2022-6054 Letter of Approval
Date: Tuesday, April 26, 2022 at 3:13:18 PM Atlantic Daylight Time
From: ethics@dal.ca
To: Shanon Phelan
CC: Research Ethics



**Social Sciences & Humanities Research Ethics Board
Letter of Approval**

April 26, 2022
Shanon Phelan
Health\School of Occupational Therapy

Dear Shanon,

REB #: 2022-6054
Project Title: Equitable access to inclusive childcare and early childhood education for disabled children: The family experience

Effective Date: April 26, 2022
Expiry Date: April 26, 2023

The Social Sciences & Humanities Research Ethics Board has reviewed your application for research involving humans and found the proposed research to be in accordance with the Tri-Council Policy Statement on *Ethical Conduct for Research Involving Humans*. This approval will be in effect for 12 months as indicated above. This approval is subject to the conditions listed below which constitute your on-going responsibilities with respect to the ethical conduct of this research.

Sincerely,



Dr. Karen Foster, Chair

Funded: Employment and Social Development Canada, Government of Canada
Release of Funds issued: Mar 29, 2022

Post REB Approval: On-going Responsibilities of Researchers

After receiving ethical approval for the conduct of research involving humans, there are several ongoing responsibilities that researchers must meet to remain in compliance with University and Tri-Council policies.

1. Additional Research Ethics approval

Appendix B Interview Guide with Demographic Questions for Parents

Interview Guide for Parents

Thank you for agreeing to chat with me today- it is nice to meet you. Today I want to talk to you about the barriers and facilitators to access to, and inclusion in, childcare and early education settings for families with preschool-aged children with disabilities. This information you share with me today will help with a research project. Your perspective as a parent is invaluable. You can take a break whenever you want. If you want to stop the interview at any point, you can tell me you'd like to stop. If you want to skip a question, you can.

Do you have any questions for me before we get started?

Contextual Questions

1. Can you tell me a bit about your child?

Probes:

- What is the nature of their disability(ies) or special needs?
- Have your child's disability/special needs been diagnosed by a healthcare professional? When?

2. Can you tell me about your family? Does [child] have any siblings?

Probes:

- Who lives at home with you?
- Do you have any extended supports or family members nearby?

3. What is important to you in a childcare setting?

Probes:

- support?
- space/resources?
- affordability?
- inclusion?
- belonging?
- other children with disabilities attend there?
- location?
- other?

4. What types of childcare have you used for your child(ren)? **OR** What type of childcare do you hope to have for your child? (Prompt: this can be any childcare arrangement including regulated childcare centers, nannies, help from family/friends, regulated home-based childcare, or informal childcare in someone's home.)

Probes:

- What made you seek/require childcare?
- How old was your child when you enrolled them in childcare?
- How many changes have you made to your childcare arrangements?
- What prompted these changes?

Questions about Access

5. Can you tell me about your experience accessing/trying to access a childcare or early education center for your child?

Probes:

- Can you describe what kind of work was involved?
- Did you feel like you had to do work “behind the scenes” in order to access childcare? Can you describe...
- Did you feel like you had to do work above and beyond in order to access childcare? Can you describe...
- [If have other kids in childcare] How did the work involved in accessing childcare for [child] compare to your experience with their siblings? Could you get them in the same place?
- Describe enablers for finding and accessing childcare
- Describe barriers for finding and accessing childcare
- Did you need put your child on a waitlist for childcare?
- When did you put your child on the waitlist?
- How long was the wait?
- How many waitlists did you enlist?
- How many childcare settings contacted you from their wait list?
- How did disability play a role in your search for childcare?
- Did you contact any childcare facilities that said they did not accept children with disabilities?
- At what part in the process did you disclose that your child has a disability? How did you do this? (Probe: did they ask you, did you volunteer the information, were there forms to fill out, etc.)
- While you were trying to find permanent childcare did you have any other options for someone to look after your child, for example when you had to go to work?

