A QUALITATIVE EXPLORATION OF HOW CHILDREN BORN PRETERM TRANSITION TO PRIMARY SCHOOL: AN INSTRUMENTAL MULTIPLE CASE STUDY

by © Nicole Lewis-Power

a dissertation submitted

to the School of Graduate Studies in partial fulfillment of the

requirements for the degree of

Doctor of Philosophy

Division of Community Health and Humanities, Faculty of Medicine

Memorial University of Newfoundland

February 2023

St. John's, Newfoundland and Labrador

Abstract

Background: Given the prevalence of preterm birth, the survival rates, the complex health challenges that result from being born too soon and the costs related to this issue, it is vital the resources needed by these families are made available. These children deserve a fair and equitable education, the same as children born at term; therefore, it is essential resources and services are put in place for these families to avail of while at school and when at home. These resources and services should be available in all communities across our province.

Goals/Objectives: Research Question: How does a child born preterm (who currently has one or more disabling health challenges) and their parents experience entering the public school system?

Research Objectives:

1. To explore how families adjust to having a preterm baby with health challenges (including their time in the NICU and going home).
2. To investigate the factors within the school, their community, and the province that influence their child's ability to achieve the best possible educational outcomes.
3. To determine whether the school's size (large versus small) made a difference in how the child transitioned into school.
4. To explore whether more supports are available for the child/family depending on where they live (urban versus rural).

Methodology/Methods: This research study used a multiple-case study constructivist design. Eight instrumental, bounded cases were examined using multiple data collection methods, including direct observation, interviews, and document analysis.

Results: All families coped well with their children entering public school. While some encountered more challenges than others, their children have adapted well overall with the help of their circle of care members. This dissertation's findings include both benefits and drawbacks to attending large versus small schools, the empowerment of insider knowledge, and the need for more information regarding the services/resources available to these parents in this province. Lastly, it found that financial help is needed for these families. This project has numerous recommendations aimed at supporting the transition from home to school and ones that would be helpful to families that have children born preterm and have a health challenge.

General Summary

The number of babies born early or before term (premature) are rising and more of these babies are surviving, many living with complex health challenges. These children and their families need assistance to ensure they receive a quality education. They also need services while their child is in school and at home, and these services should be available throughout the province.

The goal of my research was to understand how parents and their children who are born pre-term experience that child entering public school. I also looked at how families adjusted to having a preterm baby with health challenges and factors within the school, their community, and the province of NL that influenced the child's ability to be successful in school. I examined if the size of the school, i.e., large versus small made a difference in how they adjusted to school and lastly, what supports were available to the child and family.

For my project I spoke to eight families and close members of their family regarding their child, including parents, grandparents, aunts, and teachers. I also looked at policies and documents used by the government and school board related to support for children with special needs. Finally, I visited one family at home to observe how they interact and to learn more about their child.

My results found all families coped well with their child entering school, with some experiencing more challenges than others. My findings include the benefits and disadvantages of attending larger community schools versus smaller community schools, the need for more information and services for parents and the need for financial help for these families. I present multiple recommendations aimed at supporting these families to help their child adapt to the transition from home to school.

Dedication

This dissertation is dedicated to my family: my parents, Bill and Gloria and to my brother, Jason. Thank you for your unconditional love and support, for always believing in me, for all your help (especially watching the kids for me), and encouragement. Without you I would not have been able to complete this project. Finally, to my children, Rachel and Joseph, you always helped me keep perspective and reminded me of our love of learning and why I started this journey. I started this journey when Rachel was a baby, and then Joseph came along. I promise that all the sacrifices we made for me to complete my PhD are worth it. I know this process has taught you both the love of learning and continued education. Mommy promises you both a trip to Disney after my graduation.

Acknowledgments

I would like to extend a sincere thank you to all those who made the completion of this dissertation a reality. Thank you to my PhD supervisor, Dr. Victor Maddalena, for his immense support, encouragement, guidance, and patience. Your guidance, kind words, and stories of your own PhD journey helped me more than you will ever know. I would also like to thank my supervisory committee members, Dr. Shree Mulay and Dr. Kimberly Maich, for their support, encouragement, and commitment. To the three of you, my thanks for all your time and patience in reviewing the many drafts and revisions of my dissertation. Your edits, comments, and suggestions were valuable and very much appreciated. Your expertise and guidance have helped me immensely throughout this research project. I am beyond blessed to have had the opportunity to work with you.

To the participants in this study, thank you for your time and willingness to share your story with me. I learned so much from you. It is because of you this research has been possible.

Thank you to the Janeway Foundation for funding this research project.

Thank you to Dr. Alice Gaudine, Dean of Memorial University Faculty of Nursing for your encouragement, guidance, and support. Thank you also to the faculty members of the Faculty of Nursing for their support and encouragement.

Lastly, a very special thank you to my family and friends, for all of your support, encouragement, and love throughout this process.

Table of Contents

List of Tables

Chapter One Introduction

1.1 Introduction to the Issue

Worldwide, billions of dollars are spent yearly on funding research in obstetrics and neonatology, exploring prevention and/or management strategies designed to improve health outcomes for mothers and their preterm babies (Manuck et al., 2018). Despite this funding and several other improvements in obstetric and prenatal care (e.g., access, technology; Johnson, 2008; Joseph, 2016), the global rates of premature births remain high. However, the survival rates of preterm infants requiring complex medical care are improving (De Jesus-Rojas et al., 2018).

The World Health Organization (WHO, 2012) defines premature birth as an infant born alive before 37 weeks gestation. Preterm infants, especially those born extremely preterm (< 28 weeks as defined by the WHO), may face several health complications due to being born too soon (WHO, 2012).

Although technological advances in neonatal intensive care units (NICUs) have contributed to the increased survival rates of extremely preterm babies, their health and developmental outcomes depend on biological and environmental factors (Cheong et al., 2020; Johnson, 2008). The NICU environment includes physical (e.g., excessive noise, bright lights, and painful procedures) and psychosocial stressors (e.g., prolonged parental separation) for the preterm infant (Coston & Aune, 2019; Johnson, 2008; Venkataraman et al., 2018). These factors, along with the complications that could arise from being born preterm (e.g., vision and hearing problems, learning impairments), may not be evident until the child is older and is not meeting developmental milestones, for example, sitting up or walking (WHO, 2012).

Once preterm babies are school-age, known health impediments (e.g., hearing impairment) may affect their school performance. Other health outcomes of being born preterm (e.g., Specific Learning Disorder [SLD]) may only become apparent once the child is in school and fails to keep up with their peers, particularly in reading and math. Several studies have concluded that children who were born preterm have lower cognitive test scores (Akshoomoff et al., 2017; Bhutta et al., 2002; Brydges et al., 2018; McBryde et al., 2020), increased behavioural problems (Ask et al., 2018; Bhutta et al., 2002; Casey et al., 2006; Jin et al., 2019; Kuban et al., 2016; Loe et al., 2019; Saigal & Doyal, 2008), and have lower academic performance scores in the domains of reading and mathematics (Akshoomoff et al., 2017; Jansen et al., 2020; McBryde et al., 2020). Studies have also found children who live with noncommunicable diseases (e.g., diabetes and asthma) may struggle with school performance. These studies show children with Type 1 diabetes may experience dysfunction in memory, attention, and processing (Foland-Ross, 2019; Roman et al., 2017). According to other studies, children diagnosed with severe asthma may have lower levels of academic achievement than their peers (Kohen, 2010; Koinis-Mitchell et al., 2019; Taras & Potts-Datema, 2005). This information is significant since preterm babies are at an increased risk of developing noncommunicable diseases, for example, diabetes (both Type 1 and Type 2) and asthma (WHO, 2012).

I became interested in this topic because I have worked with many families who have experienced preterm birth. After completing my nursing education in Newfoundland and Labrador (NL), Canada, I began my first job as a novice nurse in North Carolina (NC), United States (US). I decided to move to the US to begin my nursing career as I wanted to work with children, especially preterm babies, and the children's hospital in NL was not hiring novice nurses at that time. I worked full-time in a teaching hospital with a level-three NICU in which all babies were cared for with no exclusions for admission. I stayed in NC for two years and then moved home for six months due to a family member's illness; during this time, I worked as a casual nurse in the NICU (I was working full-time hours) for three of these months. I later moved to Halifax, Nova Scotia, and began working full time in the pediatric intensive care unit (PICU). During this time, I admitted, cared for, and discharged many former NICU babies admitted to the PICU due to their challenging health status. After four years, I returned home to NL and began teaching nursing at Memorial University of Newfoundland; I am still in this role today. I take students to the local children's hospital for their pediatric clinical experience every fall. I bring them to the medical unit, where I help care for many children, including those born preterm and admitted due to health challenges related to being born too soon. During my experiences as a nurse over the last 20 years, I have wondered what happened to the babies I cared for in the NICU and the children I cared for (in both PICU and on the medicine unit) born preterm and struggling with health challenges. I wondered what support they had and how they did once they started school: Did they have minor or major issues? Did they need extra support? Did they receive the supports they required? Were they doing well in school, and were they enjoying it?

There have been several research studies published on preterm infants and their health outcomes. There is, however, a shortage of published studies on how preterm children and their families experience school entry and how their circle of care supports them in coping with these new challenges. The articles on preterm infants and their health outcomes are related to school performance, for example, examining preterm infants' intelligence quotients (IQ) and the children's performance on standardized tests. In addition, some articles are dated (conducted in the 1990s and early 2000s), and many of these studies are not Canadian and lack qualitative data.

My study will fill some of the gaps that I found in the literature. It is important to note that a lot of research has been done on children with complex needs and disabilities and their transitions. These studies state that without appropriate access to resources these children are at risk for adverse health outcomes and possible gaps in their care (Breneol et al., 2022).

1.2 Purpose of the Study

In my research, I sought to understand how children born preterm (with one or more current disabling health challenges) and their parents experience the child entering the public school system. This research study was a multiple case study with a constructivist approach. A constructivist case study approach seeks to interpret, understand, and explore several socially constructed phenomena in human activity (Howell, 2012). A constructivist approach aims to understand all the nuances of the phenomena of interest to obtain clarification and insight into the situation, namely the facilitators and challenges these children and their parents have encountered (Howell, 2012).

This study examined how parents and their circle-of-care members' experience having a preterm infant with health challenges and how these children transition into primary public school. For the purposes of this study, I define transition as, "a change or shift from one state, subject, place, etc. to another, a period or phase in which such a change or shift is happening" (Dictionary, M.D., 2022).

The study consisted of eight case studies. For this study, I define the circle-of-care members as close family members and friends of the child. Members can include the parents, grandparents, and significant others who are not family, for example, babysitters and professionals, including home support personnel, teachers, learning assistants, guidance counsellors, physicians, and public/community health nurses. Data were collected and analyzed through semi-structured interviews, demographic information, document analysis, and a home visit (direct observation). Participants in this study were parents of preterm babies born in NL who are now registered in public school, from kindergarten through grade six, as well as members of their circle of care. The results of this study may inform national policy and approaches to supporting children born preterm as they enter the public school system in Canada.

1.3 Research Question

How does a child born preterm (who currently has one or more disabling health challenges) and their parents experience entering the public school system?

1.4 Research Objectives

1. To explore how families adjust to having a preterm baby with health challenges (including their time in the NICU and going home).
2. To investigate the factors within the school, their community, and the province that influence their child's ability to achieve the best possible educational outcomes (as defined by their parents).
3. To determine whether the school's size (large versus small) made a difference in how the child transitioned into school.
4. To explore whether more supports are available for the child/family depending on where they live (urban versus rural).

1.5 Geographical Context for the Research

NL is the easternmost province in Canada. This province has dramatic coastlines (more than 29,000 kilometres of coastline), sweeping barrens, ancient rock formations, and thick boreal forests (NL Tourism, 2020). The province's land area is 405,720 km^2, more than three times the size of the Maritime Provinces (Government of NL, 2022a). The population of NL in 2016 (when the latest census was taken) was 519,716 (Statistics Canada, 2017):

> While the province's population increased over the past decade, since 2012, there has consistently been negative natural population change (more deaths than births), and this is expected to continue for the foreseeable future. Consequently, negative natural population change is expected to constrain population growth (Government of NL, 2022b).

NL has a large landmass, low population density, and a decreasing population. All of this made completing research on a specific vulnerable population (children born preterm who are currently in particular grades and experiencing a health concern) a challenge that required creative recruitment strategies.

For the purposes of this study, I used the same definitions used by Statistics Canada (2017) for the terms urban and rural. "An urban area was defined as having a population of at least 1,000 and a density of 400 or more people per square kilometre. All areas outside population centres will continue to be defined as rural area" (Statistics Canada, 2017).

1.6 Global Pandemic

Another challenge for this research project was recruiting participants during a global pandemic. On March 11, 2020, the WHO declared a global pandemic due to the coronavirus (COVID-19, Government of NL, 2020a). On March 18, 2020, the Minister of Health and Community Services of NL declared COVID-19 a public health emergency under the Public Health Protection and Promotion Act. While a public health emergency is in effect, the Chief Medical Officer of Health can introduce special measures they believe are necessary to protect the health of the population (Government of NL, 2020a).

These measures included closing schools, the university, government offices, and businesses deemed not essential in the province. People were in close contact only with their immediate family "bubble" (i.e., those they live with). On March 17, 2020, Memorial University of Newfoundland (MUN), to assist the efforts in the community to achieve effective social distancing, suspended activities in research labs, and all fieldwork was suspended immediately. Suspended activities included face-to-face interactions (e.g., interviews, home visits), and these were to be deferred or carried out remotely using a technology solution (e.g., telephone) that allowed researchers and participants to be involved from their own homes (Memorial University, 2020).

In April 2020, the COVID-19 Alert Level System was introduced in this province, which provided Newfoundlanders and Labradorians with an overview of the steps taken as public health measures began to relax with the decreasing number of cases. NL was on Alert Level 5; people had to limit contact with others to their immediate household bubble, gatherings were restricted to five people or fewer, and people were told to stay at home as much as possible except to get essentials, for example, groceries (Government of NL, 2020b). This system, along with the news release from MUN, meant no home visits could take place for this study, and all interviews would need to be completed by phone or virtually (e.g., via WebEx, Zoom). In addition, hospitals were removing papers from walls (including research posters) to decrease possible virus transmission; this decision influenced recruitment strategies, as I was unable to post my recruitment posters in the local children's hospital. In addition, schools closed, and parents were now homeschooling while trying to work from home, and these changes also affected the time available for potential participants to complete interviews.

During the data collection phase of this study, this province moved to Alert Level 2, which meant people could move around more; outdoor gatherings of up to 50 people were permitted with physical distancing. Regional Health Authorities allowed more healthcare services to resume. During most of this time, people only socialized with a limited number of people, with the phrase “20 [people] for 2020” (Government of NL, 2020b). They were uncomfortable with having researchers in their homes and meeting to complete interviews. Therefore, home visits were not permitted, and all interviews continued to take place over the phone. All participants chose a phone interview over a virtual interview using WebEx or Zoom.

1.7 Dissertation Overview

This dissertation discusses the results of eight case studies that explored how children who were born preterm (and have one or more disabling health challenges), and their parents experienced their child entering the public school system. This first chapter introduces the study, presents an overview of the background and problem statement, outlines the purpose of the study, states the research question and objectives, and reviews the significance of the research. In Chapter Two, I review the literature on preterm birth, focusing on the causes of preterm birth, the consequences, and the reasons that the number of preterm births continues to rise. The review focuses explicitly on parental experiences in the NICU and how these children experience school, including difficulties in cognition and language, motor/neurologic outcomes, behaviour and mental health outcomes, lack of sleep and academic achievement, and noncommunicable disease and school performance. Lastly, the review focuses on resource allocation in this province. Chapter Three defines the epistemological and philosophical framework used in this qualitative study as well as the research design, participant information, data collection methods, and means of analysis. In Chapter Four, I discuss the findings of this study. Chapter Five provides the implications of this study’s findings and the strengths and limitations. Lastly, Chapter Six provides the conclusion and recommendations for future research.

Chapter Two Literature Review

2.1 Introduction

Preterm birth rates are rising, and more of these children survive into adulthood. However, many face health challenges. Their health challenges may influence their daily lives and create barriers for them in a public school setting, which can impact their education. This study looked at how children born preterm (who currently have one or more disabling health difficulties) and their parents experienced the child entering the public school system. In addition, this study explored how families adjust to having a preterm baby with health challenges, investigated the factors within the school, their community, and the province that influenced their child's ability to achieve the best possible educational outcomes. Moreover, the study explored if the school's size (large versus small) made a difference in how these children transitioned into school and explored whether more supports were available for the child/family depending on where they lived (urban versus rural).

2.2 Methods of the Literature Search

For this review, the databases searched were the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, the Cochrane Library: Evidence for Health Care Decision-Making, Psych INFO, UpToDate, and Google Scholar; the dates I searched included from inception in the 1970s, when these topics first appeared in the literature, until 2022. I chose this timeframe because I wanted to begin by reviewing the history of neonatal care, how it evolved with the introduction of new technology, how preterm children function in school, and how their performance in school has also evolved.

It was challenging to find information on neonatal intensive care units (NICUs), including when the first NICU opened in Canada and when the incubator was first used for preterm children. However, I did discover that the incubator was invented in 1880 (Baker, 2000). An article by Davis et al. (2003) outlined the use of the incubator in the 1800s and the use of oxygen in the 1930s. The Health Sciences Centre in Winnipeg opened a Maternity Pavilion and a Premature Nursery in 1950 (Health Sciences Centre Winnipeg, n.d.), and the University of Toronto (2005) reported on the first baby ward in the Hospital for Sick Children that opened in 1915 with the use of glass cubicles. Lastly, after searching for the history of the NICU throughout my time as a Ph.D. student, in May (2022), I was able to find an old book on the care of preterm infants. The first significant text written on the care of premature infants was published in 1901 by Dr. Pierre Budin; it was called *The Nursling: The Feeding and Hygiene of Premature and Full-term Infants*. Budin was a professor of obstetrics at the University of Paris. He referred to infants born before term as “congenitally feeble infants,” classifying them as “weaklings” (Budin, 1907, p.2). Dr. Budin discussed in detail how their temperature would fall and the consequence of this was their death. He also wrote about midwives who had sent him infants to care for and how they sent “infants swaddled so warmly as to place me under the most favourable circumstances for saving them” (Budin, 1907, p.6). Dr. Budin and midwives understood the need to keep preterm infants warm and how this impacted their survival.

I conducted several systematic searches to address preterm birth incidence, prevalence, risk factors, management, and interventions. I used the appropriate combinations of the following keywords with medical subject headings (MeSH); this allowed for searching health-related information in databases. I used the headings “preterm,” “infant,” “neonatal intensive care (NICU),” “preterm birth,” “incidence,” “prevalence,” “preterm labour,” and “parental experience.” In addition, the following keywords were also used: “length of stay,” “education outcomes,” “technology,” “preterm children in school,” “school performance,” and “academic outcome/achievement.” Lastly, the terms “communicable disease,” “vision,” “hearing,” “sleep,” “behavioural and mental health outcomes,” “motor/neurologic outcomes,” “cognition/language outcomes,” and “costs” were used. Along with these keywords, Boolean indicators were also used (e.g., AND, OR).

Studies published in English or published in other languages that included translation into English were considered for inclusion in this review. The reference lists of articles were also searched for additional articles. Canadian literature was the focus as this study took place in Canada, and other countries have different healthcare and educational systems that vary greatly from Canada. Grey literature sources were also searched using the following websites: Open Grey: ProQuest Dissertations and Thesis; Memorial University Research Repository; Google; websites for various neonatal associations; and the Government of Newfoundland and Labrador’s website (including departments, such as education), along with the Newfoundland and Labrador’s English school district website.

In this chapter, I present past and current literature that has explored preterm birth (including what it is and how to prevent it), the consequences of preterm birth, reasons the numbers of preterm births continue to rise, the costs of preterm birth, and parental experience in the NICU. I then present the literature on parental experience at home and experiences with starting school, including cognition and language, motor/neurologic outcomes, behaviour and mental health outcomes, lack of sleep and academic achievement, noncommunicable disease and school performance, and other factors. Lastly, I explore resource allocation in health care, education, and social justice and then discuss the significance of this study and how it will fill the identified gap in the literature.

2.3 Preterm Birth

The World Health Organization (WHO, 2012) states that to be considered born premature, the baby must be born alive before 37 weeks gestation. Subcategories of preterm birth include "extremely preterm (< 28 weeks), very preterm (28 to < 32 weeks), and moderate to late preterm (32 to < 37weeks)" (WHO, 2012, p. 1). The WHO (2012) has estimated one in ten babies worldwide is born prematurely.

Preterm birth rates are rising in many countries, and the effects of being born too soon on these babies and their families can have lifelong consequences. The global prevalence of preterm birth is approximately 15 million per year (one in ten babies born premature), a worldwide epidemic (Canadian Premature Babies Foundation, 2020; Purisch & Gyamfi-Bannerman, 2017). Here in Canada, 30,000 babies are born prematurely each year (Canadian Premature Babies Foundation, 2020); this equals 7.9% of live births in Canada (Statistics Canada, 2018). The highest provincial rate is in Nunavut at 13.7%, followed by the Yukon at 9.5%, and Manitoba at 8.7%, with Alberta and the Northwest Territories tied at 8.6%. Quebec had the lowest rate, at 7.0%, while Newfoundland and Labrador's rate was 8.5% (Statistics Canada, 2018). In Newfoundland and Labrador, one in every twelve babies is born prematurely (Toope, 2014).

Newfoundland and Labrador's (NL) only NICU is located at the Janeway Children's Health and Rehabilitation Centre in St. John's. The NICU is a 26-bed unit caring for most aspects of tertiary newborn care (newborns with extreme prematurity or who are critically ill or require surgical intervention) apart from cardiac surgery and extracorporeal membrane oxygenation. The NICU admits approximately 380 babies per year (Janeway Children's Hospital Foundation, 2019).

Babies are born prematurely for many reasons, including spontaneous preterm birth and provider-initiated preterm birth/medically indicated (iatrogenic) preterm birth (Purisch & Gyamfi-Bannerman, 2017; WHO, 2012). Risk factors for spontaneous preterm birth include infection (e.g., urinary tract infection, malaria), age at the time of the pregnancy (e.g., adolescence or advanced maternal age), underlying maternal chronic condition (e.g., thyroid disease, hypertension, diabetes), and nutritional status (e.g., obesity, undernutrition). In addition, lifestyle factors (e.g., smoking, excess alcohol consumption), multiple pregnancies (e.g., twin, triplet, sometimes because of natural and/or in-vitro fertilization), maternal psychological health (e.g., depression), and genetics (e.g., family history) are also risk factors (WHO, 2012). However, spontaneous preterm birth also occurs in women without identifiable risk factors. Therefore, preventative strategies are limited (Purisch & Gyamfi-Bannerman, 2017). Provider-initiated preterm birth, also known as medically indicated or iatrogenic preterm birth, is when labour is induced. Alternatively, preterm birth may occur in the case of an elective cesarean section before 37 weeks gestation due to a wide range of maternal and/or fetal pathologies, including pre-eclampsia, premature rupture of membranes, poorly controlled diabetes, and intrauterine growth restriction (Purisch & Gyamfi-Bannerman, 2017; WHO, 2012).

Preventing preterm birth is a challenge for healthcare providers, as the causes are complex and not well understood. The etiology of preterm birth involves complex interactions between numerous factors, including hormones, the immune system, genetics, maternal anatomy, reproductive tissue properties (e.g., uterus, placenta), the nervous system, the vascular system, and the environment (Vink & Gyamfi-Bannerman, 2017).

To help women reduce the risk of preterm birth, they are advised to improve their general health by quitting smoking and avoiding alcohol use and all drugs not prescribed by a medical professional. In addition, women should receive prenatal care as soon as they think they are pregnant and seek medical attention for any warning signs or symptoms of preterm labour (WHO, 2012). Warning signs of preterm labour include contractions (abdomen tightens every ten minutes or more often), changes in vaginal discharge (increase in the amount of discharge or leaking fluid or bleeding), and pelvic pressure (feeling baby pushing down). In addition, low, dull backache, cramps (like a menstrual period), and abdominal cramps with or without diarrhea are also symptoms. Spontaneous labour is responsible for 70 to 80% of preterm births; therefore, with labour starting unexpectedly and the cause usually unknown, women must know what signs to look for and what to do if they appear (Copper et al., 1990; Goldenberg et al., 2008; Malouf & Redshaw, 2017; WHO, 2012).

2.4 Consequences of Preterm Birth

Prematurity is the leading cause of neonatal morbidity and mortality. Infants who survive have higher long-term morbidity rates than infants born full-term (Frey & Klebanoff, 2016; Purisch & Gyamfi-Bannerman, 2017; WHO, 2012). Unfortunately, even with all the advancements in the care of the preterm baby, some, including those with very low birth weight (VLBW), are at risk for neurodevelopmental impairment.

Preterm birth is a leading cause of neurocognitive and neurodevelopmental impairment in childhood (Boardman & Counsell, 2019). The possible causes of neurodevelopment impairments include atypical sensory stimuli during brain development (Boardman & Counsell, 2019; Carbasse et al., 2013) and a stressful NICU environment where preterm babies are separated from their parents (Treherne et al., 2017; WHO, 2012). Interventions performed in the NICU (such as intubation, ventilator use, painful procedures like intravenous (IV) insertion and blood tests) can lead to chronic lung disease and adverse neurodevelopmental effects (Mitchell et al., 2013; Venkataraman et al., 2018). The noise in the NICU can also lead to disruptions in growth and development, ultimately putting the baby at risk for hearing, language, and cognitive disabilities (Ludington-Hoe, 2013; Pineda et al., 2017). In addition, being born early means the babies' organs do not have time to mature, and this can cause issues such as respiratory distress syndrome, which is immaturity of the lungs. Some of the long-term outcomes that survivors of preterm birth may face include visual impairment, hearing impairment, chronic lung disease, cardiovascular issues (e.g., increased rates of asthma, increased blood pressure), and learning impairments. Other long-term outcomes include moderate to severe global developmental delay (e.g., cerebral palsy); psychiatric and behavioural issues (e.g., increased anxiety, hyperactivity); and a higher risk of developing noncommunicable diseases (e.g., hypertension, diabetes; WHO, 2012). Extremely preterm infants are at the highest risk of motor, cognitive, and behavioural problems later in life (Medina et al., 2017).

2.5 Why Are the Numbers of Preterm Births Rising?

Each year, approximately 15 million babies are born preterm, with the preterm birth rates rising in most countries. The global preterm birth rate has risen from 9.8% in 2000 to 10.6% in 2014, with approximately one million babies dying every year due to preterm birth complications (Walani, 2020). In most "high- and middle-income countries, preterm birth is the leading cause of child death" (Blencowe et al., 2013, p. 1). The numbers of preterm births are rising for several reasons, including advanced technology, societal trends, and improved health records. Before NICUs existed, preterm babies were left to live or die with no medical interventions to help them. The average infant mortality rate in Canada in 1950 was 54.58 (per 1000 live births) compared to 4.5 (per 1000 live births) in 2020 (Statistics Canada, 2022). The care provided to these tiny babies in the hospital, more specifically in the NICU, has changed and improved over time. With advances in technology and care, survival rates have also increased (Blomqvist et al., 2012; Carbasse et al., 2013; Heidari et al., 2017).

The most helpful intervention in neonatal care has been the incubator. In the 1880s, a French doctor developed the incubator to save premature infants (Davis et al., 2003; Prescott & Hehman, 2017). It was made with glass sides to allow mothers to look at their babies. Incubators did not arrive in the United States of America until the 1900s (Davis et al., 2003; Prescott & Hehman, 2017). It is unclear when the incubator first appeared in Canada; however, the first Babies Ward at the Hospital for Sick Children opened in 1915 and had 28 glass cubicles (similar to incubators) to allow for the isolation of babies and to minimize cross-infection (Shorter, 2013; University of Toronto, 2005). In 1949, newborn care was provided to preterm infants in Winnipeg with the use of incubators and oxygen hoods in the Health Sciences Centre (Health Sciences Centre Winnipeg, n.d.).

Following the introduction of the incubator, oxygen and surfactant use became part of everyday practice in the NICU by teams of nurses, respiratory therapists, and neonatologists. These advances have helped change the way preterm babies are cared for and helped with their survival. Oxygen therapy was introduced to this population in the 1930s. Due to using large amounts of oxygen in incubators, many babies ended up blind or with retinopathy of prematurity (Davis et al., 2003; Higgins, 2019). This is due to large amounts of oxygen being toxic (Perrone et al., 2016). To avoid oxygen toxicity the amount of oxygen used is now monitored by pulse oximetry. Alarm levels can be set on pulse oximetry machines and monitored to avoid fluctuations in oxygen levels and therefore reduce the risk of oxygen toxicity (Perrone et al., 2016). The advancement of monitoring for oxygen levels has helped ensure babies can use oxygen without the long-term side effects of its use.

Preterm babies are often born with a surfactant deficiency, affecting their lung function and ability to breathe (Gallacher et al., 2016; March of Dimes, 2010; Owen et al., 2017). Pulmonary surfactant is a complex mixture of specific lipids, proteins, and carbohydrates produced by type II alveolar epithelial cells in the lungs. The mixture is surface-active and decreases surface tension at the air–liquid interface of the alveoli (Chakraborty & Kotecha, 2013). Therefore, surfactant helps to lower the surface tension in the lungs and prevent lung collapse during expiration. In the 1980s, many randomized control trials were completed testing surfactant use in preterm babies; the development and use of surfactants have helped decrease the risk of these babies developing respiratory distress syndrome and have helped decrease infant mortality rates (Halliday, 2008; Sardesai et al., 2017).

Fertility treatments, including in-vitro fertilization (IVF), have also contributed to the increase in multiple births (e.g., twins, triplets), increasing the chances of having preterm babies by nearly ten times (Blencowe et al., 2013; Sullivan-Pike et al., 2017; WHO, 2012). Researchers are now looking at whether it is the IVF treatment itself or the practice of placing multiple embryos that causes the observed increase in the preterm birth rate (Sullivan-Pike et al., 2017; WHO, 2012). The Canadian Fertility and Andrology Society has set guidelines for the number of embryos transferred during IVF. These guidelines are in place due to the realization that high-order multiples (triplets or more) are associated with adverse outcomes. Depending on the woman's age and the stage of the embryos, a transfer of one to five embryos can be considered, with the average being one to two; transferring up to five is reserved for women older than 42 years and embryos in the cleavage stage (Min & Sylvestre, n.d.).

Social trends also contribute to the increasing number of preterm births in developed countries. Some women are now booking elective cesarean sections for reasons other than medical necessity, including fear of giving birth and fear of labour pain (Schantz et al., 2019). An elective delivery may also be performed for nonmedical reasons. These may include living far away from the hospital or wanting to schedule the birth for a specific date (American Congress of Obstetricians and Gynecologists, 2017). Blencowe et al. (2013) stated that in a recent study in the United States, more than half of all provider-initiated preterm births at 34 to 36 weeks gestation were carried out without a strong medical indication. Provider-initiated births at 34 to 36 weeks are concerning, as the baby's gestational age may be incorrect, resulting in moderate to late preterm birth (Chang et al., 2013; Lassi et al., 2015; Morisaki et al., 2017).

Another issue to consider is viability. *Viability* refers to the gestational age when the critical organs (e.g., lungs, brain, and heart) can sustain life (Chau, 2019; Powell et al., 2012). The Canadian Pediatric Society issued an updated position statement in 2017 regarding the counselling and management of extremely preterm babies. Infants born at 23 to 24 weeks of gestation face a moderate to high likelihood of mortality or moderate to severe neurodevelopmental disability, and infants born at 24 weeks gestation with a weight of 350 grams or less are at an extremely high likelihood of mortality or severe neurodevelopmental disability (Lemyre, & Moore, 2017). Therefore, an accurate assessment of gestational age is imperative. The most accurate assessment is early ultrasound with fetal measurements (measurement of the babies' size including head, body, and thigh bone). Assessment based on the date of the last menstrual period is problematic. It assumes that conception occurs on the same day as ovulation and does not consider the variation in the length of menstrual cycles among women. Also, the recall of the date of the last menstrual period is subject to error (American College of Obstetricians and Gynecologists, 2017; Blencowe et al., 2013). With some babies born at earlier-than-anticipated gestational age, contributing to an increase in extreme preterm births, an accurate gestational age must be determined prior to delivery (Blencowe et al., 2013).

Data on preterm birth (including birth rates) are not routinely collected in some countries and may not be recorded using a standard international definition; therefore, accurate statistics regarding worldwide preterm birth rates are not always available (Blencowe et al., 2013; Quinn et al., 2016; WHO, 2012). Consequently, the rate of preterm births worldwide may be higher than the statistics show.

2.6 Costs of Preterm Birth

Premature birth places a substantial burden on the health, education, and social service sectors, not to mention individual families. The morbidity and mortality rates are highest among babies born the earliest. However, the morbidity impact extends past the neonatal period and into later life. Preterm birth is "the leading cause of infant death and disability in Canada" (Rios et al., 2021, p. 161). These premature babies are at risk for many health issues later in life, including developmental and learning difficulties (Johnston et al., 2014). These health issues and potential social and behavioural problems can create considerable costs to parents, governments, and insurance companies. In addition, the initial costs of having a baby in the NICU can also be high. The inpatient cost for preterm infants admitted to a NICU was estimated at $20,184 CAD (Rios et al., 2021). It is estimated the annual outpatient costs of a preterm baby (born < 28 weeks) are $9,356 CAD for the first year of life, while a normal-term infant costs approximately $1,430 CAD (Luu et al., 2010). Preterm birth costs the Canadian health care system over eight billion Canadian dollars per year (Shah et al., 2018).

Premature babies are admitted to the NICU and have varying lengths of stay based on gestational age at birth and complications (e.g., lung development issues, cerebral hemorrhage, and sepsis). Due to these factors, the costs of admission also vary among babies. According to the latest statistics available from the Canadian Institute for Health Information (CIHI, 2006), hospitals in this country spend approximately $29,500,000 CAD on newborns each year. Birth costs vary among babies born at a healthy weight; for example, in 2002-2003, the hospital cost on average for a baby delivered vaginally with a healthy birth weight (with no issues) was around $800 CAD. In contrast, the average cost for a baby born via caesarean section was $1,400 CAD (CIHI, 2006).

Preterm births are associated with higher morbidity rates (Johnston et al., 2014; Lee et al., 2019a; WHO, 2012). The costs associated with caring for these babies also increase, especially when they experience complications (e.g., respiratory difficulties and problems regulating their temperature), which can also result in extended hospital stays. According to CIHI (2006), in 2003-2004, 13.6% of newborns spent time in a NICU. The average cost per baby in 2002-2003 was just over $9,700 CAD. Larger hospitals spent more per baby ($10,942 CAD) than smaller hospitals ($7,553 CAD). This increase in cost may be due to the types of babies they care for, as sometimes the sicker babies are sent to larger hospitals (many of which are teaching hospitals) with additional resources and services. These high costs are attributed to the need for medical technology (e.g., ventilators, intravenous pumps) and healthcare personnel. In addition, from 2002 to 2003, over 12 million Canadian dollars was billed by fee-for-service physicians who worked in NICUs in Canada (CIHI, 2006). From 2002 to 2003, the average hospital cost per baby admitted to the NICU was estimated to be $9,700 CAD. However, the average inpatient hospital costs for patients who had a vaginal delivery with no complications for the same time frame were about $2,700 CAD. The average cost of cesarean deliveries (about $4,600 CAD per patient) was also higher than vaginal deliveries (CIHI, 2006).

It is difficult to find updated Canadian statistics on newborn care costs in the NICU. On the costs associated with giving birth, Rios et al. (2021) found costs for preterm infants in the NICU increase as gestation decreases and length of stay increases. The median cost of hospitalization before NICU discharge was estimated at $20,184 CAD (for all infants); $11,810 CAD for infants born at 33 to 36 weeks; $30,572 CAD for 29 to 32 weeks; and $100,440 CAD at a gestational age of less than 29 weeks (Rios et al., 2021). According to the Canadian Institute for Health Information (2019), Canada's total health spending was expected to reach $264 billion in 2019, or $7,068 per Canadian. Hospitals (26.6%), drugs (15.3%), and physician services (15.1%) were expected to continue to use the largest share of health dollars in 2019 (CIHI, 2019).

Premature infants have a higher rate of hospitalization during childhood than those born at term, which also increases costs (Johnson et al., 2014). The Perinatal Program Newfoundland and Labrador (PPNL) follows up on those babies at high risk for developmental delays, including those with a birth weight of 1,500 grams or less, those ventilated for 48 hours or less, those who have had complex surgeries, or those for whom a physician has recommended follow-up. While the program is physically located in St. John's, it is a provincial program operated by Eastern Health. They offer clinics across the province at certain times throughout the year (Eastern Health, 2014). The costs for running this program and clinics across the province are not publicly available.

The costs associated with preterm birth start with mothers. Mothers at risk for preterm birth are often admitted before birth for observation and require more care, including additional obstetrician visits and medications (e.g., oxytocin receptor antagonists). The cost for inpatient stays, additional doctor visits, and medications adds up and can cost approximately $950 CAD.

Once a baby is born, the cost of neonatal intensive care is $1,628.60 CAD (unit cost). Future admissions are also expensive, with a pediatric intensive care unit stay costing on average $2,002.86 CAD (Johnson et al., 2014).

According to Johnson et al. (2014), costs per infant over the first 10 years of life were estimated to be $67,467 CAD for early preterm infants, $54,554 CAD for moderately preterm infants, and $10,010 CAD for late preterm infants. The care needed for these children costs parents, insurance companies, and governments tremendous amounts of money. It "corresponds to total national costs of $123.3 million for early preterm infants, $255.6 million for moderately preterm infants, $208.2 million for late preterm infants, and $587.1 million for all infants" (Johnson et al., 2014, p. 7). These costs are very high; provincial and territorial health insurance plans generally cover medically necessary hospital and physician services related to childbirth (CIHI, 2006), while private insurance coverage depends on providers. Costs not covered by the province or insurance companies will be left to the parents.

Table 2.1

Costs Associated with Hospital Admissions (CIHI, 2006) from 2002-2003

Average hospital cost per baby admitted to the NICU	Average hospital cost for a patient who had a vaginal delivery (no complications)	Average hospital cost for a patient who had a Caesarean delivery
$9700 CAD	$2700 CAD	$4600 CAD

Table 2.2

Costs to Care for Preterm Infants (Johnson et al., 2014)

	Early preterm infants	Moderately preterm infants	Late preterm infants
Cost per infant over the first 10 years	$67, 467 CAD	$54, 554 CAD	$10,010 CAD
National costs	$123.3 million CAD	$255.6 million CAD	$208.2 million CAD

It is difficult to find new statistics on preterm birth and term birth costs in Canada. With the cost of living and most commodities increasing in this country, one can only assume that the costs of having a baby and caring for a preterm baby are also increasing.

Another point to consider is how expensive it is to care for a child with a health challenge or disability long term. The cost of things these children will need (e.g., wheelchair, medications, braces) can have direct effects on the household, including indirect costs, for example, job loss to care for the child or having to work fewer hours (Shahat & Greco, 2021). Shahat and Greco (2021) state that the lifetime cost to care for a child with a disability like cerebral palsy can range from $41,000 to $4,300,000 CAD, which would correspond to $450 to $69,500 CAD annually. This high cost can be a substantial expense for families, depending on the child's health challenge, considering most provincial medical and insurance plans do not cover 100% of medical costs.

2.7 Parental Experience in the NICU

Motherhood can be an emotional time in a woman’s life, with many experiencing mixed emotions including happiness, isolation, fatigue, exhaustion, guilt, and a sense of loss (Barclay et al., 1997; Lee et al., 2019b; Ruthven et al., 2018). When babies are born prematurely, they are immediately separated from their parents and brought to the NICU to be assessed and treated because they require specialized care (Bry & Wigert, 2019; Lemmen et al., 2013). This separation is a crisis for parents expecting a full-term healthy newborn. They may begin to grieve for the baby they thought they would have (Stikes & Barbier, 2013). Mothers of preterm babies face more challenges with the added separation and stress that comes with a NICU admission. They face added fears surrounding the care they need to provide to their baby in the NICU and at home. In addition, they may have added anxiety and worry about the health outcomes their baby may face due to being born prematurely (WHO, 2012).

When a baby is admitted to the NICU, parents may feel that their worlds have stopped, but they soon realize they still have obligations at home. They face balancing time spent in the NICU (Lewis et al., 2019) with household tasks that still need to occur (Blomqvist et al., 2012). In addition, if the parents have other children at home, they may find it hard to leave siblings with other caregivers and finding caregivers can also be a challenge (Kymre, 2014; Carvalho et al., 2019).

The equipment in the NICU may also increase anxiety in some parents (Bry & Wigert, 2019) and may cause parents to refuse or be reluctant to hold and touch their infants or provide skin-to-skin care (Blomqvist et al., 2012; Bonner et al., 2017). Machines like ventilators and intravenous pumps have many wires, tubes, and alarms that may scare parents. Parents are afraid that wires or tubes may become tangled or disconnected and that machines may trigger alarms indicating something is wrong with their baby (Blomqvist et al., 2012), both of which may jeopardize the safety of their baby (Valizdeh et al., 2013).

In addition to the above, there is often less interaction between parents, especially mothers, and their premature baby, which some people feel is related to the NICU environment (Ionio et al., 2016). In the NICU, mothers sometimes feel like outsiders (Solomons & Rosant, 2012). They are afraid to touch their babies due to the physical appearance and the preterm infant's inconsistent and limited responsiveness, which may impair positive parental-infant attachment (Ionio et al., 2016; Stikes & Barbier, 2013). The associated feelings of uncertainty regarding their babies' health and well-being may also deter parents from getting close to and interacting with their babies (Miles & Holditch-Davis, 1997; Ionio et al., 2016). Early interactions between mothers and babies play a critical role in brain development and overall health and well-being. These interactions also play a crucial role in the early regulation of the stress response, which influences the long-term healthy development of the baby (Shonkoff, 2012).

