MAPPING THE EARLY LITERACY ECOLOGY OF CHILDREN WITH DISABILITIES IN THEIR HOMES AND COMMUNITIES:

PERSPECTIVES FROM PARENTS AND CHILDREN’S LIBRARIANS

by

TERESA JANE PRENDERGAST

B.A., University of Regina, 1986

M.L.I.S., The University of British Columbia, 1996

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Abstract

While prior research has investigated the home and preschool literacy experiences of young children with significant disabilities (Craig, 1996; DesJardin, 2010; Flewitt, Nind, & Payler, 2009; Hadadian & Weikle, 2003; Marvin & Mirenda, 1993; Ricci, 2011), little is known about how families of children with disabilities interpret mainstream early literacy discourses, most of which presume normative child development, nor how they participate in community-based early literacy learning. While the work of children’s librarians has evolved to include a significant role in the early literacy movement (American Library Association, 2011; C. Ward, 2007), librarians’ impact on the early literacy experiences of children with disabilities remains largely unexplored. This critical study begins with an analysis of early literacy discourse (McTavish, 2012; Nichols, Nixon, & Rowsell, 2009; Smythe & Toohey, 2009) found in government, community and commercial spaces (including virtual spaces, i.e., websites) in a large urban community in British Columbia, Canada. The study then explores the perspectives of parents of children with disabilities as they consider how their children participate in early literacy experiences in the context of their daily lives and routines. The study concludes with an exploration of children’s librarians’ perspectives on providing early literacy programs and resources for young children with disabilities and their families, while parents share their experiences in public libraries with their children with disabilities. The purpose of this study was to explore how early literacy is supported by communities in the lives of families whose children have disabilities. The conclusion was that children with disabilities are under-represented in early literacy discourse and practice, and that enduring ableist practices may result in the exclusion of children from early literacy opportunities in their communities.
Lay Summary

This is a qualitative multiple-case study that explores the inclusion of children with disabilities in early learning opportunities in their homes and communities. Early literacy in the lives of children with disabilities is explored by analyzing a collection of data from a sample of early learning texts, child-activity logs, parent interviews, librarian interviews, and document scans of library and information curricula and professional development programs. In general, social discourse surrounding childhood and early learning presumes normativity as a prerequisite for participation in early learning, and inclusion of children with disabilities is usually only accomplished by the addition of scattered supports, if any are available. Moreover, parents are charged with the responsibility of advocating for, and in most cases arranging, their children’s supports in various informal learning settings. When looking at libraries in particular, parents and children’s librarians rarely collaborated on inclusive strategies and moreover, librarians lacked significant knowledge about how to maximize inclusiveness in their libraries.
Preface

This dissertation is an original intellectual product of the author, T. Prendergast. The case study research reported in Chapters 4-6 was covered by UBC Ethics Certificate number H13-03058.

A version of Chapter 6 was published as


I wrote the entire manuscript.
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Dedication

I dedicate this work to my family. To my amazing husband Warren, thank you for agreeing to go on this journey with me, for putting up with my long absences from family life, for going above and beyond to help me cope with the stress, for feeding me when I was hungry, offering me a drink when I was thirsty and for going out to get potato chips, chocolate, wine or beer (or all of the above) when the going got rough! To my incredible son Calum, you inspired this entire thing. I would not have even come up with this topic without you, nor would I have had the wherewithal to finish it without you in my life. To my effervescent daughter Bronwen, you have literally grown up while I have done this degree. Watching you mature into a brilliant young woman has given me much hope for the future because you are in it. I hope all three of you think this has been worth the chaos that has reigned for the past six years. Thank you for sticking by me, I love you.
CHAPTER ONE: INTRODUCTION TO THE STUDY

From Parenting to PhD

Welcome to my doctoral dissertation, which is the culmination of six years of intellectual and emotional work that I hope makes a significant impact on the field of early literacy and ultimately ends up contributing to a more inclusive society. Generally speaking, I have always been interested in and motivated by the pursuit of inclusion as an overarching social goal where everyone has a place, and a part to play, in their communities. I know I chose a career in librarianship because I strongly believed in the importance of a free and democratic society in which everyone was afforded access to the information they needed to live their lives in pursuit of their own goals. So, I like to think it highly likely that social inclusion would have always floated to the top of my general concerns about how to improve the world we live in. Nonetheless, something happened two decades ago that I believe really cemented my commitment to contributing to inclusion for children with disabilities. I had one. I had a baby with a disability, and my husband and I had to learn quickly how the world works (and in many ways, doesn’t work) for families like ours.

I understand “disability” to be an umbrella term for a vast array of diverse experiences within the human condition across history and contexts. The term and its correlates (i.e., disabilities and disabled) defy precision and require ongoing contextualization. Turning back to my personal experience with disability in my family, although we were recipients of much support from families, friends and professionals, our son Calum’s early childhood was a very confusing and overwhelming time. We still struggle through a complex system of supports on a frustratingly regular basis and worry about his future a lot. Calum was diagnosed with a seizure disorder at 1 year old, more developmental delays at 3 years old, and was eventually assigned a
label of significant (and presumed to be permanent) cognitive disability when he was 5 years old.

Meanwhile, I was building my career as a professional librarian and was gaining expertise in programs, services, and collections that aimed to provide young children and their families with early literacy learning opportunities. Children’s librarians regard story times as the hallmarks of our early literacy work where we model interactive, engaged storybook reading, oral storytelling, singing, playing, and rhyming with great enthusiasm for the sheer joy of it, as well as the perceived and widely held opinions that this kind of stuff is great for getting kids ready to read. We wanted parents and caregivers of all the children in our communities to know about the benefits of early literacy experiences, and our increasingly crowded story times seemed to indicate that we were hitting our marks. But when Calum was still little and I was doing story time several times a week with very large groups of people, I started to wonder if children like my son, as well as children with even more challenging disabilities, were coming to story time. If they were, were we able to offer tailored help and support to those families?

We read to our son several times a day, but he was still unable to speak in full sentences until the age of 5, a full two years after all the developmental charts indicated that he should be able to do so with ease. We sang, rhymed and played “I Spy” with him, enrolled him in enrichment classes like painting and gymnastics, and went to story time at the library. Nothing seemed to speed up his delayed development. Consulting experts like speech-language pathologists, occupational therapists, physiotherapists, and pediatric neurologists finally helped us uncover the specific features of his disability conditions. We painstakingly learned to model language for him and waited and waited (and wrung our hands) while he slowly learned to speak in sentences and gain other social skills. It did seem to take forever but he learned to talk in perfectly grammatical sentences. Learning to read was another story. Having read The Hurried
Child (Elkind, 1988) when I worked at a daycare centre and well before I had children of my own, I was never keen on teaching my preschooler to read anyway and also was very skeptical of all the Baby Einstein\(^1\) early learning videos that emerged in the mid-1990s. However, I do remember having some moments of serious doubt when I read his very dire Pre-K assessment that predicted he was likely to face significant academic challenges across the board. Would he not be able to *read*? But that thought (that fear) just didn’t make sense to me. As an early literacy practitioner, I knew he had all the building blocks. He loved stories, he took an interest in letters - in fact he knew all the letters of the alphabet in preschool - and he knew the names of things and people and he seemed to have a terrific memory. At the same time, he had terrible fine motor control, poor visual integration, and very scattered focus. I remember thinking that sight reading (learning and remembering what each word looks like) was probably better than trying a phonetic / word chunk approach with him, as I supposed that he would not be able to focus on disambiguated word chunks and lists of rhyming words. My instincts were correct and his sustained interest in books about trucks and trains eventually led to him mastering decoding of text on the page. We are not sure, but we think he literally memorized what words looked like. Despite a whole lot of other academic challenges, reading has remained a strong skill with consistently high peaks when compared to his other developmental and academic abilities, which still have some very deep valleys.

No one has been able to explain how a child with such significant disabilities could learn to read without an enormous number of interventions and tailored supports such as those offered to children with learning disabilities like dyslexia. Even his neurologist was baffled and, for a

\(^1\) The Baby Einstein Company has discontinued their videos and now sells multiple types of products (mainly toys) aimed at parents of babies and toddlers see [http://www.kidsii.com/brands/baby-einstein/](http://www.kidsii.com/brands/baby-einstein/) for more information.
time, we all thought his cognitive disability diagnosis might have been wrong (it isn’t). I put it down to the fact that his mom was a librarian and his perhaps extraordinarily literate environment overrode any predispositions to reading challenges. It was not until I started meeting other children with diagnoses like his that I realized he was indeed somewhat unique. His peers with cognitive disabilities all struggled to master reading. I also found out that many children with special needs designations spent a lot of their school day doing non-academic things away from their peers (physiotherapy, speech therapy and so forth). I realized at that point that I was probably taking a bit too much credit for my son’s flourishing reading ability.

Throughout three years of preschool and then in elementary school, he only attended classroom environments that I later realized that many other kids like him did not have: they were all inclusive. In preschool, he was with his same-age peers at all times, and in kindergarten and grade 1, he only rarely and briefly left the classroom for one-on-one time with his education assistant. He was always grouped with both typically developing peers, as well as a few others who also had disabilities of various kinds. They learned together. I volunteered to read to his classes many times and saw how things worked there. He was included in everything that went on. He was socially included in the cultural work of learning to read in that environment. Yes, his literacy development was supported by a strong orientation towards books, words, and learning in our home. His interests were honoured and supported and he was encouraged along the way by people who loved him, but in those inclusive classrooms, where he spent several hours a day most of his week, he was part of what Kliwer (2003) calls a “literate community.”

Given the dire predictions that came out of his developmental assessment, and the many years I have had to think about this, I surmise now that his literacy accomplishments can be attributed to two interconnected factors I have described: an early childhood spent with engaged
family members and in communities of people who share the richness of literacy in everyday life; and, inclusive early literacy learning environments. My son had both of these, and both of these are necessary for a child with disabilities to achieve their potential.

Parents of children newly diagnosed with disabilities often start looking for connections with other parents of similar children, and I was no different. There were parent discussion boards on the Internet in those days, but no such thing as a parent blog was available to me to either tell my story or learn from others. I found a few friends on an online discussion board and eventually made friends with some families in my own city who had kids like mine. Since I also spent my working days with families at the library, I started looking there too. And I looked, and I looked and I continue to look. Over 20 years on, the encounters I have had with families of children with any disability, never mind one like my son’s, have been quite rare. I have met and talked to thousands of families over the years and think it is a struggle for me to identify 10 or 20 families who had children with disabilities of any kind, of any age, who came to the library.

Not all disabilities are visible either, as my son’s is not apparent by looking at him. Even so, living with a child who has developmental delays makes one quite aware of the clues that such children give observant adults, and I can say without a shadow of doubt that kids like mine - as well as kids whose disabilities are more obvious (Down syndrome, for instance) - very rarely come to library story time, and I have only rarely seen them at all in the spaces of the public libraries I have worked at over the past 20 years. Their absence said a lot to me and in fact led

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2 In this dissertation I use the gender neutral pronouns they/their/their when the gender is unknown
me to question my profession’s ability to meet the early literacy needs of families whose children had developmental disabilities.

Throughout my doctoral work, I have been mainly interested in the experiences of families whose children have disabilities, and how they encounter and participate in, or do not participate in, community early learning opportunities including, of course, those offered at public libraries. In this dissertation, constructed as a multiple-case study and organized as a collection of three linked explorations, I attempt to examine critically some of the current early literacy discourses and practices in order to uncover assumptions about early literacy and learning, as well as identify any issues and/or obstacles to participation in community-based early literacy learning for families whose children have disabilities.

I have seen the benefits of rich literacy experiences and inclusion in early literacy in my own family life, and now as a researcher I have studied the work of scholars who have worked in, and written about, the area of inclusive early childhood literacy. As someone who has studied this carefully, in this dissertation, I take a stance on inclusion and my scholarly and professional work is explicitly oriented towards examining issues of access to inclusive early learning. Used specifically in the context of my research, inclusive early literacy ensures that children with disabilities have access to the same kinds of literacy learning opportunities as their age peers without disabilities in any environment, including formal settings such as licensed group daycare centres and informal community settings such libraries, with the assumption that social inclusion in the cultural work of early literacy is a good thing. A significant body of research indicates that inclusive education, including early years education, reaps better learning outcomes for children with and without disabilities (Odom, Buysse, & Soukakou, 2011). Done properly, inclusive early childhood education ensures that children like mine are supported in the development of their
literate selves (McDonnell et al., 2014). As most inclusive education research about young children takes place in preschools, daycares, kindergarten, and primary classrooms, my research attempts to respond to a significant gap in the literature that is concerned with less formal learning opportunities such as those offered in communities, including libraries.

My linked inquiries, constructed together as a multiple-case study, are community-based, and explore what families living in these communities might have access to, and any barriers or obstacles that they might encounter in their efforts to support their children’s early learning.

I found the results of the multiple-case study to be both heartening and disheartening at turns. I did hear stories of inclusion and heard how many children are thriving and meeting their potential with adequate, inclusive supports in place. Usually these were found to be within the children’s daycare and school settings, where planning for the provision of inclusive supports is much better established in both policy and practice. I also heard about difficult, time-consuming and emotionally draining advocacy work that parents undertook in order to obtain inclusive supports for their children’s learning. Often these were for less formal settings such as community centre classes and enrichment programs like gymnastics and sometimes public library programs. As an insider in the disability parenting community, I had empathy for the parents in my study and completely understood those that opted out of the informal, mainstream community programs that were not able to accommodate their children’s needs. I believe that my multiple-case study uncovers something significant, something that points to an inherent tension in my scholarly work: parents of children with disabilities may already and automatically assume that a mainstream setting will not be inclusive, by default. They might persist in going anyway, they might ask for accommodations to be made, or they might decide it is not worth it to try at all.
When I was discussing the topic of finding appropriate activities with one of my participants, I was suddenly struck with my own bad memory: a well-respected and popular gymnastics program failed to accommodate my then 4-year-old child’s need for extra support, and I remember being told, quite bluntly, that we should register him in private lessons. The program staff failed to understand that I had registered him in this program for him to do something fun with other children, not to excel in gymnastics. Suggesting he take gymnastics separately from his age peers was an inadequate, exclusionary, and unjust solution to what they clearly saw as the problem of accommodating his support needs in this setting. Needless to say, we left that program. So, given that I have endured the heartache of early learning programs that cannot, or will not accommodate children’s support needs, why am I so interested in parents of children with disabilities taking their kids to early learning programs when they already know that so many are not actually very inclusive? What would the value be in attending a community program run by facilitators who have never thought about how to accommodate a child with a disability? Instead of focusing on inclusion, should I not be advocating for the development of more specialized community programs for these families where they feel more comfortable, where they are able to meet parents like themselves, where their children can meet other children with similar disabilities? I grapple with this conundrum in my professional life all the time, too. At the library where I work, I co-developed a program just for children with language delays. It is not inclusive in that children with more typical developmental trajectories do not attend, but it is rich in literacy learning with age peers who have various language impairments. I see the benefits of specialized early learning programs. However, if I ignore the remaining gaps that I found in informal early learning, I do nothing to help advance what I believe is a global focus on
the recognition and advancement of the rights of people with disabilities to participate in whatever they want, whenever they want, to meet their own goals.

This macro-movement towards the social inclusion of people with disabilities began when families refused to continue to institutionalize their own children (Lalvani & Polvere, 2013) but it is by no means completed. I believe my research can contribute to the movement, however slow the progress of the movement. It is true that many current mainstream programs are not designed to meet the needs of children who do not have typical development, and parents like me likely know this. But it is also true that in my role as researcher, I can advocate for the application of the same principles of inclusion to these informal settings as those that have been and are applied in multitudes of already inclusive early learning settings (such as those described in the literature review chapter). My vision is for these heretofore non-inclusive settings to become inclusive by taking the same or similar approaches as programs and settings that are already inclusive. Based on what we already know about inclusive early learning and applying it to other settings will increase the early learning opportunities for children with disabilities to participate alongside their age peers without disabilities. Frequently reflecting on my experiences as a parent and as an early literacy practitioner, the goal of the past six years of my life has been to explore this topic from a number of different angles and to consider ways that the advancement of inclusion in informal community-based early learning, especially those offered by public libraries, might be accomplished.

Definition of Terms

When I use the term early literacy I intend to extend beyond the common definitions that refer to children’s knowledge of, and skills in, reading and writing before they are able to read and write independently, or, what is often labelled emergent literacy in the literature (American
Library Association, 2011; Roskos, Christie, & Richgels, 2003; Saracho, 2017b). Drawn from sociocultural literacy studies (Gee, 1996; Heath, 1982, 1983; K. H. Perry, 2012), my expanded definition intends to encompass the broad range of experiences that young children have within their cultural contexts (i.e., family, school, community) with language (i.e., verbal and gestural/sign), all forms of social communication (including those that use digital technology tools) and symbol systems and artifacts to make meaning. These are often collectively referred to as multimodal literacies (Hamer, 2005; Lawson, Layton, Goldbart, Lacey, & Miller, 2012; Wolfe & Flewitt, 2010). In this study, this definition includes experiences that might focus on aspects of children’s physical development, but still includes a communicative/language component (for example, learning to swim would include learning key vocabulary).

When I use the term inclusive early literacy, I intend to refer to early literacy policies, discourses, programs, practices, and opportunities that consider the needs of diverse children and their families in order for children to participate together in the same setting. Therefore, one of the aims of inclusive early literacy is to ensure that young children with disabilities are given the same, or similar, opportunities to have early literacy experiences as their age peers without disabilities. With these definitions in mind, I include many activities that extend beyond traditional print literacy activities, such as reading books and scribbling with crayons. For example, children’s attendance at fine arts or sports programs would involve literacy learning in multimodal ways (i.e., learning vocabulary and various modes of self-expression). I use the terms early literacy and early literacy learning interchangeably. I use the more generic term early learning when generalizing about sources that support early childhood learning across developmental domains.
In this dissertation, I deliberately and interchangeably use the terms *children with/who have disabilities*, *children with/who have disability labels* and *disabled children*. While “person-first” terminology (Block, 2016) is widely used in both research and media, I have found compelling rationales stemming from self-advocates in various disability communities for using identity-first language as well. In particular, I have followed the suggestions of Collier (2012) and Ladau (2015) who recommend using both person-first and identity-first terminology to acknowledge both of these perspectives. These terms are all meant to refer to children who have received at least one diagnosis or label that refers to a perceived impairment, delay or difference in one or more areas of their development in early childhood.

**Problem Statement**

Over the past 20 years that I have worked in a professional early literacy role, I have noticed an increasing focus on early learning in our society. This sharpened focus on the importance of early learning experiences is made evident by national, provincial, and local initiatives, advice, and resources aimed at parents of young children. However, drawing on my own experience as a parent of young child labelled with disabilities, as well as existing research, this current study points to the problem that families of young children with disabilities may still be at risk of exclusion from experiences and resources that might support their children’s early literacy development. My exploration of the research literature in early literacy reveals that very little is known about how families of children with disabilities interpret and respond to the early literacy discourses found in their communities, how they might take up or adapt any advice about their children’s literacy learning, or about why they might choose to participate, or not participate in both formal and informal, community-based early literacy learning opportunities. Also, while the work of children’s librarians has evolved to include a significant role in the early
literacy movement (American Library Association, 2011; C. Ward, 2007), their role in providing early literacy experiences of children with disabilities remains largely unexplored.

