Moving through the system: The ruling relations of migration, mobility, and childhood disability

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DEDICATION

I dedicate my PhD dissertation to my Biji (Grandma) and Babaji (Grandpa). Although they haven’t been able to witness the journey of this PhD, it is their teachings, knowledge, love, and support that has allowed me to achieve this milestone.

ABSTRACT

This thesis is about institutional interactions of young disabled children and families who have migrated or have travelled to access services. Through an institutional ethnography, I seek to understand these families' everyday activities and to make the invisible work of these families visible, and ultimately to interrogate the systems connected to childhood disability and different forms of human movement. For this dissertation, I examined longitudinal data from the Inclusive Early Childhood Service System Project (IECSS; 2021). The IECSS project is an institutional ethnography, a methodology originally developed by the Canadian sociologist and feminist studies scholar, Dorothy Smith (2006). The central problematic of interest for this dissertation was the intersection of childhood disability and human movement in the form of transnational migration, internal migration, and travelling to access services. Through this institutional ethnography, I entered into the everyday experiences of disabled children and their families through the standpoint of the IECSS family informants from across Canada. An analysis of the institutional maps, interview transcripts, and attribute tables led to six (6) key findings: (1) Migration and travelling: What is the context of human movement and childhood disability?; (2) People move, texts stay still; (3) Duplication and replication of services across different communities; (4) Formal and informal support networks: making it work when you're mobile; (5) The importance of gaining perceived and official citizenship status and; (6) Restarting the process: The added work on families and disabled children. The findings of this study are significant for research, policy, and practice in the area of early childhood, disability, and human movement.

Keyword: Childhood, disability, human movement, migration, and access

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Chapter One: Introduction

This thesis is about institutional interactions of young disabled children and families who have migrated or have travelled to access services. Through an institutional ethnography, I seek to understand these families' everyday activities and to make the invisible work of these families visible, and ultimately to interrogate the systems connected to childhood disability and different forms of human movement. For my research, I engaged with data from the Inclusive Early Childhood Service System project (IECSS; 2021), a longitudinal study about the institutional interactions of families with young disabled children across Canada. For my dissertation I was interested in a problematic that was emerging from the data: the intersection of human movement and disability. More specifically, experiences of transnational migration, internal migration, and travelling to access services were discussed by families of disabled children in IECSS project interviews. Based on this emerging problematic, I examined data about these experiences for my dissertation.

Migration can be both disruptive and transformative, leading to reconsiderations of what home, family, and belonging mean (Sandhu, Ibrahim & Chinn, 2017). Moreover, by choice or necessity some families may have to travel to different communities to gain access to services and programs. Although migration and travelling for the purposes of accessing services can be different experiences, both involve the fundamental idea of leaving one's home community to go to another. In an effort to document and understand these patterns of movement and their implications for policy and practice, this dissertation will focus on the experiences of families who have migrated or have travelled to access services and have a young disabled child.

Broadly, the United Nations (2020) defines a migrant as someone "who is moving or has moved across an international border or within a State away from [their] habitual place of residence" (p. 4). The concept of borders emerges in the definition of a migrant here, but it is important to take note of the connotations of this term. For example, in a discussion of Indigenous Sovereignty, Dylan Miner (2015) critically examines the role of borders and suggests that borders represent settler-colonialism and enact violence. In this way, borders can enact power on both Indigenous people and those who have migrated, a notion I will address more fully later in this dissertation. As we begin to engage in a discussion about transnational migration, internal migration, and travelling to access services, the role of international and national borders will be present, although implicitly at times. However, as I progress into the findings and discussion section of this dissertation, I aim to further explicate and foreground the role that borders play in the lives of families seeking services for their young disabled children.

Institutional Ethnography and the Inclusive Early Childhood Service System Project

In 2013, the IECSS project began with representatives from Wellington County, Hamilton, Toronto, and the District of Timiskaming. Through discussions, the communities worked collaboratively to develop the design and implementation of the project (IECSS, 2021). The IECSS project is, in essence, an *institutional ethnography*, a methodology originally developed by the Canadian sociologist and feminist studies scholar, Dorothy Smith (2006). It can be described as an alternative approach to research, with a focus on going "*beyond any one individual's experience* including the researcher's own and putting into words supplemented in some instances by diagrams or maps what she or he discovers about how people's activities are coordinated" (Smith, 2006, p. 1). Institutional ethnographers seek to discover how things are "put together so they happen as they do" (Campbell & Gregor, 2008, p. 29), or, put more simply, the goal is to learn how things work. In collaboration with community, co-investigators, collaborators, and partners, the IECSS project developed a methodological approach to learn more about the coordination of everyday institutional engagements of family informants with disabled children.

One focus of the initial data analysis in institutional ethnography is forming the research problematic. The problematic is based on the collected data and formed by examining the disjunctures between authorized and experiential knowledge (Rankin, 2017). The problematic helps to draw the researchers' attention to particular questions. For this dissertation, the problematic that arose in the data was about the nature of human movement in relation to disability and the complex set of bureaucratic and institutional processes entangled with this movement. The process of forming the research problematic requires time with the data. Early on within the IECSS project, researchers began to notice the intersection of human movement and childhood disability. When I joined the IECSS team in 2017, as a research assistant I came in with an interest of migration and childhood disability. As I engaged with the data in my role, the institutional interactions, processes, and pathways intertwined with human movement, such as transnational migration, internal migration, and travelling to access services drew me in.

Transnational Migration

Transnational migration, more commonly known as immigration, has continued to increase in Canada between 1996 and 2021 (Statistics Canada, 2022a). In an examination of the total Canadian population, the census estimates that approximately 23% of the total Canadian population has immigrated to Canada (Statistics Canada, 2022b). More recently, between 2016 and 2021, Canada has welcomed more than 1.3 million immigrants (Statistics Canada, 2022a). When looking at the demographics of those who immigrated to Canada in the last 5 years, a large percentage are between the ages of 25 to 44 years, followed by those aged 0-14 years (Statistics Canada, 2022a). With the continued increase in immigration, including recent announcements about immigration targets for Canada (Government of Canada, 2022a), it is both methodologically and ethically prudent to include this population within research. Research focusing on children and families who have immigrated would both contribute to the representativeness of the research base and provide greater depth to our understanding of the experiences of immigrant families following a move to Canada.

The continuous increase in immigration to Canada, then, provides a strong foundation for including those who have immigrated to Canada in the research process. What is of particular interest in the present work is the way that immigration—both historically and contemporarily—intersects with the issue of disability. As I discuss more fully below, the historical context of this intersection highlights the biases and ableism built into the Canadian immigration system and our treatment of particular groups of immigrants. In *Disabled Upon Arrival*, for example, Jay Dolmage (2018) provides a historical reflection on immigration policy in Canada and the United States of America connected to the intersections of race and disability at borders. Dolmage (2018) suggests that immigration restrictions are about more than just immigration; they are also connected to discourses about racialization, eugenics, and xenophobia. Tracing back early immigration to North America at the ports of Ellis Island (USA) and Pier 21 (Canada), Dolmage (2018) points out that difference began to be stigmatized at the point of entry through inspection processes which examined bodies and picked out those who were considered deficient. The diagnostic and classificatory gaze placed on newcomers led to the identification of people who were deemed unfit and hence subject to exclusion—those who were racialized and/or disabled being especially vulnerable to this selection process. Exclusionary eugenic practices were occurring at these ports, as “race and disability rhetorically reinforced each other and worked together to stigmatize” (Dolmage, 2018, p. 25). The processes at Ellis Island, Pier 21, and other ports in Canada allowed White, European, able-bodied people to enter easily, whereas those who were dark skinned and/or disabled were pushed out.

Although Dolmage is providing a historical reflection on immigration policy, it is important to note that disability and race continue to function as markers that distinguish citizens from non-citizens through immigration policy (Hanes, 2009). Canadian immigration legislation is in this regard a site of both historical continuity and discontinuity. Notwithstanding progressive changes in immigration legislation in the period spanning the first Immigration Act in 1869 to current immigration legislation, immigration law over this time has continued to direct its gaze onto disabled people and their families. Hanes (2009) provides a summary of immigration legislation timelines in Canada and various legislative updates that connect back to racialized and disabled people. For example, in 2001 the Immigrant and Refugee Protection Act had an excessive demand clause which asked immigration workers to consider the demands the newcomer would place on social and healthcare systems upon arrival to Canada (Hanes, 2009). If the demand was deemed to be more than that of the average Canadian, they would be denied citizenship. Although this legislation has been updated, in practice the excessive demand clause continues to make it difficult for disabled people to become citizens in Canada (Hanes, 2009). Although the excessive demand clause has changed to increase the monetary threshold for excessive demand (Government of Canada, 2022b), disabled people continue to be denied citizenship based on this clause. When considering disabled children in particular, news articles outline many cases where disabled young people were denied citizenship based on their disability because they would be a burden on the social and healthcare systems in Canada (CBC News, 2011, 2015).

Ableist discourse specifically focused on immigration is found in other government documents as well. For example, the Government of Ontario report from 1913 titled *Feeble-Minded in Ontario*, has a specific section focused on immigration. In this report, immigrants who are "feeble-minded" are described as being a danger and trouble to Canadian society (Government of Ontario, 1913). Overall, the language used to describe immigrants in this report aims to create a fear of disabled immigrants in Canada and suggests that more processes need to be in place to prevent them from entering the country. The report, which embodies the eugenic thinking of the time, goes on to discuss the role of medical exams in categorizing and determining who should be eligible to immigrate. As I discuss in more detail below, the medical exam in 1913 and in present day is built around ableist assumptions of who is worthy of being a Canadian citizen. A pattern emerges in these documents: Canadian immigration legislation, policy reports, and medical assessments position disabled people as being a burden. The discourse present in these documents then begins to emerge in the day-to-day attitudes and practices of individuals, for example when a particular diagnosis is the reason used by home schools to direct disabled children and their families to travel for specialized school programs (see Builiung et al. 2021; Ross & Builiung, 2019).

Beyond the historical context of disabled people's experiences of immigration and immigration legislation outlined above, the processes involved in immigrating to Canada are reliant upon a medical exam. The medical that must be completed before getting approval for immigration has specific questions about disability, physical and mental health, and children's development (Government of Canada, 2019). For example, one of the questions on the medical report asks if there is "an ongoing physical or intellectual disability affecting your current or future ability to function independently or to be able to work full-time" (Government of Canada, 2019). There are also similar questions asking people about health conditions, such as diabetes, psychological disorders, and blood conditions. These questions can be linked to the immigration legislation which hints at the potential burden that newcomers would place on the Canadian healthcare system. Further, the questions listed on the medical relate to the importance of being an “independent contributing member of society,” which reflect ableist assumptions about the value of independence. The medical report also has specific questions about children. For example, at the end of the questionnaire, the individual is asked “are there any physical or mental conditions which may prevent this person from attending mainstream school, gaining full employment or living independently in the future” (Government of Canada, 2019). This question similarly indicates that certain types of bodies are considered a burden on the Canadian education and healthcare systems as reinforced by immigration legislation which makes mention of the excessive demand those with developmental differences may present to Canadian society (Hanes, 2009). The focus remains on ensuring individuals are or can become independent. The theoretical positioning of this dissertation, based on Critical Disability Studies (CDS), works to challenge these constructs and pushes for an emphasis on our fundamental interdependence.

The historical tracing of immigration policies and processes in relation to disabled people provided by Dolmage (2018) helps to set a context as to why further research about the intersection of disability and immigration is required. Bringing to light current immigration legislation and the ableism built into immigration practices emphasizes the need to learn more about these groups in the Canadian context. In this thesis, the experiences of families who have immigrated to Canada and have a disabled child will make visible the processes they engage in as a result of their “citizenship” status, identities, and family characteristics.

Internal Migration

Similar to transnational migration (or immigration), internal migration continues to account for a significant amount of people’s movement within Canada. The data from the recent Canadian census reveals that over 900,000 Canadians moved from one province to another between 2016 and 2021 (Statistics Canada, 2022c). Interprovincial migration is a significant area of interest within the literature, specifically focusing on describing and explaining patterns of movement: who is moving and why? One of the key findings from this research base is that those who are married or have children are less likely to move to a different province (Finnie, 2004). However, what happens when they do move? In this dissertation, I will examine the processes that families must engage in or re-engage in to access services when they move from one province to another. As we will see, upon arrival in a new province, families and disabled children engage in work to adjust to different provincial programs and services, which are linked to the differing provincial and territorial guidelines for healthcare, early childhood education and care, school services, and disability services across Canada.

The 2021 Canadian census data also found that over 5 million Canadians engaged in intraprovincial travel between 2016 and 2021 (Statistics Canada, 2022d). Similar to research focused on interprovincial migration, there are gaps in the research on intraprovincial migration. The research that does exist, however, suggests that intraprovincial moves can lead to loss of services and task families with joining new waitlists, (re)engaging in intake processes, and building new relationships, for example. Families of disabled children already engage in work to fill out applications, find services, and build relationships (Davies et al., 2021). However, once they move they are also leaving behind the products of the work they had completed when they initially engaged with services. This dissertation seeks to address the gap in the research in this area by exploring the impact of internal migration on disabled children and their families. It is important to learn more about what happens when these children and families move so that we are better positioned to support their efforts to find and engage services.

Travelling to Access Services

From a geographical standpoint, there are vast differences in the development of different cities, ranging from dense urban centers to rural and remote communities. Statistics Canada uses population size as one way to categorize areas across the county (Statistics Canada, 2002). One key geographical distinction includes the difference between urban, rural, and remote regions. When considering the Canadian context, the 2021 census revealed data about rural and remote communities. Overall, less than 1 in 5 Canadians live in rural communities (Statistics Canada, 2022c). Further, between 2016 and 2021, rural population growth has decreased in Canada (Statistics Canada, 2022c). One hypothesized reason for the decline is an increase in immigration, with many newcomers preferring to settle in urban communities. Although there is a decline in population growth in rural and remote communities, their geographic and demographic characteristics contribute to the importance of conducting research focused on these populations. Within the current literature base, there has been a growing interest globally about disability, healthcare, and education service access for those who live in rural and remote communities. Much of this research has been conducted in Australia and has started to grow within the North American landscape as well, suggesting an increasing awareness of how the rural/remote/urban divide shapes the experiences of disabled children and their families.

As discussed above, research examining geography in relation to accessing services for disabled people has largely focused on differences between rural and remote communities compared to urban communities. However, an understudied area includes understanding the differences between urban communities and how they may impact the experiences of disabled children and families living in those communities. For example, Yellowknife, Northwest Territories is now considered an urban community and is the home to almost half of the population of the entire territory (Statistics Canada, 2022c). However, Yellowknife is in a more Northern region of Canada, with demographics and geography quite different than other urban communities, such as Toronto or Vancouver, for example. How might the differences between and within these urban communities' impact families? While research has started to examine travelling to access services for those who live in urban communities (see Builiung et al. 2021; Ross & Builiung, 2019), it is important to build on this literature base to better understand who is travelling, why they are travelling, and their experiences travelling to different urban communities.

An examination of these three forms of travel—transnational and internal migration, and travel for services—reveals that while there is a growing literature base on families who have experienced transnational migration and their experiences navigating health, disability, and education services for a child with a disability or developmental concerns (see Cummings & Hardin, 2017; Fellin, King, Esses, Lindsay & Klassen, 2013; Liu & Fisher, 2017; Sandhu et al., 2017), neither internal migration nor travelling for services has been the focus of research that could shed light on the implications of these forms of movement for families accessing or waiting for development or disability services. As I discuss in more detail in the next section, it is important to examine the experiences of families who have migrated (transnational or internal) or have travelled to access services to better understand their interactions with different systems and processes, and to compare the different services systems they interact with.

Importance of the Study

There are several reasons why this research is important. First, as mentioned above, there is a large population immigrating to Canada and migrating within Canada. The reasons for this pattern of movement are multiple: people pursuing job opportunities, joining family members, fleeing dangers in their home community, and, more generally, seeking to gain access to better resources and opportunities for their families. Further, family informants also share experiences of travelling to access services in communities outside of their own. For example, disabled children and families who reside in rural, remote, or small communities may, by choice or force, travel to a larger community to access services. In the current research, through gaining an understanding of these human movement patterns, we can examine how migration or having to travel to access services impacts the everyday activities of families working to navigate services for disabled children.

Second, across Canada, policies and services for Early Childhood Education and Care (ECEC) services (Massing, Kikulwe, & Ghadi, 2020), along with healthcare and education services, are under provincial or territorial legislation and to date Canada has not developed a universal ECEC (Underwood & Frankel, 2012) or healthcare system. Regional differences in policy may impact which programs are available in one community compared to the next. Families who migrate from one community to another within Canada could be impacted by these regional differences; for example, families may be required to engage in different types of work or, as noted earlier, restart what they began in their previous community, such as having to take part in a new intake process for disability related services. Furthermore, specific groups, such as immigrants, may not be addressed in regional ECEC legislation (Massing et al., 2020), a state of affairs that may reflect the current division of governmental labour, which sees immigration policy as a federal matter and ECEC services as a provincial or territorial responsibility. Due to the differing ECEC legislation across the country and the division of responsibility between ECEC and immigration policy, then, ECEC policies and programs may not all address the inclusion of immigrant families and disabled children. In my research, I explore the intersecting power that is held by these two systems and seek to disclose how the roots of certain practices, policies, and institutions can be discriminatory and lead to barriers in access for families. ECEC policy addressing cultural awareness and cultural sensitivity on the part of professionals and organizations is necessary to support disabled children and their families (Brown et al., 2020). Accordingly, it is important to examine the effect of legislation, policy, and practice on the service system.

Third, through an institutional ethnography we can gain a better understanding of how human movement is interdependent with social constructions of people as disabled, and racialized, classed, or gendered, for example, from the standpoint of family informants. It is important to better understand if family and child characteristics such as race, class, gender, or citizenship status impact the experiences of disabled children and families who travel to access services. For example, families in rural or remote communities might not have access to as many specialized services (Underwood et al., 2018). These families may have to travel to another community by need or choice to get access to these services. Characteristics such as class, or the ability to access private services may also lead some families to travel to other communities to gain access to specific professionals or programs not available in their community. The possibility of differences between families is important to investigate to better understand the way service systems are designed and respond to families with diverse characteristics.

The current research hopes to interrogate how policies and procedures impact the interactions and experiences of navigating different service systems for families who have migrated (transnationally or internally) or those who have had to travel to access services.

The main research problematic guiding this project is:

> What do the everyday experiences of disabled children and their families tell us about how human movement (transnational migration, internal migration, or travel to access services – both forced and voluntary) and disability are intertwined in the institutional processes associated with accessing and navigating early childhood, disability, and education service systems?

As I explored the research problematic outlined above, several other areas of inquiry emerged and informed the analysis of the data.

> In what ways do migrant families work to support service systems?
>
> In what ways do institutions organize children and families (with a focus on intersectional identities), and how do institutionally produced categories impact experiences in navigating systems and interactions with service providers?
>
> What are the impacts of a diagnosis on institutional procedures?
>
> How do child and family engagement with these systems shape disabled children's identity?

These areas of inquiry represent elements that emerge through institutional ethnography including the focus on textual records such as a diagnosis and the work people do in their everyday lives including the work of disabled children and their families. Further, these areas of inquiry will support in understanding how family and child characteristics intersect with childhood disability and human movement to shape experiences.

A note about language

For the purposes of the current research, the terms *immigration* or *transnational migration* will be used to refer to the process of moving across international borders. *Internal migration* will be used to reference the process of moving to a different community, province, or territory within Canada. Lastly, *travel* will be used in relation to individuals who have travelled to a different community for the purposes of accessing services.

In this dissertation, I will be using identity-first language such as "disabled people" or "disabled child." According to the National Center on Disability and Journalism (2021), the term disabled person follows the preferred terminology of many disability activists. The use of identity-first language as opposed to person-first language (e.g., "person with a disability") is preferred because activists believe their disability cannot be separated from who they are (National Center on Disability and Journalism, 2021). Further, as I will discuss in the next chapter, the theoretical underpinnings of this dissertation include Critical Disability Studies and Disabled Children's Childhood Studies (DCCS), both of which follow identity-first language.

Conclusion

In this chapter, I introduced the study and rationale for why it is important to conduct research focused on migration (transnational or internal) and families who travel to access services in relation to disability and childhood. In presenting this institutional ethnography to the reader, I will begin by providing a research framework in Chapter 2. The framework I present in that chapter begins by centering the research problematic and the ontological shift proposed in institutional ethnography. Chapter 2 will also further integrate my research standpoint, theory, and literature that I engaged and its connection to the emerging problematic. Chapter 3 provides an outline of the methodology, with a focus on the foundations of institutional ethnography. In

Chapters 4 and 5, respectively, I present the findings and engage in a discussion about what was learned in the study.

Chapter 2: Research Framework

Institutional ethnography, as outlined by Dorothy Smith and others, stems from a social ontology (Smith, 2006). A social ontology orients us to how the social, or institutions and systems, coordinate the activities of people (DeVault & McCoy, 2006). Campbell and Gregor (2008) describe a social ontology as an "alternative way of knowing" (p. 69) because institutional ethnographers work to learn what happens in people's lives and what leads to those processes or interactions by entering the data from the standpoint of a particular group with the goal of gaining a deeper understanding of institutional processes. Further, institutional ethnography proposes a shift from doing research on a marginalized group to a methodology that can be used to change the social relations that lead to the marginalization aligning institutional ethnography with an activist framework. This ontological shift in institutional ethnography asks the researcher to begin from a particular standpoint. Standpoint in an institutional ethnography is used "as a way of directing attention to the starting place of the inquiry" (Smith & Griffith, 2022). It is also important to note Garland-Thomson's (2005) use of "sitpoint" from a feminist disability lens which challenges the assumption that people experience and see the world while standing rather than sitting. As I begin to outline the research context in this chapter and methodology in Chapter 3, the importance of the standpoint of the family informants will emerge.

For this dissertation, there are two standpoints to consider. The standpoint of the family informants is central to the Inclusive Early Childhood Service System project (IECSS) and my dissertation. It is through their standpoint that we learn about the institutional engagements and processes, as the study is grounded in their everyday lives. The researcher's standpoint can also help the reader understand where they come from and more importantly, to better understand why they chose to explore a particular problematic arising in the research (Smith & Griffith, 2022). Introducing my standpoint here is important as it connects to how I see the problematic. However, my goal in this dissertation is to report the family informants' experiences from their standpoint. The discourses connected to theory and literature I present here help us to situate the problematic, but they are not necessarily the ways in which family informants see institutions.

In this chapter I will be providing an overview of the framework for this study. The framework presented here is through the lens of an institutional ethnography. I will begin by discussing the research problematic to set the context of the present study. Next, I will discuss the standpoint of the family informants through which we enter the data, along with the standpoint through which I entered the problematic. Then, I will discuss relevant theory and literature to situate the problematic within the broader discourse of early childhood, disability, and human movement.

Research Problematic

In institutional ethnography, the research problematic serves as a mechanism to organize the direction of the research. As a result, the problematic is often described as "a starting place and a direction in which to take our research" (Smith & Griffith, 2022, p. 78). In the current research, the problematic that is the starting point is focused on the intersection of human movement and childhood disability. This problematic arose in the data by learning directly from people, family informants, about what they do in their everyday lives. As I will discuss further in the methodology chapter, institutional ethnography asks the researcher to engage in a dialogue. The first phase of this dialogue requires the researcher to begin by learning from the people who they are speaking to. It is during this initial dialogue that problematics arise. When starting the research project, the problematic may not always be visible. It is through this dialogue with the data and learning from the informants that it emerges. As researchers on the IECSS project started to speak with family informants, they began to see the intersection of human movement and mobility emerge. For example, the IECSS project has published elsewhere about geographic disparities in access to services (Underwood et al., 2018, 2019c).

When I entered the project in 2018, I came in with a particular interest in learning about the experiences of newcomer families in the study. As I will describe further below, my standpoint led to my interest in diving deeper into a problematic that was already emerging in the project. Similar to other institutional ethnographers, the problematic I wanted to learn more about was something that connected to my experiences and was something I had an interest in (Smith & Griffith, 2022). When I started to engage in a dialogue with the data and learn from the family informants, I began to see patterns and processes that occurred for families who were moving internally in Canada but also for those who were travelling to access services for their disabled child. I was beginning to learn more about how the work and activities these families took part in during their everyday lives was different from the work and activities of other family informants. Through this dialogue, I decided to broaden the scope of my initial entry point into the data and focus on three types of human movement and their intersection with childhood disability. In my discussion of standpoint below, I will discuss the standpoint through which I began to learn about disabled children and families' everyday activities and show how my own standpoint led to me diving deeper into this area of work.

As I began to engage with the data from the IECSS project, the scale and depth of the project became evident. With two cohorts of participants, the amount of data present would have been beyond the scope of the current dissertation. As I will describe in more detail in Chapter 3, family informants in cohort 1 joined the study starting in 2015 and were based in communities across Ontario. Cohort 2 participants started to join the study in 2018 and were based in communities across Canada. At the time of data analysis, participants in cohort 1 had completed up to 6 interviews and participants in cohort 2 had completed up to 3 interviews. Based on the time constraints and purpose of the current study, I made a decision with project director Kathryn Underwood to go into a more in-depth focus on participants who were recruited for cohort 2. Interviews for participants in cohort 2 began in the summer of 2018; thus, at the time of my dissertation the IECSS research team had already conducted multiple interviews with some of these participants. Further, family informants' first interview typically took place while the child was preschool aged thus, the data analyzed from cohort 2 allowed greater focus on the early years and the transition to kindergarten. Although I did not specifically engage with the interviews from cohort 1, I began to learn about experiences of human movement and disability from these participants when I began working on the project. Further, it was during interviews with cohort 1 when Dr. Underwood and other researchers on the project saw the problematic of human movement and disability emerge. Overall, although I did not specifically engage with all of the data for the purposes of my dissertation, the data across both cohorts shapes the emergence of this dissertation and the findings that arose through the analysis.

Standpoint

The starting point of any institutional ethnography is learning about people's activities from a particular standpoint (Smith & Griffith, 2022). Institutional ethnographers have engaged in research starting from various standpoints, such as mothers, families, healthcare workers, and other frontline staff. The IECSS project specifically starts from the standpoint of families with disabled children. The family informants provide a lens through which we can learn about the work they engage in but also how their work coordinates with what others are doing. A component of the ontological shift proposed by institutional ethnography is that the study is grounded in people’s everyday lives. The informants are not the objects of the inquiry; rather they should be seen as subjects whose knowledge of activities we want to learn from (Smith & Griffith, 2022). The data in the IECSS project comes directly from family informants who share the work and activities they engage in from their standpoint. Through the information they share we can learn more about the work they do and how they do it. As the family informants share with the IECSS team what they do in their everyday lives and how these activities occur, their interactions with services systems, the subsequent coordination or ruling relations and textually mediated practices emerge.

Researcher Standpoint

As institutional ethnographers, we come into our research from a certain place, a particular position or interest point. An important point made by Campbell and Gregor (2008) is that many researchers who use institutional ethnography have a personal interest and motivation in doing their research. My goal here is not to simply list out who I am by using social categories; rather as a researcher I need to continuously interrogate how my invisible (and visible) positionings impact my analysis (Choi, 2016). This reflexive process is integral to institutional ethnography because the researchers’ interests guide their work (Smith & Griffith, 2022). My identities as an able-bodied, South Asian first-generation Canadian woman from a working-class family have impacted my experiences as a child and adult. For example, as I enter many spaces, I am welcomed with a question: “Where are you from?” (James and Shadd, 2001). I hesitate when this question is asked of me as I don’t know how to answer. I am not alone in being asked this question as it is a question posed to many non-white people living in Canada, including first, second and even third generation Canadians (Dossa, 2009). The message conveyed through this question is that of not belonging here in Canada. Gaining a sense of belonging in childhood and as one grows up is important. However, when questions like this are posed one begins to question the impact of their identity on their experiences. Here, I want to take a moment to engage with how my different identities weave into my research and to acknowledge the importance of reflexivity in the research process. Just as families in this study are informants, whose standpoint allows us to learn about experiences of human movement and disability, as a researcher I can also be positioned as an informant. Through my standpoint described here, I was intrigued by these experiences of human movement and disability shared by the families and wanted to engage further with the experiences they shared with the IECSS research team.

Through my undergraduate degree in psychology, I was provided with a very medicalized understanding of disability and a restricted view of what disabled children's lives should look like. Entering research, it's important to be attentive to how my disciplinary training impacts my research (Foley, 2002). As I began to work in the field of early intervention, I started to question this knowledge. Entering the field of early intervention in the Region of Peel, my cultural background and proficiency in Punjabi led to working with many South Asian mothers and their young disabled children. Further, many of these children and families had newly immigrated to Canada, an experience I shared through my families immigration to Canada and landing in Peel. Our shared culture and language helped me in building rapport and having uncomfortable but necessary conversations with them. Through this experience, I continued to develop a greater interest in childhood disability and the complexities that come from it, partially because of cultural understandings of disability. These experiences led me to explore different theories, outside of what I had learned through my educational training. Engaging with theories such as Critical Disability Studies (CDS), Dis/ability Critical Race Studies (DisCrit), and

Disabled Children’s Childhood Studies (DCCS) supported me to find new ways of thinking and working with disabled children and their families. As I engage with the everyday experiences shared by family informants in the IECSS project, I continue to develop new ways of thinking about the intersection of childhood disability and human movement.

Growing up in an immigrant working class family, we didn’t have many conversations about difference and disability. Whenever I heard about disability, there were negative connotations and stigma associated with it. Then, psychology courses about disability built on this knowledge base and continued to perpetuate disability as negative. These invisible positionings can shape my analysis (Choi, 2016); thus it’s important to reflect on my previous understandings and teachings throughout the research process. This is one way in which I begin to engage in reflexivity of discomfort (Pillow, 2003). My theoretical understandings, beliefs, and hunches about disability and disability experiences may not align with participants’. However, for this research project it is important for me to continuously return to the informants’ standpoint and work to understand their everyday experiences in relation to the work they do engaging with institutions and professionals.