6. How was/is your family life affected by looking for and accessing childcare?

Probes:

- work life? (are you currently employed/on parental leave/seeking employment/not working)
- social life?
- relationship with partner?
- other children?
- child with disabilities?
- social life?
- financially?
- others?

7. Can you describe your current childcare/early education situation? Probes:

- Do you feel like you had a choice about which daycare you sent your child to? Why or why not?
- Can you describe your childcare schedule
- What “room” they are in (infant, toddler, pre-school)?
- Are you involved in your childcare center? In what capacity? Why?

8. How did you choose your current (or past) childcare setting/option?

Probes:

- Word of mouth?
- Interview/Tour?
- A health/education professional recommendation?
- Internet or social media?
- Location?
- Know other families there?

9. Have you felt like your access has been limited/enabled by costs/finances?

Probes:

- How has your child’s special needs or disabilities impacted your family’s employment and financial security?
- Are you aware of any financial benefits that would help parents with the extra cost of childcare for a child(ren) with a disability? What are you able to cover with this support? What needs are still not addressed at all?
- What are your thoughts on the universal childcare plan? Will this impact your family?
- Did you pay for childcare fully, partially, not at all; were you able to qualify for a subsidized spot?
- Did you encounter any daycare settings that did not accept subsidies?

10. Have you felt like your access has been limited/enabled by other social and environmental factors like disability stigma? Cultural background? Geographical location? Transportation? Etc.
11. If your child(ren) is in a regulated childcare center, what barriers/supports, if any do you/they encounter in their day-to-day attendance?
(Help text for informants: By barriers we mean something that could be removed, modified, or done differently.) Probes:
 - How have these barriers been addressed by the center? (Prompt, for example, training of staff, a special resource teacher, 1:1 support?)
 - Have you needed to intervene or advocate for supports or to remove barriers? Can you describe...
12. What requirements or accommodations were needed for your child(ren) to attend a childcare center (Prompt: special funding, child's own resource person, providing disability awareness to the center, etc.)? Probes:
 - Did you need to request specific supports? If so, were any requests denied? Did this require any extra work on your part?
 - Are there (additional) resources/supports that your child needs but does not have access to? What are these?
13. If special resources are provided to your child(ren), can you explain how these resources support your child(ren)'s physical, social, and emotional needs?
Probes:
 - Technology? Assistive devices?
 - Education related accommodations?
 - Others?
14. Do you know the nature of the training provided to your child(ren)'s teacher? Do you think this training is adequate to meet your child(ren)'s physical, social, and emotional needs? Why or why not?

Questions about Inclusion

15. How important is inclusion and belonging to you and your child/family? What does inclusion mean to you? What does belonging mean to you?
16. How is inclusion and belonging taken up at your child(ren)'s center? Probes:
 - Does the childcare/early education center that your child attends have an inclusion policy?
 - What do you know about inclusion at your child's center?
 - What kinds of practices does your center engage in to facilitate inclusion and belonging?
 - Are these practices sufficient to fully integrate your child(ren) into their classroom? If not, what more could be done to accommodate your child?
 - Would you consider your child's center/program inclusive? Why or why not?

17. How would you describe your child's experiences of inclusion and belonging at the childcare/early education center?

Probes:

- Do you think your child feels included with their peers? How so?
- Do you think your child feels a sense of belonging? How so?
- Did you feel like you had to do work "behind the scenes" in order for your child to be or feel included? Can you describe...
- Did you feel like you had to do work above and beyond in order for your child to be included? Can you describe...
- How does your child talk about childcare/early education experiences at home?
- Is your child excited/anxious to go to the center each day?
- Does your child socialize with other children/friends from the center in your free time?