**Purpose Statement**

I conducted this multiple-case study to learn more about how children with disabilities are positioned in early learning discourse and practice. I sought to increase knowledge about the lived experiences of families of children labelled with disabilities vis-à-vis their interpretations of early literacy discourses, their thoughts about their own children’s early literacy experiences, as well as how they were able to support their children’s early literacy development in their daily lives. By learning about the lived experiences of families whose children have disabilities and how they received, interpreted, and acted on discourses about early literacy, and by paying attention to their decisions about participation in public library and/or other early literacy programs, I hoped to understand from their perspective how they believed or hoped that their children with disabilities could be better supported in their communities. With a focus on the role of public libraries in communities, I intended to learn about the perspectives of professional library practitioners who actually provided early literacy collections, services, and programs within the public library context.

**Research Questions**

The research questions guiding this dissertation were:

**Research questions addressed in Chapter 4**

1. What are some of the implicit and explicit messages about child development and early learning that are present in artifacts from government, community and commercial domains that are aimed at parents of young children in this community?
2. How do some parents of children with disabilities interpret and respond to the implicit and explicit messages about child development and early learning that they encounter in some of the texts within such artifacts?

**Research questions addressed in Chapter 5**

1. For families of young children with disabilities, what routines and activities of their daily lives influence how their children participate in early literacy learning both inside and outside the home?

2. Specifically, what resources do their children access and what activities do they participate in both at home and in the community that may support early literacy learning?

3. In what ways do parents interpret how their children’s disabilities influence their ability to participate in, or not participate in, early literacy learning?

4. How do parents respond to any perceived challenges and barriers for accessing early literacy learning (at home and in the community) for their children?

**Research questions addressed in Chapter 6**

1. What are children’s librarians’ experiences with, and perspectives of, serving children with disabilities in their communities?

2. What do parents of young children with disabilities say about their experiences with early literacy resources of the public library?

3. What are professional children’s librarians’ reports about any training they have received and their thoughts about training they believe they need to receive for providing early
literacy programs, services, and collections that meet the needs of children with disabilities?

**Significance Statement**

I hope my study will contribute to the elimination of society’s presumptions of disabled children’s incompetence (Biklen & Burke, 2006) and help to enhance the provision of inclusive early literacy experiences for all children across settings and contexts. I hope that the findings of this multiple-case study will help to determine what parents of young children with disabilities may need in order to best support their children’s early literacy development. I hope that my study’s findings point towards some recommendations about how public libraries and other community-based settings can work towards ensuring the inclusion of children with disabilities.

**The Chapters**

In Chapter 2, I present theories that underpin my study. Through a sociocultural, interpretivist frame, I draw mainly from Bronfenbrenner’s bio-ecological systems theory and critical disability theory. I then review some of the relevant literature that informed this dissertation.

In Chapter 3, I outline the methodology and explain how I implemented various methods for collecting and analyzing the data.

In Chapter 4, I present the findings of Case 1, a critical examination of early literacy discourse, and offer some recommendations for producers of early learning discourse based on my findings.

Chapter 5 presents the findings from Case 2, a narrative study of 13 families of children with disabilities. I used aspects of Bronfenbrenner’s bioecological theory as follows:
1. Microsystems: Processes surrounding children’s early literacy learning at home: Print literacy practices; digital literacy tools; heritage language strategies

2. Mesosystem Influences: Contexts, processes and supports for early literacy learning; Interactions with therapists; mainstream and specialized group programs

3. Macrosystem Influence: Inclusion; ableism; advocacy

This chapter concludes with recommendations for the field of early learning, including critical areas for future research.

Chapter 6 reports on the findings of Case 3, in which I focused on the early literacy resources of the public library and the perspectives of the librarians who provided such resources. As well, I reported the perspectives of parents of children with disabilities who went to public libraries in pursuit of early literacy resources for their children. Building on my findings, I conclude with some recommendations for the field of librarianship.

In Chapter 7, I conclude by summarizing my findings and discussing the impact I hope my research is able to make in what is a critically understudied area of early literacy.
CHAPTER TWO: THEORETICAL FRAMEWORK AND LITERATURE REVIEW

Theoretical Framework Introduction

In this chapter, I present the theoretical framework informing my study. Grant and Osanloo (2014) stressed the importance of a soundly constructed theoretical framework in doctoral dissertations. They used the metaphor of an architectural blueprint to demonstrate how a theory or theories guide dissertation research from beginning to end, and emphasized that authors should choose theories that acknowledge their preconceived notions, as well as reflect their own epistemological and fundamental beliefs.

As I began my doctoral studies, I acknowledged my own lack of theoretical fluency and was not sure how to approach this aspect of my work. Two years of course work helped develop my ability to relate my research studies to some of the theories found in literacy education. In Chapter 1, I explored my experience of having a child with a disability. I arrived at my doctoral program after fifteen years of contending with a society that viewed my son’s needs as ‘extra,’ ‘special,’ or ‘additional.’ I came to understand that these views of his abilities and perceived support needs reflected an ableist society’s notions of normative development. I wanted my work to problematize the concept of normativity and, from this stance, I felt strongly that I needed to adopt a theoretical lens informed by the emerging traditions of critical disability theory (Devlin & Pothier, 2006a; Watson, 2012). Also, my familiarity with early childhood education (having worked as an early childhood education assistant prior to becoming a librarian) meant that when I became knowledgeable of Bronfenbrenner’s (2000) ecological systems theory, I felt I was in somewhat known territory. I had of course encountered reports and other literature that presented diagrams of the child within the nested circles of support that are equated with Bronfenbrenner’s earlier work, but I had not at that point considered the full theory in relation to my research topic.
Moreover, before beginning doctoral studies, I had not considered the application of this theory to the study of children’s librarianship (Rankin, 2016).

From the outset, and building on some of the barriers and issues I observed as a practitioner before I began my doctorate, I always intended this to be a critical study that contributes to what is known about children with disabilities and their early literacy lives. By critical, I meant that I would endeavor to question taken-for-granted assumptions and status quo understandings about young children and early literacy learning, across contexts. Thus, in this dissertation, I examine aspects of the early literacy lives of children with disabilities, their representation in official and unofficial texts about early learning and development, and their access to informal and formal opportunities for early literacy development, through the lenses of critical disability theory and Bronfenbrenner’s bio-ecological systems theory.

Through these perspectives, I explored some children’s experiences with early learning within various contexts, mainly through their parents’ eyes. I focused on whether and how programs and resources to support young children’s literacy development in informal, community-based early learning settings, particularly those offered at public libraries, were responsive to the needs of children identified as having a disability. As a library professional, I also believed that a consideration of the role of children’s librarians in the lives of families of children who have disabilities was of paramount importance. After considering a number of other theoretical standpoints, I concluded that critical disability theory, with its focus on the impact that ableist society has on individuals with disabilities, and Bronfenbrenner’s bioecological systems theory, with its focus on factors that affect development in human beings, both suited the topic. I believe that these theories complement each other in ways that have
allowed me to critique the enduring ableist practices that impact the lives of the children and their families, such as those who participated in this study.

Next, I describe critical disability theory and Bronfenbrenner’s bio-ecological systems theory and how I endeavored to blend and use these theories through each stage of my study.

**Critical Disability Theory**

According to Hosking (2008), critical disability theory is “a member of the critical theory family” (p.3), and provides a framework in which disability is centred, and the ableist assumptions that shape society are challenged. Critical disability theory focuses on the impact that negative social responses to a person’s specific difference or impairment have on that person’s life (Devlin & Pothier, 2006a, 2006b; Goodley, 2013; Goodley, Hughes, & Davis, 2012; Mladenov, 2015). The emphasis is placed on societal influences, rather than on specific individual characteristics. In a critical disability paradigm, the historically prevalent medical model of disability (also referred to as a “deficit-model”) is rejected as oppressive, dehumanizing and unjust, and disability is construed as mainly a social construct. In the introduction to *Critical Disability Theory: Essays in Philosophy, Politics, Policy, and Law*, Devlin and Pothier (2006a) stated that “North American societies take pride in promoting themselves as bastions of liberty, equality, and inclusion” (p.1). However, they noted that, despite grand narratives to the contrary, people with disabilities in Canada, currently estimated to comprise between 5% to 15% of the population (Canada Office for Disability Issues, 2003), continue to contend with “recurring coercion, marginalization, and social exclusion” (Devlin & Pothier, 2006b, p. 1) and rely on either charity or social assistance to access the same basic rights as other Canadians.
They go on to state that:

…social organization according to able-bodied norms is just taken as natural, normal, inevitable, necessary, even progress. It’s just the way things have to be done. The resulting exclusion of those who do not fit able-bodied norms may not be noticeable or even intelligible. (p. 7)

Devlin and Pothier (2006b) problematized both the privileged position that those without disabilities enjoy in North American society and the “pervasive impact of ableist assumptions, institutions and structures that disadvantage persons with disabilities” (p. 13). Critical disability theory aims to challenge some of society’s taken-for-granted assumptions of normalcy, while seeking to expose the injustice of social exclusion based on ability. Critical disability theorists advocate for the discontinuation of the dominant society’s overt ableism and encourage the construction of a barrier-free society in which all persons with disabilities can equally belong (Devlin & Pothier, 2006b).

A tenet of critical disability theory is that society’s responses to a person’s impairment (physical, cognitive, sensory and so on) both create and contribute to that person’s experience of being disabled (Devlin & Pothier, 2006a; D. J. Gallagher, Connor, & Ferri, 2014; Goodfellow, 2012; Goodley & Runswick-Cole, 2010). Theorists, therefore, acknowledge that while a person’s physical, sensory, or cognitive impairment has a definite impact on their life, social responses to the person and their impairments greatly exacerbate the experience, mostly by way of overtly or covertly throwing up barriers that lead to their exclusion from participating in social and cultural life. Building on this notion, for this study, I propose that ableist society impacts the lives of families of children with disabilities in much the same way, especially with regard to early learning (Lyons, 2013). Barriers to social, educational, and cultural participation are
inadvertently constructed that contribute to disabled children’s exclusion from activities in which their non-disabled peers participate.

Historically, much of the research about parents of children with disabilities has taken the position that a child’s disability is tragic, with consequences to parents similar to a death, and grief and mourning are commonly discussed themes (Fajardo, 1987; Hugger, 2009; Solnit & Stark, 1961). However, as critical disability has emerged as a discipline, research in this area has taken a much more critical stance and has revealed that many parents have critiqued the medicalized and negative framing of their child’s disability as a tragedy to be endured and worthy of interminable grief (Goddard, Lehr, & Lapadat, 2000; Kelly, 2005; Lalvani, 2008; Lalvani & Polvere, 2013). In fact, parents of children with disabilities in some of these studies reported that the most negative aspect of parenting children with a disability is not the children but dealing with a society that pityes them and/or is hostile towards them (Francis, 2012; Lalvani, 2008). It was through this lens of disability as a social construct within an ableist society that I examined aspects of the daily lives of the participating families whose children have disabilities, with a focus on their experiences with and access to early learning opportunities outside their homes.

By viewing the general notion of barriers to access for people with disabilities as both a human rights issue and a significant social problem (United Nations, 2006; World Health Organization, 2011, p. 10), I also examined prevailing discourse in texts (e.g., pamphlets from government agencies, websites) about early learning found in the community for commonly held beliefs about childhood ability/disability, particularly beliefs that position children with disabilities separately from their able-bodied, typically developing peers. I speculated that images of, and discussions about, children with disabilities may be largely absent from discourse
about childhood in general because of widely-held, ableist perceptions that such children belong to a different type of childhood - one that requires special, usually separate, supports such as camps and classes for disabled children. However, the United Nations Convention on the Rights of the Child (United Nations, 1989) advances a vision of unified childhood, regardless of ability, explicitly stating that children of all abilities should receive equal opportunities to participate in their communities. For example, Article 23 calls for “the child’s active participation in the community …in a manner conducive to the child's achieving the fullest possible social integration” (p. 7). Additionally, the preamble to the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) states “children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children…” (p. 2). While these position statements promote participation and access, research suggests that most families still experience exclusion and barriers because of what Lyons (2013) refers to as “enlightened ableism” (p. 1). The current study aims to explore the incongruence between the United Nations’ stated objectives of inclusion for children with disabilities and the actual experiences of families with “enlightened ableism” across contexts.

Critical disability theory tenets underpinned each of the three cases in which I examined: early learning discourse (specifically those containing advice texts aimed at parents); parents’ perspectives of their disabled children’s opportunities for early literacy learning; and children’s librarians’ perspectives on how they prepared and provided appropriate early literacy programs and resources for children with disabilities. In the early learning discourse case study, this critical lens helped me to critique how able-bodied children are positioned as “normal” while children with disabilities remain mostly invisible and excluded. In the parent-interview study, this lens helped me to frame the parents’ explorations of how their children’s opportunities to learn and
socialize were sometimes obstructed when their children’s needs were not accommodated in their community. In the librarian-interview study, the critical disability lens formed a backdrop against which the question how of a young child with a disability would or could participate in the early learning resources available at the public library, and how a specific child’s label of impairment might have impacted their access to early learning resources there. I also reflected on my experiences as library practitioner and as a parent of a child with a disability. Consistent with a critical disability perspective, when I considered libraries and other community settings as sites of participation in early literacy, I placed the onus for the identification and removal of barriers on the field of children’s librarianship in general and specifically on library practitioners, rather than on children with disabilities and/or their parents and caregivers.

**Bronfenbrenner’s Bio-ecological Systems Theory**

This study is also framed by Urie Bronfenbrenner’s conceptualization of human development. As shown in Table 2.1., his early theory, also known as his ecological systems theory, conceptualized a child at the centre of five overlapping systems (the *microsystem, mesosystem, exosystem, macrosystem and chronosystem*) that interact with and influence a child’s development (Bronfenbrenner, 1979, 1986; Hayes, O'Toole, & Halpenny, 2017). In this framework, homes, therapy centres, recreation programs, and libraries can all be considered different microsystems, or the child’s immediate environments and settings. The mesosystem can be understood as forces within microsystems interacting and influencing each other. When considering early childhood contexts, the mesosystem is most easily explained by describing the interaction of different influences in a child’s specific microsystem or between different microsystems. Therefore, the mesosystem is not a place, setting, nor even a context, but rather it is best conceptualized as an exchange of knowledge that results in an influence on a child’s
experiences within a particular microsystem or across microsystems. For example, a speech therapist may teach a parent specific ways to work with a nonverbal child to support her spoken language development. Another example of a mesosystem is a father who comes to a toddler story time and learns how to play a rhyming game about getting dressed; when the father plays the game at home with his child and the child responds by following the actions of the song, the child is supported in learning this new skill (i.e., putting socks on).

Moving out from the mesosystem, the exosystem can include friends and extended family, employers, as well as government services, educational policies, and laws that have an impact on the development of the child in some indirect way. For example, a parent’s workplace that allows time off to attend medical appointments would indirectly influence the child’s development and experiences because this flexibility may make it possible for the parent to take a child to medical appointments, and the information and support gained at these appointments may have a positive impact on the child’s development. Also, the way that institutions organize the work of their employees, such as librarians’ story time schedules and attendance policies (e.g. advertising programs as being for specific ages of children), can exert indirect influence on a child by impacting the way that children and families can gain access to resources at the library. To illustrate how macrosystem discourse influences the exosystem, librarians may create program content and attendance rules based on their status quo understanding of normative child development. The resulting structures may mean that disabled children are unable to attend programs that best meet their developmental needs because they do not match up with any of the “right” age guidelines of the story time programs.

The macrosystem incorporates the larger society’s cultural norms, practices and attitudes. To illustrate this, we can consider the influence of prevailing attitudes in North America about
the value of libraries (Pew Research Center, 2013) and the importance of literacy in people’s lives, as well as the relative willingness of governments to fund public libraries. Supporting literacy learning in early childhood through the provision of programs and resources, therefore, becomes easier because the benefits of literacy are well established in the values and attitudes of the larger society, and thus there is a political will to provide stable funding and support.

Finally, the chronosystem accounts for changes over time. Effects of the chronosystem can be seen in the changes that take place over the life course of a child. An example relevant to this study is the time around age five when most children transition to kindergarten entry. For children with disabilities, this entry into a new, formal schooling system coincides with the cessation of early intervention services, as well as the transfer of remaining therapies and services from health authorities to school boards (Janus, Lefort, Cameron, & Kopechanski, 2007; B. Perry, Dockett, & Petriwskyj, 2013; Pivik, 2008). The chronosystem includes change that has occurred over history, including macro-social changes that have taken place over decades. The historical transformation of education for children with disabilities, from segregation models to inclusion models, provides a relevant example of such change.

As shown in the following diagram, Bronfenbrenner’s early ecological systems theory provided a conceptual framework from which to consider the overlapping influences at play in the lives of families whose children are labelled with disabilities.
Many contemporary studies of families and communities utilize only Bronfenbrenner’s early framework (Algood, Harris, & Hong, 2013; Sensenig, 2012; Tudge, Mokrova, Hatfield, & Karnik, 2009). However, in later iterations of his theory, Bronfenbrenner elaborated on processes within the systems framework. His later, “mature” model, which he called the Process-Person-Context-Time PPCT (Bronfenbrenner, 2005; Bronfenbrenner & Ceci, 1994; Hayes et al., 2017) includes the person’s unique characteristics or biology (here the “bio” was added to, and extended what was once just referred to as an “ecological” systems theory) in the framework. In this elaborate model, human development takes place as a result of progressively more complex reciprocal interactions between a child and the “persons, objects and symbols” (Bronfenbrenner & Ceci, 1994, p. 572) in his or her immediate environment. A person’s unique “biology”
(including things like temperament) is, therefore, considered to influence the individual’s development and to affect the developmental influences on him/her from external factors (i.e., experiences or interactions with people, objects and symbols). Some researchers have begun to utilize the mature version of the Bronfenbrenner framework in their examinations of various aspects of the disability experience (B. Perry et al., 2013; Saxena & Adamsons, 2013). In the PPCT framework, interactions and experiences are therefore considered to be the processes by which a person’s development takes place.

The contexts are considered to be the various settings in which children live and interact in their daily lives (home, school, therapy clinics, lessons, libraries, etc.) Finally and most importantly, Bronfenbrenner’s PPCT model emphasizes that processes and contexts are repeated over extended periods of time and that both the frequency and intensity of all these influences over time together affect development (Bronfenbrenner & Ceci, 1994). Bronfenbrenner’s mature bioecological model of human development (Bronfenbrenner, 2005; Hayes et al., 2017; B. Perry et al., 2013) added important aspects to the framework of my study.

To elaborate, parents who contributed to this study had children with disability labels in one or more developmental domains. These characteristics, along with the children’s temperaments and other aspects of their personalities, constituted the person segment of this framework. Along with the children’s developmental characteristics, the processes that surrounded them (interactions with parents, teachers, therapists, librarians), and the various contexts in which they participated (homes, preschools and schools, libraries, clinics, parks, etc.) were all considered to help me understand what might have encouraged (or impeded) a child’s opportunities to access and participate in literacy learning experiences. Bronfenbrenner also emphasized time and pointed out the importance of both repetition and intensity of experiences
over a stretch of time. Building on the examples offered above, the following figures illustrate mesosystem influences in the lives of children in two microsystems (therapy office; story time).

**Figure 2.2. Mesosystem: Therapist, Parent, Child**

In the **context** of an appointment, a therapist influences the child’s development by providing the parents with knowledge about specific tools and activities (**processes**) with which to provide the child (**person**) with experiences to support development/learning.

New knowledge or resources learned by the parent during therapy sessions constitute the **mesosystem** influence as the parent and therapist work together to provide the child with beneficial activities (**processes**) to be experienced repeatedly over a length of **time**.