As a young person I began to support the caretaking responsibilities for my grandparents, who with age had acquired disabilities. When I was 20 my grandmother was diagnosed with brain cancer and I had to begin to navigate new service systems, engage with professionals, and fill out government documentation. Engaging with neurologists, oncologists, occupational therapists, speech therapists, social workers, case coordinators, nurses, and other professionals became central to my everyday life. It was when I was engaging with these services and trying to get supports in place that the vast work asked of families who care for someone with a disability, chronic illness, or palliative condition became clear to me. Going through these processes led me to work in advocacy. Critical disability studies emphasizes that disability studies cannot be a concern for only those with disabilities (Shildrick, 2012). Rather, we are all "complicit in the construction and maintenance of normative assumptions" (Shildrick, 2012, p. 30). This call from CDS reiterates the need for both disabled and non-disabled people to engage in research challenging normative ideas about disability. This is where my work with families and young disabled children comes into play. Through my research, I hope to engage with families and disabled children to determine how power differentials with institutions shape disability experiences and to gain a better understanding of the day-to-day work families engage in to access services and navigate different service systems.

As discussed by DeVault and McCoy (2006) institutional ethnographers have critical goals. There is a desire to "reveal the ideological and social processes that produce experiences of subordination" (DeVault & McCoy, 2006, p. 19). Dominant views of what is considered normal lead to the oppression of disabled people. We must question the positioning of the disabled and non-disabled (Shildrick, 2012), or, alternatively, the self and the other or the privileged and the oppressed. Further, it is important to work with the community and the individuals being studied (Creswell & Poth, 2018). To make changes, dialogue with these two groups is necessary, especially in the field of disability services. The knowledge created through this research can then lead to changing oppressive systems. One goal of my research is to learn from family informants about the processes involved in institutional interactions with respect to human movement and childhood disability using the institutional maps created by the IECSS project. By gaining a deeper understanding of the activities and work they engage in, I aim to make policy and program recommendations focused on transformation and change.

Working with the IECSS project. One of the reasons I will be using data from the larger IECSS project is my involvement with the project. In 2017, I joined the IECSS project as a research assistant and then became a project coordinator in 2018. As a project coordinator, I worked alongside other project coordinators and research assistants to support project activities. Alongside these other team members, I have been involved in recruitment efforts across the different communities. Recruitment activities the team has worked on involve reaching out to organizations, presenting on the project, and speaking with parents at different programs. In my role, I also worked alongside IECSS researchers and staff to conduct interviews across the different communities we work in. Transcription, creating attribute tables and maps from the interview data, and processing data from the questionnaires are all important day-to-day activities the IECSS team works on. My involvement in these roles has allowed me to learn about the different activities involved in the larger project and become more familiar with the project methodology and data. Having knowledge and experience with the processes the research team works on supported my understanding of how the project data is processed and organized. Overall, my long-term exposure to the project put me in dialogue with the research team about human movement. Human movement was an area of interest for me, and it was present in the data. The presence of human movement in the data led me to consider how it might be examined. Although I started this process with a focus on transnational migration, I began to consider other forms of human movement, such as internal migration and travelling to access services and the impact these forms of human movement had on the way that families of disabled children accessed services. My standpoint and position as a researcher along with the experiences shared by the family informants are central to the emergence of the problematic of human movement and childhood disability that will be explored in this dissertation.

Theory

The standpoint of the family informants provides an entry point into developing a deeper understanding of the intersection of human movement and childhood disability. To build on the research framework, I will first turn to theory to show how the problematic sits within a broader discourse. As I provide an overview of the broader discourse focused on human movement and childhood disability, from a theoretical position, it is important to keep in mind that the problematic is the central component helping to organize the direction of the research (Smith & Griffith, 2022). While other traditional qualitative studies may be grounded in theory, institutional ethnographies are grounded in the informant's everyday lives. Although institutional ethnography provides guiding concepts for analysis, such as ruling relations, work, and texts, they are not meant to be used for the interpretation of data. As Smith and Griffith (2022) point out, heavily focusing on theory can lead the informants to become the objects of the inquiry, rather than subjects because theory begins to dominate and generalize experiences.

In the current study, the concepts emerging from the three theoretical approaches can contribute to exploring the research problematic (Mykhalovskiy et al., 2021) and institutional ethnography concepts such as ruling relations, work, and texts. The interplay of Critical Disability Studies (CDS), Dis/ability Critical Race Studies (DisCrit), and Disabled Children's Childhood Studies (DCCS) help to position the research problematic within the discourse of disability studies. Traditionally, disability has been largely framed within the medical model of disability, focusing on the individual or impairment, with the aim of identification and treatment (Rosenbaum & Gorter, 2011). In response to the medical model, the social model of disability foregrounded the disabling nature of society, such as inaccessible environments, discriminatory attitudes, and politics (Meekosha & Shuttleworth, 2009). However, the social model of disability has also been critiqued for simplifying the conversations about disability by focusing only on the disabling nature of society. Further, as discussed by Sarkar et al. (2022), the medical model and social model of disability have worked to theorize disability from two ends of a spectrum, creating boundaries around theoretical positions. These critiques and discussions have led to alternative and emerging approaches to disability, such as CDS.

To better understand the theoretical discourse in which the research problematic is situated, I turned to a bricolage of theories. Below, I will begin with a discussion of CDS to provide an overview of disability studies. Following a discussion on CDS, I will be drawing on DisCrit to address the call by Ferri et al. (2022) to apply DisCrit to migration and immigration in relation to disability. To further situate the research problematic and the standpoint I engage in for this research, I will introduce DCCS which provides a unique perspective on conducting research focused on disabled childhoods.

Critical Disability Studies

Both the medical model and social model of disability have faced critiques about their positioning and theorization of disability. While the medical model locates disability within the individual (Nguyen, 2018), the social model of disability positions society as disabling people due to barriers (Davis, 2018). In response to these models, other theories have emerged in this area of research, including critical disability studies. CDS aims to examine disability as a "cultural, historical, relative, social, and political phenomenon" (Hall, 2019, p. 1). As such, Meekosha and Shuttleworth (2009) describe CDS as including the insights of the social model of disability but also as a means to embed more complex understandings of disability into our work. Some emerging themes from CDS include embodiment, intersectionality, interdependence, and trans-institutionalization.

Disability studies require us to interrogate the ways in which institutions and systems use impairment to define and label people (Goodley, 2011). Institutional processes are built upon a notion that some bodies are flawed, suggesting that there is a normal (Withers & Ben-Moshe, 2019). Researchers on the IECSS project have worked to better understand these institutional processes. To gain access to services, qualifying criteria are required, which leads families to seek out a diagnosis (Underwood et al., 2019a). Based on the diagnosis and qualifying criteria, families may then be connected with disability services. Disability services, both public and private, "are governed by the ruling idea that disability can be treated through rehabilitation services" (Underwood et al., 2020, p. 100). However, compliance with the expectations set out by disability services differs among people based on characteristics such as financial means or employment status, for example (Underwood et al., 2020). Analysis from the IECSS project reveals the institutional processes that push disabled children and families from one organization to another with this goal of achieving normal, leading disabled children to be defined by their engagement with disability services. Some of these expectations lead families to travel to access services, especially families who live in more rural or remote areas (Underwood et al., 2018, 2019c). These findings from the project begin to highlight the emerging problematic of human movement and childhood disability. The work institutions ask of families and disabled children as a result of human movement or to engage in human movement connect back to institutional processing of disabled children.

CDS acknowledges impairment and embodiment, something that was missing from the social model of disability (Goodley, 2013). The acknowledgement of impairment and embodiment provides a shift from viewing the body as a deficit to seeing it as a "place of becoming, reflection, and production" (Goodley, 2011, p. 158). This shift in disability studies aims to develop “affirmative understandings of the disabled body and mind” (Goodley, 2011, p. 10) while also acknowledging how disablism is present in different ways in our society. Similar to relational models of disability, this focus of CDS brings our attention to the interaction of impairment and the disabling nature of society. Furthermore, rather than minimalizing impairment, we must consider the realities of impairment and impairment effects that might lead to pain, tiredness, or exclusion from activities (Goodley, 2011); but we must also bear in mind that disablement and impairment are mediated by and materialized through institutional processes (Goodley, 2011). In the study, CDS is a part of the discourse in which I am placed in relation to the experiences shared by family informants to learn about the processes and how the categorization and labelling of children results in and shapes institutional engagements. Interrogating and challenging this institutional thinking is important to prevent people from being moved from one oppressive institution to the next (Withers & Ben-Moshe, 2019). Interrogating and challenging institutional thinking can support us not only to disrupt the systems in place but to also to work on creating new systems for disabled people with different intersecting identities (Withers & Ben-Moshe, 2019).

Intersectionality is a key element of CDS. Patricia Hill Collins and Sirma Bilge (2016) describe intersectionality as an “analytical tool” (p.12) which allows us to access the complexity of the world and people. They further argue that intersectionality provides a lens through which we can look at social inequalities to address more complex issues rather than focusing on single dimensions of identity and inequality separately (Hill Collins & Bilge, 2016). As I will discuss in further detail in the literature review, Crenshaw (1993) uses the term intersectionality to account for how different components of an individual’s identity affect how their social world is constructed. Goodley (2013) and Meekosha and Shuttleworth (2009) highlight the need for an intersectional approach to disability. Withers and Ben-Moshe (2019) discuss the multiplicity of identities that exist, suggesting that disability is not a distinct or separate identity. Rather, disabled people are also from other marginalized groups connected to race, gender, class, and citizenship status. Intersections with these characteristics can lead to different experiences of injustice (Erevelles, 2018). Further, as described by Mingus (2018), being moved through medical institutions as a racialized disabled person can lead to feeling like an object that needs to be fixed. An intersectional approach to disability calls for an examination of how disability "exists and arises in and interacts with marginalized individuals and communities" (Withers & Ben-Moshe, 2019, p. 183). In attending to intersectionality in my analysis and discussion, the role of family characteristics in relation to human movement will be important to understand. For example, in the study, I aim to better understand how disability exists and arises within immigration systems in Canada. Participating in both immigration and disability systems in Canada could impact how institutions in these different systems support and respond to families. Institutional ethnography provides an approach through which we can attend to these intersectional experiences because we are starting from the standpoint of family informants and learning from their experiences about institutions.

Furthermore, with this shift proposed by CDS, interdependence is also important to consider. Interdependence further challenges and interrupts ideas around normalcy and independence. Interdependence requires us to think about how we all need each other and how we all provide care to one another (Withers & Ben-Moshe, 2019). For example, young disabled children and their families cannot be seen as separate entities or as isolated units. They rely on each other, but they also have other support networks, formal and informal, that they need and are cared for by. Interdependence and CDS further interrogate the medical model and its focus on intervening to work towards creating an independent person.

Through the lens of institutional ethnography, the term *institution* is used to discuss "complexes organized around a distinctive function" (Smith, as quoted by Church et al., 2020). This definition of institution is important in relation to the concept of transinstitutionalization, as it is through these institutional complexes that disabled childhoods are produced. Church et al. (2020) explain that disabled childhoods are produced through their interactions with assessment, diagnostic, and identification procedures, rather than being connected to who they are as individuals. Transinstitutionalization captures the idea of how disabled, deaf, and mad people are moved from institution to institution. For the current study, transinstitutionalization is important to consider in the construction of disabled childhoods because characteristics such as race, gender, economic and social status, and disability are present in the engagements with institutions and the processes disabled children and families engage in while accessing services even when they appear to be invisible. Haley and Jones (2020) state that "mapping the ways in which institutions and institutional violences are hidden in plain sight is crucial to understanding the contours of transinstitutionalization" (p. 2). Institutional ethnography can be a key methodological approach to reveal and map invisible institutional processes for us to better understand transinstitutionalization in the everyday lives of disabled children and their families. More specifically, the current study begins to map out how disabled children's lives begin to be defined by institutions and how their movement from place to place is occurring as they are also being moved from institution to institution.

Dis/ability Critical Race Studies (DisCrit)

An acknowledgement of CDS as an intersectional approach has led to the emergence of more specific approaches to disability theory, such as DisCrit. DisCrit is built upon the key themes of CDS, with a central focus on intersectionality and the multidimensionality of identity. While considering the central focus of this dissertation, the intersection of human movement and childhood disability, it was important to better understand how aspects such as citizenship status, language, and race shaped the institutional engagements of disabled children and their families. DisCrit, as described by Annamma et al. (2013), aims to understand how “racism and ableism, among other structural discriminatory processes, are enacted in the day-to-day lives of students of color with dis/abilities” (p. 8). The initial goal of DisCrit “was to create a theory that was responsive to the immense inequities occurring in daily life, one that centered those pushed to the margins” (Annamma et al., 2022, p. 19). There are seven key tenets of DisCrit which have been used in analysis in relation to the intersections of disability and race. Following Padia and Traxler (2021) and Migliarini (2017), Tenet 5 of DisCrit is of particular interest for the current study. Tenet 5 of DisCrit asks researchers to consider the legal and historical aspects of disability and race and how they work to deny rights of citizens (Connor et al., 2021). Bringing citizenship status into the conversation through DisCrit is an important contribution and development to disability studies. Family informants in the IECSS project have shared the work they have engaged in to obtain citizenship status but also how their citizenship status or perceived citizenship status has impacted their engagement with institutions. When considering perceived citizenship status, factors such as race and language can play a role in interactions and processes without being visible.

Tenet 1 of DisCrit focuses on how racism and ableism act interdependently to uphold ideas of normalcy (Connor et al., 2021). One goal of Discrit is to make visible the normalizing processes of racism and ableism, which are often invisible (Migliarini, 2017). This goal aligns with the key objectives of institutional ethnography. For example, a key goal in this dissertation is to make the invisible work of people visible to reveal the processes they engage in during their everyday lives. For the purposes of the current study, Tenet 1 provides a mechanism through which we can analyze the processes families of disabled children engage in where racism, ableism, or both may be operating. Building on the first tenet, Tenet 2 calls people to value the multiplicity of identities experienced by individuals (Connor et al., 2021). Factors such as race, language, class, and gender may impact interactions and engagement with services. Considering Tenet 2 in this study allows us to appreciate the intersectional identities of the participants and their families. Further, by using an approach that values intersectionality we can analyze how systems respond to children and families with intersecting identities and the different experiences of these children and families.

Although Tenets 1 and 2 provide important foundations for analysis regarding the intersections of disability with other identities, Tenet 5 allows more focus directly on citizenship status and migration. Research has found that citizenship status can impact access to the education system, housing, transportation, public services, culture, and community services for disabled people (Migliarini, 2017; Padia & Traxler, 2021). Further, Padia and Traxler (2021) have noted that citizenship status is denied to participants based on disability status, race, national origins, and status as English language learners, for example. This finding supports research conducted by Dolmage (2018) about the Canadian immigration system and the denial of entry based on race and disability status. Although Tenet 5 of DisCrit highlights citizenship status in relation to disability, Ferri et al. (2022) point out that future research needs to apply DisCrit to issues of migration and immigration to stretch global disability studies. Using DisCrit, we need to "work to understand the experiences of students at the intersection of migratory status and disability" (Padia and Traxler, 2021, p. 699) to learn more about how systems, institutions, and stakeholders are responsible for denying access to rights connected with citizenship status. In my study, I work towards meeting the call by Ferri et al. (2022) to examine the intersections of disability, citizenship status, and race. Moreover, a large extent of research using DisCrit has focused on the education system. In the current study, family informants share experiences with service systems beyond the education system. For example, their engagement with healthcare, early childhood education and care, disability services, and immigration systems highlight the ways in which human movement intersects with childhood disability across contexts.

Disabled Children's Childhood Studies

Disabled Children's Childhood Studies (DCCS) brings our focus directly to the concerns of disabled children and their families by drawing on CDS and childhood studies (Curran & Runswick-Cole, 2014). DCCS draws on CDS as it also challenges normalcy, oppressive structures, and the dominance of the expert (Liddiard, et al., 2018). By bringing disabled children and their families to the forefront, the traditional positioning of disabled children and their families from a deficit perspective is challenged. Furthermore, while disabled children are sometimes invisible within childhood studies, DCCS makes them visible and central. As Curran (2013) explains, DCCS disrupts the idea that there is a singular childhood. One way this is done is by making visible the practices and processes that exclude disabled children (Curran, 2013).

Further, although DCCS centralizes the experiences of disabled children, it also acknowledges the role of families in our discussions about disabled children. Runswick-Cole

(2013), for example, discusses the disablism experienced by mothers of disabled children due to the liminal space they occupy. The data collected through the IECSS project starts from the standpoint of family informants. Their accounts allow me to learn how the systems and institutions respond not only to the disabled child, but also to their families, who take up this liminal space. Following CDS, DCCS acknowledges the heterogeneity among disabled children and their families (Liddiard et al., 2018). Overall, working with DCCS builds on key ideas brought forward in both CDS and DisCrit and it further centralizes disabled children and their families, thereby aligning with the goal of entering into the data from the standpoint of families.

The three outlined theories help us to understand the theoretical discourse in which human movement and childhood disability is situated. It is important to understand the everyday activities of disabled children and their families, and how different social positionings inform and impact these activities. Starting from the standpoint of disabled children and their families is one way to learn how institutions and systems uphold ableist, racist, and other discriminatory beliefs. Families who have migrated or traveled to access services and their disabled children are subject to these discriminatory beliefs. Institutional ethnography, as a method, provides an entry point into learning more about these institutional processes, underlying ruling relations, and textual records, concepts that will be further elaborated on in Chapter 3, which dictate the work of families and define disabled children. In the discussion above and the following chapters, I hope to bring forward some of the ways that institutions and systems respond to and interact with these families and their children. Below I will further situate the research problematic by turning to literature focused on early childhood education and care, childhood disability, and human movement.

Literature Review

Building on the theoretical discourse in which the research problematic is situated, it is important to engage with current research in the area of childhood disability and human movement. Family informants in the IECSS project share their experiences navigating early childhood education, care, and intervention services along with healthcare, school, family support, community, social, and funding related services. Their engagement with services and professionals is situated in their experiences, which in some cases are connected to their family and child's characteristics. For the purposes of this dissertation, I will be exploring these experiences from the standpoint of family informants who have engaged in movement, such as transnational migration, internal migration, or travelling to access services. Considering the experiences shared by the family informants, I want to engage with literature focused on early childhood and disability and on human movement prior to introducing the key findings for this dissertation. To begin, I will provide a brief overview of literature focused on childhood disability and the early years. This literature base provides background information about the Canadian early childhood education and intervention context from a policy and program perspective. Following this, I will provide an overview of literature focused on childhood disability and the different forms of human movement that are central to this dissertation. The current research base on the intersections of childhood disability and human movement outlined below helps to better understand the discourse around the research problematic. I will conclude by discussing intersectionality with consideration of family characteristics, such as language, race, culture, class, and gender. As I engage with the literature below, it is important to continuously return to the intersection of childhood disability and human movement and the standpoint of the family informants in the study.

Early childhood development programs

Early childhood has been discussed as a period of rapid growth and development. In the Canadian context, policy development focuses on the early years, specifically for children birth to 6 years of age (see Ministry of Children Community and Social Services, 2023). A review of the literature in this area provides context around policies and legislation on ECEC programming and how understandings of disability within these programs may impact experiences of disabled children and their families.

In 2018, the G20 leaders committed to several goals for sustainable development (IISD, 2018). During these meetings, global leaders focused on policy priorities globally and developed goals to work towards for 2030. At this time, the G20 initiative for early childhood development was put into place in response to research suggesting that early childhood was a foundation for health and well-being later in life; however, as noted by Richter et al. (2018), investment in early childhood development programs is not sufficient. Without a universal early childhood education and care (ECEC) policy in Canada, the quality of programs, practices, and understandings of inclusion may differ significantly from program to program. Underwood and Frankel (2012) suggest that access, design and implementation, and ongoing evaluation are foundational to high quality ECEC programs. Due to the lack of a universal ECEC policy in Canada, understandings of what inclusion is and practices to support inclusion are highly variable. For example, in a study on understandings of disability among early childhood teachers and professionals, Purdue (2009) found that many held ideas that were aligned with a deficit perspective of disability and did not support the inclusion of disabled children in mainstream ECEC programs. The deficit orientation of the policies at some of the programs led to the exclusion of disabled children from mainstream ECEC settings and perpetuated the idea that disabled children should attend more specialized programs. Childcare policies that have conditional clauses are used to justify denying enrollment, allowing the child to attend only part-time, asking parents to pick up the child early, or using reasons such as a lack of resources or ability to exclude the child (Purdue, 2009). These policies and practices employed by childcare programs can lead to movement or impact the work of families following human movement. In the first situation, if the local childcare centre does not allow their child to be a part of the program, the family may look outside of their community for childcare. Family informants share their experiences choosing childcare programs that require long distance travel as a result of these exclusionary policies and practices. In the second example, families must search for childcare programs, rejoin waitlists, and apply for subsidies following their move. For a disabled child, families may then have to engage in more work while sharing their child's diagnosis with the childcare centre and potentially facing rejection. This continuous restarting of processes leads to additional labour for families and disabled children. Family informants in the study discuss some of these processes and provide insight into the work they engaged in, and the processes involved.

ECEC programs have benefits for children and their families, such as positive developmental and health outcomes (Anderson et al., 2003). These benefits underscore the need to examine which children are included and excluded in ECEC settings. The processes to gain entry in such programs, along with the work that families do in the face of exclusionary policies and practices, highlights the importance of investigation in this area. Furthermore, families that have migrated or have travelled to another community to access services may have differing interactions or engage in different forms of work to gain entry into these spaces, prompting the need for further research relating to their unique experiences.

The literature on early childhood development and early intervention highlights the importance of the early years for children's development and the need to provide support to children and their families during these formative years. However, the lack of investment in and universal legislation around early years services and programming suggests that for many families this message about support remains but an ideal, often one at odds with the realities they are facing. Further, the research suggests that understandings of disability vary and ultimately impact the types of interactions disabled children and families experience. These experiences further intersect with other characteristics of disabled children and their families. Although research has examined the participation of disabled children and their families in ECEC programming, research that explores the experiences of disabled children and families who have engaged in a form of human movement is a developing area. Due to challenges faced by these families in learning about and accessing services and supports, which I outline further below, it is important to focus on this specific population and their experiences.

Migration, Human movement, and Navigating Early Childhood and Disability Service Systems

There is a diversity of experiences amongst disabled children and their families. When considering intersectionality, we must acknowledge that experiences may differ and that the processes some disabled children and families engage in when accessing services are complex. As noted in Chapter 1, one of the factors that may account for some of this diversity and complexity is related to human movement. A key focus of this dissertation is the experiences of families who have engaged in transnational migration to Canada and have a disabled child. The current research base on transnational migration and disability focuses largely on barriers and facilitators in accessing health and disability services. A second form of movement explored in this dissertation is travelling to access services. Research examines the travel explicitly associated with accessing services for disabled children, much of it focused on families living in rural or remote areas, but increasingly also oriented to the travel experiences of families in larger cities and urban areas. A third form of travel explored in this dissertation, that has yet to be systematically examined, is internal migration: families with disabled children that have moved within the same country to access services and the processes that they engage in before and after the move. Research considering internal migration has focused specifically on why people move and movement patterns. As I will discuss further below, it is important to explore internal migration in Canada with respect to disabled children and their families. Below, I will provide a summary of literature on transnational migration, travelling to access services, and internal migration. In this discussion I will highlight key findings from research and connect them to the present study.

Transnational Migration and Service Navigation. A central focus of this dissertation is to learn about experiences accessing services for young disabled children from the standpoint of family informants who have migrated transnationally. Research focusing on families who have experienced transnational migration and are accessing or trying to access development and disability-related services is an emerging area of interest (see Cummings & Hardin, 2017; Fellin, King, Esses, Lindsay & Klassen, 2013; Liu & Fisher, 2017; Sandhu et al., 2017). Furthermore, researchers have also started to explore service providers' experiences of working with immigrant families (see Khanlou, Haque, Sheehen & Jones, 2015; Lindsay, King, Klassen, Esses & Satchel, 2012). What this literature makes especially clear are the barriers immigrant families experience in navigating health, early intervention, and education systems for their disabled children. In this section, I will provide an overview of research examining navigation and referral processes post-migration, as well as a discussion of research that focuses specifically on immigrant families' experiences navigating disability and education service systems.

Following migration to a new country or community, families must navigate and interact with systems, which may differ organizationally, and also in relation to culture, worldview, disability constructs, and caregiving practices from those in their home community. Navigating and getting connected with healthcare and education services could involve different interactions and pathways than those families are used to. The first experience or contact with the healthcare system for pregnant newcomer mothers, for example, is usually through an emergency room or walk-in clinic (Gagnon et al., 2010). In a study that examined newcomer mothers' experiences navigating healthcare services, Gagnon et al. (2010) found that newcomer mothers faced challenges with language, transportation, making appointments, partner's absence, absence of childcare, perceived inappropriate referral, and cultural differences when making the first contact with services and getting subsequent referrals. In the current study, family informants share how they gain entry into different programs following migration (transnational and internal). Learning from the standpoint of the family informants about these entry points and pathways can help to better understand the institutional response to movement and how institutions organize the work of families. Moreover, the participants in the study conducted by Gagnon et al. (2010) shared details about the importance of having a network that could connect them to healthcare services. The importance of friends, family, and community members following migration is a support discussed throughout the literature on immigrant families' experiences navigating services following migration (see Brown et al., 2020; Khanlou et al., 2015; Khanlou et al., 2017; Rivard et al., 2019; Son, Moring, Igdalsky, & Parish, 2018). Making the initial contact can be essential for the process of getting referrals for other services and supports (Gagnon et al., 2010).

However, healthcare professionals might be the gatekeepers to get the initial referral. The added complexity of not having an existing base to start with can be a barrier to connecting with healthcare services. Although research has focused on the experiences of immigrant families accessing services, there is a lack of research on how immigrant families or families who have migrated gain access to different service systems and what the referral pathways look like when working towards accessing services for disabled children in particular. The family informants in the IECSS project share their experiences of the process of gaining entry into services their standpoint. It is important to understand these experiences more fully, as they provide insight from the standpoint of families about the institutional engagements and bureaucratic procedures following a move.

Research examining immigrant families' experiences in ECEC programs suggests that access for these families is different due to challenges navigating administrative structures (Massing et al., 2020). Immigrant families are less likely to participate in ECEC programs than non-immigrant families because of family preferences for familial childcare rather than a structured program (Massing et al., 2020). However, due to migration there is a loss of familial childcare options, leading to challenges in accessing childcare following migration. Another barrier is the lack of information about which programs are available for immigrant families. Without adequate information about what is available, immigrant families may not know where to seek out support or information about ECEC programs (Massing et al., 2020). For disabled children and their families, this may become even more complex. For example, these families may not have family members or friends to provide them with extra supports when needed, leading to social isolation, which could be further exacerbated by the lack of information about formal supports such as childcare. Other families may turn to online resources to learn about the processes involved, thus adding more work to gain entry into programs. To better understand these complexities further research is needed about how immigrant families with disabled children learn about ECEC programs and their reasons for enrolling their child in structured programming.

This dissertation aims to shed more light on the institutional interactions that result from navigating different service systems for families and disabled children who have migrated or travelled to access services. In previous research focused on accessing early intervention and education services for disabled children, families who have migrated transnationally have discussed barriers they have faced (see Cummings & Hardin, 2017; Fellin, King, Esses, Lindsay & Klassen, 2013; Liu & Fisher, 2017; Sandhu et al., 2017). Research in this area focuses on structural support, social networks, newcomer preferences, and the transition to school. As noted above, the lack of information and difficulty understanding available information presents as a key challenge for immigrant mothers in accessing or learning about what is available for their child (Arfa, Solvang, Berg, & Jahnsen, 2020; Kahnlou, Mustafa, Vazquez, Haque, & Yoshida, 2015; Khanlou et al., 2017; Rivard, Millau, Magnan, Mello, & Boule, 2019). A delay in getting information causes a delay in getting a diagnosis and subsequently accessing services. Mothers also report that dispersed services cause difficulty locating and accessing adequate transportation to travel to appointments (Su, Khanlou, & Mustafa, 2018; Khanlou et al., 2017). These discussions, focused on travel, dispersion of services, and transportation, become more complex when considering travelling outside of one’s community to access services, an experience described by family informants in the current study. Integration and coordination of services is one way to mitigate this barrier for immigrant families. The compounding of these different forms of human movement is important to investigate further. Participants have also discussed barriers such as the excessive paperwork that they are asked to complete to gain access to different programs and supports (Arfa et al., 2020; Khanlou et al., 2017; Fontil & Petrakos, 2015). Complex bureaucratic procedures and forms that are difficult to understand are described as discouraging by some mothers (Khanlou et al., 2017; King et al., 2011; Klassen et al., 2012). However, engaging in these institutional procedures is necessary to gain access into programs and supports. Family informants in the IECSS project provide additional insight into these procedures, with a specific focus on the textual records that are required and created during their engagement with services. Further research on immigrant families' experiences engaging with these institutional procedures is required to gain a more detailed account of what these everyday activities look like.

In conversations with family informants, the absence of instrumental support is also important to understand as it relates to the institutional response to human movement. For example, immigration could lead to the loss of formal and informal support networks (Khanlou et al., 2017). The lack of a social network could lead to feelings of isolation due to limited of support from family (Brown et al., 2020; Khanlou et al., 2015; Khanlou et al., 2017; Rivard et al., 2019; Son et al., 2018) and having to start from the beginning to develop formal support networks. Although this has been an area of interest in relation to immigrant families, there is limited or no available research on instrumental support for families who engage in internal migration, as I will describe further below.

While discussions of barriers emerge in conversation with family informants, I aim also to explore how institutional processes can act as facilitators. Notably, there is a sense of gratitude expressed by immigrant families due to the availability of services and education opportunities that they would not have had in their native country (Arfa et al., 2020; Su et al., 2018). Families also describe service providers as being helpful, especially when they provided information about services and programs and supported them in getting subsidies (Rivard et al., 2019). Service providers suggest that building a partnership with families is important for the process (Brassart et al., 2016). Getting to know the home environment and other contextual factors about the family is one method to begin forming this partnership. For immigrant families this may be especially important, and it could also influence whether recommendations of service providers are taken up by the family. However, it is also important to consider whether discourses such as Canada being a "dream" location to live in impact how families share their experiences in accessing services. These discourses may drive immigration to countries like Canada but also shape people's experiences upon arrival. An institutional ethnography allows us to explore how these discourses or prevailing ruling relations shape people's experiences.

The research on immigrant families' experiences navigating services for their disabled child is a growing area of interest. Much of the research focuses on different forms of support, such as structural and instrumental support. Although research in this area has been growing, it is important to conduct further research on the interactions families have with these different institutions and systems because the processes described above at the system level are erecting barriers for many of these families. It is also important to further understand these interactions as indicators of the values embedded in the institutions and as reflections of ruling relations, which I will discuss further in the methods section. Further, the interaction of different systems ultimately impacts children's development. By learning more about these interactions, we can gain further insight into how different families work to support their child's development. Moreover, in addition to the experience of migration or travelling to access services, family characteristics could lead to differences in the interactions that occur with these different systems and institutions. Later in this chapter I will discuss intersectional identities and how they affect the experience of service navigation for families who have immigrated.