2.8 Parental Experience at Home

Bringing a new baby home can be both a happy and stressful event for families. Going home means parents will now provide all the care for their baby without the assistance and guidance of the medical team. Besides providing primary infant care, such as feeding and bathing, the parents of preterm infants may also need to administer medications and/or nutritional supplements while meeting their child's specific medical needs (Jefferies et al., 2014). In addition, parents, especially mothers, now have more control over the care of their baby and more time to build a closer bond and get to know their baby without the usual interruption of hospital routines (e.g., specific times for visiting, feeding, and bathing).

The home environment also has its challenges for parents of preterm infants. One challenge for parents is the medical technology that may accompany their child at home. When some infants leave the NICU, they are dependent on various forms of technology including supplemental oxygen, constant monitoring of the oxygen saturation in their blood, tube feeding with a pump, or home apnea monitors to ensure they do not stop breathing. Parents are required to take care of their babies and attend to the technology accompanying the infant. This may deter them from leaving home, decreasing the time spent with their social networks, thus causing isolation. The added technology can also cause loud noises (e.g., alarms, beeps), affecting how much sleep everyone in the house receives. Parents may have high levels of vigilance, especially at night. The extra vigilance can lead to higher stress levels and cause sleep deprivation, insomnia, and anxiety (Marthinsen et al., 2018' Wang & Barnard, 2004). The responsibility of caring for a technology-dependent baby or child and the routines needed can result in physical and emotional overburden on the parents (Doron et al., 2018; Wang & Barnard, 2004).

Parents with babies that go home from the NICU and do not need any added technology still face issues. While in the NICU, parents learn that their preterm babies are vulnerable to illness and therefore have a higher likelihood of readmission to the hospital. Approximately 15% of preterm infants will require at least one rehospitalization within the first year of life. Infants born at less than 25 weeks gestation have a 31% chance of readmission (Underwood et al., 2007). Rehospitalization rates among preterm infants are significantly higher than in full-term infants (Reed et al., 2019). Many parents try to reduce or limit their baby's exposure to potential sources of infection. Limiting exposure to possible sources of infection can impose constraints on their social networks, and this constant vigilance to decrease the chances of illness can lead to exhaustion (Adama et al., 2016; Hwang et al., 2013; Lahood & Bryant, 2007).

Babies born prematurely require close monitoring by medical staff and may require numerous follow-up appointments. Once home, these babies are followed by their family doctor, while neonatal or perinatal follow-up programs will follow babies who were born extremely preterm or who require closer follow-up. These programs address concerns regarding these tiny babies' developmental outcomes and long-term health outcomes (Eastern Health, 2014). Therefore, some parents may have to travel to a clinic if one is not offered in their area. In NL, the babies that require rehabilitation after discharge and throughout their lives travel to the Janeway Children's Health and Rehabilitation Centre in St. John's. Some families travel far distances frequently to access these services; for example, some families will have to drive to St. John's from Deer Lake (an almost eight-hour drive).

2.9 Experiences with the School System

As stated earlier, the survival rates for preterm birth have increased, and now more of these children are reaching school age. However, due to being born preterm, their body organs may not be fully developed, especially their lungs and brains, and these organs are susceptible to the consequences of preterm birth, including high rates of long-term neurological health problems (Ream & Lehwald, 2018; Rees & Inder, 2005; Saigal & Doyle, 2008). Children born preterm have a higher risk of mortality and morbidity; this has a considerable impact on the educational system. The cost of the added health care (Beam et al., 2020) and educational needs (Kelly et al., 2016) can also be high (Saigal & Doyle, 2008). Many studies have shown that once these children reach school age, teachers report they have more difficulties with motor, behaviour, language, writing, physical education, and mathematics skills than their counterparts born at term (Huddy et al., 2001; Palumbi et al., 2018; Saigal & Doyle, 2008). The following sections will discuss some of these children's difficulties as reported by parents, teachers, or both.

2.9.1 Cognition and Language. Peterson et al. (2000) found children born preterm (especially those weighing less than 1500 grams) in the United States of America may require specialized assistance in school. Some of these children will have higher grade-repeat rates (Jansen, 2020); nearly 20% of these children will repeat a grade by the age of eight. The higher grade-repeat rates and need for specialized assistance in school can be due to several reasons, such as language issues, motor/neurological problems, behavioural issues, and/or mental health issues (Peterson et al., 2000). Preterm birth is associated with lower cognitive test scores, reduced cognitive performance at school age (Bhutta et al., 2002; Odd et al., 2016; Vinall et al., 2014), learning and language disabilities (Nuccini et al., 2015) and academic underachievement (Brydges, 2018). Studies show that language functions generally fall within the average range for low birth weight (LBW) children, including vocabulary, verbal fluency, and memory (Aylward, 2014). However, the more complex verbal processes (e.g., understanding of syntax, auditory discrimination, language processing, and reasoning) are deficient in children born preterm (Aylward, 2014). Some children born preterm will still have deficient language skills at school age (Barre et al., 2011; Stolt et al., 2016). Some children born preterm find complex language functions (e.g., expressing and comprehending complex syntactic clauses) complicated until they are up to 12 years old (Stolt et al., 2016; Van Noort-van der Spek et al., 2012). Children born preterm also struggle with reading and mathematics. Reading issues include issues with word identification and reading comprehension (McBryde et al., 2020). With mathematics, these children struggle with mathematical knowledge, calculation, and applied problems (Akshoomoff, 2017; McBryde et al., 2020).

2.9.2 Motor/Neurologic Outcomes. While still in utero, infants are contained in enclosed spaces with 360 degrees of well-defined boundaries. In contrast, in the NICU, the natural resting position of an infant is often flat on their back, extended, and asymmetrical, with the head to one side and the extremities abducted and externally rotated (Altimier & Phillips, 2013). Potentially adverse effects can occur due to being placed in a misaligned position in the NICU, affecting early muscle and bone formation. The body position can also affect the alignment and shaping of the musculoskeletal system. Common consequences of inadequate positioning include abnormal spinal curvatures, skull deformities, and "W" arm positioning (in which the shoulders are elevated and abducted). In addition, externally rotated and excessive abduction, and external rotation in the hips (called a "frog-leg" posture) is also a common consequence of inadequate positioning (Danner-Bowman & Cardin, 2015). These misalignments can lead to motor delays and functional limitations following the infant from the NICU to childhood and adulthood (Danner-Bowman & Cardin, 2015). As a result of these positions, many children have dystonia, a movement disorder in which the muscles contract involuntarily, causing repetitive or twisting movements (Aylward, 2014). According to Aylward, "children with dystonia have an increased risk of later cognitive and motor problems including cerebral palsy, minor neurologic dysfunction, attention-deficit hyperactivity disorder (ADHD), and aggressive behaviour" (2014, p. 399).

Some neurologic impairments that preterm infants may develop include cerebral palsy, sensory impairments (visual and/or auditory deficits) and psychological disability (Ream & Lehwald, 2018; Saigal & Doyle, 2008). Studies have demonstrated children born extremely preterm or at a low birth weight are at an increased risk for neurobehavioral impairments, including cognitive deficits, learning disabilities, and behavioural and emotional problems at school age (Anderson & Doyle, 2003; Hack et al., 2009; Saigal & Doyle, 2008; Squarza et al., 2017). Difficulties in these areas have also been related to academic difficulties and the need for higher rates of educational support (Msall, 2012; Squarza et al., 2017).

2.9.3 Behaviour and Mental Health Outcomes. Behavioural and mental health outcomes among children born prematurely have not been studied as much as cognitive and physical health problems. However, research has shown that babies who are born prematurely and are at VLBW or LBW are more likely to exhibit "conduct disorders, shyness, unassertiveness, withdrawn behaviour, anxiety, depression, and social skills deficits more often than children born with a normal birth weight" (Aylward, 2014, p. 402). There is an increase in behavioural problems among LBW children, especially poor attention span and withdrawn behaviour (Leijon et al., 2016). Studies have also shown that this population is diagnosed more often with neurodevelopmental conditions, including autism spectrum disorder (ASD; Agrawal et al., 2018).

Many preterm babies, including those born with VLBW and LBW, are at a higher risk than babies born at term for having behavioural problems later in life. These issues include difficulties with attention and hyperactivity that affect school performance (Saigal & Doyle, 2008). According to Aylward (2014), symptoms suggestive of ADHD are reported two to four times more frequently in children born at VLBW and LBW (Saigal & Doyle, 2008); by early childhood, 16 to 47% of these children have symptoms of ADHD. Franz et al. (2018) found that VLBW children have an increased risk of ADHD, and there is an even stronger association with an extremely low birth weight (ELBW).

2.9.4 Lack of Sleep and Academic Achievement. Continuous bright lights and loud sounds in the NICU disrupt sleep–wake cycles. Once home, many preterm infants find it hard to sleep due to the quiet, dark environment offered at night; they are accustomed to the NICU environment. Sleep deprivation will result in loss of brain plasticity, resulting in smaller brains, altered learning, and long-term effects on behaviour and brain function (Altimier & Phillips, 2013). Reduced nighttime sleep at age one has been associated with reduced executive functioning performance at age four (Bernier et al., 2013), and shorter nighttime sleep is associated with reduced attention among children at preschool age (Lam et al., 2015; Smithson et al., 2018). Poor sleep–wake cycles at age two are associated with language delay by five years of age (Dionne et al., 2011; Lam et al., 2015; Smithson et al., 2018). Once at school age, reduced sleep is associated with poor new-word memory recall and reduced memory attention (Axelsson et al., 2016; Smithson et al., 2018). More than one-half of VLBW and 60 to 70% of ELBW children will require specialized assistance while in school. By middle school, ELBW children are three to five times more likely than their full-term peers to have learning problems in spelling, reading, mathematics, or writing, independent of IQ scores (Aylward, 2014). In addition, reading comprehension, written output, and social skills are also likely to be areas of deficit (Aylward, 2014). Cognitive deficits, learning difficulties, and behavioural problems occur more frequently among school-age children born with very low birth weight, particularly those with extremely low birth weight. The effects of poorer academic achievement in primary school persist through adolescence and into young adulthood for many of these children (Leijon et al., 2016).

2.9.5 Noncommunicable Disease and School Performance. As stated earlier, preterm babies are at an increased risk of developing noncommunicable diseases like diabetes and asthma (WHO, 2012). Studies have found that children who live with noncommunicable diseases, including children diagnosed with diabetes, have a disadvantage at school and can have cognitive and executive function problems (Gaudieri et al., 2008; Mauras et al., 2015). Pediatric diabetes relates to mildly lower cognitive test scores (Gaudieri et al., 2008). Type 1 diabetes has been related to a modest impairment that affects children and adolescents' global intelligence and motor nerve conduction velocity (Tonoli et al., 2015). Children with Type 1 diabetes have significant differences in total and regional grey and white matter growth in brain regions compared to control subjects (Mauras et al., 2015). Mauras et al. (2015) found that hyperglycemia might be detrimental to the developing brain. Roman et al. (2017) stated that children with Type 1 diabetes in primary school have shown lower grades than their peers, and children with poor glycemic control had poorer school performance.

Children born before 26 weeks gestation have high respiratory morbidity over their first six years of life, which can be exacerbated by smoking during pregnancy and at home (Hennessy et al., 2008). These children have a high prevalence of chest deformity, continuing symptoms of wheeze and poor performance on peak flow tests. In one study, the prevalence of inhaler usage at age six was over twice that of the control group (Hennessy et al., 2008). In addition, children diagnosed with severe asthma may have poorer academic achievement than their peers, according to other studies (Kohen, 2010; Taras & Potts-Datema, 2005). Children with asthma are more prone to school absences, and this missed time can lead to a disruption in their learning and social school-based activities which places them at further risk for poorer academic performances (Konis-Mitchell et al., 2019). In addition, asthma (mainly nocturnal asthma) can affect children's sleep quality and duration, affecting school performance due to lack of sleep and affecting attention span, which places these children at risk for poorer academic performance (Konis-Mitchell et al., 2019).

2.9.6 Other Factors. All the issues mentioned above result from being born preterm and numerous other factors that affect the child's health outcome variability. Other factors that add to that variability include the impact of hospitalization on neonatal development (e.g., types of medical procedures, days in the hospital, medical responses to interventions) and sociodemographic factors (e.g., socioeconomic status, social support, environmental exposures, positive and negative experiences, race). In addition, subsequent illness (e.g., sequelae at discharge, hospitalizations, need for oxygen) can also add to the variability (Aylward, 2014; Rogers & Hintz, 2016). Poor school performance may also be attributed to missed school time due to illness, physician visits, and specialist appointments (e.g., occupational or physical therapy). Children born preterm have reported high rates of ill health and increased use of outpatient services in the early years after discharge from the NICU (Kuo et al., 2017). By age ten to twelve, these children (especially if born before 26 weeks gestation) have a greater need for healthcare services (Saigal & Doyle, 2008). It is important to remember that all children are different from one another and will not have the same outcomes as other children who may have been born at the same gestation and have the same medical experiences.

These children and their families need support and resources as the child grows and enters each new stage of development. Schools need to have resources provided to them by the province to help them guide these children and their families through the school years to achieve the best possible academic outcomes.

2.10 Resource Allocation

2.10.1 Health Care. As stated earlier, the province of NL has one children's hospital, the Janeway Children's Health and Rehabilitation Centre, which houses this province's only NICU. It has 26 beds, and it is located in St. John's (Janeway Children's Hospital Foundation, 2019). While other hospitals in NL have maternal health units and deliver babies, if a baby requires intense monitoring or is born prematurely, the Janeway transport team is called and responds.

The team will transport the baby back to St. John's for treatment and care if required. Otherwise, the delivery hospital will care for the baby with the mother in the postpartum unit or in the nursery. While this makes financial sense for the provincial government, it is hard on families who must travel to St. John's to stay with or visit their preterm babies. Moreover, many babies stay in the NICU until their original due date or longer if they have medical complications. Such lengthy hospital stays can have devastating financial implications for families.

For families who live outside of the St. John's area, resources are available to help them with their stay. Some available resources include a Ronald McDonald House, Fuel the Care, and the Air Canada Foundation. When a child is admitted to the NICU, the social worker assigned to that unit will meet with each family and assess their needs to see what assistance can be provided; this may include help with finding accommodations and/or help with getting food. The Ronald McDonald House offers safe, low-cost accommodations to families who have a child receiving medical attention within St. John's. The House is located within a five-minute walk from the Janeway Children's Hospital and Rehabilitation Centre. However, the family must live at least 80 kilometres away from the house to stay there (RMHC, 2018). Since 2002, Irving has helped families with the Fuel the Care program, which provides fuel gift cards to families travelling to receive medical care for children. The Janeway Children's Hospital is a partner in the Fuel the Care program: to receive help; families must talk to their assigned social worker (Irving, 2018). The Air Canada Foundation was started in 2003. The foundation provides Aeroplan miles to pediatric hospitals across Canada (including the Janeway Children's Hospital and Rehabilitation Centre), which helps alleviate the cost of travel for families that need access to advanced medical treatment unavailable in their community or province (Air Canada Foundation, 2018).

Lakshmanan et al. (2017) found having a preterm baby and the associated hospitalization can adversely affect the family's finances and these families experience social isolation. Many families state, while caring for their preterm babies, they feel alienation, social isolation, responsibility, and confidence, all of which have the potential to influence the parent's emotional and physical health (Lakshmanan et al., 2017).

In provinces with larger populations, there are more NICUs. For example, in Ontario, many hospitals, including The Hospital for Sick Children, Mount Sinai Hospital, Sunnybrook, and London Health Science, have NICUs. Due to our smaller population, it would not be feasible for a smaller province like NL to have several NICUs. In addition, physician and nurse recruitment would be difficult, as these team members need specialized training. As seen in NL, recruitment to rural areas has challenges and issues for all health authorities (Newfoundland and Labrador Medical Association, 2010). In a press release in April 2019 directed to party leaders prior to the provincial election, the Newfoundland and Labrador Medical Association (2019) stated, "recruiting and retaining doctors in our province remains a major problem."

2.10.2 Education. The Department of Education and Early Childhood Development follow students in NL who need school-based support. The province uses the term *exceptionality* to "identify patterns of strengths and needs common to groups of students" (Government of NL, 2018b). The strengths and needs may be cognitive, behavioural, medical, physical, social, and/or emotional (Government of NL, 2018b). Some exceptionalities recognized in NL include developmental delay (which may receive accommodations or alternate programs), hearing loss (which may require assistive technology, accommodations, sign language, or an interpreter in sign language), or neurodevelopmental and related disorders (which may receive accommodations or alternate programs). In addition, intellectual disability (which may require accommodations, modified courses, or alternate programs and courses), learning disorders, physical disorders (whose needs will depend on the level of need and functioning), speech and/or language disorders, and vision loss (which may require direct teaching in braille, specialized equipment, and materials) are also recognized. Accommodations “are adaptations to the learning environment which address particular student needs. These may include physical arrangements, assistive technology, particular instructional strategies and others” (Government of Newfoundland & Labrador, 2011, p.13).

These students go through a pre-referral process where the classroom teacher decides what can be done and implements strategies. However, if the child’s needs are not being addressed and met in the classroom, they are referred to the service delivery team, and a comprehensive assessment referral is made. Students may require a range of school-based services, depending on their needs, including accommodations, programs, courses, and curriculum changes. In addition, the children may work with other educators, including educational psychologists, guidance counsellors, instructional resource teachers, speech-language pathologists, and/or classroom or subject teachers (Government of NL, 2018b). Students can only access special education services in NL if they have an exceptionality. These services are offered throughout the province, but some areas may not have all types of educators, as recruitment and retention can be a problem.

The Department of Education has developed a service delivery model for educational services in NL for students who meet the criteria for an exceptionally; this includes the prescribed curriculum which the majority of students follow, as “this is the first option for all students. It includes all of those courses prescribed and approved by the Department of Education” (Government of Newfoundland & Labrador, 2011, p.8). A modified prescribed curriculum which “maintains the intent of the provincially prescribed curriculum. However, specific course outcomes are changed, deleted, added or extended” (Government of Newfoundland & Labrador, 2011, p.16). Lastly, an alternate (functional) curriculum is for students who “are identified as having moderate, severe or profound impairments in cognition and severe deficits in adaptive functioning as evaluated through the comprehensive assessment process” (Government of Newfoundland & Labrador, 2011, p.22).

The role of classroom teachers in the inclusive school includes having a partnership with instructional resource teachers; this includes collaboration, co-teaching, and pull-out instruction. Collaboration is where knowledge, experience, and skills are merged to meet common goals and may include sharing resources and/or choosing instructional strategies. Co-teaching can include working collaboratively in the same physical space, instructing a heterogenous class, or collaborating on the delivery, assessment, and evaluation of outcomes. According to the Government of Newfoundland and Labrador, “pull-out instruction refers to implementing individualized programming for alternate programs, courses, and curriculum that occurs outside of the classroom. Instruction should be offered in the least restrictive, most inclusive environment respecting the dignity of the student” (2011, p.25).

2.11 Social Justice

Social justice is,

> the equitable, or fair, distribution of society's benefits, responsibilities, and their consequences. It focuses on the relative position of social advantage of one individual or social group in relation to others in society as well as on the root causes of inequities and what can be done to eliminate them” (Canadian Nurses Association [CNA], 2010, p. 13).

When looking at social justice one must remember that is affects multiple social determinants of health and not just healthcare access in urban versus rural areas of the province. Social justice also affects the distance one must travel for work, the distance to travel to healthcare facilities/specialists, and higher education opportunities (i.e., university, college campuses). When examining this critical concept, we also need to consider what people feel is reasonable access to these services.

Resources for preterm babies, including NICUs and follow-up care (educational, speech-language pathologists, physiotherapy, etc.), are usually located in large cities. While smaller, more rural cities and towns may have some follow-up resources, such as physiotherapists, they may not be used to working with preterm infants and their specialized needs. Some resources like educational support are in every school, but they may look different from school to school. For example, in St. John's, student assistants may have three students in a classroom. In contrast, in Baie Verte, a rural area, they may have only one student; it would depend on the needs of the individual students at that school and the availability of the student assistants. Therefore, resources will look different at different schools, some may not be available at all schools, and therefore resources may not be equal for all students in NL.

The NICU at the Janeway Children's Health & Rehabilitation Centre in St. John's has 26 beds and serves the entire province. The number of beds is currently enough to meet the needs and care for this population in NL, as the unit is rarely full, the unit census fluctuates frequently, and babies are sent to other provinces only for services not offered here, such as congenital heart repair (Janeway Children's Hospital Foundation, 2019).

Because the unit is located in the capital city, it is serving the largest population. By having a NICU transport team with access to ambulances, helicopters, and airplanes at a moment’s notice, the unit and its staff are accessible to everyone in the province, therefore providing reasonable access. In addition, the staff members in St. John’s can speak to anyone by phone or teleconference to answer care questions. Although those in St. John’s would have almost instant access, others may have to wait for the team to arrive to assess babies directly. The difference in access to care could be considered a utilitarian approach to justice in health care. The greatest happiness for the most significant numbers is accomplished when resources (NICU nurses and doctors plus the equipment needed to care for preterm babies, e.g., incubators, ventilators, and small blood pressure cuffs) are limited. Therefore, the life-saving service cannot be extended to everyone in the sense of having more than one NICU in the province; it would not be financially feasible (Hayry, 2002; Martin et al., 2018), even though the distribution of healthcare resources may not mirror the need of the population (Martin et al., 2018). Canada’s healthcare system has geographical challenges. Because “approximately 18% of Canada’s population lives in rural or remote communities dispersed throughout 95% of the area of the second-largest country in the world” (Martin et al., 2018, p. 1724), providing medical facilities and medical transport to specialized centres is both challenging and expensive (Martin et al., 2018). The province of NL needs to follow a budget regarding spending on healthcare needs, including a focus on follow-up care (e.g., education and long-term needs). NL needs reasonable resource constraints, as Daniels (2001) states: this requires us to judge what medical needs are more critical to meet than others.

2.12 The Significance of this Study

I found no studies on how children born preterm and their families expereince and cope with their children entering the public school system or how their circle of care can offer support and guidance to them. Most articles on school performance are quantitative and lack a deep, rich exploration into parents' and others' (in the circle of care) experiences with this new chapter in their children's lives. The literature also lacks information on services that may help these children in the school and their community and/or province. Similarly, I have found no studies on how the location of the school and the home community (urban versus rural) may impact the number of services/resources available to families of preterm infants. This research project aimed to fill this gap in the research by exploring how children born prematurely (who have one or more health challenges) and their families have experienced and coped with their children entering the public school system. In addition, the project explored how families adjust to having a preterm baby with health challenges, what challenges these children and families faced and investigated what enablers and barriers were in place in the school, community, and province that may have helped or hindered these children and their families from having the best possible school performance and educational outcomes. Lastly, I explored how living in an urban versus rural area may have added more challenges or facilitators for these families.

2.13 Chapter Summary

In summary, preterm birth rates are continuing to rise worldwide. In Canada, 30,000 babies are born prematurely each year (Canadian Premature Babies Foundation, 2020), and in NL, one of every twelve babies is born prematurely (Toope, 2014). As stated, prematurity is the leading cause of neonatal morbidity and mortality. Infants that survive have higher long-term morbidity rates than infants born full-term (Frey & Klebanoff, 2016; Purisch & Gyamfi-Bannerman, 2017; WHO, 2012). Preterm birth is a leading cause of neurocognitive and neurodevelopmental impairment in childhood (Boardman & Counsell, 2019). The morbidity impact extends past the neonatal period and into later life; these premature babies are at risk for many health issues throughout their lifetime, including developmental and learning difficulties

(Johnston et al., 2014). These health issues may substantially impact how well these children do in school and their overall educational outcomes. Research has shown that children who were born preterm may experience difficulties with school, and both parents and teachers have reported they have more difficulties with some of the following skills than their counterparts born at term: motor, behaviour, language, writing, physical education, and mathematics (Huddy et al., 2001; Palumbi et al., 2018; Saigal & Doyle, 2008). However, there has been very little qualitative research on how these children experience school, what resources are needed to help them succeed, and how their parents can find and avail themselves of these resources. Therefore, I needed to investigate how these children and their families transitioned to school. I reviewed what resources they were using, how they discovered those resources, and what resources they feel are needed for their children to succeed in the school system.

Chapter Three Methodology

3.1 Introduction

My research was informed by a qualitative approach to understand how children born premature and their families experienced and coped with their child entering the public school system in NL. Qualitative researchers collect data in a natural setting focusing on the participant's perspectives and experiences and the meanings they hold about the issue under investigation through a "…set of interpretive [and] material practices that make the world visible" (Denzin & Lincoln, 2011, p. 40). The result includes, "the voices of participants, the reflexivity of the researcher, a complex description and interpretation of the problem, and its contribution to the literature or a call for change" (Denzin & Lincoln, 2011, p.40).

3.2 Theoretical Perspective

There are various approaches to conducting a research study; the approach a researcher selects is dependent on their epistemological stance. The epistemological stance of this study was social constructivism. Social constructivism has its foundations in anthropology, sociology, psychology, and philosophy (Cromby, 2004; Edley, 2001; Harré, 2002). Social constructivists believe that people produce or construct their social worlds. Reality comes from social interactions with other people which leads to multiple interpretations of these worlds (Hibberd, 2006). The interpretation of meaning is pivotal, as people make sense of the world in which they live through description, interaction, and language (Gergen, 1985).

Social constructivism was helpful as the theoretical framework for this research project. According to Stake (1995), among all the roles that researchers play, the role of gatherer and interpreter is central: "most contemporary qualitative researchers nourish the belief that knowledge is constructed rather than discovered. The world we know is a particularly human construction" (p. 99). Stake (1995) defined constructivism as a belief that knowledge is mainly based on social interpretations rather than an awareness of an objective external reality.

Social constructivism was developed by Lev Vygotsky (1934). He rejected the assumption made by Jean Piaget that it was possible to separate learning from its social context. Vygotsky's theory states that knowledge is co-constructed, and individuals learn from one another. Vygotsky's called it a social constructivist theory because the learner must be engaged in the learning process. Learning happens with the assistance of other people, thus contributing to the social aspect of the theory (Burkholder & Peláez, 2000).

Success in school occurs in social settings influenced by deep contextual factors such as organizational processes, politics, culture, and health status. Social and educational environments are complicated, and the nature of student success cannot be fully understood without consideration of the contextual factors that influence the learning environment (Lincoln & Guba, 1988). The phenomenon studied in this research project was likely to be influenced by many factors that may be interrelated (e.g., health status, child's educational needs, school policy, availability of resources) and therefore needed to be explored from a holistic perspective.

Constructivism considers that reality is based on shared experiences, and research results are "created through consensus and individual constructions, including the constructions of the investigator" (Howell, 2012, p.87). I chose an instrumental case study methodology for this project because I aimed to study how children who were born preterm adapted to going to school in its real-life context. This context included how parents adapted to the child entering the public school system and the factors within the school, their community, and the province that have helped or hindered their child's abilities to achieve the best possible educational outcome. This approach allowed data to be collected that led to an in-depth understanding of how parents adapt to their child entering school and the factors that help or hinder their success in school.

3.3 Case Study

This study used an instrumental multiple case study approach (Grandy, 2010; Yin, 2003), with eight cases from different parts of the province, including both urban and rural areas. Each case has intrinsic value to the study due to its unique features. A case study was the chosen methodology for this study because the central focus of the study was the family unit (the child who was born preterm, their family, and members of their circle of care), and the phenomenon under study was how children born preterm adapted to going to public school. To truly understand how these families adapted to the child going to public school and this transition, several sources of data were explored, including interviews with a parent or parents and members of the circle of care, direct observation (one home visit), document review, and a demographic survey. In the analysis section of this study, I used participants' quotes to describe what the participants in this study said in interviews to give them a voice and to bring to life their stories. I have also described a day in the life of one of these families (from direct observation). Lastly, I used documents to understand policies and procedures that influenced and directed what supports have been permitted in the public school system.

Individuals or groups are often studied in case studies. Researchers engaged in case study research hope to understand situations and their meanings to those involved. The insights gained from this type of research can directly influence policy, procedures, and future research (Algozzine & Hancock, 2017). In case study research, the focus is typically on an individual representative of a group, an organization, or a phenomenon (Algozzine & Hancock, 2017). According to Stake, a case study is the "study of the particularity and complexity of a single case" (1995, p. xi). It is mainly used when the phenomenon of interest is complex and highly contextualized, with multiple variables unsuitable for control. Stake (1995) described case study methodology as a strategy of inquiry in which the researcher explores in depth a program, event, activity, or process of one or more individuals. In addition, "the phenomenon being researched is studied in its natural context, bounded by space and time" (Algozzine & Hancock, 2017, p. 15). Stake (1995) also stated researchers collect detailed information using a variety of data collection procedures over a sustained period. Case study research further means "identifying a topic that lends itself to in-depth analysis in a natural context using multiple sources of information" (Algozzine & Hancock, 2017, p.9).

Defining the case is a critical step in case study research (Stake 1995). The review of existing literature and an appreciation of related issues and case settings helped define the case in this study. Case studies require defined boundaries to identify the complex phenomenon of interest, also known as "the unit of analysis" (Stake, 1995). Cases need to be self-contained with distinct boundaries to identify the extent of the research. The researcher must determine what is contained within the case (and therefore included in the study) and what is outside the case (excluded from the study). The boundary also clarifies the time period covered by the case study. The boundaries of this research study are outlined in my recruitment criteria.

Stake (2005) classified case studies into intrinsic, instrumental, and collective categories. An intrinsic case study allows the researcher to understand the particular case better or collect knowledge about a particular individual, group, organization, or event (Algozzine & Hancock, 2017). The purpose is not to explain or understand the phenomenon or engage in theory building. The study is done because of an interest in the case, for example, a case regarding a particular child or clinic (Stake, 2005). An instrumental case study design is the study of a case (e.g., person, specific group) to provide insight into a particular issue; the case facilitates an understanding of something new. When using this type of case study, the goal is to gain greater insight into the theoretical explanation that underpins the issue (Algozzine & Hancock, 2017).

In an instrumental case study, the focus of the study is more than likely known in advance (Grandy, 2010). It provides a general understanding of a phenomenon using a particular case. It helps to provide insight into an issue or helps to refine a theory (Baxter & Jack, 2008; Stake, 1995). Instrumental case studies offer the potential for detailed, thick descriptions. They involve looking at the details of the case and sorting out the complex layers of understanding that structure the social world of a particular individual or group. According to Grandy (2010), the case is selected carefully, and "formal sampling may happen before selection of the case to ensure that the case will yield fruitful findings pertaining to the research question" (2010 p.2). This type of case study attempts to identify patterns and themes and compares these with other cases, which allows the reader of the research study to see the transferability of the case findings (Grandy, 2010).

A collective case study or multiple case study is when several cases are studied concurrently or consecutively to investigate a phenomenon (Algozzine & Hancock, 2017). In a collective case study, the instrumental case study extends to several cases to better understand the phenomenon (Stake, 2005). It allows the researcher to analyze within and across settings and examine several cases to understand the similarities and differences between the cases. A collective case study:

> …attempts to address an issue while also adding to the literature base that helps us better conceptualize a theory. This design usually involves performing several instrumental case

> studies to enhance our ability to theorize about some more extensive collection of cases (Algozzine & Hancock, 2017, p. 38).

Originally this study was designed to have at least two cases from an urban setting and at least two from a rural setting. However, more cases were added to the study, and the reasons for this change in the number of cases are explained later in this chapter.

The case study site was the province of NL. The population of NL in 2017 was 528,817 (Government of NL, 2022b), and it is declining. The St. John's metropolitan area has a population of 217,454 (Statistics Canada, 2017), almost half of the province's population and is the most significant urban centre. According to Statistics Canada (2016), from 2000 to 2013, NL's preterm birth rate was 8.3%, making this province third in the highest number of preterm births in the country, only falling behind Alberta at 8.6% and Nunavut at 13.7%. From these statistics, it is clear this province has a high number of preterm births and was the ideal location for a study exploring how these babies and their families transition into primary public school.

An instrumental multiple-case study design, which can also be considered a collective case study of eight instrumental cases, allowed me to answer my research question and meet my objectives. This design allowed me to better understand how parents with children born preterm (with a health challenge) prepare for, and adapt to, having their child transition to school. The specific stories provided by these families and the circle-of-care members provided insights into how these families adapted to this new aspect of their lives, including the resources and services they accessed. The document review of the policies and procedures used within the school system provided insights into institutional practices that may also have supported or hindered these families. I have combined information from the eight individual cases to better understand the more significant issue at hand, how these families adapt to having their children in the school system.

3.4 Sample

In qualitative research, sample selection has a significant effect on the quality of the research and should be judged according to the purpose of the study (Patton, 2002). Purposeful sampling was used to ensure that the participants had an experience of the phenomenon being studied (Creswell & Poth, 2016). Maxwell states that *purposeful selection* is "a selection strategy in which particular settings, persons or activities are selected deliberately in order to provide information that cannot be gotten as well from other choices" (2005, p. 88).

Accordingly, four cases were selected strategically and purposefully with consideration of the aim of the study. I planned to interview between three and five participants, including both mothers/fathers and circle-of-care participants (teachers, grandparents, significant others, etc.). After my initial four cases were complete, I met with my supervisory committee. We decided to continue with participant recruitment because each family could only recruit two circle-of-care members; therefore, each case had just three interviews (a parent and two circle-of-care members). In addition, only one rural family was interviewed. At the end of this study, a total of eight families (eight cases) were interviewed, seven of these had three full interviews (a parent (s) and two circle-of-care members), and the last family was a unique case in which both parents were interviewed for close to 3 hours. In addition, three other rural families were interviewed, for a total of four rural families.

3.5 Health Research Ethics Board Approval

Prior to commencing this study, clearance was obtained from the Health Research Ethics Board (HREB), Memorial University of Newfoundland, and from the Research Proposals

Approval Committee (RPAC), Eastern Health (Appendix A: Approval Letter). Before all interviews began, I reviewed the consent form with the parent(s) and answered all questions. Each participant was allowed to review the consent form in private (when interviews are conducted in person) before deciding whether or not to participate. Two copies of the consent form were signed, one copy for the participant to keep and one for my records (for face-to-face interviews). My copy is kept in a locked filing cabinet in my office at the Faculty of Nursing. For telephone interviews, the consent form was emailed to the participant (if an email address was given) to allow them to review the form in private prior to the interview. After parents were interviewed, as discussed in the initial meeting, I explained that I was also interested in interviewing circle-of-care members (e.g., grandparents, babysitters, teachers). I then emailed a copy of a research letter explaining the study and asked the parent(s) to give it to anyone in their circle of care who might be suitable and asked them to tell the circle-of-care members about the study. Members of the circle of care interested in participating in the study contacted me, and a meeting was set up to discuss the study.

In some cases, circle-of-care members told the parent I could contact them to set up an interview time. Therefore, the parent sent me their contact information. If they agreed to be a participant, an interview time was arranged, and at the beginning of the interview, the consent form was reviewed, and questions were answered. If a teacher wanted to participate in this study, the teacher, in some cases, needed permission from the school principal and the school board before the interview. If permission was needed for a teacher to participate, the teacher needed to obtain the permission from the correct people and this process was left up to the teacher's discretion.

In addition, all families were told that if I witnessed or suspected child abuse while in their home during a home visit that it would be reported, as this is an obligation of all adults, health practitioners, and researchers in this province. This was also specified on the consent form. Following Section 11 of the Children, Youth, and Families Act (2018), every person in the province of Newfoundland and Labrador has a legal obligation to immediately report suspected abuse and neglect of children (under age 16) to ensure children are protected from harm. If I had witnessed or been told about any potential harm to the child (e.g., abuse, neglect, unsafe living conditions), this information would have been immediately reported to the police if the child was in immediate danger or to the Department of Children, Seniors, and Social Development (Government of NL, 2018a). During this research study I did not witness and harm, abuse or neglect of children and I was not told about any potential harm, abuse, or neglect.

3.6 Recruitment

Research participants included parents and those in the circle of care and did not include children. They were recruited depending on the following inclusion criteria: (a) had a child born premature (born between 24 and 37 weeks of gestation) and that child, (b) was currently experiencing one or more health challenges including hearing and visual impairments, mobility concerns, language and/or cognitive disability, neurologic concerns (e.g., CP), psychiatric, behavioural concerns (e.g., autism, ADHD, anxiety), diabetes, and/or asthma; (c) was in kindergarten or grades one to six; and, (d) was currently enrolled in a public school in NL, and the research participants (e) were willing to take part in interviews and a home visit, (f) were willing to help to recruit other members of their child's circle of care that could be interviewed by the researcher (snowball sampling), (g) were living in Newfoundland and Labrador, and (h) were able to speak and understand English. If parents were unwilling to recruit members of their child’s circle of care, they were excluded from the study. All participants were volunteers, and no remuneration was given for participation.

A poster (see Appendix B: Original Poster) explaining the research study and the recruitment criteria was posted on Facebook in a specific group related to NL premature babies called NL NICU Parents on August 8, 2019. The advertisement of my study was expanded to other groups on Facebook related to NL premature babies (i.e., World Prematurity Day NL, Parents Helping Parents with Everyday Questions about Parenting-NL) later that month when recruitment was slow. Advertising my study in this way allowed potential participants to gain information, and parents were invited to participate in the study voluntarily. Contact information was provided so potential participants could contact me directly. The research poster was placed in all of these groups, with the most comments from parents coming from two groups, NL NICU Parents and Parents Helping Parents with Everyday Questions about Parenting-NL; the poster was reposted numerous times. The recruitment process was slow, and I sometimes wondered if I could recruit enough participants. Therefore, after speaking to my supervisor, it was decided the poster was to be placed in areas around the Janeway (specifically in the Pediatric Intensive Care Unit and in the Emergency Department) to help with visibility for the study. Ethics clearance was sought and given to allow these posters to be placed in these areas. However, with the global pandemic, all papers (nonessential) were removed from walls within the hospital to limit the spread of the virus. My research poster was also handed out at the Wee One’s Walk for Prematurity in 2019; the walk was cancelled in 2020 and 2021 due to pandemic restrictions. No parents contacted me from this event. Having no one contact me from the event attended by families that met my research criteria was devastating to me; I was hoping that parents would be interested in my study and would want to participate.

In November 2020, a new poster was designed to help with recruitment. The new poster (Appendix C: New Poster) had the same information but removed much of the medical jargon and added a picture and colour. This poster also received ethics clearance prior to being posted. The new poster was reposted on Facebook in the groups listed earlier and helped recruit more families. It was at this time, after speaking to my Supervisory Committee, that I realized how important the words I was using on my poster were and how my original poster may have turned off some families who may have wanted to participate. This experience was a huge learning curve for me, and it helped me realize how medical jargon can confuse some parents and how using too many words might have caused people not to want to take the time to read my poster.

3.7 Data Collection

As stated earlier, Yin (2003) stated that a carefully conducted case study benefits from having several sources of evidence, which helps to ensure that the study is as robust as possible. I collected many data sources for this study, including interviews, demographic data, direct observation (home visits), and documents. Using multiple data sources enhanced the richness of the data and allowed me to create a narrative that honours each participant's meaning-making process.

3.7.1 Interviews

Humans interact with each other through language, communication, and interaction. We talk to each other, interact, and have conversations to get to know other people and learn about their experiences, feelings, and world (Kvale & Brinkmann, 2009). According to Kvale and Brinkmann (2009), interviews are important because during an interview, the researcher asks about and listens to what people have to say about the world they live in and about their opinions of their world and learns about their family, social, school, work and life situations. The interview is "where knowledge is constructed in the interaction between the interviewer and the interviewee" (Kvale & Brinkmann, 2009, p. 1).

Participants were advised that all interviews would be audio-recorded and take 45 to 60 minutes. Participants could take a break, stop, or reschedule an interview if needed. They were also advised to refuse to respond to any question if they preferred not to answer. The study participants determined the time and location most convenient for conducting the interviews. It was expected to be a place where comfort and confidentiality would be ensured. Data was collected using a semi-structured interview guide (Appendix D: Interview Guide) with specific open-ended questions. This guide ensured all subject areas and research objectives were addressed during the interviews.

Two face-to-face interviews were completed. All other interviews were conducted over the phone, partly because of participant preference and partly due to the global pandemic and protocols initiated by Memorial University of Newfoundland. I found myself very comfortable with the face-to-face interviews when conducting the interviews. I am familiar with talking to people about medical experiences as my profession is nursing. I am not as familiar with completing phone interviews, so I was nervous prior to calling a participant. However, once I was on the phone, within a few minutes, I was comfortable, and I found all interviews went well, and there were no awkward moments or pauses.

3.7.2 Demographic Information

At the end of the interview, demographic information was collected on the preterm child's parent(s). The purpose of completing the demographic questionnaire (Appendix E: Demographic Questionnaire) was to assist with describing the study sample in aggregate terms in planned future publications and presentations.

3.7.3 Direct Observation

Direct observation as “a source of evidence can contribute to the development of a strong case” (Pauly, 2010, p.302). It allows the researcher the opportunity to observe things that are happening directly in the social setting, interact with participants, and participate in activities (Pauly, 2010). Direct observation was conducted to allow me to observe the family’s living situation and meet the child. The visit took place only if the parents consented, and it was done at a time convenient for the family. The purpose of the home visit was to observe the child in their home environment and view interactions with parents, significant others, and siblings and observe the child at play and during regular household routines, not to evaluate the family. I created and used an observation guide to give myself a more comprehensive overview of the family and their routine (See Appendix F: Observation Guide).

I planned and did visit one family’s home; I met their children and observed how the family interacted with one another and their living space. I observed the family home’s general state, including looking at how crowded the house was, who lived in the home, how the house was organized, and if the space was conducive to healthy child development.