Over **time**, and with repeated occurrences, the child’s (**person**) experiences in therapy are considered to be some of the **processes** in which development can be encouraged by his or her interactions with objects, symbols and people in various settings (**contexts**).
Another example of the PPCT model, this time in the children’s library, is presented next.

**Figure 2.3. Mesosystem: Librarian, Parent, Child**

The mature model of Bronfenbrenner’s theory provided a useful lens in my study, particularly through which to explore parents’ insight into their children’s daily lives, routines and experiences with early literacy. It also allowed me to consider where libraries and librarians...
might fit into each of the unique bioecological systems of children who are labelled with
disabilities. I found this theory to be useful for exploring the potential influence of librarians on
the development and learning of children with disabilities as they interact with them and their
families at the library.

I acknowledge that an inherent tension may have been created by drawing on critical
disability theory and Bronfenbrenner’s bio-ecological systems theory in the same study. I think it
important to address the potential tension. Bronfenbrenner’s theory, along with other early
childhood development theories, can be, and often are, used in ways that reinforce normative
understandings of early childhood development. However, as I will point out in the literature
review, widely held assumptions about “normal” child development, emerging from the
developmental theories of Piaget, Erikson, Bowlby and others (Piaget & Cook, 1952; State of
New South Wales, 2006) are evident in much of the early childhood literature. I believe that this
phenomenon has contributed to a critical lack of attention to the needs of children with
disabilities whose development falls outside the norms espoused by such theories. As both
practitioner and researcher, I believed that Bronfenbrenner’s bio-ecological theory offers a great
deal of promise for the strengthening of our collective understanding of how libraries and
librarians (as well as other community resources and people) can and do contribute to the early
literacy learning of all children, including those with disabilities.

Bronfenbrenner, unlike other developmental theorists, does not overtly encourage the
mapping out of specific skills at specific chronological ages, nor does Bronfenbrenner’s theory
include age ranges at which certain abilities should emerge, nor does his theory propose discrete
stages of development. In contrast, Bronfenbrenner’s mature theory, as explained above, allows
for a thorough examination of what influences are present in, or absent from, any specific child’s
life, and his theory encourages the recognition that all children, each with unique biological characteristics, develop (or are hindered from developing) within microsystems that they move through throughout their days, having interactions with objects, symbols, and people as they do. While critical disability theory reveals how ableism and ableist attitudes and practices might actually be disabling for some individuals in and of themselves (Goodley, 2014; Slater, 2013), Bronfenbrenner’s theory encourages the exploration of the constellation of contexts in which children develop and learn and is especially concerned with whether the contexts are developmentally beneficial or detrimental.

By exploring what can and does happen in the early literacy lives of children with disabilities, and including both the opportunities and the barriers, the two theories are complementary in ways that I believed to be suited to examining various aspects of early literacy in the lives of children with disabilities, with a particular interest in the role of informal early learning settings, including public libraries. As libraries are situated in communities, and librarians are frequently engaged with children and their families, I considered this theory to be a good fit for the exploration of libraries as sites of early literacy learning for diverse children in diverse ways. In his concept of a macrosystem, Bronfenbrenner’s theory acknowledges the influence of social norms, customs, cultural practices, and attitudes on the development of individuals, and critical disability theory makes visible how those same norms, customs, cultural practices, and attitudes perpetuate ableism (Titchkosky, 2014) and its impacts on the lives of people with disabilities in Western society. For these reasons, I drew on both of these theories throughout this study and found this linked theoretical framework to be productive for me, as I gained new insights into the relationships between discourse, practice, and parents’ experiences across different learning ecologies with their children.
Other Sociocultural Theories

I also drew on other theories that, like Bronfenbrenner’s, emphasized the social nature of literacy across the lifespan (Heath, 1983, 2012; Mahn, 1999; K. H. Perry, 2012; Street, 2003; Vygotsky, 1978). For example, Vygotsky found that social context is especially important in the development of literacy in all its forms. His thoughts about children with disabilities deserve special attention. A household name in the general fields of education and psychology, Vygotsky is not as well known for his contributions to special education theory, but he was, in fact, a pioneer in that field as well. Vygotsky considered the primary problem with disability not to be the sensory or neurological impairment but the social implications of the impairment. He concluded that expectations, conditions, and attitudes created by society influence “the access of a child with a disability to sociocultural knowledge, experiences and opportunity to acquire psychological tools” (Vygotsky, 1983, p. 102). Pointing out that the outcomes of children with disabilities are influenced by the society in which they live, Vygotsky argued that children with disabilities should be afforded the same kinds of opportunities to build their skills, via support from parents, caregivers, teachers, specialists and others, as those offered to their non-disabled peers (Gindis, 1999; Smagorinsky, 2012; Wang, 2009). Vygotskian theory also pays attention to the historical aspect of child development that takes place within the context of his or her family history (John-Steiner & Mahn, 1996; Vygotsky, 1978). Parents of all children, both with and without disabilities, come to any situation with their unique history of understanding, working with, and supporting their own child. For this study, I considered each child’s place within their family and that their particular disability label can be considered part of that child’s family history. This theoretical lens helped in the examination of how different families chose to
negotiate their children’s access to learning opportunities outside their home environments, and if and how they leveraged their child’s disability status to help negotiate such access.

In summary, in this study I drew from critical disability theory and Bronfenbrenner’s bioecological systems theory along with insight from sociocultural literacy research (i.e., Vygotsky and others). I believe that they all overlap in their focus on emphasizing and critiquing where necessary the social aspects of human development and learning. This theoretical framework guided my critique of the collected parent advice texts and helped in the re-storying of the parents’ narratives about their children’s daily lives, as well as my synthesis of the children’s librarians’ perspectives on their work with regards to early literacy resources for children with disabilities.

**Related Literature**

**Introduction**

Carspecken (2008) described critical research as “a loosely defined genre of social inquiry whose central theme involves the problematization of knowledge” (p. 84). It involves the exploration of a phenomenon with the aim of uncovering (and problematizing) taken-for-granted (status quo) assumptions about the phenomenon of interest. Therefore, I believe one of the primary goals of critical research is to identify and critique the social implications of widely held beliefs. Specifically, critical research should seek to expose the impact of such assumptions on people’s lives, and work towards dismantling the macrosocial views that result in marginalization and exclusion.

This review of relevant literature informs each of the three cases that comprise my multiple-case study. I begin this literature review with a consideration of how children with disabilities are positioned in early learning discourse aimed at parents and caregivers. I first
review some key pieces that focus on normative developmental psychology and brain science as representative of macro-social views and taken-for-granted assumptions and how they are reflected in parent advice texts. I note the absence of parents of children with disabilities in any of the extant critiques of parental advice discourse and speculate about how parents of children with disabilities might respond to such normativity when they seek advice about their own children’s learning. This is the background literature for Case 1 presented in Chapter 4.

Next, I review early literacy research concerning children with disabilities, organizing it into four key areas of focus. These are (a) barriers to early literacy learning opportunities for children with disabilities; (b) home literacy experiences of young children with disabilities; (c) inclusive early learning settings; and (d) digital technology and early literacy for children with disabilities. This is the background literature for Case 2 presented in Chapter 5.

Finally, I provide an overview of professional librarianship literature as well as research on the role of the library in providing early literacy support and services for children with disabilities and their families. This is the background literature for Case 3 presented in Chapter 6.

**Parent Advice Literature**

Cooper (2013) traced the origin of contemporary notions of normalcy through a study of baby and child care manuals, and proposed that as society became more able to detect so-called abnormalities in children, parenting became more fearful as parents sought to avoid anything that could impinge on their child’s perceived normality. She went on to explore how baby care manuals tended to present normal development, metaphorically, as milestones stating, “The noun ‘milestones’ suggests a normative route, and works to produce a notion of a ‘normal child’ who follows a particular, predetermined path through life” (p. 140).
Lowe, Lee, and Macvarish (2015) criticized what they refer to as “neurocultural” claims made in the UK policy statements they studied. They problematized the focus on the child’s brain and the emphasis that social and health policy statements that they reviewed placed on parents’ roles and responsibilities in ensuring children’s brain development. They argued that by having widespread policy statements that over-emphasize the role that parents have in ensuring their children’s healthy brain development, the state is relieved of its role in providing supports to families and children. However, there are relatively few other critiques of early learning discourse in the Western world (see Hoffman (2009); Sunderland (2006) for examples), suggesting that the dominant narratives found in such discourse are, as Cooper (2013) suggested, mainly considered to be taken-for-granted, and they endure because they remain largely uncontested. Socially constituted ideas of normalcy in childhood are both pervasive and persuasive and they are reproduced constantly in both educational and health practices as well as parenting resources.

Some researchers have investigated how parents interpret some of the messages directed at them about their children’s learning and development; for examples, see studies by Nichols (2014); Nichols, Nixon, et al. (2009); Nichols, Pudney, Nixon, and Jurvansuu (2009); Ramaekers and Suissa (2012); Smythe and Isserlis (2002); Wall (2004, 2010). Although these studies confirmed that parents are presented with normative views of child development in almost all of the parent advice literature, I was not able to find any studies that provided much insight into how children with disabilities and their families are positioned in this literature, nor was I able to find any literature that asked parents of children with significant disabilities how they responded to, or indeed if they used, any of the parent-advice materials available to them. Apart from brief mention of a child with hearing impairment, a child who struggled with reading (Nichols, Nixon,
et al., 2009), and two gifted children (Nichols, Pudney, et al., 2009), the parents who participated in the aforementioned studies, for the most part, were raising children without disabilities.

J. Anderson, Lenters, and McTavish (2008) and J. Anderson, Streelasky, and Anderson (2007) examined early literacy and learning as it is presented on the World Wide Web. Similar to the aforementioned studies of parent-advice texts, consistently narrow views of family and early literacy were found across the online spaces analyzed in these studies as well. Their studies showed that most web resources aimed at parents usually invoked messages about reading aloud to children as the best way to prepare them for later success in reading at school. Many also delivered variations on the message that the parent is the child’s first and most important teacher, while at the same time implying that parents needed support and instruction on how to become that teacher for their children. J. Anderson et al. (2008) summarized their findings by saying

… if we were to distill the messages in these texts it would be that family literacy is about parents reading books to young children to insure school readiness, which insures academic success and a healthy, productive, engaged life, which in turn leads to a more civil society. (pp.74-75)

While these studies all problematized the narrowly framed concepts of early and family literacy as well as the many instances of deficit-language used to describe families found on these websites, none noted the absence of messages aimed at providing information about early literacy to parents raising children with disabilities.

Parents of children with disabilities (like me) are aware that even intensive interventions are unlikely to completely remediate their children’s impairments. Smythe and Isserlis (2002) critiqued parent advice literature for frequently implying that “if parents follow the instructions and activities carefully, their children should become readers, and their academic and social
success will be assured” (Smythe & Isserlis, 2002, p. 9). After reviewing the parent advice material I gathered for this study, as well as the published critiques of such material, as a parent of a child identified as having a disability, I thought that even if families of children with disabilities applied all the recommended advice dispensed to them both in print and online, they would still not achieve the implied results. As a parent whose own child’s development was dramatically different from any milestone chart I ever encountered, I considered the perspective of parents like me who have children with disabilities and thought about what they might make of discourse that positions parents as solely responsible for their children’s intelligence and capabilities, social and otherwise. Because high intelligence and social prowess are presented in parent advice texts as the expected goals of optimal stimulation, I thought this kind of advice was problematic when considering the realities of parents raising children with developmental disabilities, particularly those that have an impact on cognitive growth, but I did not see this issue raised in any of the research literature.

To summarize, studies that critique early learning discourse as normative clearly pointed out that there are widely held, though not uncontested, notions of optimal child development and that parents are largely responsible for ensuring it takes place. However, other than one mention of hearing impairment, one mention of a struggling reader, and another mention of giftedness (framed as a special educational need), none of the studies included in-depth discussions of various disability conditions and their impacts on children’s literacy development, nor how normative discourse might be encountered by parents of children with disabilities.

**Early Literacy and Children with Disabilities**

Research about young children with disabilities suggests that their opportunities to develop early literacy skills are shaped by a number of factors. Some researchers speculated that
therapeutic activities intruded on children’s routines, leaving less time for literacy than would presumably be available to their same-age peers without disabilities (Hadadian & Weikle, 2003; Harry, 1995). Several studies reported that assumptions by both practitioners and parents about lower levels of competence persisted, suggesting that early literacy development may simply not be given the same priority in the lives of young children with disabilities (D. J. Gallagher et al., 2014; Kliwer, Biklen, & Kasa-Hendrickson, 2006; Mirenda, 2003). However, research in this area also emphasized that children with disabilities can and do acquire literacy skills if they are provided with appropriate supports and opportunities (Basil & Reyes, 2003; Colozzo, McKeil, Petersen, & Szabo, 2016; Green, Terry, & Gallagher, 2014; McDonnell et al., 2014; Towson, Gallagher, & Bingham, 2016) and that many of the activities and experiences thought to contribute to literacy development in typical children, also build skills in children with disabilities (Katims, 1994; Moses, Golos, Roemen, & Cregan, 2016; Stone, Rivera, & Weiss, 2016). This was certainly the case for my son; well before we even knew the extent of his disabilities, we provided him with many literacy experiences such as daily book-reading as well as drawing, painting, and singing, etc. and he also attended a high-quality early childhood program. Even though his spoken language skills were very delayed and not at all what the charts said were expected of preschoolers, it was clear to me that he was learning to be literate, in the way that I understood early literacy, anyway.

In order to align as closely as possible with my research questions, I organize this segment as follows: Barriers to early literacy experiences; early literacy in the home context; inclusive early childhood education context; digital technology and early literacy context.

**Barriers to early literacy experiences.** Research concerning early literacy in the lives of children with disabilities reveals the influence of history on how children with disabilities have
been provided with literacy learning opportunities (Kliwer et al., 2006; Kliwer, Biklen, & Petersen, 2015). Due to the historical educational segregation of children with disabilities, until more recently, many people (including teachers) have had limited experience with people who have disabilities. For example, a recent study of Head Start centers in the USA suggested that children with disabilities still “have less access to literacy related materials and learning activities” than their non-disabled peers (McDonnell et al., 2014, p. 517). Additionally, research indicates that those who work with children with disabilities and their families need to be aware of and, if necessary, confront their own assumptions and biases about disability (Kliwer et al., 2004). Chandler-Olcott (2003), in particular, argued that teachers must see diverse groups of students as all being capable of acquiring or learning literacy. She also reflected on her own journey to understanding that “beliefs, prior knowledge, and personal experiences make an enormous difference in our perceptions of learners” (Chandler-Olcott, 2003, p. 73).

Researchers have also pointed out barriers to literacy learning that are constructed by inaccurate perceptions of some features of specific disability labels. For example, Mirenda (2003) described six-year-old Stanley’s problem. Because of his autism diagnosis, Stanley’s interactions with books were interpreted by his teachers as self-stimulatory in nature. He often turned the pages of books quite rapidly, without seeming to look at the content, and because autistic behaviour can include idiosyncratic, repetitive movements, his teachers interpreted his page turning as only “stimming.” Thus, he was cast as “not really a reader,” by his teachers, even though he frequently demonstrated interest in books about trucks. It seemed that Stanley’s disability label clouded the evidence of his actual literacy development and engagement, as his interest in books was misinterpreted as a symptom of his autism rather than “real” reading. Mirenda concluded that Stanley, like many other students with disabilities, was at great risk of
being deprived of opportunities to develop more sophisticated literacy skills alongside his age peers.

In a Canadian survey of 224 parents and guardians of people with Down syndrome, Trenholm and Mirenda (2006) asked respondents to report on both home and community literacy activities. Of particular interest to the current study was a question about library use. While 70% of respondents said that their son or daughter with Down syndrome went to the library with family members, nothing specific was reported about attendance at literacy programs offered in libraries, particularly those geared to young children. Also, less than one-third of respondents said that they had contacted either a school or public librarian and/or had used a library collection regarding their child’s literacy growth. The study also inquired about perceived barriers to literacy development and revealed a range of issues regarding access to appropriate literacy programs for people of all ages with Down syndrome. The lack of literacy programs was rated as one of the biggest barriers, suggesting that these families did not consider mainstream early literacy programs to be suitable for their children.

Other researchers noted the problems posed by mainstream early literacy curriculum that emphasizes skills that are commonly disrupted in children with disabilities, for example, in their spoken language or hearing abilities (Moses et al., 2016; Rohde, 2015). Kliewer (2008a) noted that both of the emergent literacy and reading readiness paradigms emphasize the importance of spoken language as a precursor to literacy skill development in typical children. However, since many children with significant disabilities demonstrate speech and language difficulties, they have historically been excluded from early literacy learning opportunities based on either the emergent literacy or the reading readiness paradigms, since both presume speech skills as a prerequisite for reading. However, alternative early literacy strategies for children with such
disabilities, including picture symbols, digital technologies, and/or sign language appear mainly in early literacy research about teaching literacy to children with disabilities (see for example: Lacey, Layton, Miller, Goldbart, and Lawson (2007); Lawson et al. (2012); Rivera, Spooner, Wood, and Hicks (2013); Towson et al. (2016)).

In another Canadian study, Heydon and Iannacci (2005) challenged some of the ways that disability was “produced and practiced” (p.1) in the early literacy curricula of a school in Ontario. They problematized the ways that children were evaluated within an educational framework that viewed literacy through what they termed a biomedical lens, which viewed children’s literacy problems as pathological ailments rather than part of the whole child and his or her social and cultural background. The approaches taken to “treat” the children with perceived literacy problems were to focus on children’s brains and the presumed deficits in their families. They stated that “…children were deemed abnormal through their performance on criterion- and norm-referenced assessments, which did not take into consideration their socio-cultural and linguistic backgrounds. They were subsequently pathologized and seen, for their own good, as in need of labeling…” (p. 12)

In summary, the literature showed that children with disabilities were sometimes, but not always, provided with early literacy opportunities in formal early learning settings. Furthermore, children with disabilities and their families contend with a variety of barriers (i.e., historical attitudes about disability as well as skills-based and/or “biomedical” approaches to early literacy learning) to their inclusive participation in literacy activities that include early literacy activities that do not heavily rely on oral language as a precursor to literacy.