Travelling to access services. In addition to different forms of migration, human movement in this study also captures the process families engage in to travel to access services. Based on location, wait-time, or specialty, for example, some families may be asked to travel to another community to gain access to services for their disabled child. There is a growing literature base examining this movement, especially when families who live in rural or remote regions are required to travel to urban regions to gain this access. Further, there is a small literature base about travel within larger cities, which although limited can add to our understanding of the work families and disabled children engage in during the process of accessing services. In this section I will review literature regarding travel from rural and remote areas and then discuss research connected to travel that occurs for those who live in urban and large cities.

According to Statistics Canada (2021), the population in rural communities across Canada continues to grow, although the growth has slowed down compared to previous years. In addition to its data on those who live in rural communities, Statistics Canada (2021) points out the importance of considering remote communities, some of which are considered urban cities. The literature base focusing on the experiences of disabled children and their families living in rural and remote communities in Canada and globally has been increasing. The research base focuses primarily on barriers to accessing health, education, and disability services for those who live in these communities but also touches upon the importance of community for those who live in rural and remote areas.

When considering the intersection of human movement and childhood disability, the travel disabled children and their families who live in rural and remote areas engage in to access specialized services is important to better understand. Researchers from the IECSS project have discussed elsewhere some of the geographic disparities in availability of services for disabled children (Frankel et al., 2019; Underwood et al., 2018, 2019c). The findings suggest that families and disabled children who live in rural or Northern communities are required to travel to other cities to access services (Frankel et al., 2019; Underwood et al., 2018, 2019c). Similarly, when examining the experiences of families with disabled children in rural and remote areas, Dew et al. (2012) found that there were limited local options for services, and when available the services did not have the capacity to support more children. Although there may be general practitioners available, finding more specialized professionals can be a challenge (Barr et al., 2018; Boydell et al., 2006; Dew et al., 2012). As outlined by Dew et al. (2012), this affects healthcare, education, childcare, and allied health services. In some communities, steps are taken to try to bring more specialized professionals into the community. However, it is difficult to find professionals to relocate and, if they do, turnover is high, with some children getting only a few sessions with a professional before they move (Boydell et al., 2006). As a result of the limited services in rural and remote areas, disabled children and their families must make a decision about travelling to larger communities to gain access to services.

Due to the limitations in services discussed above, many disabled children and families travel to other communities to access services. In these situations, families sometimes must engage in extensive travel to larger communities (Barr et al., 2018; Stehlik, 2017; Walker et al., 2016). Stehlik (2017) points out that the travel adds more work for mothers who usually travel with their child. When travelling, different considerations are required from the perspective of families. For example, when travelling to access services for one child, other children might be left at home (Stehlik, 2017). Further, to travel families might have to take time off work, pay for gas, parking, and meals, and arrange for accommodations (Boydell et al., 2006). Although some families may receive funding or grants to cover these expenses, this usually requires them to fill out forms, coordinate with different professionals, and engage in more work to access services for their child. When travelling to access services, disabled children and their families are also asked to leave their home communities without consideration of the possible adverse impact of the travel on families' sense of place and community.

When considering travelling to access services, Stehlik (2017) discusses the importance of place for people's identity, and as noted above this isn't considered when disabled children and their families are asked to travel outside of their community to access services. It is important to ensure access to local services and support programs that are more culturally acceptable and less disruptive for children (Boydell et al., 2006). The way the current system operates, children begin to be defined by diagnostic categories, which can usurp their cultural, spiritual, and social identities (Frankel et al., 2019; Underwood et al., 2018, 2019a, 2019c), while also neglecting to support the development of a positive disability identity. This is especially true for disabled children and their families whose everyday activities begin to be shaped travelling to access services away from their home community and relationships. Further, for many people, community provides an important social support, especially for those in rural and remote areas. The cohesiveness of these communities (Stehlik, 2017) can be beneficial when considering access to services and supporting disabled children and their families within their home community. Having access to local services also creates an opportunity for professionals to deliver services in the child's environment or home (Boydell et al., 2006). Meeting families and children in an environment that they are familiar with and comfortable in can allow professionals to get to know them better and provide strategies and supports that are more appropriate. Not surprisingly, then, a final theme that emerges in the literature is the importance of place and community when considering the everyday lives of disabled children and families who live in rural or remote areas.

Although travel from rural and remote areas to larger urban cities to access services occupies a larger portion of literature about travelling for services, there is also some exploration of travel within urban cities. More specifically, research emerging from Toronto, Ontario has examined the travel of disabled children who go to specialized schools (Buliung et al., 2021). The foundation of this research is the absence of infrastructure available to provide accessible education to disabled children at their home school. In Ontario, Identification, Placement, and Review Committee meetings are a mechanism through which disabled children are placed in a school (Government of Ontario, 2022). This placement can range from being in their home school to being in a specialized school within the same school board but in a different community. Buliung et al. (2021) note that due to the agreed upon placement, some disabled children might require transportation or travel for longer distances to get to school every day. The additional travel time these students engage in every day can further limit access to peers, curriculum, and other activities due to arrival and departure times (Ross & Buliung, 2019). In their study, Buliung et al. (2021) found that disabled children placed in special education programs experienced more travel than their peers and spent more time and travelled further to attend the special education program compared to their home school. Overall, both Buliung et al. (2021) and Ross and Buliung (2019) highlight the inequitable access to education for disabled children in their home communities. In the current study, I hope to extend this conversation by looking at the travel associated with attending specialized childcare services.

The research presented in this section demonstrates that families of disabled children engage in additional travel compared to other families to access services and the education system. The research base described primarily focuses on travel from rural and remote communities, but it also asks us to consider travel that occurs for those who live in larger cities. In the current study, experiences of travel from rural and remote communities and within larger cities or from one large city to another is discussed. Research conducted by Buliung et al. (2021) links this travel to inequitable access in home communities, adding another layer to the complex processes and activities disabled children and their families already engage in during their everyday lives. In my analysis I am interested in how an institutional ethnography approach will expand understanding of what travelling for services looks like and how it is experienced from the standpoint of families of disabled children across Canada. The literature to date about travelling to access services emerges largely from outside of Canada or from large Canadian cities. Family informants in the IECSS project live in communities across Canada and provide a lens to examine the experiences of those from different types of Canadian communities. The current research will contribute to the literature base by examining how procedurally disability arises in interactions with institutions. Further, while a large extent of the research reviewed here focuses on healthcare and education service systems, I aim to examine service systems more broadly to learn about human movement and childhood disability within healthcare, pre- and post-natal, disability and early intervention, education, early childhood, and community and social service systems. Interactions and processes across these systems can also be made visible by examining how families engage and experience these services systems.

Internal Migration. As noted in the introductory chapter, internal migration includes both interprovincial migration and moving within the same province. In the context of the present study, I am interested in the existing literature on the general pathways of migration and reasons for migration. Internal migration in Canada is both interprovincial as well as following rural-urban migration pathways. In this section I will briefly outline literature which discusses internal migration, why it occurs, and patterns of migration. I will conclude with a rationale for why further research is required on internal migration, childhood, and disability.

Interprovincial migration patterns and reasons for migration in Canada have been documented in research. A substantial amount of literature in this area draws on the Longitudinal Administrative Database created by Statistics Canada. This database is generated from the Canadian census (Finnie 1999; 2004) and includes data from 1982 to 1996 (Finnie, 2004). Finnie (1999) outlines three reasons for why it is important to conduct research on interprovincial migration: to understand its impacts on population demographics; to examine its connection to the economy; and to understand its connections with social policy. An examination of the data from 1982 to 1995 reveals several trends regarding interprovincial migration. Finnie (1999) concludes that while most Canadians did not migrate to another province, 7.4% of the population did move to another province at least once. Within this data, we see that there is a high likelihood of people to migrate out of certain provinces compared to others. For example, due to provincial language use, residents of Quebec and New Brunswick are less likely to migrate to another province (Finnie, 2004). Those who live in rural and remote areas, small cities, and towns are also less likely to move to a different province (Finnie, 2004). In contrast, those from smaller provinces are more likely to migrate to another province. Considering other demographic variables, Finnie (2004) identified age, marital status, and children as factors connected to interprovincial migration. Younger people are more likely to be mobile, whereas those who are married and/or have children are less likely to be engage in interprovincial migration.

Moving beyond the patterns in relation to who is moving, studies of interprovincial migration focus heavily on *why* people move (Finnie 1999; 2004). Importantly, this discussion is largely centered around economics and employment opportunities (Coulombe, 2006; Day & Winer, 2006; Finnie 1999; 2004). Similar to research on immigration, economic opportunities are a key reason for people to consider moving. A limitation of the available literature is the absence of discussion around other important variables that may affect people's decisions to move, such as the availability of housing, social networks, and educational or other opportunities for children. Further, the impacts or activities families must engage in following migration within Canada is not discussed in the available literature base.

Although the analysis of census data, which focuses strictly on interprovincial migration, highlights the limited human movement within the Canadian population, research focused on rural-urban migration highlights that within the North American context, most people migrate or move at some point in their lives (Maggi et al., 2010). Further, Howard and Lobo (2013) note that for Indigenous people human movement was an important tradition; however, due to colonization it has become significantly reduced. Although Indigenous people have migrated to urban areas for many reasons, we also need to consider that many were forced to leave their land to attend residential schools and various other relocation programs (Howard & Lobo, 2013). As I will discuss further in the next section, it is important to consider intersectionality in relation to internal migration and experiences of disabled children and families.

Considering that the Canadian census (Statistics Canada, 2006) shows that 14% of Canadians had migrated in 2005 and 19% had migrated between 2001 and 2006, it is important better understand the experiences of those who engage in internal migration. Questions such as who is moving, why they are moving, and what happens after moving are important to consider as the processes and activities families and children must engage in during this transition are invisible within the current literature base. Gaining a better understanding of these processes from the standpoint of parents can begin to answer some of these questions. Further, the current study builds on an important point raised by Finnie (1999), which is to understand the relationship between social policy and internal migration. Understanding the impact of social policy on disabled children and families following a move will contribute to the current literature base on internal migration and add to the discussion about the lack of universal policies across Canada and within provinces.

Intersectional Identities

Crenshaw (1993) describes intersectionality, starting with race and gender, as accounting for how multiple forms of identity affect how the social world is constructed. Annamma et al. (2013) argue that it is important to examine the intersection of race and dis/ability because placing boundaries on each of these categories and considering them as independent fails to capture important aspects of people's experiences. In addition to race, language, culture, gender, and class are key areas where intersectionality with disability and citizenship status takes place for some families (Annamma et al., 2013). To address institutional interactions and processes, the recognition of intersecting identities can lead us to better understand differences in experiences and also help to disclose systemic discrimination. Families who have migrated or travel to access services and have a disabled child may have different intersecting identities. In this section I will briefly highlight research on how different social locations or identities may influence the experiences of families accessing disability or development-related services for their child.

Race. As expressed by Annamma et al. (2013), racism and ableism are interdependent; thus, when examining the intersection of human movement and childhood disability, it is important to learn about the experiences of racialized disabled people. Annamma et al. (2013) suggests that racialized students are more likely to be placed in specialized education programs compared to their White peers. Brown and Parekh (2014) found that Black children are more likely to be labelled as having behavioural issues, intellectual disability, and developmental disabilities. Due to the interdependence of ableism and racism (Annamma et al., 2013), we need to learn more from families and children about their experiences in different systems. For example, immigrant families of disabled children have raised concerns about the potential of race-based discrimination by service providers (Son et al., 2018). However, these families describe uncertainty about whether the discrimination is in fact due to their race or other factors. The current study adds to the current literature base on human movement, disability, and race by focusing on how these three identities can interact and operate in the lives of families and their disabled children.

Language. Discussions of human movement, particularly transnational migration, must consider the role of language. Language differences can impact how concerns are expressed by families (Gagnon et al., 2010). In these cases, families may avoid expressing their concerns or questions to professionals. Further, interactions with different service systems leads to the creation of documents or textual records, which may not be in the family's native language (Brassart et al., 2016). The complexity of the language in these documents presents as a barrier to understanding the process, intervention, and recommendations (Brassart et al., 2016). Families also have concerns about how their limited English language skills could impact collaboration with professionals or agencies (Fontil & Petrakos, 2015). For example, limited communication could lead to less parental involvement with professionals. Although interpreters can be used to mitigate these barriers, families describe positive and negative experiences working with interpreters (see Arfa et al., 2020; Son et al., 2018). Among the concerns they express is the fear that the interpreter, as a member of their small community, may not keep the families' experiences confidential. Further, families worry that they may not be getting all of the information through the interpreter, owing to the complex nature of the language used in these interactions (Son et al., 2018). Further, in Canada English is the primary language used in institutional interactions. For example, documentation being provided in English rather than the families native language suggests that families must be comply with the language requirements and standards. Beyond documentation, the language services are provided in continues to perpetuate the discourse of what it means to be a Canadian resident. Family informants in the IECSS project share their experiences with navigating services and the conflicting beliefs around using the language from their home country or complying with the discourse focused on English use in Canada.

Culture. Cultural differences in perspectives on development and disability could also play a mediating role in decisions to seek out professional support and in the resultant interactions with services, professionals, and the community. Culturally based stigma around disability is one reason some families avoid attending programs or accessing services (Khanlou et al., 2017; Poureslami et al., 2013; Rivard et al., 2019) Cross-culturally there can also be different understandings of disability categories. Many families may not know about these different ways of understanding disability. Lack of awareness in their native country about disability (Rivard et al., 2019) or differences in approaches to disability (Gagnon et al., 2010) could lead to ignoring the diagnosis or limited access to specialized services. Poureslami et al. (2013) and Brown et al. (2020) suggest creating more culturally relevant programming to better support immigrant families from different cultures.

Class and gender. Class and gender have also emerged as characteristics that could impact families' experiences interacting with different service systems. Immigrant families express concerns related to financial barriers due to changes in occupation upon arrival to Canada (Khanlou et al., 2015), limited job opportunities (Khanlou et al., 2017), and mothers having to stay home with their child (Su et al., 2018). Further, the conflict between public and private services, along with financial barriers, can cause obstacles for some families. The costs of private assessments or services can be prohibitive for some families; however, they also express feeling that it is necessary to engage with the private system to get adequate support (Rivard et al., 2019).

Moreover, much of the work in navigating and interacting with services is gendered (Khanlou et al., 2017). Mothers tend to leave the workforce more often to stay at home with their child and engage in this work. However, some mothers indicate that they cannot go to appointments without their partner for reasons such as language and transportation (Son et al., 2018). There is limited research on the work fathers engage in to support their child's development and access to services. Although some researchers have started to explore these experiences in relation to families who have immigrated to Canada, research on these intersections for families who have migrated internally or travel to access services is still limited. My research aims to redress this gap by examining class and gender in relation to families who have migrated or have to travel to access services.

Purpose Statement

The goal of an institutional ethnography is to learn what people do and why they do it, starting from the standpoint of the particular group we are talking to (Smith & Griffith, 2022). Thus, the purpose of the current study is to better understand how human movement is mediated by institutional constructions of children as disabled (and racialized, classed, gendered) from the standpoint of family informants. Learning from family informants about the work they engage in will also support developing a greater understanding of how their work is coordinated with the actions of other people. The theoretical overview and literature review above help to situate the problematic of human movement and childhood disability. The current research can add to this knowledge base in several ways.

This dissertation provides a different way of thinking about how human movement is implicated in the institutionalization of disabled children. There are several ways in which I aim to provide a different way to think about the intersection of human movement and childhood disability First, while much of the extant research focuses on older children and young adults, my research will focus on families with children in early childhood (under the age of 12). As outlined above, the early years are described as a significant time period for development (Guralnick, 2011; Ministry of Children Community and Social Services, 2023), thus making it an important age group to consider. Furthermore, by focusing on this age group we can also gain information about key transitions, such as the transition to preschool and transition to kindergarten.

Second, while much of the literature focuses on transnational migration, my research will explore the experience of different forms of migration and human movement. It is important to examine the differences and commonalities in experiences with different service systems in connection to the different forms of migration and human movement experienced by families with disabled children. The standpoint of the family informants and my standpoint as a researcher provide a different perspective in understanding human movement and the institutional construction of disability and childhood, and how institutions organize families. This extends to working towards learning more about different forms of human movement, rather than focusing on only one form of movement, such as transnational migration. Again, the current study aims to explore different forms of human movement (transnational migration, internal migration, and travelling to access services) to better understand the commonalities and differences between them. As discussed in the literature review, transnational migration is associated with leaving one community and joining another. When this movement occurs, there is an impact on the everyday lives of disabled children and their families, such as needing to gain entry into programs, finding formal supports, and losing informal supports. Although internal migration is premised on moving within the same country, disabled children and their families are still relocating and joining new communities. Consequently, some of the processes and procedures they engage in may overlap with those of families who have migrated transnationally. Similarly, there is limited focus in the research on families who, while not moving within or between provinces, travel to other communities to access services for their disabled child. It is important to examine which families engage in this travel and what causes them to travel to access services. The literature on transnational migration suggests family characteristics or intersectionality may impact service access. Extending this to analyze family characteristics in relation to different forms of human movement can help to better understand the institutional construction of disability and childhood.

Third, as I will discuss in the next chapter, the focus of analysis of this study is to learn about institutional power through the accounts of families and the work they engage in with institutions in their everyday lives. For example, Underwood et al. (2019a) outline some of the work families do to gain access to and participate in different systems. This work requires families to "do paperwork, set up appointments and follow up on connections, travel, and engage in relationships across the programs and services" (Underwood et al., 2019a, p. 144). Furthermore, families are required to advocate for their children and comply with the requirements set out by institutions (Underwood et al., 2019a). In my research, I will build on this work by learning from family informants who have the specific experience of engaging in human movement and who, in virtue of that experience, can shed light on the institutional processing of disabled children and their families.

Finally, as I detail more fully in Chapter 3, this study uses longitudinal data, offering a significant methodological extension of existing research in the area and allowing for the analyses of how migration or travel has impacted access over time. The longitudinal nature of the study builds on the research outlined in the literature review as it allows for an examination of how changes over time impact the processes and interactions in which families and disabled children participate. For example, when specifically looking at participants who have moved to another community during the course of the longitudinal study, we can compare their experiences before and after migration and track how the move impacted the work they engage in over time. The mapping of these experiences over time can make visible the sequences of work and institutional processes that are often invisible, a key aim of institutional ethnography.

A central purpose of my research project is to examine the power that services hold and the ways in which intersectional experiences of disability are constructed from the standpoint of families of disabled children that have immigrated, migrated, or had to travel to access services. Accordingly, to reiterate, the main research problematic guiding this project is:

> What do the everyday experiences of disabled children and their families tell us about the role of human movement (transnational migration, internal migration, or travel to access services – both forced and voluntary) in accessing and navigating early childhood, disability, and education service systems?

Building off of the problematic outlined above, there are several areas of inquiry that I will be exploring further to support in explicating the ruling relations (Chapter 3) and to understand institutional interactions of disabled children and families who have migrated (transnationally or internally) or travelled to access services. These areas of inquiry provide a branching point from the main question posed above in order to specifically examine different aspects of the everyday lives of disabled children and their families. Again, the areas of inquiry are:

> In what ways do migrant families work to support service systems?
>
> In what ways do institutions organize children and families (with a focus on intersectional identities), and how do institutionally produced categories impact experiences in navigating systems and interactions with service providers?
>
> What are the impacts of a diagnosis on institutional procedures?
>
> How do child and family engagement with these systems shape disabled children’s identity?

Chapter 3: Methodology

In the previous chapter I provided an overview of the research problematic focused on understanding how human movement and disability are interdependent in the institutional engagement of children and situated it within theory and literature. The current research focuses on gaining a better understanding about the processes and procedures families with disabled children who have migrated or travelled to access services engage in during their everyday lives from the standpoint of family informants. Institutional ethnography as a method provides us with an entry point to learn more about institutional processes and procedures, thus building on the current theory and literature. In this chapter I will start by providing an overview of institutional ethnography. Following this, I will detail the study design, specifically focusing on the IECSS project, the ongoing data collection, and project activities. To conclude this chapter, I will outline data analysis and ethical considerations pertaining to the research study. It is important to keep the research problematic in mind throughout the methodology section.

For this dissertation, I committed to reading the data from the Inclusive Early Childhood Service System project (IECSS) with the goal of understanding how human movement and disability are co-constructed and used to govern the lives of children and families. The methodology used for the IECSS project is institutional ethnography. Institutional ethnography begins from the standpoint of the people to learn about the work and activities they engage with in their everyday lives. In engaging with the data, I was interested in a problematic that was emerging from the data collected by the IECSS project—the intersection of human movement and disability.

Institutional Ethnography

Institutional ethnography uses the standpoint of informants and their experiences to learn about the work people engage in to make things work and happen the way they do (Smith, 2006). Some of this work is done by families. For instance, researchers on the IECSS project have learnt from family informants about the work they do in their everyday lives accessing services for their disabled child (Church et al., 2020; Underwood et al., 2018; 2019a; 2020a). Others such as Nichols et al. (2015) have engaged with newcomer families to learn about the work they do to engage with healthcare services for their children. Frontline workers are also implicated and do some of this work. Parada et al. (2020) learned about the work of frontline workers such as settlement workers, employment support workers, immigration counselors, and referral specialists to learn about the practices of individuals working in settlement services. In their work, Parada et al. (2020) started from the standpoint of practitioners to learn how their practices shaped the experiences of refugees. In the current study, I am starting from the standpoint of the family informants to learn about the work they do; as they share their experiences, the work of frontline workers is also shared, thus allowing me to look at specific institutional practices through the intersection of human movement and childhood disability. Institutional ethnographies are grounded in what actual people do in their everyday lives (Smith & Griffith, 2022). The informants whose standpoint we begin with, families of disabled children, are implicated in complex networks of relations that are not always visible. Institutional ethnography proposes an ontological shift by providing a methodology that can be used to change these social relations. With this ontological shift, the focus is on learning what people do and the translocal coordination of their activities (Mykhalovskiy et al., 2021) to gain an understanding about institutional practices and processes that impact people's everyday experiences (DeVault &

McCoy, 2006). In the current study, I am listening to the family informants to learn about their work and the work of others connected to the intersection of human movement and childhood disability, such as procedures, processes, how things are organized, and what could be different.

Smith and Griffith (2022) highlight that the way in which participants are centered in an institutional ethnography differs from other research methodologies; thus they are considered informants. For example, participants in an institutional ethnography are the subjects of the inquiry instead of objects (Smith & Griffith, 2022). Further, institutional ethnography not only examines what people do but it is also concerned with how what people are doing is coordinated with the work of others beyond their immediate setting (Smith & Griffith, 2022). For the current study, I am interested in examining how the work of families and disabled children is coordinated through processes linked to human movement and disabled childhoods. The focus on how the work people do is coordinated and organized by relations beyond local settings relates to the concept of ruling relations, a term which will be discussed in detail later. For the current study, I will be examining how these institutional processes or ruling relations coordinate the work of disabled children and their families who migrated transnationally, migrated internally, or travelled to access services are processed. As they move, they become cases who are moved through the system.

One purpose of institutional ethnography is to make the invisible visible. This requires starting from the detailed accounts of activities and experiences of people, in order to better understand the relations and organization that are present but not directly observable (Smith, 2006). In other words, the detailed accounts provided by informants are not to learn about their inner experiences but rather are an entry point to learn about the ruling relations that shape their experiences (Smith, 1996). This approach, outlined by Dorothy Smith and others, stems from a social ontology (Smith, 2006). A social ontology brings us to see how the social coordinates the activities of people (DeVault & McCoy, 2006). Campbell and Gregor (2008) describe a social ontology as an "alternative way of knowing" (p. 69) because institutional ethnographers work to learn what happens in people's lives and what leads to those processes or interactions. These foundational concepts of institutional ethnography provide a shift in the focus of this study in relation to the literature outlined earlier. By learning more about the social organization (Campbell & Gregor, 2008), or how families' daily activities and interactions are coordinated based on their child's disability or their family characteristics, I mapped out ways in which changes can be made both at the policy and community level.

Research Design

Inclusive Early Childhood Service System Project

My study is part of the ongoing IECSS project. IECSS is a partnership, and the study was designed in response to community partners, who continue to participate in the analysis, mobilisation, and responses to what we are learning. IECSS has been underway since 2013 and as such there is a wide range of research team members, including the partners, collaborators, co-investigators, and advisory committees, as well as more than 100 staff and students, all of whom contribute as part of the governance model designed by the partners in 2013. A full list of the IECSS research team is available on the website (see https://www.torontomu.ca/inclusive-early-childhood-service-system/). The data collection methods were developed through the IECSS project.

In 2013, the IECSS project began a longitudinal study with interviews with families once a year for up to 3 years through a SSHRC Partnership Development Grant (PDG). At the time of the first interviews, families had children who were preschool aged and accessing or waiting for development or disability-related services. The PDG grant was a collaborative effort between the project director, co-investigators, collaborators, and partners in the different communities. The communities represented in the PDG study include Wellington County, Toronto, Hamilton, the District of Timiskaming, and Constance Lake First Nation. Currently, the project is in the fifth year of a SSHRC Partnership Grant (PG). The PG expands on the initial PDG study in several ways. First, participants from the PDG study can continue to be interviewed for subsequent years (IECSS, 2021). Second, the project expanded to recruit a second cohort of participants (IECSS, 2021). Third, in addition to the communities involved in the PDG grant, additional communities have been added to examine differences across Canada (IECSS, 2021). The new communities include Yellowknife, Brandon, Comox Valley, and Powell River. In 2019, the project expanded to include the Region of Peel.

Data collection is ongoing in the communities involved in the IECSS project. Active recruitment for participants ended in December 2022. As of November 28, 2022, 156 families have participated in the IECSS project. Based on the project's interest in early years, recruitment is focused on families who have a preschool aged child at the time of the first interview; and families must be accessing or waiting for development or disability-related services for their child within one of the communities in the study.

Data Collection

Data collection for the IECSS project consists of one interview with each family every year, for up to 9 interviews per family over the course of the study. Data collection for both cohorts is ongoing. In conversation with IECSS Project Director, Dr. Kathryn Underwood, I chose to examine the experiences of human movement, as they were present in the experiences that families have been sharing with the IECSS project. As a Project Coordinator with the IECSS project, I was a part of a team involved in recruitment, interviewing, transcription, data cleaning and analysis. This close relationship to the project and knowledge of the experiences of families provided me insight into that fact that many families had moved. I entered into this project with an interest in transnational migration. However, in dialogue with the team, I became interested in how many families had moved internally to other provinces/territories or communities. Through this dialogue and over time, I came to a place where I was interested in learning more about human movement as a shared experience. To learn from the family informants, I entered into the data first through the institutional maps and interview transcripts. The institutional maps used in the IECSS project provide a visual way to trace the services and interactions with service systems shared by the family informants during the interview. The data is represented along a timeline beginning with the child's birth and traced through to present time. As I continued to learn from the data, I also turned to the attribute tables due to their method in organizing the data. The attribute tables present another approach to organize the data. Data from interviews provides information about the types of services, professionals, frequency of visits, length visits, and distance travelled, for example. This data is categorized within the attribute table for every service and professional families and disabled children have interacted with. The attribute tables help to inform the development of the institutional maps but provide greater details about the different services disabled children and families engage in.

When I entered the project in 2017 data collection was ongoing and the problematic of the intersection of human movement and childhood disability was already emerging in the data. At this time, the research team was collecting data for the first group of participants, cohort 1. The experiences shared by the family informants in cohort 1 encompassed experiences of transnational migration, internal migration, and travelling to access services. In the summer of

2018, the research team began to recruit family informants for cohort 2 and conduct interviews with them, while simultaneously conducting interviews with the family informants in cohort 1. For this dissertation, the data from both cohorts contributed to my understandings of human movement and childhood disability. For the purposes of my analysis, however, I took a more in-depth look at the data from family informants in cohort 2, collected up until June 17, 2020. In June 2020, family informants in cohort 2 had taken part in up to 3 interviews with the IECSS research team. For my dissertation I focused specifically on participants in cohort 2 for three key reasons. First, due to the timing of the interviews the focus was on children who were preschool age and transitioning into school programs. A central focus of the analysis presented in this dissertation is about accessing early childhood education and care services for families and disabled children who have engaged in human movement. Second, data from cohort 2 includes family informants from across Canada due to the addition of communities in British Columbia, Northwest Territories, and Manitoba. Learning from families in different parts of Canada provides a mechanism to better understand how policies and legislation connected to early childhood, education, healthcare, and funding can lead to differing experiences and processes. Lastly, due to the longitudinal nature of the IECSS project, an in-depth analysis of data from both cohorts would be beyond the scope of the dissertation.

The main form of data used in this study is from interviews with parents and caregivers of young disabled children. Interviews typically last 1-2 hours. Interviews require open-ended inquiry, oriented towards gaining more insight into the coordinated activities of the participant (DeVault & McCoy, 2006). The focus of the interviews is to learn how things work from the standpoint of a specific group, the informants. In order to learn how things work, the interviewer focuses on asking about different processes and interactions the informants engage in during their everyday life. In institutional ethnography interviews, the goal of the interviewer is to get a clear account of what happens in the work the participant engages in even if the participant sees it as standard or ordinary (Campbell & Gregor, 2008). For example, when the participant shares information about this work it is important to probe their responses to get a description of what they did, and the steps involved. One distinct feature of institutional ethnographic interviews is that they are "produced by the researcher's developing knowledge of institutional processes" (DeVault & McCoy, 2006, p. 24), allowing the researcher to probe and listen to gain further insight into institutional connections (Please Appendix A for the IECSS Interview Protocol).