18. How would you describe your family's experiences of inclusion at the childcare/early education center?

Probes:

- Do you feel included/welcome in the community? How so?
- Do you feel a sense of belonging? How so?
- Do you feel supported by staff and other families? How so?
- Did you feel like you had to do work "behind the scenes" in order for your family to be or feel included? Can you describe...
- Did you feel like you had to do work above and beyond in order for your family to be included? Can you describe...
- Do you socialize with other families outside of the setting?

Optional Closing Questions (time dependent)

19. If you could create a childcare setting that would be most ideal for your child, tell me what that would look like?
20. What suggestions would you have for a family trying to access (inclusive) childcare in Nova Scotia for their child with disabilities?
21. Is there anything else you would like to talk about that we didn't get a chance to talk about?

Before we end, I just have a few **demographic questions** to ask you. We ask these questions to help describe the group of families that participate in the study.

1. May we ask how old you are in years?

[probes if needed]

- a. 19 years or younger
- b. 20-24 years
- c. 25-29 years
- d. 30-34 years
- e. 35-39 years
- f. 40-44 years
- g. 45-49 years
- h. 50-54 years
- i. 55-59 years
- j. 60 years or older
- k. I prefer not to answer

2. May we ask your gender?

[probes if needed]

- a. Woman
- b. Man
- c. Non-binary
- d. Prefer not to answer
- e. I identify as: [blank]
- f. I prefer not to answer

3. May we ask which city is your primary residence is located in?

4. May we ask which is your highest level of education?

[probes if needed]

- a. Some high school or high school graduate
- b. Some college/technical school or college/technical school graduate
- c. Some university or university graduate
- d. Some post-graduate or post-graduate complete
- e. I prefer not to answer

5. May we ask your marital status?

[probes if needed]

- a. Single
- b. Common law or civil partnership or married
- c. Separated or divorced
- d. Widowed
- e. I prefer not to answer

6. May we ask your ethnic or cultural origins of your ancestors?
[probes if needed]
- a. British Isles (e.g., English, Irish, Scottish)
 - b. Caribbean (e.g., Jamaican, Barbadian, Cuban, West Indian)
 - c. Latin Central or South American (e.g., Mexican, Argentinian, Peruvian)
 - d. East and Southeast Asian (e.g., Chinese, Korean, Japanese, Filipino, Vietnamese)
 - e. South Asian (e.g., East Indian, Pakistani, Goan, Sri Lankan)
 - f. African (e.g., South African, Ethiopian, Nigerian)
 - g. Arab/West Asian (e.g., Lebanese, Iranian, Moroccan, Turk)
 - h. Oceania (e.g., Australia, New Zealander, Fijian)
 - i. Indigenous (e.g., Mi'kmaq, Innu, Maliseet)
 - j. Other European (e.g., French, German, Italian, Norwegian)
 - k. Other North American (e.g., Canadian, American)
 - l. I identify as:
 - m. I prefer not to answer
7. May we ask your household income? [probes if needed]
- a. Less than \$25,000
 - b. \$25,001-50,000
 - c. \$50,001-75,000
 - d. \$75,001-100,000
 - e. 100,001-150,000
 - f. 150,001, 200,000
 - g. More than \$200,000
 - h. I prefer not to answer
8. May we ask about your family composition? [probes if needed]
- a. How many children, preschool or younger?
 - b. How many children, school age?
 - c. How many adult children?
 - d. How many adults?
 - e. Do they all reside in the home? Full or part-time?
9. May we ask how old your child is in years [the referent child]?
10. May we ask your child's gender? [probes if needed]
- a. Girl
 - b. Boy
 - c. Non-binary
 - d. Prefer not to answer
 - e. They identify as: [blank]
 - f. I prefer not to answer

Thank you!