I recorded field notes in my research diary throughout and after my time observing; this included not only what I had seen but also how I felt at that time, based on Pauly (2010):

> In field notes, the researcher records what he or she has seen, heard, felt, smelled, and experienced through his or her direct observation; they provide an opportunity to reflect on one’s values, beliefs, and assumptions that may be influencing perceptions (p. 304).

According to Schensul et al. (1999), good field notes use exact quotes, describe activities in the order in which they occur, provide descriptions without inferring meaning, and include relevant background information to situate the event. In addition, field notes separate the researcher's thoughts and assumptions from what one observes and records the researcher's date, time, place, and name on each set of notes.

Prior to the beginning of the global pandemic, I was able to complete one home visit. Once the pandemic began, and alert systems were put in place in the province, Memorial University of Newfoundland did not allow in-person data collection; therefore, all home visits were stopped. I was very nervous about completing my only home visit (prior to the pandemic). I did not know what to expect, and I was unsure of what I might encounter. However, once I got to the home, the family was amicable and inviting, and my nervousness quickly disappeared. I also felt that being a pediatric nurse helped my comfort level as I am used to interacting with parents who have children with medical challenges. I have had the pleasure of caring for many children with different diagnoses.

3.7.4 Document Analysis

A document review was included as another method of data collection. Document analysis is a form of data collection in which the researcher interprets documents to give a voice and meaning to a topic (Bowden, 2009). According to O'Leary (2014), there are three primary types of documents: public records (the official, ongoing records of an organization's activities, e.g., mission statements, policy manuals, handbooks); personal documents (first-person accounts of an individual's actions, experiences, and/or beliefs, e.g., emails, journals, Facebook posts); and physical evidence (physical objects found within the study setting, such as flyers of agendas).

I reviewed public records on the internet (e.g., policies, statements) that provided more information on how the child may be treated in school. I searched both the Department of Education and Early Childhood Development (e.g., *Handbook for Parents of Students with*

Exceptionalities, *Inclusive Education*) and the School Boards (e.g., *Administration of Medications, Medical Intervention*) websites for policies and procedures. These records outlined resources available to the child and family related to school (e.g., accommodations); appertaining to how the child's medical history may affect their school performance (e.g., medication use in school, alternative forms of transportation available); and/or regarding services with which the family has been in contact related to school entry and performance (e.g., special equipment needed).

3.8 Data Analysis

In most case study research, multiple methods of data collection are employed and therefore need to be analyzed. Data analysis began with the analysis of my interviews and then moved on to analyzing all other data points (e.g., documents, field notes, and demographic information).

3.8.1 Interview Analysis

I used the voice-centred relational method to analyze interview data as described by Mauthner and Doucet (1998). The Mauthner and Doucet approach of analysis was based initially on the method developed by Brown and colleagues at the Harvard Graduate School of Education (1989, as cited by Mauthner & Doucet, 1998). While completing their Ph.D. research, Mauthner and Doucet found a lack of information on analyzing qualitative research data. Mauthner and Doucet used the original voice-centred relational method under the guidance of Carol Gilligan (visiting professor at the University of Cambridge) from Lyn Brown and colleagues (Mauthner & Doucet, 1998). They then adapted it to reflect their interdisciplinary backgrounds and specific research interests of their Ph.D. research, which was rooted in feminist research practice and qualitative research. As a novice researcher completing my Ph.D. research, I liked how their approach to analysis gave me step-by-step directions on how many times to read each transcript and what to look for in the interview transcripts. In addition, it helped me keep the participants' voices and perspectives intact and at the forefront of each reading while also recognizing the role of the researcher (Mauthner & Doucet, 1998).

This method of data analysis helps the researcher explore individuals' narrative accounts in terms of their relationships with themselves, their relationships with the people around them, and their relationship to the broader social, cultural, and structural contexts in which they live (Mauthner & Doucet, 1998). This method included two distinct phases of data analysis: the first involved four readings of each interview transcript to balance the voices and stories of all participants, the researcher, and the perspectives of theories researchers may bring into their study. The second phase was the thematic breaking down of the data and summaries. Each transcript was divided into several overlapping themes and sub-themes in this stage.

The first distinct phase began when I reviewed my transcripts. The first stage in this phase is reading for the plot and my responses to the narrative. The transcript is read for the overall plot and story that the participant is telling; the reader looks for the main events, recurrent words, images, metaphors, and contradictions and tries to put herself/himself in the narrative to allow for an understanding of how their assumptions and views may affect the interpretation of the transcripts. The first reading allows the researcher to examine their views and assumptions and how this may affect the interpretation of the participant's words or how the researcher may write later about that participant. This process allows the researcher to be reflexive about the data analysis processes and, according to Mauthner and Doucet (1998), allows for (1) locating oneself socially in relation to my research participants; (2) attending to one's emotional responses to the participants; (3) it allows for examining how we make theoretical interpretations of the participant’s story; and (4) documentation of the process. As I read through each transcript, I wrote keywords and ideas that the participant expressed in the margins of the transcripts to understand the overall plot. Some examples of keywords included mother, NICU, scared, anxious, and not ready.

The second reading of the transcript searches for the voice of “I” and focuses on how the participants experience, feels and speaks about themselves. As per Mauthner and Doucet (1998), I used coloured pencils/pens and underlined personal pronouns such as “I,” “we,” and “you” in each transcript in an attempt to understand how they live in their world. This reading focuses on how the participants experience, feels and speaks about themselves.

The third reading is concerned with relationships. This reading looks at the interpersonal relationships of the participant with their partners, their relatives, their children, and the broader social networks within which they live, parent, and work (Mauthner & Doucet, 1998). As per Mauthner and Doucet (1998), I used a coloured pen (different colour from reading number two) and underlined their words as they spoke about their relationships. For example, I underlined words that spoke about marriage in blue, while words that spoke of a parental relationship were underlined in red.

The fourth reading looks at placing people within cultural contexts and social structures and their experiences within the broader social, political, cultural, and structural contexts. As suggested by Mauthner and Doucet (1998), I looked for words like “should,” “ought,” good,” “bad,” “right,” and “wrong.” Once again, I used a coloured pen (different colour from previous readings) and underlined these words and each applicable sentence.

The initial analysis of the interviews was done in two stages. In the beginning, I familiarized and immersed myself with the data. As stated above, I read and reread my interview transcripts, and I also listened to the audio recordings as an active way to search for meanings and patterns. Phase or stage two is summaries and thematic breaking down of the data. During my analysis, I looked at all the various words I had underlined and then reviewed all the words and sentences I had written down. I noticed several general categories while looking at the sentences where things would fit, for example, several follow-up appointments and travel time. I started the initial production of codes from the data. Coding is a process of reflection and a way of interacting with and thinking about data (Savage, 2000). Coding allowed me to simplify and focus on specific aspects of the data; this process consisted of looking at and rereading the transcripts and identifying recurring words, ideas, or patterns (Savage, 2000). During the coding process, I identified important text sections and attached labels to them (King, 2004), for example, travel time (families travel time to their appointments). I used different coloured pens to indicate several codes, and I put brackets around all sentences with similar ideas. Some sentences had multiple colours if they fit in more than one category; for example, one sentence I wrote was that *she had hope and felt lucky she was healthy. She visited the NICU every day, and the nurses kept her informed*. This sentence fits into the categories of hope and NICU. I worked through an entire case (three interviews, an entire data set) and gave full and equal attention to each transcript.

I then began to look at all the codes that I had created from my transcripts and developed a master code list. These codes were then placed into a category or phase that described that set of data: my themes and sub-themes. King (2004) suggested that the best place to start is with a few predefined codes to help guide analysis when searching for themes. Creswell and Creswell (2017) described a systematic process for coding data in which specific statements are analyzed and categorized into themes that represent the phenomenon of interest. DeSantis and Ugarriza defined the concept of a theme as “an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. A theme captures and unifies the nature or basis of the experience into a meaningful whole” (2000, p. 362). My next step was writing out my codes on paper and putting sentences under the appropriate code. After this step, I read the groups of sentences and looked for essential themes and sub-themes; the themes were identified by bringing together fragments of ideas or experiences, such as child resilience and stigma. Themes appear as significant concepts that link substantial data portions (DeSantis & Ugarriza, 2000). I then reread all of my transcripts to ensure that my themes adequately represented the data. I ended up with themes, sub-themes, and some themes that were unique to a single interview participant. I repeated these steps for each family’s interview transcripts. As a novice researcher, I found it hard to develop exciting themes that were not too broad; it took time. Braun and Clarke (2006) suggested that theme names need to be punchy and immediately give the reader a sense of the theme.

After analyzing the transcripts, I organized the themes and sub-themes that I had created and placed passages from the transcripts into similar thematic categories; this process allowed me to generate exact names for themes and sub-themes. I had approximately three to five pages for each case (three interviews), which represented the participants and their stories, highlighting major themes and sub-themes. The findings will be explained in detail in the chapter on results.

To help with the analysis process and the trustworthiness of my study, my supervisor also reviewed the first set of transcripts (three interview transcripts, one case). Both my supervisor and I read the transcripts and completed independent coding, and then we compared our analyses (separate list of codes identified from the interviews). We found similar codes through our analyses and discussed possible themes. Having this process of review and finding similar results helped me, as a new researcher, gain confidence in developing themes from the transcripts.

Due to the global pandemic, my supervisor and I were no longer located in the same province. Transcripts were emailed to my supervisor so we could complete the analysis. All identifying information (including names, locations, and school names) was removed from the transcripts, and the emails were password-protected. The password was sent to my supervisor in a separate email. In addition, the sensitivity of each email was set to confidential, and a request for delivery receipt and request for read receipt was added. In the second stage of the analysis, I reviewed all the remaining transcripts and reached out for assistance when required.

During this time, I realized how much data I had. During the interview process, I was aware of how many interviews I completed and the length of each interview. However, it was not until I printed each transcript that I realized the sheer amount of data I had collected. It took me a long time to go through each reading for each transcript.

3.8.2 Demographic Analysis

This study consisted of eight cases; therefore, I had eight family units filling out the sociodemographic data. The purpose of collecting this data was to help describe the study sample in aggregate terms to understand the cases fully. For analysis, means were calculated using descriptive statistics.

3.8.3 Direct Observation/Home Visit Analysis

I used Bernard and Weisner's (1998) suggestions to code my observation notes and field notes; they suggested that coding should be used to select and then emphasize the vital information to record. Coding helps the researcher to eliminate all extraneous information. After the home visit was completed, I finished filling in my observation guide and wrote field notes.

To begin my analysis, I reviewed my field notes and observation guide to becoming more familiar with the data; I then developed codes; coding is a process of reflection and a way of interacting with and thinking about the data (Savage, 2000). I looked for essential parts of the text and attached labels to them, for example, “safety,” “toys,” and “family.” I then organized the collected data into a narrative in which I could tell the story of a day in the lives of the informants. There are sections in the narrative that reflect my interpretation of specific themes that make the scene clear to the reader (Kawulich, 2005). The results of the home visit that was completed are in the next chapter.

3.8.4 Document Analysis

An essential part of document analysis is not to consider the data as “necessarily precise, accurate, or complete recordings of events” (Bowen, 2009, p. 33). Therefore, looking at the steps outlined by O’Leary (2014) is an essential first step:

1. Gather relevant texts.
2. Develop an organization and management scheme.
3. Make copies of the originals for annotation.
4. Assess authenticity of documents.
5. Explore the documents’ agenda and biases.
6. Explore background information (e.g., tone, style, purpose).
7. Ask questions about a document (e.g., who produced it? Why? When? Type of data?).
8. Explore content. In other words, the researcher quantifies the use of particular words, phrases, and concepts.

Document analysis is a process of "evaluating documents in such a way that empirical knowledge is produced, and understanding is developed" (Bowen, 2009, p. 33). The next chapter will discuss the results of my document analysis.

The documents used in this study were found on the Government of Newfoundland and Labrador's website, the Department of Education's website, and the Newfoundland and Labradors English school districts' websites (Appendix G: Documents Analyzed). The documents/policies/pamphlets may include the *Accommodation and Exemption Policy* (reading and writing), the *Roles of Instructional Resource and Classroom/Subject Teachers in Inclusive Schools*, the *Bullying Intervention Protocol*, and the *Administration of Medications and Medical Interventions*. In addition, the *Chronic Care Policy*, the *Alternate Transportation Policy, Inclusive Practice Guidelines: School Level*, the *Handbook for Parents of Children with Exceptionalities*, *Communication Disorders*, and *Your Child Has Hearing Loss?* (a pamphlet) were reviewed. Lastly, the *Handbook for Teachers Serving Students Who Are Deaf-Blind, Deaf or Hard of Hearing with Additional Disabilities, and Blind or Visually Impaired with Additional Disabilities* and the *Programming for Individual Needs, Alternate (Functional) Curriculum Guide* were also reviewed.

3.9 Confidentiality and Storage of Data

I took all reasonable precautions to protect the confidentiality of participants and confidentiality of all information. It is important to note that the parents helped me recruit members of their child's circle of care to interview. Therefore, parents were aware of who might have been interviewed but were not aware of what was said. In all recorded and transcribed data, the participants were identified by a number to act as a code. All identifying information (i.e., consent forms) is kept in a locked filing cabinet in a locked office. All interviews are stored on a

USB stick (password-protected), and the transcribed copies of the interviews are kept in a separate locked filing cabinet in the same office. All electronic data files are password-protected and stored on password-protected and/or encrypted devices. My research supervisor was provided with copies of all consent forms, interview recordings, transcripts, and field notes on an encrypted USB stick (as per university policy). Participants were told that the completed study would be available at the Health Science Library (and published online after two years) and that the results would be published in health journals. Data will be kept for five years, as required by Memorial University of Newfoundland's policy on integrity in scholarly research.

If a participant became upset during or after an interview, they were advised to call Eastern Health's mental health crisis line. This phone line is open 24 hours a day, seven days a week: (709) 737-4668 or 1-888-737-4668. During the interview process, due to the nature of the subject, some participants were emotional. Some cried while retelling their story of having a child or grandchild in the NICU; I validated their feelings as signs of empathy and let them express their feelings. After the interview, they were referred to the crisis line.

A professional transcription service was used through the nursing research unit at Memorial University of Newfoundland. The transcriptionist signed an oath of confidentiality. All participant interview transcripts and audio files were password protected and transferred via encrypted email.

3.10 Trustworthiness

Researchers should establish the protocols and procedures necessary for their study to be trustworthy (Connelly, 2016). The trustworthiness of a research study refers to the degree of confidence in the data, interpretation, and methods used by the researcher to ensure the quality of the study (Connelly, 2016). Trustworthiness refers to qualitative research findings' quality, authenticity, and truthfulness. It relates to the readers' trust or confidence in the results (Cypress, 2017). Trustworthiness in qualitative studies aims to support the argument that the study's findings are "worth paying attention to" (Lincoln & Guba, 1985). Lincoln and Guba (1985) proposed four criteria for assessing qualitative research data's trustworthiness: credibility, dependability, confirmability, and transferability. This framework of trustworthiness set up by Guba and Lincoln (1985) has been contested by other researchers (Morse et al., 2002; Redwood, 2005) however, is still considered the gold standard for qualitative research (Cresswell & Cresswell, 2017).

3.10.1 Credibility

For Lincoln and Guba (1985), credibility refers to the accuracy of the findings in a qualitative research study or the confidence in the truth of the study and, therefore, the findings (Connelly, 2016). One activity to enhance credibility in research is prolonged engagement (Lincoln & Guba, 1985). Prolonged engagement implies the investigator performs the study for an extended period, a considerable length of time, enough to learn about and/or understand the phenomenon of interest and explain the subject matter under investigation (Lub, 2015). One interview may not provide the researcher with an ample opportunity to have a long period of engagement with a particular participant. However, completing three interviews related to each child and interviewing eight families (along with listening to the audio recording and reading the transcripts of each interview) has enhanced my engagement with the data. I have worked as a neonatal intensive care nurse in the past, both in this province and in another country, so I am familiar with preterm infants, the care they receive while in hospital, and their potential health conditions. In addition, I have also worked in the Pediatric Intensive Care Unit and on a medicine floor, where many of these children are readmitted due to their health challenges.

Another activity to enhance credibility in research is triangulation. Triangulation refers to using multiple methods or data sources in qualitative research that helps the researcher establish a comprehensive understanding of the phenomena under study. There are different types of triangulation, including method triangulation and data source triangulation, both of which were used in this study (Carter, 2014). Method triangulation involves using multiple methods of data collection (Carter, 2014); this study included various methods, such as interviews, one home visit, demographic questionnaires, and document analysis. Data source triangulation involves collecting data from different people, including individuals, families, and communities (Carter, 2014). For this study, parents were interviewed separately (with one exception where the father and mother were interviewed together). Members of the child's circle of care were interviewed separately, including grandparent's, aunts, family friends, and teachers. The interviews were primarily separate, but in one group, both grandparents were together for the phone interview. Interviews allowed me as the researcher to gain multiple people's perspectives and helped to validate the data. Lastly, another activity to enhance credibility is peer debriefing, in which a qualified researcher (in this case, my supervisor) helps to review and assess transcripts, looking for emerging and final categories from those transcripts, and then reviewing the final themes or findings of a given study (Janesick, 2007).

3.10.2 Dependability and Confirmability

Dependability ensures the research finding is consistent and can be repeated (Lincoln & Guba, 1985); it refers to the stability of the data over time and the conditions of the study (Connelly, 2016). While confirmability refers to the stability of the research data over time and ensures the findings are a result of the inquiry and not the researcher (Lincoln & Guba, 1985). Confirmability is how the findings are consistent and can be repeated (Connelly, 2016).

An activity to ensure both dependability and confirmability is an audit trail. An audit trail ensures that all study records are kept (Cresswell & Cresswell, 2017). I have kept all original transcripts and each step of my data analysis to show how my major themes were generated, including thematic maps. During my analysis, I also kept a reflexive journal, in which I recorded information about the research process and my thoughts and feelings. My journal provided a place for me to record the reasoning for my methodological decisions, provide information to help with my data analysis, and show how decisions were made (Lincoln & Guba, 1985; Norwell et al., 2017).

3.10.3 Transferability

Transferability ascertains that similar judgments are possible when sufficient descriptive data is provided to the readers. It is the extent to which the findings of one study are helpful to people in other settings; it is where the reader would determine how applicable the findings are to their situation (Connelly, 2016). One activity to ensure transferability is thick description (a description of the time and context of the findings versus stating facts without meaning). A thick description requires the researcher to describe the time, people, places, and context of the finding, making transferability judgments possible by other researchers (Lincoln & Guba, 1985 & Henry, 2015). When using thick description, the emphasis is placed on including the accounts of the context and the research methods and examples of raw data; this will allow the readers to consider their interpretations of the study (Stake, 1995). Providing a rich and vigorous representation of the findings also enhances transferability (Graneheim and Lundman 2004); this will be seen in my results chapter, where appropriate quotations are used. The context for this study is detailed throughout this dissertation.

3.11 Dissemination of Results

A copy of this research study will be available at the Health Science Library as a final dissertation and published on the library's webpage (after two years). The results will also be published in peer-reviewed health journals (to be selected after the study is complete) and presented at national and international maternal and child health conferences.

I will also provide recommendations to different organizations (including the government and the NICU) on how they can better address the challenges of children who are born preterm and have health challenges.

3.12 Chapter Summary

In this chapter, I discussed my theoretical perspective of social constructivism, understanding that there are multiple realities, both subjective and constructed by the researcher and the research participants; the constructivist lens is appropriate for my research study (Lincoln & Guba, 1985). My methodological frameworks and method techniques were also outlined in this chapter. The characteristics of case study methodology aligned with my goals for this research project, exploring how a child born prematurely and their family adapted and coped with their child entering the public school system. In addition, to explore what challenges these children and families face and investigate what facilitators are in place in the school, community, and province to help these children and families have the best possible school performance and outcome. Lastly, to explore how living in urban versus rural areas may add more challenges or facilitators for these families. The methods of data collection chosen for this study included interviews, demographic data, home visits, and document analysis. These methods allowed me to gather a substantial amount of data and helped with the trustworthiness of this study. The results and data analysis will be presented in the next chapter.

Chapter Four Results

4.1 Introduction

Qualitative research is a form of social inquiry that focuses on how people interpret and make sense of the world they live in and their life experiences (Holloway, 1997). Qualitative research is used to understand how people experience the world; it allows the researcher to explore participants' perspectives, feelings, and experiences. For this study, qualitative research allowed me to understand how parents and circle-of-care members experienced giving birth preterm, bringing home a preterm baby with a health challenge, and adapting to that child (with a health challenge) going to school.

My epistemological stance was social constructivism, as I believe that people experience and understand their social world as a construct of social conditions and relationships (Hibberd, 2006). The inclusion of, and emphasis on, multiple realities and personal stories made social constructivism compatible with my stance regarding this study. Social constructivism acknowledges that participants (parents and circle-of-care members) are in the best position to describe their emotional experiences regarding preterm birth and adapting to a child born preterm (with a health challenge) going to school. This epistemology provided me with a set of lenses that enables awareness of my social and cultural context and how I perceived and experienced preterm children with health challenges and children's adaptation to school. I was able to bring myself, my experiences, and past learnings (as a former NICU nurse and a mother) and enter into a conversation with parents and circle-of-care members, remaining aware of my social and cultural context and the personal biases I may have.

The purpose of this research was not to gather facts but to start a conversation and understand what these families experience. Social constructivists acknowledge the equal engagement of research participants and researchers as co-creators of a shared reality.

This research study used an instrumental multiple case study methodology as this allowed me to gain an in-depth understanding of what the participants were experiencing with a preterm child with health challenges and how their families adapted and coped with their child entering the public school system. Data collection included in-depth interviews with participants (parents, circle-of-care members), demographic data, direct observation (one home visit), and relevant document analysis.

In this chapter, I discuss the results of my data analysis. To begin, I present the results of my demographic data. Demographic data was collected from the parents of the eight families who participated in this study. Results will be presented using aggregate terms (e.g., mean). Then, I present the results of my direct observation. I present a day in the life of one family I interviewed and with whom I completed a home visit. I used a combination of my observation guide (Appendix F: Observation Guide) and my field notes to complete this section.

Next, I will present my analysis from my document review. I used the steps outlined by O'Leary (2014) for this analysis. I began by looking for relevant documents on the Newfoundland and Labrador English School Districts website and the Government of Newfoundland and Labradors Department of Education's websites. I organized the documents from each website and looked at when the document was written and last revised, who wrote or revised the document, whether it was current, and asked questions about the document (e.g., who produced it? Why? When? What type of data was included?). I also reviewed the *NL Building's Accessibility Act* (Government of NL, 2018d) and the *Accessibility Act* (Government of NL, 2021b) because, in my interviews, two families brought up the issues they had gone through regarding not being able to enter certain businesses with a wheelchair. The documents that I reviewed were pertinent to the stories told to me during the interviews.

Table 4.1

Documents Analyzed

NLESD	Department of Education	Other
Safe and Caring Schools Policy (2013)	*English Program Curriculum Guides (2021)*	*The NL Buildings Accessibility Act (2018)*
Bullying Intervention Protocol (2013)	*French Immersion Curriculum Guides (2021)*	*Accessibility Act (2021)*
Alternate Transportation Policy and Application Package (2012)	*Inclusive Practices Guidelines: School Level (2014)*	
Administration of Medications, Medical Intervention and Chronic Care (2015)	*Responsive Teaching and Learning Policy (2020)*	
	Handbook for Parents of Children with Exceptionalities (2015)	
	Handbook for Teachers Serving Students who are Deafblind, Deaf or Hard of Hearing with Additional Disabilities, and Blind or Visually Impaired with Additional Disabilities (2003)	
	Programming for Individual Needs Alternate (Functional) Curriculum, Curriculum Guide (2008)	

Lastly, I present the analysis of my interviews. My semi-structured interview guide directed all 22 of the interviews. (See Appendix D: Interview Guide). This guide was an outline of questions ensuring consistency and structure in the interview process and that all pertinent topics were covered during each interview. To analyze the data from the interviews, I used the voice-centred relational method as described by Mauthner and Doucet (1998). This method involves two distinct phases of data analysis: the first being four readings of each transcript to ensure balance in the voices and stories of all participants and the researcher. The second phase was the thematic breaking down of the data and summaries.

During the first phase, I read each transcript to (a) examine my own views and assumptions, which allowed me to be reflexive; (b) search for the voice of “I”; (c) look for and explore relationships; and (d) look at placing people within cultural contexts and social structures (Mauthner & Doucet, 1998). The second phase included a thematic breaking down of the data. Recurring words and messages, ideas, and patterns were coded. Codes were then placed into a category or a phase, which turned into my themes and sub-themes (Mauthner & Doucet, 1998).

The following chart portrays the three significant transition periods by which my data analysis is organized, along with the themes and sub-themes that emerged from the data during each transition. The sub-themes are noted with an asterisk, as these only appeared with a few families. I considered the data from the sub-themes relevant and essential to include. The third transition has more themes as this was where the research objectives were discussed with the participants. In addition, the bulk of the interviews spent time talking about transition three.

Table 4.2

Three Major Transitions with Associated Themes and Sub-themes

Expecting a healthy baby/child to having a preterm baby with a health challenge	**NICU to home**	**From Home to Starting School**
The Expectation of Pregnancy versus the Reality of Pregnancy	The Long Journey to Home	To Register or Not to Register?
Unexpected Health Challenges	Scheduling Challenges	Separation Anxiety *

	The Discovery of Health Challenges	Communication and Accommodations Sub-themes: Looking for Resources* & Medications at School*
One Discharge, Not Two	Financial Worries & Unlikely Support	Teacher Appreciation
The NICU Experience: Stress, Learning, and Comfort	Insider Knowledge	Acceptable Behaviour *
The Impact of Having a Sick Child	The Resilience of Children	Urban versus Rural Living
		Where to Find Support
		Stigma and Labelling *
		What Would You Change if Given a Chance?
		Resources Needed

The story told in this research was constructed with the assistance of the participants' stories: the mothers, fathers, grandparents, family friends, and teachers, and it was filtered through my own experiences as a NICU nurse and a mother. The collective interviews from each family form one case, with eight case studies in total.

4.2 Demographic Data

Eight families agreed to be interviewed. Two other mothers were interviewed and completed the demographic questions, but they could not find any circle-of-care members that agreed to be interviewed; therefore, their information was not used in this study as per the consent forms. I made this decision prior to the beginning of data collection to ensure that a minimum of three participants represented each case to enrich the data. At the end of all interviews with the parents, demographic data were collected. This information included the parents’ age, a list of those who lived in the family home, their relationship status, education level, and work status (Appendix E: Demographic Survey). The purpose of completing the demographic questionnaire was to assist with describing the study sample in aggregate terms for this dissertation and in planned future publications and presentations.

Of the eight families who completed interviews (and had circle-of-care interviews), four of these families live in urban areas of NL, while the other four families live in rural areas of the province. In all eight cases, the mother was interviewed, and in four cases, the father was also interviewed. In one case, both parents were interviewed together, but all others were separate interviews. Seven of these parents remain together in a relationship, with six of them married to one another, one couple lives as a common-law couple, and one mother is now remarried to another man who is a stepdad to her child born prematurely.

The average age of participating mothers was 38. Six mothers had bachelor’s degrees, while the other two had some college education but no degree. Four of these mothers were stay-at-home mothers, three worked full time, and one worked part time. Of the mothers who stayed at home, most stayed at home due to the complex nature of their child’s health challenges.

The average age of fathers who participated was 39. One father had a graduate degree, one had a bachelor’s degree, and six had some college education but no degree. Seven of these fathers worked full time while one had been laid off due to the COVID-19 global pandemic. Prior to the pandemic, he was working full time, and he was hoping to be working full time again after the pandemic.

Table 4.3

Demographic Data Table

Location (Where the family lived at the time of the interview)	**Martial status**	**Average Age** (At time of interview)	**Education** (Mothers)	**Education** (Fathers)	**Job Status** (Mothers)	**Job Status** (Fathers)
4 – urban areas	6 – married couples	Mothers – 38 years old (Average 31-48)	6 – have bachelor's degrees	1 – graduate degree	4 – stay at home	7 – worked full time
4 – rural areas	1 – common law couple	Fathers – 39 years old (Average 28–49)	2 – some college education but no degree	1 – bachelor's degree	3 – worked full time	1 – laid off (due to global pandemic)
	1 – couple is remarried			6 – some college but no degree	1 – worked part time	

4.3 Direct Observation (Home Visit)

Due to the COVID-19 pandemic, public health restrictions, and instructions from Memorial University of Newfoundland during data collection, only one home visit was completed. This visit happened in the fall of 2019, prior to the pandemic beginning in the winter of 2020. During the visit, I used my observation guide (Appendix F: Observation Guide) to help direct me to observe specific things during the visit; this included general family dynamics and the general condition of the home, as well as who was present, who was interacting with the child, whether medical equipment was present around the house, whether the environment was crowded, who lived in the home, and whether there were any safety concerns for the child. After the visit was complete, I wrote field notes regarding my experience, including my thoughts and feelings regarding the visit. Next, I present the data from my home visit as a day in this family's life. Names, locations, and certain family features have been changed to protect the confidentiality of the family, and no identifying information will be shared. A pseudonym of "Lilly" will be used for the child involved in the home visit.

On a sunny fall day in 2019, I had the privilege of visiting one of the families whom I had just finished interviewing for my research study. I had connected well with both parents during the interview stage, during which they were both interviewed separately. When I asked about the possibility of completing a home visit and discussed the purpose of the visit, both parents smiled and said they would love for me to meet their daughter and son. Their daughter Lilly was born preterm and was diagnosed with autism between the ages of two and three. Through the interviews, I learned how the diagnosis of autism had changed the parents' lives (and the lives of their families) and how it has influenced every aspect of their lives since they noticed something was different with their child when she was not acting like other children her age.

During the interviews, the parents spoke about how Lilly did not progress through all the developmental stages like other children and how this was a concern. She did not speak and still is nonverbal. In the beginning, they feared that she was deaf because she did not respond to her name, and when they spoke to her, Lilly would remain focused on whatever task she was doing. At a doctor's appointment, her hearing was tested, and there were no issues related to hearing. The parents also noticed that their daughter would get upset quickly, especially if there were any changes in her routine, she did not wave or point at things, and she did not notice when other people were around her in the same room. The parents brought this to the attention of their family physician, and shortly after their daughter turned two, she was diagnosed with autism spectrum disorder by a specialist at the Janeway Children's Health and Rehabilitation Centre. When asked how the mother felt about the diagnosis, she stated:

> *I was relieved at the time because I knew that [Lilly] had autism. I could just tell from all the research we had done, and we'd seen signs of it already, early signs and everything that we read fully met [the diagnosis].*

This family was very open in the interview process and during the home visit. The mother stated that Lilly is a *"runner, [Lilly] don't understand safety and danger."* Therefore, this issue was at the forefront of my mind as I began my visit to the family home. At the time of my home visit, Lilly was eight years old. When I entered their driveway, I noticed that the front and backyards were both fenced in, and when I went to open the gate, I could not figure out how to open it. There was an opening in the wood in which you needed to put your hand and move your hand down and to the side to find the latch; however, even after finding the latch, I could not figure out how to open it. I could not believe that, as an adult, I could not open the gate. The father came out when he noticed that I was struggling and helped me. He showed me how the gate worked and explained that the gate was designed to keep Lilly safe in her yard. She had figured out how to unlatch the gate and lock before, so they had to be more creative and cover the latch so that she could not watch someone unlatch it and know herself how to do it. I was impressed that the parents figured out a way to lock their gate and keep their children safe, and I was embarrassed that I could not open the gate. This interaction was only my first encounter with something that the parents had to consider to keep their child safe, extra safety precautions that other parents do not need to consider, as regular locks would keep their children safe. I remember thinking that as a mother, I had never even given thought to the idea that my children could open our gate and leave the yard.

Once in the home, I was greeted by the mom, and I met both children. I did not ask very much about Lilly’s sibling as this was not the focus of the interview. In hindsight I wish I asked more about how they were handling all the attention that Lilly is given. Lilly looked at me but ignored me while her younger brother greeted me. The living room was clean and tidy, and I noticed no toys, no coffee table, and no clutter at all. The children started playing on the piano, and the parents explained to me that Lilly loved music and it helped calm her. In the room was a small trampoline and a children’s hammock swing in the corner. The mother told me these two things also helped calm Lilly, and that is why they were in the living room; they were easily accessible to her at any time that she needed them.

I was given a tour of their home. Again, everything was clean and tidy, and no toys were on the floor in the main areas of the house. According to Lilly’s parents, this was done so that Lilly was not overstimulated. The only toys were in Lilly’s room and her brothers’ room; the brothers’ toys were age-appropriate for a child in school. However, Lilly’s toys were all toddler toys, not toys geared for her age group. Her having toddler toys was due to Lilly being developmentally behind her peer age group. In addition, all her brother’s smaller toys were kept in containers and placed up high so that Lilly could not reach them or get to them, again a safety concern.

I also noticed little chain locks (door chain guards bought at local hardware stores) on the tops of all the bedroom doors, similar to what you would see in a hotel but on the outside of the door in the hall. The chain locks were also a safety feature for Lilly; the bathroom also had a similar lock to prevent her from playing with the water unsupervised. Likewise, the bedroom doors had locks to keep her out of the other bedrooms and away from things that could hurt her during the day (e.g., small toys in her brothers' room or hair dryers and curling irons in the parent's room). At night, the parents would place the chain across Lilly's door to know she was safe inside, not leaving her room and possibly getting out of the house without them knowing. As a mother, I was surprised to see these locks and later thought, *what if there was a fire*? However, listening to the parents, I realized that they have to deal with many safety issues every day that most parents do not have to think about once their child is a certain age. They had to look at the benefit-to-risk ratio for their decisions regarding her safety. Upon reflection, if I had thought about it sooner, I would have asked the parents about fire safety concerns.

Another thing I noticed was there were not many pictures on the walls, and what pictures were hanging were in frames with no glass. Again, this was for Lilly's safety, as she loved pictures and would take them down off the wall to look at them. However, in the past, she dropped one, and the glass broke, so to prevent this, all glass was removed to allow Lilly to take the pictures down.

In the kitchen, there were two locked cabinets, and this was where all household cleaners and medications were kept, again to ensure the safety of the children in the home. The cabinets had the usual childproof locks that you can buy at department stores (that most parents use, including me) and a padlocked bolt gate latch that you can buy at your local hardware store. The bolt gate latch ensured that Lilly could not get into the cabinets (a safety concern), as she could sometimes open the childproof locks after watching an adult open them.

During my visit, which lasted approximately one and a half hours, I witnessed the family interact with one another, and it was apparent that this was a very loving family. Everyone was smiling at one another; there was a lot of laughter and an overall sense of calm. Lilly went about her way as if I were not there and played the piano, played in her hammock, and looked out of the window, pointing to her swing set and moaning at her parents, letting them know she wanted to go outside. One parent always had an eye on her, and she was always with someone, usually sitting on their lap or right next to them, unless she went to her hammock, which seemed like where she went to be alone (even though her parents were sitting on the couch in the same room and could see her). Once outside, Lilly grabbed my hand and pulled me toward the swings, and she jumped on; this was her way of asking me to give her a push. Even though she could not tell her parents or me what she wanted, she let us know in other ways. Her family instinctively knew what she needed and what made her happy and just did these things. It was lovely to see the siblings laughing and smiling together on the swings.

I also observed how Lilly would go to whichever parent did not seem busy at the time and take them by their hand and lead them to where she wanted to go or to something she wanted to eat or play with. Her nonverbal communication was easy to read after just a short time with her. Everyone in the family was interacting, smiling, and enjoying a lovely day in their yard.

After my visit was done and I had thanked the family for allowing me to visit their home, I said my goodbyes and went to my house to reflect on what I had just observed. When I looked around my house as a mother of two children, I realized how much this family adapted to ensure that their child's needs were being met. Her environment was not overstimulating, and she had things easily accessible to her to help calm her. Her safety was the number one priority (no glass in frames, chain locks on doors, etc.). In contrast, my house had toys in most rooms, frames with glass on all walls, the bedroom and bathroom doors had no locks, and a simple lock, one bought at the local toy store, was on cabinets where cleaners and medications were kept.

While reflecting, I realized how every aspect of this family's life was centered on their daughter's safety and overall well-being. The younger sibling grew up like this; this was the only world he knew, and it was clear that he loved his big sister as evidenced by the multiple big bear hugs, I witnessed happen between the two and all the smiling and laughter shared. Everything the parents enjoyed doing to relax was adapted to meet their child's needs. The computer and books they enjoyed reading were locked away in their room. The television in the living room had been adapted to meet safety concerns; it was bolted to the wall with the wires all covered with plastic, and the plug into the wall was also covered with a large plastic box. The remote controls were put up in a high cupboard in the kitchen where Lilly could not reach, and the parents stated they always placed it up there when she was not in the room, so she was unaware of where it was kept. They said if she knew it was there, she would climb the counters to get it.

This family had adapted their physical home to address all safety concerns, they also adapted their communication styles. Lilly has found ways to communicate non-verbally with her family, and the family speaks to her in soft tones, using eye contact, getting down to her level and always smiling. I had several notes in my field notebook regarding how they adapted their physical home and how everyone was always smiling and hugging each other.

4.4 Document Analysis

The last part of my data analysis was my document review. My primary objective of this review was to understand what information and documents are available to families and the public related to children with health challenges receiving public school education. The document review also served as a means of triangulating and confirming data obtained from the interviews. The province of NL has numerous schools and two school districts, Newfoundland and Labrador English School Board and the Conseil Scolaire Francophone. Due to this, I searched the Newfoundland and Labrador English School Districts (NLEDS) website and the Government of Newfoundland and Labrador Department of Education's website. I did not search on the Conseil Scolaire Francophone's website as I do not speak or read French.

In addition, I reviewed the NL Building's Accessibility Act (Government of NL, 2018d) and the Accessibility Act (Government of NL, 2021b) based on information brought up in interviews. These acts were found on the Government of Newfoundland and Labrador's webpage.

4.4.1 NLESD

On the NLESD's website, viewers can go under the "About" tab and click on "Policies" to see board, finance and administration, department of education, human resource, operations, and program policies. The policy name, number, the date it was added, a copy of the policy, and related documents are all posted, which is easy to follow. The policies had been posted to the website between 2016 and 2021 (Appendix E: List of Documents Analyzed).

The Safe and Caring Schools policy (# EECD-901) was revised in 2013 and was added to the website in 2018 (NLESD, 2013). This policy was created to address concerns around the issues of bullying and violent behaviour among youth. The policy's purpose is to provide "guidance to educational stakeholders, particularly to schools and districts, in the development and maintenance of a safe, caring, and inclusive learning environment" (NLESD, 2013). The policy states that a safe, caring, and inclusive school includes an environment free from bullying, with active adult supervision, advocacy for student well-being, and equity and equality (NLESD, 2013). This policy also addresses school-wide positive behaviour supports (SWPBS) as an effective way of implementing a school's code of conduct, including three levels of prevention and intervention. The policy also includes forms, such as the inappropriate student behaviour documentation form. Types of behaviour that would fall under this include bullying, illegal substance possession or use, inappropriate sexual behaviour, inappropriate physical or threatening behaviour, and school safety issues. It also includes the SWPBS implementation checklist, "SWPBS: Classroom Management Self-Assessment, and Classroom Management Plan." In addition, it includes the code of conduct guidelines, the *Bullying Intervention Protocol*, nonviolent crisis intervention guidelines, guidelines for teaching digital citizenship, and the *Safe and Caring Schools Policy* implementation process, which states it is under development.

While the *Safe and Caring Schools Policy* is easy to find, it is lengthy at 61 pages and includes a lot of information and forms. I was also surprised that the caring schools policy still states it is under progress. I chose to review this policy because two families discussed with me during the interview process that their child had been bullied. However, this policy was revised in 2013, which was nine years ago. This policy needs to be updated, especially with the accounts of bullying in schools that are currently in the media. In these news stories, parents spoke of how they went to the school about their child's bullying and that school officials did nothing. The parents did not know where to go. This policy needs to include more information for parents, or a new policy on bullying needs to be created for parents on the steps to follow when their child is bullied. This document needs to include information on whom to contact at the local school their child is attending and whom to contact at the school board level if the parents feel their voice is not being heard and their child's safety is at risk. In addition, information on when to contact and whom to contact in the police department is vital as some of the cases reported in the media have included assault (with charges laid by the police). Teachers also need more professional development on bullying to ensure that these incidents do not progress to physical assault or to the point where charges are being laid. If this education is being provided, it needs to be more transparent on the government's website.

The *Bullying Intervention Protocol* (#EECD-900) was added to the website in 2016 (NLESD, 2013). This policy is procedure three of the *Safe and Caring Schools Policy*.

The *Alternate Transportation Policy and Application Package* (#EECD-903) was added to the website in 2017; however, the document is dated 2012 (NLESD, 2012). This policy ensures that students with a physical disability, medical needs, or legal requirements can receive transportation to and from their zoned school. This policy includes the application process, guidelines, and all forms. This document is 21 pages long and easy to follow. I chose this document to review as three families brought up that their children were using alternate transportation, and they have had no issues with this service. However, this document is outdated and needs to be reviewed to see if any updates are needed.

The *Administration of Medications, Medical Interventions and Chronic Care* policy (#PROG-301) was added to the website in 2019 (NLESD, 2015). The policy was approved in 2015 and has been in effect since 2016. The policy states that the administration of medications, medical interventions, and chronic care is the primary responsibility of the parent or guardian. However, administration of medications and medical interventions by school staff is authorized "if, in the opinion of a practicing physician, the medication or intervention is necessary for the student to attend school. This applies only to medications and interventions that can be safely administered by a layperson with no or limited training" (NLESD, 2015, p.1). Under policy directives, this policy also states that "school administrators will be responsible for arranging appropriate training for staff, in consultation with parents/guardians, regarding medical interventions and care deemed necessary by a physician in order for a student to attend school"

(NLESD, 2015, p. 3). The website also has posted the regulations related to this policy (approved in 2015 and amended in 2016 and 2019). This document stated that the school district authorizes the administration of medications by school staff only when the medication has to be taken and the parent or guardian is not reasonably able to attend the school to administer the medication and when it is not appropriate for the student to self-administer the medication (NLESD, 2019). Under other documents related to this policy, there are *Guidelines for Diabetes Management in Schools*, a 23-page document (NLESD, 2014). This document states that when a child with diabetes attends the school, an

> information session must be provided to all appropriate school personnel at the beginning of each school year or as soon as possible, additional training will be required for school personnel with more direct contact with the student with diabetes, all school personnel will receive basic information (e.g., recognize the signs of hypoglycemia and hyperglycemia) and school personnel with more direct contact with the student with diabetes will receive additional training. (NLESD, 2014, p. 8).