Prior to the COVID-19 lockdown in March 2020, interviews predominantly took place in person unless the participant requested a phone interview. In-person interviews took place in various locations such as the participant's home, libraries, community centers, EarlyON centers, coffee shops, and TMU for example. Following the March 2020 COVID-19 lockdown, the research team updated procedures to conduct interviews on the phone. Interviewers on the IECSS project open the interview with a general question asking the participant to tell them about their child. As the informant begins to provide an overview, the interviewers ask prompts to get specific details about the activities the families engage in. For example, they ask for more details about specific interactions, assessments, meetings, and appointments. Learning about these details from the standpoint of the family informants supports the researcher to learn about the ruling relations that shape the everyday actions and decisions of people (DeVault & McCoy, 2006). These ruling practices are in place to coordinate people in the interest of bureaucracies, administrations, and institutions. The analytical focus is on ruling relations to determine how people (caregivers, professionals, etc.) are engaged in institutional processes and discourses that organize their everyday work (DeVault, 2021). Some of these processes and discourses are the result of extra-local forces. Ruling relations are embedded within these processes which are based on particular ideologies that are embedded within systems (DeGeer, 2019). Examples of ideologies can include “good citizen”, “good parent”, or “normal child”, for example. As discussed earlier, institutional ethnography is concerned with how work is coordinated beyond local settings, for example through extra-local settings. Many of the actions that occur in local settings are connected to these extra-local forces and settings (Campbell & Gregor, 2008). Examples of extra-local forces include government and policies. Smith (2005) discusses how ruling relations are the result of these extra-local forces. Put more simply, ruling relations support us in explaining how one institution or organization organizes the work of another through texts (DeGeer, 2019). For example, we can look at how the work of one agency structures the work of another, through referrals for instance.

Again, it is important to acknowledge that we are all participating in these ruling relations without knowing, as they may appear to be invisible. One goal of this research project is to explicate how ruling relations shape the service access experience of families who have migrated or traveled for services and have a disabled child. The knowledge families and caregivers have about their experience with different services and programs can help to track what is actually happening in the processes of ruling. The methods used by the IECSS project to learn more about what is happening and how it happens through prompts helps to get accounts from family informants about different processes they engage in.

Central to this process of getting more details from the family informants during the interview process, is learning about the work they engage in during their everyday lives. Questions focused on service coordination, communication between professionals and services, referral pathways, and getting information to support their family and child, for example, are centered on gaining a more detailed account of the work families and disabled children engage in. The concept of work in institutional ethnography differs from our common understandings of the term. In IE, work does not only capture paid labour people engage in. Rather, work, as described by Smith (2005), is “anything done by people that takes time and effort” (p. 151), including things “that they mean to do, that is done under definite conditions, with whatever means and tools, and that they may have to think about” (p.151-152). DeVault (2021) further explains that people do work in their everyday lives. They learn to know how to do this work, with knowledge being gained in different ways and implicitly from previous experiences. To gain a better understanding of the visible and invisible work families engage in, the researcher listens to specific words, discourses, and activities (Ion, 2021). Gaining this knowledge from the standpoint of the family informants is central in learning about the everyday lives of disabled children and their families who have engaged in human movement.

As the details begin to emerge, the interviewers aim to fill in the blanks by asking which professionals were present, what the results were, and what the next steps are. These prompts help to build the account and get further details about the work people do, as discussed above, and learn about the textual records. Learning about texts is an important component of institutional ethnography. Campbell and Gregor (2008) describe texts as a way to create “organizational versions of what people say, do or know for organizational action” (p. 25). The power embedded in these texts becomes the groundwork for further action and support the invisible work to actually happen. DeVault (2021) also highlights that there is a hierarchical nature to texts: those developed by people in higher positions control the texts developed and used within frontline work. However, this hierarchy is also an example of what may be seen as invisible within the processes families and disabled children engage with in their everyday work.

During the interview, the interviewers ask participants specifically about any textual records that have been produced. Examples of textual records include intakes, application forms, meetings, assessments, reports, medical exams, and other documentations produced about the child or family. While disabled children and families are engaging in movement, it is important to ask whether the textual records are moving as well. Engaging in this conversation allows for the examination of how textual records are produced and used, as well as who is doing the work to coordinate and communicate the information in the textual records. While the participant discusses their everyday activities, the interviewers continue to prompt the participant to share these details and get a full account of the work that families and disabled children are engaging in. In the process of getting this account from the informant, knowledge about the institutional processes become clearer.

Following the interviews, the IECSS project team transcribes the interviews. The transcripts are then used to produce attribute tables and maps for each participant. Attribute tables developed by the IECSS research team help to organize the interview data through the categorization of interactions with different organizations, services, activities, and professionals. An attribute table is developed for each participant and updated by the research team following each interview. Details such as where the service is, when it was accessed, the frequency and duration of the interactions, cost of services, and the transportation required are recorded in the attribute tables. The different texts or textual records that have been produced and shared with the interviewers by the informants are outlined in the table. The attribute table is then used to create an institutional map, which I will describe further in the data analysis section. The institutional maps consist of information about type of service, professionals, textual records, referrals, and significant events or transitions. These different forms of data were included in the analysis for this study.

The attribute tables and maps produced by the IECSS project, are key mechanisms to organize the information and to “see” the experience from a new standpoint. Through the attribute tables, the IECSS team organizes the detailed accounts of interactions with any institutions that families can remember. These accounts are then “mapped” in a visual representation over time of families’ engagements, including formal and informal texts that are part of the institutional process. Examples of texts related to human movement include permanent residency and citizenship applications, medical cards for universal healthcare, travel grants and documentation, child and family files, and re-assessments. When considering the intersection with childhood disability other texts, such as assessments, reports, strategies, diagnoses, medical tests, and plans are also discussed by family informants. The approach to considering texts in an institutional ethnography differs from other methods (Kearney et al., 2019). Rather than engaging in a discourse analysis of the text, for example, the institutional ethnographer is interested in examining the context in which the text is used and the processes it is involved in (Kearney et al., 2019). It is the researcher’s goal to learn how words used in texts are central in organizing people’s everyday work (Smith, 2021). Words used in texts can place boundaries or work to categorize and sort people. As Smith (2021) states, “generalizing categories and concepts of the relevant institutional texts organize what people do to coordinate with others engaged in and with the same sequence” (p. 69). The categorization and boxing in of people, done through forms and institutional processes, can displace the depth of the actual experiences people have (Smith, 2021) by pulling out the information the institution requires, rather than looking at the full picture of the experiences people have. Further, these institutional categories and terms begin to define and organize people's everyday work.

In this dissertation, I am focusing on the engagements and texts as they related to human movement. Text-mediated practices refer to the interactions that happen between people through texts. Campbell and Gregor (2008) describe text-mediated processes as the work that is happening through these different texts to process people, control people, and to suppress subjectivity. When considering the way these processes and texts are set up, we can begin to see how the complex and messy realities of people's everyday lives are not being addressed by institutions. Moreover, Turner and Bomberry (2021) point to the fact that texts used by institutions are not always culturally appropriate. Through a greater understanding of texts and the words used within texts, we can work towards exploring ruling relations. Learning about how the textual records are produced, used, and shared can help to learn more about institutional governance. When considering the research problematic and the intersection of human movement and childhood disability, the textual records described by the family informants help to gain insight into which texts lead to or support movement, emerge during and after movement, and are required for movement. The connection between these texts and how these texts then coordinate further activities can also be elucidated from the accounts provided by the family informants. In these accounts, we also gain knowledge about qualifying criteria connected to the intersection of human movement and childhood disability, which impacts the services children and their families can and cannot access in some circumstances.

During the interviews, family informants are also asked to complete a demographic questionnaire. The demographic questionnaire has data such as number of siblings, work situation, how long they have lived in Canada, how often they have moved in the past 3 years, income, education, language, and race, for example. The information provided in the demographic questionnaire supplements the interview data.

Inclusive Early Childhood Service System Family Informants

For my dissertation, I engaged with interviews conducted by the IECSS research team. Based on the emerging problematic of human movement and disability from the interviews, I specifically engaged with data from 66 informants across the different communities in the project. Due to the timing of my dissertation, I only worked with data collected prior to June 17, 2020. Based on this timing and the interviews conducted, I examined 143 interviews. Interview transcripts, maps, and attribute tables from these 143 interviews were analyzed for the purposes of the current study. Table 1 provides a summary of the communities the informants lived in at the time of the interviews. Several of the communities that are a part of the IECSS project are in Ontario, Canada. However, they encompass large metropolitan centers, smaller rural communities, and Northern cities. The remaining communities are based in Western Canada. Similarly, these communities have different geographic properties such as being smaller cities, remote locations, or more Northern cities. During the initial phase of data analysis, I read through maps and attribute tables to learn about the types of human movement experienced by the informants. Then, I read through interviews to get more information about this human movement and to learn about the differences between the participants who had informed us about their experiences with human movement and those who did not. Table 2 provides a summary of how many participants engaged in the different forms of human movement. For the analysis of the data, the context about the different forms of human movement engaged in highlights the pathways of human movement that occur and more generally the extent to which the family informants in the IECSS project were mobile.

Table 1:

Location of IECSS Project Participants in Cohort 2 Who Have Migrated (Transnationally or Internally) or Travelled to Access Services

Community	**Number of Participants**
Brandon (MB)	8
Constance Lake (ON)	1
Comox Valley (BC)	3
Hamilton (ON)	5
Non-community	1
Region of Peel (ON)	7
Powell River (BC)	5
Temiskaming (ON)	5
Toronto (ON)	20
Wellington County (ON)	5
Yellowknife (NWT)	6
Total	66

Table 2:

The Number of IECSS Project Participants Based on the Type of Human Movement They Have Participated In

Type of Travel	**Number of Participants**
Transnational Migration Only	11
Internal Migration Only	2
Travelled to Access Services Only	30
Transnational Migration and Internal Migration	5
Transnational Migration and Travel to Access Services	4
Internal Migration and Travel to Access Services	11
Transnational Migration, Internal Migration, and Travel to Access Services	3

As Table 2 indicates, some participants engaged in a single form of human movement, whereas others engaged in two or all of the forms of human movement that are central to this dissertation. For example, some families first moved to Canada from another country (transnational migration) and then moved to a different city in Canada (internal migration) later. Approximately, one third of the participants engaged in multiple forms of travel.

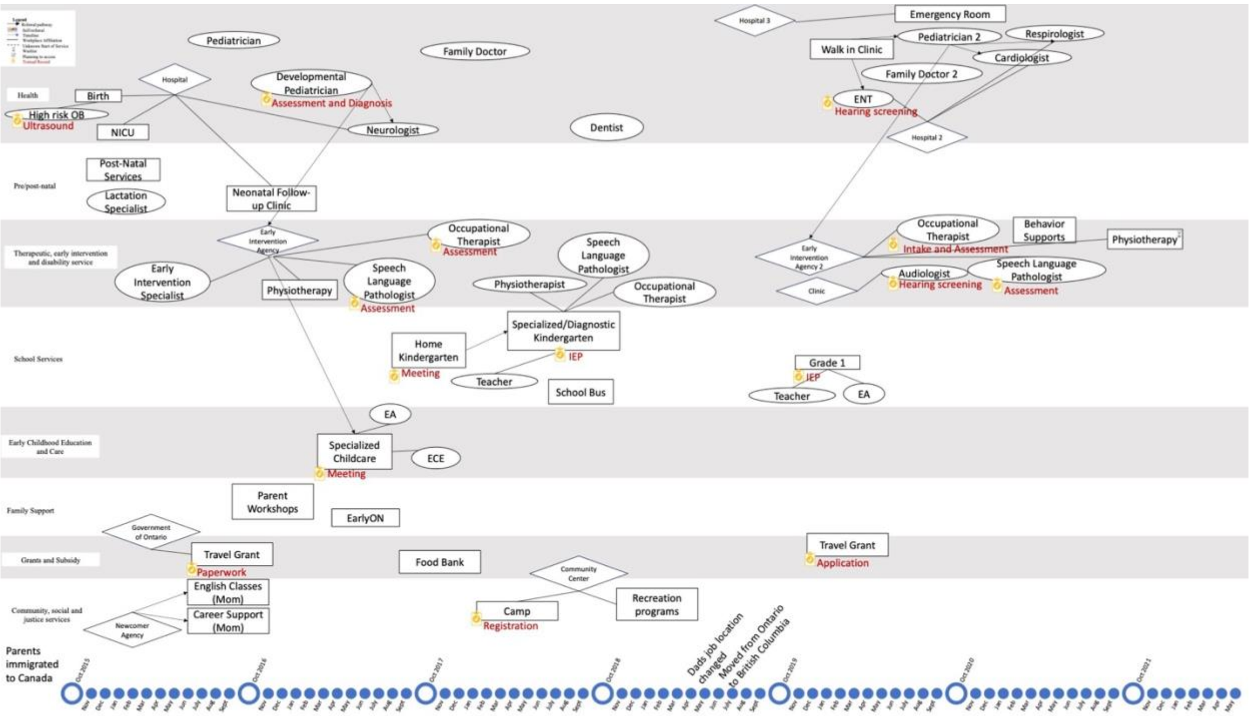
Data Analysis

For my dissertation, my focus was on engaging with a particular problematic that emerged from the data and taking an in depth to look at experiences of human movement in relation to disability, as discussed by the research informants. As I engaged with the data, I learned more about the different types of human movement that were present in the data and shared by the research informants. Detailed accounts provided by families were analyzed to learn about human movement related to accessing early childhood, disability, and education service systems. In this analysis, I examined how human movement, such as migration or travelling to access services, impacts the different processes and work families engage in. The core concepts of institutional ethnography, such as ruling relations, work, and texts will be central to the data analysis. The interviews provide the data for me to analyse the experiences of human movement (migration and travelling to access services) and early childhood disability as it is organized by institutions. As I engaged with the attribute tables, interview transcripts, and institutional maps I was able to learn from the informants about their movement and see which families engaged in or did not engage in this type of movement. An analysis of the institutional maps, attribute tables, and interview transcripts helped me to see the work disabled children and their families, and to track the texts and ruling relations related to the intersection of human movement and childhood disability. Below, I will start by outlining the central role of institutional maps in my data analysis, connecting back to concepts from institutional ethnography. Then, I will discuss the general area of focus of analysis for institutional ethnography along with the techniques I used to conduct my analysis.

Conducting an analysis for an institutional ethnography can take many forms. Here I will outline some of the strategies that I employed throughout my analysis. Data analysis began by using the techniques of institutional mapping (see Underwood et al., 2019b). Mapping allows the researcher to present a visual display of the findings. The institutional maps are generated using the attribute tables. Both attribute tables and institutional maps helps to see the work of families and institutions, and to track the texts and ruling relations. To start the mapping process, ruling relations are tracked based on the work described by the participants. By starting from people's everyday accounts, the maps begin to reveal ruling relations and make the invisible visible. Drawing on concepts from institutional ethnography, the IECSS project has developed institutional mapping techniques to learn about the types of work disabled children and their families engage in while navigating different systems. Further Underwood et al. (2019b) discuss how this type of mapping, which focuses on work sequences, can provide researchers "the ability to gain deeper understanding of the complexities of socially organized experiences by revealing the invisible (or text-based) processes of institutions" (p. 134-135). The maps generated from the data, using PowerPoint, take up a particular standpoint; for the IECSS project this is the standpoint of the family members who are interviewed (Underwood et al., 2019b). The maps represent the work and activities that are described from the standpoint of the families. In Figure 1, I have provided a generic map using the different elements included within the maps that are generated for each family informants.

Figure 1

Generic institutional map showcasing the elements used within IECSS participant maps



The IECSS institutional maps represent 8 categories of services: (1) health; (2) pre- and post-natal; (3) therapeutic, early intervention and disability services; (4) school services; (5) early childhood education and care; (6) family support; (7) Grants and subsidies; and (8) community, social, and justice services, as shown in Figure 1. A timeline at the bottom of the map starts with the child's date of birth and progresses forward as the child gets older. Within each category, agencies, type of program, personnel, and textual records are presented. Further, information about referrals between professionals and organizations, and self-referrals are shown. The words and visuals on the maps show what is happening in terms of social relations and practices using words and/or diagrams (Rankin, 2017). The IECSS project team develops a map for each participant, which is updated yearly by the research team, highlighting the different work they have engaged in, the texts involved with the different processes and work, and the ruling relations that are operating. The ruling relations are observed through the different pathways that emerge on the map. For example, the red text indicating a textual record is conducted by a professional, who uses the results to send the child to another institution or professional, indicated by the arrows. This pathway illustrates the ruling relation or dominant discourse of the need for a textual record such as a diagnosis to gain entry into other services and supports.

The mapping process is a helpful analysis strategy to show the coordination that is happening within texts and practices. Moreover, maps can support our understanding of work organization, works sequences, and how texts are connected to them (Turner & Bomberry, 2021). For example, sequences are visualized through arrows indicating referrals from one service to another. Another way this is represented is through the red text and yellow graphic indicating that a textual record such as an assessment or diagnosis was produced. By mapping out what is happening and laying on the textual records, we can begin to see what is going on before and after the activities described by participants. Further, the mapping process can reveal areas that need to be examined further (Dalmer, 2021).

In the current study, I examined the institutional maps to learn about institutional responses to human movement and childhood disability, and the work that is being asked of families. When I was examining the maps, I was specifically looking for the work families and disabled children engaged in, the ruling relations, and textual records that were required, produced, and moved. DeGeer (2019) describes the mapping process as iterative and a method to examine the different processes and experiences people engage in and how they connect to other processes and experiences. For example, if a child was diagnosed or assessed in their home country, it is important to examine how Canadian organizations use this information. How do they take up the work that has already been done by families in other countries or communities and what further work does the family have to engage in following migration to gain access to supports for their child? Institutional maps provide a visual way to look at the different interactions and what is being asked of families. Starting with the maps allowed me to gain a greater understanding of these processes so that I can further explore them in the subsequent analysis. The maps need to be connected back with the accounts provided by the participants to provide more depth to the analysis (Turner & Bomberry, 2021). Following an examination of the maps, I took this next step to gain a deeper understanding of what the maps revealed by going into the interview transcripts. In the findings section I will provide specific accounts and quotes from family informants to provide a deeper understanding of the work they engage in during their everyday lives.

The work that is described and the discourses that operate in the accounts provided by families are central areas to keep in view during data analysis. The work that is detailed by participants directs the analysis towards making visible the activities that shape and are shaped by ruling relations (McCoy, 2006). Guiding questions focus on the activities families describe in relation to the work they do and what is involved in that work. Some examples of the guiding questions for the interviews conducted by the IECSS project focus on getting information about how families get connected with professionals and services and then asking, “what happened next”. Through the guiding questions, interviewers try to gain more detailed information about the different institutional interactions families engage in. By focusing on the work families engage in during their everyday life, we can develop a better understanding of what they do. Furthermore, these accounts bring forward the institutional sites where the experiences are located. As I better understand these activities and institutional sites, I will also be trying to uncover how discourses operate in people's lives (McCoy, 2006). Analyzing the data helped me to better understand the ruling discourses taken up by families of disabled children and how they impact how they talk about their experiences and how they know the information they know. During this process, I also examined the differences between participants in their degree of participation in these ruling discourses, such as the medical model and standardized understanding of development, and which characteristics or circumstances might impact this participation. To gain a thorough understanding of this in my analysis, background knowledge such as emerging theory and literature about different discourses that are present within early childhood, disability, and education service systems in relation to families who have migrated or travelled to access services is required. Using work and discourses as central concepts allowed me to reveal and analyze the ruling relations of human movement and childhood disability in the accounts provided by family informants.

During the initial read through of the attribute tables, maps, and transcripts, I adopted a strategy suggested by Rankin (2017), namely, to "elicit a conversation with the data" (p. 4). I adopted this process by making notes on the maps where I saw the emergence of social relations, ruling relations, and text mediated relations, along with questions I have. These early readings of the attribute tables, maps, and transcripts helped me to see the work being done and the invisible work that we don't always see. The goal of analysis in institutional ethnography is to discover the ruling relations. In order to systematically analyze the ruling relations, I used NVivo to index and then organize the writing accounts.

In this dissertation, different strategies helped to illuminate the ruling relations, institutional processes, textual records, and social relations involved in accessing services for families. Using NVivo I set up a running record to build the data set of ruling relations. Indexing helped to organize the ruling relations and writing accounts provided specific accounts and details from the data set that reveal those ruling relations. Rankin (2017) describes indexing as an analytical tool that helps to prevent the researcher from falling into a thematic analysis. Indexing helps to discover the linked practices or to notice the social relations (Rankin, 2017). The indexing process works side by side with institutional mapping as it helps to see linked processes. Following my initial examination of the maps, I turned to the transcripts and began to index using NVivo by setting up a running record of the linked practices and social relations that were emerging from the accounts provided by family informants. For example, based on the experiences of family informants, the importance of citizenship status emerged as a ruling relation. Under this ruling relation, I began to make linkages to the different systems in which citizenship status was implicated and the role it played in the institutional organization of disabled children and their families. The goal of indexing is to discover relationships and learn when, where, and by whom social relations and texts are activated (Rankin, 2017). For example, looking at the ruling relation of citizenship status, I began to outline the different textual records related to gaining citizenship status as described by the family informants, and the textual records that were required to fill out as a result of not having citizenship status. Then, based on the participants' experiences, I wrote up descriptions of their work and the hidden institutional processes (Rankin, 2017). Writing multiple accounts helped to examine if the different accounts are linked by the "overarching texts and practices that ruled" (Rankin, 2017, p. 7) and how the process proceeded. Mapping, indexing, and written accounts all focus on starting from the experience of those whose standpoint you are interested in and then working to bring in broader organizational and institutional elements that are implicated in these experiences. These accounts reveal different tensions, but ultimately, they help to describe the institutional processes involved in the experience.

Overall, the data organization methods of attribute tables and institutional mapping from the IECSS project were central components in the data analysis process. Turning to the transcripts and developing written accounts of the work and texts that I saw and tracked led to several key findings about the intersection of human movement and childhood disability. The process outlined here for analysis can be considered as a part of the dialogue I engaged in. I started by listening to the family informants to gain an understanding of the research problematic from their standpoint (Smith & Griffith, 2022). As I move into Chapter 4 and 5, I will engage in a second dialogue with a focus on bringing together what I have learnt across the informants and provide an ethnographic account to tell the reader about the experiences of disabled children and their families who have engaged in human movement.

Ethical Considerations

The IECSS project initially received ethics approval from the Toronto Metropolitan University (TMU; formerly known as Ryerson University) Research Ethics Board (REB) in 2013. Once REB approval from TMU was obtained, the research team completed the ethics requirements for the other institutions connected to the research project. Currently, the IECSS project has REB approval from 8 institutions across Canada. The REB process requires ongoing renewals across these different institutions. The IECSS project also has ethics approval from numerous organizations that have agreed to help with participant recruitment. Prior to working with the data for my dissertation, I worked with IECSS research team members to complete the REB process at Brock University. The initial approval from Brock University was in May 2021 and the ethics application was renewed in April 2022. I was also added to the TMU REB application as a student researcher by the IECSS research team.

According to TCPS-2 guidelines, vulnerable persons are those who face social or legal stigmatisation based on their identity. It is important to note that TCPS-2 (Government of Canada, 2018) states that belonging to one of these groups does not mean that they should be excluded from research studies. Rather, we need to consider the vulnerability of participants in the context of the research. Based on the approach and methodology of the IECSS project, research participants are considered informants. The project aim is not to study the participants as such; rather, the focus is on learning from the informant's standpoint about institutional processes. Thus, although on paper participants in the study come from different groups who are considered "vulnerable", the research participants in the IECSS study should be viewed as informants, whose standpoint informs us about institutional processes.

Based on TCPS-2 guidelines, the research procedures are important to consider in relation to the ethics of the project. The consent form (attached in Appendix B) provides an outline of the project, the questions that will be asked in the interview, confidentiality procedures, risks and benefits, and voluntary participation. Participants are asked if they agree to participate, be audio-recorded, and contacted again the following year for another interview. Processes to maintain confidentiality are explicitly outlined in the consent form. Some examples of the processes in place include the use of participant codes and code names, to help mitigate some risks for participant identification. Further, during data collection, the COVID-19 pandemic occurred. Due to the restrictions and subsequent changes developed by REBs across Canada, the IECSS project shifted from conducting in-person interviews to phone interviews. Ethics approval was sought out to make this change and additional processes were developed by the team to ensure participant confidentiality. The data I engaged with in this dissertation comes from interviews that were done prior to and during the COVID-19 lockdowns. Interviews that occurred prior to the lockdown happened in-person or on the phone. During the lockdown, the IECSS team conducted all interviews over the phone in line with the REB amendment. As a part of the interview process, each participant receives a $30 gift card as an appreciation for their time. Prior to the transition to phone interviews, gift cards were provided in person prior to starting the interview. Following the changes in procedures due to COVID-19, gift cards were sent out by mail following their interview.

In addition to consideration of ethical guidelines outlined by TCPS-2, it is also important to consider the ethical practices the research project engages in. As described earlier, the work of the IECSS project is driven by community interests. The partnerships with communities and community organizations (see consent form in Appendix B for list of partnerships) allows the researchers on the team to share back with people who make decisions about services and policies. Reporting back to communities includes presentations, written reports, and consultation meetings, for example. From an ethical standpoint, this mechanism ensures that the experiences of family informants are shared back directly to the communities they are accessing services in. Further, due to the longitudinal nature of the study, subsequent interviews provide an opportunity to share back what we learned from the family informant the previous year and fill in any gaps or clarify information as needed. From an ethical perspective, this approach helps to ensure that what was recorded by the research team is valid from the standpoint of the family informant. Another process embedded within the project is to share back the work of the project and the emerging findings through the project website. The research team regularly updates the project website with the activities of the project, including publications, reports, policy briefs, podcasts, videos, and events connected to the project. The website information is also shared with family informants during the consent process prior to the interview and with the gift card sent out following the interview. Further, the governance structure of the project includes communities and researchers. This structure ensures that decisions about the project are made in dialogue with these different groups rather than by a single decision maker. Due to the longitudinal nature of the study, these decisions can be revisited as the study progresses and updates can be made as needed.

Chapter 4: Findings

In this chapter I will be presenting six key findings that emerged through an analysis guided by institutional ethnography focused on the intersection of human movement and childhood disability. The analysis, as described in Chapter 3, included an examination of institutional maps, transcripts, and attribute tables. As I engaged with the data, there were overlaps and differences in experiences for those who have migrated transnationally, migrated internally within Canada, and travelled to access services. The experiences shared by the family informants provided an entry point to learn more about the intersection of human movement and childhood disability.

In the previous chapters I provided an overview of the research framework and methodology which grounded this dissertation. As noted, three key goals of an institutional ethnography include learning how things work, discovering how activities are coordinated, and making the invisible visible. As I detail the key findings below, I have three aims, including 1) detailing from the standpoint of the family informants the processes involved with human movement in relation to childhood disability, 2) providing accounts from the standpoint of the family informants focused on the coordination of activities, and 3) understanding disabled children and families' everyday activities to make their invisible work visible.

As I provide an overview of the findings below, it is important to keep the research problematic in view.

> What do the everyday experiences of disabled children and their families tell us about the role of human movement (transnational migration, internal migration, or travel to access services – both forced and voluntary) in accessing and navigating early childhood, disability, and education service systems?

The six key findings include: 1) Migration and travelling: What is the context of human movement and childhood disability? 2) People move, texts stay still; 3) Duplication and replication of services across different communities; 4) Formal and informal support networks: Making it work when you're mobile; 5) The importance of gaining perceived and official citizenship status; and 6) Restarting the process: The added work on families and disabled children. Below, I will present these 6 findings using examples from the institutional maps and accounts provided by the family informants. The key findings discussed here will then be further examined in chapter 5 by bringing together the accounts provided by the family informants and key concepts from institutional ethnography.

Migration and travelling: What is the context of human movement and childhood disability?

One of the findings that emerged during analysis includes the general processes that are connected to the intersection of human movement and childhood disability. These processes connect to family and child characteristics, as well as characteristics of the types of services. For example, seeking out opportunities and where disabled children and their families live are key factors linked to human movement. Further, the institutional processes disabled children and families must engage in when there is human movement emerged in the accounts provided by family informants. The processes and factors I will discuss further include what leads to human movement, where a institutions families engage, and what the travel looks like.

Who is mobile?

When considering who is mobile, there was some overlap in characteristics between the different types of human movement: transnational, internal, and travelling to access services. While engaging with the data from the maps and transcripts, particular circumstances or characteristics emerged as being linked to human movement. Table 2 (Chapter 3) provides an overview of how many family informants in cohort 2 described experiences of human movement, including transnational migration, internal migration, and travelling to access services.

Families we spoke with had a wide range of interactions with migratory processes depending on how they began their journey and the information shared in the process. For example, the processes involved in moving across national borders differ from those associated with moving across provincial or municipal borders, but there are also similarities. There are also shared motivations for these types of migration such as job opportunities. For example, many family informants first discuss transnational migration to Canada due to the discourse of the potential of job opportunities, followed by internal migration within Canada as they begin to learn about opportunities for jobs in other parts of the country. Internal migration in these situations included both within the same province they initially moved to or to a different province in Canada. The longitudinal nature of the IECSS project allowed for yearly follow-up with participants. Through these yearly interviews, the mapping of families movement as their child got older made visible the many forms of human movement they engaged in. In Table 2, for example, 23 of the 66 family informants engaged in multiple forms of human movement over time.