Appendix C Demographic Information of the Participant Sample of Mothers

Pseudonym	Age/ Age Range	Gender	Location	Education	Marital Status	Ethnicity/ Cultural Group Identified	Employment Status	Household Income	Child Pseudonym	Age of Child	Childcare Status
Chelsea	27	Female	Brooklyn (rural)	NSCC- community college	Married	Caucasian (Irish)	Employed	b/w 75-100k	Connor	18 mos	About to start at a daycare (currently has someone come in their home Monday – Friday for 5 hours each day)
Pamela (Pam)	45-49	Female	Cole Harbour (urban)	College Graduate	Married	Caucasian and Acadian	Employed	b/w 100-150	Aiden	4 yo, almost 5 yo	-finished Pre-primary, may go back to Pre-primary -no after-school care or summer care at the time of interview
Teresa (identified as having a disability)	30-34	Female	Lower Sackville (urban)	Bachelor's degree	Married	Canadian/ American (earlier she said she is originally from England)	Employed	b/w 100-150	Liam	4 yo	-attends pre-school for 2 ½ hours each Monday-Friday mornings from Sept. to June -for the remainder of each day he is with his mom for 3 days and his paternal grandparents for 2 days
Jennifer	35-39	Female	Halifax (urban)	Bachelor's degree	Married to Andrea	French White	Employed	100-150k	Peter	5yo	Finished Pre-primary
Tiffany	25-29	Female	Glace Bay (rural)	Currently in College	Common- law	White, Caucasian	Employed part-time (student)	25-50	Aaron	3.5 yo	Daycare centre
Erica	35-39	Female	Hammonds Plains (urban)	Master's Degree	Married	European	Employed (currently on mat leave)	150-175K	Justin	2.5 yo	Daycare centre
Kiana	33	Female	Glace Bay (rural)	Bachelor's degree	Single	Canadian, Scottish (UK/ European)	Employed	25-50K	Not given	4 yo	Daycare centre
Lena	26	Female	Wagmatcook (rural)	Currently an ECE student	Single	Indigenous	Employed, in a school so off in the summer	Unknown	Carly	4.5 yo	P3 and starting Pre-primary, Lena is off in the summer and cares for her

S

Pseudonym	Age/ Age Range	Gender	Location	Education	Marital Status	Ethnicity/ Cultural Group Identified	Employment Status	Household income	Child Name	Age of Child	Childcare Status
Anna	35-39	Female	Truro (urban; outside of HRM)	Grade 12	Married	Caucasian	Stay at home mom	75-80K	Nelly	3yo	Started pre-school
Sandra	25-29	Female	Halifax (urban)	University Degree	Married	Acadian/ Caucasian	Stay at home mom	120K	Levi	5yo	He initially went to a daycare centre and then his mother stopped working to care for her children at home Starting school – looking for after school care
Bridget	35-39	Female	Halifax (urban)	College Graduate	Common- law	Caucasian/Ac adian French	Self-employed	75-100K	Leo	4yo almost 5 yo	Daycare, transitioning to school (did not go to Pre- primary)
Andrea	35-39	Female	Halifax (urban)	University graduate	Married to Jennifer	Caucasian	Employed	100-150K	Aaron	5 yo	Finished Pre-primary
Maria	30-34	Female	Wolfville (rural)	Bachelor's Degree	Married	Black American	Employed	50-75K	Ellen	4yo	Not currently accessing childcare
Samantha	35-39	Female	Halifax (urban)	Master's Degree	Married	Did not answer	Employed	100-150K	Faye	4.5yo	Daycare centre
Lorraine	25-29	Female	Shelburne (rural)	Bachelor's Degree	Married	Black	Stay at home mom	~52K	Marissa	almost 3yo	Not currently accessing childcare
Cara	35-39	Female	Halifax (urban)	Bachelor's of Arts and B.Ed.	Common- law	Caucasian	Employed	75-100K	Twins Vance & Richard	both 5 y.o.	Daycare centre