**Early literacy in the home context.** Many other theorists have emphasized the influence of the family on child development (Bronfenbrenner & Ceci, 1994; Mahn, 1999; Vygotsky,
1978). While the literature on early literacy development and learning focuses the role of parents in their child’s literacy development (American Library Association, 2011; Nutbrown et al., 2016; Weigel, Martin, & Bennet, 2010), some research also reflects an interest in understanding the more specific family literacy environments of children with disabilities (Al Otaiba, Lewis, Whalon, Dyrlund, & McKenzie, 2009; Jordan, Miller, & Riley, 2011; Justice, Logan, Işıtan, & Saçkes, 2016; Ricci, 2011; Vander Woude & Barton, 2003). For example, Carlson, Bitterman, and Jenkins (2012) used data from the Pre-Elementary Education Longitudinal Study (Markowitz et al., 2006) in their study of home literacy environments of a representative sample of 3104 American preschool-age children who had mild to severe disabilities to determine the association between home literacy environment and the children’s scores on subsequent literacy measures. Their query included the frequency with which parents or other household adults read with their children, how often the children looked at or read books alone, whether or not children had been taken to a library in the past month, and whether or not they had attended at least one library story program in the past month. For the group of children with less severe disabilities, being read to at home was associated positively with their literacy achievement. However, none of the measures of the home literacy environment for children with more severe disabilities were predictive of their achievement. Children with more severe disabilities were read to at home less frequently than their age peers with milder disabilities. On average, about half of the families said they had taken their child to a library within the past month while less than one-quarter had attended a story time program during the same time frame. Families indicated that all early literacy activities happened less frequently for children with more severe disabilities, regardless of socio-economic and cultural factors, but the authors did not speculate about why that might be the case.
Marvin and Mirenda (1993) investigated the home literacy experiences of 291 preschoolers in the United States. They looked at three distinct groupings of children: children who were considered to be “at-risk”; children with identified special educational needs; and typically developing children. They found that the parents of children with disabilities prioritized their children’s literacy less than parents in the other two groups and had the lowest expectations of literacy development for their children. The authors suggested that the perceived severity of their children’s disabilities may have negatively impacted the development of high expectations of literacy for their children. Similarly, a study by Hadadian and Weikle (2003) of 392 parents of preschoolers with and without disabilities revealed significant differences in parents’ beliefs, practices, and concerns regarding their children’s literacy development. Both groups of parents indicated that they supported their children’s literacy development in the home but the authors speculated that parents’ low expectations of literacy for their children with disabilities may have been contributing factors in their children’s lower literacy achievement. Hadadian and Weikle summed up their concern, stating that, “If parents do not fully believe that their child is capable of achieving the goals set for literacy, then the likelihood of a self-fulfilling prophesy for the child exists” (p. 95).

van der Schuit, Peeters, Segers, van Balkom, and Verhoeven (2009) explored the home literacy environments of preschool children with intellectual disabilities in the Netherlands and compared them with two groups of children without disabilities: Their same-age non-disabled peers; and younger non-disabled children who were deemed similar in perceived “mental age” to the children with intellectual disabilities. Their findings suggested a number of differences between the children with intellectual disabilities and those without. For example, most of the parents of children with disabilities reported that they did not know what to expect for their
child’s future reading ability. The researchers also found that the literacy expectations for this group were generally much lower than those of parents of children without intellectual disabilities. In a recent study of the home literacy environment and activities of 618 children with and without disabilities, Justice et al. (2016) found that, compared to parents of children without disabilities, parents of disabled children indicated that their children displayed less interest in literacy activities (what they refer to as “print interest”), even though they were provided with books and read to at similar rates as their non-disabled peers. The authors speculated that this might be due to the fact that children with disabilities often have language impairments that may preclude their interest in participating in reading and writing activities at home, meaning that they may be reluctant to pursue and engage in activities that pose difficulties for them. They also speculated that autistic children with stereotypical interests in very specific topics may be less interested in literacy activities that do not pertain to these topics. While acknowledging the need for more research in this area, they suggested that parents incorporate more manipulative, interactive reading materials (i.e., lift-the-flap books) into their home reading activities. They also suggested that the print interest of children with disabilities might be more carefully monitored by the use of a simple rating scale, such as the one developed by Kaderavek, Guo, and Justice (2014).

Together, these studies of home literacy experiences for children with disabilities point out that while children with disabilities’ home literacy experiences are often similar to those of children without disabilities, there remain some significant differences that may have an impact on their overall early literacy learning potential.

**Inclusive early childhood education context.** Theorizing from Street’s concept of literacy as social practice (2003), Flewitt et al. (2009) conducted a case study that explored the
early literacy experiences of a child with disabilities in which they put forth a view of literacy as “the development of shared meanings through diverse symbol systems in social contexts” (p. 213). They extended this understanding to a view of literacy as meaning making through the multiple “modes” of communication that include gesture, gaze, movement, vocalizations, and augmentative and alternative communication systems\(^3\) (p. 214). The authors analyzed the multimodal literacy events that occurred in various settings in the life of 4-year-old Mandy who attended two preschools: one inclusive community preschool and one specialized preschool for children with disabilities. They noted that, in the specialized environment, Mandy spent proportionally much less time engaged in literacy activities, which tended to be one-on-one with a teacher. In contrast, in the community playgroup setting, she was involved in group literacy activities for much of her day, either with the whole class or in small groups, and much less often one-on-one with a teacher. Flewitt et al. (2009) argued that “…separating children from literacy experiences due to perceptions of their cognitive ability effectively devalues how they construct meanings in the social worlds they experience and, ipso facto, can breach the principles of inclusive education” (p. 213). Mandy’s case illustrated the need for understanding inclusive early literacy “as social practice rather than as a narrow set of technical sub-skills required for reading and writing” (p. 231). This study provided further evidence that the skills-based paradigm of early literacy sometimes casts children with disabilities as less than capable learners, and disregards other significant demonstrations of meaning-making.

\(^3\) Augmentative and alternative communication (hereafter referred to as AAC in this dissertation) is an umbrella term for any non-oral communication used to express thoughts, needs, wants, and ideas and these may include picture and symbol boards as well as electronic devices (American Speech-Language-Hearing Association).
Rogow (1997) provided teachers with strategies for including children with a variety of significant disabilities in their classrooms. First, she noted that the fundamental principles of literacy “apply to all children whether they have special needs or not” (p. 10). While acknowledging that many teachers are not prepared to teach literacy to children with disabilities, Rogow encouraged the inclusion model as being of benefit to everyone as, “children learn to respect and feel comfortable with their differences; teachers develop their creativity and find new ways of stimulating, enriching, and enhancing literacy instruction…” (p. 13). Rogow also emphasized the important role teachers can play in a child’s life: “imagine the influence of a teacher who believes in the capacity of a child with a disability to become an active and eager learner. Children flourish in the warming glow of a teacher’s belief in their abilities” (p. 105).

Kliwer’s (2007) notion of “local understanding” is woven throughout many of his ethnographic studies of children with disabilities and their literacy development in inclusive settings. Local understanding is similar to the concept of “local knowledge” (Geertz, 1985) and an underpinning principle is that teachers and others must first acknowledge each child as having a rightful place in the literate community of the setting. Kliwer (2008b) described local understanding as “the communal recognition that educational value and participation may be ascribed and enacted around a specific child, whereas history has primarily supported an abstract dehumanization and segregation” (p. 14). He asserted that deeply entrenched attitudes and assumptions about nonverbal (or minimally verbal) children with disabilities contribute to the reality that many are simply not given opportunities to learn and experience literacy in ways that build on the capacities they already have (such as using picture symbols or adaptive technologies) for making meaning. Kliwer urged the consideration of different routes to literacy for children who are often deemed to be incapable of learning to read or otherwise engage with
literacy due to their labels and impairments. He documented how children who would have traditionally been left out of early literacy learning opportunities demonstrated engagement, produced new narratives, constructed complex knowledge, and displayed enjoyment in their experiences when placed in inclusive settings (Kliwer, 2008a). He also proposed to practitioners without expertise in special early childhood education that the strategies needed to accommodate and include children with disabilities are also enjoyable for children without disabilities. He used the example of a teacher who created a box of illustrated song title cards so that a nonverbal child could still take her turn choosing what song the group should sing next. All the children enjoyed using the box to find their favourite songs, so it became an inclusive way of giving each child a turn to choose songs. The focal child’s need to make her selection nonverbally was accommodated, and all children benefited from the opportunity to use print to demonstrate their choice of song.

A study by Towson et al. (2016) explored the effect of a dialogic reading intervention on a group of children with significant disabilities. In general, dialogic reading strategies seek to make children active participants in the stories being read or told via a number of adult-initiated prompts and questions. The researchers found that children with disabilities who participated in this reading strategy which included pause time and repeated exposure to words across three different storybooks, showed significant increase in vocabulary.

To sum up, research that examined early literacy practices within inclusive early childhood settings revealed a number of avenues to meaningful literacy development in children who have historically been cast as less capable than their age peers without disabilities.

**Digital technology and early literacy context.** Just before the iPad arrived on the market, Burne, Knafelc, Melonis, and Heyn (2011) reviewed the literature from the previous two
decades in the role of assistive technology in early literacy learning and teaching. They noted the scarcity of empirical research that demonstrates the benefit of assistive technology to promote early literacy learning in young children with disabilities. Even though they found evidence of the benefits of technology for early literacy learning for all children, as well as evidence of the benefits of assistive technology in intervention for children with disabilities, they believed that there had not been enough research linking these two areas. They suggested that more studies that investigated specific approaches in the use of assistive technology to help develop early literacy in children with disabilities might help to build a rationale for, and an understanding of, the effective integration of assistive technology into inclusive early childhood literacy settings. The authors concluded that assistive technology is effective in supporting early literacy in young children, particularly those with disabilities. Importantly, they also noted that some teachers use technology in ways that adhere to universal design principles, and it can, therefore, be used by children with and without disabilities in the same setting. These universal design practices with technology can lead to “greater homogeneity” (p. 212) between children with and without disabilities, supporting the need for more inclusive classrooms and other literacy learning sites.

Up until the arrival of the iPad and other touchscreen computers, researchers (e.g., Shamir, Korat, and Fellah (2012); Verhallen, Bus, and de Jong (2006)) investigated the affordances of the e-book for at-risk and disabled children. iPads and other tablet applications seem to offer promising avenues for children deemed to be at-risk, and/or children with disabilities, to participate in early literacy learning (e.g., Aronin and Floyd (2013); Chai, Vail, and Ayres (2015); D’Agostino, Rodgers, Harmey, and Brownfield (2016); More and Travers (2013); Musti-Rao, Lo, and Plati (2015); Stone-MacDonald (2014). Across these studies, the
consensus is that well-designed apps are able to offer multisensory experiences for children in ways that are different from interacting with printed or other traditional literacy learning material. For instance, an app that incorporated sound, as well as visual elements, helped young children learn individual letters (D’Agostino et al., 2016). Interestingly, in that study, the iPad intervention group was compared to a group that learned letters with magnetic letters. The iPad group made greater gains than the group using magnetic letters. While teachers tended to prefer the magnetic letters overall, the researchers speculated that the iPad letters (designed to look exactly like magnetic letters) did not fall, slide or change orientation as real magnetic letters do. Thus, children using iPad letters would not have to continually re-orient them and would have more time to learn to identify them the right way up without having to ponder which way to put them. Moreover, tablet-based learning opportunities often take place alongside other age peers in inclusive settings. Musti-Rao et al. (2015) reported gains in sight word reading for children with and without special educational needs, noting increased academic engagement across the two-phase intervention study with a sight word app. They concluded the iPad and other tablets provide children who struggle to learn literacy with engaging activities through which they learn more effectively.

The potential impact that the iPad and similar tablet computers has had on children’s learning appears to be far-ranging, even with the necessary caveats about appropriate selection and usage that researchers are also urging (Northrop & Killeen, 2013; Wooldridge, 2016). Since Canadian children with and without disabilities are likely to have opportunities to learn via touch tablet applications, a review of current literature about iPads and early literacy for children with disabilities was warranted to inform this study of what I anticipated would be a range of ways in which children with disabilities were supported in their early literacy experiences across their
home and community settings. This review of digital early literacy research helped inform the findings presented in Chapter 5.

Libraries and Librarians

In general, the preponderance of literature about librarianship is professional and the research literature, while growing, has not kept pace. My impression as a veteran children’s librarian who has published in both professional and research venues is that most children’s librarians learn and develop their professional skills via other more experienced professional children’s librarians. In contrast, children’s librarians rarely participate in research (i.e., as study participants or volunteers, or by conducting research with faculty members). Similarly, children’s librarians rarely attend or present at research conferences. This situation posed a significant problem for my research project: I did not have much research literature from which to draw. In an article in *Library Trends* three decades ago, Rovenger (1987) wrote that “libraries and librarians have been overlooked and underutilized as resources for children with learning differences” (p. 427). An examination of the professional literature about children’s library services indicates that the children’s librarian profession now appears to be committed to improving how libraries are able to provide for children with diverse abilities (Akin, 2004; Baldassari-Hackstaff, Kerber, Krovontka, & Olson, 2014; Banks, 2004; Grassi, Huth, & Jin, 2013; Klipper, 2013, 2014; Patte, 2002); however, there are still relatively few studies as to whether and how this commitment is being enacted. Indeed, in general, research on the role of children’s librarians in supporting young children’s literacy development is scanty (Campana & Dresang, 2011; Celano & Neuman, 2001; Dresang, Burnett, Capps, & Feldman, 2011; McKechnie, 2006; McKenzie & Stooke, 2007; J. E. Mills, Bayo Urban, Campana, & Nelson, 2014; Stooke & McKenzie, 2011). Expectedly then, only a small number of studies have

Moreover, while the work of children’s librarians has evolved to include a significant role in the early literacy movement (American Library Association, 2011; Campana & Dresang, 2011; Celano & Neuman, 2001; Dresang et al., 2011; J. E. Mills et al., 2014; C. Ward, 2007), the impact on the early literacy experiences of children with disabilities remains largely unexplored.

It would appear that a gap in the research about the role of libraries in providing early literacy programs and resources has led public libraries to draw heavily from a single resource, Every Child Ready to Read @ Your Library®, hereafter referred to as ECRR® (American Library Association, 2011). Developed through a partnership that began in 2000 between the American Library Association and the National Institutes for Health, in its first iteration, ECRR® identified these six early literacy skills: phonological awareness, print awareness, print motivation, letter knowledge, vocabulary, and narrative skills. These six skills were promoted as fundamental to a child’s reading readiness. The resource was meant to be used as a train-the-trainer manual by which librarians taught parents about these skills and how to help their children acquire them. After an evaluation of the first 5 years was completed, the resource was revised and expanded. It now identifies many of the everyday things that parents can do to support literacy development and in particular, describes the literacy benefits of playing, singing, talking, reading, and writing with young children while emphasizing the importance of providing literacy-rich environments and hands-on learning opportunities. Librarians who follow the
ECRR® 2nd edition curriculum are now trained to demonstrate ways that parents and caregivers can (and should) play, sing, talk, read, and write with their children in order to provide them with ways to build the aforementioned six literacy skills and best prepare them for school and learning to read.

Although the program itself does not reference Bronfenbrenner, its emphasis on interactive relationships involving librarians, caregivers and children, and the modelling and description of these practices provided by librarians to caregivers, are both reflective of the bioecological model. However, ECRR® is drawn from educational studies that emphasize phonological skills, oral language abilities and letter knowledge, while sociocultural aspects of literacy learning are less apparent. While it is intended to be universally applicable across communities, and focused on parent and caregiver education, the ECRR® resource would appear to have a limited capacity to inform children’s librarians about the range of early literacy theories, especially those that reflect a sociocultural paradigm, which informs much contemporary research in language and literacy education.

In their critique of how research is mobilized in children’s library work, Stooke and McKenzie (2011) stated that “literacy practices derived exclusively from cognitive research cannot be responsive to the cultural and linguistic diversity that characterizes Canada and the United States” (p. 24). I agree with their assessment and suggest also that the narrow frame of the ECRR® resource that includes adherence to developmental norms, as well as normative descriptions of desired literacy behaviour in early childhood, may also limit its applicability for librarians working with families of children with disabilities. However, there remains a gap in the research about the extent to which librarians rely on the ECRR® resource, and whether and
how they are able to use or adapt its tenets in their work with diverse families, including those whose children have disabilities.

In a study of an early literacy initiative provided by a library in Pierce County, WA., Campana and Dresang (2011) measured the effectiveness of an intensive early literacy training program for childcare providers over the course of six months. They found that increasing the early literacy knowledge and skills of caregivers via workshops, early literacy kits, newsletters and one-on-one interactions with a librarian had a significant impact on the children’s early literacy development compared to children in the control group whose caregivers did not participate in any workshops or receive extra resources. Results from a related study called Valuable Early Learning Initiatives that Work Successfully VIEWS2 (Campana et al., 2016) suggested that when librarians who received training in early literacy development emphasized specific early literacy skills during story time programs, measurable changes in children’s literacy knowledge occurred.

As the VIEWS2 study suggested, children’s librarians are now frequently cast as key players in the early childhood literacy movement, alongside early childhood educators and family literacy practitioners. In the absence of research that identifies what parents of young children want and need from their public libraries, children’s librarians are responding to calls for their participation in the early literacy movement, such as the one promoted by the National Early Literacy Panel (Lonigan, Shanahan, & National Institute for Literacy, 2009) and these efforts are reflected in both ECRR® and VIEWS2 projects. While the idea that children’s librarians should play a critical role in the effective provision of early literacy resources in communities is indeed welcome, the narrowly focused conceptualization of early literacy as a set of skills that are developed by following specific practices and doing specific activities leaves
understudied other, diverse approaches to early literacy that might be taking place in public libraries. Given the diverse needs of children identified with disabilities and their families, the need to document what librarians actually do to address this issue is of critical importance, and thus is one of the areas I address in Chapter 6 of this dissertation.

Beyond the continued uptake of the revised ECRR® initiative, the recent professional literature in librarianship provided evidence that the topic of children with disabilities is of high importance to practicing librarians (Baldassari-Hackstaff et al., 2014; Jarombek & Leon, 2010; Kaiser, 2007; Leon, 2011; Prendergast & Lazar, 2010; Winson & Adams, 2010). However, there were comparatively fewer resources about this topic for librarians to develop their own expertise in serving families of children with disabilities (e.g., Barker (2011); Farmer (2013); Feinberg (1999); Feinberg, Jordan, Deerr, Langa, and Banks (2014); Klipper (2014); Prendergast (2015, 2016); Walling and Stauffer (1993).

By examining the professional literature, it became clear that even with the dearth of research literature that could inform practice, programs that address the perceived needs of children with disabilities are becoming more common in public libraries across North America. Many such programs were started by librarians in response to parents’ requests that their children with disabilities have their own story time programs, while others are run in partnership with early intervention therapists such as speech-language pathologists (Prendergast & Lazar, 2010). Such programs most commonly attempt to address the sensory needs of children with autism spectrum disorder (Baldassari-Hackstaff et al., 2014; Twarogowski, 2009). There are also a number of training initiatives and resources available for librarians and other library staff (Association for Library Service to Children, 2015; Farmer, 2013; Jarombek & Leon, 2010; Klipper, 2014; Leon, 2011), and many of these also emphasize providing services to children.
with diagnoses of autism. I was not sure why autism was identified so frequently but I speculated that these autism-focused activities in libraries may be a result of increased awareness about autism in North American society.

Other professional literature describes approaches to the creation of inclusive spaces, collections and programs. For example, Banks (2004) described a Brooklyn Public Library program, “The Child’s Place for Children with Special Needs.” Contrary to what the program’s name suggests, The Child’s Place is for children both with and without disabilities, in an inclusive setting built on principles of universal design and multiple intelligences theory. Activities and events are mindfully planned in advance with “the flexibility to accommodate all children rather than scrambling to adapt a program to the needs of a child with a particular disability” (p. 6). The librarians have sought to create a “fourth model” (p. 10) of service to children with disabilities by going beyond the usual three ways to serve this group: special programs; accommodating individual needs; and outreach. The program reflects the belief that children are children first and are afforded the same or similar opportunities to learn alongside other children, regardless of their developmental variations. In this inclusive service model, early literacy is supported for a diverse range of children simultaneously, within the same activity or program, with individual children benefitting from within their own unique developmental stage. One of their many program offerings is called “Read and Play,” which includes book-sharing and creative educational playtime for children under 5 with and without disabilities, along with their caregivers. In this setting, all children receive support for their social skill and language development by having the opportunity to play with age appropriate toys and to interact with one another. American Sign Language interpreters are made available on request in advance.
In a critical analysis of a sample of 20 urban Canadian public library websites, Prendergast (2013) concluded that the vast majority of the sites presented views of typical child development in the ways that children were invited to participate in programs that matched their age levels. Moreover, early literacy tips aimed at parents of very young children frequently mentioned oral language and phonological skills as ways to build pre-reading skills. She found very few instances of program story time descriptions through which parents of children with disabilities might conclude that their child could or would thrive, while multiple examples emphasized that age and developmental expectations were to be adhered to for participation. Prendergast speculated that the way early literacy story times were sometimes described as being designed for children with typical developmental trajectories might be a deterrent for parents whose children had disabilities.