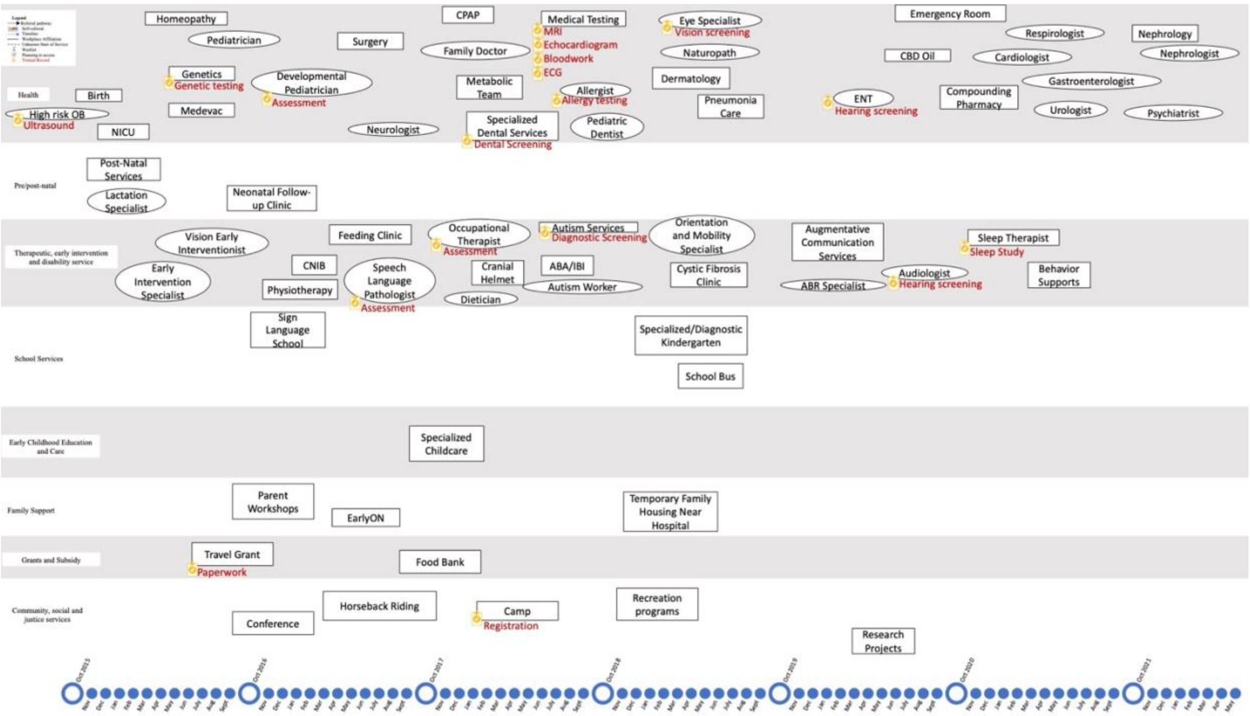
In addition to discussions focused on transnational and internal migration, family informants described their experiences travelling to access services outside of their home community. When family informants discussed travelling to other communities to access services, particular pathways of travel emerged. First, many families who were asked to travel to access services lived in rural, remote, or small communities. For example, all the family informants in Comox Valley, British Columbia and Yellowknife, Northwest Territories described that they travelled at least once to access services. Second, there were some families who lived in urban cities but travelled to access services. Examples include travelling for specialized childcare, schools, or prenatal services. Many times, this travel was from one urban city to a neighbouring urban city, for example from the Region of Peel to Toronto or from Guelph to Hamilton. Third, some of the families described finding services in other communities that they wanted to access and choosing to travel for them. Overall, 48 of the 63 family informants discussed travelling to access services. For some this was the only form of human movement, but others also described other forms of human movement such as internal or transnational migration in addition to travelling for services. The services that did not require referrals, typically private services, were accessed by some of the family informants. This option of choosing to travel, however, is not available to everyone due to factors such as knowledge of services, income, available transportation, funding, and access to insurance.

What leads to human movement?

Gaining an understanding of who is mobile sets a foundation to better understand the intersection of human movement and childhood disability. However, for the purposes of this study, gaining insight into why disabled children and their families are mobile helps to make visible the set of characteristics that are structurally built in and supports our understanding of the organizational framework for human movement. Within the accounts provided by family informants, several reasons for transnational migration, internal migration, and travelling to access services emerged. A map summarizing the programs, services, professionals, and textual records connected to this human movement is provided in Figure 2 below.

Figure 2

Institutional map showing services and professionals family informants described when travelling to access services.



Family informants frequently told us that they moved to Canada or internally within Canada for reasons, such as better opportunities relating to work, school, or to life more generally, and due to relationships, such as joining or leaving a partner or family members. Through an analysis of the stories, an institutionally produced narrative for transnational migration emerges. The family informants in this study present a complex description of human mobility. International migration is situated within an active discourse of Canada as a good place for opportunities, being safe, and being a good place to have a family. This discourse is shared through institutional discourses coming from family, friends, media, government, and advertising. One family informant described their experience in Canada and the need to make it in Canada now that they have decided to settle here:

> P01: Basically I didn’t gave up at that time like. I had no options to either move back again. But again when you think that you have chosen a particular path, you have chosen a particular country, to make your career, to make your life and it was not working out. It was tough at that time but yeah, like I think so like I stayed positive and that—that was going on, yeah.

In this quote, the family informant describes how they need to move forward with their decision of being in Canada because it was a path they chose regardless of any difficulties that have emerged. Through an analysis of the institutional maps and attribute tables, we begin to see the similarities in transnational and internal migration. Both forms of human movement are connected back to access to opportunities and relationships, or more generally to the view of seeking a “good life,” the articulation and elaboration of which emerges through social and media discourses.

Seeking opportunities for a “good life” also connects to finding housing in Canada and moving internally for this purpose. Housing was described as a reason for people to move internally in Canada. Housing waitlists and availability differ across communities in Canada. Some family informants describe being put in a position where they have wait for housing in their current community or move to another community to gain access to housing. The waiting period to get housing in their home community can push them to seek housing opportunities elsewhere, as reflected in the following exchange:

> P02: P: I was living in Selkirk at the time, but we had no place to live at the time. So, we were waiting on housing. Yeah, so that’s why we ended up in Brandon.
> I: Because you were able to find house in here?
> P: Her dad had a friend out here, and we got to stay with them until Emma was about 5 months until we got into housing finally. But it was lot better than the year and half wait, that they told us. It would [be] for Winnipeg and Selkirk. Unless, I want to go into the north end, and then, that was just, I grew up in there, this is not an option, where they wanted to put us, because I’m Native they were trying to put us in Native housing. I just didn’t. Didn’t want my kid to deal with that hassle just because you know we don’t look it or act stuffs like that. So the hassle.

During the process of seeking adequate means of living, such as housing, jobs, and security, people are asked to complete different forms and applications. Checking off certain boxes such as indicating the number of children you have, or marital status can then begin to shape the process of movement. The process of moving and finding housing also involves being added to waitlists and factoring in the amount of time you have to wait to get to an adequate means of living. The long waitlists and institutional constraints presented play a central role in the decision-making process of engaging in human movement.

One of the other factors connected to human movement was fostering and adoption. The data revealed how institutional processing of foster children led to human movement between different communities. The result of this human movement will be discussed later in the findings section.

The reasons for disabled children and their families' travel reflects different institutional needs. For example, disabled children and their families who live in larger urban cities are asked to engage in long distance travel to access services. A key reason for this travel for services, as described by family informants, was to access specialized childcare and kindergarten programs. Although this travel may be framed as being the choice of the parents, the way in which the education system organizes disabled children into separate specialized programs can lead families to "choose" a program that is further away from their home. These situations present an example of the "fallacy of choice" (Underwood et al., 2019a). Acceptance into a specialized childcare program does not always guarantee that the family and child will decide to engage in the travel to access the service. Rather, the travel time and distance can deter families from agreeing to send their child to a specialized program, as suggested in the following informant's account.

> P03: P: Yeah, so we kind of school board shopped, or school shopped. We considered—we applied for a program at [Specialized childcare in a children's rehabilitation hospital]. So we applied there, got accepted to an interview. Went to the interview and I left it thinking, nope, that's not…
> I: Mhm. Why?
> P: It was partly logistics. It was partly that my daughter would be commuting. Again, commute to Holland Bloorview. I wish Holland Bloorview as a regional rehab and therapeutic centre for the city would have more satellite sites. Anyway, that's a different story but related.

Despite living in a large urban center, specialized programs still require disabled children and their families to travel long distances, restricting access to specific programs. However, in the accounts provided by family informants we also learn that some "choose" to send their child to a specialized program that is outside their community even when transportation is not provided by the service:

> P04: She goes to [specialized nursery school] in Etobicoke but because we live kind-of outside of their catchment area, it's actually pretty inconvenient because we don't have access to their bus service and it's—but it's actually been amazing because before we were getting occupational therapy through 3 different service providers, all like once a month and then it was just like, it was essentially a waste of time because like you, know 2 and a half year old seeing an occupational therapist through the LHIN for like I don't remember what other service—I think [Specialized Childcare] also gave us access to OT and through—you know it just wasn't—like we weren't seeing progress.

Although the processes in place may prevent access to the transportation services and the long distance to the specialized program, some family informants describe the program as being beneficial for their child. The descriptions provided by family informants suggest that they find ways to attend services outside of their community due to preferences for a particular service or due to the lack of availability in their own community. In these situations, family informants find their own pathways to attend these services, such as setting up their own transportation because they do not qualify for transportation. The two examples of institutional processes provided here are based in large urban cities where there is a fallacy of choice regarding the decision to have a disabled child travel a longer distance for specialized childcare services. However, based on the institutional requirements and how institutions group disabled children and their families, decisions about engaging in the process of travelling to access services can differ.

Bureaucratic processes and institutional constraints also lead to human movement. This human movement occurs for those in rural and remote communities, as well as some urban cities because large facilities such as hospitals with specialized care are in large urban centres. The result is that disabled people have to travel more to get access. This has challenges specific to each person's experience, but transportation, funding, and even relationships, such as those involving family and paid caregivers, are impacted by this travel. Non-disabled people do not have this level of institutionally driven travel, which means that, locally, most services, such as early childhood education and care, don’t take this into account. An example of this is travelling to access services such as pre-natal and childbirth services. This human movement occurs for those who live in rural, remote, small cities, as well as those who live in larger urban cities. Although this experience is more common for those who live in rural, remote, and small cities, families from larger urban cities may also travel to other urban cities because their community does not have the required specialized medical services or hospital infrastructure. The institutional maps help us to trace the organization of people through bureaucratic processes when there are special circumstances or complications during the pregnancy or birth of a child. One map that provides an example of the pathways comes from Comox Valley, British Columbia. This small city does not have all the specialized pregnancy and birth services a larger city may have. The IECSS project mapped the institutional interactions that coordinate actions around pregnancy, childbirth, and post-natal care of infants and mothers. When examining the institutional maps across the communities, we can see the referral pathways. For example, following visits with a local healthcare professional, family informants describe being referred outside of their community for tests (such as ultrasounds) or specialized healthcare professionals (such as a high-risk OB/GYN). These visits can lead to subsequent referrals in the community they travelled to, or they may be asked to travel to another community.

Although the experiences of families may differ due to the organization of them into demographic groups (e.g., programs for low-income families), the institutional interactions that occur during the different timepoints of pregnancy and childbirth are important to examine. Family informants in the study describe complications during pregnancy or a history of medical circumstances that require a specialized OB/GYN or other medical exams. For example, referral pathways for those who live in smaller communities begin with an initial referral to a specialized OB in their own community but are then further referred outside the community for care. Due to establishing a connection with a specialized OB outside of their home community, the institutional maps show that the coordination of interactions leads to also accessing care for the child's birth in the other community, with ongoing access to services outside of their community, which becomes more evident due to the longitudinal data and follow-up with family informants over time. This ongoing travel outside of their home community and resultant institutional interactions, such as coordinating appointments, transferring textual records, and follow-up appointments and assessments, are a consequence of the role of the specialized OB they were initially sent to.

Following the birth of the child, circumstances such as a pre-mature birth or complications during birth may lead to a stay at a neonatal intensive care unit (NICU). However, not all hospitals have a NICU or a NICU with the capacity and ability to care for all children. While this is especially true in rural, remote, and small cities, this situation has also been described by families who live in larger cities. As evidenced in the following account, in some of these situations, the family may be transferred or referred to a different hospital for the birth:

> P05: I: At Sunnybrook [large research hospital in an urban setting], and was that – you live in Brampton [a suburban city], why was, can I ask you why you went to Sunnybrook?
> P: Well when I went into labour at Brampton Civic, which is the nearest hospital they told me due to my gestation, they're a level 2 hospital, so I was a transfer to Sunnybrook.
> P: So at Sunnybrook, in our, like in his patient room and then Sunnybrook is also equipped, they have two what they refer to as family rooms, so their larger rooms kind of look like studio apartment, has a kitchenette like you might have a kettle then you have a full, actual bed because I'm almost six feet tall and I was sleeping on a bench that was probably five foot six or something for like 4 months.

While the family informant stayed at the hospital with their child for the first 4 months, their partner travelled back and forth between Brampton and Toronto to be with their family. In other examples, children are transferred to a different hospital following birth because the hospital determines that they are not equipped to support the child. Institutions may also make the decision to move the child without also moving the parent or family with the child.

Through an examination of the institutional maps and transcripts, what emerges is a story about institutions, such as hospitals requiring people to come to it, rather than going to children and families. This happens in rural and suburban settings when children are seeing specialists. These specialists may be the first people who tell them about disability and may be critical to the children staying alive. But the effect is that the family members may be moving. In many cases we heard that mothers stayed in hospitals far from their homes. The movement to the hospital may have disconnected them from their children; for example, one mother told us that the ambulance did not have equipment to transport her and her child together. Further, once this movement has been initiated at birth, disabled children and their families continue to be directed by the institution to engage in ongoing travel to access services.

The experience of accessing specialized or niche services is another reason for travel described by families. There are a range of services disabled children and families travel for, including healthcare, disability and early intervention, school, early childhood education and care, family support, and social and community services. In Figure 2, there is a breakdown of services under the different categories that have been discussed by families in relation to travelling to access services. For some of these services, disabled children and their families might only have to make one trip, whereas for others there may be ongoing follow-ups that require travel. When there are multiple services based in the same location that require travel, coordination may be required to schedule appointments for a single trip. In some cases, parents describe undertaking this work while in other situations the institution, such as the hospital, will undertake this work to coordinate the appointments. Overall, travel for these specialized and niche services was more common for disabled children and families who live in rural, remote or small cities.

Analysis of the institutional maps and attribute tables support the understanding of the intersection between human movement and childhood disability, and also the general pathways related to human movement. Driving forces for transnational and internal migration are connected to opportunities, informal networks of support, and housing. Similarly, when considering disabled children and their families travelling to access services, several processing interchanges related to travel emerge including for specialized childcare or kindergarten programs, prenatal and childbirth, and specialized and niche services.

Where are the institutions?

The analysis conducted for this dissertation makes visible the extent to which disabled children and their families are engaging in travel to institutions. Institutionally governed borders have the power of creating boundaries between cities, regions, provinces, and countries. These borders hold the power to reinforce boundaries of coverage for services. From a historical perspective, the borders that are in place to divide different communities are colonial constructs aimed at organizing and managing people and human movement (Howard & Lobo, 2013). When it comes to crossing borders to access services, some children and families may receive referrals making them eligible for the services. However, due to the organization of disabled children and their families, they are not always allowed to choose if they want to cross a border to access services. We can see how the colonial construct of borders impacts the work of families and disabled children who live close to provincial borders. For example, family informants who reside in Quebec cannot choose to access services across the border in Ontario unless a specific referral is made. In situations where families are trying to access private services across borders, there is the option to move forward without the referral outside the community. For some disabled children, the travel occurs from one end of a large city to the other, or from one large city to another. For others, travel might require crossing borders. Institutions require families and disabled children living in certain communities to travel to services. For example, institutions in Yellowknife, Northwest Territories tend to send disabled children and their families to services in Edmonton, Alberta. On the other side of the country, institutions in Temiskaming, Ontario send disabled children and their families to services in Toronto or Ottawa, Ontario.

What do the processes for travelling look like?

When institutions require disabled children and their families to travel to access services, multiple interconnected and separate processes are involved: for example, having a professional or service send in paperwork to refer to a professional outside of the community, completing paperwork to access the service, completing paperwork to access funding for travel, making travel arrangements, getting time off work and childcare, and reconnecting with the professional back in their home community following the travel. The steps in the process require different forms of work on the part of disabled children and their families. These steps also differ depending on the type of service it is and how it is funded. There are also processes connected to both transnational and internal migration before, during, and after engaging in human movement. These experiences of transnational and internal migration will be discussed later in this chapter.

One of the first steps institutions require prior to disabled children and their families travelling for services is documentation connecting them to the agency or service outside of their community. Many of the specialized disability and healthcare services discussed by family informants require documentation or a diagnosis from a professional to gain access. In some situations, professionals will initiate the process of putting together documentation, whereas in other situations families are put in a position where they must engage in meetings, appointments, and additional work to get access to these services. Once the documentation has been created, family informants typically describe a wait-time that they experience before the intake or assessment occurs. For example, one family informant described waiting four months for a family doctor following internal migration and up to 2 years for child care following internal migration. Whereas, we heard about long waitlists following transnational migration for assessments, with one describing waiting 5 years for a psychoeducational assessment. Further, the yearly interviews with family informants provided an opportunity to follow-up about their wait for services. In some situations, we heard that they were able to gain access, whereas in others, more information was provided about their ongoing wait. During this time, family informants are once again put in a position by institutions to engage in work, such as making phone calls, sending emails, and contacting different professionals to find out more information about their wait time or to get access to the service.

Once an intake or appointment has been scheduled, the next form of work that families engage in is the process of accessing travel grants or funding. The process and documentation connected to access funding is connected to particular qualifying criteria set out by the government and other institutions. For example, qualifying for particular travel funding and grants can be dependent on characteristics such as location, occupation, income, and status as Indigenous. The process to access funding can include filling out forms, getting documents signed by professionals, phone calls, and emails for approval. Families describe the different sources of funding that are available to them. Some agencies such as *You Are Not Alone* have a travel assistance program which covers and supports travel to access services. In other situations, it is social assistance or welfare agencies that hold the power of granting travel funds for accessing services. Yet another method of accessing travel funding is through workplace medical travel coverage. The processes across these different institutions are different and disjointed, leading to more work for families. The work required to access this travel funding through different agencies and services can prevent or deter families in accessing funding for their travel.

Based on the institutional maps and attribute tables, a common experience emerges where the institutional processes required for the funding lead to more work for families. Different documents and forms are required to qualify and access funding. Further, there are guidelines around which forms of travel will qualify for the funding; for example, coverage is available for driving in some communities but not for air travel. Although many family informants describe the funding as important in accessing the services, the experience is not described as being the same for all family informants. The bureaucratic processes involved to get access to this funding may be deemed too much or not worth it for some family informants to engage in.

Once the appointment has been set, institutions then require families to engage in the work to make arrangements for the trip. The distance and time required for the trip can range from 1-2 hours in a car to a 10-hour car ride or a flight. Arrangements can include transportation, accommodation, and food. When the arrangements for travel are being made family informants discuss the need to consider their work situation; however, institutions that are making disabled children and their families travel to services may not take this into consideration. For some family informants, flexible employers support the travel while for others their work situation may limit what the travel looks like and how it happens.

Another consideration on the part of families, and not always for the institutions, is who can and will be going on the trip. Families who have multiple children are sometimes faced with the decision to pay for their other child to go with them or arrange for care while the child stays at home. Factors such as the number of adults in the house or access to other informal supports were described as contributing to decisions about who is travelling. In accounts provided by family informants they also discuss bringing along another adult with them for the travel, such as a partner or parent. The purpose of bringing another adult is described as a form of support and care during the time they are away from home, as this is not always provided in the location where they are travelling to.

The work that disabled children and their families engage in continues once they arrive at their destinations. In some situations, agencies set up a full day of appointments with different professionals. The child is moved from appointment to appointment undergoing different assessments, intakes, meetings, observations, or tests. Following the appointments, some agency may arrange and schedule the follow-up appointments, while in other situations the agency may require the family to wait for additional information to be shared.

Overall, there are several key processes that result from institutions requiring disabled children and their families to travel for services. Prior to, during, and after a trip to access services family informants must consider several factors and engage in different types of work. While travelling to access services disabled children and their families engage in many institutional interactions and bureaucratic processes. Some of these processes are further connected to textual records, as I will discuss below.

People move, texts stay still

During the early years, family informants describe the different types of paperwork and documentation produced and shared while accessing services. When engaging in human movement, then, disabled children and their families are engaged in processes of gathering, sharing, and storing these textual records. For example, when disabled children and their families are required by institutions to travel to another community to access services, further paperwork and documentation begin to be produced when they meet new professionals. The processes that take place prior to the travel, such as referrals, phone calls, and forms were described above. Below, I will describe what happens when disabled children and families engage in human movement, and the textual records that are produced as a result of these interactions.

The institutional maps and attribute tables make visible work connected to the movement of textual records when there is both transnational and internal migration. When examining institutional responses to transnational and internal migration, a key finding that emerges is that textual records created in one location are not always accepted in another community following migration. For example, assessments produced in a Canadian community or another country are not always deemed valid or sufficient in the new community. Accounts provided by family informants suggest that a diagnosis that occurred on one side of Canada may not be valid on the other side of Canada. The work associated with moving the textual records from one province to another is placed on the families, such as institutions requiring disabled children and their families to engage in processes to validate the assessment or re-do it. In examples of transnational migration, the institutional maps make visible the work families do in bringing over textual records such as reports and diagnoses. However, upon arrival in Canada these textual records are not accepted. Due to the refusal of the textual records that have moved to Canada or to a new community within Canada along with a disabled child and their family, we begin to see the additional work these families engage in to gain entry into services and programs.

Rather than accepting textual records that are provided following human movement, institutions require disabled children and families to re-engage in processes they have already completed. These processes involve wait times and re-assessments to be eligible for publicly funded services. What becomes evident within the institutional maps and attribute tables is the work of families in transferring or validating the documents, rather than institutions engaging in this work themselves. Based on these accounts, we see that disabled children and families move, but the textual records don’t always move with them, adding to the work families have to do. When looking at the movement of textual records alongside human movement, the institutional maps also make visible the ways in which professionals and institutions hold onto textually produced descriptions of disabled children and their families. For example, family doctors have required family informants to pay to have their documentation transferred to their new family doctor. This transfer is also not always instant, as family informants once again describe having to wait or make additional phone calls for this transfer to occur.

When disabled children and their families are travelling to services in another community, the textual records that are produced during the travel do not always move between the communities themselves. Prior to the visit, services and programs may require particular textual records. In some situations, the professionals will engage in this work, while in other situations the work of transferring and gathering textual records is placed on families. Moreover, this information sharing or movement of textual records is sometimes supported through provincial electronic systems, removing the work on the part of families to transfer documents themselves. For example, as the following informant's account suggests, hospitals within the same province might have a shared electronic record to store and share this information:

> P06: P: So that's like kind-of like their follow-up like kind-of talk with him about respiratory stuff, he asked why she was sick, he got all the records from there because he's in Ontario and the joys of having medical documents passed around easier [laughs] so he had all that information. So he was able to help and assess. He said "please have an x-ray because it needs to be looked at again."

When this work is not done by the professionals, institutions require families to gather reports, assessments, and other documents that they have collected since their child was born and move it themselves.

Appointments connected to travel for services can vary. In some situations, appointments are coordinated such that disabled children and their families might visit multiple professionals during one trip. In other situations, this coordination may not be present, resulting in multiple trips to one location. As a result of these visits, different texts may be produced, such as assessments, diagnostic reports, medical reports, and observation notes. Although a professional from their home community may have sent them to a service in another community, the textual records produced during the trip are not always transferred back to the child's home community. Family informants describe the process of asking for print outs, making phone calls, or personally delivering texts to the professionals in their home community to ensure that the information is transferred back. Getting multiple copies, scanning documents, and keeping binders with this information are some examples to ensure this information is available and can be transferred. However, the work that families take part in, illustrated below, is often invisible:

> P07: When I go to Vancouver, I ask for photocopies, two. One copy for me and the other copy I drop off at medical clinics so that they can have it on file. He goes, no moms do this, he goes, this is awesome. That way, we don't have to hunt it down. You make our job amazingly simple. You know, I do, always do this.

The work of ensuring continuity of care and information sharing as a result of human movement is placed on families; the onus is not on professionals and services to establish this continuity or communicate this information. Without families' work in this regard, the textual records would remain still, their failure to be transferred often necessitating a follow-up with services, as described in this informant's account:

> P08: P: So I had to kind-of follow-up on it a bit more and yeah so they had the results but it got lost between Edmonton and Yellowknife and computer system and blah, blah, blah so when I followed-up on that, they did tell me it was normal but they were gonna try the Restoratran to speed it up because if we could speed it up, maybe he won't get constipated.

Accounts provided by family informants also reveal that there are circumstances in which textual records are lost in the process of transferring care to another specialist. As a result, information about a diagnosis or intervention might not be transferred back to the professionals who are in contact with the child and family in the home community. This delay can lead to further waits and work for disabled children and their families, along with a lack of continuity in care.

Human movement is also a common experience for disabled children in foster care. Their experiences of moving are described by family informants in the study. The institutional maps make visible that institutions hold onto information about children in the foster care system, such as their history and previous engagement with institutions. When children are transferred into the care of someone outside their home community, they get connected with a new set of services, while their textual records do not always move with them. With the textual records remaining still under the ownership of a particular institution, information is not always relayed, leading to a break in the care the child receives. These textual records remaining still can lead to additional work on the part of foster families, such as trying to connect with previous workers, making phone calls, and attending additional meetings.

Whether it be transnational migration, internal migration, or travelling to access services, we see that while disabled children and their families are moving to get access and participate in institutionally governed services, textual records are not moving with them. In some situations, such as provincial electronic systems, procedures may be in place to support this information sharing; however, this is often not a smooth process. Institutions require families to engage in work to ensure documents are available or transferred so that professionals working with their child have the information available to them to provide support. The bureaucratic processes of institutions may lead to these texts being still, contributing to a lack of communication across institutions.

Duplication and replication of services across different communities

As a result of human movement, we have seen that communication across institutions can be limited, leading to situations where disabled children experience a replication or duplication of services across different communities. When disabled children and families travel to access services in different communities, professionals they visit may pass them onto professionals in other communities. It is through this process that disabled children are moved across various communities and can encounter a replication in services. As discussed above, one cause of this can be the lack of communication between professionals in different communities. When there is replication of services, children may be provided with different diagnoses, recommendations, and strategies across the different professionals. The lack of centralization and coordination on the part of the system can lead to the creation of different textual records across different communities, impacting the type and amount of work disabled children and their families engage in.

When looking across the institutional maps that have been generated through conversations with family informants, this repetition or duplication becomes visible. Looking across the service systems and timeline of the institutional map helps to see which services and professionals are duplicated. For example, we can see when there are multiples of the same professional providing support in different communities at the same time or one after the other without the transfer of information. Examples of programs and services that have been duplicated across communities include speech and language therapy, physiotherapy, occupational therapy, and audiologists–the quadruplet of services, as discussed by Underwood et al. (2018). The duplication of services across communities can lead to additional intake processes, assessments, appointments, and diagnoses.

Further examination of the institutional maps makes visible how this replication of services can lead to receiving multiple overlapping but different diagnoses from different professionals in different communities. For example, when looking at diagnoses connected to hearing, children and families are usually sent to audiologists and Ear/Nose/Throat specialists, or both. However, this can lead to different results and different diagnoses following an assessment. When looking at the accounts provided by family informants, this typically occurs when these professionals are being seen in different communities and across different borders. Similarly, family informants describe different professionals providing assessments and diagnostics results regarding children's vision across different communities. Referrals to ophthalmologists, Auditory Brainstem Response (ABR) professionals, and pediatricians in different communities can lead to different types of assessments focused on a child's vision. Due to the differences in assessments used or the lack of communication across professionals, there is the possibility of receiving different results and recommendations.

Overall, what becomes visible in the institutional maps is that human movement in the form of travelling to access services can lead to a duplication or replication of services across different communities. As a result, professionals may provide differing diagnoses, strategies, and recommendations. The pathways and processes leading to this replication illuminate the lack of coordination and centralization of care across communities.

Formal and informal support networks: Making it work when you're mobile

Human movement, whether by choice or force, can lead to a disruption of formal and informal support networks for disabled children and their families. Family informants provide accounts of the institutional responses (or lack thereof) prior to, during, and following human movement. Within these accounts, family informants describe the role of both formal and informal support networks connected to human movement.

There are a series of institutional responses that occur when institutions make disabled children and their families travel to services rather than providing the services in their home community. These institutional responses can either disrupt or facilitate support. For example, family informants discuss the institutional response of using air transport for an infant or young child. In some instances, the use of air transport forces the family to allow the child to travel alone with medical professionals to another institution. Medical teams will deem air transport a necessity in an emergency, but sometimes families are told there is not enough space or capacity to also transport a caregiver with the child. In these situations, the child is transferred, and the family must find another method of travelling to their child. For both the child and family, there is a lack of support in the way institutions respond to the deemed necessity of travel. There is additional work that families engage in to arrange their own travel to where their child has been sent, along with the emotional labour of coping with being away from their child.

In the absence of institutional support, when disabled children and their families engage in travel to access services, some families have the capacity to bring along other family members with them to provide additional support. The work of families in arranging for this and taking the time and resources to do this is invisible at many times. For some families, choosing or being put in a situation where travel was required meant that they had to be away from their family members, such as children, partners, and parents. Family informants describe situations where the adults split up responsibilities so that one adult stays at home with the children who are not accessing services:

> P06: P: Um so that was our biggest thing and uh then too going to Ottawa was another thing like his dad had stayed here with him and I was with Belle in Ottawa and then on like weekends they would come and visit us.

Families are once again having to do the work to ensure that they can be together because institutions are requiring them to travel long distances and be separated from their informal support networks.

On the other hand, some institutional responses to travel facilitate and support the child and family. Many hospitals are connected to organizations that provide temporary family housing, such as the Ronald McDonald House, which provides living space, kitchens, or private space for families. This resource connected to hospitals provides families an opportunity to stay close to their child and a space outside of the hospital setting for family members to be with each other. As illustrated in the following excerpt, the proximity to hospitals and resources available through these temporary housing spaces provides a support while there is a short or long-term stay for children in a hospital setting:

> P09: So I was very fortunate that we got into Ronald McDonald House we were able to stay there because it was a five-minute walk, well 5 to 10 mins to get into the NICU. And that was really helpful because you don’t wanna coach surf for 16 weeks or put somebody out of their bed for 16 weeks. That’s a long process.

Although informal supports such as family and friends may be available for some families, temporary family housing provides an important long-term support for disabled children and their families. Further, for those who may not have an informal support network close by or available, the support of the hospital or outside agency for this care can be very important for the child and family.

The institutional response, or lack thereof, when families move internally or transnationally is also evident from the accounts provided by family informants. Following a move, institutions require disabled children and their families to work to re-establish formal and informal support networks. In terms of formal supports, there is a pattern where families must do the work to connect with new organizations, professionals, and services following the move. They must also engage in the work of getting texts transferred to establish communication between the previous agency and the new one, if needed. There is a lack of institutional response here as the institutions themselves are not engaging in communication or able to transfer care to another community when people move.

When transnational migration occurs, there is a lack of institutional response in relation to what supports are provided to newcomers. Institutions require newcomers to do the work to find organizations that can provide them support to learn about Canadian systems. Programs include ESL classes, resume building, job placements, and permanent residency or citizenship supports. However, within these spaces the formal supports are not easily accessible or sufficient for families. Further, due to limited coordination or centralization of service systems, families must engage with additional organizations to connect with early childhood, health, disability, and community services. Although some families know English or are learning English, the language requirements of institutions and dominance of English can lead to further difficulties finding the right resources.