Table C1. Demographic Information of the Participant Sample of Mothers

Appendix D Thematic Mapping Example

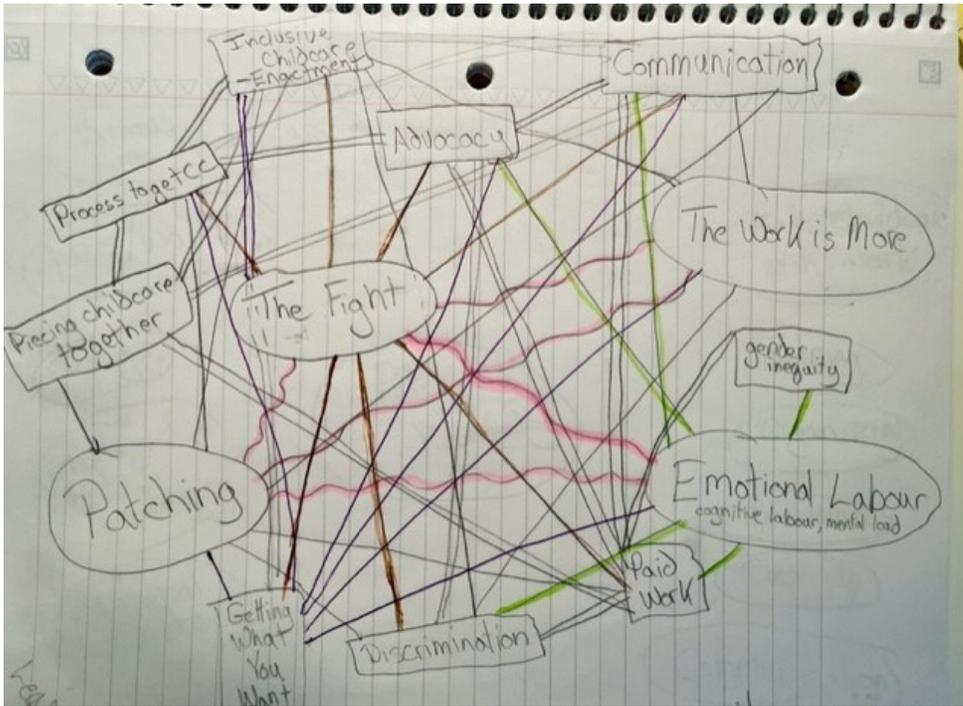


Figure D1: Initial thematic map of patterns across this study's dataset based on Braun and Clarke (2022).