This training includes verifying the amount of food consumed by the student and counting carbohydrates, supervising the student as they calculate and prepare the correct amount of insulin, supervising the student during blood glucose checking, and supervising the student's self-administration of insulin. This document also includes information on hypoglycemia and hyperglycemia, including the signs and symptoms and what to do in an emergency. In addition, the diabetes management and emergency plan form are included. I chose to review this policy and the related documents because I had interviewed a family in which it was brought up many times that the child has diabetes. The parents' responsibility was to find someone to observe this child giving herself insulin and checking her blood sugar; this was not the school's responsibility due to liability concerns. I found it interesting to find this document since the mother I interviewed who has a child with diabetes is also a teacher. As a teacher, I think she would be aware of all school board policies and not shocked about having to find someone to help administer insulin to her child. However, she encountered multiple issues, and she and her husband had to find someone to help their child check her blood glucose levels and observe her giving herself insulin. I wonder if all schools across the province are following these policies and who is monitoring this. I also found this interesting since one of my child's friends has diabetes, and his kindergarten teacher helped him monitor his blood sugars and helped him manage his insulin pump (including helping to program his pump to give more insulin). There were many days I would be waiting to pick up my son after school, and their class would be running late, and the teacher would say it was because so and so was having a low sugar and she needed to take care of him first.

The NLESD's website is easy to navigate. However, several policies and documents are older, and there is no mention of when these policies or documents will be reviewed again.

4.4.2 Department of Education

On the Department of Education's website, nested under the link title "Kindergarten to Grade Twelve, Busing, and Policing and Guidelines" are all the policies and guidelines posted regarding busing. The policies and guidelines include the *Alternate Transportation Policy and Application Package* posted on the NLESD website.

While still under the K–12 curriculum, you will see the *English Program Curriculum Guides* (Government of NL, Dept. of Education, 2021a) and the *French Immersion Curriculum Guides* (Government of NL, Dept. of Education, 2021b), but there is no guide for an ASL curriculum. Having no ASL curriculum guide is very worrisome since, in this province, some children use ASL as their first language, as I leaned in my interviews, the same as most children use English. A French immersion guide speaks of French as a second language. So how does the Department of Education and the school board ensure children that use ASL as their first language receive an adequate education? If a guide exists, it needs to be placed online with the other curriculum guides to help with transparency, and if it does not exist, one needs to be created as soon as possible to ensure these children are receiving adequate education, one that is equal to their counterparts who speak English as a first language. Or the English curriculum guide needs to be updated with how the curriculum standards will be met with children that use ASL as their first language.

When selecting inclusive schools, you will find a PDF document called *Inclusive Practice Guidelines: School Level* (Government of NL, Dept. of Education, 2014). The document is 59 pages and is dated September 2014. The documents were intended to be used by schools to help implement inclusive education. This document includes guidelines that include developing a school-wide understanding of inclusive education, evaluating the current status, identifying and addressing barriers to implementing inclusive practice, and planning for how students will be supported. In addition, there are several appendices, including an inclusive education action plan template, sample parent information letter from the principal, learning style inventories, and inclusive, reflective classroom checklist. I chose this document to review because many of the families I interviewed have children that require inclusive education. This document is older, and there is no mention of when it will be revised. In addition, one of the IRTs I interviewed spoke of changes to inclusive education this past year that included having the child spend more time in the inclusive classroom with their primary homeroom teacher, and there is no mention of this information on the website. The document lists many guidelines for schools including identifying and addressing barriers to implementing inclusive practices and developing a school profile. However, it is not clear if all schools have completed these actions as there are not updated provided. It would be nice to see an updated version of this document stating what schools have done (e.g., provide example school profiles) and what still needs to be done, including what barriers to implementing inclusive practices were encountered and how were they addressed.

There is also a *Responsive Teaching and Learning Policy* (Government of NL, Dept. of Education, 2020). It is version four, dated October 2020. This policy is a 60-page document and includes ten policy standards, procedures, and forms. Responsive teaching and learning is "a collaborative approach to education that emphasizes social-emotional and academic learning in a safe, healthy and inclusive school environment" (Government of NL, Dept. of Education, 2020, p. 8). I chose this document as social-emotional learning is a focus at schools in this province, which came up in interviews completed with teachers. This policy was excellent, according to an IRT I interviewed who emphasized social-emotional learning more and explained how this was a new initiative. I did not ask the IRT how it is being implemented into the school system and how she feels this policy is working in the school system as this was not part of my research study.

The *Handbook for Parents of Children with Exceptionalities* is posted (Government of NL, Dept. of Education, 2015). It is a 25-page document and includes a lot of information, including information on the program planning team, the parents' role on the program planning team, what to expect at a program planning team meeting, accommodations, modified prescribed courses, alternate (functional) curriculum, and planning for transitions. In the summary, they list approximately 21 provincial parent groups; no contact information for the groups is included. Contact information would be helpful to list so parents could contact these groups directly. The groups listed include the Autism Society of NL, the Canadian National Institute for the Blind (CNIB), NL Association for the Deaf, Canadian Hard of Hearing Association of NL, and Cerebral Palsy Association of NL. I reviewed this document because most of the families I interviewed have children with exceptionalities. The handbook is good for parents, but I wonder if all parents know where it is on the website. It would be helpful if all parents of children with exceptionalities were given a direct link to this handbook and/or given a hard copy of the handbook.

The *Handbook for Teachers Serving Students Who Are Deaf-Blind, Deaf, or Hard of Hearing with Additional Disabilities, and Blind or Visually Impaired with Additional Disabilities* is also posted (Government of NL, Dept. of Education, 2003). It is a 22-page document and was written in 2003. It includes information on the child who is deaf or hard of hearing with multiple disabilities, the child who is blind or visually impaired with multiple disabilities, the referral process, procedures for determining the types and frequency of the Atlantic Provinces Special Education Authority (APSEA) services, and service plans, and extra resources. I chose to review this document because I interviewed two families with children who are diagnosed as being deaf. However, once again, this document is older and outdated (over 15 years old), and a lot has happened in NL in the last 15 years with these children, including the closure of the school for the deaf. This document needs to be updated with current information as soon as possible. For example. The process that is outlined in the handbook for a referral may need to by be updated. This should include how to contact public health nurses and who to contact if the family does not have a family physician. In addition, under the section regarding special equipment that is needed to write in braille, there maybe new technology/programs that maybe able to help these children that should be included into their educational program. Another section that needs to be updated included the section regarding special transportation, it states to follow the Department of Educations Transportation Division Special Needs Transportation: Government Guidelines (1998) which is no longer available. For the families I interviewed, two children were legally deaf. One of these children were receiving appropriate accommodations and the parents had no concerns. However, the other family had major concerns regarding the accommodations their child was receiving and spoke at length about how it was not enough, and he was not receiving an adequate education.

The *Programming for Individual Needs, Alternate (Functional) Curriculum Guide* was published in 2008 and is a 77-page document (Government of NL, Dept. of Education, 2008). This guide included information on how to use the guide as well as information on inclusion, functional curriculum, and different domains, including career development, personal development/interpersonal, independent living, and functional academics. I chose to review this document to learn more about functional curriculum since one family discussed the different types of curricula available to their children. Once again, this is an older document, 13 years old, and needs to be updated.

The website for the Department of Education is hard to navigate and use to find relevant policies and documents. Users need to know where to look, or it will take time to open many tabs and search. In my opinion, it is not parent or public-friendly. In addition, many documents and policies are older, and there is no indication of when a review of these documents will occur. Lastly, the Department of Education's website defines exceptionalities and lists exceptionalities recognized by the department; the site includes details on exceptionalities, such as descriptions of services the department will provide at the school. However, not all of this information is in the *Handbook for Parents of Children with Exceptionalities*, including some exceptionalities that the department recognizes are based on the same criteria as published in the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR).* For example, an intellectual disability and specific learning disorder must be identified by a qualified person (with level-C assessment tool qualifications), and they must reference the *DSM-5-TR* for diagnostic criteria (Government of NL, n.d.). The website then states that the child may require a range of services while at school, depending on their individual needs and level of functioning. Some exceptionalities (for example, intellectual disability) do not list any accommodations that can be made.

In contrast, others (for example, Specific Learning Disorder) list a few options like accommodations and alternate noncurricular or pre-requisite programs, which would be hard for most parents and other laypeople to understand. There is also a section that states that caution should be exercised with any curriculum alterations (e.g., modified prescribed or alternate courses below grade level) because these alterations may negatively impact graduation and postsecondary options for the students involved, which may deter parents from asking about these options or choosing these options. Then the website states that the student's program planning team makes programming decisions, and there is no mention that this is done in consultation with the parents. All this information needs to be included in the parents' handbook and should be easily accessible and easy to understand so that all parents with a child with an exceptionality are up to date on what can be done at the school level to ensure their child receives the best possible education.

4.4.3 Accessibility Acts

The *NL Building's Accessibility Act* (Government of NL, 2018 (d)) and the *Accessibility Act* (Government of NL, 2021b) were also reviewed during my data analysis as two families brought up how they could not enter certain businesses with a wheelchair because no ramp was provided. Both acts were difficult to interpret, and I could not decipher which businesses would have to ensure they installed a wheelchair ramp or what other services should also be included (e.g., self-opening doors). Both acts were easy to find on the internet under the Newfoundland and Labrador government webpage.

4.5 Interviews

As stated earlier, eight families participated in this study and comprised the case studies. The eight families consisted of ten children born preterm and facing at least one health challenge, within which four families had multiples (a set of twins or triplets). However, not every child born as part of a multiple had a health challenge (e.g., only one twin had a health challenge; therefore, only that child was included in this study). In addition, no assisted fertility methods were used during these pregnancies. One challenge with conducting a study with a unique population (children born preterm and in grades kindergarten to grade six with a health challenge) in a small province is that the participant may be easily identified from the data presented. Therefore, I presented my participant data more broadly to protect all participants' privacy. For example, I will not identify if the child was one of twins or one in a set of triplets. Instead, I will just state they were one of a multiple birth. All children in this study were born between 24 weeks to 36 weeks and spent between a few hours to four and a half months in the NICU in St. John's, NL. Of the ten children in this study, five were biologically male, and five were female. Two were in kindergarten, one was in grade one, five were in grade two, one was in grade three, and one was in grade four.

Table 4.4

Child Demographics

Number of children in the study and their sex	**Grade each child was enrolled in (at the time of the interview with the parent (s))**
Male - 5	Kindergarten - 2
Female - 5	Grade one – 1
	Grade two – 5
	Grade three – 1
	Grade four – 1

The health challenges varied and included autism spectrum disorder, anxiety, attention deficit hyperactivity disorder, hearing impairment, diabetes, specific learning disorder (reading and math), hydrocephalus, vocal cord paralysis, cerebral palsy, asthma, vision issues, reflux, and chronic lung disease.

I used the voice-centred relational method to analyze interview data as described by Mauthner and Doucet (1998). An overarching theme of transitions was identified, with three significant transitions identified for most if not all families. I have broken my analysis into three distinct phases of transition. They include (a) the transition of expecting to have a healthy baby/child and having a preterm baby/child who has health challenges, (b) the transition of leaving the NICU and going home, and lastly, (c) the transition of having your child with health challenges attend public school.

4.5.1 Transition: Expecting a Healthy Baby/Child to Having a Preterm Baby with Health Challenges

4.5.1.1 The Expectation of Pregnancy versus the Reality of Pregnancy

When most couples find out they are expecting a baby, they plan for a healthy pregnancy, delivery and a healthy baby; they also start to dream about what the future will hold for their family. I could relate because I expected a healthy pregnancy and baby as a mother. During my four readings of the transcripts using Mauthner and Doucet's (1998) approach, it was clear that expecting a perfect pregnancy and the reality of pregnancy was one of the themes that kept surfacing from the data. All mothers mentioned the shock they felt after delivering a preterm baby and discussed their child's health challenges after birth. Mothers do not plan for complications with their pregnancy or for having a baby born preterm unless they were aware of complications that could probably arise if they became pregnant or were already being followed due to having a high-risk pregnancy: "*you're expecting to have that perfect delivery.*" (Mother, family four)

Of the eight mothers in this study, one mother was being followed by the Maternal-Fetal Unit due to the baby not growing at the rate expected, one was being watched closely by the healthcare team due to having a high-risk pregnancy (due to carrying multiples), and another mother was being followed closely due to having a hard time getting pregnant. Lastly, another mother was being followed because she was diagnosed with polyhydramnios (increased amniotic fluid volume). These mothers and their families were aware that they could go into labour early and have a preterm baby: "*I had been spotting throughout the pregnancy but was followed pretty closely because we had been trying for some time to get pregnant*" (Mother, family three). For one mother who was having a high-risk pregnancy, knowing that she could go into labour early was very hard:

> *I knew I was going to have a high-risk pregnancy. . .. It was every day waking up and wondering if I was going to go into labour if I was going to lose [them]. It was six weeks of pure torture.* (Mother, family five)

The other four mothers interviewed were experiencing a healthy pregnancy with no complications until approximately two to four weeks before the baby was born. Complications with the pregnancy included the baby not growing, the mother having high blood pressure, and premature rupture of membranes. Once they found out they were pregnant, all of the mothers I interviewed expected a standard delivery with no complications, with a full-term baby and a short stay on the maternal newborn floor. During this planned short admission, mom and baby would be together, and it would be a time to bond, to get to know one another and to have visitors (family and close friends) meeting the newest member of the family:

> *like you're expected to have that perfect delivery. In your mind, people are going to, you're going to have balloons, there are gifts, and people are going to be like, oh hey, congratulations, you know, all that kind of stuff.* (Mother, family four)

However, for some the reality of the pregnancy is that it maybe cut short and the baby maybe premature. Some participants mentioned being put on bed rest during the pregnancy, receiving visits from the NICU team, having a difficult birth, being airlifted to St. John's, and being sick after delivery.

Two mothers were put on bedrest between 22 and 24 weeks (one of these women was being followed closely by the healthcare team); they were aware that they might go into preterm labour and deliver a preterm baby. At the same time, some mothers and fathers were only given hours to adjust to the idea that the baby was coming early and would be born preterm. This time was very stressful for these families.

The two mothers who were put on bedrest each received a visit from the NICU team in which they told the parents what to expect at the birth, what the odds of survival were, and if anything could be done to increase survival odds: "*they come up and chat to you about the* *probability of having a baby and what the prognosis is. It didn't really sink in, but the doctor was pretty matter of fact too"* (mother, family two). Both mothers found this conversation with the NICU team to be very stressful:

> *It was a lot of information at once. . .. here are your three options. Do you want us to do everything possible? Do you want us to do nothing? Do you want to make our best decision based on what we see and how they are?* (Mother, family three)

In addition, they were given a lot of information to process at one time:

> *they admitted me, and I met with the gyne and NICU teams and got inundated with all sorts of information on what to expect. . .. It was a lot of information at once.* (Mother, family three)

This time was stressful for these families as they tried to come to terms with what was happening and what could happen in the short-term. The mothers and fathers I interviewed remembered this life-altering conversation and how they were unsure how to process the information given to them: "*I guess they kind of set you up for the worst-case scenarios so that you're sort of prepared."* (Mother, family three)

At the time, many were worried for their own life and the life of their unborn child, and many husbands and grandparents were worried they also might lose the mother of the child. One mother (family four) recalled being told, "Y*our life and the baby's life are in danger."* A father (family three) stated, *"I was afraid if I fell asleep that I would wake up and my daughters would be gone, or my wife would be gone."* A grandmother (family four) reflected on her experience and what she was thinking at that time:

> *are both of them going to make it because it was, you know, scary. . .. It was a very trying and scary experience. . .. It was an experience that I will never forget as long as I live*.

One mother mentioned that she was given steroids to help mature the babies' lungs so they could breathe easier after the birth and help with their transition to breathing on their own: "*because as soon as they knew that I was going to have to deliver this baby, I did have two shots of steroids to help with the development of her lungs."* (Mother, family four)

Of the families interviewed, two mothers had difficult births, with both being airlifted to St. John's for delivery. One of these women ended up in intensive care herself after delivery for a few days. For at least one mother, the birth of her child was a terrifying time: "*It was scary and surreal all at the same time . . .probably the most traumatizing event of my life."* (Mother, family four)

The other mothers were admitted to the maternal newborn floor (5th floor of the Health Science Centre), and the baby was admitted to the NICU (3rd floor of the Janeway Children's Health and Rehabilitation Centre), two different hospitals, although they are attached. Being in a different hospital from their baby was not what the mothers and fathers expected, "*all of a sudden, I was up in a private room, and I didn't have my baby there with me."* (Mother, family four)

On the unit, they heard other babies cry and saw posters on the walls about the importance of breastfeeding and kangaroo care/skin to skin. Some of these mothers had a hard time with pumping breastmilk, which is not uncommon for the first week after delivery for some mothers, especially for moms with babies in the NICU, "*I kind of felt like a milking machine."* (Mother, family four) She also stated, "*I don't have this kangaroo carry. I can't breastfeed my* *baby".* While working on the maternal unit with students, I have helped several mothers with babies in the NICU with pumping breastmilk. These mothers were usually exhausted and anxious to finish pumping to go to the NICU to visit their babies. Most mothers liked to pump in their room on the maternity unit, however there are breastfeeding/pumping rooms in the NICU where moms can either breastfeed their baby (if the baby is stable and can leave their room) or pump.

4.5.1.2 Unexpected Health Challenges

While reading the interview transcripts and listening to the audio recordings of the interviews, unexpected health challenges were a clear theme. Parents and circle-of-care members spoke not only about the preterm child's health condition, which was very emotional for some but also about the mother's health condition and how dealing with this was very scary.

Some mothers did not have much time to process that their babies were coming early. During data analysis, it was clear that experiencing health challenges was a significant theme in the data, where two mothers talked at length about their health challenges and how that affected visiting their babies. One mother had to wait a few days to see their baby for the first time due to their health challenges after delivery. These challenges included high blood pressure, low blood sugar, fatigue, very low energy, low vital signs, and dizziness.

Due to her health challenges, one mother found it hard to get to the NICU to visit their baby and could not visit for as long as they wanted to due to her health:

> *every time I would move or do anything, my blood pressure would go skyrocket, and my vitals were all over the place, and so I was about 48 hours before I actually got to go and see her in the NICU, and when I went to go see her, I wasn't there very long at all, and then they had to take me back.* (Mother, family four)

In addition, one mother mentioned how hard she found it not being able to hold her baby when she wanted to, which she expected to be able to do. However, while her baby was in the NICU, she had to wait for the staff to say the baby was stable enough to hold. She stated, *"that I didn't get to touch my baby very often. I didn't get to hold her very often."* (Mother, family two)

However, all moms recovered and have no long-term health challenges due to having a preterm baby.

4.5.1.3 One Discharge: Not Two

Participants repeatedly mentioned how their preterm baby was not ready to leave the hospital when the mom was and how they had to leave their baby in the NICU and go home. Most mothers were discharged from the hospital after two to four days (now most mothers are only admitted for 24-36 hours), and parents who lived outside of the St. John's metro region then faced the consequences of where we go, their home could have been hours away, but the baby was not discharged from the hospital. The parents did not want to leave their baby and go to another town or city; therefore, most stayed with family members that lived close by. Two families stayed at the Ronald McDonald House (located in the same parking lot as the Janeway Children's Hospital and Rehabilitation Centre). Both families stated they liked staying at the house, "*Ronald McDonald House is just a home away from home"* (Mother, family seven). One family I interviewed spent a long time at the house. They stayed at two different Ronald McDonald Houses and stated both were nice, *"13 months I stayed in the Ronald McDonald house, between Toronto and St. John's. And then and then three more months that following summer too."* (Mother, family seven)

4.5.1.4 The NICU Experience: Stress, Learning, and Comfort

Of the seven families interviewed that spent time in the NICU, they all spoke for a considerable amount of time regarding their babies' stay in the NICU.

Seven of these families spent time in the NICU, between a few hours to over 100 days. It was during this time that their baby went through many health challenges, including breathing issues (some requiring supplemental oxygen, some required continuous positive airway pressure (CPAP), some required a ventilator, and two required an oscillator (a different type of ventilator usually used for very sick babies). In addition, some babies developed intracranial hemorrhages (brain bleeds), necrotizing enterocolitis (severe gastrointestinal disease), retinopathy of prematurity (an eye disorder that can result in blindness), chronic lung disease, slow growth (very tiny), some requiring extra calories, and one required the use of total parenteral nutrition (parenteral nutrition (PN) can supply all the calories, vitamins, minerals, carbohydrates, amino acids, fats, and trace elements needed for growth, healing, and other health-sustaining functions). PN can be administered via the intravenous route and is used when oral or enteral support is impossible (Sealock et al., 2020). One baby had a patent ductus arteriosus (a congenital heart defect in which the fetal ductus arteriosus fails to close within the first weeks of life. The fetal ductus arteriosus is an artery that connects the aorta and pulmonary artery. Patients may be asymptomatic or show signs of heart failure (Perry et al., 2022). At the same time, other babies had meningitis and bone breaks (due to decreased calcium). Some had surgery the day they were born (and some underwent multiple surgeries throughout their stay in the hospital), *"he was very, very sick. So, he was intubated right away because he had to have surgery that same day."* (Mother, family seven).

During my four readings of the transcripts, it was clear that the stress of having a baby in the NICU was important as it kept surfacing from the data. All of the parents that had a child in the NICU spoke about this added stress, and many circle-of-care members also spoke regarding their time visiting the NICU. As stated earlier, some mothers had to wait to see their baby for the first time, and this first time was in the NICU. The NICU was a period of both stress and learning for these parents, "*I was petrified because no one thinks that they're going to have a preterm baby nor the baby with these problems"* (mother, family five), grandparents and family friends also found visiting the NICU hard, "*naturally the first visit was very emotional."* (Grandmother, family seven)

Most of the babies were in incubators and hooked up to numerous machines. Some were very sick, tiny, had almost transparent skin, and were covered with fine hair. As a former NICU nurse, I remember how parents and families react to seeing the baby for the first time. Most people have never seen a tiny baby and are shocked to see the baby, "*I didn't feel like she was mine"* (Mother, family two). For people that have never seen a sick preterm baby, the experience of seeing their child or grandchild can be terrify*ing,* "*so scary, like seeing all those tubes coming out of her and everything like that that at that point it was just like, oh my gosh!"* (Grandmother, family two). Many parents and families are not used to seeing babies hooked up to monitors and other machines, and seeing their child hooked up to so many machines is very hard to deal with, *"the first day I saw him, it was hard, it was one of the hardest things I've had to deal with, him hooked up to everything and things like that, it was hard"* (Family friend, family seven). An aunt (family two) stated,

> I was astounded that something that small could live to be quite honest. I didn't think it was possible for a human being to be that small and still be alive. It was shocking

> actually. I couldn't believe because her face was still underdeveloped and she pretty much still had the fuzz on her, that sort of down and she was almost translucent and so amazingly tiny.

Many parents talked about how all the monitors would make a lot of noise (lots of beeps) and how scary this was for them, "*it was a joy watching her, but it was frightening when all the systems would be going beep, beep, beep"* (Aunt, family two) and a grandmother (family two) stated *"every time there was a beep, every time she moved there was a beep and you would look you know. But after a while you adjusted to it.*". Another aunt (family three) stated, "*It's a stressful environment. I know when we were in there, there was a lot of beeping. It was a very, you can sense the I guess the risk that's in there"*. As a NICU nurse, I have told many parents that they will hear these beeps at home in their sleep. *"I can still hear the monitors beeping actually like that's a sound that you don't ever forget if you're a parent of a NICU baby."* (Mother, family five). As a former NICU nurse, you hear the beeps of the machines even when you are not in the unit until you get used to these sounds and what they mean.

The time spent in the NICU for parents is like riding a roller coaster. One day, your baby may be doing well, and the next, they may be experiencing a health issue. For most families, their baby was not discharged to go home until close to their original due date, which for some meant an extended NICU stay, "*it just seemed like when that happened, it just set him on a roller coaster of sickness, so he spent seven months in total in the NICU . . .we spent six months in the NICU . . .he was thirteen months in the hospital."* (Mother, family seven)

One family spoke about almost losing their child, how sick they became at one point and how scary that was for them:

> *once, a doctor who had said to us, you know if you have any family that you want to see her, maybe you should get them to come and see her. And my thing was well, why? Is she not coming home? Well, there is that possibility.* (Mother, family four)

Some of these babies experienced more health challenges and a more prolonged NICU admission than others, and for some, there was no reason why this happened:

> *he couldn't catch a break. It was one thing after another, and I remember feeling so defeated and just looking at him and begging anybody to make this stop, make him well . . .it seemed like everything happened to him.* (Mother, family seven)

For families, it was hard to look towards the future as they did not know what to expect while in the NICU. One grandmother (family two) stated "*well the fact that she was an extreme preemie and we didn't know what the outcome would be… we were told about how fragile she was. But she had come out fighting and there was hope.*"

Of the seven families that spent time in the NICU, six families found the staff in the NICU comforting, a source of good information, and people they could rely on that offered them much-needed support. As a former NICU nurse, I loved hearing this information. I was trained not only to care for the baby in the NICU but also to care for their family, they come as one package, and it was my job to keep them as updated as possible: "*the nurses there were very much hands-on, making sure we knew at all times like this is how they are doing . . .we were constantly being informed . . .I could call any minute of the day"* (Mother, family three). Other family members also found the NICU staff to be helpful, "*the hospital staff was so, so encouraging and so accommodating"* (grandmother, family four), and they found that they received a lot of information even though they were not the parents, "*they were marvellous; absolutely marvellous . . .we received lots of information on her progress and what was* *happening"* (Grandmother, family seven). Another grandmother (family two) stated, "*we received lots of information on her progress and what was happening.*"

One family found the NICU environment isolating and found a lack of privacy. The NICU has six rooms, and the sicker babies are cared for in rooms that can hold four babies. The only thing that separates the bed spaces is a curtain. This mother stated that the NICU experience was a "*very isolating experience . . .the complete and utter despair that was there sitting in front of the incubator for so long"* (Mother, family two). An aunt (family two) stated, "*we were really close proximity with other visitors to other units so that was kind of you were very aware that there were other family people in there with their children.*"

An aunt stated that she was happy to see almost one nurse assigned to every baby and that it was a positive atmosphere to be in even though very sick babies surrounded her. She was surprised that the unit was locked and that she had to buzz in on a speaker system to be able to ask a nurse if she was able to visit her niece, "*there were nurses there to answer the questions; there was a nurse there almost constantly"* and *"the unit itself was locked down. You had to be buzzed in and that was good I mean for the fact that it's a nursery but also it is an ICU I guess but that was pretty impressive"* (Aunt, family two). The unit is locked so that people cannot just walk in; it is an intensive care unit. Even the staff have to use their badge to unlock the doors.

One interesting thing that came up in one interview was that the father was also a preterm baby that spent time in the same NICU, and while his child was in the NICU, he found out that some of the nurses that were caring for his child, cared for him as a baby, he stated:

> *A couple of the NICU nurses had been my NICU nurses while I was in the NICU . . .which was a great way to make the nurses feel old. It was a great way to make me feel old.* (Father, family three)

Furthermore, it was interesting that while the mother was in labour and this father knew that his child would be born preterm, he started to blame himself. After all, he thought it was happening because he was born preterm, "*at some level, my brain was like, is this my fault?" (*Father, family three). However, the doctors, parents, and his wife assured him that this was not his fault.

4.5.1.5 The Impact of Having a Sick Child

Throughout the interviews, I listened to each family's story of living with a child born preterm, their health challenge or challenges, and their family's struggles. We need to remember that these parents have gone through a lot, with each raising a child born preterm with health challenges: "*we were told when we went to the NICU, just let you know this, that like 90% of marriages don't last when you have a sick child."* (Mother, family seven)

One mother feels that she and her husband have post-traumatic stress disorder (PTSD). Her husband has insomnia, and of course, they are facing the financial stresses and strains of having a sick child every day:

> *A lot of stress and pressure on both of us; [X] hasn't coped as well as me with regards to talking about my feelings. And I am convinced that we both had PTSD, two of us. . .. I'm on an anti-anxiety medication. . .. I went, and my husband set up an appointment to go see a psychologist because I was so depressed, I think, very upset by it. And trying to find out how do I cope with this? And how do I go forward?* (Mother, family seven)

We must not only care for these children and ensure the necessary resources are in place for them at home, in their community, and in their province but also ensure the correct resources and supports are in place for their parents.

4.5.2 Transition: NICU to Home

The second transition that families went through was having their baby discharged from the NICU and getting to take their baby home for the first time.

4.5.2.1 The Long Journey to Home

During my four readings of the transcripts using Mauthner and Doucet's (1998) approach, it was clear that the day the baby was discharged from the hospital and the long journey home was one of the themes; most families mentioned this in their interviews and spoke of how they felt on that day. All families stated they were happy when the day finally came when they could take their baby home. Discharge day is the day that everyone waits for: the parents and the staff. As a former NICU nurse, I remember being so happy for the parents that this day finally arrived. For some, it seemed like discharge day would never come. It was a day to celebrate the baby finally could go home, and the nurses and the parents would shed many happy tears. Nevertheless, taking their baby home was also a tough challenge for many interviewed parents. A grandparent that was living with her daughter, son-in-law, and preterm baby stated:

> *well, the first night she was home, I don't think any of us slept . . .after that first night, well, she got through that night, so everything was fine. And she was doing so well . . .the first couple of weeks was a bit nervous, you know we were nervous over the fact that we were the sole caregivers then instead of the medical profession.* (Grandmother, family two)

These families had to figure out how to care for their babies independently with no help from the medical team, "*at first, we had to kind of revolve our lives around figuring out how to take care of two little sick babies."* (Mother, family three)

For two families, it meant driving a long distance on the highway to get home and/or taking a plane home:

> *so, it was a really long drive back. We had to stop so often. It took us probably about 12-13 hours to actually get back that day. So, when we got home, I mean, it was just complete exhaustion! . . . like I wanted to cry behind the steering wheel because we finally made it! And we had her with us, which we didn't think for a while that we would, and it was such a relief to get back and to actually be able to bring her into the house.* (Mother, family four)

4.5.2.2 Scheduling Challenges

Once home, families also had to get used to bringing their baby to numerous appointments, sometimes weekly, over varying lengths of time. These appointments were for many disciplines, including speech-language pathology, audiology, ophthalmology, physiotherapy, occupational therapy, nephrology, dietitian, pediatrician, perinatal program, breastfeeding clinics, cardiology, and public health. How often the appointments took place varied according to the health challenges experienced by the child. They ranged from weekly to monthly appointments, and this took place for most families (six out of eight interviewed) for at least a few specialties until their child started school. Most families stated the appointments were the busiest right after discharge from the NICU until around two. A few families are still followed every six months. For most families, these appointments started within a day or two of being home with an appointment with the public health nurse, "*I mean that next week right away the public health nurse was at the house, and then regular visits started*" (mother, family four).

In NL, all first-time mothers will have a visit from a public health nurse, usually the first week after discharge from the hospital. This visit is part of the Healthy Beginnings program

(Eastern Health, 2011). After a child is born in NL, a referral is sent to the community/public health nurse; all parents are called and visited by a nurse. For most, this is short-term and consists of only one visit, but some families may be given long-term support (e.g., if the baby has a known disability or has developmental risk factors but is not followed by the perinatal program). This program's services include an assessment of potential risk, education, support, counselling, and referral to other diagnostic and intervention services (Eastern Health, 2011). The mother in family three said: "*at one point, I was like, have we left the hospital? We've had an appointment every day this week."* The perinatal program followed three families:

> *she had several checkups with different specialists like the dietician and the pediatrician and vision, well vision screening and hearing, and that was probably about every six months or something like that, whatever the perinatal program kind of suggested, we just followed that. We followed that until I think she was three.* (Mother, family two)

Keeping track of all the appointments, the providers they were going to see at which appointment, and the travel to see the specialists was also a challenge for some families: "*I can't even remember half of them now. Think of an '-ology', they've seen them at one point"* (mother, family three). For families with other children, going to multiple appointments was a challenge:

> *But I did have a lot of trips back and forth, and I did find that a little bit difficult even though I do live in the city. It was just trying to keep track of them all and then still having another child.* (Mother, family two)

Families noted that most of their appointments were when they first got home and for the first few years of their child's life: *"there are a lot of appointments in the early years. So that was definitely something we had to deal with"* (mother, family three). Going to appointments for families that live far away from the hospital may mean a lot of time travelling: *"we were going* *back and forth to Corner Brook once or twice a week for the first few months. So, it felt like we were always on the road."* (Mother, family four).

Another challenge was having appointments on different days instead of making a single trip to the hospital per week; some families had to make multiple trips the same week: "*I spent a lot of time there at the hospital. It would have been nice to have clustered appointments. I guess they try their best, but they're not all working together."* (Mother, family two)

In addition, one family had to (and still does) wait for the pediatric nephrologist to visit the Janeway Children's Hospital and Rehabilitation Centre from the IWK Health Centre in Halifax, which usually happens approximately once every four months. The visits from the nephrologist have been delayed in the last 18 months due to the global pandemic, although "*she does still see nephrology, but that's when he comes in because he's from Nova Scotia."* (Mother, family three)

Four families still have multiple appointments to attend at present. One family still sees their pediatrician and ophthalmologist every six months; another family still sees specialists four times a year, "s*o we're still followed by the Janeway."* (Mother, family five)

Two families whom I interviewed also had the added stress of going to Toronto to the children's hospital (Toronto Sick Kids) to see specialists as there were no such specialists in NL. The added travel to another hospital outside of the province was an added worry for them and an added stress.

Some specialists to whom parents had to bring their child for an appointment, like speech-language pathology, now follow these children in school and will see them during the school day. Having an appointment during school cuts down on appointment times for the families but means that the parents are not there for the session: "s*peech is done through school now. . .. She sees her I think it's twice every seven-day cycle."* (Mother, family three)

4.5.2.3 The Discovery of Health Challenges

During my four readings of the transcripts using Mauthner and Doucet's (1998) approach, it was clear that the discovery of health challenges was a theme, as many parents and circle-of-care members spoke regarding how and when their child received their medical diagnoses. Once the families were home, more health challenges became apparent as their baby began to grow and progress through developmental milestones. Some babies were later meeting milestones (e.g., sitting, walking) than children born at term: *"she was not just late walking. She was late doing everything, you know"* (mother, family two). Some parents were not sure if their child was late meeting milestones due to being premature or something else: "*they seemed like they did everything a little bit later, but I'm not sure if that's due to the month premature"* (mother, family one). One family was told to be on the lookout for health issues prior to their NICU discharge: *"we were told that there may be some health issues that may arise over a period"* (grandmother, family two).

Two mothers prepared for these possible health challenges by reading books on premature birth and searching the internet for information on preterm birth and the possible complications that may come with it: "*I've bought some books and things like that and reading up on it about the likelihood of having a learning disability, vision problems, hearing. So, it prepared me to watch for it for sure"* (mother, family two). Other family members also read up on premature babies and possible health challenges*, "and I had read a lot on preemies, and my daughter had, and so we knew what we were facing."* (Grandmother, family two)

Some families knew their children's health challenges when they were leaving the NICU, as these were already diagnosed, and treatment or rehabilitation had already begun. Health challenges included vision and/or hearing problems, an enlarged heart, high blood pressure, chronic lung conditions, hydrocephalus, torticollis, meningitis, quadriplegia, esophageal atresia, feeding issues, and/or cerebral palsy. At the same time, others did not know of the health challenge until later when their child was not meeting developmental milestones like babbling or walking. Four of these families picked up on issues their child was having like not recognizing their names, not recognizing words that rhyme, problems with focusing, messy writing, excessive tantrums, issues with reading, or dark themes in hand-drawn pictures (everything was black with blood on it). Then they went to their family doctor, public health nurse and/or school educational psychologist or guidance counsellor and/or sought outside help, such as from a pediatric counsellor, for a correct diagnosis. The mother of family two explained that "*I just had this hunch because she was a premature child, so I was looking for those things too. . .. we were kind of expecting that as she gets older that there are going to be these issues with some learning"* (mother, family two). Another mother (family seven) stated that *"we noticed stuff about X around when she was three, like tantrums and she is creative, but she's also hyper and things like that."* (Mother, family six)

Some diagnoses came more quickly than others (e.g., diabetes, epilepsy, tremor, asthma, migraines, tethered spinal cord, deafness); others were not diagnosed till later, as some health challenges are not usually assessed until certain ages (e.g., autism spectrum disorder, specific learning disorder, developmental delay, attention deficit hyperactivity disorder). Some of these families did not know of their child's diagnosis until the child was two to three years old, and some children did not receive a diagnosis until the child was in school (e.g., closer to the age of eight) and had some trouble keeping up with their schoolwork. These families then had to learn to live with these diagnoses, and the children who had to wait to be tested for specific diagnoses also had to wait for the support to help with these diagnoses. For one mother, having a diagnosis for her child was a positive thing even though she knew the road in front of her child would be hard: "*it was a nice relief because the big thing is you can't get a lot of services until they're diagnosed.*" (Mother, family one)

In addition, some resources have a set age range for their services. For example, the Learning Disabilities Association of Newfoundland and Labrador offers tutoring services in math and reading; however, they state this service is designed for children aged seven and older (Learning Disabilities Association of Newfoundland and Labrador, 2019).

One family I interviewed faced another challenge when it came to their child's health challenge: inclusion and mobility. The child is in a wheelchair, and although the family tries to include the child in everything they do, they have found that some places are not accessible:

> *because I'm all about inclusion, but there are just places that you can't include him, and that's hard. And just even places that we've gone to that we can't even get in the building because there's no button on the door or there's a step to get in, like bowling places where it's impossible to get him in if I'm by myself.* (Mother, family five)

Another family with a child with autism also found that businesses and events were not inclusive but were now starting to offer sensory hours and Caroline's Carts, which is a massive help for this family to go out as a complete family unit. A Caroline's Cart is a shopping cart that has a seat in the front for users with disabilities (Wanzl, 2020):

> *that's a pretty big barrier for us, too, is that part of the inclusion. . .. we could go to stores, but the only stores we can go to are ones now that have Caroline's Cart, so if we go to a store that has that cart we can.* (Mother, family one)

4.5.2.4 Financial Worries & Unlikely Support

During data analysis, financial concerns emerged as a clear theme. Most families spoke regarding the financial constraints they have encountered and their hardships. Some services also have a fee that the parents must be able to cover for their child to avail of that service. While some parents can apply for help with financing and get a discounted price, it is still expensive for many families. An example of a service is private tutoring to help with specific learning disabilities (SLD) or different therapies to help with ASD (e.g., pivotal response training): *"it is expensive. It's over $1,000 a semester, so it is expensive. . .. So, the X program I think I paid about $900 to do it, so there was no funding for that one"* (mother, family one). Grandparents were also aware of the financial concerns that their child was dealing with regarding their preterm child's health condition: "*it's rather expensive for young parents, parents with children and especially two children with disabilities"* (grandmother, family one).