In the absence of an institutional response to support families and disabled children who have migrated, families engage in work to create their own networks of support. For example, many family informants describe turning to social media platforms and parent groups to engage with people in similar situations or from similar backgrounds. These networks connect families to professionals, programs, research studies, and respond to general questions about children's development. The following account offers an illustration of families' reliance on these online support networks:

> P10: And one Brazilian lady was there and she said, "Oh, we have one group all for moms with children with autism and also for another like special needs like down syndrome, west syndrome, everything" and then I said, "Oh, can I be part of the group?" and she said, "Yeah, I'll put your name on the list." And then at the same day, become part of the member, the family. It was very, very interesting because every day they post something interesting about, about anything! Like any studies about autism. So, it's easier—because we don't have time to sit and look for a specific thing. So somebody just post for you and makes easier for you.

These online spaces provide a platform to access resources and find information. This type of informal support allows families who do not have prior knowledge about services in Canada to easily access information and connect with other families.

Further, due to immigration processes, many people move to Canada without their informal support networks. Family informants describe the early years of a child in their home country and the role family and friends played in caretaking. Upon arrival to Canada they experience a different institutional system which is more formalized. As the following account indicates, child care in other countries can, for example, take the form of grandparents supporting while parents go to work:

> P11: Like our everyday compared to when we were in the Philippines. Because from the Philippines, so she—probably still remember—we had an extended family very close to us and now it's just the three of us. So, in the Philippines, she had her Grandma. Her Grandma was my daycare [Laughs].

Upon arrival to Canada, there are changes in what families expected their child's early years to look like due to the institutional organization of childhood in Canada. The accounts provided by family informants who had migrated transnationally focus on this loss of support from family and friends, and the process of turning to more formal supports once in Canada.

Overall, an analysis of the institutional maps and attribute tables in conjunction with data from the transcripts makes visible the role of both formal and informal support networks for disabled children and their families who have engaged in human movement. Although there are instances described where the institutional response recognizes this, there are also accounts showing that families and disabled children have to establish their own process such as reaching out to other parents, to establish networks when they engage in human movement.

Perceived and official citizenship status: What does it mean to be a citizen?

Status as a Canadian resident or citizen, whether it is official or others' perception of what it means to be a Canadian citizen, can be important in relation to inclusion and exclusion that occurs for families and their disabled children. The perception that someone does not have citizenship status can impact access to supports and relationships with professionals. Further, the perception of what being a Canadian citizen entails can shape what supports look like for disabled children; however, this may not fit with the child and family identity. Lastly, gaining status in Canada has implications for which supports are available in relation to health, early intervention, and education services.

Holding official citizenship status on paper does not always lead to institutions treating families and disabled children as Canadian citizens. Factors such as race and language proficiency, rather than the official citizenship status, may be used to make determinations about which services are available to disabled children and their families, and how they will be treated if they gain entry into programs. A result of this exclusion includes changes in how interactions occur with professionals and how one perceives their place in society. For example, as illustrated in the following account, family informants have described experiences accessing services in which they have been told, troublingly, to go back to where they are from:

> P01: We have been subjected to racial profiling here also in Hamilton, which was actually a deal breaker for my wife and, whereas I look at Canada as like very open and I think that it's a great country to live in, my wife doesn't… So, again I was told like go back to my own country and I told him like, "Hey dude, like I belong here like this is my country. So, I can't go back." Now you tell me like what we want to identify here in this question.

In these situations, factors such as race, language, and family culture interact with citizenship status and disability as being a key factor in shaping the experience of disabled children and their families while accessing services, and the perception that they do not belong.

Access to services is also connected to having official status in Canada. Official status, such as having Canadian citizenship, is important to get access to provincial universal healthcare programs such as the Ontario Health Insurance Plan (OHIP, the provincially funded public health care insurer). Gaining immigration to Canada can happen through multiple routes. One path to immigrate to Canada described by family informants is through marriage. If one spouse has permanent residency or citizenship status in Canada, they can do paperwork to invite their spouse to Canada. However, this entry is on a spousal visa or work permit and the invited spouse must begin the process of gaining permanent residency or citizenship. Family informants provide accounts of the steps to gain this status and what happens while they are waiting. When the government agency has not issued permanent residency or citizenship status in Canada, families end up paying for health care services, such as prenatal doctor appointments and costs associated with the birth process. Further, due to the organization of services by the government, children may also be denied OHIP status at birth when the mother does not hold the status of a permanent resident or citizen in Canada. Rather than automatic enrollment to OHIP, the families must engage in the process of completing additional paperwork regardless of the child's status as a Canadian citizen.

Perception of citizenship status is also connected to the ability to speak English. However, for many people migrating to Canada, English may not be their first language. Forms, applications, and tests connected to gaining citizenship status are generally provided in English, emphasizing the belief that fluency in English is central in navigating services in Canada. These beliefs then influence the idea of what it means to be a "good citizen" in Canada. For disabled children and their families, this discourse is also present when considering the language services are provided in, with English being the primary language in most provinces. This prominent discourse is particularly evident when considering speech and language services. The accounts provided by family informants detail the interactions with services providers in relation to language use in the home. When engaging with speech services, a tension arises about speaking English or a family language with their child. Some professionals put families in a position where they must make the decision to only speak English with their child because they have been told it would support the child's language development. The implication of these conversations led by professionals and the way in which services for disabled children are organized is that it is in the family and child's best interest that they continue to focus on English within their home environment. The following excerpt is representative:

> P01: Talking to my wife or keeping like one language at home. Like this was also like brought into me that, "Oh, because you would be using a different language at home,

> that's why your kid is not saying as," like you are the kids who speak actually two languages, or three languages they are smart. They are not—
> I: Can I ask who said that? One of the professionals?
> P: One of like I would say when like you are going to the therapies and when you're like talking different [Sighs].

Family informants describe this tension between using English or their family language at home. With the lack of speech services in other languages outside of English, institutions put families in a position where they must either comply with the language used by institutions across Canada or they are told they will confuse their child by speaking multiple languages. Due to the structuring of programs and the prominent discourse of the ability to speak English as a Canadian, family informants describe the limited choice they have in language use at home, even though using their family language may be an important element for their identity and family. These accounts also outline a form of assimilation through language use upon arrival to Canada to be a "good citizen", which is further promoted by different services and professionals.

The intersection of citizenship status, language, human movement, and disability also arises in relation to interpretation services. Family informants provide accounts of the process to get interpretation services, which begins with institutions requiring families to make a request for an interpreter when there is a meeting or appointment. However, when this request is made family informants describe uncertainty about receiving this service. For example, requests are made for interpreters ahead of meetings, such as identification, placement, and review committees or individualized education plan meetings with the school. Although the request is made in writing, the service is not always provided, impacting the families participation in decisions about their child's education, as the following excerpt illustrates:

> P11: P: I asked for a translator during the IPRC like before the meeting yeah I found out the meeting schedule and then I requested a translator and then the meeting date arrived and they didn't give a translator so I started the meeting very flustered and frustrated. And then I was candid about like, okay so I was getting like emotional and see, this is

> why I needed the translator so that I can just focus on the things I wanted to say and not have to worry about how to say them. And one of them actually commented, “You’re English is fine.” Like that’s not the point. I didn’t say that out loud but just thinking back. Because yeah it’s a second language for me so.

Denial of a request for an interpreter can be based on the perception of the families’ English proficiency by the professionals and institution. The institutional response to a request for an interpreter, or lack thereof, privileges English speakers and allows the institution to make decisions about the need for an interpreter based on their own perceptions, impacting the participation of the family in their child’s care.

Overall, having official citizenship status and the perception of what it means to be a citizen impact the work disabled children and their families engage in and the types of services they have access to and the type of access they receive. Although Canada is described as having a universal healthcare system, the limitation in access as a result of not having official citizenship status contradicts this belief. The perceptions of professionals impact interactions and access for disabled children and their families. Ultimately, institutions require families who have engaged in transnational migration to fill out additional documents, engage in meetings differently, and restrict or change their behaviors and language in order to participate.

Restarting the process: The additional work asked of disabled children and their families

As family informants describe the processes connected to their movement, whether it is transnational or internal migration, the work they do following their move focuses on institutions requiring them to restart processes. These processes are connected to service systems such as healthcare, education, early intervention and disability services, early childhood education and care, family support, and grants and subsidies. For disabled children and their families, these processes of restarting result in more work, such as finding new entry points into services, the diagnosis process, waitlists, and the emotional work of recounting one’s story. Due to differences in disability services across municipalities, provinces, and countries, there is an additional layer of work that they must engage in during these processes to re-learn the disability service systems in their new home location.

To get reconnected with services and get an assessment following migration, services require families to first engage in the process of finding a healthcare professional. This is a particularly pressing for families with disabled children, because family doctors are required to get referrals to almost every other specialist. In some cases, professionals from their original community may make a connection referral to someone in their new community. However, in many situations, families must engage in the work to make these connections. As a first step, family informants describe trying to find an entry point into services in their new community. The process of finding a family doctor or pediatrician requires multiple steps and waiting. In accounts provided by family informants, they describe first trying to find a new family doctor or pediatrician. However, waitlists for family doctors and the need for a referral to see a pediatrician can lead families to search for an entry point another way, such as by going to a walk-in clinic or emergency room with the hope of getting referrals to other healthcare providers in the community. This work may have been initially done in the community they moved from. However, due to limited communication and coordination across institutions and professionals, they must engage in work they already did in their previous community. The following account illustrates this process:

> P12: I started the process of getting him diagnosed in [one city], by that time we had to essentially escape so when we came here, I had to start the process all over again. And the process had to start with first finding a family doctor. So I found a family doctor but the family doctor wouldn't see us for something like four months from when we found them. And I was like I need—I was losing it. I essentially just googled doctors that can diagnose children in [the city where we moved to]. And I found Dr. Randolph [a pediatrician] And what I did—cause my family doctor was useless. I couldn't go to him until June of that year. So what I then did was I found a walk in. I went to the walk in and

> I literally bawled my eyes out and I said, “please refer me to this doctor. I have no…” and they’re like, “no we don’t usually do this.” And I said, “please, I can’t do this anymore. Like I am on the verge of losing my mind. This is too much.” So they did, and I was very grateful for that because that was my one break in all of this. Like the fact that walk-in doctor referred me to her.

The activities outlined by family informants detail the different people they try to connect with, the wait that is involved, and the conversations they have to gain access to a pediatrician to restart the diagnosis process for their child. Social media platforms are another mechanism used following a move to reach a wider audience and gain either access or a referral to a professional in their new community. These processes to gain an initial entry following internal migration are substantial to gain further access, connections, and a diagnosis to qualify for services. This work becomes visible as we look at the institutional processing interchanges, or the process of moving the bureaucratic responsibility for a child from one site to another.

A key text produced by professionals is a diagnosis. Due to the organization of systems and disabled childhoods, receiving a diagnosis is essential in connecting with health, disability, early intervention, and education services in Canada. Without an official diagnosis, children might not meet the qualifying criteria for services. Although some children may have received a diagnosis, migration could lead that diagnosis to become invalid. For example, when families move to Canada from another country, due to the diagnostic procedure or language of the assessment, it may not be accepted by schools to access services. Instead, families must re-engage with services in Canada, get referrals, join waitlists, and undergo further assessments to get a “valid” diagnosis in Canada. The lack of validity of diagnoses across countries highlights the lack of universality of a diagnosis in a global context. Based on accounts provided by family informants, one consequence of having to get an updated diagnosis upon arrival in Canada is the extension of waiting time to get access to services. Rather than accepting diagnoses and reports from other countries, Canadian institutions require children to wait for a new assessment and in the meantime the child does not officially meet the criteria to access services.

These same processes are present when looking at internal migration within Canada. Diagnoses and reports provided in one province or territory may not be valid in another province or territory. Following internal migration, family informants describe having to get an official diagnosis re-validated in their new province:

> P13: P: We just needed a Pediatrician to sign the bottom of this piece of paper from the Ministry saying, "Hey, yeah, I think autism in BC looks the same as autism in New Brunswick."
> I: They wouldn't take your autism diagnosis from New Brunswick—
> P: They would not.
> I: —to qualify for service here?
> P: Exactly. So when we came, they're just like, "No, yeah, I don't know what autism looks like in Ontario but it's not what it looks like in BC."

Institutions require the child and family to have the diagnosis "signed off on" or validated by a qualifying professional in the new province. Engaging in this process means that disabled children and their families replicate some of the work they have already done. Further, the time and process of connecting with professionals in a new province adds on to the waiting time to gain access to services. Through the accounts provided by family informants, we see a pattern where an official diagnosis may not be universally accepted and across Canadian provinces and territories.

Family informants who have experienced human movement provide accounts about experiences with waitlists following a move. Due to the organization of systems, institutions require disabled children and their families to re-join waitlists following human movement even if they had already gone through that process for the same type of service in their previous community. In these accounts, what becomes visible is the lack of continuity of care across cities, regions, and provinces in Canada as disabled children's services are not transferred from one community to another. When disabled children and their families move to a community close to their previous one, they may choose to continue to travel back and forth to retain access to services and avoid joining new waitlists, leading to more engagement with human movement. More commonly though, families and disabled children are required to connect with services in their new community and rejoin waitlists for services they already had access to or were waiting for.

As family informants provide accounts of their movement and the processes they engage in to connect with new professionals and services, they must do the work of retelling their story during intakes and meetings following their move. Without a universal system and limited communication amongst professionals across communities, disabled children and families must repeat work they had already done, which leads to this additional emotional labour. These processes not only add to the work of families, but disabled children are also implicated in this work as they must meet new professionals, undergo observations, complete new assessments, and build relationships with new people.

The processes of restarting and connecting with new professionals and services can also be a deterrence to moving for families and disabled children. There is a lack of transparency on the part of institutions about what these processes will look like following migration. Although they may desire to move for work, housing, or joining a new community, they may make a decision not to move due to the work they would have to engage in due to the intersection of human movement and childhood disability. Concerns about restarting are expressed in the following account:

> P11: P: I was thinking back to the risks you were saying in the start, talking about it can make you emotional [Laughs]. I've been thinking about—buying a home and I kind-of get locked because then I need to think about if "I'm going to move from where we are now to a new neighbourhood", I'm going to have to figure out all these resources again

> and I don’t know where I can afford a home where there will be even services there so, then—that just kind of just stops me [Laughs] and then I go, “never mind, I’ll just stay put.” I wish it was just transparent. To see where all the audiologist are and if a deaf child moves to what place and what the services are going to be there and then yeah I wish it was just transparent like that.

For families of disabled children, choosing to migrate may not be a simple decision. The accounts from those who have migrated and those who are interested in migrating highlight the intersectional nature of human movement and childhood disability. Due to the institutional response to childhood disability, families must consider these additional implications and processes of human movement.

Overall, the institutional maps and attribute tables reveal the processes of restarting and reconnecting with services following migration. Multiple processes and steps are involved in getting access to services and professionals following human movement, such as gaining the initial entry, the waiting process, and the intake process where they are required to retell their story. The work to reconnect with services and lack of transparency on the part of institutions can also deter some families from moving.

Chapter Summary

Family informants in the IECSS project shared their experiences of human movement in relation to childhood disability. An analysis of these accounts led to several key findings, including: 1) Migration and travelling: What is the context of human movement and childhood disability?; 2) People move, texts stay still; 3) Duplication and replication of services across different communities; 4) Formal and informal support networks: making it work when you’re mobile; 5) Perceived and official citizenship status: What does it mean to be a citizen?; and 6) Restarting the process: The additional work asked of disabled children and their families. In Chapter 5, I will discuss these findings in more detail in relation to the central research problematic focused on the intersection of human movement and childhood disability. Further, I will use key concepts emerging from institutional ethnography to provide an in-depth discussion of the findings outlined in Chapter 4.

Chapter 5: Discussion and Conclusion

This institutional ethnography explores the intersection of human movement and childhood disability, a problematic arising in the accounts provided by family informants in the Inclusive Early Childhood Service System (IECSS) Project. Conversations with family informants about their interactions with institutions, experiences related to human movement in the form of international migration, internal migration, and travelling to access services related to childhood disability provided information about how institutions operate from the standpoint of families with young disabled children.

In this chapter, I will begin by providing an overview of the previous chapters. Then, I will return to the key findings presented in Chapter 4 to engage in a discussion about what we have learned from family informants about institutional interactions. In this discussion I will also present these findings in relation to the broader context of theory and literature, which was provided in Chapters 1 and 2. Finally, I will turn to the implications of this dissertation for practice and future research, followed by a discussion on the future directions of research focused on human movement and childhood disability.

Dissertation Summary

In Chapter 1, I began by introducing the IECSS research project, institutional ethnography, and the context of the intersection of human movement and disability. The family informants who are a part of the IECSS project shared their experiences interacting with service systems and through their accounts we saw the problematic of human movement and childhood disability emerge. These experiences captured human movement in the form of transnational migration, internal migration, and travelling to access services. Learning through their experiences about institutional interactions adds to our understanding of what the everyday lives of disabled children and their families look like and the work they are asked to do. As explored in the introduction, there is a growing body of research focused on what happens when disabled people and their family systems move and what leads to this movement.

Then, in Chapter 2, I centred the research problematic and connected it to theoretical perspectives and the current literature base. As interviews with family informants unfolded, the problematic focused on the intersection of childhood disability and human movement arose and through conversation with the research team it became central to this dissertation. As further discussed in Chapter 2, this problematic arises from the standpoint of families with disabled children who have engaged in human movement. Starting from this standpoint is a central feature of institutional ethnography as it allows us to enter into the everyday experiences of disabled children and their families from their position. Using a systematic approach to reviewing mapping, attributes tables, and interview transcripts, I identified points of tension that illuminated the systemic mechanisms through which disability and migration are categories that are managed through institutional processes. These are then described using the theoretical and conceptual ideas found in the literature. Concepts from critical disability studies, DisCrit, and disabled children's childhood studies help to situate the research problematic within a broader discourse of disability studies. This bricolage of theories allows for a more nuanced understanding disability studies, considers migration in relation to disability and race, and centres our work on disabled children and their families. The research problematic was analysed using literature that focused on the Canadian early childhood education and intervention context from both a policy and program perspective, while centering our focus on the intersection of childhood disability and human movement. The context provided in Chapter 2 supports the discussion in Chapter 3, which provides an overview of institutional ethnography as the methodology used for this dissertation and the methodological approaches used for the IECSS project.

In Chapter 3, I built on the introduction to institutional ethnography with a more detailed description of the research method, the approaches used in the IECSS project, and the central elements of the current study. Key concepts such as ruling relations, work, texts, and discourse introduced in Chapter 3 were central to the analysis of the institutional maps, transcripts, and attribute tables. The analysis procedures outlined in Chapter 3 led to six key findings discussed in Chapter 4. The first finding outlined in the Chapter 4 provided an overview of the context of human movement and its interaction with childhood disability. This overview provided a picture of what human movement looks like for disabled children and their families, when it happens, and who we see engaging in human movement. Next, I outlined the processes where we see disabled children and their families travelling to institutions, while the textual records that are produced and requested remain still and do not move with them. The third key finding made visible the duplication and replication of services when human movement in the form of migration or travelling for services occurs. The replication of services also leads to the production of additional textual records and documents, some of which do not align with each other. Next, in considering the institutional interactions of disabled children and their families, I outlined the importance of both formal institutional and informal support networks in the form of family and parent groups. The fifth key finding focused specifically on experiences of transnational migration and citizenship status. Holding an official document for citizenship status is important in gaining entry to services, however, others' perception of one's status can also impact their interactions with institutions and service providers. Lastly, a consequence of human movement made visible through the analysis was the process of restarting and reconnecting following human movement. A key consequence of restarting these processes is additional work on the part of disabled children and their families. Below, I will explore these 6 key findings further while addressing the problematic that opened up this study and the areas of inquiry which emerged as a result of the problematic.

Discussion

At the beginning of this dissertation, I outlined the research problematic guiding the current study and then, in Chapter 4, I provided an overview of the 6 key findings that emerged following an analysis of institutional maps, attribute tables, and interview transcripts. The key findings that emerged through the analysis include (1) Migration and travelling: What is the context of human movement and childhood disability?; (2) People move, texts stay still; (3) Duplication and replication of services across different communities; (4) Formal and informal support networks: making it work when you're mobile; (5) The importance of gaining perceived and official citizenship status and; (6) Restarting the process: The added work on families and disabled children. The aim of this discussion is to return to the research problematic and areas of inquiry to engage in a discussion of what was learned through the analysis and what it means in the everyday lives of disabled children and their families. As a reminder, the main research problematic guiding this dissertation is:

> What do the everyday experiences of disabled children and their families tell us about the role of human movement (transnational migration, internal migration, or travel to access services – both forced and voluntary) in accessing and navigating early childhood, disability, and education service systems?

Below I will attend to the research problematic and areas of inquiry and situate the research findings within them.

What do the everyday experiences of disabled children and their families tell us about the role of human movement when accessing and navigating early childhood, disability, and education service systems?

The accounts provided by family informants highlight the central problematic of this dissertation, the intersection of human movement and childhood disability. Through the accounts provided by the family informants, we can learn about experiences of transnational migration, internal migration, and travelling to access services, as well as the common experiences that emerge across these three types of human movement. What these everyday experiences tell us is that human movement changes and adds to the work of disabled children and their families when accessing and navigating service systems, experiences which differ for nondisabled people and those who have been in the same community for a long time. Factors such as type of service, where someone is migrating from, citizenship status, borders, opportunities, engagement with professionals, and support networks are all factors that affect the interactions families have with services. However, from the standpoint of families, we learn that institutions require families and disabled children to come to them; people move but texts stay still; there continues to be a fallacy of choice (Underwood et al., 2019a) when it comes to travelling for services; and pre-determined categories dictate what the everyday experiences look like for disabled children and their families.

One of the key goals of institutional ethnography is to learn how things work (Smith, 2006). Through the conversations with family informants in the IECSS project, we have learned that institutions work by requiring families to go to them rather than institutions going to disabled children and their families. Through my analysis in this dissertation, we have learned that disabled children and families are continuously asked to move, especially if they live in particular communities, such as rural and Northern communities, or if the child needs a specialized service, such as those outlined in Figure 2. When disabled children and families are required to travel to institutions, the work they engage in is not always accounted for. However, through mapping the institutional interactions of disabled children and their families, I was able to reveal some of these invisible institutional processes. This work includes the completion of documentation, waiting for services, travelling, and connecting with professionals in different communities, for example. In many ways, the institutional mapping reveals just how disabled children and their families are pushed from institution to institution across communities. Withers and Ben-Moshe (2019) suggest we interrogate why disabled children and families are being asked to travel to institutions rather than having services and supports available to them locally. We also begin to see how the actual institutional process such as re-joining waitlists following internal migration, and the extended wait for services is inconsistent with dominant discourses that suggest that early intervention is essential for disabled children's development. Further, the findings presented in this dissertation and other work conducted by the IECSS team (see Frankel et al., 2019; Underwood et al., 2018, 2019c) show that intersectionality plays a role in this type of travel. Factors such as geographic location, socioeconomic status (SES), diagnosis, family structure, race and gender are all implicated in this conversation. Over time, the family informants learn how to do this work of travelling to access services and gain different forms of knowledge that can support this work going forward (DeVault, 2021).

The institutional maps make visible that institutions' work by making disabled children and their families travel to them, but also that during this process of people moving, textual documents remain still. Institutions work by having families of disabled children act as the mechanism through which textual documents get transferred from community to community, service to service, and professional to professional, often without any changes or additions. A key contribution of this dissertation is understanding the movement of texts as disabled children and their families move. Institutional ethnography provides a methodological approach that allows us to better understand the power of texts. The power of texts is seen in how they drive action and the invisible work that occurs due to differences in these texts themselves (Campbell & Gregor, 2008). As described in Chapter 4, this work asked of families includes getting print outs, making phone calls, personally delivering texts, and paying for the transfer of files, as examples. Institutions exert their power by holding onto textual records or making disabled children and families engage in processes, such as redoing intakes, observations, and assessments to create new textual documents. Kearney et al. (2019) also reinforces the notion that the contexts in which texts are used and how they coordinate the activities of others can be described as extra-local forces (Campbell & Gregor, 2008). When families move or are asked to travel, the texts that have been developed elsewhere do not move along with them automatically. Rather, families are asked to engage in the work to move the texts themselves.

The categorization that occurs through institutional processes and texts also influences what the everyday experiences of disabled children and families look like in relation to human movement. One of the key points Smith (2021) highlights in discussions of institutional ethnography is the effect categories have in organizing and coordinating the activities of people and the sequences of these activities. A result of this categorization through texts, such as forms, is the displacement of the depth and nuances of the experiences of disabled children and their families. In accounts provided by family informants, what becomes visible is how pre-determined categories such as location, borders, disability, and type of service shape the everyday experiences of disabled children and their families, while influencing the type of human movement they engage in. Location and borders emerge as key categories that dictate human movement for disabled children and their families. Previous research has discussed the role of location, specifically residing in rural and remote communities, as a key factors in the organization of activities (Barr et al., 2018; Boydell et al., 2006; Dew et al., 2012; Frankel et al., 2019; Underwood et al., 2018; 2019c). This concept was supported by the experiences shared by family informants in the current study. Family informants in rural and remote communities are frequently directed to travel to another community to gain access to services due to the lack of availability in their home community. Borders thus, play a significant role in organizing and coordinating the activities of disabled children and their families trying to access different service systems, which I will come back to later in this discussion.

The power and control held by institutions over disabled children and their families also leads to the fallacy of choice (Underwood et al., 2019a). Underwood et al. (2019a) describe the fallacy of choice as the perception that the individual is making the choice, when institutions are actually organizing and dictating the activities of disabled children and their families, and therefore, limiting choice. In the context of the present study, the experiences shared by family informants further exemplify how the fallacy of choice plays a role in the everyday experiences of disabled children and their families when travelling to access services. Many times, the option to travel for services, such as a specialized childcare centre or a specialist, is framed as a choice for parents to make. However, the way in which service systems organize disabled children leads families into a position where they are pressured to travel to gain access to supports. Although this service may be farther for the family and child, they choose to access these services due to the lack of options presented in their own community. Ho (2008) suggests that institutions and systems “structure people’s alternatives in such a way that certain options are never considered as viable and other decisions are made" (p. 194). The accounts provided by the family informants make visible how this happens within early intervention, child care, and school service systems across Canada. Ableist ideologies, as identified by Ho (2008), held by institutions lead to a form of pressure which impacts the decisions and choices made by families.

Analyzing the institutional maps and transcripts also makes visible how this fallacy of choice is present across different communities, including both urban and rural settings. Building on research conducted by Ross and Builiung (2019), I highlighted that disabled children in urban centers travel long distances to access services, particular early childhood education programs and schools due to the limited options in their own community. These findings are important to consider, as Ross and Builiung (2019) have highlighted the negative consequences for children resulting from travel, such as limited time with peers, curriculum, and other activities.

The experiences of disabled children and their families who engage in human movement also tells us about the key role of entry points. Previous research focused on newcomers' first experience with the healthcare system has described the pivotal role settings such as walk-in clinics and emergency rooms play as a point of entry into service systems (Gagnon et al., 2010). This initial contact or entry point becomes essential in getting connected to other resources, services, and professionals. Although this entry point may present some barriers, such as excessive paperwork and intake processes (Arfa et al., 2020; Khanlou et al., 2017; Fontil & Petrakos, 2015), the analysis presented in this dissertation makes visible how essential these entry points are for all types of human movement. For example, following human movement in the form of transnational or internal migration, family informants in the study discuss needing to get connected to service systems and the barriers that exist in getting in contact with services and professionals. Work in the form of posting on social media, going to walk-in clinics, and visiting emergency rooms was described as strategies to get connected to the broader service system for their child. DeVault (2021) discusses these ruling practices that coordinate people in the interests of institutions. The analysis in this dissertation makes clear that disabled children and their families are funneled through particular entry points such as walk in clinics and emergency rooms following a move in an effort to coordinate the work of various service systems.

Institutional ethnography provided an entry point into the everyday experiences of disabled children and their families and the intersection with human movement when accessing and navigating early childhood, disability, and education service systems. This central research problematic of the intersection of childhood disability and human movement focuses in on institutional processes and how they shape everyday experiences. The experiences shared by family informants highlighted institutional processes, such as making families travel to them; requiring people to move but holding on to textual records; the fallacy of choice in relation to travelling to access services; the ways in which pre-determined categories shape experiences; and the role of entry points when disabled children and their families engage in human movement. To gain a deeper understanding of these experiences and the work disabled children and their families who engage in human movement do in their everyday lives, I will further explore some of the emerging areas of inquiry.

In what ways do migrant families work to support service systems?

What becomes apparent through family informants’ accounts of their everyday lives is the work they do support various service systems. Although we hear about this work from all the family informants in the IECSS project, this work can look different for families who have migrated. This work emerges in the form of assimilating to what the Canadian system asks of them, adapting to different ways of being compared to their home community, engaging with providers in a new community, and moving texts from community to community. Without this work done by migrant families following migration, there would be gaps and disruption to service systems and to the care provided to children.

The analysis presented in this dissertation made visible the many ways in which migrant families work to support the service system, such as complying with societal beliefs of what it means to be Canadian. Ideologies such as “good citizen” and “good parent” are ruling relations that are embedded within institutional processes (DeGeer, 2019). Further, there is ongoing public discourse focused on the increase in immigration to Canada, including ongoing discussions about how this increase in immigration to Canada (Government of Canada, 2022a) is driven by particular discourses, such as Canada being a “dream” country to live in and in which to raise children. This discourse is present across institutions and media. This immigration is driven by several factors, such as better opportunities for children, job prospects, or family reunification. However, we also know from examination of immigration policies that disabled children and adults are placed at a disadvantage (Government of Canada, 2019). The ideologies embedded within immigration policy are then embedded into service systems (DeGeer, 2019) through the dominance of English within service systems, for example. The push to assimilate through multicultural policies takes people away from their own culture and heritage, in an effort to remove negative connotations of what it means to be an immigrant (Cui, 2024). The result of this is that families and disabled children are put in a position where they must comply with the societal beliefs of what it means to be Canadian to support service systems. Although formal processes are in place to request and receive interpretation services, it is not guaranteed that families will receive this as English is privileged within institutional spaces in Canada. However, we know from previous research that language impacts how communication happens (Gagnon et al., 2010), which may prevent families from openly expressing concerns or questions to professionals. Further, we have learned from family informants in the IECSS project about the abundant amounts of paperwork that needs to be completed as a part of the work of supporting service systems. These documents are largely presented in English and the complexity of the documents for non-native English speakers may present as a barrier (Brassart et al., 2016). Although the lack of interpretation and complex documents have been presented as barriers in previous research, the analysis presented here demonstrates that families engage in the work of complying with the expectations, specifically using English, to support service systems and gain access to services for their child.