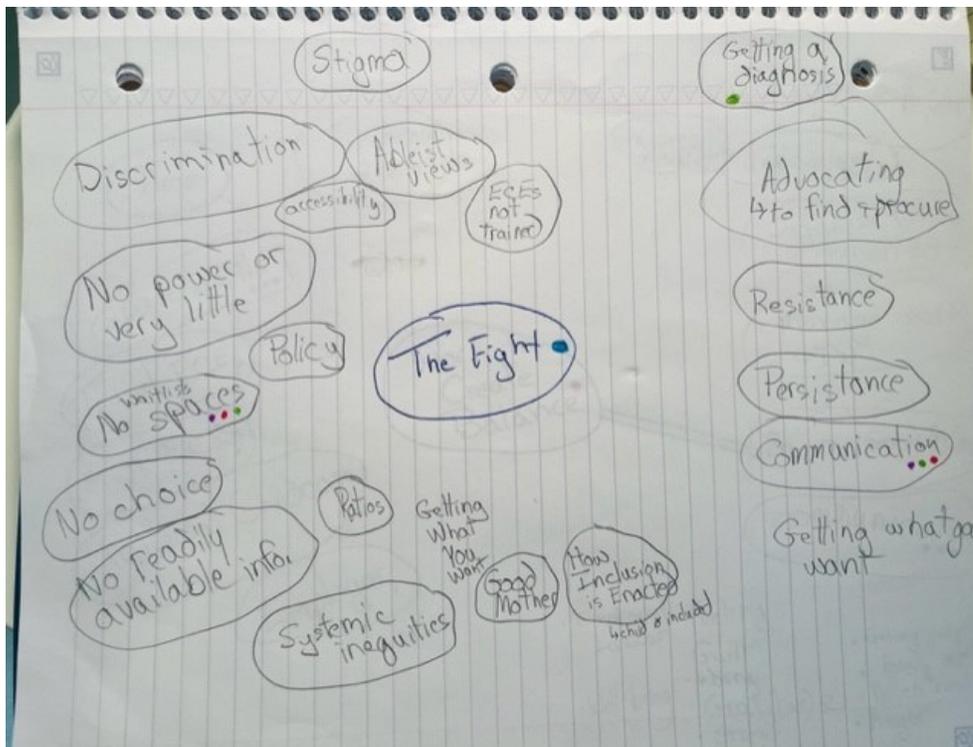


Figure D2: Initial thematic map for the theme of 'the Fighter' based on Braun and Clarke (2022).