When it comes to services available to these families, some are only discovered through word of mouth from other parents. An example of this is the Learning Disabilities Association NL; this organization has tutors available to help children diagnosed with a learning disability at a reduced rate, but "*I did not hear about it and many of the teachers that I talk to have never heard about it before."* (Mother, family two)

The parent-to-parent support and sharing of services are essential in helping these parents cope with this diagnosis and find appropriate services for their children. Many of these parents are also in many Facebook groups together; one example is the group called NL NICU Parents:

> *we have a support group. We started that up. Some of them I just met through Facebook groups. . .. We started our own support group, myself and a friend did, so we got our own little group of about 125 parents here locally.* (Mother, family one)

It is also important to note that some of the supports available to these children are also time-consuming for the families and children. For example, tutoring can be twice a week in the evening after school; this may not include homework, which creates extra work for these children after an already-long day at school. An aunt (family two) stated, "*she's doing extra tutoring and that's 4 hours a week outside of school time. So that's definitely a lot of extra work that she has to do that her peers might not have to do."*

Taking care of a child with health challenges can also be expensive. As mentioned above, the cost of services can add up: "*those three months cost us $2,100 just to do that. We couldn't keep up with it all year because of the cost."* (Mother, family one)

In addition, the cost of medications and medical supplies (e.g., wheelchair, braces, glasses, hearing aids) also add up and is not always covered by the Medical Care Plan (MCP) or private health insurance. As well, travel expenses add up (e.g., airfare, accommodations, and meals), and "*the biggest challenge would be the cost of a lot of stuff"* (mother, family seven). The equipment needed for some children is very expensive and will need to be replaced frequently as the child grows. For example, *"the braces that he has to get once every year because he keeps growing, they're $1,200"* (mother, family five). The cost also includes the money paid upfront before reimbursement and waiting for that reimbursement*, "but it was a bit of a hassle to go to MCP to get that reimbursement. . .. We had to pay for it out of pocket initially, and it took probably almost a year to get it reimbursed partially*." (Mother, family seven)

Some parents essentially paid double for everything in the beginning due to the amount of time they were away from home:

> *paying basically another mortgage and groceries and double gas, everything. . .. and I don't have any sick time left. So, I have taken unpaid leave. So, for four weeks. I was off in November and December with him. I had to take unpaid leave. Which then affects my pension, and which then affects everything.* (Mother, family seven)

4.5.2.5 Insider Knowledge

Lastly, an essential support for four families is having an "insider". For one family, the grandmother was a nurse, and her knowledge and support helped support this family through all the health challenges; for another family, the mother was also a nurse. As a nurse, I completely understood this. When someone is sick in my family, everyone calls me "the nurse" and asks me what I think is happening and what could happen. They also ask me to explain things to them that they did not fully understand at the time. For other families, the mother or grandmother had been a teacher, so they were very familiar with how to prepare the child for the transition of going to school:

> *that's another thing that we're very lucky about that we have a few healthcare professionals in the family, especially Nanny that we poke at. She's been there both as a parent from a preterm delivery and also as a nurse that worked at the Janeway.* (Mother, family three)

Another mother is a nurse, and she stated, "*I know the system." (Mother, family seven)*

Once the child started school, insider knowledge once again became an important theme. Some families had insider knowledge regarding accommodations and the process to receive them; either a parent, aunt or uncle, or grandparent had been a schoolteacher and therefore was aware of the process. One mother stated, "*it is like kind of a benefit of being in school system. I knew what steps we had to go through."* (Mother, family four)

4.5.2.6 The Resilience of Children

In addition, almost everyone interviewed brought up their child's resilience: "s*he was a little fighter right from the beginning"* (grandmother, family four). It was a challenging process for families to watch their loved ones in the NICU: "i*t was definitely a really hard time for a little bit. But then yeah, she just like, she was a trooper. It's amazing how resilient they are"* (mother, family four). These children go through a lot in the hospital in the first few months of their lives:

> *they are very unique children, I must say, they're stronger than you or I. . . . when they see him, they just, they are just shocked, amazed that how well he is, and you wouldn't say there was a thing wrong with him, except for all the scars on him, all the scars on his body.* (Grandmother, family seven)

One child was in the hospital for the first year of his life:

> *when he first came home, he was like, he was over a year old then, and he wasn't even walking or crawling because he couldn't because of all his tubes and things right, so like literally when they came out, it was like nothing, nothing could stop this child, nothing at all. . .. he has succeeded way more than anybody's expectations. I believe he has become a little boy with a big heart who would do anything to please anybody. He wants to be the best of the best and happy in his life.* (Family friend, family seven)

As a former NICU nurse, I was always amazed at these babies and the number of procedures and treatments some went through. They were the best patients, always smiling and loving life, never complaining.

4.5.3 Transition from Home to Starting School

Six families decided to enroll their children into early learning and childcare experiences, and/or extracurricular activities such as swimming, ballet, soccer, and hockey. These experiences help all children (not just those born preterm) to transition to school (they experience a new environment, discover new things, make new friends) and they also help children learn more socialization skills, especially with other children their age. These programs also help prepare children for school by learning to listen to other adults for instructions or follow rules (and to work independently and to participate in group tasks), for example. Most parents will register their child for preschool or extracurricular activities, and I know as a parent I put both of my children in preschool, swimming, and soccer. In my mind, this helped them socialize with other children and helped them to learn to follow the rules.

4.5.3.1 To Register or Not to Register?

The time to register their child for school, for most families, was a very stressful time for them, when they needed to decide whether it was the correct time to send their child to school or not. This decision was more complicated for three families since their child was born in December. When families register their child to start kindergarten in NL, the child must turn five before December 31 of that year. Therefore, some children are only four when they start school in September. Children born preterm are even younger if you look at their corrected or adjusted age, which is their chronological age minus the number of weeks or months they were born early. Some parents with children born between September and December chose to wait to put them in school the following year; they would be five that September. Two families interviewed decided to do this, and in the process, two children were able to attend KinderStart twice (once the year that they were four and again the following year at age five) and have a longer time in preschool:

> *We held them back for a year, so we let them have an extra year in preschool years to kind of adjust, and they were December babies, so they were kind of young anyway going into it. . .. Give them an extra year to mature before they would go in, that was our big deciding factor. Even if they weren't December babies, I think we would have anyway just to give them another year because developmentally and with their diagnosis, and they do have struggles with learning and things like that, that I just figured it would give them an extra year to be a little bit more adjusted by the time they go. . .. KinderStart—we did that twice because where we held them back a year, we were allowed to do both years, which was nice to give the school a really good chance to get to know the boys.* (Mother, family one)

Kinderstart is a program that is offered to all children in NL, it is a

> school transition program offered in the year prior to Kindergarten entry. The program consists of orientation sessions organized and promoted at the school level for children and their parents/caregivers. The sessions support children's adjustment to the school environment and provide parents/caregivers with information on how to support their children's learning at home (Government of Newfoundland, 2019).

The second family did not attend KinderStart twice but did delay kindergarten:

> *She didn't actually go to school when she was four. I signed her up for KinderStart, but we didn't go because she just wasn't ready. So, I delayed kindergarten for a year. And then we did the KinderStart program, and she went on.* (Mother, family two)

One family stated that the KinderStart sessions were when they realized the impact their diagnosis was having on their children's development:

> *But you kind of walk in, and it hits you that they're very different from everybody in that class, so I think for us, it kind of solidified that it was a good decision to hold them back a year because they were quite significantly behind their classmates.* (Mother, family one)

I asked the mother what she meant by they were different than other children in the same class and she did not elaborate much on this topic but did say they were not verbal and not interested in playing with the other children. She then continued on with her story.

These parents all stated that the school their child was registered in supported their decision to wait another year before their child started school, and were "*very supportive, and they even said that there are many kids that are December babies that probably should wait even without the prematurity in place."* (Mother, family one)

All other families felt their child or children were ready to go to school when the time came to register them. Even though many mothers did not feel ready themselves, they were confident that their child was ready for school. As a mother, I related to this. I was not ready for my children to start school, but I knew deep down that they were ready. The mother of family three explained:

> *They were my babies. I wasn't ready for them to start school. I couldn't believe that the time had actually come that we were registering them. But yes, they were definitely more than ready for school.*

One grandmother (family six) stated "*I was sure that she was ready to go to school…she was prepared for kindergarten, very well prepared.*"

4.5.3.2 Separation Anxiety

Separation anxiety is a sub-theme under this transition from home to starting school as only two families spoke about this during the interviews. These two families discussed its impact on their families in detail; therefore, I felt it was essential to include it in my analysis as a sub-theme. However, this is a concept that many families experience when a child starts school and is not limited to children born preterm. These two families had to deal with children who experienced separation anxiety when they started school, as they missed their mothers and wanted to be with them. Going to school was a big adjustment for them, and it took a while for these children to get used to their new routine:

> *Some days I would have to carry her out and put her in this van, and she would be crying that she didn't want to go, which was typical of a lot of kids, too, that whole separation anxiety and things like that. . .. So, it's always been if she can't see me in a public place or if she can't get ahold of me at school she gets really, really upset. So that's about the only thing that at the beginning of school that was hard. . .. She gets really overwhelmed with a lot of people, loud music, and stuff like that.* (Mother, family four)

4.5.3.3 Communication and Accommodations

During my four readings of the transcripts using Mauthner and Doucet's (1998) approach, it was clear that communication with the school was one of the themes. Parents spoke regarding the meetings they have had at the school and how often they take place and who attends these meetings. Six of the families' children had already been diagnosed with health challenges before starting school. Due to these diagnoses, the families met with school officials (e.g., their teacher, principal, and/or guidance counsellor) prior to kindergarten to discuss their child's needs and to have everything set up for the child when the school opened in September: "*We had meetings with the guidance counsellor to get everything put into place for when they started kindergarten. . .. We did a lot of work with the school to start off." (Mother, family one).* A father stated (family four)

> *so we had meetings probably maybe once or twice a year to go over their individual independent lesson plans or what they're doing with extra help from in class assistance or what have you. We had to go set all that up with the school when the girls started and we've had to sign a fairly substantial realm of paper work just to get everything set up.*

One family that had children diagnosed with autism sent in books about their children so that the staff could get to know them before starting school. These books included pictures, information pertinent regarding their health, their triggers, and how to calm them:

> *We sent in books, "All About Me" books, so they got all the information about the boys' needs, things that they like, things that trigger them, that kind of stuff. . .. I gave it to the principal and vice principal, the guidance counsellor and the classroom teachers and the RTs [resource teachers], and then I gave them permission to share it with whoever else would be on their team, like the school speech therapist and student assistants, things like that. Then they gave it out as needed.* (Mother, family one)

These books were like a resource manual for the school staff regarding these children and how to decipher their behaviour. It helped all staff who would work with them in the school that could not make it to all meetings with the parents. It was also a comfort to the parents that the staff had these books with everything they needed to know about their children. Another family sent the school a book similar to this regarding their child's complex health needs.

For one family, due to the COVID-19 pandemic, the KinderStart sessions were cut short, and the child (ren) could only attend one or two sessions. For the 2020–2021 school year, parents were not allowed to bring their child (ren) into their classroom on the first day of school, which was very stressful for the parents:

> *How I felt at the end of this summer prior to them actually starting school. It was a nightmare! Number one, because we hadn't met anybody and then all this COVID situation, it was a hard year just sending children to school.* (Mother, family five)

For this mother, the school was very accommodating and understanding of her situation:

> *Now I got to give a shout-out to the school; absolutely amazing. I contacted the principal and the social worker prior to school starting, and I voiced my concerns about [X] not meeting anybody. Like I really wasn't comfortable with just dropping him off at the door. I needed him to meet somebody, so he had a familiar face, someone to greet him on the first day of school. So, they went above and beyond. They made sure it was okay for us to enter the school prior to their first day and meet [X]'s team, so the student assistants and the IRTs [instructional resource teachers] who would be working with him throughout the year and his kindergarten teacher, they were all there.* (Mother, family five)

However, that was not the case for another family:

> *I'm in his school; I'm in his classroom, it's his kindergarten classroom, obviously, first day kindergarten, first day of school, first time being in this new environment other than just a couple times for KinderStart. . .. So, I mean, there was a multitude of things that need to be covered. That is not your typical interaction when a parent just drops off their child for their first day of school. . .. I spent the whole time talking to this woman*

> *about the things that she needed to know to take care of my child. I was interrupted by the principal saying, "Ms. [X], you have to trust our teachers and our staff, and you have to leave now." He kicked me out of school.* (Mother, family eight)

The first day of school was very stressful for this mother, who continued to have concerns about her child's needs throughout that year.

Many of the children discussed in this research project were exceptional. The Department of Education uses the term "exceptionality" to "identify patterns of strengths and needs common to groups of students. In Newfoundland and Labrador, a student can only access special education service if he or she has an exceptionality" (Department of Education, n.d.). Some parents stated that their child had an inclusive education plan with the school, which is a document that helps guide the instruction planned for the child based on their unique needs. Some of the supports that were needed and granted in the school system included spending time with IRTs both in the regular classroom and in a smaller classroom, which meant more one-on-one time (Government of NL, 2015); choosing the right curriculum for the child, whether prescribed, prescribed with modifications, or alternate (Government of NL, Dept. of Education, 2008); accessing an iPad with assistive technology; having extra time for writing tests, having the test read out loud, or taking writing tests in an alternate setting; having a journal so the child can write how they feel; or using noise-cancelling headphones, a break card, and special transportation (Government of NL, n.d.). The child in one family has migraines, and the school has a quiet room with pillows and blankets so that if she gets a headache, she can go to this room and rest and hope that it will pass, and she can join the class again:

> *She had a break card as well, so she had a break card that she could use. So, whenever she needed that break, she could do whatever she wanted. She could listen to some*

> *calming music or whatever, out with like the teaching and learning assistant or the IRT, whoever was available.* (Teacher, family four)

The child's grandmother (family four) also stated, "*once you turn five and you start school, your problems don't disappear. . .. Because her needs are many, and some days, she might not have any needs. But her needs could be many because of medical reasons."*

Of the eight families I had the opportunity to interview two families had children who are legally deaf; one uses hearing aids and can vocalize, while the other uses American Sign Language. One family was assigned to a deaf IRT as soon as they were diagnosed with a hearing impairment, and she would visit the child at home:

> *Before she started school, but when she had her diagnosis, she'd see her once a week at the house during the school year from September to June. She'd come into the house and work with her for an hour, an hour and a half.* (Mother, family three)

The other family was not aware of this service until their child was over the age of two. When the mother heard of this resource, she called around and discovered that her child should have been receiving this service, but the referral was somehow lost. Therefore, they missed out on this resource for a long time: "*my child, obviously, was impacted by that severely because he lost two and a half years of getting some critical service that he should have had."* (Mother, family eight) However, the IRT would only see the child in school once the child started school.

IRTs can also specialize; one of my participants was an IRT for the deaf, so her job differs from other IRTs:

> *As an itinerant teacher for the deaf and hard of hearing and we service children from diagnosis when we get referrals, so it could be even younger than one, so as soon as they are diagnosed and we get the referral from the Janeway that they have a hearing loss,*

> *they refer to us, and if the parents choose to have itinerant service, then we go into the homes or preschoolers or daycare, and the children are serviced up until they complete school and transition to the workforce or post-secondary, so we help with transitioning.* (Teacher, family three)

Seven of the families I interviewed had their child work with an IRT, although one only saw an IRT for one year. How often they see the child is very dependent on their diagnosis and how often the parents meet with the IRT also depended on the child's condition; this could be once a semester (every four months) to more frequent (every two weeks, or once a month):

> *So even right now, the parents still do request the meetings, and the teachers kind of all get together and facilitate it around their schedules . . . with schedules and everyone being busy, but we try to get it every three to four weeks.* (Father, family one)

Most of the families stated that they have easy access to their child's IRT and can call or text them anytime, and the IRT responds quickly. They also stated how important the IRTs are to their child and their education: *"she's really, really warm and loves her job."* (Mother, family three)

Some children work with their IRT in the primary classroom with the rest of their classmates, while some children are pulled out of the large classroom to go to a smaller classroom. Some children may be with their IRT for a short time (e.g., one class period), and others have one-on-one time or work in a small group setting with their IRTs in a smaller classroom all day. One set of parents interviewed brought things to the IRT's classroom to help their child adjust and self-regulate; this included sensory toys and a tent. The IRT and the school also had many things in the room to help the children adjust and self-regulate:

> *We brought some favourite toys like that they had there, and that was the big thing, they have one of the IKEA surface tents, so they had that there, and the mini trampoline for jumping on, things like that just to make it kind of homey, and their teachers had a bit of stuff there too that they had accumulated, so it was nice.* (Mother, family one)

The IRT and classroom instructors have also used agendas or journals to communicate what is happening in the school and the child's progress to the parents: "*you always look in their agenda and find out what they're going to be doing the next day."* (Mother, family one)

Another role for some IRTs is educating the main class about the child with whom the IRT are working, including their medical condition and why they may appear different or act differently, "*and our IRTs do it as well. They would go in and do a little presentation specifically about the boys."* (Mother, family one)

Lastly, some IRTs go out of their way to help these children in any way possible: "*his IRT has come to several of his physio appointments with us so that she can see the stuff that he's working on because she wants to do it with him at school as well."* (Mother, family five)

Another resource that three family's access within the school is a student assistant who works with their child. They help the child with eating, changing, and self-care, and "*the student assistant is always available for changing, things like that"* (mother, family one). Another part of the role of a student assistant is helping the child to go back and forth to different classes: *"he's provided with a student assistant all day, which helps him transition back and forth between classes to my classroom, music and gym, his classroom, changing, feeding, those sorts of things."* (Teacher, family five)

Only one family who I interviewed had issues with their assigned IRTs or student assistants, and all the issues related to their qualifications for teaching their child using American

Sign Language (ASL). Ensuring staff can use ASL has been an issue for this family throughout their time in this school and one about which they are in direct communication with the school, the school board, and the government trying to come up with a solution.

In addition, one mother mentioned that the school her children attend, a newer school, offers a sensory gym and sensory music: "*they have sensory music and sensory gym at our school. So that's with other special needs children throughout the school, so different grades.*" (Mother, family one)

The teachers and assistants working with preterm children with special needs also had to become familiar with some of the special equipment they require for their care. The equipment included special walkers, chairs, helmets, hearing aids, or a frequency modulation (FM) system. An FM system is a wireless device that uses radio waves to transmit audio signals to the listener via hearing aids to help in noisy environments. Other equipment included braces, tabletop scissors (self-opening scissors that are mounted on a no-slip base), slanted boards (a flat surface that is set at an angle/slant), and a Tobii eye gaze system (monitors eye-tracking and gives commands to a computer system that then speaks for the user).

Six parents also mentioned that it has become easier for their children to get the accommodations they need each year. They attributed this to the school knowing their child and their needs (through prior communication with the parents and from previous school years); all the paperwork is already done and in the child's file, which is a big help. Most parents still meet with the school teachers (as well as the principal and sometimes the guidance counsellor) prior to school starting to ensure that all the accommodations would be set up for their child and ready for the first day of school: "*what was recommended to me was to have a meeting at the beginning of the year outlining her accommodations.*" (Mother, family two)

Sometimes staffing issues affected the support that could be offered to a child on some days:

> *Our school is really good, and they really do try to do everything that they can, but sometimes there are issues with like staffing type issues that they don't have enough supports to get them out of their little spaces to have more time to go in with their class.* (Mother, family one)

A sub-theme under the major theme communication and accommodations is *looking for resources*. For one family, the mother was very familiar with and comfortable going on the internet and looking at the school board's website and the Department of Education's website and reviewing policies. She and her husband were aware of accommodations they could ask for from the school and their child's rights concerning their education. This information helped them navigate meetings with the school more easily. It was also a help that the child's grandmother was a retired teacher, so she was familiar with the system as well. The mother in family one explained "*that was my own research mostly. I'm a big researcher, so I just went in and found that on their site. I knew the gist about it too because my mom is a teacher.*"

I included this sub-theme because if more families knew about the resources available on the government's websites, more families would be aware of the accommodations their child could receive in school. Ensuring families are aware of resources available through the government is one of the recommendations that I will discuss in the next chapter.

Another sub-theme for this major theme of communication and accommodations was *medications at school*. One family and their circle-of-care members spent a long time speaking about how the child needed medication during school hours and how important this was for her health. Medications are an essential topic for preterm children as many are on multiple medications for their health challenges. This family encountered an issue in which the school that their child was registered to attend had a policy that the family needed to find someone to administer the child's insulin and check the child's blood sugar. Finding someone was a challenge for this family and an added stress for them since their child was diagnosed with diabetes. Luckily, they were able to find a teacher who was also a friend of the family who was willing to help:

> *In order for her to be able to go to school, we had to make sure that somebody could be at the school and give her insulin and things like that. . .. That was like a big thing for us was that with the school system and that like they do have their own protocols and stuff put in place, but their thing was they didn't want anybody to do anything with insulin because of liability.* (Mother, family four)

A teacher at that school (family four) stated:

> *Because I mean, God love her, she can't help it when her sugars drop or spike, or she gets sick or whatever. But the staff at the school were excellent. Everyone knew of [X]'s needs, and everyone was willing to step in where need be, so the staff was looking out for her, which works really well.*

I was surprised to hear that this family encountered this issue because a boy in my son's class has diabetes, and their teacher helped him with his insulin and checked his blood sugars. Due to this, I wanted to look for a school policy regarding medication administration, which I did find and will be discussed under document analysis (NLESD, 2014 & NLESD, 2015).

4.5.3.4 Teacher Appreciation

Another clear theme was teacher appreciation; seven families spoke about how they appreciated their children's teachers and how they go above and beyond for the children they teach. Seven families interviewed said they were happy with and appreciated the teachers and all the hard work they put into helping their child to be successful in the school environment: "*the teachers at the school are very supportive"* (father, family one). A grandmother (family one) also stated:

> *I have total faith in the system because I know that special needs teachers and administrators are on top of that the best that they can, student assistants, you know, and everybody is trying to work together to find the best things for these children.*

4.5.3.5 Acceptable Behaviour

Another sub-theme was that of acceptable behaviour. One family spoke about their child's experience regarding acceptable behaviour in specific locations. I included this because I feel that other families may also work with their children on acceptable behaviour, but it was not brought up in the other interviews, and I think it is valuable information for other families to learn about.

One set of parents worked a lot with their child regarding acceptable behaviour while at home and how to hold in certain emotions while at school and let them out at home (for example the child was not suppose to yell or raise her voice at school or hit anything but she was allowed to do this at home). The parents decided upon what they considered was acceptable behavior at school and encouraged their child to follow this and there was no consequence if she could not abide by this rule. The parents felt that this helped their child with school and therefore, they worked a lot with their child on this so that their child could be more successful in school: "*when you're at school, this is what you do. Home is your safe place. That's where if you're upset, this is where you're going to let it out is when you get home."* (Mother, family four)

4.5.3.6 Urban versus Rural Living

All parents were asked about the barriers or challenges they faced when preparing to send their child to school. Two of the prompts were: “Do you feel that where you live, and the location of the school or size of the school plays a role in [child’s name] transition to school? If yes, how?” Another prompt asked, “furthermore, do you think that the location of your school/or the size of the school contributes to the challenges or number of resources available to you and [child’s name]? If yes, how?” These prompt questions brought up much discussion about living in urban versus rural areas, the size of the school their child attended, and the resources available at the school.

Parents interviewed spoke about the school regarding being small or large, urban or rural, and the benefits or downfalls. Some benefits of attending a larger school in an urban setting included having more resources available to students with a lot of extracurricular activities and a lot of field trips: “*when she started out, it was over 700 people. It’s a huge school for an elementary school. But with that also comes resources, I feel like they do seem to have a lot of resources”* (mother, family two). A grandmother (family two) stated, *“I think sometimes with the bigger schools you have more remedial help.”*

One father (family one) felt that going to a larger school meant more programs were available to his child:

> *where it is a bigger school, they have different programs like a sensory gym and sensory music, so sometimes the kids might not go with the typical class with music class, they might have a sensory music class which sometimes the music is not as loud or the instruments are not as loud, things like that.*

On the other hand, with large schools also comes larger classrooms, which can also have a negative impact:

> *A large classroom can't be great for anybody really because the noise level, just alone. And the teacher is only there, they have a lot of trouble trying to help everybody, and there are a lot of kids in the classroom that have needs.* (Mother, family two)

In contrast, other families stated they enjoyed the benefits of their child (ren) attending a smaller school:

> *classroom teachers, along with the teachers, they knew all of them from beforehand as well, and because our school is rather small and community-minded, they knew of the girls before they even started. . .. Like I feel as though I am blessed with the school that we have due to the size of it, due to the technology, due to the fact that the teachers are so hands-on. I was like, I do not know where my children would be now if it wasn't for the school that we are in*. (Mother, family three)

One father (family four) also agreed that teachers in a smaller school know all the children, "I mean all the teachers know who they are. I mean all the teachers know who their little brother is. He's not starting kinderstart until next year, but they all know who he is because they've seen him since he was a baby."

Another mother liked the fact that the teachers had more time to get to know each student individually:

> *one benefit to the rural school is that our numbers are so small that the teachers definitely have time. There are pros and cons, don't get me wrong, but they definitely have more time to really get to know that student. And they can definitely have more one-on-one time with the student and things like that.* (Mother, family four)

One father (family six) stated, "*it's a smaller school and a smaller area, so I think it's a little easier to get along and make friends,"* while one grandmother (family four) found comfort in knowing her granddaughter attended a smaller school, saying, *"the smaller schools where I think there is a comfort zone for me in knowing that the people, they really know her and she's not just a number."* Another positive aspect of a smaller school is that people get to know one another and are closer: *"it's a very small school, and it's very community-driven, and people are close, and I think it's a nice atmosphere for everyone"* (Teacher, family four).

A drawback of attending a smaller school is that there may not be as many resources available: *"we are smaller; we don't always get the same resources as bigger schools. It's a numbers game"* (Teacher, family four*)*. A grandmother (family four) also stated, *"so, I think bigger schools would have more things to offer them in terms of technology."* Another mother compared a smaller school to a school in a larger center: "*I'm sure if we lived in St. John's or somewhere else larger, there would be more at our fingertips."* (Mother, family six)

Two families stated that they were happy that their children were attending newer schools (both in urban settings): "*it's a newer school, so they got state-of-the-art equipment there and really good teachers and sensory rooms and things like that"* (Father, family one). A mother (family three) stated, *"we were lucky they got a new school built when we started grade one, so all the classrooms and all the rooms have FM systems built into them."*

There are benefits and drawbacks to living in different places, either in urban or rural areas. A benefit of living in a rural area for some is that "*everyone here knows everybody, and everyone is just so, they are very inclusive"* (mother, family four), but this can also be considered a drawback for other families. For one family, it took time for the mother to adjust to living in a rural area:

> *that was really hard to get used to living in a rural place. I was like, okay; these people think they know more about me than I even know about myself. And I found that really, really difficult because I'd go to a store, and somebody would say something to me, and I'm like, they'd ask me like a really personal question.* (Mother, family four)

Another drawback is that when living in a smaller community, that community may not have as many supports to offer children. For example, the community may not have as many extracurricular activities or family physicians, and the family may have to travel to another community for these; this was true for two families I interviewed. One of these families also stated that the community where they live did not have a preschool available for the years that their child was the correct age to attend: "*they do have a Family Resource Centre for little kids, but there's not a whole lot of programs or anything like that offered"* (mother, family four). The child's grandmother (family four) stated:

> *and that's the one thing that's lacking when you're in a rural community is that you don't get that where you can have them where they can register where they go maybe a couple of mornings a week to socialize with other children before they're going out into that big school.*

A mother from a small community found few medical staff in the community who could care for her child:

> *I think it is very much challenging was regards of medical stuff. There's only one doctor here, maybe two that would know his history. . .. Like the lack of medical, there's no there's no pediatrician here.* (Mother, family seven)

A family friend (family seven) who lives in a small community with the family mentioned above noted:

> *this place is great for family help. The school system is amazing. But like our healthcare definitely lacks, in any situation, especially when it comes to a small child who has been through so much like so. That's the worst that this place like they have to travel a lot for him because of everything that goes on.*

4.5.3.7 Where to Find Support

All families mentioned looking for support and resources for their children. Some challenges these families faced were finding some of the resources available within their communities and this province; however, by word of mouth and family-to-family support (e.g., Facebook groups), this was not an issue for the families I interviewed.

One mother stated she joined the school council, so she was aware of all the support that the school could offer to the children that attended: "*I'm very hands-on to make sure the kids get all what they need, so I thought what's a better way to do that other than join the school council and make sure the supports are in place."* (Mother, family two)

Some of these children are living with very complex health challenges and still engage in many extracurricular activities outside of school; these include Girl Guides, hockey, horseback riding, and swimming, just to name a few. During these activities, the children have made good friends, and the parents have also made friendships with other parents and have gotten a lot of support.

4.5.3.8 Stigma and Labelling

One issue brought up in three interviews was the stigma and labelling of these children due to their health challenges and how these families are coping with this concern. Stigma and labelling were a sub-theme because of the importance of this topic. Two children were teased or made fun of due to their health challenges by other children in school: "*I know that there was a* *little bit of teasing with [X] . . . when she first started school. But that quickly got nipped in the bud between her older brother and her twin sister"* (mother, family three), another mother (family six) stated, *"she has experiences I'm going to say really mild bullying, nothing severe."*

One mother and a grandmother from a different family stated they were worried that with their diagnosis, their child/grandchild might be labelled in school and that the label could follow them throughout their school years and not help them: "*she needs more help than a regular normal child, and I knew as well, but I didn't want to label her so early in life*" (mother, family six). A grandmother (family four) also brought up labelling children:

> *and sadly, kids get labelled as being not a good kid, being a bad kid, the words I totally despise because I've worked in schools before . . . where kids get labelled. And it's sad. I find if they get labelled that year as somebody who is a little bit more rambunctious than somebody else, it follows them and then they don't seem to lose that label.*

4.5.3.9 What Would You Change if Given the Chance?

All parents spoke about what they would change if given a chance to do everything again. This theme arose due to a particular line of questions and is important to acknowledge as a prominent theme in my study because other parents going through similar circumstances may decide to do something different based on these parent's experiences. Some families wished they would have begun to look for help earlier, "*I think that maybe we would have started to look for help for her earlier*" (Grandmother, family six). Some parents stated they wished they had known about early intervention programs and that their child could have availed of them: "*I would have taken the money from daycare and not put her in daycare and put her in an intense early intervention"* (Mother, family two). The mother in family two also mentioned that more information would have been nice:

> *some sort of program could have been extended to help you deal with things that wouldn't necessarily have come up until school age; something like that would have been nice, even if it was just a support group or something like some sort of information session.*

Another family member stated that her family *"was on the alert for anything that was out there that would help her because she didn't know what she would be facing. So, she was finding out what the resources were for preemies."* (Grandmother, family two)

Other parents stated that they would have limited screen time and would have started some therapies to help manage their child's condition sooner (i.e., counselling, starting some medications sooner). Lastly:

> *if I could change anything or make anything better, it would be the nonverbal part. For him to be able to communicate with us, it would just make life so much easier. He can't tell us when he's hurting. He can't tell us if there's a pain anywhere, so that's hard.* (Mother, family eight)

4.5.3.10 Resources Needed

At the end of each interview, I asked each participant what resources they would have liked to have been in place for their family because all families spoke about the what ifs, for example, what if I had this resource earlier, what if I was aware of this resource. Therefore, resources needed became a central theme.

Many families stated that more staff were needed, including teaching assistants and more IRTs. Included with this was having the same support person (student assistant or IRT) for the child on a more consistent basis and having better communication between the support person and the parents: "*more student assistants is needed throughout the school" (mother, family eight)* and "*there are not enough support workers sometimes per children in the school*" (mother, family five).

Also, two families mentioned more sensory times and zones. Early intervention for children with learning disabilities was mentioned, along with more one-on-one time with teachers and having the perinatal program made longer: "*I wish there was a more concrete laid out plan in place for early intervention for reading difficulties.*" (Mother, family two)

Lastly, a resource that is needed for families of this province is equal education for all students regardless of their health challenges; this is especially important for children whose first language is American Sign Language, as there is no longer a school for the deaf (Government of NL, 2010) and families interviewed are still struggling to try to ensure their children have all the supports and resources needed to ensure their child has access to a proper education.

4.6 Chapter Summary

The demographic data collected allowed me to describe the families participating in this study in aggregate terms. The home visit (direct observation) allowed me to experience for a short time what it is like to live with a child with health challenges. I was able to see what priorities the family needs to focus on, which included the child's safety, and I was able to see how this family copes with dealing with a health challenge every day.

The documents I reviewed were pertinent to the stories told to me during the interview process. Each family had a remarkable story, starting with having a child born preterm and ending with transitioning that child into public school. I had the privilege to hear their stories and am now trusted to share them with more people.

Lastly, the interviews with mothers, fathers, grandparents, family friends, and teachers had rich data, and everyone had a critical story to tell. The diversity of health challenges these families face and the many appointments they attend as well as the resources and supports needed to help these children learn and grow at school is no small task for these parents to face every day. In my data analysis, I selected pertinent passages from interviews to highlight their stories and experiences and give my participants a voice. While these cases had similar experiences, as seen within the themes chosen, some unique experiences were also outlined as sub-themes.

In the following chapter, I relate my findings to the existing research literature and identify new information discovered in this study not previously reported. I discuss the strengths and limitations of this study, and lastly, I discuss reflexivity and its importance in this study.

Chapter Five Discussion

5.1 Introduction

This doctoral research project was an instrumental multiple case study that sought to understand how a child who was born preterm (and currently has one or more disabling health challenges) and their parents experience the child entering the public school system. Given the prevalence of preterm birth, the number of children surviving, the complex health challenges that result from being born too soon, and the costs to the health care system and families, it is vital there are adequate resources and support for these families. These children deserve equitable access to education, the same as children born at term. Therefore, these resources and services must be in place at home and in schools, within communities, within provinces, and within this country.

The overarching research question for this study was, "How does a child who was born preterm (who currently has one or more disabling health challenges) and their parents experience entering the public school system?" This study had four research objectives:

(1) To explore how families adjust to having a preterm baby with health challenges (including their time in the NICU and going home).

(2) To investigate the factors within the school, their community, and the province that influence their child's ability to achieve the best possible educational outcomes (as defined by their parents).

(3) To determine whether the school's size (large versus small) made a difference in how the child transitioned into school.

(4) To explore whether more supports are available for the child and family depending on where they live (urban versus rural).

This research study used a multiple-case design in which eight instrumental, bounded cases were examined using several data collection methods, including direct observation (one home visit), interviews, and document analysis. This approach allowed for a more extensive exploration of the phenomenon under study in this case: how a child born preterm and their parent's experience the child starting school. My epistemological stance of social constructivism aligns with this research as each family and case lives in their own reality and has their own social interactions with other people, which leads them to their own unique interpretation of the world around them.

5.2 Synopsis of Key Results

A synopsis of the key results from the interviews will be presented in the following paragraphs utilizing the three main transition periods: the first being the transition from expecting a healthy baby/child to having a preterm baby with health challenges. As stated in Chapter Four, when families find out that someone is pregnant, everyone expects the woman to have a healthy pregnancy and deliver a healthy baby. No one expects or wishes for preterm birth, and most people are unaware of the health challenges of having a preterm baby. The families in this study had to find ways to deal with having the pregnancy cut short and then having to adapt to a baby born preterm and the complications that arise with the birth, including challenging health conditions, NICU stays, and the emotions that come with it.

The second transition was from the NICU to home. Once the baby was stable and ready to go home, as determined by the healthcare team, the family had to adjust to their new normal. The families finally got to take their baby home, about which they were happy but also anxious and nervous. In the NICU, the healthcare team provided most of the baby's critical care. The NICU team was there as a resource for the parents to ask questions and, of course, be there for both the baby and the family if anything happened medically to the baby. Once home, the parents were the primary caregivers, and they had to rely on each other and circle-of-care members (e.g., grandparents, family friends) to help them care for their child if needed. This transition period included multiple appointments with different specialists; for some families, their child was diagnosed with a new condition(s), and many families had to deal with the financial strain of buying medical equipment and medications for home.

The third and final transition was from home to starting school. During this transition, parents had to adjust to having someone new watching their child, providing appropriate education, and ensuring their healthcare needs were met. Many of these children required accommodations in the school, including longer times for test-taking and assistive technology. Some children also required help from an instructional resource teacher (IRT) and, for some, a student assistant. If the child went to a larger or smaller school, that choice provided benefits for some and drawbacks for others. Some of these children encountered bullying while in school. In addition, parents came to terms with their mental health struggles from what they had endured.

5.2.1 Transition 1 Key Results: Expecting a Healthy Baby/Child to Having a Preterm Baby with Health Challenges

This study found that mothers expect to have a normal pregnancy, and once a baby is born preterm, this is an added stressor and challenge for them. They worry about the challenges their baby may face in the NICU and future, along with the separation they experience with a NICU admission.

This notion that having a preterm delivery was stressful is not new and has been reported in the literature. Many authors (Lomotey et al., 2020; Trumello et al., 2018) have stated that premature birth is an unexpected and often a very stressful event for parents. Preterm birth is a situation for which the parents were unprepared since many were expecting a healthy pregnancy and delivery (Arzani et al., 2015, Medina et al., 2017). As a former NICU nurse, I remember meeting many very stressed parents who did not know what to say or do and were exhausted due to all the events happening so fast.

Parents of preterm babies face many difficulties after birth. Many authors have written about how the separation of mother and baby after preterm birth when the baby is going to the NICU and the mother is going to the postpartum unit is a distressing and traumatic event for these parents (Treyvaud et al., 2019). The significant stress parents experience is related to the separation from their baby, the loss of their parental role as they had imagined it, and the change in roles that can happen with a NICU admission (Lomotey et al., 2020; Medina et al., 2018; Purdy et al., 2015; Trumello et al., 2018). As a former NICU nurse, I remember when mothers visited their baby for the first time and just sat, looked at their baby, and cried. Some never even had a picture of their baby without tubes and wires hooked up. I also remember parents crying because they had to leave the unit for the night but did not want to leave their baby.

The NICU environment itself is also very stressful for parents. The physical environment encompasses the monitors, the tubes, and all the wires connected to the baby, the noises the monitors make, and the chemical scents present in a hospital (Trumello et al., 2018). New parents are unprepared to see their baby in an intensive care unit; many do not even know one exists. I remember as a NICU nurse trying to explain what all the wires and tubes do to parents and just seeing their faces and realizing that they were in shock and not taking in most of what I said. During the first few visits, many things needed to be repeated.

In my study, two women commented on how their own health challenges after the birth of their child affected their ability to see their baby in the NICU. Both pregnancy and childbirth are major life events, and they both have the potential to significantly impact a woman's health. Many mothers of preterm babies have health problems in the early postnatal period, including more anxiety and fatigue (Henderson et al., 2016), which may affect their ability to visit their baby in the NICU. Many mothers try to go to the NICU to see their babies and do not realize how sick and tired they are. As a nurse, I have had to take some mothers back to the postpartum unit due to them not feeling well.

Another finding consistent with the literature is that participants in this study discussed how sick their baby was after birth. Some were sick for a long time and seeing their babies sick was very emotional. Babies born preterm are at an increased risk for an extensive range of poor health outcomes, including respiratory distress syndrome, neonatal sepsis, cerebral intraventricular hemorrhage, and lung damage (Vazquez & Cong, 2014). In the long term, they are more likely to experience a cognitive impairment, motor and/or sensory impairments, and behavioural problems than babies born at full term (Henderson et al., 2016). Many preterm babies have serious medical conditions after birth, which is an added stressor for parents (Ionio et al., 2016). In addition, when parents first see their preterm baby, many are shocked at the baby's appearance as preterm babies show less infantile facial features and are perceived to be less physically attractive than full-term babies (Ionio et al., 2016).

As stated earlier, having a sick baby in the NICU is very stressful for parents, so parents need to be kept informed on their babies' status and all medical procedures. Having good open communication with medical staff and having staff listen to parental concerns can lessen parental fears and reduce their anxiety (Ionio et al., 2016). Parents perceive open communication and a caring attitude as necessary qualities in nurses to help parents interact more with their babies (Feeley et al., 2016). NICU parents report they need to receive accurate information about their baby and want to be included in decisions regarding their infant's care. These parents also report a lack of control and a striving to be normal mothers (Vazquez & Cong, 2014). The need to have good communication with NICU staff was also found in this study, where all families except one reported good communication with the NICU team and how this communication helped them adjust to having a sick baby. As a NICU nurse, I remember how important keeping the families updated was to the parents. Most parents wanted to be in the unit all the time but could not and found it hard to leave their baby, so the good communication and constant updates helped them reduce their stress.

5.2.2 Transition 2 Key Results: Transition: NICU to Home

Another finding consistent with the literature is that once the baby is discharged from the NICU, parents are happy to go home but are still stressed about caring for their baby by themselves with no help from the healthcare team. Parents of preterm babies also experience stress after the baby is discharged from the hospital (Purdy et al., 2015). Many parents feel unprepared to bring their preterm baby home. They may have anxiety regarding their baby's safety and may not feel practically or mentally prepared, resulting in increased anxiety (Aloysius et al., 2018). Many parents often have mixed emotions of joy and fear upon hospital discharge (Aloysius et al., 2018). I remember parents crying happy tears that they finally were getting to take their baby home but also crying sad tears because they were leaving the only home their baby knew. Many would say to me, how am I going to care for them on my own? And I would always say, you are their parent and know what to do, and we are only a phone call away.

Parents in this study reported they had many follow-up appointments to attend once they were discharged from the hospital and that these appointments were with numerous disciplines and could be weekly or monthly, depending on their child's needs. They stated the appointments were hard to track, and for some, the travel time was a lot, especially for two families who had to travel outside of the province.

The prognosis for each baby is unknown at discharge from the NICU, so follow-up is essential for the early identification of health challenges and coordinating health services from multiple team members (Seppanen et al., 2021). After discharge from the hospital, some parents may feel overwhelmed by their babies' health problems, scheduling, and rescheduling of appointments, and seeing doctors and specialists unfamiliar with their babies' history and conditions (Purdy et al., 2015). However, no articles were found relating to the number of appointments these families needed to attend and how difficult and time-consuming it was to keep track of these appointments. This information is current knowledge this study is contributing to the literature.

As stated earlier, premature birth can lead to many health challenges; these challenges may include visual and/or hearing impairments, chronic lung disease, learning impairments, moderate to severe global developmental delay, and psychiatric and behavioural issues, to name a few (WHO, 2012). The earlier a baby is born, the more likely they are to experience health problems. Being born prematurely can cause problems for babies throughout their lives, and some problems may not be evident for several years (March of Dimes, 2019). Some long-term health problems are vision and hearing concerns (March of Dimes, 2019). In this study, some babies were diagnosed with health challenges before discharge from the NICU, while others did not have actual diagnoses until their child was older.

Parents stated it was essential to have their child diagnosed because they could not access some services unless their child had been formally diagnosed. The Centers for Disease Control and Prevention (CDC, 2021) confirms that many children with developmental delays and/or behaviour concerns are not diagnosed as early as needed. Due to the delay in diagnosis, these children need to wait to get the help they need to do well in school and other social settings, like at home or in the community. Many children are not identified and diagnosed until they are in school, and at this time, significant delays may have occurred, and opportunities for some treatments may have been missed (CDC, 2021). Once a problem is identified, it should lead to evaluations, diagnosis, counselling, treatment, and early developmental intervention (Lipkin et al., 2020). The early identification and intervention for developmental disorders are critical for the well-being of these children these conditions include deafness/hard-of-hearing, intellectual and motor disabilities, autism, and behavioural conditions. However, we must remember that some behaviour concerns are hard to diagnose and may not be possible to diagnose early.

A study by Zeleke et al. (2019) highlighted the importance of having a formal diagnosis so parents can access the necessary services to help their children. In this study, parents of children with ASD and parents of children with SLD spoke about the importance of having a diagnosis so they could avail of services that were unavailable until a health care provider made a diagnosis. While these observations seem obvious, not many studies confirm this finding. ASD can be reliably diagnosed by two years of age by an experienced clinician (CDC, 2022). It is vital for parents who have concerns that their child may have ASD to seek out assistance from healthcare providers as soon as possible so that a diagnosis can be made, and treatment can begin (National Institute of Mental Health, 2018). Early identification and intervention services are critical for an effective outcome for children with ASD (Zeleke et al., 2019).