In addition to doing work by complying with beliefs of what it means to be Canadian, migrant families change their ways of being and work to develop new informal support networks following migration. By engaging in this work, families support the service system or supplement the work of service systems by finding alternative ways to provide care for their child and themselves. Previous research focused on newcomers (Brown et al., 2020; Khanlou et al., 2015; Khanlou et al., 2017; Rivard et al., 2019; Son et al., 2018) and disability theories, such as critical disability studies and disabled children's childhood studies, have provided context for the importance of informal support networks, and more concretely the idea of interdependence (Withers & Ben-Moshe, 2019). The findings in this study contribute to our understanding of families who have also migrated across Canada and provide a more detailed picture of the processes of finding new networks following migration. Family informants who have migrated emphasize the supports they had prior to migration. These supports include family and friends. For example, the experiences shared by the family informants made visible differences in societal norms and investments in childcare across countries. Family informants described childcare being provided by other family members rather than seeking out formal institutionalized childcare in the early years. The expectations for institutional childcare may be different in Canada compared to their home country due to the institutional organization of childhood in Canada. Further, while they may have had friends and family they could reach out to for advice and guidance in their previous community, they may no longer have access to this information or support. Rather than reaching out to people they know, family informants describe the work of finding new social groups either in the form of family groups or social media platforms to get access to this information. These experiences and processes shared by the family informants highlight the importance of interdependence for disabled children and their families. While migration may interrupt the interdependence that has been established through informal support networks, families and disabled children work to develop new networks to maintain access to a larger community. These relationships become vital in navigating the institutional organization of childhood in Canada.

Families who have migrated also do the work of engaging with new formal service systems. Their role in getting information, making connections, and developing new relationships is one way in which they continue to support different service systems. Previous research focused on newcomers to Canada has found that they are not equipped with information about what is available to them and their child and how to get access to this type of information (Massing et al., 2020). My analysis contributes a Canadian perspective, similar to Massing et al. (2020), but builds on their focus on transnational migration to show the common experiences of those who engage in transnational and internal migration. The experiences make visible not only the work family informants do to engage with new service systems following migration, but also how this labour is coordinated with the work of those in other settings (Smith & Griffith, 2022).

There is limited institutional connection between families and different service systems both through internal and transnational migration. Rather, family informants must do the work to make these new connections. When disabled children and families move between provinces or municipalities, the lack of continuity and coordination of care is evident because information is not always transferred from one city to another. In some situations, there are institutional connections such as through immigration and settlement services, or between services across provinces. However, based on the experiences shared by family informants, this is not a universal experience. The process of connecting to services following a move requires families to rejoin waitlists, complete new intake processes, develop new relationships, and retell their story. The limited communication across institutions in different communities leads migrant families into work that ensures connections with new service systems can be established.

The findings and analysis presented in this dissertation made clear that different experiences of human movement are related but there are also some differences for disabled children and their families who have migrated, transnationally or internally. Previous literature and research have focused significantly on the intersection of immigration and childhood disability. However, the methodology in the current study allows us to methodically visualize the everyday activities of disabled children and their families to gain a better understanding of the work they do following migration to support service systems, such as complying with ideologies of what it means to be Canadian and engaging with new ways of being due to the organization of childhood in Canada. Although this may be a unique experience for families who have migrated transnationally, we also learned that there are shared experiences between transnational or internal migration such as engaging with new service systems following movement.

In what ways do institutions organize children and families, and do institutionally produced categories impact experiences in navigating systems and interactions with service providers?

What we hear from family informants is the key role that intake forms and pre-defined categories play in access and navigation of different service systems. As discussed earlier, borders, which are produced politically and govern institutions, play a role at the intersection of human movement and childhood disability to organize disabled children and their families. Further, other institutionally produced categories, such as citizenship status, race, class, language, and custodial status interact with experiences in navigating service systems and interactions with service providers. Based on the experiences shared by the family informants in the IECSS project, we learned that some families had to pay for pre-natal services due to the lack of citizenship status for one parent. In other situations, foster parents shared how their status meant that information was not always shared with them, limiting their knowledge on services the child previously accessed. These are just two examples illustrating the central role of intersectionality in service access for those who engage in human movement. I will describe this further below.

One way in which institutions organize disabled children and their families is through political borders. Prior to colonization in Canada, the movement of people, specifically Indigenous people, was less restricted (Howard & Lobo, 2013). However, one consequence of colonization is the power of institutionally governed borders. These politically produced borders divide cities, regions, provinces, territories, and countries. These borders regulate human movement, but more relevant to this dissertation is the way in which these borders reinforce boundaries for services. The experiences shared by family informants highlight the power of institutionally produced categories, which vary across borders. When considering Indigenous communities in Canada, these borders continue to reinforce colonial ideologies for families working to access services for their child (Haché et al., 2020). For example, the community of Timiskaming First Nation is located in Northern Quebec at the border with Ontario. Although services in Ontario may be more accessible in terms of distance, language, and family connection, children and families must access services in Quebec due to the presence of the border. The analysis presented here made visible the ways in which institutionally produced categories such as borders work to organize disabled children and their families by managing where they can access services and to reinforce colonial ideologies.

Borders are also connected to the categorization of people as citizens and non-citizens, which gives access to services. Historically, borders have played a role in regulating who can and cannot immigrate and consequently gain citizenship status in Canada (Dolmage, 2018). More specifically, disabled people and their families face greater barriers to immigration and citizenship in Canada (Hanes, 2009). The historical texts that governed immigration and citizenship have led to the belief that some people are worthy, and others are not worthy of gaining entry into Canada and citizenship status. This ruling relation continues to be embedded within policy (Government of Canada, 2022b), processes, application forms (Government of Canada, 2019a), and documents pertaining to immigration and citizenship. These perceptions and processes inherently lead to the view of categorizing people, based on characteristics such as disability and race, as citizens or non-citizens regardless of official status. In my analysis, family informants describe how others' perception of their lack of status impact their access and experiences with service systems. A key result of this categorization and perception of people as not belonging is a change in how service providers interact with them and support them. What becomes evident through the descriptions of interactions is that characteristics such as disability, race, and language begin to shape the intersectional experiences of disabled children and their families. As discussed by Connor et al. (2021), the historical and legal aspects of disability and race described earlier in this dissertation are the mechanisms through which this ruling relation continues to lead to the exclusion or mistreatment of particular groups engaging with service systems.

Institutionally produced categories play a central role in assessment and intake forms for all disabled children and their families, but there are specific differences for those who have engaged in human movement. Forms, or various textual records, are used as a key mechanism to organize the work of disabled children and their families when they are engaging in human movement. For families and disabled children immigrating to Canada, one of the first processes they must participate in is a medical exam where they are asked to identify any disabilities and report on children's development (Government of Canada, 2019a). From the start, the government uses this medical record to organize who cannot or can come to Canada. A closer examination of the findings of this dissertation also reveals ways in which family informants experienced this categorization in the documents they are required to complete. Categories such as being a foster child, location, socioeconomic status, and housing were discussed as categories leading to travel for disabled children and their families. For example, socioeconomic status presents as a category that impacts the availability and choices people can make--for example, having to move due to a lack of housing in their home community. In a smaller community there may also be fewer services available, and consequently families may move again to have access services. As Smith (2021) describes, one goal of institutional ethnography is to better understand how words used in texts are central in the organization of people's work. Specific words and categories have significant implications for the pathways of human movement disabled children and their families engage in.

More specifically, institutionally produced categories are also the basis for how travel funding is provided when disabled children and their families move. Family informants share a variety of processes involved in travelling to access services. One of the key processes leading up to the travel and following travel is travel funding. In the descriptions of accessing travel funding, family informants describe getting documentation, completing forms, and submitting receipts or evidence of the travel. However, looking across the experiences of family informants it is evident that there are different types of travel funding available to different groups, and consequently different ways of accessing the funding. Textual records such as policies and forms once again dictate how people begin to be categorized to access funding related to travel. Campbell and Gregor (2008) describe the power that these texts have in organizing people and developing the groundwork for further actions. Although this may seem invisible, the analysis presented in this dissertation begins to reveal how travelling for services is organized based on categories such as disability, type of service, employment, citizenship status, geographical location, race, and socioeconomic status. Qualifying criteria, or child and family characteristics, are the key mechanism through which families get access to travel funding. A result of different forms of qualifying criteria is that the processes to access funding are not shared across multiple institutions, adding to the work required on the part of disabled children and their families. Ultimately, institutional ethnography provides an entry point for seeing how categorization is central in the organization of work for disabled children and their families when moving.

The experiences shared by family informants made visible the many ways in which institutions organize disabled children and their families who have engaged in human movement.

We were able to see how borders, which are politically produced categories that govern institutions, can in turn govern access for disabled children and their families. Related to this, family informants who have immigrated shared that their perceived or official citizenship impacted whether they gained access to services. Again, these experiences made visible how borders work to organize disabled children and their families. Overall, what we see is that institutionally produced categories shape the experiences of disabled children and their families when they are moving, ultimately leading to more work to engage in service systems.

What are the impacts of a diagnosis on institutional procedures?

In many instances, a diagnosis serves as an entry point in specific service systems such as early intervention and disability services (Underwood et al., 2019a). Researchers from the IECSS project have written extensively about the power a diagnosis can hold in institutional procedures, such as gaining access to services, funding, and additional supports. When considering the intersection of human movement and childhood disability, a diagnosis can be seen as a ticket to get connected with other services and professionals. Within the context of migration, we see the addition of different processes that disabled children and their families must undergo, such as getting assessments validated or re-done. Further, if we look at the other side of human movement in the form of travelling to access services, the particular diagnosis or situation in conjunction with other child and family characteristics leads to disabled children and their families having to travel to gain access to services.

When disabled children and families migrate, they carry texts with them in the form of files, assessments, and reports. This work of transferring documents is often invisible to institutions, as it is not discussed by families; however, families learn through their work in the system that they must lead this process. What appears to be less evident is that the work they do in moving texts from one community to the next may not be sufficient in connecting to new supports and services. Family informants describe the process of transferring documents between provinces and territories in Canada, and across international borders. These assessment results, reports, and diagnoses are not always accepted by professionals in the new community when disabled children and their families move. Within the context of childhood, disability, and accessing services in Canada, we have learned from critical disability studies scholars (Goodley, 2011; Withers & Ben-Moshe, 2019) and previous work from the IECSS project (Underwood et al., 2019a) that institutional processes are constructed such that these texts are necessary to gain entry into service systems. Receiving that official documentation in the form of a diagnosis, for example, begins to shape the institutional engagements disabled children and their families have. Further, through the institutional maps analyzed for this dissertation we can track the different processes disabled children and their families engage in and how they connect to other experiences or processes, such as human movement (DeGeer, 2019). What becomes clear through the experiences shared by family informants is that having a valid diagnosis or a formal report is not sufficient. Rather, following human movement disabled children and their families must engage in repetitive work where they are asked to either re-do processes, such as assessments, or have those documents verified by a professional in their new community. As discussed by DeGeer (2019), what we begin to see is that the process of re-doing an assessment or getting it validated then leads to other processes, such as extending the wait for services, contradicting dominant discourses surrounding the importance of early intervention. What we learn through the story emerging in the institutional maps is the lack of a universal system or understanding of disability globally, and the lack of a universal or coordinated approach within Canada itself.

When looking at the institutional maps and experiences shared by family informants, we learn that for children with particular diagnoses and family characteristics, there is a greater likelihood of travel. In the previous chapter, I presented an institutional map in Figure 2 that outlines some of the specialized services disabled children and their families are asked to travel for. One particular example of this interaction is geographic location and what is described as complex pregnancy and pre-term birth. Institutional ethnography makes visible how one organization or agency may structure the work of another (DeGeer, 2019). When we use the concepts of work and organization to look at the experiences of families during pregnancy and the birth of a pre-term child, we see that an initial visit to a local agency shapes the consequential interactions with service providers. When a mother experiences “complexities” in pregnancy in a rural, remote, or smaller urban community, she is sent to a more specialized professional outside of her community. Based on the connection formed through this initial referral, the mother and later the child get connected to services in the larger community, starting the process of ongoing human movement to engage with services. The specialized services that may result from these interactions include specialized OB, genetics, NICUs, cardiology, respirology, neonatal follow-up clinics, temporary family housing, physiotherapy, occupational therapy, and surgery. Critical Disability Studies (CDS) helps to contextualize these processes that were illuminated through institutional ethnography. The categorization that results from identification for children and families with particular characteristics shapes their institutional engagements over time (Goodley, 2011). As outlined above, being categorized as a premature baby leads to particular pathways of institutional interactions such as connections to specialists, developmental pediatricians, and neonatal follow-up clinics. Further, being labelled as a premature baby may come with the perception that the child will be developmentally delayed, further pushing them into particular pathways such as early intervention services. Overall, what becomes visible here is that one interaction or textual record can lead disabled children and families down specific pathways which may stay with them through the early years and into the transition to school.

When looking deeper at the interaction of human movement, diagnosis, and child and family characteristics, the experiences shared by family informants also make visible the ways in which travelling to access services can lead to differential diagnosis and, consequently, differing recommendations and referrals. Leading up to a diagnosis, there may be initial contact with a central service or professional, such as a pediatrician or family doctor. Following the intake, there may be connections made to specialized services inside and outside of the home community. When examining the institutional maps, we see that there is duplication in services as well as differential diagnoses as a consequence of being sent to multiple professionals. As we follow this process in the institutional maps, we also begin to see that this duplication in services or differential diagnoses can then lead to differing recommendations and referrals. This process is governed by the ruling idea that services can treat or fix the disability or condition (Underwood et al., 2020). The process of tracing these interactions has helped to make visible what happens in the lives of disabled children and their families as a result of seeing multiple professionals in different communities or receiving multiple diagnoses from professionals in different communities. A result of these interactions and the lack of communication between professionals in different communities is additional work for disabled children and their families, as evidenced through their discussions of having to engage with multiple professionals across communities and facilitating the sharing of information across services and communities.

Making visible the ways in which a diagnosis impacts institutional procedures is important in better understanding differences between communities across Canada. Entering into the experiences of childhood disability and human movement from the standpoint of family informants highlighted that specific diagnoses are a requirement to gain initial entry into service systems, especially following movement. Although family informants described their initial experiences of getting this diagnosis, they recounted that this record was not universal, as they had to re-engage with services to get a diagnosis transferred or verified. When we then look more specifically at experiences of travelling to access services, we see diagnosis is one of many characteristics that may lead to travel. These experiences make visible the intersectional nature of childhood disability and human movement. Family informants describe being sent to multiple professionals, some belonging to the same profession, who may provide different diagnoses. As a result, we see in the institutional maps that different recommendations and referrals are made, leading to more work for disabled children and their families.

How do child and family engagement with these systems shape disabled children's identity?

For disabled children who are also engaging in human movement, there is additional work that occurs, such as travelling to different communities, meeting additional professionals, joining new spaces, and being pulled out of their school, communities, and relationships for full days or longer. Through the descriptions shared by family informants, we were also able to learn more about what the everyday lives of disabled children look like when there is human movement. What emerges is how the additional work asked of disabled children who engage in human movement begins to define disabled children's identity as medicalized and bureaucratic rather than relational and positive; as disabled children engage in human movement they are also moved through different systems as numbers.

A key point of consideration while analyzing the institutional maps presenting the experiences of disabled children and their families is what the everyday experiences of disabled children look like when they are also engaging in human movement. The visual representation in the institutional maps (see Figure 1 and Figure 2) makes clear the additional work disabled children do as they move homes or as they move from place to place to access services. Smith (2005) describes work as anything that people do that takes effort or their time. Further, as DeVault (2021) explains, as people engage in work, they build a knowledge base of how to do that particular type of work. As disabled children and their families move, whether it be by choice or not, they must begin the work of restarting processes and engaging with new services and professionals, as described previously. Although we have discussed this in relation to families, disabled children are also implicated as they do work in the form of meeting new professionals and building relationships with them and undergoing further observations or assessments. Although we know from previous work that all disabled children go through these processes (see Davies et al., 2021; Frankel et al., 2019; Underwood et al., 2018, 2019a, 2019c), for disabled children who engage in human movement, these processes are continually repeated, creating additional work for them. In addition to the work that they must do, there is a reinforcement of diagnostic categorization that begins to define their identity for them. Disabled children who have this experience are being moved from appointment to appointment, place to place, all due to diagnostic categories and the institutional requirement for particular documentation and for disabled children and families to travel to them rather than institutions going to them. The experiences shared by the family informants help to center disabled children and make their work visible within institutional processes and engagements. This builds on work emerging from DCCS by centring the everyday experiences of disabled children (Curran, 2013). Consequentially, we also begin to see how disabled children's participation in everyday experiences are organized by institutional processes and expectations.

When accounting for the work disabled children do when engaging in human movement, as described above, we also get a picture of their participation in other everyday experiences. Disabled children's participation in institutional engagements impacts how they participate in such everyday experiences (see Underwood & Atwal, 2019). Through the experiences shared by family informants and an examination of the institutional maps we see that disabled children who have engaged in human movement travel to other communities to access services, being withdrawn from childcare, school, and other programs, as well as from their family, friends, and larger community for days to weeks at a time. Previous research has looked at the impacts of disabled people travelling to access services, noting that this travel impacts people's sense of self and identity as it is strongly connected to place (Stehlik, 2017). For disabled children and their families, being asked to travel outside of their community due to diagnostic categories and the lack of supports in their home community can be disruptive for the child and family. Further, having service providers travel to children in their communities can be beneficial as the professionals may gain a better understanding of the child's environment (Boydell et al., 2006), home life, culture, and ways of being. When ongoing travel for services is prominent for disabled children, then, their diagnosis and service access begin to define what their everyday experiences look like, and in turn their identity begins to be shaped by these institutional engagements. The requirement to travel to institutions also means that disabled children may get pulled away from relationships. Relationships that have been built with both formal and informal networks are important to consider for disabled children, as interdependence is central in the care disabled children need and provide to others (Withers & Ben-Moshe, 2019). Maintaining these key relationships with siblings, peers, educators, relatives, and coaches, for example, can be fundamental for disabled children's participation in their own communities. However, the current study makes visible the different reasons (see Figure 2) that disabled children get pulled away from relationships and their community.

Colonial conceptualizations of what it means to be Canadian, such as the need to speak English, can begin to shape disabled children's identities through their interaction with service systems. We learned from the standpoint of the family informants that services and professionals encouraged the use of English in their homes over the use of their own home language. Although using their own home language may be more comfortable for them or allow them to continue to feel connections to their culture and home country, the requirement to use English with their child is presented as the best option. Research conducted by Cui (2024) presents a historical perspective on multiculturalism and the resultant linguistic assimilation for immigrant families. Upon moving to Canada, conforming to using English over a home language is dominant for children from immigrant families (Cui, 2024). Family informants shared their experiences with this dominant discourse, but it also makes visible how disabled children's early experiences may be impacted by others perception of which language should be used in families' homes. Loss of language due to forces of assimilation and multiculturalism impact how young people identify with their ethnicity and home culture (Cui, 2024). There is heterogeneity in the lives of disabled children (Liddiard et al., 2018) and it is important to further explore the role of language and how it shapes identity.

Institutional ethnography is a methodology that is interested in learning about what people do in their everyday lives and how things happen the way they do. What we learned in the current study is that disabled children are also at work when there is the intersection of human movement and childhood disability. Human movement leads to additional work for disabled children as a result of engaging with new services and professionals and organizing their childhoods. This additional work then begins to shape their identity through their participation in service systems. The additional work that results from human movement also pulls disabled children out of other everyday experiences in their family, community, and social activities. Being pulled out of these spaces and relationships to travel to access services, for example, impacts their sense of self as their everyday activities are consumed by their engagements with institutions.

Implications of the Current Study

Past research on human movement and childhood disability has pointed towards the role of policy and practice in the everyday experiences of disabled children and their families. The current study entered into the problematic of human movement and childhood disability from the standpoint of family informants to learn from the experiences of disabled children and their families and the complex network of institutional interactions they engage in. I want to briefly explore the significance and implications of the current study as they relate to the areas of research, policy, and practice.

The current study builds on the breadth of research conducted using the methodology of institutional ethnography. Using institutional ethnography was key in being able to not only learn about the institutional processes connected to childhood disability and human movement, but also as an entry point to learn about the experiences of families and disabled children themselves. Institutional ethnography is a methodology that differs from other qualitative research methods, as it starts from the standpoint of a group of people to learn more about the institutional processes and procedures (Smith, 2006). A large extent of research conducted using institutional ethnography has started from the standpoint of professionals to learn about the work they do in their everyday lives (see for example Parada et al., 2020). However, using Smith's (2005) definition of work opens up the possibilities of looking at the work done by other groups, such as families and children in their everyday lives; thus others have used institutional ethnography starting from the standpoint of mothers and families, for example (Nichols, 2015; Underwood et al., 2018; 2019a; 2020a). The IECSS project and current study start from the standpoint of families of disabled children. Through this standpoint we were able to learn about the work families do and the work that disabled children engage in when there is human movement. The analysis presented in this study helped to centre the everyday lives of both disabled children and their families, which is a central focus of disabled children's childhood studies (Runswick-Cole, 2013). Through this study and other research published by the IECSS project team, we have evidence of the power of using institutional ethnography to learn about the experiences of different groups, particularly those who have been historically marginalized.

Further, this study has built on previous work using institutional mapping to trace institutional engagement and processes as described by the family informants. Institutional maps are beneficial in tracking institutional pathways and processes, along with making visible all the work that is done from point A to point B. Institutional mapping as an approach has implications for research in the area of human movement, as it can trace the processes people engage in as they move. DisCrit calls for more research focusing on the intersection of transnational migration, disability, and race (Connor et al., 2021). A part of this research is dissecting the institutional pathways involved in this human movement and the role texts play in dictating these pathways. The current study used institutional mapping to start exploring this in relation to disabled children, demonstrating the power held in the maps of making the invisible visible. Institutional ethnography as a methodology and institutional mapping as a key analytical approach are fundamental in moving this work forward.

From a methodological position, the longitudinal nature of the IECSS project was significant in learning about the intersection of human movement and childhood disability over time. A single timepoint provides great perspectives on past and current experiences. However, the longitudinal approach used in the IECSS project helps to learn about experiences and how they change over time, and the processes that unfold through the movement process which can take years. This is significant for human movement in the current study because many of the family informants who had engaged in one form of human movement had multiple experiences of human movement over time. For example, following a move to one part of Canada, some family informants described moving elsewhere in the country for various social, economic, and political reasons such as housing and job opportunities. Further, those who travel to access services describe their ongoing experiences with travel year after year. By learning from the family informants' experiences over a longer period, we were able to gain a deeper understanding of what their everyday lives look like in relation to human movement and childhood disability. Using a longitudinal approach in examining human movement is a significant extension of previous work in the area and the current study presents a case for further research using this approach to learn about experiences with human movement.

The literature and policy reviewed in Chapter 1 and 2 set the context for the research problematic of the intersection of human movement and childhood disability in relation to the lack of universal systems across Canada (Underwood & Frankel, 2012). The experiences shared by family informants in the current study highlight the lack of universal systems such as healthcare, early childhood education and care, early intervention, education, and funding across Canada, as well as the lack of value placed on texts produced in other countries. What we see when disabled children and their families engage in human movement is the additional work they must do and the differences in criteria and processes across Canada and between Canada and other countries. As a result, one of the key implications of this study from a policy perspective is the unification of policy related to childhood and disability across Canada across different service systems. As we saw in Figure 2 childhood and disability intersect with multiple service systems not just education and early intervention. For example, we know that an official diagnosis presents as qualifying criteria to gain entry into service systems in a lot of situations (Underwood, 2019a), thus, we need to ensure that there are policies and processes in place that allow for the acceptance of reports and assessments from across Canada and globally. Asking disabled children and their families to re-engage in work that they have already done has an impact on their overall access and support following human movement. Further, we also see the work attached to the sharing of information when there is human movement within Canada, once again due to the lack of universal systems and coordination. As such, another implication of the current study is the need for a more coordinated system across Canada. Through policy, healthcare professionals, educators, early intervention professionals, and other support professionals should have mechanisms in place to transfer information, with the consent of the family, when human movement is happening.

Previous policies and literature also brought our attention to immigration policy in relation to human movement and childhood disability, while also highlighting the lack of policies addressing internal migration and the intersection with human movement and childhood disability. Research conducted by Dolmage (2018) contextualizes how immigration policy has shaped the experiences of disabled people trying to immigrate to Canada and their experiences following immigration. We see similar stories about the experiences of families who have immigrated to Canada and have a disabled child trying to gain citizenship status within Canada and being denied due to the burden it could put on Canadians (CBC News 2011; 2016). The family informants in the current study shared their experiences interacting with the immigration system and how citizenship status is a criteria to access certain programs, such as the healthcare system. Further research is required to better understand the interactions with the immigration system prior to and soon after transnational migration. The family experiences shared in the current study highlight the need to re-examine current policies and forms related to immigration and criteria used to assess qualification for equal access to programs. In terms of internal migration, the experiences shared by family informants set a foundation as to why a policy is required to support disabled children and families who move within Canada. As discussed in Chapters 4 and 5, disabled children and families who move internally must engage in additional work to gain access and supports following their move. The family informants also show the gap in information available to families who are considering moving or have moved. Ensuring that there is a policy outlining the roles and responsibilities of service systems to support the coordination of services through a move and the responsibilities of service systems when disabled children and families enter their system from other communities in Canada would help to reduce work on the part of families and disabled children and ask institutions to do more work on their behalf. Guidelines that support service systems, disabled children, and their families during internal migration can close the gap and reduce the work that these different groups must engage in during this process.

Building on the implications from policy, it is also important to consider what the analysis presented here means for practice. Based on the findings and analysis presented in Chapters 4 and 5, there are several implications for practice. First, building on the discussion on universal service systems above, the findings of this study emphasize the importance of direct communication between services and professionals. Family informants shared the process of signing consent to share forms for various professionals, yet they also described doing the work of moving textual records from service to service in different communities. Further, family informants discussed being asked to pay to gain access to their child's documents and their own when moving and needing to provide this information to other professionals. These textual records should not be "owned" by any one professional or service as they are a record of the child and family. The work described by families in these situations highlights the need for more open communication between professionals in different service systems and communities to better facilitate care for disabled children and their families, and to reduce the amount of work they have to do when engaging in human movement.

Second, the experiences shared by the family informants highlighted the processes they engage in to go to institutions for services and the work connected to this. Figure 2 provides an overview of the services family informants described travelling to, many of which were considered specialized services. This finding highlighted the extent of travel that occurs and the intersection with child and family characteristics. Based on what we learned from the family informants, it is important for services and professionals to go to disabled children, at least some of the time, rather than making families travel. Boydell et al. (2006) emphasize the importance of services and professionals going to children to gain a better understanding of the child's environment, which in turn help with learning about their home life, culture, and ways of being. The institutional maps provide a powerful mechanism to track how families move through the system. What I learned was that certain characteristic, such as location, SES, and diagnosis lead to higher instances of travelling to access specific types of services, which I described in Chapter 4 as specialized services. The list of these services (see Figure 2) can be used as a starting point to understand which services disabled children and their families are asked to travel to and then develop strategies in practice to reduce this travel. For instance, in communities where many families discuss the lack of a NICU in their community, conversations need to happen to determine ways to ensure that children and families can continue to access specialized services in their home community following the child’s return to home. One way to begin to work towards this in all communities across Canada is having local centralized points for early childhood services. Creating these spaces would also further support coordination of services, communication amongst professionals, and engaging with children and their families in their own communities.

Lastly, as we consider the importance of going to the child’s community and environment, we need to explore the use of more diverse approaches to service delivery and understanding intersectionality in relation to the experiences of disabled children and their families. A consequence of using more diverse approaches is ensuring that processes used by institutions are more inclusive of disabled children and their families with intersectional experiences. Two key examples emerge when we consider this implication for practice. Family informants in the study discussed the importance of their home language in their everyday lives. However, current institutional ideologies reinforce that English needs to be the primary and dominant language for Canadians. Ultimately, due to these institutional ideologies, proficiency in English is viewed as linguistic capital in public spaces (Cui, 2024). Rather than reinforcing this dominant ideology, services should support the use of a family’s home language in services such as speech therapy. Further, ensuring that there is access to interpretation services when requested would help to support the participation of families in institutional processes and reduce the work families engage in while taking part in these processes. These are two examples of how services could be more inclusive of families who immigrate to Canada and have different experiences based on what we heard from family informants. Their intersectional identities bring value to service systems such as early childhood education and care services, and thus more inclusive approaches should be used to engage them in services and programs.

The implications outlined for research, policy, and practice also highlight the key original contribution of the current study, the role of different forms of human movement in the lives of disabled children and their families. Previous research has looked at transnational migration and travelling to access services, without direct regard for internal migration or the overlap between these different forms of human movement. The analysis presented in the current study drew on each of the experiences separately but also outlined how there are common experiences shared through human movement such as the work disabled children and their families engage in through human movement, the role of textual records, and how intersectionality impacts experiences. Looking across these three forms of human movement in relation to the experiences of disabled children and their families made visible the ways in which disabled people's lives are organized by institutions.

Overall, the current research study provides a starting point for making changes in research, policy, and practice. From a research perspective, the methodology of institutional ethnography allows us to enter the research problematic from a particular standpoint and gain a deep understanding of institutional processes and how they impact the work people do in their everyday lives. With respect to policy, the findings from the study point to changes needed to support universal access to services; the adjustment of immigration policies and documents to be more inclusive of disabled people; and the development of policies related to internal migration. Development of more inclusive policies could have impacts on the organization of disabled children’s lives. From an everyday perspective, concrete implications for practice were outlined to ensure that the work disabled children and their families do is centred, while also focusing on how to reduce the work they are asked to do in their everyday lives. Through universal, centralized, coordinated, and diverse approaches to service delivery we can move towards a system which is more accessible and inclusive for all disabled children and their families.

Future Directions

The current study presents a starting point to build on for future research. Although this study captured the experiences of disabled children and families across Canada who have engaged in different types of human movement, further research in this area can help to develop a stronger understanding of the experiences of disabled children and their families, as well as of the implications of policies and practices related to human movement and childhood disability.