Appendix E Visual Mapping Example of Mother’s Childcare Journey

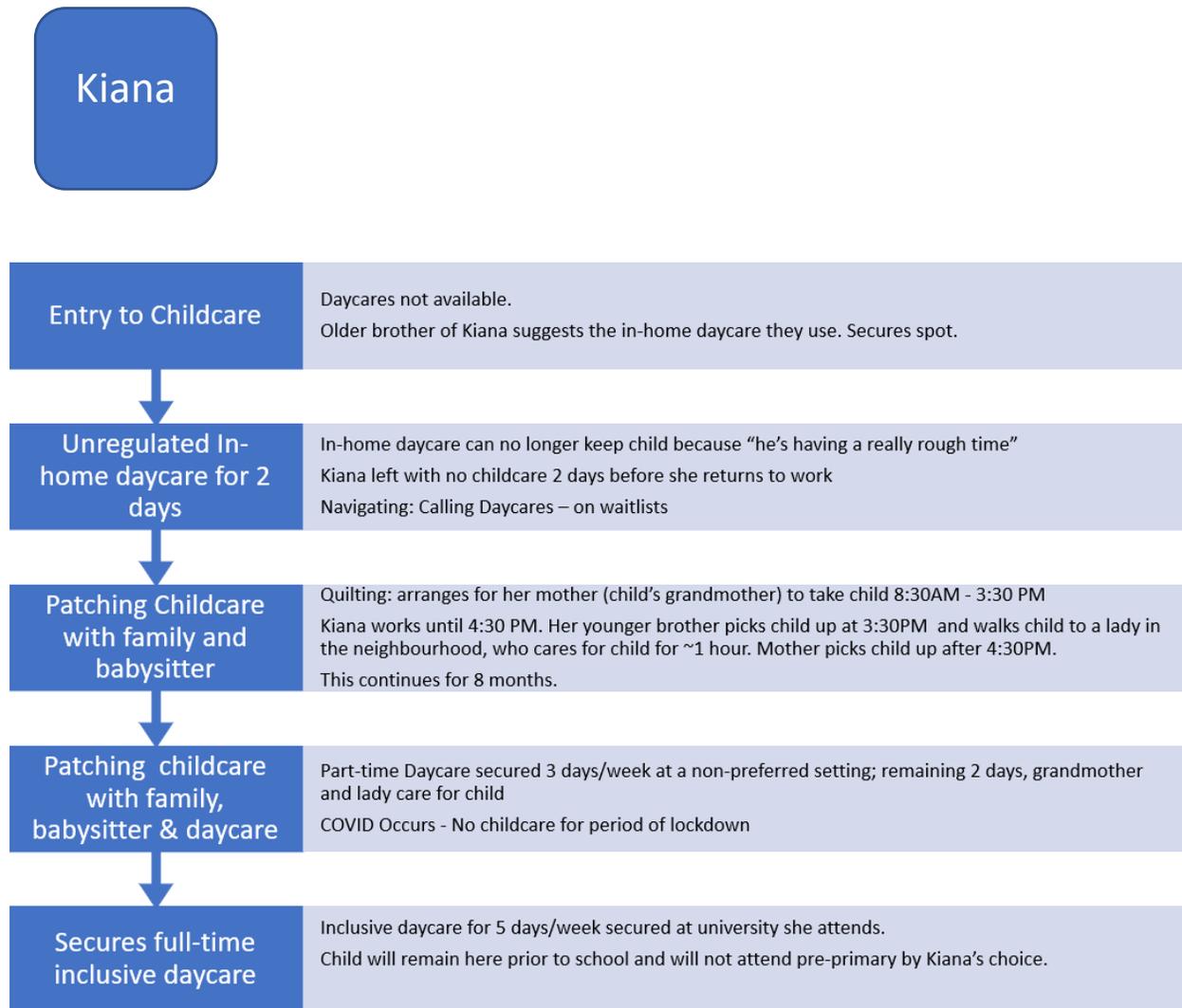


Figure E3: Visual Map Example of Kiana’s Childcare Journey.

Appendix F Eight “Big-Tent” Criteria for Excellent Qualitative Research

Criteria for quality (end goal)	Various means, practices, and methods through which to achieve
Worthy topic	The topic of the research is: Relevant Timely Significant Interesting
Rich rigour	The study uses sufficient, abundant, appropriate and complex: Theoretical constructs Data and time in the field Sample(s) Context(s) Data collection and analysis process
Sincerity	The study is characterised by: Self-reflexivity about subjective values, biases, and inclinations of the researcher(s) Transparency about the methods and challenges
Credibility	The research is marked by: Thick description, concrete detail, explication of tacit (non-textual) knowledge, and showing rather than telling Triangulation or crystallization Multivocality Member reflections
Resonance	The research influences, affects, or moves particular readers or a variety of audiences through: Aesthetic, evocative representation Naturalistic generalisations Transferable findings
Significant contribution	The research provides a significant contribution: Conceptually/theoretically Practically Morally Methodologically Heuristically
Ethical	The research considers: Procedural ethics (such as human subjects) Situational and culturally specific ethics Relational ethics Exiting ethics (leaving the scene and sharing the research)
Meaningful coherence	The study: Achieves what it purports to be about Uses methods and procedures that fit its stated goals Meaningfully interconnects literature, research questions /foci, findings, and interpretations with each other

Table F2 Eight “Big-Tent” Criteria for Excellent Qualitative Research adapted from Tracy (2010).

Appendix G 15-Point Checklist for Good Reflexive Thematic Analysis

No.	Process	Criteria
1	Transcription	The data have been transcribed to an appropriate level of detail; All transcripts have been checked against the original recordings for ‘accuracy’.
2	Coding and theme development	Each data item has been given thorough and repeated attention in the coding process.
3		The coding process has been thorough, inclusive and comprehensive; themes have not been developed from a few vivid examples (an anecdotal approach).
4		All relevant extracts for each theme have been collated.
5		Candidate themes have been checked against code data and back to the original dataset.
6		Themes are internally coherent, consistent, and distinctive; each theme contains a well-defined organizing concept; Any subthemes share the central organizing concept of the theme.
7		Analysis and interpretation – in the written report
8		Analysis and data match each other - the extracts evidence the analytic claims.
9		Analysis tells a convincing and well-organized story about the data and topic; Analysis addresses the research question.
10		An appropriate balance between analytic narrative and data extracts is provided.
11		Overall
12	Written Report	The specific approach to thematic analysis, and the particulars of the approach, including theoretical positions and assumptions, are clearly explicated.
13		There is a good fit between what was claimed, and what was done – i.e. the described method and reported analysis are consistent.
14		The language and concepts used in the report are consistent with the ontological and epistemological positions of the analysis.
15		The researcher is positioned as <i>active</i> in the research process; Themes do not just ‘emerge’.

Table G3 Braun and Clarke’s 15-Point Checklist for Good Reflexive TA – version 2022 adapted from Braun & Clarke. (2022, p. 269).