In some recent research, Kaeding (2014, 2015) and Kaeding, Velasquez, and Price (2017) proposed that libraries could be key resources in the lives of children with disabilities but that, due to lack of experience and training, library workers are often underprepared or unprepared for planning for their inclusion. This research also suggested that parents of young children with disabilities avoid library spaces based on their assumptions that their children’s behaviour will be seen as unacceptable there. These authors recommended developing training for library staff members who deliver services and programs to families, as well as effective outreach initiatives to families that are not currently using libraries.

**Summary of Literature Review**

To summarize, this literature review revealed that children with disabilities are frequently invisible in the discourse about early literacy development aimed at parents, which suggested that such children, and their particular learning needs, may not be considered to be potential
participants in early literacy learning either. Furthermore, researchers who have critically analyzed this parental advice about early learning, while paying attention to issues of diversity generally, tended not to focus on disability. Research about children with disabilities suggests that some parents and educators indicated that they lacked confidence in disabled children’s abilities to learn literacy, while in other cases, they thought that existing programs were not appropriate for them. For example, programs that focused on the development of phonological awareness or oral language generally presented significant problems for children with hearing, speech, or language difficulties, if they were not also provided with opportunities to learn through other modes of strength (e.g., visual modes). However, other research, particularly framed within sociocultural views of literacy, provided evidence that children with disabilities can and do learn literacy alongside their age peers when literacy experiences that build on their existing strengths and interests are provided.

Library research about children with disabilities is scant. Existing library research about early literacy emphasized oral language and phonological skills, thereby creating potential barriers for children with disabilities. However, recent professional library literature revealed a high level of commitment to achieving the goals of diversity, inclusion and social justice (e.g., Johnson (2015); Naidoo (2014); Storytime Underground (2016); Todd (2014)), including the recognition of the importance of effectively serving children with disabilities in libraries.

To conclude, the examination of the related literature revealed that children with disabilities are frequently left out of early literacy discourse and research (including parent advice texts and librarians’ early literacy manuals). This lack of attention may impact disabled children’s opportunities to access early literacy learning opportunities across contexts. Informed by this review of related literature, the case studies that follow sought to address some of the
knowledge gaps revealed in this literature review, with a particular focus on the role of children’s librarians and public library resources in the lives of children with disabilities.
CHAPTER THREE: RESEARCH METHODOLOGY

Introduction

In this chapter, I first draw on sociocultural theory, especially Bronfenbrenner’s bioecological theory and take a critical interpretive stance (Bogdan & Taylor, 1990; Bronfenbrenner, 2005; Kliwer et al., 2006) to trace the steps I took to learn about, and ultimately select, case study methodology. Next, I elaborate on how I conceptualized this as a multiple-case study and then explain each of the three “cases” that comprise it. Then, I describe the data collection techniques I employed, reflecting on the interviews I did, and explain the data analysis procedures I followed to arrive at the findings. I conclude with a summary.

Linking Theory to Methodology

As discussed in chapter 2, Bronfenbrenner (1979) proposed that in an ecological view of human development, a person’s development happens by way of complex interactions between beings from within and across linked systems (i.e., the macrosystem, exosystem, mesosystem, and microsystem) within an ecology. He aptly used the metaphor of a Russian nesting doll to explain the linked systems. For this study, I used Bronfenbrenner’s theory to frame three linked aspects of what I have called an “early literacy ecology” in the lives of children with disabilities. First, I conceptualize the study of early literacy discourse as stemming from a macrosystem, meaning that advice to parents found in such discourse stems from, and perpetuates, macro-social views of normative childhood found in a particular part of the world. I present the findings of this critical discourse analysis in Chapter 4. Next, I conceptualize the study of children’s daily activities, and their parents’ narratives about their daily lives as different microsystems of individual children. To illustrate these microsystems and address questions about access to early learning, I present the findings from the parents’ logs and interviews in Chapter 5. Thirdly, I
conceptualize libraries and the work of librarians as embedded in both the mesosystems and microsystems of individual children in this linked ecology. In Chapter 6, I explore some ways in which librarians might influence the lifeworlds and the development of children with disabilities in this linked early literacy ecology.

**Rationale for Multiple Case Design within Case Study Methodology**

Employing a case study methodology in sociocultural research offers engaging ways to present stories about peoples’ lives that help to address social and educational issues for which there is limited empirical understanding, and to answer researchers’ questions (Yin, 2009). The following definition from Creswell (2007) helped me as I formulated the overall plan for the multiple case study:

Case study research involves the study of an issue explored through one or more cases within a bounded system (i.e., a setting, a context)…Case study research is a qualitative approach in which the investigator explores a bounded system (a case) or multiple bounded systems (cases) over time, through detailed, in-depth data collection involving multiple sources of information… (p. 73)

Building on this definition, I delineated the main issues and topics of concern so that the data I gathered would help me to explicate overarching themes or ideas and thereby help me answer, or at least illuminate, my research questions, as introduced in Chapter 1. I also investigated additional case study resources to inform further my initial approaches to setting up the study. Dyson and Genishi (2005) referred to the “messiness” of the case study approach, and their examples demonstrate that case study research is neither straightforward nor easy. Duff (2008) diagrammatically (p. 100) provided an elaborate view of case studies that suggested to me the complexity of the case study approach and processes. These sources resonated with me as I
contemplated the complexities of my different roles. I thought about how the roles of parent and librarian might have informed my interest in this topic. My parenting experiences have been extraordinarily complex (some would say messy, too) as I navigated a scattered, ableist system of social and educational supports for families like mine. My professional path was similarly uneven as I attempted to develop my own working expertise from a field of professional knowledge that largely ignored the needs of children like my son. Duff’s chart includes bi-directional arrows between elements such as research design and data collection, data analysis and interpretation, which suggested to me the immersive and non-linear nature of a case study investigation. After 15 years of contemplating the conundrum of working in a field of professionals who did not seem to know much about how to provide resources for families and children like mine, I thought I was in a good place to begin tackling some of the complexities of understanding aspects of early literacy and resources and support for early literacy learning in the lives of children with disabilities. Because I had insight from two distinct angles, I knew that I would need to take multiple viewpoints to build a more complete understanding of this phenomenon.

Yin (2009) emphasized that a case study approach allows researchers to gather data from multiple sources (e.g., interviews, observations, and artifacts) to provide a comprehensive understanding of the phenomenon of interest. Because investigation takes place at an intense level, the researcher is more likely to notice, observe, record, and ponder things that were not apparent before. As noted, there is a dearth of research with families of children with disabilities, so very little is known about the interpretations families make of their children’s early literacy experiences and opportunities. Similarly, very little is known about parents’ decisions to participate (or not) in early literacy learning programs such as those offered at public libraries,
one of the main providers of this service. Finally, research in children’s librarianship reveals almost nothing about how children’s librarians are prepared to provide early literacy resources to families with children who have disabilities, nor about how they actually deliver these resources and services. Given so little is known about these three areas, and given the ecological framework that I adopted, a multiple-case study design in which each area of interest comprised a different “case” (Chmiliar, 2010; Yin, 2009) was a good fit for this study.

A case study is an effective way to tell a story that addresses important social issues. Although told within a specific research framework, compelling human stories can be found in good case study research and case studies are able to relate nuanced stories in areas of research where there are known gaps in knowledge (Walters, 2006; Yin, 2009), such as the early literacy field of inquiry concerned with children who have disabilities. My goals in this study were to:

- Identify and analyze discourse about early learning and childhood found in a sample of artifacts (e.g., parenting magazines, government websites) that contain texts meant as advice about early literacy learning for parents. This was to determine the degree to which children with disabilities were represented in such discourse, which I conceive to be representative of the macrosystem in this ecology.

- Learn from parents about their response to these advice texts in terms of their own experiences within this particular macrosystem.

- Learn from parents about their children’s daily lives and routines across various mesosystems (e.g., therapists helping parents learn how to help their child at home) and microsystems (e.g., family home) and learn from their perspectives how services, programs, and other resources might be constructed and deployed to provide more
responsive and more inclusive early literacy experiences for their young children with disabilities.

- Learn from librarians about their perspectives of how, in their education and professional development, they think they were prepared for the role they might play in the provision of early literacy resources for the children in their communities (i.e., the mesosystem) including those who have disabilities, how they provide these services, and how they use their knowledge.

**My Methodological Metaphor: A Spotlight on a Stage**

At an early supervisory committee meeting, my research supervisor asked me to speak about what I had done with my study up to that point. First a bit of background: I grew up in a theatrical family and had worked in many “behind the scenes” kinds of roles over the years, so I am aware of the complexities involved in even the barest stage productions. Given this, I thought about illumination as my goal and a spotlight metaphor emerged as I began talking. No doubt I used it clumsily at that meeting but afterward I kept thinking about what this metaphor might be able to offer my inquiry. Here, I metaphorically set up my study as a stage upon which I could show the living ecology of a child’s early literacy life. On this stage, the ‘star’ or protagonist is a child with a disability; the supporting cast members include the child’s parents and family members (a microsystem), the community in which the child and parents live (other microsystems and exosystems), and the people involved in various aspects of the child’s and parents’ lives (mesosystems). When the curtain rises, I first shine a spotlight on the discourse about early learning that swirls about in this ecology; this is the macrosystem that is sometimes in the background, sometimes in the foreground, sometimes in the hands of the actors themselves, and sometimes on their computer screens or on the streets they walk down and the
places they stop to visit within their community. Then the spotlight falls on a representative sample of artifacts such as pamphlets, websites, and other messages aimed at parents of young children; this illumination allows me to focus on them as a representative discursive case that a family of children with disabilities might experience. While the spotlight shines on this discourse, I ponder the following questions: What might we learn about this macrosystem, this society’s assumptions about childhood? What effect (if any) does this discourse have on parents of children with disabilities? What might be some consequences of navigating this discourse?

Next, the spotlight falls on the actual lived experiences of families within this ecology, their microsystems and mesosystems (i.e., the interacting microsystems). The spotlight may show them reading books and baking cookies, taking walks, and/or visiting friends. While watching this scene unfold, I ponder the following questions: Which day-to-day occurrences and activities can be seen in this ecology that might contribute to (or hinder) the child’s early literacy experiences? What are some of the things that parents and other family members and other adults who interact with this child do in this ecology to cultivate the child’s early literacy growth?

Finally, a spotlight shines on one specific early literacy resource in this ecology: the public library. The various configurations of resources and staffing are lit up while I ponder the following questions: What kinds of experiences, if any, does this child with a disability have in this particular microsystem? What kinds of scenes might play out between the actors in this mesosystem of interactions? What kinds of experiences do the professionals in this linked ecology have working with this child and family? By the conclusion of this study, I have separately shone my metaphorical spotlight on each of three aspects (construed as “cases”) of this early literacy ecology, as shown in Figure 3.1. below.
Figure 3.1. An Early Literacy Ecology

Image adapted from Pixabay.com CC0 Public Domain
Methods

Although data collection and analysis for each of the three cases took place concurrently at different points over the year I conducted the research, in the following sections I explain the context of the study, recruitment activities and the methods I employed in each of the three cases in this linked ecology. For the purpose of clarity, I have simply numbered each of the three Cases 1, 2, and 3, as shown below in Figure 3.2. However, as I explain in more detail later, I sometimes reconsidered, re-examined and re-used some data for more than one of these three cases. In this way, I make the linkages between the three cases or aspects of this linked “early literacy ecology” more evident since they sometimes draw on the same evidence.

Figure 3.2. Cases and Findings

Location/Context

I gathered all the data for this multiple-case study in a large metropolitan regional district containing 21 different municipalities on the west coast of Canada. The most current at the time this study took place, Canada’s 2011 census estimated that 2,280,695 people lived in this region and, of these, 40% were immigrants from other nations. The employment rate of people in the labour force over age 15 was 61.4% and the median household income was $63,347 CAD. In
terms of Canada’s official languages, 69% spoke English most often at home and French was spoken most often at home by just 0.4%. Other languages spoken most often at home in this region included: 4.75% Panjabi; 4.6% Cantonese; 3.3% Mandarin; 4.6% Chinese (specific language (i.e., Mandarin, Cantonese or other Chinese languages) not specified by respondent); 1.5% Korean; 1.5% Tagalog; 1% Persian/Farsi; 1.1% German; 0.8% Spanish; 0.7% Vietnamese; 0.6% Hindi; 0.5% Polish; 0.5% Russian; and 0.3% Arabic (Statistics Canada, 2011). About 49% of the adults in this region had completed at least one post-secondary level certificate, degree or diploma. Additionally, a consortia of 18 public library systems (most with multiple locations) served this region (Public Library InterLINK). I sent out recruitment flyers to 10 municipalities that I could reach easily by public transportation and succeeded in recruiting participants from seven of these. Parent participants came from four municipalities and librarian participants worked in four municipalities, with overlap occurring in one municipality.

**Participant Recruitment**

**Parents/caregivers inclusion and exclusion criteria.** In order to be included in the study, an individual had to be:

- A parent (birth, foster, adoptive) or legal guardian/custodial relative (such as a grandparent, aunt, or uncle) who both lived with, and provided daily unpaid caregiving to, a child labelled with a “significant disability or multiple disabilities in any area of their development (i.e., physical, sensory, cognitive)” between 0 and 8 years old. There were no specific criteria regarding the type of the child’s disability/disabilities for inclusion in this study.

- Sufficiently fluent in both written and spoken English to participate in the study.

Individuals were not eligible for inclusion in the study if they were:
• Live-in nannies or other paid daily caregivers (such as nurses).
• Grandparents or other non-custodial relatives who did not live with their grandchildren.
• Parent/guardians who were not sufficiently fluent in both written and spoken English to participate. I am an English-speaking researcher and the costs for interpreters and translators would have been beyond my means for this study. I acknowledge that families who are not fluent in English may live in the region and have children with disabilities and whose insights would have added to this study.

**Parent recruitment procedures.**

I recruited parents by widely distributing the parent recruitment poster (see Appendix A) in which I described the research project and invited their participation. In doing so, I used the following four strategies:

1. **Third Party Recruitment via Community Notice Boards mailout:** I used Red Book Online (Red Book Online), an online community agency database, to search for agencies and organizations serving families of young children and compiled a list of 120 addresses within the study region. I mailed copies of the poster to these agencies and included a handwritten note saying, “Please post.”

2. **Third Party Recruitment via Family-serving Agency personnel:** Using Red Book Online’s searching function (Red Book Online), I entered search terms such as “disability” and “children” to compile a list of 31 agencies that specifically serve families of children with disabilities (e.g., developmental therapy centres) and that were located within the same geographic region. Along with a copy of the recruitment poster, I sent a letter (Appendix B) explaining the project in more detail than was on the recruitment poster and offering to come to their location to meet families and explain the
project in person. I also provided extra copies of the recruitment poster in a flyer-sized format and asked agency staff (i.e., infant development consultants, social workers, nurses, etc.) to consider distributing the flyers to families who they believed might be interested in participating.

3. Third Party Recruitment via Word-of-mouth/snowball sampling: Over email, I asked 15 personal contacts whom I knew to have had some personal and/or professional connection to disability communities in this region to help me to “spread the word” about the study among their social and professional networks. I attached a PDF copy of the recruitment flyer to this email and asked them to send it to anyone who they thought might be interested.

4. Social media posts: I posted the call for participants on my early literacy blog, Inclusive Early Literacy found at www.inclusiveearlyliteracy.wordpress.com. This call was identical to the text in the print poster that I distributed, except that it only included my email contact information and not the telephone contact information that I included on the print flyer. I also sent out links to this blog post through my Twitter and Facebook accounts and encouraged my social media contacts to help spread the word across the community. I deleted this blog post at the conclusion of the recruitment phase.

When parents/caregivers contacted me, I sent them more information about the inclusion criteria for this study either over the phone or over email. I clarified with them that anyone who played a primary and custodial family caregiving role in the life of a young child with a disability could participate. As I wanted the study to reflect the experiences of a diverse group of families found in this part of Canada, I worried that the recruitment strategies would produce a list of potential participants who were all white, native English speaking, middle-class mothers,
and who, like me, were in relatively privileged social positions. However, the group of people who participated in the study included both mothers and fathers from several different cultural, linguistic, and socio-economic groups found in the region’s diverse population.

In total, 30 parents contacted me about the study. After verifying over email or over the phone that they met all the inclusion criteria, I sent them a letter explaining the study in more detail along with the consent form (Appendix C). Eight of these parents decided not to participate. After the remaining signed their consent forms, I then asked them to begin the first stage of the study, which was to complete a one-week child activity log whenever they were ready to do so. I sent reminder emails to the 22 parents over the course of two months. Fourteen parents (from 13 different families) from five different urban and suburban municipalities completed and returned the child’s activity logs within a few months. I assumed that the remaining eight parents were unable to participate for various reasons, so I stopped contacting them and dropped them from the study.

In stage 2 (interviews), 12 mothers and two fathers (one couple chose to be interviewed together) participated in interviews, for a total of 14 interviewees in 13 families. I compensated families who participated with a gift certificate for a local bookstore which I gave them at the beginning of each interview. Table 3.1. depicts the parent participants (with pseudonyms that participants chose for themselves and their children), their children, their child’s disability, their family composition, and the language(s) spoken at home, according to parent report.
## Table 3.1. Parent Participants

<table>
<thead>
<tr>
<th>Parent name</th>
<th>Child name, gender, age (yrs.)</th>
<th>Child disability</th>
<th>Family composition</th>
<th>Language(s) spoken in the home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abigail</td>
<td>Thomas, male, 4</td>
<td>Autism spectrum disorder</td>
<td>Two-parent, heterosexual</td>
<td>English; Tagalog</td>
</tr>
<tr>
<td>Amy</td>
<td>Evan, male, 7</td>
<td>Autism spectrum disorder</td>
<td>Two-parent, heterosexual</td>
<td>English</td>
</tr>
<tr>
<td>Anna</td>
<td>Andy, male, 4</td>
<td>Language &amp; motor delays</td>
<td>Two-parent, heterosexual</td>
<td>English; Mandarin</td>
</tr>
<tr>
<td>Annie</td>
<td>Michael, male, 6</td>
<td>Autism spectrum disorder</td>
<td>Two-parent, heterosexual</td>
<td>English; Mandarin</td>
</tr>
<tr>
<td>Diane</td>
<td>Jane, female, 8</td>
<td>Cerebral palsy</td>
<td>Two-parent, heterosexual</td>
<td>English; Arabic</td>
</tr>
<tr>
<td>Elizabeth</td>
<td>Maggie, female, 8</td>
<td>Cerebral palsy</td>
<td>Two-parent, heterosexual</td>
<td>English</td>
</tr>
<tr>
<td>Jessa</td>
<td>Benjamin, male, 2</td>
<td>Autism spectrum disorder</td>
<td>Two-parent, heterosexual</td>
<td>English; Mandarin</td>
</tr>
<tr>
<td>Joanna</td>
<td>Nicolas, male, 7</td>
<td>Autism spectrum disorder</td>
<td>Two-parent, heterosexual</td>
<td>English</td>
</tr>
<tr>
<td>Laura</td>
<td>Blossom, female, 6</td>
<td>Learning disability</td>
<td>Two-parent, heterosexual</td>
<td>English</td>
</tr>
<tr>
<td>Leslie</td>
<td>Natalie, female, 4</td>
<td>Global developmental delay</td>
<td>Two-parent, heterosexual</td>
<td>English</td>
</tr>
<tr>
<td>Mary</td>
<td>Mark, male, 8</td>
<td>Autism spectrum disorder</td>
<td>Single parent</td>
<td>English; Vietnamese</td>
</tr>
<tr>
<td>Richard</td>
<td>Bobby, male, 7</td>
<td>Autism spectrum disorder</td>
<td>Two-parent, heterosexual</td>
<td>English</td>
</tr>
<tr>
<td>Steve &amp; Cindy</td>
<td>Lulu, female, 2</td>
<td>Autism spectrum disorder</td>
<td>Two-parent, heterosexual</td>
<td>English; another European language (not identified to protect family’s identity); Mandarin; Cantonese</td>
</tr>
</tbody>
</table>
Librarian inclusion and exclusion criteria.