The financial burden associated with caring for preterm infants after NICU discharge has not been adequately documented in the literature. The cost of medical equipment, prescription medications, along with out-of-pocket expenses, and the increased financial worry in parents was identified by numerous participants in this study. These costs can contribute to increased parental and family strain (Lakshmanan et al., 2021) and stress (Purdy et al., 2015). Nusinovivi et al. (2017) found that the birth of a preterm infant frequently had a substantial economic impact on the family involved.

A new finding from this study, not found in the current research literature on preterm birth, is that many parents interviewed found out about hospital, community, and provincial services and resources by word of mouth from other parents who were going through similar circumstances. Some families also took it upon themselves to start support groups via social media (especially on Facebook), where parents could reach out to each other easily, ask questions, and receive support from people in similar situations.

Another piece of knowledge identified in this study is the empowerment of insider knowledge. Some parents and grandparents in my study were nurses and teachers. They used their knowledge from their job to support their child or grandchild. This insider knowledge of policies, procedures, medical conditions, and medical tests lessened the stress for mothers who were nurses; they were already aware that specific medical procedures needed to be done, and they knew what to expect. On the other hand, the insider knowledge caused increased stress when staff nurses expected a mother who was a nurse to perform medical procedures on her child, including giving several injections daily. However, overall, this mother was empowered and more vocal about the care her child needed due to her background knowledge, and she had earned the respect of the healthcare team that cared for her child, as they usually listened to her regarding what her son needed. Other parents who had family members who were teachers knew how to look online for policies and procedures regarding inclusive education, so they were aware of what they could ask from the school, and they were prepared for school meetings with this knowledge. This insider knowledge empowered these couples as they knew what was possible regarding curriculum and support available to children in the school system. They felt prepared for school meetings, were not surprised by any information discussed, and felt that their children received the support they needed sooner because of this knowledge.

Two families in this study brought up inclusion and how one cannot access some buildings because there is no wheelchair ramp. In addition, one of these families could only go to a store as a complete family if there was a Caroline's Cart available, as this is needed for one of their children to ensure his safety while shopping. In NL, the Buildings Accessibility Regulations under the NL Building's Accessibility Act (Government of NL, 2018d) state that a public building with greater than 600 square meters of the floor area must have an entrance capable of accommodating persons with disabilities. The NL Buildings Accessibility Act (Government of NL, 2018d) and regulations also provide minimum standards for accessibility features, including width, running slope, landings, and handrails for ramps. However, it is unclear to a lay reader which businesses would need to ensure ramps are installed. In addition, in 2021, the NL government passed Bill 38, the Accessibility Act (Government of NL, 2021b). This act aims to improve accessibility for persons with disabilities by removing barriers so they can fully participate in society. It authorizes the establishment of accessibility standards to improve accessibility. However, it is unclear to a lay reader what barriers will be removed, how long it would take to remove the barriers and where they exist in the province.

A Caroline's Cart is a specialized cart created for special needs individuals. It allows people to transport a special needs individual through a store without having to maneuver a wheelchair and a typical shopping cart simultaneously (Wanzl, 2020). It is up to stores to purchase these carts for the public to use, and at this time, there is no provincial requirement for them to be available at business locations. In addition, the cost of the Cart is not available on the website.

Another new piece of knowledge gained from this study, although known anecdotally (hard to quantify), is how strong and resilient these children are. Resilience is the process of positive adaptation despite the experience of risk or adversity (Masten, 2001). Only a few studies have focused on identifying resilience processes in preterm infants, although no studies have focused on resilience in preterm children during their transition into public school. Poehlmann-Tynan et al. (2015) found that less negative parenting (e.g., lower levels of anger and criticism) predicted a likelihood of resilience in multiple domains of development. Anecdotally, the majority of nurses, physicians, and families who have cared for children who were born preterm speak about how strong these children are even after all they endure in the NICU (e.g., medical procedures). They are born into circumstances out of their control, and many undergo painful procedures and endure more than many adults could handle.

5.2.3 Transition 3 Key Results: Transition from Home to Starting School

Multiple parents enrolled their children in either a daycare or preschool setting or extracurricular activities to help them socialize with children close to their ages. Shah et al. (2016) found that early intervention with the preschool age and preschool experience was associated with school readiness. These families stated they felt these experiences helped their children transition into the school system more efficiently. Maleki et al. (2019) found social skills development helps children create successful relationships with others, helps prepare them for school (school readiness), and improves their adaptation to the formal setting of the school and academic performance. They also found a lack of social skills in children can lead to feelings of loneliness, poor interactions with parents, teachers, and peers, mental and behavioural problems, and issues with school adjustment.

Two families in this study delayed starting their child in kindergarten because they felt their child was not ready to attend school then. These children were also only four years of age at the time they would have started kindergarten (they would have turned five by the end of December that same year), so they were also younger than the average kindergarten child (even younger if you look at their corrected/adjusted age). This information aligns with the literature, which states infants born before 32 weeks show the most significant risk for poor school readiness, especially in reading and math (Shah et al., 2016). Children born preterm have lower school readiness skills (Agarwal et al., 2021) and this is also associated with other factors, not just being born preterm (Shah et al., 2016). These factors include a younger age at the start of kindergarten as seen in this study and less school experience as also seen in this study, as these families, when they decided to delay kindergarten, did not have their children enrolled in a preschool or a school-like setting. Shah et al. (2016) also found that children with a risk of poor school readiness, like children born preterm, should be targeted for intervention before kindergarten starts. Shah et al., (2016) recommended preschool enrollment as a possible means of fostering school readiness. However, not many preschools can take children with complex health conditions.

Another piece of knowledge discovered in this study is parents asking for meetings with school personnel before the start of the school year so everything could be put into place in time for the start of the school year in September. This included, for some, creating and sharing "all about me" books and, for others, having time to show teachers and assistants how to use special equipment their child needs (e.g., apply their braces) and to go over important information regarding their health (e.g., how to feed them correctly and/or give them medications). Lendrum et al. (2015) stated that the role of parents in their children's education is critical, and their relationship with the school can positively affect their child's educational outcome. However, Lendrum et al. also found that school engagement is typically lower among parents with children with disabilities, which is a concern since these children are at an increased risk of experiencing poor outcomes in school. It was nice to see the families I interviewed were very involved in their child's education and ensuring their child receives the best possible education. These meetings also ensure all documentation is complete prior to school starting; this may include medication forms that must be filled in and signed by a physician for the school to administer a medication to a child as noted in the Administration of Medications, a related document to the *Administration of Medications, Medical Interventions and Chronic Care Policy*.

Several parents and other members of the family's circle of care spoke about the accommodations a child received while at school. The Department of Education and Early Childhood Developments webpage states that the department follows students in this province who need school-based support. Students may receive many different accommodations or alternate programs, including assistive technology, sign language, specialized equipment, and/or clarification of instructions or having material read aloud (Government of NL, 2018b). Providing accommodations is part of receiving an inclusive education promoted by the Canadian Charter of Rights and Freedoms (1982) and is governed by provincial legislation and policy (Lyons et al., 2016). According to Lyons et al. (2016), there are several standard components and qualities of an effective inclusive school; they include:

> (a) a clear vision focusing on all students that are supported by school personnel; (b) all students are valued members within classrooms and are educated together; (c)

> comprehensive support for students and teachers; (d) a collaborative team approach; (e) efficient use of resources; (f) flexible curriculum and high-quality instruction using evidence-based practices; (g) supportive leadership that includes shared decision-making; and (h) quality professional development. (McLeskey et al. 2014)

These qualities align with the document I reviewed called the *Handbook for Parents of Children with Exceptionalities* (Government of NL, 2015). This book outlines a clear vision of how children with exceptionalities are identified, the role of parents, and the role of the team, which includes formal and informal assessments and making programming decisions based on the students' strengths and needs, including decisions regarding accommodations, alternate courses/curriculum, the setting, and delivery personnel.

In addition, many families spoke about how their child was assigned to an IRT and the IRT's role; this was highlighted more when I spoke to an IRT. In addition, families also spoke about their child being assigned to a student assistant and what that role involved. The use of these two resources with children born preterm with health challenges is not known, however their role is evident from this study. The standards of practice for IRTs are composed of eight standards that include the foundations of special education, development and characteristics of learners, educational assessment, planning instruction, delivering instruction, learning environment, collaborative partnerships, and having reflective practice (Government of NL, 2015). Part of the application of these standards includes but is not limited to accessing and applying information on exceptionalities when planning educational and transitional programs, administering formal and informal assessments that respect cultural and linguistic diversity, using the information gathered (e.g., cumulative file, assessment data, anecdotal records, interviews) to plan for instruction, and using evidence-based strategies and methods when creating individualized programming (Government of NL, 2015).

School districts throughout this province are provided with student assistants to support teachers in meeting students' severe physical care needs, behaviour management, and personal care needs (Government of NL, 2021a). Several participants I interviewed had children assigned to a student assistant, which helped them tremendously while at school.

This study also saw the many benefits and drawbacks of urban versus rural schools and living in these communities. Several participants in this study commented on the many benefits of urban schools, including, for example, having access to more resources than in rural settings and having a new school that includes a sensory gym and music. The drawbacks of urban schools included a lack of IRTs and student assistant hours, and large numbers of students assigned to the same IRT, limiting time with each child. There were benefits associated with rural schools; for example, the school felt more like a community, and the teachers knew everyone, including information regarding a child's health challenge(s). At the same time, the drawbacks of rural schools included a lack of field trips and a lack of resources. Information regarding the benefits and challenges of attending urban versus rural schools and living in an urban versus a rural area regarding children born preterm with health challenges cannot be readily accessed in the literature. Therefore, this may or may not be a new finding to add to the current literature. More research into the role of living in and attending school in rural versus urban areas with a child with a health challenge is needed.

A few families in this study reported they did not want their child to be labelled with a diagnosis or a disorder. Labelling, name-calling, and stigma are not new phenomena in society or the school system. People are called names or labelled for various reasons; this can be due to certain stereotypes based on their looks, illness, or academic ability. Research has shown the harmful effects of labelling on students' self-image, academic performance, and behaviour (Marsh et al., 2018). Stigma refers to negative beliefs about an individual based on a particular characteristic (Major & O'Brien, 2005). Lyons and Roulstone (2017) stated many people want to keep their impairment or disability, or in the case of this study, their health challenge, private. Keeping their health challenge private is particularly true for those with less visible impairments (e.g., a SLD) because of feelings of shame and embarrassment and the persons' concerns regarding how other people would see them (Baumeister et al., 2008; Haft et al., 2022). Students with SLD may be physically separated from their classmates during school to receive more one-on-one time with an IRT; this may show other students that they are different, which can lead to stigma and bullying (Baumeister et al., 2008; Haft et al., 2022). Research has shown that being diagnosed with an SLD can stigmatize individuals, leading teachers and parents to have lower educational expectations for these students than for their peers (Haft et al., 2022; Shifrer, 2013). In addition, two families spoke about their children being bullied partly due to their health challenges. Being a victim of bullying is predictive of low self-esteem, anxiety, and depression, and if it is long-term, it can be linked to eating disorders and suicidal ideations (Chatzitheochari et al., 2016). In addition, children who are disabled are at a higher risk of being bullied (Chatzitheochari et al., 2015). Due to the parents speaking about labelling and bullying, I reviewed the NLESD's policy on bullying, which is procedure three in the *Safe and Caring School's Policy* (#EECD-901). There is a protocol for reporting and responding to bullying behaviour, which states that bullying always has a significant impact on students (NLESD, 2013).

One mother in this study reported NICU staff told her most marriages do not survive after having a very sick preterm infant. This mother's relationship with the father was under a lot of stress for the first few years after their preterm baby was born due to hospitalizations, added stressors, and lack of sleep. They spent much time separated while the child was in the hospital, and when they were together, their focus was on their child, not their relationship. The literature states that having a very low birth weight infant has been associated with marital discord and separation (Treyvaud, 2013). There is an increased risk of separation for parents of very low birth weight infants, and the discovery of associated severe infant disabilities or neurodevelopmental delays can profoundly challenge the parents' relationship (Nusinovici et al., 2017). The increased prevalence of separation is due to repeated stressful events within the first year of the infant's life (Nusinovici et al., 2017). In addition, parents who experience a neonatal death have significant distress in their marital relationship, which has been related to increased divorce rates (Eke et al., 2019). One family I interviewed lost one of their multiples shortly after his birth.

While none of the families interviewed underwent separation, the parents of preterm infants faced increased anxiety, depression, and symptoms consistent with post-traumatic stress disorder (PTSD), a finding consistent with the literature (Henderson et al., 2016; Treyvaud et al., 2019). PTSD is a trauma and stressor-related disorder (Schecter et al., 2020) according to the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition- TR* (American Psychiatric Association, 2022). Parents of preterm infants have a higher rate of experiencing psychological distress and depressive symptoms following the baby's birth (Nusinovici et al., 2017). Mothers of very low birth weight infants have a higher risk for depression symptoms within the first year postpartum. Parents also report more post-traumatic stress symptoms (Treyvaud, 2014). PTSD prevalence has been noted to be as high as 53% among NICU mothers and 33% among NICU fathers (Schecter et al., 2019). Experiencing PTSD can negatively impact parental well-being, with the potential for debilitating psychological symptoms, which can affect parenting skills. Some mothers may have problems bonding with their infant because the infant reminds them of their traumatic birth experience; PTSD can also affect the parent's decisions to have another child and may cause the parents to develop negative attitudes toward their infant (Schecter et al., 2020). In addition, the infants of these parents with PTSD are more at risk for cognitive, developmental, and emotional issues. Therefore, these parents must receive support for their PTSD (Schecter et al., 2020). I did not find any policies on the Eastern Health website; all of their policies are internal documents. I did, however, ask a NICU nurse if there were any policies related to parental PTSD, distress, or well-being, and they stated that there were not. However, the NICU has a social worker who follows these families and is available to offer support.

Lastly, this research project provides new knowledge surrounding what supports and resources parents and circle-of-care members feel are necessary for their child and their family. The supports and resources include having a place to find the resources and services available in this province, including what is available in different communities and how to access these supports and services since most families found out about services via word of mouth from other families. More IRTs and student assistants in the schools are also needed. More students require these services, and according to the families I interviewed, their children could benefit from having more time with their IRT. In addition, IRTs I interviewed stated that they wished they had more time with some of their students with more complex needs (like the ones in this study), as this would benefit them and help them meet their developmental and educational milestones.

Some families also mentioned that help with finances, including help with knowing what is already available and how to complete related documentation, would be beneficial. One mother stated that she completed some paperwork for financial reimbursement and had the physician sign it (this is mandatory to receive the reimbursement), and due to an error on the form, it was rejected. Therefore, she not only had to fill in new papers, but she also had to make an appointment and have the physician sign the new forms. This type of exercise is very time-consuming for parents, who have stated in this study that they spend a lot of time going to appointments, which also wastes a physician's time. A navigator role in assisting families in filling in these forms would benefit these families and help eliminate any errors in completing documentation. In addition, one mother was so frustrated with all the paperwork that it was causing increased stress and anxiety. Her parents, who were also interviewed as circle-of-care members, stated that they saw their daughter lose sleep over all the paperwork that was needed and told her to call her local member of the house of assembly (MHA, elected person in the provincial government) and ask for their help. Luckily, their MHA was able and willing to help with all the paperwork. However, many parents are left to fill in the paperwork independently, and others are unaware of the process of getting financial reimbursement. Financial concerns for parents who have preterm children with health challenges are also a finding from this study. Literature on children with disabilities does cite financial challenges these parents face (Clasquin-Johnson & Clasquin-Johnson, 2018; Einfeld et al., 2010; Genereaux et al., 2016)

Another support parents mentioned in the interviews was that inclusive events in the community and throughout the province are needed. In my interviews, only inclusive events for ASD were mentioned. Some families cannot attend regular family gatherings like the Santa Claus Parade or Canada Day celebrations due to the nature of the events, the number of people, and the noise. Many children with ASD cannot handle the extra stimulation these events create; therefore, these families elect not to attend these events. However, some communities are starting to include sensory-free zones so all families can attend. One family mentioned that a sensory-friendly zone had been established in Conception Bay South (CBS) for the Santa Claus Parade. The mother said the sensory-friendly zone is a short section of the parade in which there are no sirens or flashing lights, and music is turned down low, and an accessible bus was also included in the shuttle service. This family (the mother, father, and grandmother) stated that CBS has begun having sensory-friendly zones at their community events, and this meant a lot to them since they can now go to these events and enjoy them as a family.

5.4 Strengths and Limitations of this Research Study

One main strength of my research is that it addressed a gap in the literature related to an absence of Canadian qualitative data on how families of babies born too soon adapt to various transitions, including the transition of their child into the school system and how their circle of care supports them in coping with these new challenges. This study provides new information related to this topic, and in the next chapter, I will provide recommendations to improve the lives of families with similar challenges.

Another strength is that because half the families who participated in this study lived in an urban area while the other half lived in a rural area, it was possible to compare and contrast the similarities and differences in their experiences concerning where they live. Another strength of this study is that while, usually, mothers tend to be the focus of interviews in many studies on parental experiences, in this study, and fathers also participated in interviews in addition to many circle-of-care members, including grandparents (both grandmothers and grandfathers), aunts, family friends, and teachers. Interviewing so many different people presented other people's perspectives and views on how the child was adapting to school, which strengthened the results, improved the study's trustworthiness, and provided rich perspectives from multiple points of view.

Another strength was that I could recruit many participants, eight families total, even though recruitment took place during a global pandemic. Additionally, several sources of data were used (home visit/direct observation, demographic questionnaire, interviews, and document analysis), which allowed for more trustworthiness of the findings.

One of the most significant limitations of this study was recruiting participants during the COVID- 19 pandemic. At the height of the pandemic, most businesses were closed (if considered nonessential) along with all schools (K–12). This left parents at home with their children trying to cope with working from home and helping them complete school online, leaving little time to complete interviews. In addition, the university did not allow in-person, face-to-face interaction with research participants. Therefore, all home visits (direct observation) were stopped by Memorial University of Newfoundland, and all interviews had to be completed via telephone and/or online. All participants in this study preferred telephone interviews.

Another limitation of the study was that there was only one family from Labrador, and it is unclear whether other families living in Labrador face similar challenges, for example, issues with travel, including the expense to access health care, as this family does. This family was also from a larger centre in Labrador, so it is unclear if families living in remote areas of Labrador face similar or more challenges, especially high expenses regarding travel for healthcare. As noted at the beginning of this dissertation, the province of NL is vast geographically, and it was impossible to interview families from all areas of the province. The participants included in the study were all volunteers. Therefore, there is no way to know if people in other centres or remote areas of the province experienced similar issues to those described in this study. However, all families had to travel to large healthcare facilities to deliver their babies. In this study's case, all participants had to travel to St. John's to deliver their babies.

In addition, the intent of this study was not to be able to generalize from the results. Instead, this study intended to tell the story of my research participants using their voices to identify the strengths, weaknesses, and resilience of the families with preterm babies.

Lastly, a limitation of this study is that the sample of families participating in this research project are heterosexual, meaning that the parental relationships were between a man and a woman. There were no lesbian, gay, or transgender couples. Therefore, it is unknown if the participants' experiences would have been the same or different if a lesbian, gay, or transgender couple was part of the sample. In addition, all families participating in this research project had a middle- to upper-class background and some postsecondary education. Having this background may have positively impacted their ability to seek out and ask for help and resources for their children and their ability to navigate the school system. It is unknown if the participants' experiences would have been the same or different if participants had been from a low-socioeconomic background or had less education. In addition, all families that volunteered to participate in this study were coping well with their child going to public school. It is unknown if they responded because they were doing well (possible sampling bias) or if families that were not coping well were too busy to respond to my poster.

5.5. Reflexivity

One of the most challenging and vital pieces of work in qualitative research is reflexive practice (Mitchell et al., 2018). Reflexivity is when researchers clearly describe the intersecting contextual relationships between themselves and their participants (e.g., race, age). These relationships help increase the credibility of the research study findings and deepen the researcher's understanding of the work (Mitchell et al., 2018). All my participants were White like me, and all but one mother (from Nova Scotia) was born and raised in NL, again like me. All parents were around the same age as me, and many had bachelor's degrees like me.

Whether the researcher is an insider or an outsider and whether they have a shared experience with the study's participants is essential when looking at the similarities and differences between the researcher and participant. According to Dodgson (2019), "the quality of the work depends on the researcher(s)' ability to articulate these similarities and differences to self and others, which include participants and readers" (p. 220). As stated in my inclusion criteria, all participants had to have a child born preterm in NL with a health challenge who was presently enrolled in the public school system. I am also a mother of two children born in NL, and while neither of my children needed the NICU since they were both born full-term and healthy, I was a patient in the postpartum unit where these mothers were also admitted, and I have taught nursing students on this unit. Therefore, I was aware of this unit's layout and general day-to-day processes. As stated earlier, I also worked in the NICU 20 years ago, where these children were admitted. During the interview process, at the end of each interview, when I chatted with the participant and thanked them for their time, I made sure that the participant was aware that I was a former NICU nurse and that I currently teach nursing students on the postpartum unit in the Health Sciences Hospital. I also stated I was a mother of two healthy children in public school. Sharing this information allowed for total transparency, and all participants stated that they were happy that I was a nurse and that since I worked in the NICU, I would have a better understanding of what they experienced. Many parents also stated that since I also have children in school, I understand how difficult completing school at home was during the lockdown and global pandemic. Multiple mothers stated they were happy that a former NICU nurse was interested in seeing how these children do in school.

Reflexivity means turning the researcher's "lens back onto oneself to recognize and take responsibility for one's situatedness within the research and the effect that it may have on the setting and people being studied, questions being asked, and data being collected, and its interpretation" (Berger, 2015, p. 220).

During the interview stage, I made sure not to let my insider knowledge of the NICU and policies and procedures influence the conversation. Instead of assuming things happened in the same manner as when I worked in the unit, I was careful to ask the participants to explain to me in their own words what they experienced. I asked them to describe the unit to me, including the sounds and smells, and that if they spoke about a procedure, I asked them to explain it to me.

My insider knowledge was used during an interview when a mother was trying to explain to me why one of her daughters' doctors was from Nova Scotia. She struggled to explain to me why the doctor was in another province. However, due to my past work experience at the IWK Health Centre in Halifax, I understood that the pediatric nephrologists (from the IWK) visit the Janeway Children's Hospital and Rehabilitation Centre quarterly (usually) to visit patients as there are no pediatric nephrologists at the Janeway. I did ask her to clarify if my presumption was correct or not.

In addition, during data analysis, for one family (and the corresponding three interviews), my supervisor and I independently reviewed and developed codes that led to my themes, which helped ensure credibility. Lastly, my supervisory committee has read this dissertation to ensure that non-nurses understand the language and context included in my writing.

5.6 Chapter Summary

This chapter provided a synopsis of this study's key results, including an exploration of the three main transitions reported from the data analysis. These overarching transitions included the transition from expecting a healthy baby/child to having a preterm baby with health challenges, the transition from the NICU to home, and the transition from home to starting school. Under each theme, I highlighted what was already known in the literature and featured the new knowledge this study provides. The new knowledge included the empowerment of insider knowledge, the resilience of these children, and the initiative of these parents in creating their support groups and passing on available support and resources to each other.

The new knowledge helps fill the gap in the evidence by providing new, Canadian, qualitative information that focuses on parental experiences and circle-of-care members' experiences. Lastly, a section on reflexivity was included to situate me within the research.

In the next chapter, recommendations from this study's results will be discussed.

Chapter Six Conclusion

This research project set out to answer the question, "How does a child who was born preterm (and currently has one or more disabling health challenges) and their parents experience entering the public school system?" Moreover, the goal was to also address four research objectives, namely, (a) to explore how families adjust to having a preterm baby with health challenges (including their time in the NICU and going home), (b) to investigate the factors within the school, their community, and the province that influence their child's ability to achieve the best possible educational outcomes and (c) to determine whether the school's size (large versus small) made a difference in how the child transitioned into school and, (d) to explore whether there are more supports available for the child/family depending on where they live (urban versus rural). I used a qualitative research approach and a social constructivist lens to complete my research study. I chose to conduct a qualitative study as I wanted to focus on my participants' perspectives and experiences and give them a voice to express what they experienced, both the good and the bad. I used an instrumental multiple-case study design and completed eight cases. I chose case study as my methodology, as my central focus was the family unit (the child born preterm, their family, and members of their circle of care). Each family had a unique experience with some similarities and some differences. To be able to understand how each family and child adapted to going to public school and their transition, I used several sources of data, which included a demographic questionnaire (for parents), direct observation (home visit), interviews (with parents and circle-of-care members), and document analysis. Doing this allowed me to fill a gap in the research and answer my research question.

This project fills a gap in available knowledge surrounding urban versus rural schools, including benefits (i.e., more resources available for larger schools and in rural schools the teachers know all the students very well) and drawbacks (e.g., lack of resources like sensory gym and field trips in rural schools, and large class sizes in urban schools), the empowerment of insider knowledge (insiders knew the system and policies so were aware of everything available for their child), and the need for more information regarding what services and resources are available throughout this province for these families (most families found out about resources through word of mouth). In addition, financial help is needed for these families, along with help with filling out the correct forms to obtain these funds.

To answer my research question, I found that all families coped well with their children who were born preterm (and currently have one or more disabling health challenges) entering the public school system. Some families experienced more difficulties than others; for example, they needed more meetings with the school to ensure the correct supports were in place for their child at the beginning of the school year. One family, in particular, experienced a difficult time; since their child uses ASL as a first language, they had a hard time ensuring that a qualified IRT was hired that could teach in ASL. Most of these families experienced no issues and had support from their families, the school, and the community. However, even the two or three families that experienced more stress and obstacles, in the end, adapted well and relied on each other and their circle-of-care members to help them through the rough patches they encountered.

I initially sought to have four families, which would be four cases. I was hoping to have two families from rural areas and two from urban areas. However, due to the global pandemic, I initially struggled with recruitment and finding enough families willing to participate in my study. In addition, each family I had recruited was only able to get two circle-of-care members to participate, so each case was composed of three interviews. Therefore, I edited my research poster to include a picture, more colour, fewer words, and less medical terminology, hoping that it would help recruit more families. With this revised approach, I successfully recruited eight families; each family/case was three interviews, except for one family/case, which was unique because it was one interview with both parents that was close to three hours in length.

My inclusion criteria included that the family must have a child who was (a) born preterm (born between 24–37 weeks gestation); (b) who was currently experiencing one or more health challenges, including hearing and visual impairments, mobility concerns, language, and/or cognitive disability, neurologic concerns (e.g., CP), psychiatric/behavioural concerns (e.g., ASD, ADHD, anxiety), diabetes, and/or asthma; (c) in kindergarten or grades one to six; and (d) currently enrolled in public school. Additionally, the family had to be (e) willing to take part in interviews and a home visit, (f) able to recruit other members of their child's circle of care that could be interviewed by me (snowball sampling), (g) living in Newfoundland and Labrador, and (h) able to speak and understand English. If parents were unwilling to recruit members of their child's circle of care, they were excluded from the study. All participants were volunteers; there was no remuneration for participation. With this criterion, I recruited eight families: four lived in urban areas of the province of NL, while the other four lived in rural areas of the province. In all eight cases, the mother was interviewed; in four cases, the father was also interviewed. In one case, both parents were interviewed together, but all others were separate interviews.

6.1 Recommendations

My research study highlighted the many challenges faced by the families included in this study; I will now present my recommendations, which will focus on my research question and objectives. The first set of recommendations supports the transition from home to school, and the second would be helpful to all families with children who were born preterm and have health challenges. With each recommendation, I will highlight which organization this recommendation should be directed to so that they can work on ensuring that all proposals are taken into consideration and/or are acted upon.

6.1.1 Recommendations that Support the Transition from Home to School

Recommendation One: Provide all parents with an information booklet with all relevant policies/procedures/handbooks related to their child's health condition when they register for KinderStart. The booklet should also include how often meetings with school officials will be.

Few parents were aware of the policies, procedures, and handbooks available online regarding different health challenges, accommodations regarding inclusive education, and medication administration at school. Parents who were aware had insider knowledge (i.e., either they were a teacher or someone in their family was) and were aware of these resources and knew where to find them. Giving all parents information regarding policies, procedures, and handbooks available regarding health challenges, accommodations, and medication administration at school will ensure that they are informed on what the school system can offer their child. The parents can then review this information privately, so they have time to process it and formulate any questions they may want to pose to educational leaders.

In addition, families gave different time frames for meetings with the school, and most had to take the initiative themselves to request these meetings. If a minimum number of meetings at certain times of the school year were a standard protocol, nothing would be missed. Parents and/or school officials can always request more meetings to discuss the child's progress. The responsibility to set up a meeting to get an update on how a child is doing in school should not be left to the parents: the school should take the lead, as some parents stated they did not want to bother the teacher because they know they are busy.

This recommendation is directed toward the Department of Education to ensure that they have hard copies of policies, procedures, and handbooks available at all KinderStart sessions for parents to review and take a copy of if they need one. In addition, an email should be sent to all parents informing them of all policies, procedures, and handbooks available regarding their child's education, including a link to those resources. This information could be added to the email sent to all parents once they register their child for school. In addition, I could add the link to these resources to the Facebook group for NL parents with preterm children. The department should also ensure that meetings regarding accommodations and exceptionalities are streamlined so that every family affected by this can avail of a meeting at certain times throughout the school year.

Recommendation Two: Set up a website (through the Department of Education or Department of Health and Community Services) with a list of available resources and services in all health districts for children with different health conditions.

During the interview, several parents stated they were unaware of different resources or services that could help their children with their health challenges. Many found out about these resources and services by word of mouth. The government should create an up-to-date website with tabs for each health district and, once under that tab, selections for different health challenges (e.g., ASD or a SLD) and, under that, a list of resources available in the different communities within that health district. Resources and service information could be listed along with contact information and information regarding any costs. This site can be given to parents upon discharge from the NICU and advertised in the province so people will be aware of the service. To help alleviate costs of the website design and upkeep, maybe listed service providers (e.g., tutoring places, private psychologists) could pay a small fee to have their information listed, and/or the Janeway Foundation could fundraise for money needed for this vital service. By having the website through the Department of Education or Health, it would be easy to find and can be maintained by the department. In addition, this website should be available (and advertised) to all parents as children not born preterm may also avail of the services listed.

Another part of this website could be a list of self-help or other support groups already established throughout the province. Contact information could be listed so parents interested in joining could have a point of contact. During the interview stage of this project, many families stated that having support from other families experiencing the same or similar things was very helpful, and one mother took the initiative to set up a support group on her own.

This recommendation is directed at the Departments of Education and Health. As stated earlier, it would be easier for a government department to maintain a website like this and add and remove information as needed.

Recommendation Three: Schools, including teachers, instructional resource teachers, and teacher assistants, need professional learning on the consequences of preterm birth and what to look out for. In addition, they should be updated on the resources and services available to help these children in their community.

I had the pleasure of interviewing a few teacher participants, but none had received any formal education regarding preterm birth, the consequences, and what to look for (e.g., difficulty with math). Professional learning in this area can help teachers identify who was born preterm in their class so they could be looking for known problems like math and reading issues, which could be identified early. Therefore, help could be offered earlier, leading to less anxiety and stress and better school performance. Johnson et al., (2015) found that education professionals do not have knowledge regarding the impact that preterm birth has on a child’s learning and development. They also found that these professionals feel that they are not equipped to support these children in school (Johnson et al., 2015). Therefore, training (professional learning) about preterm birth is crucial in preparing education professionals to support children born preterm in school (Johnson et al., 2015).

However, responsive teaching and learning does not demand a diagnosis or identification of an impairment prior to service provision. I am hopeful that responsive teaching and learning, which is newly implemented by the Department of Education, will help all children, regardless of their health history meet their education milestones.

Knowing what resources and services are also available in the community will allow the teacher to mention this to the parents and provide the family with more support.

This recommendation is directed toward the School Board as they decide what professional development sessions teachers must take in this province.

Recommendation Four: All schools in NL should offer sensory music and gym classes.

Parents who have children attending newer schools stated that their school offered sensory music and gym. In NL, we offer an inclusive school environment; therefore, these options should be made available to all students in public schools in the province, regardless of the age of the school building. In addition, for children with ASD or sensory issues, sensory gym and music may be more enjoyable instead of having to deal with loud noises, which may be overstimulating for some children. Qualified teachers need to be hired and time for sensory music and gym needs to be made available in the current curriculum guides.

This recommendation is directed toward the Department of Education and the school board to ensure that all schools offer the same programs so that all children in the province have the same opportunities.

Recommendation Five: An American Sign Language (ASL) Curriculum Guide must be implemented.

I had the pleasure to interview two families who have children who are legally deaf. One child's primary language is ASL; however, on the school boards and Department of Education's website, there is no curriculum guide for ASL. There are curriculum guides for English and French as a second language. For some deaf children, ASL is considered their primary language. In school, this is the only way they communicate; therefore, a curriculum guide is needed to ensure all educational standards are being met, just like with English and French as a second language. Lastly, this provision will help children with their primary language as ASL transition to school and help them understand their teachers. While the current English and French curriculum guides could be updated to include specific information on language acquisitions and learning approaches for children with a hearing impairment, this will ensure these guides are inclusive. However, the concern with this is that ASL would not get the recognition it deserves as a primary language. It should be treated the same as other languages (English and French) and given its own curriculum guide.

This recommendation is directed toward the Department of Education and the school board, who are responsible for curriculum development.

6.1.2 General Recommendations

Recommendation One: Standardized information should be given to parents expecting to have a preterm birth; this should be in person and in writing.

Parents stated in their interviews that receiving the information that their child would be born preterm, what this could mean for the baby, and what decisions the parents had to make regarding what they would like the medical team to do was very stressful. This information can be a lot of information to give to people at a very stressful time, and parents may not remember everything said. While the NICU team must continue to meet with these families in person to discuss this vital information and answer questions, it would also be helpful to have some standardized information written on sheets per gestational age (e.g., have an information sheet done up for 24-week gestation infants, with treatments that are common at this age, what to expect, and essential things to consider). Parents who will be facing a preterm birth ideally should have several meetings with health care professionals to share information and decide upon a plan of care (Lemyre & Moore, 2017). Lemyre & Moore (2017) recommended that parents need to receive individualized, accurate information about their infant's survival and outcomes, and that providing information to parents in a written format improves parental understanding and recall, parent information handouts can help to facilitate parental involvement and understanding (Lemyre & Moore, 2017).

This recommendation is directed toward the Janeway Children's Hospital and Rehabilitation Centre, specifically the NICU. The NICU team is trained in caring for preterm births of all gestations from 24 to 37 weeks and should ensure that whoever is meeting with these parents has sufficient knowledge to discuss the care of the infant with the family and knows how to communicate well with upset and stressed parents.

Recommendation Two: For follow-up appointments at the children's hospital, all appointments should be clustered and appointment email reminders be sent to parents.

Parents stated in their interviews that they may have numerous appointments at the hospital in one week, all on different days, and that this is frustrating, as some parents need to take off multiple workdays to attend all appointments, which is very time-consuming. For families who do not live close to the hospital, attending these appointments also may mean having a travel day; some must travel the day before and stay overnight. Therefore, clustering the appointments so they all happen on one day would be beneficial to the parents and for parents who have long travel times. Ensuring they are notified at a minimum of 36 hours in advance of cancellations is crucial, so they do not spend time travelling and money on accommodations. In addition, for other parents who need to travel a long distance but plan to return home the same day, scheduling an appointment later in the morning or the early afternoon is ideal, so there is enough time to travel.

Parents found it hard to keep track of all their child’s follow-up appointments. A computer system that automatically sends out an email reminder, text message, or phone call to parents reminding them of their appointment date, time, and location (within the hospital) along with the specialist’s name and specialty will help ensure that parents remember the appointment time. This reminder system can hopefully help reduce the number of people not showing up to their scheduled appointments and, therefore, reduce the cost to the healthcare system and wait times for specialists. This issue has been in the news in Newfoundland as a continued issue in Eastern Health (CBC News, NL, 2019). Lastly, it would be beneficial if appointments could be made after school hours (and convenient for the family) so that school-age children do not miss school. Opon et al., (2020) found that patient reminders of appointments reduce missed appointment rates and improve clinic attendance rates and that the use of electronic notifications were more effective that phone call reminders.

This recommendation is directed toward the Janeway Children’s Hospital and Rehabilitation Centre, as their personnel are the ones who book and handle all the child’s appointments. A computer system is already in place; therefore, it should not be hard to ensure that an email reminder or text message or phone call is sent to parents regarding their appointment (also verifying the location of the appointment, who it is with, and their specialty). The program should be updated to show all of one child's appointments so that the person entering the appointments can cluster them when possible.

Recommendation Three: All policies, procedures, and handbooks on the government and school board's websites should include a statement of when they were last updated and when the next update is planned.

When completing my document analysis, I was shocked that some of the documents have not been revised in over eight years (e.g., the *Safe and Caring Schools' Policy* and the *Alternate Transportation Policy*). The *Handbook for Teachers Serving Students Who Are Deaf-Blind, Deaf or Hard of Hearing with Additional Disabilities, and Blind or Visually Impaired with Additional Disabilities* was written in 2003, and many things have changed with their education since then, including the closing of the Newfoundland School for the Deaf in 2010 (Government of Newfoundland and Labrador, 2010). All policies and procedures should state on the document when they were last reviewed and when they are up for the following review to aid in transparency and ensure that these critical documents are reviewed and updated as needed.

Many services and practices have changed in the education system in the last ten years, including the closing of the school for the deaf, inclusive classrooms, and now COVID-19 protocols that impact how things are done in schools. Therefore, this review process is needed. In addition, all relevant policies and procedures should be placed on the government and school boards' websites in an easy place to find so that the public has access to them; this is important in a public school system.

This recommendation is directed toward the Department of Education and the school board as they are the ones that review their policies and procedures and should make these necessary changes.

Recommendation Four: More funding should be made available to help cover the costs of having a child born preterm with several health challenges.

Most parents interviewed discussed the added costs they had to cover related to their child's health condition, the long wait to get reimbursed from the province or their insurance company, and the complicated paperwork for them to fill in to receive compensation. As a province, if we are dedicated to helping preterm babies survive, we are obligated to support them as they navigate their health challenges and determine what supports are necessary for their health, quality of life, and education. More funding needs to be made available and should not be limited to low-income families. Families with two working parents are also struggling with this financial strain and time away from work, which was evident when I interviewed one family in particular. Help with travel costs should also be covered, especially for families who need to travel from Labrador and those who need to visit children's hospitals outside of this province. In addition, there should be support people available to help guide these families on how to complete any paperwork necessary for financial compensation.

This recommendation is directed toward the Department of Health and Community Services and the Department of Finance. These departments oversee healthcare funding in this province and should ensure that families who need help accessing healthcare both in and out of the province have the support they need, including financial support. In addition, part of the budget should be set aside to help care for children with complex needs, and this should include a navigator to help these families become aware of the financial resources available to them and to help them complete the correct required forms.

Recommendation Five: Communities must ensure they have more accessible services, including sensory times, Caroline's Carts, and wheelchair ramps.

Communities must ensure all community members can attend all events and businesses regardless of their health challenges. Sensory times should be mandated for essential businesses like grocery stores, post offices, and drug stores so parents can bring their children with ASD or other medical conditions requiring a quiet environment. During the interviews, one family stated that when the father is working, the mother cannot even pick up a prescription without having someone available to watch her child with ASD because the drug store is too stimulating. Caroline's Carts should be mandatory at all essential services like grocery and department stores so that families can easily access them, allowing them to shop with comfort and less stress. All businesses should ensure that they are accessible to people who are in wheelchairs, and this includes having wheelchair ramps and self-opening doors.

Community events like Santa Claus parades, pumpkin walks, and Canada Day events should have sensory times or zones so all members of the community can attend as a family. In addition, playgrounds should be fenced so that children cannot run away from the playground area and possibly get hurt.

This recommendation is directed toward the Department of Health and Community Services, as their role involves working in partnership with communities, community organizations, consumers, and other government departments.

6.2 Areas for Further Research

After completing this study and reviewing the results, other areas of future research became apparent. For example, this study should be expanded to include more families in Labrador (especially remote areas) and remote Newfoundland to see if they experience the same things as the families in this study or if there are differences due to the conditions of where they live. A study that involves Indigenous families throughout the province would also be beneficial to see if they have the same access to support and resources as other families and if they experience any discrimination related to their heritage, as has been stated in some studies (Gone et al., 2019; Loppie et al., 2014).

A study looking at how extended stays and having a very sick child affects parental health and relationships is also essential as it was mentioned in this study that many relationships with these stressors do not last, and parents experience significant stress, anxiety, and possibly post-traumatic stress responses after a long NICU stay. In addition, a study looking at just the supports and/or resources that families with a health challenge (not limited to prematurity) use would be interesting. Many other resources and supports may be being utilized by other families, and this information would be helpful for all families who have a child with a health challenge.

A study examining how preterm children with health challenges adapt to private school would be beneficial. It would be interesting to see if these families experience the same benefits and drawbacks as families who send their children to public school. However, a limitation might be recruiting enough families that choose private schools over public schools. In addition, if these parents can afford private school, they may be able to afford other services and resources for their child that other families may not have the privilege to provide.

Lastly, creating an information booklet with all relevant policies, procedure, and handbooks related to a child's health condition and what parents will need to know once their child starts school and setting up a website with a list of all available resources and services available in all health districts for children with different health concerns would be a great project to collaborate on and one I am very interested in pursuing once my Ph.D. is complete.