The current study started with the standpoint of the family informants, which helped to also gain a better perspective of what the everyday lives of disabled children who engage in human movement look like. Future research can build on these findings by conducting a more in-depth analysis of disabled children’s participation in everyday experiences and the work they do accessing services in relation to human movement. For example, the current study and previous research has highlighted that the work disabled children do to access services while moving impacts their participation in everyday experiences, such as their relationships. Further, family informants also provided insight into how engaging with institutions took them away from formal and informal support networks. Focusing on the role of institutions in shaping relationships for disabled children and their families would help to better understand the importance of interdependence and the impact on a child’s larger network of relationships and support.

When the work of disabled children and their families who have engaged in human movement was made visible through the analysis presented here, we saw how there are overlaps in the experiences across the different types of human movement—transnational migration, internal migration, and travelling to access services. At the same time, the analysis also presented some of the nuances of the experiences that were connected to both family and child characteristics as well as the type of human movement. When we consider the findings and analysis presented in this dissertation and previous research, there remains space to explore the problematic of the intersection of human movement and childhood disability further with particular focus on the intersectional nature of the experiences. Engaging with professionals and policy makers could provide a different standpoint to enter into these experiences in future research and build on the experiences shared by family informants.

Entering into this research, I began with a particular interest in families and disabled children who had migrated transnationally because of my family history with immigration and my work with newcomer families in Peel, a community that continues to become home to many newcomers to Canada. Based on the analysis presented here and literature on disability and transnational migration, it would be beneficial to use an institutional ethnography methodology to connect with families and disabled children who are starting the process of transnational migration and those who recently migrated transnationally and are working to complete the processes to gain citizenship status for themselves and their children. An examination of the documentation and processes involved in transnational migration provided perspective on who is deemed competent and "good enough" to migrate to Canada, but learning more about this process from the standpoint of family informants and disabled children would provide a different entry point into learning about the institutional engagements and ruling relations operating within the immigration system. As I engaged with the experiences shared by family informants, I was also interested with the intersection with gender. More specifically, I was interested in the experiences shared by fathers who were also newcomers to Canada and the work they did to navigate service systems in Canada. However, gender did not emerge in the conversations with the family informants. Future research focused on the role of newcomer fathers would support the development of our understanding of the experiences of families who have engaged in transnational migration and the intersection of gender with human movement and childhood disability.

Further exploration of the problematic of human movement and childhood disability would be beneficial to the field of disability studies, early childhood studies, and migration studies across Canada and globally. The three outlined approaches above would build on the current dissertation and make a significant contribution to research, policy, and practice. As the landscape of Canada continues to change and with increases in movement within and to Canada, we need to continue to better understand the experiences of disabled children and their families who are engaging in human movement.

Conclusion

The current study set out to learn from the experiences shared by family informants from the Inclusive Early Childhood Service System project who had engaged in human movement. Entering these experiences from the standpoint of family informants, the problematic of human movement and childhood disability arose. Using the concepts of work, ruling relations, discourse and texts from institutional ethnography, the institutional maps, interviews, and attribute tables revealed the complex networks of institutional engagements disabled children and their families participate in during their everyday lives. Although the experiences of transnational migration, internal migration, and travelling to access services have differences, the analysis presented here also demonstrates the ways in which these experiences overlap for disabled children and their families interacting with various service systems. The findings of the current study have implications for research, policy, and practice, and are important for us to continue to focus on as disabled children and their families continue to do work institutions ask of them as they move through the system.

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APPENDIX A

INTERVIEW SCRIPT

Introduction

Thank you for agreeing to meet with us again this year. We would like to ask you some questions about the changes that you have experienced over the last year and any new ideas you might have about how the early childhood education and care system can be more inclusive. In particular, we are interested in your goals for your child and the supports that they get in childcare and other early years programs.

1. Since I have not spoken to you since last year, could you refresh my memory and tell me a bit more about your child?

- Tell me about the changes that you have seen/experienced in the last year.
- Is your child or your family participating in any new activities or programmes this year? Are there other programs/supports you wish your child had?
- Are you getting the support you want?
- Tell me about how you accessed this support. What did you have to do, and what did others do to get this service?
- What changes over the last year led to changes in programmes or access to services? Note: be careful not to describe their experience in terms of emotions (e.g. that must be hard, if they haven't said that it is hard).
- What do you think are important experiences or skills for your child to have at this time e.g. some children might be learning to feel comfortable in new situations? Is your child getting this opportunity?
- Do you have the information you think you need to support your child? (Probe: Are you looking for more information or support? What kind of information?)
- Does your child attend school (JK)? What have been his/her major successes?
- If not yet, what do you imagine will be his/her biggest successes at school?
- What do you imagine will be his/her biggest challenges?

2. We are interested in understanding how early childhood services support children and their families. We have developed a map of the services that you told us about last year. Looking at this map, can you tell us:

Are there any services that we did not put on the map that you are accessing? There is a list on the back of this page that you can use as a reference. Can you tell us when you started this service? (Interviewer to add it to the map, then ask the questions below).

- Does your child still attend these services? How often and for how long do they attend?

- What is your child's experience in these programs? (Probe: social relationships, fun, engagement).
- What are the staff like in the program? (Probe: Responsive to your child? Responsive to your family? What does responsive look like for you? Specific teacher/educator/therapist behaviours and your perception of whether they are effective/helpful, what does your child think of these services?)
- When you look at the map, can you describe how you came to get these services? How do you usually get information about services?
- Who coordinates your scheduling and sharing of information between services/agencies?
- How do you keep all of the information about these services organized? (e.g., a binder, a file folder, etc. What is in your information dossier and how do you use it?)
- **In which of these services have assessments been done with your child?** Tell me about that experience (Probe: purpose, information gained, use of the information in services).
- What other supports do you have that help you to access these services? (e.g., grandparents, work colleagues, neighbours, etc.)
- If your child is attending school, what services do you have through the school? Have you attended any meetings at the school? (Tell me about them, who was there, why? what information did you get, were decisions made?)
- Have you received any written documents specifically about your child (IEP or IPRC)?

3. When you are thinking about access to services, what characteristics of your family do you think affect your access?

- Where you live? Distance to services?
- The number of adults in your house? The number of children in your house?
- Your work situation?
- Your family's language or culture?
- Your finances?
- The information you have about what is available?
- The rapport you have with service providers? (e.g. alignment with your child rearing values, or your cultural viewpoint?)
- Availability of services?
- The way other people understand your child?

Are there any other family experiences that you have had over the past year that might affect your access to services? (Some examples might include housing concerns, moving, employment changes or loss of jobs, divorce or separation, birth of a child, death of a family member, or interactions with service providers, etc.)

PROGRAMS AND SERVICES CHECKLIST

Health Services	
Family Doctor	
Pediatrician (ex: developmental or other pediatric specialist)	
Drop-in health/infant clinics	
Psychologist (ex : developmental or child)	
Maternity Ward/Delivery Room	
Emergency Room	
NICU	
Air and Ground Patient Transfer (ex: Medevac)	
Neonatologist	
Ophthalmology/Optometry/Eye surgeon	
Nurse Practitioner	
Nurse (e.g, RN)	
Cardiologist	
Respirologist	
Geneticist/Genetic Analyst	
Endocrinology	
Oncology	
Gastronomy	
Child Life Specialist	
Osteopath	
Dermatologist	
Naturopath	
Chiropractor	
Surgeon/Surgery	
Allergist	
Ear/nose/throat	
Psychiatrist	
Local Health Integration Network (LHIN)	
Audiologist	
Neurologist	
Researcher	

Pre/post-natal	
Breastfeeding Clinic, Lactation Consultant	
Prenatal Programs/Pregnancy Clinic	
OB/GYN	
Midwife	
Doula	
Public Health Nurse	
Home Visits after Birth	

Therapeutic, early intervention, and disability services	
Occupational Therapy	
Orthotist/Orthotics/Orthopedics	
Physical/Physio Therapy	
Blind/Low-Vision supports for children	
Hearing screening and/or supports	
Speech pathologist	
Communication Disorders Assistant	
Autism	
ABA	
IBI	
Other behaviour supports	
Infant or Children's mental health services	
Respite	
Healthy eating/dietician/nutritionist services	
Feeding support	
Infant and Child Development program	
Children's Treatment Centre	
Music Therapy	
Listening Therapy	
Vision Therapy	
Bio-feedback/Neurotherapy	
Therapeutic horseback riding	

Dentist/Orthodontist	
Medication/Pharmacist	
Hospital (other)	
Therapeutic, early intervention, and disability services (continued)	
Dental Screening	
Developmental Screening (Nippissing LookSee, ASQ)	
Occupational Assessment/ Consultation	
Speech assessment	
Conductive Education Therapist	
Consultant	
Intake Worker	
Service Coordinator	
Referral Services	
Massage Therapy	
Oral Myofascial Therapy	
School Services	
School Board (if they have had direct contact)	
Resource Consultant/Teacher/Educator	
Classroom teacher	
Early Childhood Educator	
Educational Assistant/Special Needs Assistant/Lunch Assistant	
Principal	
Kindergarten	
Junior Kindergarten	
Senior Kindergarten	
Grade 1 to 3	
Grade 4 to 6	
Individualized Education Plan (IEP)	
Identification Placement and Review Committee (IPRC)	
School Psychologist	
Itinerant support (e.g. speech, OT, behaviour specialist, hearing, ESL)	

Snoezelen/Sensory Room	
Personal Support Worker/Home worker	
Assistive Devices	
Community Care Access Centre	
Enhanced 18 Month Well Baby Visit	
School Services (continued)	
Librarian (In school)	
Home School	
Meetings	
Parent Council	
School Bus	
Early Childhood education and Care	
Preschool/nursery	
Nanny or babysitter	
Child care – centre-based	
Child care – home based	
Child Care – Before & After School	
Montessori, or other alternative Early Childhood program	
Individual Program Plan	
Individualized Family Service Plan	
Resource Consultant (in childcare)	
Drop-in and Play Programs	
School Readiness/Pre-Kindergarten Programs	
Family Support	
Parent Information Workshop	
Young parent supports	
Ronald McDonald House	
Child and Family Programming (ex: Early ON Centres)	
Online Forums/Groups	
Travel Support/Flight Assistance	
Parenting Supports (Other)	
Grants and Subsidy	
Food subsidy (including food banks, and other food security programs)	
Housing subsidy	
Child Care Subsidy	

Multiple Exceptionalities Coordinator	
Secretary	
Home School	
Alternative Programs (e.g. ESL, DD Class)	
Academic Programs (e.g. Math, Literacy)	
Tutor (eg. Kumon)	
Grants and Subsidy (continued)	
Assistance for Children with Severe Disabilities (ACSD)	
Child Disability Benefit (CDB)	
Special Services at Home (SSAH)	
Provincial Child Tax Benefit	
Funding for Recreation	
Dental funding (ex: healthy smiles)	
Easter Seals	
IBI funding	
Indigenous and Northern Affairs Canada (INAC)	
Travel Grant	
Ministry of Health and Long-Term Care Grant	
Assistive Devices Program	
Special Equipment Amount Funding (Education)	
Funding (Other)	
Community, social and justice services	
Church/temple or other religious support	
Addiction support	
Mental Health Support for adults	
Counselling (ex: family, crisis)	
Supports for adults with disabilities	
Domestic violence supports	
Housing Programs	
Shelters	
Employment Services	
Community Living	
Police/Fire/Ambulance Services	
Community Centres	
Recreation programs	

Childcare Support Funds	
Private grants (President's Choice, Eater Seals, etc.)	
Social Assistance _ employment	
Workplace Benefits	
Social Assistance - Welfare	
Disability Tax Credit	
Employment and Income Assistance for people with disabilities(ex: ODSP, EIA, BCEA)	
Community, social and justice services (continued)	
Social worker	
Child and Youth Worker	
Child protection services	
Fostering services	
Adoption services	
Family Support Worker/ Investigation Worker/Protection Worker	
Government Officials [interacted with]	
Legal Aid	
Family Court	
Restorative Justice	
Probation	
Penitentiary	
Financial Resource Worker/Accountant	
College (Participant attending)	
Associations [supporting a specific group]	
Events/Conferences	

Swimming	
Camps	
Special Needs Camps	
Volunteers	
Playground Rebuilding	
Fitness Centres	
Public libraries	
Book Bank	
Big Brother, Big Sister	
Cultural services (e.g. Indigenous (formerly called Aboriginal) or Francophone services)	
Immigration or newcomer services	
Cultural activities (e.g. Pow Wow)	

PROGRAMS AND SERVICES CHECKLIST

The following table contains information about the services that you have described to us in previous interviews. Please check that we have included all services, and that the information in the table is accurate. You may also look at the map that we have created for reference when filling out this table.

Agency/Program:	Personnel Involved:	Textual Record (type: diagnostic, intake, meeting, assessment, IEP, etc.)	Start date for service	End date for service	Frequency (Number of visits/month/ year) may include # of blocks	Duration of each visit (approx.)	Wait-time	Travel time and means	Cost

Version date: Feb 17, 2023

PROGRAMS AND SERVICES QUESTIONNAIRE

Please respond to the following questions as they relate to your experiences in accessing supports for your child **over that past year**.

Family Outcomes

	Almost Always	**Usually**	**Sometimes**	**Seldom**	**Never**	**Not Applicable**
Many people feel that talking with another person helps them deal with problems or celebrate when good things happen. How often does your family have someone your family trusts to listen and talk with when they need it?	❍	❍	❍	❍	❍	❍
Families sometimes must rely on other people for help when they need it. For example, to provide a ride, run an errand, or watch their child for a short period of time. How often does your family have someone they can rely on for help when you need it?	❍	❍	❍	❍	❍	❍
Most families have things they enjoy doing. How often is your family able to do the things your family enjoys?	❍	❍	❍	❍	❍	❍
All children need medical care. How well does your family's medical care meet your child's special needs?	❍	❍	❍	❍	❍	❍
Many families want their child to play with other children or participate in religious, community, or social activities. How often does your child participate in these activities right now?	❍	❍	❍	❍	❍	❍

Additional Comments:

Please respond to the following questions for the service that you are **currently accessing most frequently**

Program or Service Name	Name and site: Postal code:
Time spent	Start date: End Date: Number of visits (per week or month): Time spent at each visit:
Referrals	Who referred you to this program/service? What programs/ services were you referred to through this program?
Assessment	Has your child undergone a developmental assessment through this service? Yes No Did the assessment help you to access programs/services? Yes No Did the assessment give you information that was useful to you? Yes No
	How much do you pay for this service?

Processes of Care

To what extent do the people who work with your child…	**To a Very Great Extent**	**To a Great Extent**	**To a Fairly Great Extent**	**To a Moderate Extent**	**To a Small Extent**	**To a Very Small Extent**	**Not At All**	**Not Applicable**
…help you feel competent as a parent?	○	○	○	○	○	○	○	○
…provide you with written (or verbal) information about what your child is doing?	○	○	○	○	○	○	○	○
…let you choose when to receive information and the type of information you want?	○	○	○	○	○	○	○	○
…make sure that at least one team member is someone who works with you and your family over a long period of time?	○	○	○	○	○	○	○	○
…provide opportunities for you to make decisions about your child?	○	○	○	○	○	○	○	○
…give you information about the types of services offered at the organization?	○	○	○	○	○	○	○	○
…give you information about the types of services offered in your community?	○	○	○	○	○	○	○	○
…have information available about your child’s disability (e.g., its causes, how it progresses, future outlook)?	○	○	○	○	○	○	○	○
…have information available to you in various forms, such as a email, app, etc.?	○	○	○	○	○	○	○	○
…provide advice on how to contact other parents (or organizations such as parent resource library)?	○	○	○	○	○	○	○	○

DEMOGRAPHIC QUESTIONNAIRE

Are you the child's: ○ Mother ○ Father ○ Other (please specify):

When was your child born? Month: Day: Year:

Which of the following best describes your family situation?

○ One Parent ○ Two parents at a home ○ Two parents sharing custody ○ Other (please specify):

How many siblings does your child have?

○ None ○ 1 ○ 2 ○ 3 ○ 4 More, specify ☐

Does anyone else in your family have special needs or a disability? Explain:

☐

In which community do you live or access services?

○ Wellington
○ Brandon
○ Toronto
○ Yellowknife
○ Hamilton
○ Comox Valley
○ Timiskaming
○ Powell River
○ Constance Lake
○ Other(s): ☐

What is your postal code? ☐

What best describes yours (and your partner's) work situation?
Please mark your partner's work situation with a P

○ Working full time
○ Working part time
○ Looking for work
○ Working as a parent at home
○ Self-employed
○ Employed outside the home
○ Student full-time
○ Student part-time
○ Other (please specify):

How long have you lived in this community?

○ Less than 1 year ○ 1 to 3 years ○ 3 to 5 years ○ More than 5 years

In the last 3 years, how often has your child moved to a different home?

○ Never ○ Once ○ Twice ○ 3 times ○ 4 times ○ 5+ times

What best describes where you live?

○ Rent
○ Own
○ Other, please specify (e.g. live with family or friends, no permanent housing, shelter, in transition)

☐

How long have you lived in Canada?

○ Always ○ More than 10 years ○ 6 – 10 years ○ 3-5 years
○ 1-2 years ○ Less than 1 year

What is *your* highest level of education? Choose only one answer.

○ Elementary ○ Some High School
○ High School graduate ○ Some post-secondary (college or university)
○ Graduated college ○ Graduated university
○ Post graduate or professional degree

What is the highest level of education in *your household*?

○ Elementary ○ Some High School
○ High School graduate ○ Some post-secondary (college or university)
○ Graduated college ○ Graduated university
○ Post graduate or professional degree

What is your total household income before taxes?

○Under $5,000 ○ 5,000 to $9,999 ○ $10,000 to $14,999 ○ $15,000 to $19,999
○ $20,000 to $24,999 ○ $25,000 to $29,999 ○ $30,000 to $34,999 ○ $35,000 to $39,999
○ $40,000 to $44,999 ○ $45,000 to $49,999 ○ $50,000 to $59,999 ○ $60,000 to $69,999
○ $70,000 to $79,999 ○ $80,000 to $89,999 ○ $90,000 to $99,999 ○ $100,000 to$144,999
○ $150,000 to $199,999 ○ $200,000 to $249,999 ○ $250,000 and over

What is the language(s) most often spoken in your home? You may choose more than one.

○ Albanian ○ Arabic ○ Bengali ○ Cree ○ Chinese ○ Mohawk
○ English ○ French ○ Greek ○ Gujarati ○ Hindi ○ Korean
○ Ojibway ○ Persian (Farsi) ○ Portuguese ○ Punjabi ○ Romanian ○ Russian
○ Serbian ○ Somali ○ Spanish ○ Tagalog ○ Tamil ○ Turkish
○ Urdu ○ Vietnamese
○ Other(s): ☐

Which of the following best describes your racial identity: (Pick one only.)

○ Indigenous (formerly called Aboriginal)
○ Asian- East (e.g., China, Japan, Korea)
○ Asian- South (e.g., India, Pakistan, Sri Lanka)
○ Asian- South East (e.g., Malaysia, Philippines, Vietnam)

○ Black - Africa (e.g., Ghana, Kenya, Somalia)
○ Black - Canada
○ Black - Caribbean Region (e.g., Jamaica, Trinidad and Tobago, Barbados)
○ Latin American (e.g., Argentina, Chile, Costa Rica)
○ Indian-Caribbean (i.e., Guyana with origins in India)
○ Middle Eastern (e.g., Egypt, Iran, Israel, Palestine)
○ Mixed background
○ White - Canada
○ White - Europe (e.g., England, Greece, Italy, Portugal, Serbia)
○ Other(s):

What is your ethnic or cultural background? You may write more than one. Fill in the box.

(For example, African, Arab, Canadian, Chilean, Chinese, Cree, Dutch, East Indian, East African, English, Filipino, French, French-Canadian, German, Greek, Grenadian, Inuit, Irish, Italian, Jamaican, Lebanese, Mennonite, Metis, Micmac, Mohawk, Ojibway, Polish, Portuguese, Russian, Scottish, Somali, Ukrainian, Vietnamese, West African etc.)

APPENDIX B: CONSENT FORM

Version Date: Feb 17, 2023

Inclusive Early Childhood Services System Project
Interview participant consent

Thank you for coming today!

Dear Parents and Guardians:

We would like to interview you for a research study. Before you consent to become a study participant, it is important to read the following information. Please ask as many questions as you want. We want to make sure you understand what you are being asked to do. Please let us know if you require child care and/or a translator.

INVESTIGATORS: This study is a partnership between Toronto Metropolitan University, University of Guelph, McMaster University Carleton University, several municipal governments (Wellington County, City of Toronto, District of Timiskaming, City of Hamilton) and community organizations (Brandon Friendship Centre, Childcare Resource and Research Unit, Comox Valley Child Development Association, Native Child and Family Services, Niwasa Kendaaswin Teg, Keepers of the Circle (Temiskaming Native Women's Support Group), Toronto District School Board, Yellowknife Women's Society and Macaulay Child Development Centre). The researchers on the project are Kathryn Underwood, Nicole Ineese-Nash and Elaine Frankel from the School of Early Childhood Studies, Toronto Metropolitan University, Karen Spalding (Ted Rogers School of Management, Toronto Metropolitan University), Gillian Parekh (Faculty of Education, York University), Magdalena Janus (Offord Centre, McMaster University), Patty Douglas (Faculty of Education, Brandon University), Brenda Poon (Healthy Early Learning Partnership, University of British Columbia, Tricia van Rhijn (Family Relations and Applied Nutrition, University of Guelph), Virginia Caputo (Dept. of Sociology and Anthropology, Carleton University), Arlene Hache (Keepers of the Circle), Joanne Weber (Faculty of Education – Educational Psychology Department, University of Alberta) and Martha Friendly (Childcare Resource and Research Unit).

This research is funded by the Social Sciences and Humanities Research Ethics Board, Partnership Grant #895-2018-1022. If you have any questions or concerns about the research, please feel free to contact Kathryn Underwood (Principal Investigator) at inclusion@torontomu.ca, toll-free 1-833-671-8003 or (416) 979-5263.

PURPOSE OF THE STUDY:

The purpose of the study is to understand families' experiences of institutions that are focused on their children's disability, special need, or gifts. We are asking parents or guardians about their experiences getting support for your child. Examples of support include:

- A resource consultant
- Autism support services
- Speech and language
- Behavior supports
- Physical therapy
- Mental health services
- Occupational therapy
- Indigenous (formerly called Aboriginal) family supports
- Other advice or assessment related to your child's growth or development

We will interview an average of 15 participants in each of nine geographic areas (Wellington County, City of Hamilton, City of Toronto, Peel Region, District of Timiskaming, Constance Lake First Nation/Hearst, Brandon, Powell River, Comox Valley, and Yellowknife). Results of the study will contribute to social policy recommendations, academic publications, and may be used in graduate student research for theses or dissertations. We would like to interview family members once per year for three years, in the preschool stage of the project, and once per year for three years in the school-age stage of the project with possibility of another additional three years in the school-age stage of the project.

WHAT YOU WILL BE ASKED TO DO

In the interview you will be asked about:

- Your child's current development and engagement with services related to their development
- How support happens for your family
- Your interactions with professionals and service organizations

After the interview, we will ask you to complete a questionnaire. The questionnaire asks about your interactions with services, the amount of support your family has, and demographic information for the purposes of understanding characteristics of the group of families in our study.

You may view a video description of the project online at http://inclusiveearlychildhood.ca/videos/.

By agreeing to participate in this research, you are not giving up or waiving any legal right in the event that you are harmed during the research.

CONFIDENTIALITY:

COVID-19 UPDATE At this time phone interviews will continue to be the primary approach to interviews with the option for in-person interviews at the request of participants.

- Maintaining participant data remains of the upmost importance to the project: all material is still being kept on password protected USBs and will be transferred using encrypted software. Work is being done remotely using secure networks.
- We will summarize information from the interviews and surveys at a community level. We may use individual data to present examples of experiences that are representative of the group. We will ensure these data do not identify individuals.
- The interview is 1.5 to 2 hours long and will take place in a public place, or a location that is convenient to you. The interview will be private and will not be overheard by other members of the community.
- The actions and/or questions used in this study are not experimental in nature. The only experimental aspect of this study is the gathering of information for the purpose of analysis.
- We will audio record the interview. We will take audio recordings back to our offices and transcribe them (type out). We will ask you to complete a paper survey about the types of services you have used and your satisfaction with them. The interview and survey material will be kept as part of our data collection. The transcriptions and survey copies will be kept in offices at Toronto Metropolitan University, or one of the partner universities. The materials will be password protected in computers or locked in filing cabinets.
- Researchers (listed above) and staff of the project will have access to data. Any information shared with partners will use pseudonyms, and have identifying information removed.
- All information and data collected will be destroyed within seven years of the end of the project. Confidentiality will be maintained to the extent allowed by law.
- Interviewers may be hired from within your community. It is possible that you may know them. If you do not feel comfortable with the interviewer, you may request a different interviewer.

WHAT ARE THE POTENTIAL RISKS TO YOU AS A PARTICIPANT?

- The interview questions are personal because we want a full understanding of your experiences with services to support your child. Our interviewers are trained to support you during the interview process.
- During the interview or upon reviewing recordings, if any disclosed information causes reason to suspect child abuse or neglect, a report will be given directly to the Children’s Aid Society.
- Being in physical contact with anyone at this time presents the risk of contracting an illness (i.e. COVID-19, the flu etc.). Interviewers and participants will physically distance and wear masks during any in person contact.

VOLUNTARY PARTICIPATION AND WITHDRAWAL:

- Participation in this study is completely voluntary. You can choose whether to be in this study or not.
- If any question makes you uncomfortable, you can skip that question.
- You may stop participating at any time and you will still be given the incentives and reimbursements described above. If you choose to stop participating, you may also choose to not have your data included in the study.
- You are only consenting to one interview at a time. You can withdraw your data from the study until the data has entered the group data set and been part of a publication.

- Your decision to participate in this study will not affect your access to services in your community, or your relationship with the County of Wellington, Toronto Metropolitan University, University of Guelph, or McMaster University or any other group associated with the project.
- Information from the project will be shared with early childhood education and care service providers in provinces and territories across Canada. We also plan to publish our research in academic journals and share findings with the Ministry of Education. Your name or the names of any of your family members will not be shared.

- The information you share will help researchers understand whether early childhood education and care services in your community are meeting your needs. Sharing information from this study is helpful for planning services and may be useful to service providers and policy makers.
- Explore the IECSS project website https://www.torontomu.ca/inclusive-early-childhood-service-system/ for ongoing publications, presentation etc. from the project as well as the final report for the study when the project is complete.

POTENTIAL BENEFITS:

- We cannot promise that you will receive any direct benefits from taking part in this study. But, many people want to participate in a study that may have broad benefits to society.

INCENTIVES FOR PARTICIPATION:

- We would like to give you a $30 gift certificate to say thank you for participating in our research. You will still receive the gift if you decide to leave the study. We will give you an additional $30 gift certificate for each interview.

Questions about the Study: If you have any questions about the research now, please ask. If you have questions later about the research, you may contact:

Kathryn Underwood (Project Director)
Toronto Metropolitan University
350 Victoria Street
Toronto, ON M5B 2K3
Tel: 416-979-5000 ext. 552519
Email: kunderwood@torontomu.ca

This study (REB # 2014-344) has been reviewed by the Toronto Metropolitan University Research Ethics Board. If you have questions regarding your rights as a participant in this study please contact:

Toronto Metropolitan University, Research Ethics Board
c/o Office of the Vice President, Research and Innovation
Toronto Metropolitan University
350 Victoria Street
Toronto, ON M5B 2K3
416-979-5042
rebchair@torontomu.ca

The following ethics boards have also reviewed the study:

University of Guelph, Research Ethics Services
Director, Research Ethics
437 University Centre
Guelph, ON N1G 2W1
Tel: 519-824-4120 x56606
Email: reb@uoguelph.ca

Hamilton Integrated Research Ethics Board
Office of the Chair of HiREB
Tel: 905-521-2100 x42013

Brandon University Research Ethics
270 – 18th Street
Brandon MB, R7A 6A9
Tel: (204) 727-9712
Fax: (204) 728-7340

Northwest Territories Scientific Research Licence
Aurora Research Institute – Licence No. 16764
PO Box 1450 Inuvik NT, X0E 0T0
Tel: (867) 777-3298
Fax: (867) 777-4264

University of British Columbia
#102, Technology Enterprise Facility III
6190 Agronomy Road Campus map
Vancouver, BC, V6T 1Z3
Tel: 604-827-5113

York University
Office of Research Ethics
309 York Lanes - 4700 Keele Street
Toronto, ON, M3J 1P3
Tel: 416-736-5914

Version date: Feb 17, 2023

Inclusive Early Childhood Services System Project

Interview consent

Agreement:

Your signature below indicates that you have read the information in this agreement and have had a chance to ask any questions about the study. Your signature indicates that you agree to be in the study.

It also indicates that you were told that you can withdraw your consent to participate at any time. If this occurs your information will not be used in the final analysis and report. All other data collected from you will be destroyed.

You have been given a copy of this agreement.

You have been told that by signing this consent agreement you are not giving up any of your legal rights.

____
Name of Participant (please print)

_______________________________________ ___________________
Signature of Participant Date

_______________________________________ ___________________
Signature of Project Director Date

I agree to be audio-recorded for the purposes of this study. I understand how these recordings will be stored and destroyed.

_______________________________________ ___________________
Signature of Participant Date

We have received approval to continue interviewing cohort 2 participants for 3 more years. We would like to contact you to interview you again next year. If you agree, we will contact next year to be re-interviewed. Participation in follow up interviews is completely voluntary. You can choose whether to be re-interviewed or not. By providing your contact information, you are consenting to us contacting you for a follow up interview:

_______________________________________ ___________________

Signature of Participant Date

____
Contact information (telephone and/or email)

May we contact you again in the future, if we do a follow up to this project. When we contact you, you can choose whether to participate or not. By providing your contact information, you are consenting to us *contacting you* for future projects or follow ups:

_______________________________________ ___________________
Signature of Participant Date

____
Contact information (telephone and/or email)

Inclusive Early Childhood Services System Project
Confirmation of Gift Card transfer

Agreement:

Your signature below indicates that you have received a $30 gift card as a result of participating in the study.

Thank you for participating in the study!

____
Signature of Participant

____
Signature of RA Interviewer