In order to be included in the study, an individual had to be:

- A professional librarian with a Master’s degree in library and information studies accredited by the American Library Association (currently, this specific credential is required to hold librarian positions in all of the participating libraries).
- Currently working at a public library with responsibilities in early literacy resources in either a full-time, part-time, or auxiliary/on-call substitute basis

Individuals were not eligible for inclusion in the study if they were a:

- Retired professional librarian
- Former children’s services librarian now working in other roles
- Para-professional library staff member (i.e., library technician or other library worker)

Librarian recruitment procedures. Of the 18 library systems that provide public library services in this region, I selected 10 that I could access easily on public transit so that I would be able to get to participants’ places of work for interviews, if they chose that location. These 10 library systems were in the same municipalities where I distributed the parent recruitment flyer. I contacted the 10 public library directors by letter (Appendix D) and asked them to consider approving the participation of some of their employees in the study by distributing the recruitment flyer (Appendix E) to professional children’s librarians on staff. I asked the directors to send back a signed consent (Appendix D) to this effect and seven emailed the signed form back to me. As all public libraries in this region of Canada must offer services in English, I assumed that librarians who wished to participate would have sufficient English language abilities to do so. Twelve librarians who worked at five different public libraries responded to the recruitment flyer and I invited them to participate in one face-to-face, semi-
structured interview of 45-60 minutes in length. I scheduled these interviews at a location convenient to the librarian (i.e., their workplace, a coffee shop, or home). I sent them the consent form (Appendix C) and asked them to sign it in advance of our scheduled interviews. One librarian from one library system had to withdraw from the study before the interview took place. I compensated the remaining 11 librarians for their time with a gift certificate for a local bookstore that I gave them before starting their interviews. Table 3.2. lists the librarians by name (pseudonyms chosen by the participants), year of completion of their graduate degree in librarianship (i.e., Master of Library Science, MLIS), and employment status at the time of the interview.

Table 3.2. Librarian Participants

<table>
<thead>
<tr>
<th>Name</th>
<th>Year of Master’s Degree Graduation</th>
<th>Current Position Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annika</td>
<td>2006</td>
<td>Part-time</td>
</tr>
<tr>
<td>April</td>
<td>1992</td>
<td>Full-time</td>
</tr>
<tr>
<td>Belle</td>
<td>2012</td>
<td>Auxiliary</td>
</tr>
<tr>
<td>Lana</td>
<td>2008</td>
<td>Full-time</td>
</tr>
<tr>
<td>Molly</td>
<td>1996</td>
<td>Full-time</td>
</tr>
<tr>
<td>Natasha</td>
<td>1990</td>
<td>Full-time</td>
</tr>
<tr>
<td>Piper</td>
<td>2004</td>
<td>Full-time</td>
</tr>
<tr>
<td>Robert</td>
<td>2013</td>
<td>Auxiliary</td>
</tr>
<tr>
<td>Sally</td>
<td>2010</td>
<td>Auxiliary</td>
</tr>
<tr>
<td>Sandy</td>
<td>2013</td>
<td>Part-time</td>
</tr>
<tr>
<td>Sophia</td>
<td>2003</td>
<td>Full-time</td>
</tr>
</tbody>
</table>
Defining Terms

Consistent with case study methodology in which data can be collected across multiple sources using multiple methods, I employed a number of strategies to gather and analyze data across the multiple cases. In this section I describe how I gathered and analyzed the data. First, I provide definitions of the key terms I use in this section.

Drawing on similar studies of early learning material aimed at parents (e.g., Nichols, Nixon, et al. (2009); Nichols, Nixon, and Rowsell (2011); Nichols, Rowsell, Nixon, and Rainbird (2012)), I use the term “artifact” in this study to mean the entirety of one of the printed or digital materials that contained cultural content, such as English text and/or images, about early learning, particularly those artifacts designed for parents/caregivers. For example, the whole website, (which may have included multiple tabs or pages) about a provincially funded early learning program counted as one artifact for this study. Drawing again on the work of Nichols et al. (2011), as well as Van Dijk (2001) and others, in this study, I use the term “text” to mean a printed message in English of any length, or signs for any purpose that I found in either or both a printed physical artifact or a digital artifact. For example, the following Figure 3.3 shows one such text found in the section of an arts program catalogue that listed classes for children 2 to 6 years old.

Figure 3.3. Sample Early Learning Text

```
Early Learning classes provide children ages 2 to 6 their first experiences with the arts, at a key point in their cognitive development. Emphasis is placed on exploration, creativity and fun in classes that engage each age group in play.
```
This description was counted as one of hundreds of texts found in this program flier. Only the ones that directly pertained to early learning were analyzed in this study.

Drawing on the work of Boholm (2016); Fairclough (1995); van Dijk (1995), and others, I use the term “discourse” to refer to the overarching social meanings (i.e., those emanating from the macrosystem) that I ascribed to the texts found in the that contained advice for parents/caregivers about children’s early learning.

Case 1: Discourse

Here, I drew on the work of Nichols et al. (2011); Nichols et al. (2012) that explored representations of early literacy “in place,” meaning those representations of early learning found in places such as libraries; shopping centres; medical clinics and so forth. I reinterpreted this approach as I considered the print and digital material I gathered within the large community (macrosystem) described earlier and then analysed it in terms of its implications across various microsystems (homes, community centres, libraries, etc.) for families of children with disabilities.

Gathering web artifacts. As an early literacy practitioner who works in community settings, I already had a degree of familiarity with programs that aimed to provide information about early literacy and children’s learning to parents of young children, so I used this knowledge to conduct an Internet search. My Internet search started with provincial government webpages about early learning programs and school-readiness information for parents with which I already had some familiarity. I used the search terms “early learning,” and “early literacy,” “StrongStart,” and “Ready, Set, Learn,” to name a few examples. After this, I conducted a broader search for digital resources aimed at parents using search terms like “early childhood activities,” “children’s recreation,” “early childhood education,” “early learning,”
“early literacy,” and “early enrichment,” in order to find more specific programs and resources about early learning. This search led me to some enrichment class program websites, library story time descriptions and schedules, and recreation centre program brochures. On the Internet, I found a total of 26 URLs (each comprised one artifact) that contained texts that focused on early literacy. I took screenshots of the content on these sites or downloaded the PDF documents linked at these sites.

Gathering print artifacts. At the same time as I undertook participant recruitment, I spent time visiting public places in each municipality to look for printed artifacts to add to the data set. Over the course of the study year, and in particular when I went to different communities to interview participants, I stopped at places where I looked around for material aimed at parents about early learning. I built a collection of artifacts, which included library program flyers, websites about programs for children that pertained in some way to early learning and early literacy, and so forth. I had simple selection criteria: I included everything I found that contained content about any aspect of learning and/or child development aimed at parents and caregivers of young children. In addition to artifacts that pertained to reading and language development (such as book lists and advertisements for toys that claimed to help children develop reading skills), I also selected artifacts that advertised or promoted activities such as gymnastics and bicycling. Through this process, I gathered 45 printed artifacts from the following locations: five different libraries, eight different recreation centres, two children’s gymnastics programs, one toy store, two book stores, and two grocery stores. In addition to these 45 printed artifacts, I took 28 photographs (each comprised one artifact) of posters, displays, advertisements and other text-based signage in these places. These photographs were not used as
elicitation devices in the interview. They were analyzed along with the gathered print and digital artifacts in the discourse study.

Creating discursive domains. Instead of printing out all the electronic documents so that I would have a print copy of a digital artifact, I decided instead to photograph each of the print documents and put them into one large file containing 99 artifacts (i.e., 26 web artifacts; 45 print artifacts; 28 photographs). Regardless of original format (i.e., screenshot jpeg; e-PDF file; print artifact; photograph of print jpeg), I then organized the artifacts into seven e-file folders labelled by the name of the community of origin, and I then copied them all and re-sorted them into three general domains:

- Provincial government ministries and agencies that fund public education and health initiatives
- Municipal, community, and other not-for-profit organizations such as public libraries and community centres
- Private, for-profit businesses or entities such as children’s enrichment programs, toy stores, book stores and magazine publishers

I conceptualized these domains as representative of the macrosystem in the ecology in this study. To reiterate, the macrosystem influences other systems (i.e., microsystems such as preschool; community centre; library; therapy centre, etc.) in so far as the macrosystem represents the macrosocial and cultural factors that affect how specific policies might be enacted, how well certain programs are funded, and so on. Under each domain, I then grouped artifacts together by their unique names and points of origin. I uploaded all 99 files to Atlas-Ti for coding and analysis. Therefore, the analysis of the artifacts focused on what Bronfenbrenner refers to as the macrosystem, and the discourse about early learning that emanates from, circulates in, and is
reproduced by this ableist society and that some parents of children with disabilities might encounter and respond to. The findings of this analysis are reported in Chapter 4.

Case 2: Parents

Child activity logs. Originally, I considered recruiting families whom I would follow around to various Microsystems (such as appointments and programs) as a participant observer. I had hoped to explore mesosystem influences firsthand (i.e., what a therapist taught them; what song they learned at a library program, and so on.) However, due to the complexities of gaining appropriate ethics approvals for each setting in a timely manner, with input from my committee members, I decided instead to try to capture some sense of the families’ daily lives and routines via a child activity log, somewhat analogous to the parent diaries that Flewitt et al. (2009) employed in their study of children with disabilities. In another example, Ryan and Campbell (2009) found that parent diaries about children’s use of assistive technology and mobility aides in the home to be both practical and reliable. More recently, Plowman and Stevenson (2012) reported on a study in which they asked parents to send both photographs and text messages via their mobile phones as a “visual diary of family activities” (p. 540). In my study, I intended that the content of the child activity log (see Appendix F for sample) would provide context for the semi-structured interviews that followed, as well as help capture a snapshot of daily life across the group of families. After parents signed the study consent form, I sent them a blank child activity log either by email or post (their choice) with detailed instructions about how to complete it over a 7-day period. I also provided parents who asked for the logs to be sent by mail with a self-addressed envelope and sufficient postage for them to return it to me when they completed it. If I did not receive a completed log after 2 weeks, I sent an email to remind the parent to return it. I also reminded them that we would then set up an interview time and that
they would receive a gift card at the interview appointment. This process resulted in 13
completed child activity logs being returned to me via email or post. As soon as I received a
completed log, I contacted the parent to set up an interview within the next few weeks, at a time
and location of their choosing. See Figure 3.4. for a sample page from one participant’s child
activity log. Further on, I describe how I analyzed the logs.

**Figure 3.4. Segment from Thomas’s Child Activity Log**

<table>
<thead>
<tr>
<th>DAY 4 THOMAS</th>
</tr>
</thead>
<tbody>
<tr>
<td>TODAY IS: ____________ Mon, May 12 ____________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>MORNING</th>
<th>MIDDAY</th>
<th>EARLY AFTERNOON</th>
<th>LATE AFTERNOON</th>
<th>EVENING</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whenever you and child get up until 11:30</td>
<td>Approximately 11:30 – 1:30</td>
<td>Approximately 1:30-3:30</td>
<td>Approximately 3:30-6:30</td>
<td>Approximately 6:30pm onwards</td>
</tr>
<tr>
<td><strong>What?</strong></td>
<td>1245 – read book on his own</td>
<td>230-330 walk outside</td>
<td>345 – 430 quiet time with books and toys</td>
<td>645 – baking with mummy</td>
</tr>
<tr>
<td>830 – awake</td>
<td>1 – lunch</td>
<td>430 – 530 play with mummy, read book to mummy</td>
<td>745 bath, story, bed</td>
<td></td>
</tr>
<tr>
<td>850 - breakfast</td>
<td>2 – play with mummy hide and seek</td>
<td>530 dinner</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10-12 - playgroup</td>
<td></td>
<td>6-630 colouring books</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Who?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drop in playgroup (community session with Interventionist)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Where?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Local Family Place</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Interviews with the parents.** I intended for interviews to capture parents’ perceptions
and interpretations of their experiences in supporting early literacy learning of a child labelled
with a disability in the context of a macrosystem that currently emphasizes the importance of
early literacy (see Appendix G for parent-interview protocol). As is apparent in the protocol, the
interview focused on three main topics, each of which took about 20 minutes for a total of 1
hour. I interviewed the parents and recorded the interviews with a tablet voice memo app and later uploaded them all to Express Scribe dictation software for transcription.

For the first topic, at the beginning of the interview, I asked parents if they were familiar with some of the artifacts that I had already been gathering for this study. I wanted them to have a chance to comment on the same samples, so instead of unloading my entire folder, I decided to show them recent issues of the following free resources aimed at parents: *BC Parent Magazine, West Coast Families* and *Urban Baby and Toddler*. These magazines can be found in public places such as libraries, community centres and shopping centres across the region. When possible, I also showed them a community centre flyer and library program flyers from their own municipality. If they said they were familiar with one, some, or all of the samples, I asked them to tell me their general impressions of each artifact and their assessment of its relative usefulness and relevance to them as parents. I asked them to tell me about a time when they had read or in some way used one of the artifacts themselves. Whether or not they had seen or used these or similar artifacts before, I then asked them how they went about finding information for supporting their child’s early learning. The findings from this part of the interview are presented in segments of Chapters 4, 5 and 6, as appropriate to the particular Case.

In the second part of the interview, I asked about the information they had provided in the child activity log that they had completed prior to the interview. I formulated specific questions about one or more of the activities noted in the log. I also asked about their child’s involvement in various activities, and how they sought these and other activities for them. I asked them about any barriers they experienced in finding activities for their children, as well as opportunities for social support for themselves. I present the findings from this part of the interview in Chapter 5.
which explores the barriers and opportunities encountered by these families across their children’s various early learning Microsystems.

In the third part of the interview, I asked about the parents’ experiences, if any, at their local public library and if and how they were able to access early literacy resources there. I also asked them if they had any specific suggestions for librarians to consider when planning services and acquiring or developing resources for children like theirs. Further on, I describe analysis of the parent interview data. I present the findings of this part of the interview alongside the analysis of the librarians’ interviews in Chapter 6.

Case 3: Librarians

Library and information studies curriculum. Consistent with Bronfenbrenner’s notion of mesosystem, the literature suggests that children’s librarians are professionals who have the potential to reach and positively impact diverse community members, including those who experience various forms of social exclusion based on socioeconomic status, language and ability (Barker, 2011; Becker, 2012; Celano & Neuman, 2001; de Groot & Branch, 2009; Rankin, 2016). Also, recent research from the United States indicates that most people place high value on their public libraries (Pew Research Center, 2013) and similar smaller scale surveys (e.g., French, 2015) suggest the same sentiments are held by most Canadians. However, as my own professional experience suggested that gaps remained in my colleagues’ and my own academic preparation for working in Canada’s diverse communities, I also wished to explore the extent to which topics relating to early literacy and serving people with disabilities were covered within a sample of graduate librarianship programs. The American Library Association website maintains a list of accredited institutions that offer graduate degrees in library and information studies (LIS) programs, including those in Canada. In 2014, I compiled a complete list of
accredited programs and assigned each program a number. Of 54 programs that were accredited at that time, I eliminated one French language program and one Spanish language program. Of the 52 remaining programs, I randomly selected 20 programs. I then went to websites of these programs and looked up their course listings. I constructed a table of course offerings on (a) early literacy and/or (b) people with disabilities, and included children’s literature courses if they referenced early childhood literacy, and/or disability issues. Further on, I describe the analysis of this data.

**Professional development document scan.** In addition, throughout the data collection period (January-December 2014), I searched for professional development opportunities that were: (a) offered either locally (i.e., in the aforementioned metropolitan region on Canada’s west coast) or available online via a webinar or online course; (b) aimed at children’s librarians, and (c) offered at least some content on topics related to serving people with disabilities and/or early literacy learning. I identified these opportunities by regularly checking the British Columbia Library Association and American Library Association websites as well as several other library-focused professional development websites, and by reading social media posts that led me to specific learning opportunities offered by other entities. I undertook this brief overview of this sample of LIS course descriptions and professional development opportunities in order to provide some contextual background for the conversations about LIS course content and continuing professional development that I would be having with the librarians. Further on, I describe my analysis strategy for this data and report the findings in Chapter 7.

**Interviews with the librarians.** These took place at either their place of work, their home, or at a coffee shop convenient for them and lasted for approximately 45 minutes each. I recorded the semi-structured interviews (Appendix H) with a tablet voice memo app. I uploaded
the recordings to Express Scribe and transcribed them into text for coding and analysis. I started the librarian interviews by reminding them I would not be evaluating them or their work, nor was my goal to critique their or their colleagues' practices. Rather, I emphasized that I considered their insight into the work of children’s librarians to be extremely valuable to my study. I reminded them that as I worked as a children’s librarian too, I considered the interview to be a way for us to work collaboratively towards enhancing the reach of public library early literacy resources. The librarian interviews addressed the following topics: (a) physical accessibility of spaces; (b) accommodating cognitive/behavioural disabilities; (c) picture book collections about disability (NB: data from this segment was not included in this study); (d) serving families of children with disabilities; (e) their own library’s inclusion statements, policies and actions; (f) MLIS training on this topic; (g) professional development on this topic; and (h) participant’s recommendations. Further on I describe how I analyzed this data and I present the findings of it in Chapter 6.

**Reflecting on Interviews as Co-constructions**

Many research methods include conducting interviews as a way to generate knowledge about something (Creswell, 2007, p. 140). As I described previously, interviews offer a means to explore experiences that are little documented or represented in research. Drawing on literature about the nature of qualitative interviews (Edwards & Holland, 2015; Hollway & Jefferson, 2012), and from my stance as an interpretive qualitative researcher, I entered into the interview stage of my study with the idea that the interchanges I was about to have with these people would become the actual data; the conversations themselves would be the source of whatever I learned from them, and from us together. Edwards and Holland (2015, p. 17) presented the notion that interviews are co-constructed dialogues in which both players interact and influence
and teach one another. Given that my methodology metaphor involves a spotlight on a stage, I thought this conceptualization of dialogic data as performed by two or more players to be particularly apt for my study.