6.3 Contributions to the Field

This research project has brought a lot of new knowledge to the field of pediatric research and especially the field of neonatal research. First, this study is Canadian and focused on Newfoundland and Labrador families, which has not been done before. My study is also the first to look at parental experiences and circle-of-care members' experiences, which is essential to highlight since caring for a child with health challenges is difficult; as the old saying says, it takes a village to raise a child, so imagine what it takes to raise a child with health challenges. This study also looked at the differences and similarities between families living in rural and urban areas, another first in this field. This study found that many families learn about resources and services to help their children through word of mouth. Healthcare providers and schools must be aware of this so that more families can avail themselves of these resources and services. Therefore, a website with all this information for our province is recommended. Another new piece of information this study adds to the literature is the power of insider knowledge. Insiders are aware of policies and procedures, and that helps them navigate the system with ease and less stress and anxiety. Therefore, I recommend that, when they register for KinderStart, all parents be provided with an information booklet with all relevant policies, procedures, and handbooks related to their child's health condition so that all parents can navigate the educational system with more ease and feel empowered. Lastly, this study adds the power of resilience to the field.

This study reports on how many parents and circle-of-care members report how resilient these children are, and even after all they go through, including numerous medical procedures, many painful, they still smile and love life. These children look at the positives that life gives them, do not deal with the harmful and painful parts, and look forward to the future. These children are courageous role models for other members of the community, and to some in their communities, they are called superheroes.

6.4 Personal Reflections

I started my Ph.D. journey as a former NICU nurse, wondering whatever happened to the children I cared for in the NICU, in the PICU, and on the medical unit. I wondered how they made out in school and how their families were. Through this journey, I was delighted to learn how well most of these families are doing. While it is not always easy for them, and some days are hard and filled with emotion and stress, they are making it and adapting. Learning this made my heart happy. When parents spoke so positively about the role of the NICU nurse and how much support they had received from the NICU staff, I was once again happy and proud to be a NICU nurse, and I even cried happy tears after some interviews. As a nurse, there are many hard days and days you wonder why you chose to nurse, why you chose the NICU and trying to save these tiny babies but hearing all the positive memories from the families makes it all worthwhile. I plan to visit the NICU and share some of the positive memories these families shared with me.

I also think back to how hard it was to recruit families during the beginning of the global pandemic and how thankful I am for the families who volunteered to speak with me and share their experiences. It was clear from their interviews how busy they are. I am beyond thankful they gave me an hour or so of their time.

I was so happy to hear about communities banding together to raise money for some of these families and about communities having sensory spaces at events. However, we as a province can do better. These families should not have to worry about finances when they must focus on their children and health. Families should also be able to attend community events as a complete family, and the government should mandate sensory spaces at events and sensory hours for shopping.

Lastly, as I reflect on this project, I am forever grateful that, as a nurse, I was able to work with families of preterm infants in several stages of their children's lives, and I feel privileged that I played a small role in helping these families through their long journey. I also feel privileged that the participants in this study trusted me and shared with me their stories. Some participants found it difficult to relive some of the past events during the interview, especially when their child was struggling while they were in the NICU. It was painful and emotional; despite the tears, they continued to tell me their story, and I am grateful for that.

6.5 Summary of Dissertation

In Chapter One, I introduced my understanding of the complexity of preterm birth, the factors that surround why health challenges happen with this population, and the consequences of these challenges on their education. This research study reaffirmed the complexity of preterm birth and the many health challenges of being born too soon. In addition, this chapter identified the purpose of this study, my research question, research objectives, and the impact of the global pandemic on this study.

Chapter Two outlined what was already known in the literature and how I completed my literature search. This chapter included information on preterm birth in general (including the prevalence), the consequences of preterm birth, a section on why preterm birth numbers are rising, the cost of preterm birth, parental experience in the NICU and at home, and experiences with starting school, including sections on cognition and language, motor/neurologic outcomes, behaviour and mental health outcomes, lack of sleep and academic achievement, and noncommunicable disease and school performance. Lastly, I discussed resource allocation in health care and education. Then I stated the significance of this study.

In Chapter Three, I described my theoretical perspective and methodology and how these fit with my research question and design. I then discussed my recruitment strategies and my data collection and analysis methods, including interviews, demographic information, direct observation, and document analysis. Lastly, I discussed trustworthiness, ethics clearance for this study, and dissemination of this study's results.

In Chapter Four, I discussed my results from the demographic questionnaire the parents filled in. I also outlined a day in the life of one of my families by reviewing my home visit and what I discovered and felt during the visit. I then discussed the themes that I found from my analysis from my interviews, which all related to transitions, the transition from expecting a healthy baby/child to having a preterm baby with health challenges, the transition from the NICU to home, and the transition from home to starting school. Lastly, I discussed the analysis of documents I completed and why I chose the documents I included.

In Chapter Five, I reviewed the main results from my data analysis and compared them to the current literature available. I highlighted that my research results aligned with published research and emphasized the new knowledge my research study discovered.

Lastly, in this concluding chapter, I highlighted my recommendations that came from this research study and gave a summary of this dissertation.

References

Adama, E. A., Bayes, S., & Sundin, D. (2016). Parents' experiences of caring for preterm infants after discharge from neonatal intensive care unit: A meta-synthesis of the literature. *Journal of Neonatal Nursing*, *22*(1), 27-51.

Agrawal, S., Rao, S. C., Bulsara, M. K., & Patole, S. K. (2018). Prevalence of autism spectrum disorder in preterm infants: a meta-analysis. *Pediatrics*, *142*(3), e20180134.

Agarwal, P. K., Zheng, Q., Yang, P. H., Shi, L., Rajadurai, V. S., Khoo, P. C., Quek, B. H., & Daniel, L. M. (2021). Academic school readiness in children born very preterm and associated risk factors. *Early Human Development*, *155*, 105325–105325. https://doi.org/10.1016/j.earlhumdev.2021.105325

Air Canada Foundation. (2018). *Hospital transportation program*. Air Canada Foundation. https://www.aircanada.com/en/about/community/foundation/htp.html

Akshoomoff, N., Joseph, R. M., Taylor, H. G., Allred, E. N., Heeren, T., O'Shea, T. M., & Kuban, K. C. (2017). Academic achievement deficits and their neuropsychological correlates in children born extremely preterm. *Journal of Developmental and Behavioral Pediatrics*, *38*(8), 627.

Algozzine, B., & Hancock, D. (2017). *Doing case study research: A practical guide for beginning researchers*. Teachers College Press.

Aloysius, A., Kharusi, M., Winter, R., Platonos, K., Banerjee, J., & Deierl, A. (2018). Support for families beyond discharge from the NICU. *Journal of Neonatal Nursing*, *24*(1), 55-60.

Altimier, L., & Phillips, R. M. (2013). The neonatal integrative developmental care model: Seven neuroprotective core measures for family-centred developmental care. *Newborn and Infant Nursing Reviews*, *13*(1), 9-22.

American College of Obstetricians and Gynecologists, & Committee on Obstetric Practice. (2017). Methods for estimating the due date. *Obstetrics and Gynecology*, *129*, 959-960

American Psychiatric Association. (2022). *Diagnostic and Statistical Manual of Mental Disorders, Firth Edition, Text Revision (DSM-5-TR).* American Psychiatric Association Publishing

Anderson, P., and Doyle, L. W. (2003). Neurobehavioral outcomes of school-age children born extremely low birth weight or very preterm in the 1990s. *Journal of the American Medical Association,* 289, 3264–3272. DOI: 10.1001/jama.289.24.3264

Arzani, A., Valizadeh, L., Zamanzadeh, V., & Mohammadi, E. (2015). Mothers' strategies in handling the prematurely born infant: a qualitative study. *Journal of Caring Sciences*, *4*(1), 13–24. https://doi.org/10.5681/jcs.2015.002

Ask, H., Gustavson, K., Ystrom, E., Havdahl, K. A., Tesli, M., Askeland, R. B., & Reichborn-Kjennerud, T. (2018). Association of gestational age at birth with symptoms of attention-deficit/hyperactivity disorder in children. *JAMA Pediatrics*, *172*(8), 749-756.

Axelsson, E. L., Williams, S. E., & Horst, J. S. (2016). The effect of sleep on children's word retention and generalization. *Frontiers in Psychology, 7*, 1192.

Aylward, P., G. (2014). Neurodevelopmental outcomes of infants born prematurely. *Journal of Developmental & Behavioral Pediatrics, 35*(6), 394-407. doi:10.1097/01.DBP.0000452240.39511.d4.

Baker, J. P. (2000). The incubator and the medical discovery of the premature infant. *Journal of Perinatology*, *20*(5), 321-328.

Barclay, L., Everitt, L., Rogan, F., Schmied, V., & Wyllie, A. (1997). Becoming a mother -an analysis of women's experience of early motherhood. *Journal of Advanced Nursing, 25*(4), 719-728. doi:10.1046/j.1365-2648.1997.t01-1-1997025719.x

Barre, N., Morgan, A., Doyle, L. W., & Anderson, P. J. (2011). Language abilities in children who were very preterm and/or very low birth weight: a meta-analysis. *The Journal of pediatrics*, *158*(5), 766-774.

Baumeister, A. L., Storch, E. A., Geffken, G. R. (2008). Peer victimization in children with learning disabilities. *Child and Adolescent Social Work Journal*, 25, 11–23. https://doi.org/10.1007/s10560-007-0109-6

Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The Qualitative Report, 13*(4), 544-559.

Beam, A. L., Fried, I., Palmer, N., Agniel, D., Brat, G., Fox, K., Kohane, I., Sinaiko, A., Zupancic, J.A.F., & Armstrong, J. (2020). Estimates of healthcare spending for preterm and low-birthweight infants in a commercially insured population: 2008–2016. *Journal of Perinatology*, 1-9.

Berger, R. (2015). Now I see it; now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research, 15*(2), 219–234. DOI:10.1177/1468794112468475

Bernard, H. R., Weisner, T., & Ryan, G. (1998). *Using methods in the field: a practical introduction and casebook*. Rowman Altamira.

Bernier, A., Beauchamp, M. H., Bouvette-Turcot, A., Carlson, S. M., & Carrier, J. (2013). Sleep and cognition in preschool years: specific links to executive functioning. *Child Development, 84*(5), 1542-1553. DOI:10.1111/cdev.12063

Bhutta, A., Cleves, M. A., Casey, P., Cradock, M., & Anand, K. (2002). In Bhutta A. (Ed.), *Cognitive and behavioral outcomes of school-aged children who were born preterm: A meta-analysis* doi:10.1001/jama.288.6.728

Blencowe, H., Cousens, S., Chou, D., Oestergaard, M., Say, L., Moller, A., Kinney, M., & Lawn, J. (2013). Born too soon: the global epidemiology of 15 million preterm births. *Reproductive Health* 10 (Suppl 1): S2. http://www.reproductive-health-journal.com/content/pdf/1742-4755-10-S1-S2.pdf

Blomqvist, Y., Thernström, Rubertsson, C., Kylberg, E., Jöreskog, K., & Nyqvist, K., Hedberg. (2012). Kangaroo mother care helps fathers of preterm infants gain confidence in the paternal role. *Journal of Advanced Nursing, 68*(9), 1988-1996. DOI:10.1111/j.1365-2648.2011.05886.x

Boardman, J. P., & Counsell, S. J. (2019). Invited Review: Factors associated with atypical brain development in preterm infants: insights from magnetic resonance imaging. *Neuropathology and applied neurobiology*, 46(5), 413-421.

Bonner, O., Beardsall, K., Crilly, N., & Lasenby, J. (2017). 'There were more wires than him': the potential for wireless patient monitoring in neonatal intensive care. *BMJ Innovations*, *3*(1), 12–18. https://doi.org/10.1136/bmjinnov-2016-000145

Bowen, G. A. (2009). Document analysis as a qualitative research method. *Qualitative Research Journal*, 9(2), 27-40. Doi:10.3316/QRJ0902027.

Braun, V., Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101. Doi:10.1191/1478088706qp063oa

Breneol S, Doucet S, McIsaac JL, Riveroll A, Cassidy C, Charlton P, McCulloch H, McKibbon S, Luke A, Splane J, Curran JA. Programmes to support transitions in community care for children with complex care needs: a scoping review. BMJ Open. 2022 Jul 8;12(7):e056799. doi: 10.1136/bmjopen-2021-056799. PMID: 35803631; PMCID: PMC9272111

Bry, A., Wigert, H. (2019). Psychosocial support for parents of extremely preterm infants in neonatal intensive care: a qualitative interview study. *BMC Psychology,* **7,** 76 (2019). https://doi.org/10.1186/s40359-019-0354-4

Brydges, C. R., Landes, J. K., Reid, C. L., Campbell, C., French, N., & Anderson, M. (2018). Cognitive outcomes in children and adolescents born very preterm: a meta‐analysis. *Developmental Medicine & Child Neurology*, *60*(5), 452-468.

Budin, P. (1907). *The nursling; the feeding and hygiene of premature and full-term infants*. Caxton.

Burkholder, E. O., & Peláez, M. (2000). A behavioral interpretation of Vygotsky's theory of thought, language, and culture. *Behavioral Development Bulletin*, *9*(1), 7.

Canadian Institute of Health Information. (2006). *Giving birth in Canada. The costs*. Canadian Institute of Health Information https://secure.cihi.ca/free_products/Costs_Report_06_Eng.pdf

Canadian Institute for Health Information. (2019). *Health spending*. Canadian Institute of Health Information https://www.cihi.ca/en/health-spending

Canadian Nurses Association (CNA). Social justice…a means to an end, an end in itself. 2nd ed. Author: Ottawa; 2010.

Canadian Paediatric Society. (2017. August 11). *Counselling and management for anticipated extremely preterm birth*. Canadian Paediatric Society. https://www.cps.ca/en/documents/position/management-anticipated-extremely-preterm-birth

Canadian Premature Babies Foundation. (2020). *Worldwide situation*. Canadian Premature Babies Foundation https://www.cpbf-fbpc.org/world-prematurity-day.

Carbasse, A., Kracher, S., Hausser, M., Langlet, C., Escande, B., Donato, L., Astruc, D., & Kuhn, P. (2013). Safety and effectiveness of skin-to-skin contact in the NICU to support neurodevelopment in vulnerable preterm infants. *Journal of Perinatal & Neonatal Nursing, 27*(3), 255-262. DOI:10.1097/J

Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. J. (2014). The use of triangulation in qualitative research. *Oncology Nursing Forum, 41*(5), 545

Casey, P. H., Whiteside-Mansell, L., Barrett, K., Bradley, R. H., & Gargus, R. (2006). Impact of prenatal and/or postnatal growth problems in low-birth-weight preterm infants on school-age outcomes: an 8-year longitudinal evaluation. *Pediatrics*, *118*(3), 1078-1086.

Carvalho, S. C., Facio, B. C., Souza, B. F. D., Abreu-D’Agostini, F. C. P. D., Leite, A. M., & Wernet, M. (2019). Maternal care in the preterm child’s family context: A comprehensive look towards the sibling. *Revista Brasileira de Enfermagem*, *72*, 50-57.

CBC News, NL. (2019). *Huge number of missed appointments comes at big cost, says Eastern Health.* CBC News, NL. https://www.cbc.ca/news/canada/newfoundland-labrador/hacking-health-missed-appointments-1.4987861

Centers for Disease Control and Prevention (CDC) (2021). *Developmental monitoring and screening*. Centers for Disease Control and Prevention. https://www.cdc.gov/ncbddd/childdevelopment/screening.html

Centers for Disease Control and Prevention (CDC). (2022). *Screening and diagnosis of autism spectrum disorder.* Centers for Disease Control and Prevention. https://www.cdc.gov/ncbddd/autism/screening.html#:~:text=ASD%20can%20sometimes%20be%20detected,they%20are%20adolescents%20or%20adults

Chakraborty, M., & Kotecha, S. (2013). Pulmonary surfactant in newborn infants and children. *Breathe, 9*(6), 476-488. DOI:10.1183/20734735.006513

Chang, H.H., Larson, J., Blencowe, H., Spong, C.Y., Howson, C.P., Cairns-Smith, S., Lackritz, E.M., Lee, S.k., Mason. M., DPhil. A.C., Walani, S., Simpson, J.L., Lawn, J.E. & Born too Soon Preterm Prevention Analysis Group. (2013). Preventing preterm births: analysis of trends and potential reductions with interventions in 39 countries with very high human development index. *The Lancet*, 381 (9862), 223–234. DOI:10.1016/S0140-6736(12)61856-X

Chatzitheochari, S., Parsons, S., & Platt, L. (2016). Doubly disadvantaged? Bullying experiences among disabled children and young people in England. *Sociology*, *50*(4), 695-713.

Chau, A. (2019). Ethical Decision Making. *MICH: The Student Journal of the Michener Institute of Education*, *1*(1).

Cheong, J. L., Burnett, A. C., Treyvaud, K., & Spittle, A. J. (2020). Early environment and long-term outcomes of preterm infants. *Journal of Neural Transmission*, *127*(1), 1-8.

Clasquin-Johnson, M. G., & Clasquin-Johnson, M. (2018). 'How deep are your pockets?'Autoethnographic reflections on the cost of raising a child with autism. *African Journal of Disability*, *7*(1), 1-8.

Connelly, L. M. (2016). Trustworthiness in qualitative research. *Medsurg Nursing*, *25*(6), 435.

Copper, R. L., Goldenberg, R. L., Davis, R. O., Cutter, G. R., DuBard, M. B., Corliss, D. K., & Andrews, J. B. (1990). Warning symptoms, uterine contractions, and cervical examination findings in women at risk of preterm delivery. *American Journal of Obstetrics and Gynecology, 162*(3), 748-754.

Coston, A., & Aune, C. (2019). Reducing noise in the neonatal intensive care unit. *Pediatrics, 144*, 1.

Creswell, J.W., & Poth, C.N. (2016). *Qualitative inquiry and research design: Choosing among five approaches.* Sage Publications.

Creswell, J.W. & Creswell, J.D. (2017). *Research design: Qualitative, quantitative, and mixed methods approaches* (Sage publications.

Cromby, J. (2004). Between constructionism and neuroscience: The societal co-constitution of embodied subjectivity. *Theory & Psychology, 14*(6), 797-821

Cypress, B. S. (2017). Rigor or reliability and validity in qualitative research: perspectives, strategies, reconceptualization, and recommendations. *Dimensions of Critical Care Nursing*, 36, 253–63. https://doi.org/10.1097/DCC.0000000000000253.

Daniels, N. (2001). Justice, health, and healthcare. *American Journal of Bioethics*, *1*(2), 2-16.

Danner-Bowman, K., & Cardin, A. D. (2015). Neuroprotective core measure 3: Positioning & handling — A look at preventing positional plagiocephaly. *Newborn and Infant Nursing Reviews, 15*(3), 111-113. doi:10.1053/j.nainr.2015.06.009

Davis, L., Mohay, H., & Edwards, H. (2003). Mothers' involvement in caring for their premature infants: An historical overview. *Journal of Advanced Nursing, 42*(6), 578-586. doi:10.1046/j.1365-2648.2003.02661.x

De Jesus-Rojas, W., Mosquera, R. A., Samuels, C., Eapen, J., Gonzales, T., Harris, T., McKay, S., Boricha, F., Pedroza, C., Aneji, C., Khan, A., Jon, C., McBeth, K., Stark, J., Yadav, A., & Tyson, J. E. (2018). The effect of comprehensive medical care on the long-term outcomes of children discharged from the NICU with a tracheostomy. *The Open Respiratory Medicine Journal*, *12*, 39–49. https://doi.org/10.2174/1874306401812010039

Denzin, N. K., & Lincoln, Y. S. (2011). *The Sage handbook of qualitative research*. Sage.

DeSantis, L., Ugarriza, D. (2000). The concept of theme as used in qualitative nursing research. *Western Journal of Nursing Research*, 22, 351–372. doi:10.1177/019394590002200308

Dictionary, M. W. (2002). Merriam-webster. *On-line at http://www. mw. com/home. htm*, *8*, 2.

Dionne, G., Touchette, E., Forget-Dubois, N., Petit, D., Tremblay, R. E., Montplaisir, J. Y., & Boivin, M. (2011). Associations between sleep-wake consolidation and language development in early childhood: A longitudinal twin study. *Sleep, 34*(8), 987. doi:10.5665/SLEEP.1148

Dodgson. (2019). Reflexivity in qualitative research. *Journal of Human Lactation*, *35*(2), 220–222. https://doi.org/10.1177/0890334419830990

Doron, H., Hen, M., & Sharabi-Nov, A. (2018). Relationship quality among chronically ill children and their parents. *Journal of Child and Family Studies*, *27*(12), 3866-3876.

Eastern Health. (2011). *Healthy Beginnings, supporting newborns, young children and their families. Program Manual.* Eastern Health.

Eastern Health. (2014). *About the perinatal program, Newfoundland Labrador.* Eastern Health http://www.easternhealth.ca/WebInWeb.aspx?d=3&id=1966&p=1965

Edley, N. (2001). Unravelling social constructionism. *Theory & Psychology, 11*(3), 433-441.

Einfeld, S. L., Ellis, L. A., Doran, C. M., Emerson, E., Horstead, S. K., Madden, R. H., & Tonge, B. J. (2010). Behavior problems increase costs of care of children with intellectual disabilities. *Journal of Mental Health Research in Intellectual Disabilities*, *3*(4), 202-209.

Eke, O. H., Chukwuma, G. E., Ebulum, G. C., & Onyenyirionwu, U. G. (2019). Family relationship and gender as correlates of post-traumatic growth among parents of neonatal death. *Journal of Women's Health and Development*, *2*(2), 29-36.

Feeley, N., Genest, C., Niela-Vilén, H., Charbonneau, L & Axelin, A. (2016).. Parents and nurses balancing parent-infant closeness and separation: a qualitative study of NICU nurses' perceptions. *BMC Pediatric*s, 16(1), 1-13. https://doi.org/10.1186/s12887-016-0663-1

Foland-Ross, L. C., Buckingam, B., Mauras, N., Arbelaez, A. M., Tamborlane, W. V., Tsalikian, E., Cato, A., Tong, G., Englert, K., Mazaika, P.K., Reiss, A. L. & Diabetes Research in Children Network (DirectNet) (2019). Executive task-based brain function in children with type 1 diabetes: An observational study. *PLoS Medicine*, *16*(12), e1002979.

Franz, A. P., Bolat, G. U., Bolat, H., Matijasevich, A., Santos, I. S., Silveira, R. C., Procianoy, R.S., Rohde, L.A., & Moreira-Maia, C. R. (2018). Attention-deficit/hyperactivity disorder and very preterm/very low birth weight: a meta-analysis. *Pediatrics*, *141*(1).

Frey, H., & Klebanoff, M. (2016). The epidemiology, etiology, and costs of preterm birth. *Seminars in Fetal and Neonatal Medicine, 21*(2), 68-73.

Gallacher, D. J., Hart, K., & Kotecha, S. (2016). Common respiratory conditions of the newborn. *Breathe (Sheffield, England)*, *12*(1), 30–42. https://doi.org/10.1183/20734735.000716

Gaudieri, P. A., Chen, R., Greer, T. F., & Holmes, C. S. (2008). Cognitive function in children with type 1 diabetes: A meta-analysis. *Diabetes Care, 31*(9), 1892. doi:10.2337/dc07-2132

Genereaux, D., Bansback, N., & Birch, P. (2016). Development and pilot testing of a tool to calculate parental and societal costs of raising a child with intellectual disability. *Journal of Intellectual and Developmental Disability*, *41*(1), 11-20.

Gergen, K. J. (1985). The social constructionist movement in modern psychology. *American Psychologist, 40*(3), 266.

Goldenberg, R. L., Culhane, J. F., Iams, J. D., & Romero, R. (2008). Epidemiology and causes of preterm birth. *The Lancet, 371*(9606), 75-84.

Gone, J. P., Hartmann, W. E., Pomerville, A., Wendt, D. C., Klem, S. H., & Burrage, R. L. (2019). The impact of historical trauma on health outcomes for indigenous populations in the USA and Canada: A systematic review. *American Psychologist*, *74*(1), 20.

Government of Newfoundland and Labrador, Department of Education. (no date). *Exceptionalities*. Government of Newfoundland and Labrador. https://www.gov.nl.ca/education/k12/studentsupportservices/exceptionalities/

Government of Newfoundland and Labrador. (2010). *News Releases. Newfoundland School for the Deaf to Close.* Government of Newfoundland and Labrador. https://www.releases.gov.nl.ca/releases/2010/edu/0802n10.htm

Government of Newfoundland and Labrador, Department of Education. (2011). *Service Delivery Model for Students with Exceptionalities. Professional Learning Package*. Government of Newfoundland and Labrador. https://www.gov.nl.ca/education/files/sdm_document.pdf

Government of Newfoundland and Labrador. (2015). *The standards of practice for instructional resource teachers*. Government of Newfoundland and Labrador. https://www.gov.nl.ca/education/files/k12_studentsupportservices_s_and_p_irt_standards.pdf

Government of Newfoundland and Labrador. (2018) (a). *Children, youth, and families act.* Government of Newfoundland and Labrador. https://www.assembly.nl.ca/Legislation/sr/statutes/c12-3.htm

Government of Newfoundland and Labrador. (2018) (b). *Inclusive schools*. Retrieved from Government of Newfoundland and Labrador https://www.ed.gov.nl.ca/edu/k12/inclusion.html. doi:10.1542/peds.2012-3892

Government of Newfoundland and Labrador. (2018) (c). *Health and community services*. Government of Newfoundland and Labrador. https://www.health.gov.nl.ca/health/grantsfunding/bursaries.html

Government of Newfoundland and Labrador. (2018) (d). *Building Accessibility Act*. Government of Newfoundland and Labrador. https://www.assembly.nl.ca/legislation/sr/regulations/rc961140.htm

Government of Newfoundland and Labrador (2019). *KinderStart/Bon depart.* Government of Newfoundland and Labrador. https://www.gov.nl.ca/education/earlychildhood/kinderstart/

Government of Newfoundland and Labrador (2020) (a). *N.L. life with COVID-19*. Government of Newfoundland and Labrador. https://www.gov.nl.ca/covid-19/

Government of Newfoundland and Labrador (2020) (b). *N.L. life with COVID-19, a foundation for living with COVID-19*. Government of Newfoundland and Labrador. https://www.gov.nl.ca/covid-19/files/A-Foundation-for-Living-with-COVID-19.pdf

Government of Newfoundland and Labrador. (2021) (a). *Student assistant*. Government of Newfoundland and Labrador. https://www.gov.nl.ca/education/k12/studentsupportservices/services/

Government of Newfoundland and Labrador (2021) (b). *Bill 38, AN ACT RESPECTING ACCESSIBILITY IN THE PROVINCE*. Government of Newfoundland and Labrador. https://www.assembly.nl.ca/HouseBusiness/Bills/ga50session1/bill2138.htm

Government of Newfoundland and Labrador. (2022) (a). *About this place. N.L. facts*. Government of Newfoundland and Labrador. N.L. Facts - Newfoundland and Labrador, Canada (newfoundlandlabrador.com)

Government of Newfoundland and Labrador. (2022) (b). *Population Projections — Demographic Overview*. Government of Newfoundland and Labrador. https://www.gov.nl.ca/fin/economics/pop-overview/https://www.gov.nl.ca/fin/economics/pop-overview/

Government of Newfoundland and Labrador, Department of Education. (2003). *Handbook for Teachers Serving Students who are Deafblind, Deaf or Hard of Hearing with Additional Disabilities, and Blind or Visually Impaired with Additional Disabilities*. Government of Newfoundland and Labrador. https://www.gov.nl.ca/education/files/k12_studentsupportservices_publications_teachin studentsblind.pdf

Government of Newfoundland and Labrador, Department of Education. (2008). *Programming for Individual Needs Alternate (Functional) Curriculum, Curriculum Guide*. Government of Newfoundland and Labrador. https://www.gov.nl.ca/education/files/k12_studentsupportservices_publications_functionalcurriculumguide.pdf

Government of Newfoundland and Labrador, Department of Education. (2014). *Inclusive Practices Guidelines: School Level.* Government of Newfoundland and Labrador. https://www.gov.nl.ca/education/files/k12_inclusive_practices_guidlines.pdf

Government of Newfoundland and Labrador, Department of Education. (2015). *Handbook for parents of children with exceptionalities*. Government of Newfoundland and Labrador. https://www.gov.nl.ca/education/files/k12_safeandcaring_handbook_parents_children_exceptionalities.pdf

Government of Newfoundland and Labrador, Department of Education. (2020). *Responsive Teaching and Learning Policy.* Government of Newfoundland and Labrador. https://www.gov.nl.ca/education/files/RTL-Policy.pdf

Government of Newfoundland and Labrador, Department of Education. (2021) (a). *English Program Curriculum Guides.* Government of Newfoundland and Labrador. https://www.gov.nl.ca/education/k12/curriculum/guides/

Government of Newfoundland and Labrador, Department of Education. (2021) (b). *French Immersion Curriculum Guides*. Government of Newfoundland and Labrador. https://www.gov.nl.ca/education/k12/french/immersion/curriculum/

Grandy, G. (2010). Instrumental case study. *Encyclopedia of case study research*, *1*, 473-475.

Graneheim, U. H, Lundman, B. (2004) Qualitative content analysis in nursing research: Concepts, procedures, and measures to achieve trustworthiness. *Nurse Education Today*, 24, 2, 105-112.

Hack, M., Taylor, H. G., Schluchter, M., Andreias, L., Drotar, D., and Klein, N. (2009). Behavioral outcomes of extremely low birth weight children at age 8 years. *Journal of Developmental and Behavioral Pediatrics,* 30, 122–130. DOI: 10.1097/DBP.0b013e31819e6a16

Haft, S. L., Greiner de Magalhães, C., & Hoeft, F. (2022). A systematic review of the consequences of stigma and stereotype threat for individuals with specific learning disabilities. *Journal of Learning Disabilities*, 00222194221087383.

Halliday, H. L. (2008). Surfactants: Past, present, and future. *Journal of Perinatology: Official Journal of the California Perinatal Association, 28 Suppl 1*, S47-56. doi:10.1038/jp.2008.50; 10.1038/jp.2008.50.

Harré, R. (2002). Public sources of the personal mind: Social constructionism in context. *Theory & Psychology, 12*(5), 611-623.

Hayry, M. (2002). Utilitarian Approaches to Justice in Healthcare. In Rhodes, M., P. Battin, A. Silvers (Eds), Medicine and social justice: essays on the distribution of health care (pp. 53-64). Oxford University Press.

Health Sciences Centre Winnipeg (no date). *HSC Archives/Museum*. Health Sciences Center Winnipeg. https://hscarchives.com/history-of-womens-and-maternal-health-at-hsc/neonatal-intensive-care/

Heidari, H., Hasanpour, M., & Fooladi, M. (2017). Stress management among parents of neonates hospitalized in NICU: A qualitative study. *Journal of Caring Sciences*, *6*(1), 29–38. https://doi.org/10.15171/jcs.2017.004

Henderson J, Carson C, Redshaw M. (2016). Impact of preterm birth on maternal well-being and women's perceptions of their baby: A population-based survey *BMJ Open*, 6:e012676. DOI: 10.1136/bmjopen-2016-012676

Hennessy, E. M., Bracewell, M. A., Wood, N., Wolke, D., Costeloe, K., Gibson, A., & Marlow, N. (2008). Respiratory health in preschool and school-age children following extremely preterm birth. *Archives of Disease in Childhood, 93*(12), 1037. doi:10.1136/adc.2008.140830

Henry, P. (2015). Rigor in qualitative research: Promoting quality in social science research. *Research Journal of Recent Sciences* ISSN, 2277, 2502

Hibberd, F. (2006). *Unfolding Social Constructionism.* Springer Science & Business Media.

Higgins, R. D. (2019). Oxygen saturation and retinopathy of prematurity. *Clinics Perinatology*, *46*(3), 593-599.

Holloway, I. (1997). *Basic concepts for qualitative research*. Wiley-Blackwell.

Howell, K. E. (2012). *An introduction to the philosophy of methodology*. Sage.

Huddy, C. L. J., Johnson, A., & Hope, P. L. (2001). Educational and behavioural problems in babies of 32- 35 weeks gestation. *Archives of Disease in Childhood, 85*(1), F23-F28.

Hwang, S. S., Barfield, W. D., Smith, R. A., Morrow, B., Shapiro-Mendoza, C., Prince, C. B., Smith, V.C. & Mccormick, M. C. (2013). Discharge timing, outpatient follow-up, and home care of late- preterm and early term infants. *Pediatrics, 132*(1), 101

Ionio, C., Colombo, C., Brazzoduro, V., Mascheroni, E., Confalonieri, E., Castoldi, F., & Lista, G. (2016). Mothers and fathers in NICU: The impact of preterm birth on parental distress. *Europe's Journal of Psychology*, *12*(4), 604–621. https://doi.org/10.5964/ejop.v12i4.1093

Irving. (2018). *Fuel the care*. Irving.
https://fuelthecare.ca/

Jansen, L., Peeters-Scholte, C., Wiggers-de Bruine, S., van den Berg-Huysmans, A., van Klink, J., van Steenis, A., Rijken, M., Vermeiren, R., & Steggerda, S. (2020). Classroom-evaluated school performance at nine years of age after very preterm birth. *Early Human Development*, *140*, 104834.

Janesick, V. J. (2007). Peer debriefing. *The Blackwell Encyclopedia of Sociology*.

Janeway Children's Hospital Foundation (2019). *About the Janeway Hospital*. Janeway Children's Hospital Foundation.
https://janewayfoundation.nf.ca/about-us/about-the-janeway-hospital/

Jefferies, A. L., & Canadian Paediatric Society, Fetus and Newborn Committee (2014). Going home: facilitating discharge of the preterm infant. *Paediatrics & Child Health*, *19*(1), 31–42.

Jin, J. H., Yoon, S. W., Song, J., Kim, S. W., & Chung, H. J. (2019). Long-term cognitive, executive, and behavioral outcomes of moderate and late preterm at school age. *Clinical and Experimental Pediatrics,* 63 (6), 219.

Johnson, A. N. (2008). Promoting maternal confidence in the NICU. *Journal of Pediatric Health Care*, *22*(4), 254-257.

Johnston, K. M., Gooch, K., Korol, E., Vo, P., Eyawo, O., Bradt, P., & Levy, A. (2014). The economic burden of prematurity in Canada. *BMC pediatrics*, *14*(1), 1-10.

Johnson, S., Gilmore, C., Gallimore, I., Jaekel, J., & Wolke, D. (2015). The long-term consequences of preterm birth: what do teachers know? *Developmental Medicine and Child Neurology*, *57*(6), 571–577. https://doi.org/10.1111/dmcn.12683

Joseph, R. (2016). New technology in the NICU: Challenges to parents and clinicians. *Neonatal Network, 35*(6), 367-372.

Kawulich, B. B. (2005, May). Participant observation as a data collection method. In *Forum qualitative sozialforschung/forum: Qualitative Social Research* (Vol. 6, No. 2).

Kelly, M. M. (2016). Educational implications of preterm birth: A national sample of 8-to 11-year-old children born prematurely and their full-term peers. *Journal of Pediatric Health Care*, *30*(5), 464-470.

King, N. (2004). Using templates in the thematic analysis of text. In Cassell, C., Symon, G. (Eds.), Essential guide to qualitative methods in organizational research (pp. 257–270). Sage.

Kohen, D. (2010). Asthma and school functioning. *Health Reports, 21*(4), 35-45. doi:10.3354/dao02054

Koinis-Mitchell, D., Kopel, S. J., Farrow, M. L., McQuaid, E. L., & Nassau, J. H. (2019). Asthma and academic performance in urban children. *Annals of Allergy, Asthma & Immunology*, *122*(5), 471-477.

Kuban, K. C., Joseph, R. M., O'Shea, T. M., Allred, E. N., Heeren, T., Douglass, L., Stafstrom, C.E., Jara, H., Frazier, J.A., Hirtz, D., & Leviton, A. (2016). Girls and boys born before 28 weeks gestation: risks of cognitive, behavioral, and neurologic outcomes at age 10 years. *The Journal of Pediatrics*, *173*, 69-75.

Kuo, D. Z., Lyle, R. E., Casey, P. H., & Stille, C. J. (2017). Care system redesign for preterm children after discharge from the NICU. *Pediatrics*, *139*(4).

Kvale, S and Brinkmann, S. (2009) *Interviews: Learning the Craft of Qualitative Research Interviewing.* Sage.

Kymre, I., G. (2014). NICU nurses' ambivalent attitudes in skin-to-skin care practice. *International Journal of Qualitative Studies on Health & Well-being,* 9, 1-8. doi:10.3402/qhw.v9.23297

Lahood, A., & Bryant, C. A. (2007). Outpatient care of the premature infant. *American Family Physician, 76*(8), 1159.

Lakshmanan, A., Agni, M., Lieu, T., Fleegler, E., Kipke, M., Friedlich, P. S., McCormick, M.C., & Belfort, M. B. (2017). The impact of preterm birth < 37 weeks on parents and families: A cross-sectional study in the 2 years after discharge from the neonatal intensive care unit. *Health and Quality of Life Outcomes, 15*(1) doi:10.1186/s12955-017-0602-3

Lakshmanan, A., Song, A.Y., Belfort, M.B., Yieh, L., Dukhovny, D., Friedlich, P.S. & Gong, C.L. (2021). The financial burden experienced by families of preterm infants after NICU discharge. *Journal of Perinatology* (2021). https://doi.org/10.1038/s41372-021-01213-4

Lam, J. C., Koriakin, T. A., Scharf, S. M., Mason, T. B., & Mahone, E. M. (2015). Does increased consolidated nighttime sleep facilitate attentional control? A pilot study of nap restriction in preschoolers. *Journal of Attention Disorders*, 1087054715569281.

Lassi, Z.S., Middleton, P.F., Crowther, C., Bhutta, Z.A. (2015). Interventions to improve neonatal health and later survival: an overview of systematic reviews. *EBioMedicine,* 2(8), 985–1000. doi:10.1016/j.ebiom.2015.05.023

Learning Diaabilities Association of Newfoundland and Labrador. (2019). *Programs and Services, Reading and Math Tutoring Programs.* Learning Diaabilities Association of Newfoundland and Labrador.
https://www.ldanl.ca/tutoring-2/

Lee, A. C., Blencowe, H., & Lawn, J. E. (2019) (a). Small babies, big numbers: Global estimates of preterm birth. *The Lancet Global Health*, *7*(1), e2-e3.

Lee, K., Vasileiou, K., & Barnett, J. (2019) (b). ‘Lonely within the mother’: An exploratory study of first-time mothers’ experiences of loneliness. *Journal of Health Psychology*, *24*(10), 1334-1344.

Leijon, I., Ingemansson, F., Nelson, N., Wadsby, M., & Samuelsson, S. (2016). Reading deficits in very low birthweight children are associated with vocabulary and attention issues at the age of seven. *Acta Paediatrica*, *105*(1), 60–68. https://doi.org/10.1111/apa.13094

Lemmen, D., Fristedt, P., & Lundqvist, A. (2013). Kangaroo care in a neonatal context: Parents' experiences of information and communication of nurse-parents. *Open Nursing Journal,* 7, 41-48. doi:10.2174/1874434601307010041

Lemyre, B. & Moore, G. (2017). *Canadian paediatric society position statement: Counselling and management for anticipated extremely preterm birth*. Canadian Paediatric Society.

https://www.cps.ca/en/documents/position/management-anticipated-extremely-preterm-birth.

Lemyre, B., & Moore, G. (2017). Counselling and management for anticipated extremely preterm birth. *Paediatrics & child health*, *22*(6), 334-341.

Lendrum, Barlow, A., & Humphrey, N. (2015). Developing positive school-home relationships through structured conversations with parents of learners with special educational needs and disabilities (SEND). *Journal of Research in Special Educational Needs*, *15*(2), 87–96. https://doi.org/10.1111/1471-3802.12023

Lewis, T. P., Andrews, K. G., Shenberger, E., Betancourt, T. S., Fink, G., Pereira, S., & McConnell, M. (2019). Caregiving can be costly: A qualitative study of barriers and facilitators to conducting kangaroo mother care in a U.S. tertiary hospital neonatal intensive care unit. *BMC Pregnancy and Childbirth*, *19*(1), 227.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Sage

Lincoln, Y. S., & Guba, E. G. (1988). *Criteria for Assessing Naturalistic Inquiries as Reports*.

Lipkin, P. H., Macias, M. M., Norwood, K. W., Brei, T. J., Davidson, L. F., Davis, B. E., Ellerbeck, K.A, Houtrow, A.J., Hyman, S.L., Kuo, D.Z., Niritz, G.H., Yin, L., Murphy, N.A., Levy, S.E., Weitzman, C.C, Bauer, N.S, Childrens Jr, D.O., Levine, J.M... & Voigt, R. G. (2020). Promoting optimal development: Identifying infants and young children with developmental disorders through developmental surveillance and screening. *Pediatrics*, *145*(1).

Loe, I., Heller, N., & Chatav, M. (2019). Behavior problems and executive function impairments in preterm compared to full-term preschoolers. *Early Human Development, 130*, 87-95.

Lomotey, A. Y., Bam, V., Diji, A. K. A., Asante, E., Asante, H. B., & Osei, J. (2020). Experiences of mothers with preterm babies at a mother and baby unit of a tertiary hospital: A descriptive phenomenological study. *Nursing Open*, *7*(1), 150-159.

Loppie, S., Reading, C., & de Leeuw, S. (2014). Indigenous Experiences with Racism and Its Impacts. *National Collaborating Centre for Indigenous Health: Prince Geoge, BC, Canada*.