I am a member of both the parent and librarian groups I interviewed. First, the parents and I all have children with disabilities. I believe that my own membership in this particular group played an important role in the interviews. My familiarity with this terrain likely made it easier for me to understand what the parents were telling me about their lives and their children. Their perspectives resonated with me on many occasions and I found myself nodding and concurring. Upon reflection, I think this all unfolded naturally as I did not identify myself as a parent with a child with disabilities during the recruitment stage, nor did I begin each interview by announcing that status. Rather, I approached the interviews with parents with empathy. In order to convey this empathy in the course of our conversations, I made many spontaneous statements about my own experiences in light of the ones they had shared. From my experience, I can assert that this is often how parents of children with disabilities talk to each other outside of qualitative interviews, out in the real world: they share their stories. I know that the community of parents of children with disabilities is not monolithic so I also took the opportunity to ask about their experiences which were different from mine or unfamiliar to me. In this way, I expanded my own understanding of parenting children with disabilities beyond my own and my friends’ experiences. I believe that these kinds of spontaneous, informal exchanges helped create a supportive atmosphere of mutual understanding. I wanted them to understand that even with my background in early literacy and my parenting experience thus far, it was important to me to be able to conduct a study that could offer suggestions for how to make early literacy more accessible to their children.
For the interviews with librarians, I did not include my own qualifications as a professional librarian in the recruitment information. However, because the children’s library community in this region is quite small, I know that the librarians I interviewed knew me as a professional librarian with the same qualifications (i.e., a Master’s degree in library studies) that were prerequisites for participation in this study. I hoped they would see me as a professional peer in our conversations, regardless of how well they already knew me. However, as discussed by Murphy and Dingwall (2001), conducting interviews comes with its own set of power imbalances and I wanted to ensure that the librarian participants did not perceive me as holding a position of professional power over them due to my position as a doctoral researcher with a few years more academic credentials on top of our shared qualifications as professional librarians. I found it natural to talk to my professional colleagues about this topic. Over the years of pondering this area of librarianship, I had already had many similar conversations with colleagues and had a strong sense that many of us shared a belief in the importance of early literacy, about reaching everyone in our communities, and about the importance of making the library a welcoming place for everyone. Not surprisingly, the librarians I interviewed demonstrated enthusiasm for this topic; they were all eager to give their input into research about an area of librarianship that they were strongly committed to improving. I have no doubt that there are children’s librarians who feel differently about this topic but none of them answered my call for participants.

Data Analysis

In his chapter devoted to analyzing case study evidence, Yin (2009) emphasized the critical need for researchers to devise an overall analytic strategy and acknowledged that there are few “fixed formulas or cookbook recipes to guide the novice” (p. 133). To begin with, he
proposed that researchers “play” with their data by making matrixes and data displays or by putting data together via some kind of temporal or chronological scheme. He also encouraged memo writing about what researchers are observing as they gather data. I followed some of Yin’s general strategies -- specifically, relying on theoretical propositions (p. 136), developing case descriptions, (p. 139) and the analytic technique of cross-case synthesis (p. 164). Next, I summarize how these strategies unfolded and give some examples from the data analysis stage.

**Relying on Theoretical Propositions**

As I explained in Chapter 2, I drew on critical disability theory that seeks to expose the enduring impacts of an ableist society on those with impairments. One of the assumptions of the study is that the parents and their children are currently living in such an ableist society and that evidence of such ableism could be discerned by an examination of some of the discourses about early childhood learning (including advice to parents about their children’s early learning) found in their communities as well as in the attitudes and practices found in these communities. As I describe at the outset of this chapter, I also included Bronfenbrenner’s (2005) ecological systems theory in the theoretical framework because I wanted to seek out and examine some of the specific contexts or practices that reflect society’s enduring ableism (Titchkosky, 2009). I wanted to determine whether or not participant families encountered ableism and if so, to examine these instances from the perspective of multiple layers of influence within this linked ecology. Thus, as I proceeded through analysis, I continually considered the data through these theoretical lenses.

**Developing Case Descriptions**

I interpreted the suggested strategy of developing good case descriptions by assigning pseudonymys to and writing descriptive summaries of each participant, including some of their unique characteristics. For example, I selected unique features or activities from each
interview/child activity log set and included them in the descriptive summary for that family. I wrote similar summaries for each librarian (see below for two sample summaries). This process helped to familiarize me with the participants and enabled me to see their unique characteristics and what new insight they shared with me. An example from these summaries is found below in Table 3.3.

Table 3.3. Example Summaries

<table>
<thead>
<tr>
<th>Parent Participant</th>
<th>Librarian Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joanna has son Nicolas, age 7, who has autism spectrum disorder and he was diagnosed as a toddler. Nicolas is verbal and is involved in various activities with his family during a typical week. He rides a bike, swims and enjoys playing games on his iPad. His mother recalls struggling to find programs for him to participate in when he was younger and remembered that he was not able to participate in the same kinds of classes that his sister did. Because of sensory issues related to his autism, Nicolas used to run around inside the library. Joanna does not remember any library staff ever offering her help but rather she recalls feeling scrutinized for not being able to control her child. With the help of his behaviour interventionist, they taught him how to behave appropriately when he is at the library. He now visits the library regularly without any issues.</td>
<td>Natasha, who graduated from her master’s program in 1990, was planning a career in academic librarianship. When she was unable to find a job in that sector, she found work in a busy urban public library which eventually led to an opportunity to try children’s library work. She developed her considerable expertise through a combination of mentorship by other more experienced librarians, as well as some trial and error. Natasha focusses on the needs of each individual family and makes any accommodations that they need in the moment. She also understands why some families of children with disabilities might choose not to come to busy, loud programs but instead she focusses on making them feel welcome and helping them to find books and other material for their children.</td>
</tr>
</tbody>
</table>

I found that this initial strategy, along with frequently re-reading all of the interview transcripts, enhanced my familiarity with the interview data. The descriptions of individual participants helped me to foreground their experiences during analysis. I felt confident that I knew what they meant, how they said it, and the emotional tone behind each statement because I had listened to, read and reread and intensively “played with” the interview data throughout the study.
Three Analytical Approaches

To analyze the data, I used three approaches. For the artifacts, I drew on critical discourse analysis/studies (Fairclough, 1995; Fairclough & Wodak, 1997; Rogers, 2002; Rogers & Schaenen, 2014; Smythe, 2006; St Clair, 2004; van Dijk, 1995, 2001). For the parents’ and librarians’ interview transcripts, I used a modified version of the constant comparative method (Conrad, 1978), and drew from some of the adaptations made to this grounded theory data analysis by Boeije (2002) and Fram (2013). For the child activity logs and document scans of LIS course material and professional development opportunities for librarians, I used content analysis (Hsieh & Shannon, 2005; Mayring, 2000). These analytic approaches and procedures are defined and explained next, along with examples to explicate how I arrived at the findings.

Critical discourse analysis/studies. Van Dijk (2001) defined critical discourse analysis (also called critical discourse studies or CDA) as:

…a type of discourse analytical research that primarily studies the way social power abuse, dominance, and inequality are enacted, reproduced, and resisted by text and talk in the social and political context. With such dissident research, critical discourse analysts take explicit position, and thus want to understand, expose, and ultimately resist social inequality (p. 353).

One of the tenets of critical discourse studies is that they are intended to address social problems (Rogers & Schaenen, 2014; van Dijk, 2009; Wodak & Meyer, 2009) and understand why and how social problems are constituted and reproduced through language. Moreover, CDA intends to uncover, explore, and upset the role of society’s language in use, specifically with regards to these aforementioned issues of power, dominance, and inequality (Rogers & Schaenen, 2014; van Dijk, 1995). Fairclough and Wodak (1997) stated that discourse is socially constitutive and
socially conditioned. They explained, “It is constitutive both in the sense that it helps to sustain and reproduce the social status quo, and in the sense that it contributes to transforming it” (p. 258). Fairclough (1995) also observed that, “Analysis of implicit content can provide valuable insights into what is taken as given, as common sense.” (p. 6). Therefore, I viewed the artifacts as both constitutive of, and contributing to, the majority culture’s thoughts and beliefs about young children’s learning. As pointed out in Chapter 4, prior studies of discourse surrounding the linked disciplines of psychology, child development, neuroscience, and early learning have critiqued the notion of developmental normativity found in various guises throughout such discourse (Cooper, 2013; Gleason, 1997; Ramaekers & Suissa, 2012; Wall, 2004, 2010). For many years leading up to this study, probably because I became a parent of a child with a disability myself, I noticed the prevalence of healthy, able-bodied, almost-always-white, and seemingly middle-class children featured in parenting resources. Therefore, as I began gathering artifacts, I expected to find the same reliance on normative views of children and childhood, in images and in the language used in describing them. As I analyzed and interpreted the artifacts, in keeping with the aims of CDA, I also attempted to identify some of the social justice implications of status quo representations of normativity in early literacy learning as they applied to families of children with disabilities.

I followed Fairclough’s (1995) recommendation to analyze texts through the lenses of both **production** and **consumption**. Production is concerned with where the text comes from and the aims of those producing the text. Consumption refers to the effect the text might exert on the consumer or recipient/reader of the text. I brought both these lenses to the analysis across three levels suggested by Fairclough: description, interpretation and explanation (p. 97). For example,
I began to analyze this booklet produced by the provincial ministry of education and distributed to families of preschool aged children across the province like this:

**Text: Ready, Set, Learn Booklet (ReadNowBC, 2009)**

Production: Government organization, written to encourage parents to provide children with opportunities that are thought to prepare them for school (reflecting macrosystem – societal attitudes about importance of readiness for schooling and parents’ roles and responsibilities in preparing their children for schooling)

Consumption: Parents and other caregivers who provide care to young children (reflecting mesosystem and microsystem). Text might offer some parents/caregivers some ideas about activities to provide for their children with the aim of supporting their school readiness.

Description (text analysis)
Aimed at parents of young children, this text includes recommendations and advice about the following topics: talking; books; numbers; feelings; getting along with others; the wider world; play; TV and electronic media; vision and hearing; physical activity; healthy snacks (microsystem; children’s interactions with “objects, symbols, people” across different contexts)

Interpretation (processing analysis)
Relationship between governmental goals of early learning resources and support that parents are expected to provide for their children voluntarily and parents seeking community resources and information about school readiness (macrosystem influence particular contexts in which parents receive advice from others (mesosystem) i.e., Ready, Set, Learn community events, public health nurses, pre-K programs etc.)

Explanation (social analysis)
Content revealed many examples of taken-for-granted assumptions about universal stages of children development as well as Western cultural values reflected in advice for parents about beneficial activities for young children i.e., books, limiting TV exposure, etc. These are reflective of the macrosystem in which families in this community are living.

In describing the texts found in the artifacts, I included some of the data’s linguistic features and, using Atlas-Ti and my research journal, took note of elements such as the common reliance of phrases and metaphors, for example, referring to children’s developmental “milestones” and describing their brains as “sponges” which I found in various artifacts’ texts across the sample. Following Fairclough’s (1995) description, I then used interpretive lenses to consider relationships between the producer and the consumer (or sender and receiver) of the
text. So, with regard to the Ready, Set, Learn booklet example, I interpreted a relationship between the provincial government (producer) that promoted what the producers (government employees charged with the dissemination of information about early learning) believe to be some of the early learning experiences that parents (consumers) should provide for their children and the developmental benefits of children attending early learning programs, as well as suggestions for how parents might go about preparing their children for entering school. They are linked at the level of the mesosystem in that the resource is brought into the lives of families by some interaction between microsystems. For example, a community program staff person might put up a poster about the Ready, Set, Learn program. A local school that hosts the event might send out invitations to families with young children living in their catchment. Through mesosystem influences, the parent is brought to the information within the booklet, assuming they choose to read it (and act upon it) once they have it in their possession.

Finally, at the explanation level, I drew on social theories while examining social processes and power structures involved in the text’s production and consumption (Bloome et al., 2008, p. 135; Fairclough, 1995). For example, in the example Ready, Set, Learn booklet described earlier, I considered the fact that most parents choose to send their children to public school (funded by the government) and would, therefore, wish to know about the school system’s current expectations of children who are starting kindergarten.

**Constant comparative analysis.** The constant comparative analysis process grew out of grounded theory research methodology in which theory is either generated from, or discovered in, the data (Creswell, 2007, p. 63). The metaphorical adjective “grounded” refers to the notion that theory is grounded in -- or, to use another metaphor, “grows out” of -- the data itself. In grounded theory research, the method of constant comparison offers researchers an analytic
strategy involving the identification of “incidents, events and activities” that are constantly compared to each other in order to build thematic categories (Creswell, 2007, p. 238).

I used a modified version of the constant comparative method proposed by Boeije (2002) in her study of people living with multiple sclerosis. She noted that, “The term ‘constant’ might be a slight exaggeration, but comparison is at the heart of the analysis process” (Boeije, 2002, p. 406). Following her example, and using the qualitative data analysis software Atlas-Ti, I began with open coding (Boeije, 2002). During the first interview, I assigned a descriptive (or “open”) code to each passage, for example “Story time experience”. I then used that same code consistently each time the same topic or phrase came up in subsequent passages in the transcript. Atlas-ti also contains a memo feature where I could write my impressions of statements as I coded them; I continued to write memos “in the moment” at each stage of coding. For example, I compared each instance of a particular code assignment to other instances within the same interview to check for inconsistencies in coding. If I found different meanings between passages, I added sub-codes to differentiate them from one another. This process of open coding helped me to develop the content categories that I initially used to summarize each transcript and formulate each interview’s “core message” Boeije (2002, p. 395).

I continued the process of open coding with each interview within the same set (i.e., within interviews with parents or with librarians). Then, with each subsequent interview after the first two were open coded, I re-examined the collection of interviews by looking at their comparisons to determine if and how the same codes applied to passages across all of the interviews in each participant group. As I analyzed the interviews, I further refined codes by conducting axial coding (a process of determining relationships between codes and then co-aggregating my initial set of open codes). This recursive process resulted in a collection of
compared thematic categories, also known as a “code tree” (Boeije, 2002, p. 398). I had one code tree for each group of interviewees (parents and librarians). I reread associated memos and wrote more memos at each stage of coding. This process allowed me to create additional thematic categories where I thought they were warranted. In Case 1, where I focused on the early learning discourse aimed at parents found in this region and considered its impact on families raising children with disabilities, I merged codes from my data analysis with codes from the parent interviews related to their responses to the early learning texts I asked them to respond to in the interviews as previously described. Again, in Case 3, in order to represent parents’ experiences within libraries, I compared the code trees from the parent interviews with the code trees from the librarian interviews. Because the interviews were intended to elicit the perspectives of two different groups, as expected, there were differences in some of the concerns, ideas and issues raised. Both groups spent some time answering questions about their library experiences and about library resources, including such things as story time. From these dual perspectives, and drawing on my memos -- many of which included reflections on my own experiences both as a parent and as a children’s librarian -- this cross-case analysis helped to contextualize some of the statements from participants in each group on topics with which they both had experience with (e.g., story time), thereby enriching the meanings brought by each group of participants. The following Figure 3.5. displays a sample from this stage of the coding and analysis process.
Content analysis. Given that I wanted to explore specific content found in texts and some of what I found in participant interviews, I selected content analysis as the most efficient way to address the analyses of the child activity logs, LIS course descriptions, and professional development opportunities scans. According to Hsieh and Shannon (2005), content analysis has been used by researchers since the 18th century in both qualitative and quantitative studies across several disciplines. They described different types of content analysis, including summative content analysis, which focuses on the frequency of specific words and phrases from which researchers seek can gain insight into specific contexts.

For Cases 2 and 3, I intended for the child activity logs to capture aspects of the daily lives of children with disabilities and to inform parent interview questions about routines, activities and early learning opportunities, including those in public libraries. Once I had the 13 children’s activities organized by day and time, I found it useful to summarize across the type of activity (e.g., reading, playing, eating) across the families. This summary allowed me to develop
a description of the children’s activities as a group and I was able to consider the range of activities in which they participated, while choosing salient examples to highlight. I was able to count instances of activities in order to gather some quantitative data about the children’s daily routines, what they did, and with whom. I include a more detailed discussion of the child activity log content in Chapter 5. Appendix I is a compilation of all the logs’ content.

For Case 3, to analyze the LIS course descriptions, I read through the course descriptions found on each site and then copied and pasted course numbers and their descriptions if they included any of the following key words and/or phrases: children’s services; diversity; multicultural; early childhood; early literacy; diversity; inclusion (or any derivatives thereof); special needs; disabilities; accessibility; accommodations and Universal Design. I included children’s literature courses if they included some or all of the above keywords in their descriptions resulting in 53 unique course descriptions. To analyze the content from the 19 professional development opportunities I had identified, I first created a table that included the name of workshop, webinar or online course and copied their course descriptions. Next, I divided the courses into in-person and online categories and I noted whether the opportunity was free or not. I analyzed the content of these professional development opportunities by looking in particular for instances of terms such as: inclusive; inclusion; accessibility; equity; special needs; and outreach. These data about LIS education and professional development opportunities for children’s librarians helped to provide contextual background to the segment of the librarian conversations that focused on their own knowledge, of and access to professional development in this area of practice. I report the findings from this part of Case 3 in Chapter 6.

Content analysis differs from the critical discourse analysis in that the issues of production and consumption, and the power imbalances inherent in social problems are not at the
forefront of content analysis. This is not to say it cannot be used in critical ways; however, for this study, my goal was to describe what the parents included in their logs in order to capture some snapshots of days in the lives of the participant children and to help me tailor some interview questions to their unique contexts. For the librarians, this overview of current LIS course listings and the professional development workshop descriptions helped guide my interview protocol, and inform me about what professional colleagues had covered in their LIS programs, and what kinds of professional development opportunities had come their way since they graduated.

**Data Triangulation**

Yin defines case study triangulation as “the convergence of data collection from different sources, to determine the consistency of a finding (Yin, 2009, p. 241).” He states:

The use of multiple sources of evidence in a case study allows a researcher to address a broader range of historical and behavioural issues. However, the most important advantage presented by using multiple sources of evidence is the development of converging lines of inquiry (p. 120).

For example, in this study, I compared the data from the artifacts, the interviews with parents, and the interviews with the librarians, and found that the relative absence of inclusionary practices in community based early literacy programs for children with disabilities was evident in all three domains.

**Limitations and Conclusion**

Yin (2009, p. 168) described four principles of high quality analysis, as listed Table 3.4, which includes examples of how I addressed each of these principles in this multiple-case study.