Lub, V. (2015). Validity in qualitative evaluation: Linking purposes, paradigms, and perspectives. *International Journal of Qualitative Methods*, *14*(5), 1609406915621406

Ludington-Hoe, S. (2013). Kangaroo care as a neonatal therapy. *Newborn & Infant Nursing Reviews, 1*3(2), 73-75. doi:10.1053/j.nainr.2013.03.004

Luu, T. M., Lefebvre, F., Riley, P., & Infante-Rivard, C. (2010). Continuing utilization of specialized health services in extremely preterm infants. *Archives of Disease in Childhood. Fetal and Neonatal Edition, 95*(5), F320-5. doi:10.1136/adc.2009.173138 [doi]

Lyons, Thompson, S. A., & Timmons, V. (2016). “We are inclusive. We are a team. Let's just do it': commitment, collective efficacy, and agency in four inclusive schools. *International Journal of Inclusive Education*, *20*(8), 889–907. https://doi.org/10.1080/13603116.2015.1122841

Lyons, & Roulstone, S. (2017). Labels, identity, and narratives in children with primary speech and language impairments. *International Journal of Speech-Language Pathology*, *19*(5), 503–518. https://doi.org/10.1080/17549507.2016.1221455

Major, B., O’Brien, L. T. (2005). The social psychology of stigma. *Annual Review of Psychology*, 56, 393–421. https://doi.org/10.1146/annurev.psych.56.091103.070137

Maleki, M., Mardani, A., Mitra Chehrzad, M., Dianatinasab, M., & Vaismoradi, M. (2019). Social Skills in Children at Home and in Preschool. *Behavioral sciences (Basel, Switzerland)*, *9*(7), 74. https://doi.org/10.3390/bs9070074

Malouf, R., & Redshaw, M. (2017). Specialist antenatal clinics for women at high risk of preterm birth: a systematic review of qualitative and quantitative research. *BMC Pregnancy and Childbirth*, *17*(1), 51.

Manuck, T., Fry, R., & Mcfarlin, B. (2018). Quality improvement in perinatal medicine and translation of preterm birth research findings into clinical care. *Clinics in Perinatology, 45*(2), 155-163.

March of Dimes. (2010). *In the NICU – what is surfactant?* March of Dimes. https://www.marchofdimes.org/complications/common-conditions-treated-in-the-nicu.aspx

March of Dimes (2019, October). *Long-term health effects of premature birth*. March of Dimes. https://www.marchofdimes.org/complications/long-term-health-effects-of-premature-birth.aspx

Marsh, L. T. & Noguera, P. (2018). Beyond stigma and stereotypes: an ethnographic study on the effects of school-imposed labeling on black males in an urban charter school. *The Urban Review*, 50. 10.1007/s11256-017-0441-x.

Marthinsen, G. N., Helseth, S., & Fegran, L. (2018). Sleep and its relationship to health in parents of preterm infants: a scoping review. *BMC Pediatrics*, *18*(1), 352. https://doi.org/10.1186/s12887-018-1320-7.

Martin, D., Miller, A. P., Quesnel-Vallée, A., Caron, N. R., Vissandjée, B., & Marchildon, G. P. (2018). Canada's universal healthcare system: achieving its potential. *The Lancet*, *391*(10131), 1718-1735.

Masten A. S. (2001). Ordinary magic: resilience processes in development. *American Psychologist*, 56, 227 -238 .10.1037/0003-066X.56.3.227 11315249

Mauras, N., Mazaika, P., Buckingham, B., Weinzimer, S., White, N. H., Tsalikian, E., Hershey, T., Cato, A., Cheng., P., Kollman, C., Beck, R.W., Ruedy, K., Aye, T., Fox, L., Arbelaez, A.M., Wilson, D., Tansey, M., Tamborlane, W., Peng, D., . . . Reiss, A. L. (2015). Longitudinal assessment of neuroanatomical and cognitive differences in young children with type 1 diabetes: Association with hyperglycemia. *Diabetes, 64*(5), 1770. doi:10.2337/db14-1445.

Mauthner, N.S., & Doucet, A. (1998). Reflections on a voice-centred relational method of data analysis: Analyzing maternal and domestic voices. In J. Ribberns & R. Edwards (Eds.), Feminist dilemmas in qualitative research: Private lives and public texts (pp. 119- 144). Sage Publications

Maxwell, J. A. (2005). *Qualitative research design: An interactive approach*. Sage publications.

McBryde, M., Fitzallen, G. C., Liley, H. G., Taylor, H. G., & Bora, S. (2020). Academic outcomes of school-aged children born preterm: A systematic review and meta-analysis. *Journal of the American Medical Association, Network Open*, *3*(4), e202027-e202027.

McLeskey, J., Waldron, N., and Redd, L. (2014). A case study of a highly effective inclusive elementary school. *Journal of Special Education,* 48: 59–70. DOI: 10.1177/0022466912440455

Medina, I. M. F., Granero-Molina, J., Fernández-Sola, C., Hernández-Padilla, J. M., Ávila, M. C., & Rodríguez, María del Mar López. (2017). Bonding in neonatal intensive care units: experiences of extremely preterm infants' mothers. *Women and Birth,* 31 (4), 325-330.

Memorial University of Newfoundland (2020). *Statement on research at Memorial from Dr. Neil Bose, vice-president (research)- March 19, 2020*. Memorial University of Newfoundland. https://www.mun.ca/research/news.php?id=13153&type=news

Miles, M. S., & Holditch-Davis, D. (1997). Parenting the prematurely born child: Pathways of influence. *Seminars in Perinatology, 2*1(3), 254-266. doi:10.1016/S0146-0005(97)80067-5

Min, J. & Sylvestre, C. (no date). Guidelines on the number of embryos transferred. Canadian Fertility & Andrology Society. https://cfas.ca/_Library/clinical_practice_guidelines/CFAS_CPG_Embryo_Transfer_2013.pdf

Mitchell, A. J., Yates, C., Williams, K., & Hall, R. W. (2013). Effects of daily kangaroo care on cardiorespiratory parameters in preterm infants. *Journal of Neonatal-Perinatal Medicine, 6*(3), 243-249. doi:10.3233/NPM-1370513; 10.3233/NPM-1370513

Mitchell, J., Boettcher-Sheard, N., Duque, C., Lashewicz, B. (2018). Who do we think we are? Disrupting notions of quality in qualitative research. *Qualitative Health Research*, 28(4), 673–680. doi:10.1177/104973231774889.

Morisaki, Zhang, X., Ganchimeg, T., Vogel, J. P., Souza, J. P. D., Cecatti, J. G., Torloni, M. R., Ota, E., Mori, R., Mittal, S., Tough, S., Dolan, S., & Kramer, M. S. (2017). Provider-initiated delivery, late preterm birth and perinatal mortality: A secondary analysis of the WHO multicountry survey on maternal and newborn health. *BMJ Global Health*, *2*(2), e000204–e000204. https://doi.org/10.1136/bmjgh-2016-000204

Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International journal of qualitative methods*, *1*(2), 13-22.

Msall, M. E. (2012). Academic achievement after extreme prematurity: Optimizing outcomes for vulnerable children in times of uncertainty. *Acta Paediatrica.* 101, 1196–1197. DOI: 10.1111/apa.12038.

National Institute of Mental Health. (2018, March). *Autism Spectrum Disorder*. National Institute of Mental Health. https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd

Newfoundland & Labrador Medical Association. (2010). *Fact Sheet- primary care.* Newfoundland & Labrador Medical Association. http://www.nlma.nl.ca/documents/document_21.pdf

Newfoundland and Labrador Medical Association. (2019, April 23). *Doctors ask election candidates to endorse recommendations for improving access, innovation, and sustainability in the health care system.* Newfoundland & Labrador Medical Association. http://www.nlma.nl.ca/FileManager/News-Releases/docs/2019/2019.04.23-NLMA_recommendations_to_party_leaders.pdf

Newfoundland and Labrador Tourism (2020). Discover our natural landscape. Newfoundland and Labrador Tourism. https://www.newfoundlandlabrador.com/about-this-place/natural-landscape.

Newfoundland and Labrador English School District (NLESD). (2012). *Alternate Transportation Policy.* Newfoundland and Labrador English School District (NLESD). https://www.nlesd.ca/includes/files/policies/doc/1484678795422.pdf

Newfoundland and Labrador English School District (NLESD). (2013). *Safe and Caring Schools' Policy*. Newfoundland and Labrador English School District (NLESD). https://www.nlesd.ca/includes/files/policies/doc/1525099455040.pdf

Newfoundland and Labrador English School District (NLESD). (2014). *Guidelines for Diabetes Management in Schools*. Newfoundland and Labrador English School District (NLESD). https://www.nlesd.ca/includes/files/policies/doc/1504807743198.pdf

Newfoundland and Labrador English School District (NLESD). (2015). *Administration of Medicine, Medical Interventions and Chronic Care.* Newfoundland and Labrador English School District (NLESD). https://www.nlesd.ca/includes/files/policies/doc/1456153685750.pdf

Newfoundland and Labrador English School District (NLESD). (2019). Administration of Medicine, Medical Interventions and Chronic Care, Regulations. Newfoundland and Labrador English School District (NLESD). https://www.nlesd.ca/includes/files/policies/doc/1565872165703.pdf

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: striving to meet the trustworthiness criteria. *International Journal of qualitative methods*, *16*(1), 1609406917733847.

Nuccini, F., Paterlini, M., Gargano, G., & Landini, A. (2015). The attachment of prematurely born children at school age: A pilot study. *Clinical Child Psychology and Psychology*, 20(3), 381-394.

Nusinovici, S., Olliac, B., Flamant, C., Müller, J.-B., Olivier, M., Rouger, V., Gascoin, G., Basset, H., Bouvard, C., Rozé, J.-C., & Hanf, M. (2017). Impact of preterm birth on parental separation: A french population-based longitudinal study. *BMJ Open*, *7*(11), e017845–e017845. https://doi.org/10.1136/bmjopen-2017-017845

Odd, D., Evans, D., & Emond, A. (2016). Preterm birth, age at school entry and long-term educational achievement. *PLoS One, 11*(5), e0155157. doi:10.1371/journal.pone.0155157

O’Leary, Z. (2014). *The essential guide to doing research*. Sage.

Opon, S. O., Tenambergen, W. M., & Njoroge, K. M. (2020). The effect of patient reminders in reducing missed appointment in medical settings: a systematic review. PAMJ - One Health. 2020;2(9). 10.11604/pamj-oh.2020.2.9.21839

Owen, L., Manley, B., Davis, P., & Doyle, L. (2017). The evolution of modern respiratory care for preterm infants. *The Lancet, 389*(10079), 1649-1659.

Palumbi, R., Peschechera, A., Margari, M., Craig, F., Cristella, A., Petruzzelli, M. G., & Margari, L. (2018). Neurodevelopmental and emotional-behavioral outcomes in late-preterm infants: An observational descriptive case study. *BMC pediatrics*, *18*(1), 318.

Patton, M. (2002) *Qualitative Evaluation and Research.* (3rd edition). Sage Publications inc.

Pauly, B. (2010). Direct observation as evidence. *Encyclopedia of Case Study Research*, *2455*.

Perrone, S., Bracciali, C., Di Virgilio, N., & Buonocore, G. (2017). Oxygen use in neonatal care: a two-edged sword. *Frontiers in Pediatrics*, *4*, 143.

Perry, S. E., Hockenberry, M. J., Cashion, M. C., Alden, K. R., Olshansky, E., & Lowdermilk, D. L. (2022). *Maternal child nursing care-E-Book*. Elsevier Health Sciences.

Peterson, B. S., Vohr, B., Staib, L. H., Cannistraci, C. J., Dolberg, A., Schneider, K. C., Katz, K.H., Westerveld, M., Sparrow, S., Anderson, A.W., Duncan, C.C., Makuch, R.W., Gore, J.C., Ment, L.R. (2000). Regional brain volume abnormalities and long-term cognitive outcome in preterm infants. *Journal of the American Medical Association, 284* (15), 1939-1947.

Pineda, R., Durant, P., Mathur, A., Inder, T., Wallendorf, M., & Schlaggar, B. (2017). Auditory exposure in the neonatal intensive care unit: Room type and other predictors. *The Journal of Pediatrics, 183*(C), 56-66. e3.

Poehlmann-Tynan, Gerstein, E. D., Burnson, C., Weymouth, L., Bolt, D. M., Maleck, S., & Schwichtenberg, A. J. (2015). Risk and resilience in preterm children at age 6. *Development and Psychopathology*, *27*(3), 843–858. https://doi.org/10.1017/S095457941400087X

Powell, Traci L, Parker, Leslie, Dedrick, Cynthia F, Barrera, Christina M, Di Salvo, Dawn, Erdman, Felicia, Saunders, Mahala. (2012). Decisions and dilemmas related to resuscitation of infants born on the verge of viability. *Newborn and Infant Nursing Reviews, 12*(1), 27-32.

Prescott, S., & Hehman, M. C. (2017). Premature infant care in the early 20th century. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, *46*(4), 637-646.

Purdy, I. B., Craig, J. W., & Zeanah, P. (2015). NICU discharge planning and beyond: recommendations for parent psychosocial support. *Journal of Perinatology: Official Journal of the California Perinatal Association*, *35 Suppl 1*(Suppl 1), S24–S28. https://doi.org/10.1038/jp.2015.146

Purisch, S. E., & Gyamfi-Bannerman, C. (2017, November). Epidemiology of preterm birth. In *Seminars in Perinatology* (Vol. 41, No. 7, pp. 387-391). WB Saunders.

Quinn, J. A., Munoz, F. M., Gonik, B., Frau, L., Cutland, C., Mallett-Moore, T., Kissou, A., Wittke, F., Das, M., Nunes, T., Pye, S., Watson, W., Ramos, A. A., Cordero, J. F., Huang, W. T., Kochhar, S., Buttery, J., & Brighton Collaboration Preterm Birth Working Group (2016). Preterm birth: Case definition & guidelines for data collection, analysis, and presentation of immunization safety data. *Vaccine*, *34*(49), 6047–6056. https://doi.org/10.1016/j.vaccine.2016.03.045.

Ream, M. A, & Lehwald, L. (2018). Neurologic consequences of preterm birth. *Current Neurology and Neuroscience Reports, 18*(8), 1-10.

Reed, R.A., Morgan, A.S., Zeitlin, J., Jarreau, P.H., Torchin, H., Pierrat, V., Ancel, P.Y. & Khoshnood, B. (2019). Assessing the risk of early unplanned rehospitalization in preterm babies: EPIPAGE 2 study. *BMC Pediatrics,* 19**,** 451. https://doi.org/10.1186/s12887-019-1827-6.

Rees, S., & Inder, T. (2005). Fetal and neonatal origins of altered brain development. *Early Human Development, 81*(9), 753-761. doi:10.1016/j.earlhumdev.2005.07.004

Redwood. (2005). Colliding discourses: Deconstructing the process of seeking ethical approval for a participatory evaluation project. Journal of Research in Nursing, 10(2), 217–230. https://doi.org/10.1177/174498710501000201

Rios, Beltempo, M., Louis, D., Premji, S., Shah, V., Lee, S. K., Pechlivanoglou, P., Abenhaim, H., Afifi, J., Alvaro, R., Andrews, J., Armson, A., Aziz, K., Barrett, J., Berard, A., Bertelle, V., Bodani, J., Burrows, J., Butt, K., … Church, P. (2021). Costs of Neonatal Intensive Care for Canadian Infants with Preterm Birth. *The Journal of Pediatrics*, *229*, 161–167.e12. https://doi.org/10.1016/j.jpeds.2020.09.045

Rogers, E. E., & Hintz, S. R. (2016, December). Early neurodevelopmental outcomes of extremely preterm infants. *In Seminars in perinatology* (Vol. 40, No. 8, pp. 497-509). WB Saunders.

Román, R., Garrido, V., Novoa, V., Mundaca, G., Pichuante, E., Rivera, A., Torres, A., Fuentes, M., Fuentes, A., & Linares, J. (2017). Metabolic control and school performance in children with type 1 diabetes. *Revista Chilena de Pediatria*, *88*(5), 586-594.

Ronald McDonald House Charities (RMHC). (2018). *Ronald McDonald house charities Newfoundland and Labrador*. Ronald McDonald House Charities (RMHC). https://rmhcnl.ca/what-we-do/house-programs/.

Ruthven, I., Buchanan, S., & Jardine, C. (2018). Isolated, overwhelmed, and worried: Young first-time mothers asking for information and support online. *Journal of the Association for Information Science and Technology, 69*(9), 1073-1083.

Saigal, S., & Doyle, L. W. (2008). An overview of mortality and sequelae of preterm birth from infancy to adulthood. *The Lancet, 371*(9608), 261-269.

Sardesai, S., Biniwale, M., Wertheimer, F., Garingo, A., & Ramanathan, R. (2017). Evolution of surfactant therapy for respiratory distress syndrome: past, present, and future. *Pediatric Research*, *81*(1), 240-248.

Savage, J. (2000). One voice, different tunes: issues raised by dual analysis of a segment of qualitative data. *Journal of Advanced Nursing*, 31, 1493–1500. doi:10.1046/j.1365-2648.2000.01432.x

Schantz, Clémence, De Loenzien, Myriam, Goyet, Sophie, Ravit, Marion, Dancoisne, Aurélien, & Dumont, Alexandre. (2019). How is women's demand for caesarean section measured? A systematic literature review. *PloS One, 14*(3), E0213352.

Schecter, Pham, T., Hua, A., Spinazzola, R., Sonnenklar, J., Li, D., Papaioannou, H., & Milanaik, R. (2020). Prevalence and longevity of PTSD symptoms among parents of NICU infants analyzed across gestational age categories. *Clinical Pediatrics*, *59*(2), 163–169. https://doi.org/10.1177/0009922819892046

Schensul, S. L., Schensul, J. J. & LeCompte, M. D. (1999). *Essential ethnographic methods: observations, interviews, and questionnaires* (Vol. 2). Rowman Altamira.

Sealock, K., Seneviratne, C., Lilley, L. L., Collins, S. R., & Snyder, J. S. (2020). *Lilley's Pharmacology for Canadian Health Care Practice-E-Book*. Elsevier Health Sciences.

Seppänen, A.-V., Sauvegrain, P., Draper, E. S., Toome, L., El Rafei, R., Petrou, S., Barros, H., Zimmermann, L. J. I., Cuttini, M., & Zeitlin, J. (2021). Parents' ratings of post-discharge healthcare for their children born very preterm and their suggestions for improvement: A European cohort study. *Pediatric Research*, *89*(4), 1004–1012. https://doi.org/10.1038/s41390-020-01120-y

Shah, P. E., Kaciroti, N., Richards, B., & Lumeng, J. C. (2016). Gestational age and kindergarten school readiness in a national sample of preterm infants. *The Journal of Pediatrics*, *178*, 61-67.

Shah, P. S., McDonald, S. D., Barrett, J., Synnes, A., Robson, K., Foster, J., Pasquier, C., Piedboeuf, J.B., Lacaze-Masmonteil, T., O'Brien, K., Shivanada, S., Chaillet, N., Pechivanoglou, P. (2018). The Canadian Preterm Birth Network: a study protocol for improving outcomes for preterm infants and their families. *Canadian Medical Association Journal, open*, *6*(1), E44.

Shahat, A. R. S., & Greco, G. (2021). The economic costs of childhood disability: A literature review. *International Journal of environmental research and public health*, *18*(7), 3531.

Shifrer, D. (2013). Stigma of a label: educational expectations for high school students labeled with learning disabilities. *Journal of Health and Social Behavior*, 54(4), 462–480. https://doi.org/10.1177/0022146513503346

Shonkoff, J. P., Garner, A. S., Committee on Psychosocial Aspects of Child and Family Health, Committee on Early Childhood, Adoption, and Dependent Care, & Section on Developmental and Behavioral Pediatrics. (2012). The lifelong effects of early childhood adversity and toxic stress. *Pediatrics, 12*9(1), e232-46. doi:10.1542/peds.2011-2663 [doi]

Shorter, E. (2013). *Partnership for excellence: medicine at the University of Toronto and academic hospitals.* University of Toronto Press.

Smithson, Lisa, Baird, Tieghan, Tamana, Sukhpreet K, Lau, Amanda, Mariasine, Jennifer, Chikuma, Joyce, Mandhane, Piush J. (2018). Shorter sleep duration is associated with reduced cognitive development at two years of age. *Sleep Medicine, 48*, 131-139.

Solomons, N., & Rosant, C. (2012). Knowledge and attitudes of nursing staff and mothers towards kangaroo mother care in the eastern sub-district of Cape Town. *South African Journal of Clinical Nutrition, 25*(1), 33-39. http://search.ebscohost.com/login.aspx?direct=true&AuthType=ip,url,uid&db=rzh&AN=2011532268&site=ehost-live&scope=site.

Stake, R. E. (1995). *The art of case study research.* Sage.

Stake, R. E. (2005). *Qualitative Case Studies*. In N. K. Denzin & Y. S. Lincoln (Eds.), The Sage handbook of qualitative research (pp. 443-466). Sage Publications Ltd.

Statistics Canada. (2016). *Canadian community health survey*. Statistics Canada https://www150.statcan.gc.ca/n1/pub/82-625-x/2017001/article/54863-eng.htm

Statistics Canada. (2017). *Newfoundland and Labrador [Province] and Canada [Country] (table). Census Profile. 2016 Census*. Statistics Canada. https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/prof/index.cfm?Lang=E.

Statistics Canada. (2017). *Population Centre and Rural Area Classification 2016*. Statistics Canada. https://www.statcan.gc.ca/en/subjects/standard/pcrac/2016/introduction

Statistics Canada. (2018). *Births, 2015 and 2016*. Statistics Canada https://www150.statcan.gc.ca/n1/daily-quotidien/180430/dq180430f-eng.htm

Statistics Canada. (2022). *Infant deaths and mortality rates, by sex*. Statistics Canada https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1310071201

Stikes, R., & Barbier, D. (2013). Applying the plan-do-study-act model to increase the use of kangaroo care. *Journal of Nursing Management, 2*1(1), 70-78. doi:10.1111/jonm.12021

Stolt, S, Lind, A, Matomäki, J, Haataja, L, Lapinleimu, H, & Lehtonen, L. (2016). Do the early development of gestures and receptive and expressive language predict language skills at 5;0 in prematurely born, very-low-birth-weight children? *Journal of Communication Disorders, 61*, 16-28.

Squarza, C., Picciolini, O., Gardon, L., Ravasi, M., Giannì, M. L., Porro, M., & Mosca, F. (2017). Seven years cognitive functioning and early assessment in extremely low birth weight children. *Frontiers in Psychology*, *8*, 1257.

Sullivan-Pyke, C., Senapati, S., Mainigi, M., & Barnhart, K. (2017). In vitro fertilization and adverse obstetric and perinatal outcomes. *Seminars in Perinatology, 41*(6), 345-353.

Taras H, Potts-Datema W. (2005). Childhood asthma and student performance at school. *Journal of School Health*, 75(8), 296-312. DOI: 10.1111/j.1746-1561.2005.00041.x. PMID: 16179080.

Tonoli, C., Heyman, E., Roelands, B., Buyse, L., Piacentini, F., Berthoin, S., & Meeusen, R. (2015). BDNF, IGF-I, glucose and insulin during continuous and interval exercise in type 1 diabetes. *International Journal of Sports Medicine*, *36*(12), 955-959.

Toope, D. (2014). *Preemies, prenatal planning, and the colour purple. Eastern Health's Storyline*. Eastern Health. https://storyline.easternhealth.ca/2014/11/20/preemies-pre-natal-planning-and-the-colour-purple/

Treherne, S., Feeley, N., Charbonneau, L., & Axelin, A. (2017). Parents' perspectives of closeness and separation with their preterm infants in the NICU. *Journal of Obstetric, Gynecologic & Neonatal Nursing, 46*(5), 737-747.

Treyvaud, K. (2013). Parent and family outcomes following very preterm or very low birth weight birth: A review. *Seminars in Fetal & Neonatal Medicine*, *19*(2), 131–135. https://doi.org/10.1016/j.siny.2013.10.008

Treyvaud, K., Spittle, A., Anderson, P. J., & O'Brien, K. (2019). A multilayered approach is needed in the NICU to support parents after the preterm birth of their infant. *Early Human Development*, *139*, 104838.

Trumello, C., Candelori, C., Cofini, M., Cimino, S., Cerniglia, L., Paciello, M., & Babore, A. (2018). Mothers' depression, anxiety, and mental representations after preterm birth: A study during the infant's hospitalization in a neonatal intensive care unit. *Frontiers in Public Health*, *6*, 359.

Underwood, M., Danielsen, B., & Gilbert, W. (2007). Cost causes and rates of rehospitalization of preterm infants. *Journal of Perinatology, 27*(10), 614.

The University of Toronto. (2005). *Neonatology*. The University of Toronto. http://www.paeds.utoronto.ca/division/neon.htm

Valizdeh, L., Ajoodaniyan, H., Mamnabati, M., Zamenzdeh, V., Valizadeh, L., Ajoodaniyan, N., layeg, V. (2013). Nurses' viewpoint about the impact of kangaroo mother care on the mother-infant attachment. *Journal of Neonatal Nursing, 19*(1), 38-43.

Van Noort-van der Spek, Franken, M. C. J., & Weisglas-Kuperus, N. (2012). Language functions in preterm-born children: a systematic review and meta-analysis. *Pediatrics*, *129*(4), 745-754.

Vazquez, V., & Cong, X. (2014). Parenting the NICU infant: a meta-ethnographic synthesis. *International Journal of Nursing Sciences*, *1*(3), 281-290.

Venkataraman, R., Kamaluddeen, M., Amin, H., & Lodha, A. (2018). Is less noise, light, and parental/caregiver stress in the neonatal intensive care unit better for neonates? *Indian Pediatrics*, *55*(1), 17-21.

Vinall, J., Miller, S. P., Bjornson, B. H., Fitzpatrick, K. P. V., Poskitt, K. J., Brant, R., . . . Grunau, R. E. (2014). Invasive procedures in preterm children: Brain and cognitive development at school age. *Pediatrics, 133*(3), 412. doi:10.1542/peds.2013-1863

Vink, J., & Gyamfi-Bannerman, C. (2017). Current preterm birth prevention strategies. *Seminars in Perinatology, 41*(7), 385-386.

Walani, S. R. (2020). Global burden of preterm birth. *International Journal of Gynecology & Obstetrics*, *150*(1), 31-33.

Wang, K. K., & Barnard, A. (2004). Technology-dependent children and their families: A review. *Journal of Advanced Nursing, 45*(1), 36-46. doi:10.1046/j.1365-2648.2003.02858.x

Wanzl. (2020). *Caroline's Cart*. Wanzl. https://technibilt.com/carolines-cart/#:~:text=Caroline's%20Cart%20was%20created%20for,cart%20at%20the%20same%20time.

World Health Organization. (2012). Born too soon: the global action report on preterm birth.

Yin, R. K. (2003). *Case study research: Design and methods.* (Vol 5). Sage.

Zeleke, W.A., Hughes, T.L. & Drozda, N. (2019). Disparities in diagnosis and service access for minority children with ASD in the United States. *Journal of Autism and Developmental Disorders*, 49, 4320–4331

Appendix A: Ethics Approval Letter

NEWFOUNDLAND AND LABRADOR
HREB
HEALTH RESEARCH ETHICS BOARD

Research Ethics Office
Suite 200, Eastern Trust Building
95 Bonaventure Avenue St.
John's, NL
A1B 2X5

August 05, 2019

53 Dawsons Run
CBS, NL
A1W 3J4

Dear Lewis-Power:

Researcher Portal File # 20200473
Reference # 2019.136

RE: A qualitative exploration of how children born pre-term transition to primary school: four case studies

Your application was reviewed by a subcommittee under the direction of the HREB and the following decision was rendered:

X	Approval
	Approval subject to changes
	Rejection

Ethics approval is granted for one year effective August 2, 2019. This ethics approval will be reported to the board at the next scheduled HREB meeting.

This is to confirm that the HREB reviewed and approved or acknowledged the following documents (as indicated):

- Application, approved
- Research proposal, approved
- Research poster, approved
- Interview guide, Appendix B, approved
- Observation Guide, approved

- Parent consent revised, approved
- Facebook group: NL NICU parents approval to post my poster in the group, acknowledged
- Family profile, Appendix C, approved

Please note the following:

- This ethics approval will lapse on August 2, 2020. It is your responsibility to ensure that the Ethics Renewal form is submitted prior to the renewal date.
- This is your ethics approval only. Organizational approval may also be required. It is your responsibility to seek the necessary organizational approvals.
- Modifications of the study are not permitted without prior approval from the HREB. Request for modification to the study must be outlined on the relevant Event Form available on the Researcher Portal website.
- Though this research has received HREB approval, you are responsible for the ethical conduct of this research.
- If you have any questions please contact info@hrea.ca or 709 777 6974.

The HREB operates according to the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2), ICH Guidance E6: Good Clinical Practice Guidelines (GCP), the Health Research Ethics Authority Act (HREA Act) and applicable laws and regulations.

We wish you every success with your study.

Sincerely,

Dr Joy Maddigan, Co-Chair, Non-
clincial trials
Health Research Ethics Board

You Have Received Ethics Approval, Now What?: HREB Reporting Requirements

Once a study has received ethics approval from the Health Research Ethics Board (HREB), there are still associated reporting requirements. In the conduct of approved research researchers are required to report to the HREB, in a timely manner, proposed changes from approved research that affect participants at any stage of the process. This includes, but is not limited to, changes to the consent form, changes to the tasks or interventions involved in the research, or changes to measures to protect privacy and confidentiality.

Any substantive change to the research should not be implemented prior to documented approval by the HREB, except when necessary to eliminate an immediate risk(s) to the

participants. Below are examples of post approval documentation that must be submitted to the HREB:

Amendments

Any proposed change in the conduct of a study must be submitted to the HREB, and approved, before the change may be implemented. Such changes might include modification of recruitment procedures, inclusion or exclusion criteria, revised sample size, addition or deletion of study sites, changes to an intervention, consent forms, questionnaires or scripts, etc. If there are changes in project team members or changes to funding source(s)/sponsor(s), there are specific forms to complete to report this to the HREB.

Adverse Events

Serious and unanticipated adverse events that occur within Newfoundland and Labrador are required to be reported to the HREB. Such events may occur in both clinical trials and in other types of research, e.g. collapse during a rehabilitation program, emotional breakdown requiring follow up care during an interview, or breach of privacy during correspondence. Serious adverse events that are fatal or life-threatening are required to be reported to the HREB as soon as the research team is aware of the event.

Protocol Deviations

Deviations from an approved study protocol must be reported to the HREB. Changes that eliminate immediate hazards to participants do not require prior approval, but must be reported soon as reasonably possible.

Safety Reports

Safety reports providing information on all serious adverse events (SAEs) occurring in a clinical trial must be provided by the sponsor to the HREB, normally on a three or six monthly basis (i.e. in accordance with the specified reporting timelines that were outlined in the approved ethics application).

Investigator Brochure (IB) and Product Monograph (PM)

Throughout the course of a clinical trial, changes may be implemented to study documents. All revisions to approved study documents must be submitted to the HREB to ensure the record is up to date. If the revisions include new risk or safety information there may be a requirement to notify research participants.

Ethics Renewal/Study Closure

Ethics approval lasts for one year. Ethics renewal is required annually, on the anniversary of the date of the HREB notification of approval. Once data collection is no longer ongoing, a study closure form is required to be submitted to the HREB for the study to remain active or to be closed in good standing.

Appendix B: Original Research Poster

Invitation to Participate in a Research Study:

How did your child (born preterm) adapt to entering the public school system in Newfoundland and Labrador?

WHO?

I am seeking to interview adults (at least 18 years old) who have had a child born premature (born between 24-37 weeks gestation), the child is currently experiencing one or more health challenges including but not limited to hearing and visual impairments, mobility concerns, language and/or cognitive disability, neurologic concerns (e.g. CP), psychiatric/behavioral concerns (e.g. autism, ADHD, anxiety), diabetes, asthma, and that child must be currently enrolled in public school in grades 2-4, in Newfoundland and Labrador. Lastly, you must be willing to help recruit other members of their child's circle of care that may agree to be interviewed by the researcher. These members can include another parent, grandparents, significant others who are not family, for example, babysitters and professionals including home support personnel, teachers, teacher and learning assistant, guidance counsellors, physicians, and public/community health nurses.

WHAT & WHY?

I am looking for parents with children that were born preterm to talk to me about:

1. How their child and family adapted to their child entering the school system.
2. To discuss any challenges, you may have encountered during the child's transition to school
3. What resources/supports were available to you in the school/community/province

I am a doctoral student at the Memorial University of Newfoundland. This is a research study for my program.

WHEN & WHERE?

Interviews will last about 60 minutes. We will agree on when and where to talk when you contact me.

HOW?

If you are interested or would like more information, please contact Nicole Lewis-Power.

nicolelewis@mun.ca or phone 709-864-2958

Appendix C: Revised Research Poster

Invitation to Participate in a Research Study

WHO?

Do you have a child who was born before full term (premature)?
Is your child finding adapting to school challenging or did your child need extra resources or supports to adapt? Is your child in kindergarten or in grades 1-6?
If so, would you be willing to talk about your experience, as a parent?

WHAT & WHY?

I am looking for parents with children who were born preterm to talk to me about:

4. How your child and family adapted to the child entering the school system.
5. To discuss any challenges, you may have had during the child's transition to school.
6. To discuss what resources/supports were available to you in the school/community/province?

I am a nurse by training, who worked for 5 years in Neonatal Intensive Care (NICU). I am currently a doctoral student at Memorial University of Newfoundland. I am interested in knowing if babies born prematurely experienced difficulties adjusting to school and what supports were available to help them. This is a research study for my program.

WHEN & WHERE?

You would participate in one interview (about 60 minutes). We will agree when and where to talk when you contact me. With your help, I would also like to talk to other members of the child's circle of care (e. g. grandparents, teachers, close family members, neighbours and friends, etc.) who may agree to be interviewed by me about their experience in caring for and/or working with your child.

HOW?

If you are interested or would like more information, please contact
Nicole Lewis-Power.
Email: nicolelewis@mun.ca or phone 709-864-2958

If you have questions regarding your rights as a research participant, please contact the Health Research Ethics Authority at (709) 777-6974 or info@hrea.ca

Appendix D: Interview Guide

Code:_________Date: _____ _________

(Parent(s) Interview Questions)

Opening statement

I am interested in hearing about your experiences of being a parent to a child born preterm and your experiences with the transition of your child starting/being in public school. This includes the factors that helped or hindered your child's transition to school.

Please tell me in your own words what these experiences were like for you. Feel free to talk about whatever incidents, thoughts, and feelings come to mind.

1. Please tell me about your journey of having a child that was born preterm.

   Prompts:
   -what were the child's health problems at birth?
   -what are the current health problems?
   -has the health problems impacted daily life?

2. Please tell me about how you prepared for your child to enter school?

   Prompts:
   -how was the registration process?
   -how did you feel/did you feel ready/was the child ready?
   -any special meetings with the school to discuss their healthcare needs?
   -did it get easier/harder each year getting ready for the next year of school?

3. When your child was registered for school was there any assessment done to determine if the child needed additional supports? Or did you ask for additional supports to be provided for your child?

   Prompts
   -What were the additional supports?
   -Do you feel they were adequate?
   -When were these supports available to you and your family?
   -How did you find out about these supports?
   -Are they offered to everyone? If no, who are they offered to?
   -Were there any supports you wish were available?

4. Within the school that your child is registered/attending what barriers or challenges did you face when preparing yourself and your child to start school and do well in school?

    Prompt
    -What did you do to prepare the child?
    -How did you prepare the child's teacher?
    -Did you tell anyone about the challenges/barriers? If yes, who? What was their response?
    -Do you feel that where you live and the location of the school/or size of the school plays a role in (child's name) transition to school? If yes, how?
        -Do you think that this contributes to the challenges or number of resources available to you and (child's name)? If yes, how?
    -How about within the community, what resources did you find helpful in preparing you and your child for school? Any challenges/barriers?
    -How about within the province? Any challenges/barriers?

5. What, in your opinion, has helped or hindered your child's ability to adapt to the school environment?

6. Are there particular challenges you have had in the past, or are currently experiencing with your child's school experience? (emphasis on transition to school)
    -If you could go back and do it all over again (from the time your child entered school) what would you do different?

Is there anything else you would like to tell me or elaborate on?

Code: ________Date: ____________

(Circle of care Interview Questions)

Depending on who is interviewed some of the questions may not be applicable and will not be asked.

Opening statement

I am interested in hearing about your experiences of being a member of (child's name) circle of care and your experiences with the transition of (child's name) starting/being in school. Including the challenges, you may have faced and the enablers that may have helped you become ready for this new phase.

Please tell me in your own words what these experiences were like for you. Feel free to talk about whatever incidents, thoughts, and feelings come to mind.

1. Can you please tell me how you know (child's name)?

2. How often do you see them and spend time with them?

3. Have you been present at anytime when a health problem that (child's name) has impacted their daily life?

4. How did you feel when (child's name) was first registered for school and started kinder start?

   Prompt
   -Did you attend any meetings with the school prior to child's name start date to talk about their needs/health issues?

5. Within the school that (child's name) is registered/attending what resources did you find helpful in preparing him/her and helping with him/her getting ready to start school and do well in school?

   Prompt
   -When were these resources available?
   -How did you find out about these resources?
   -Were they free of charge?

-Were there any resources you wish were available?

6. Within the school that (child's name) is registered/attending what barriers or challenges did you face when preparing yourself and (child's name) to start school and do well in school?

    Prompt
    -Did you tell anyone about the challenges/barriers? If yes, who? What was their response?
    -Do you feel that where you live and the location of the school/or size of the school plays a role in (child's name) transition to school? If yes, how?
    -Do you think that the location of your school/or size of the school contributes to the challenges or number of resources available to you and (child's name)? If yes, how?

-How about within the community, what resources did you find helpful in preparing (child's name) for school? Any challenges/barriers?
-How about within the province? Any challenges/barriers?

A. Extra (for medically trained professionals or educational professionals)

7. Are you aware of the potential health complications associated with being born preterm? If yes, where did you learn this information?

8. Did you receive any specialized training in the needs of children that are born preterm?

9. Are their any resource's that you are aware of (in the school, community, province) that are available to families with a child that was born premature to help them with school readiness and school performance?

10. What resources do you feel should be available (in the school, community, and province)?

11. Are there any policies, statements or guidelines that you are aware of (in the school, community, province) that relate to families with a child born preterm and how they can be ready for school and preform better in school?

Is there anything else you would like to tell me or elaborate on?

Appendix E: Demographic Questionnaire

Thank you for agreeing to talk with me today about your experience with your child's transition to school. Before we start, I want to review the Consent Form with you to answer any question or concerns you may have about this study and this form.

Code: ________Date:____

Family Profile:

Please check who lives with the child:

Mother ______Age:________
Father _______Age:________
Child #1______Age:________
Child #2______Age:________
Child #3______Age:________
Child #4______Age:________
Grandmother______________
Grandfather_______________
Uncle____________________
Aunt_____________________
Significant Other__________
Other____________________

1. What is your relationship to this child? _____________________________

2. Are you?

   a) Single
   b) Married
   c) Divorced
   d) Widowed
   e) Separated
   f) Common-law

Please indicate if you are married/common law to your child's mother/ father: Yes___No__

3. What is the highest level of school you (Mother) have completed or highest degree you have received?

a) Less than high school degree
b) High school degree or equivalent (e.g. GED)
c) Some college but no degree
d) Bachelor's degree
e) Graduate degree

4. What is the highest level of school you (Father) have completed or highest degree you have received?

a) Less than high school degree
b) High school degree or equivalent (e.g. GED)
c) Some college but no degree
d) Bachelor's degree
e) Graduate degree

5. What is your (Mother) employment status?

a) Employed full time
b) Employed part time
c) Employed as a casual/call in
d) Unemployed

6. What is your (Father) employment status?

a) Employed full time
b) Employed part time
c) Employed as a casual/call in
d) Unemployed
e)

Appendix F: Observation Guide

Date & time of visit:____
What individuals are at the home during the visit: ___________________________________

General condition of the home (cleanliness, safety, etc.)	
Who is interacting with the child? How is the child reacting (i.e. smiling, playing), How is the adult reacting (i.e. smiling, engaging child)?	
Does the child play by themselves? Can they entertain themselves without an adult providing attention to them?	
Are there toys and developmentally appropriate toys/games around for the child to play with?	
Is there medical equipment and/or supplies around the house?	
Is the living environment crowed? How is it organized?	
Who lives in the house?	
Other	
Are there any concerns for the child's safety? (i.e., no signs of abuse or neglect)?	

Appendix G: List of Documents Analyzed

NLESD

Policy Name	Number	Date Added to Website	Related Documents
Safe and Caring Schools Policy (2013)	EECD-901	30/04/2018	None
Bullying Intervention Protocol (2013)	EECS-900	09/05/2016	None
Alternate Transportation Policy and Application Package (2012)	EECD-903	17/01/2017	None
Administration of Medications, Medical Intervention and Chronic Care (2015)	PROG-301	15/08/2019	-Physician's report forms for policy -Guidelines for diabetes management in schools -Anaphylaxis guidelines -Anaphylaxis protocol

Department of Education

Policy Name	Number	Date Added to Website	Related Documents
English Program Curriculum Guides (2021)	None Listed	Not Noted on Website	None
French Immersion Curriculum Guides (2021)	None Listed	Not Noted on Website	None
Inclusive Practices Guidelines: School Level (2014)	None Listed	Not Noted on Website	None
Responsive Teaching and Learning Policy (2020)	None Listed	Not Noted on Website	None
Handbook for Parents of Children	None Listed	Not Noted on Website	None

with Exceptionalities (2015)			
Handbook for Teachers Serving Students who are Deafblind, Deaf or Hard of Hearing with Additional Disabilities, and Blind or Visually Impaired with Additional Disabilities (2003)	None Listed	Not Noted on Website	None
Programming for Individual Needs Alternate (Functional) Curriculum, Curriculum Guide (2008)	None Listed	Not Noted on Website	None

Other

*The NL Buildings Accessibility Act (*2018)

Bill 38, AN ACT RESPECTING ACCESSIBILITY IN THE PROVINCE (2021)