**Table 3.4. Yin’s Analysis Principles and Actions**
<table>
<thead>
<tr>
<th>Yin’s Principle</th>
<th>Actions to Address</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attending to all the evidence</td>
<td>Examining all artifacts: child activity logs; interviews, academic and professional course descriptions, and relevant research</td>
</tr>
<tr>
<td>Addressing all plausible rival explanations</td>
<td>Comparing evidence from different data sources; presenting a range of experiences across a spectrum of participants; referring to existing relevant research; offering my own speculation about ambiguity</td>
</tr>
<tr>
<td>Addressing the most significant aspects</td>
<td>Allowing theoretical propositions to help guide the data reduction processes; surfacing most meaningful, relevant data to come to new conclusions about phenomena of interest</td>
</tr>
<tr>
<td>Using own prior, expert knowledge</td>
<td>Reflecting on, recognizing and addressing my biases, balanced with my own scholarly knowledge and personal insight as an “insider” of both participant groups</td>
</tr>
</tbody>
</table>

I believe this case study to be limited by the small sample size. Also, the participant groups (parents and librarians) had no specific linkages so, while they spoke on similar topics from different points of view, I cannot be sure their statements would be similar if they had each spoken about the exact same context (the same library) or interaction or event (for example, if I had been able to speak to a librarian who conducted a particular story time as well as a parent of a child with a disability who attended the same story time). Nevertheless, this area of early literacy is under-investigated and despite these limitations, I believe the study reveals a number of pressing issues that need to be addressed in order to make literacy resources and programs accessible to all families who wish to access them. This multiple-case study aimed to draw connections between early literacy discourse and experiences and to point out the ways in which taken-for-granted assumptions about, and practices surrounding children with disabilities may impact their access to inclusive early literacy learning. In this study, I wanted to learn from parents and librarians about services, collections, programs, and other resources that may support the provision of more responsive and ultimately more inclusive early literacy experiences in the lives of young children with disabilities. Case study methodology, specifically a multiple-case
design, and the processes by which I recruited participants and selected and analyzed the data used in this study allowed me to capture and ultimately portray new insights into this understudied area of early literacy which I report on in Chapters 4, 5 and 6.
CHAPTER FOUR: WHERE IS MY CHILD? NORMATIVITY AND CHILDREN WITH DISABILITIES IN EARLY LEARNING

Introduction

Heightened interest in early child development during the past few decades is reflected in a proliferation of research in early learning, and particularly, in children’s early literacy experiences. This research is, in turn, translated into information aimed at parents via initiatives, programs, services, advice and recommendations seen across the Western world, both in print and online and found within community settings (McTavish, 2012; Quirke, 2006; Wall, 2010) as well as private businesses (Nichols et al., 2012). However, most early learning research, when turned into advice aimed at parents, fails to reflect individual diversity and, in particular, only rarely provides advice or support for literacy and learning for children with disabilities (CELL: Center for Early Literacy Learning, 2015; Reach Out and Read, 2010). Moreover, existing research with families reveals very little about how parents of children with disabilities navigate this parent-focused terrain of early learning.

When parents are raising children with disabilities, they may need information about early literacy and learning that is more suited to their children’s developmental characteristics, which may significantly differ from those of typically developing children (Reach Out and Read, 2010). As explained Chapter 1, *early literacy* and *early learning* are broadly defined and include resources that have a focus on physical skills and recreation, in addition to resources more recognizably applicable to early literacy learning (i.e., oral language, songs, and stories).

In this chapter, I attend to the questions of how children with disabilities are represented in this collection of early learning texts gathered from artifacts found in an urban community in British Columbia, Canada (my methodology chapter contains my definitions of *discourse*,...
artifact and text as they are used in this chapter). I also explore what this collection of early learning texts said or did not say about the literacy and learning development of children with disabilities. I report what parents of children with disabilities say about how they navigated this terrain of research and advice, and I conclude by considering some of the implications for access to early learning opportunities and information for children with disabilities and their families. The aim of this study was to document the discursive early learning landscapes that were present in a large urban community and, in particular, the pertinence and/or relevance of the advice as perceived by 13 participant families. This research aimed to investigate both implicit and explicit representations of, and assumptions about, developmental normativity in early learning as found in this large urban community.

**Research Questions**

In this study, I analyzed a collection of artifacts on the broad topic of children’s early learning that were aimed at parents and accessible and/or viewable (either in print or online) in a large urban region of British Columbia. From a sociocultural standpoint and drawing on critical disability theory (Devlin & Pothier, 2006a; McGowan, 2014; Thomson, 2015), I used methods from critical discourse studies (Fairclough, 1995; Van Dijk, 2001, 2009) to answer the following research questions.

1. What are some of the implicit and explicit messages about child development and early learning that are present in artifacts from government, community and commercial domains that are aimed at parents of young children in this community?

2. How do some parents of children with disabilities interpret and respond to the implicit and explicit messages about child development and early learning that they encounter in some of the texts within such artifacts?
The collection included 99 artifacts gathered during 2014 in various places and spaces found in a large urban community in British Columbia. Artifacts were drawn from three domains:

- Government: Provincial government ministries and agencies that fund public education and health initiatives such as StrongStart and Ready, Set, Learn programs for families of young children (British Columbia. Ministry of Education, 2008) as well as provincially funded early intervention services (British Columbia Ministry of Children & Family Development, 2008) (9 web artifacts and 3 print artifacts);

- Non-profit/Community: Municipal, community and other non-profit organizations such as public libraries and community centres (7 web artifacts, 23 print artifacts and 5 photograph artifacts);

- For-profit Entities: Private, for-profit businesses or entities such as children’s enrichment programs, toy stores, book stores, and magazine publishers (9 web artifacts, 20 print artifacts and 23 photograph artifacts).

As described in Chapter 3, data included print, photograph and digital artifacts and the texts therein, as well as parents’ comments about a collection of such texts as well as any resources and programs promoted in such texts as they were discussed in the 13 semi-structured interviews conducted with parents of young children who are labelled with disabilities.

Building on the studies reviewed in Chapter 2 that critically examined government policy statements, parent advice literature and early and family literacy discourse, and as explained in Chapter 3, here I analyzed the early learning-focused texts found in these 99 artifacts for assumptions of developmental typicality as representative of some of the enduring barriers to access to a range of early learning experiences for children with disabilities. I also analyzed interviews with parents of 13 children with disabilities regarding some of the early learning texts.
As well, I critically analyzed some of the resources promoted in these texts. Finally, I conclude by pointing out the social justice implications of separating children based on ability, calling for a consideration of how texts about early learning should or could be altered to help reshape early learning contexts and opportunities to better anticipate and invite children with disabilities. In this way, early learning discourse may begin to reflect more inclusive views of children than currently exist and the need to provide opportunities for their participation in early learning across contexts.

**Findings**

As explained in Chapter 3, each of the 99 web, print and photograph artifacts I selected were assigned to 1 of 3 main domains (government, non-profit and for-profit) and each of these artifacts was examined for texts pertaining to early learning. Some artifacts contained multiple early learning related texts and some contained very few related texts. All texts were then coded and analyzed using tenets of critical discourse analysis (Fairclough & Wodak, 1997).

**Government Domain**

As explained in Chapter 3 (Methodology), I sought out government domain information mainly by conducting Internet searches pertaining to early learning on the Government of British Columbia website and ended up with 9 web artifacts (webpages and e-PDFs). I also gathered three printed booklets advertising government-funded early learning programs that I found in the foyers at two different public libraries. The texts in these 12 artifacts organized for analysis under the government domain category reflected very widely held notions about the importance of family involvement in early learning (Dail & Payne, 2010; Shanahan & Lonigan, 2010). Suggestions and advice to parents frequently promoted print activities, reading aloud, and avoiding too much television, as well as providing plenty of time for free, active play, rest, and
good nutrition. One resource in particular included multiple suggestions for families about how to participate in their children’s development, with a particular focus on getting them ready for school. A close analysis of the texts found in this web artifact follows.

**Ready, Set, Learn booklet (web artifact).** A provincial program called *Ready, Set, Learn* (ReadNowBC, 2009) provided funding to public elementary schools to host events for families with three-year-olds to come to find out about kindergarten readiness resources available to them in their home communities. Families attending these events were all provided with a booklet that “offers information about the typical development of a preschooler, including tips for supporting your child’s learning in key areas of development” (p. 1) and a PDF version is available for download on the province’s website (ReadNowBC, 2009). This resource provided a brief overview of typical child development and included tips for encouraging growth across different domains. As the *Ready, Set, Learn* booklet was explicitly intended to be used as a school readiness tool, it is perhaps not surprising that language and literacy skills were referred to over 50 times in this 25-page booklet with statements like, “There is a strong link between what preschoolers know about books, words, sounds and letters and their readiness for school” (p. 4). Parents were advised to ask questions of their children about the pictures in books and to make sure to pause and discuss the meanings of new words. Parents were also advised to limit their preschooler’s television viewing in favour of reading together (p. 15) and encouraged to visit libraries to borrow books about typical childhood experiences like going to the dentist (p. 18). In this way, the benefits of books and reading together were linked to other common occurrences and necessities of childhood such as dental care. Notably, parents were constructed as teachers in this document and were assumed to be able and willing to take on pedagogical stances. Some of the advice in this booklet could apply to children with disabilities. For example, the advice given
to “Share books that show people of different cultures, genders, ages and abilities” (p. 5) can be applied to all children. However, most of the tips and advice assumed normative development with no adaptations or variations for parents of children who have atypical development offered in any of the areas covered. To elaborate, a preschooler’s ability to speak was assumed in almost all of the tips in both the language and literacy segments of this booklet such as: “Expand your child’s sentences. If your child says, “Daddy cook soup,” respond with, “Yes, Daddy is cooking vegetable soup for lunch” (p. 3). The only reference to children with disabilities in this resource was found on the first page:

This *Ready, Set, Learn* booklet offers information about the typical development of a preschooler, including tips for supporting your child’s learning in key areas of development. Remember these are just guidelines. Children learn at their own pace. If you have concerns about your child’s development, talk to your doctor or public health nurse. A child with special needs may develop differently and may have goals that are more appropriate to their needs and abilities. Refer to information provided by your doctor or other health professionals for specific special needs support information. (p. 1)

I also analyzed web based and print resources about another government program aimed at preschool-aged children called StrongStart.

**StrongStart (print artifact).** *StrongStart* artifacts (from websites and handouts found in communities) included statements about activities for young children that are similar to those found in the *Ready, Set, Learn* program brochure. For example, the StrongStart website said:

The overall learning experience is shared as parents and caregivers attend with their children and are encouraged to get involved in activities like telling stories, playing games and serving healthy snacks. (British Columbia, 2014)
A StrongStart brochure advertising programs in a suburban community said:

A FREE EARLY LEARNING DROP-IN PROGRAM focusing on preschoolers 0-5 years and their parents/caregiver. Your child will feel free to explore and play in an environment that is friendly, safe and inspiring. You will get to share in the excitement and successes of your child’s early learning experiences.

This brochure continued with a list of the kinds of activities (e.g., sand and water play, art activities, literature and storytelling), and stated that “families are welcome to drop-in to these programs any time, any day” and concluded with information about registration. There was nothing specific regarding the inclusion of children with disabilities but nothing overt about normative developmental expectations either. Since the program was aimed at children from birth to 5 years old, it seemed likely that families with children who have developmental delays would find something developmentally appropriate for their children to play with at these programs, even if they ended up playing alongside younger children sometimes.

Another example of early learning texts aimed at parents emanating from the government domain was found at a family literacy community picnic in which various organizations (government services, community services and other programs had tables for parents to browse).

Public health poster (photo artifact). A poster titled “Be Kindergarten Ready!” produced by one of the province’s large health region’s public health nurses was on display at a family literacy themed community picnic. As it originated from the health authority, the poster advised parents to get their children’s hearing and vision checked and to be up-to-date on their immunizations prior to kindergarten. However, the poster also provided several early literacy tips under these headings:

Motor Skills
• Hold pens, pencils and crayons to draw

Social and reading skills
• Write and recognize own name
• Recognize some shapes, colours, numbers and letters

What can parents do?
• Read and discuss books

Overall, a standardization of early literacy learning advice found in texts emanating from the government domain was strongly evident. These resources all promoted the importance of reading books to young children, encouraged children’s familiarity with print and promoted verbal language and fine motor skills in pursuit of kindergarten readiness for children.

Parents’ interpretations of texts from Government Domain. None of the 13 parents interviewed could recall attending Ready, Set, Learn events, nor reading any of the printed materials from the program. However, four families (Richard and Bobby, Steve/Cindy and Lulu; Laura and Blossom; Jessa and Benjamin) had learned about the StrongStart programs in their communities and had attended them with their children with disabilities. Bobby’s father Richard recalled that he found it stressful and often crowded at the site where they had attended the program, so they did not continue going after a few visits.

I remember it being crowded and remember being anxious of him having to wait for the trampoline or these kinds of things and he was somewhat difficult at that age and yeah so, my wife was doing it partially for socialization with other kids and that kind of reason but that’s just really - that's more difficult if you have a child with special needs. (Richard, personal communication, June 2, 2014)
At the time of our interview, Lulu’s parents took her to StrongStart at least once a week. In this program, an early childhood educator acted as facilitator while children played and parents were encouraged to interact with and support their children, as well as meet other adults raising young children. Cindy talked about how going to the program helped her see that her daughter’s social skills were not too far off, despite Lulu’s recent autism diagnosis. She said:

The one thing about the StrongStart program is that - so when she was playing with children there she won't be playing really with them, she just plays in the same room, but I saw at the StrongStart it’s normal for children at that age, so it kind of made me less worried - other children who are 2 and 3 years old, they don't really play with others either! (Cindy, personal communication, June 4, 2014)

Laura, Blossom’s mother, noted that the StrongStart site that she attended was not busy and that quality likely helped her daughter (who has since gone on to elementary school) thrive there when she was younger:

Mine was not a big crowd - there are two in the area and I believe one was quite busy… the one we were at was not crowded. Some days there were only four or five kids there so it was really, really nice. We wanted an activity where she was running and doing stuff and then she got to do playdough and painting and really she could choose and I would just follow her around and she could choose what she wanted to do which was great - you want to do the craft - great - if you don't then go over here to do playdough –great. They could do what they wanted to so it worked out very, very well for us and it was not overcrowded and it was not busy. (Laura, personal communication, June 9, 2014)

Jessa, whose 2-year-old son Benjamin had been diagnosed recently with autism, regularly drove across the city in order to take him to a StrongStart program:
I like it because I think it kind of enforces a kind of preschool like routine and then he expects that everyone has to sit together and circle-time and stuff like that - he's a very observant kid, like he'll sit there and he won't really run around - he'll watch but he doesn't really participate… but he comes home and then participates - like he comes home and then repeats these songs to me but he doesn't do it there. (Jessa, personal communication, June 6, 2014)

Three of the four families who attended StrongStart described positive experiences while there and they valued the chance the program gave their children to play alongside other children, interact with a variety of material, learn songs, and listen to stories, although none of them identified kindergarten readiness as a motivation for attending. Cindy mentioned that if the StrongStart facilitator read a book that Lulu liked, they would head to the library afterwards to find the book and bring it home to re-read. None of the parents could remember how they learned about StrongStart and none remembered any promotions that specifically mentioned including children with disabilities. As well, none of the texts I analyzed mentioned that the program welcomed all children, including those identified with disabilities. The activities that the families enjoyed were consistent with those described in texts and I speculated that for children with “invisible disabilities,” having a successful time at a StrongStart program was more likely if contextual factors such as group size (which parents mentioned) and facilitator skill (in selecting and preparing activities that are enjoyable and appropriate for children with a range of development) were managed.

**Non-Profit/Community Domain**

As explained in Chapter 3, I gathered 35 artifacts (web, print and photographs) from community settings across five municipalities where the study took place. As described earlier, I
collected the print and photograph artifacts in various locations near where participants lived. I gathered the web artifacts by conducting Internet searches as well as following leads from parent interviews about programs in which their children had participated. I next report the findings from the non-profit/community domain,

**Public libraries.** The texts from the public library system also focused on supporting school readiness, suggesting resources designed for parents and offering advice. For example, one public library loaned out Kindergarten Readiness Theme Bags to parents. On the library website, these bags were described as follows:

Each bag contains six books that will help your child learn concepts like the alphabet and numbers and gain important social skills. Share the joy of reading together and help your child get ready for kindergarten. Reading aloud the books to your child is an excellent way to increase your child's speaking and listening skills and develop comprehension and word knowledge. The theme bags are great starting points for nurturing your child's lifelong love of reading.

The texts found in artifacts from libraries and on library websites were aligned with the developmental advice discussed in the government domain above, with a strong focus on reading aloud to children and supporting children’s oral language development. For example, one of the libraries had Every Child Ready to Read (American Library Association, 2011) pamphlets available for free in the children’s area for parents. These pamphlets offered advice to parents regarding their role in supporting their children’s early literacy development through singing, reading, playing, writing, and talking. This advice text, aimed at parents, emphasized oral language and promoted the notion that reading aloud to children is the best way to prepare them for learning to read.
Another group of artifacts gathered from public libraries provided more specific resources about various story time programs and book titles for parents of young children. Several booklists were gathered from one library with each list showing titles aimed at different age groups (e.g., “Books for Babies and Toddlers” and “Going to School”). “Books for Babies and Toddlers” featured a photograph of a father and young child reading together on the cover along with 50 recommended books to share with very young children. None of the books listed were about children with disabilities, nor did any have themes related to having differences or exceptionalities. Nonetheless, the books listed were aimed at very young children and would likely be enjoyed by children with a range of abilities. The booklist concluded with a list of suggested activities to encourage reading, such as singing nursery rhymes, giving books as presents and visiting the public library; however the advice assumed some degree of developmental typicality by referring to speech, hearing and sight.

The booklist aimed at slightly older preschoolers titled “Going to School” featured a clipart illustration of ethnically diverse children riding in a school bus on the front and contained a list of over 30 picture books about starting school. None of the titles listed were about children (or animal characters) with disabilities who are going to school for the first time. The booklist did not include any other advice aimed at parents.

While the underlying themes were the same as those found in texts emanating from the Government domain and the ECRR® texts (i.e., reading to your child is a good thing to do and will help them get ready for school), I concluded that booklists like those just described were meant to guide parents towards the material resources (i.e., the books and kits) to use in shared reading. In terms of inclusiveness, none of texts from public libraries specifically pointed to resources that might be particularly useful for, or relevant to, parents of children with disabilities.
BC Association of Speech-Language Pathology and Audiology (BCASLPA) Poster.

In this poster found on display in a public library, early literacy tips that emphasize spoken words and print activities were echoed again in the advice given by the province’s association of speech-language pathologists. The text reads as follows:

Literacy means being able to read for understanding and enjoyment and to write about your thoughts and ideas.

Research shows that reading to a child is the most important thing adults can do to help develop language, prepare a child for school, and to give them a love of learning.

Talk to a child about their world, read a book aloud, point out words on signs, or write a text or email together.

It is interesting to note that this poster did not make mention of the role that speech-language pathologists play in working with families of young children who have speech-language delays and disabilities.

Community Centres. The texts about early learning in the six Community Centre flyers were mainly directed at parents and caregivers. Rather than providing developmental checklists of milestones or suggesting discrete activities, they described specific programs or resources. These descriptions were provided to encourage registration in the programs and activities, sometimes suggesting how these types of experiences might support areas of child development. For example, text about the program, “Sing a Little Song” from the Mount Pleasant Community Centre Spring & Summer 2014 Recreation Guide included the following text:

Simple songs to encourage singing. This class also offers a little bit of movement and dance, and your child will be introduced to a wide range of percussion instruments.
Music, song, and dance are a wonderful way to connect and enjoy, and enhance your child’s ear, and social skills (sic).

Even though all community centre artifacts (both print and web) claimed the centres to be welcoming, inclusive and accessible for all, closer analysis revealed some incongruence with regard to accessibility and inclusion. For example, in addition to offering a few “adapted” programs designed specifically for children with disabilities, one city’s recreation service invited parents of children with disabilities to apply for support to attend regular programs alongside their non-disabled peers and pointed to a pdf file application. The application form asked:

What support/accommodations are required in order to take part in activities?

Personal care required and/or medications used?

Who will provide this care and/or administer the medications (City Staff/Volunteers cannot administer medications nor provide personal care).

The application form said that support was limited to the possible provision of a youth volunteer worker who would only be able to provide some companionship and one-on-one attention and noted that they were unable to provide any personal care for feeding and toileting. Children in need of such a level of care were invited to attend but needed to be accompanied by their own support worker.

*Parents’ interpretations of texts from Community Domain.* As I explained in Chapter 3, the parent interviews included time to look at, and discuss, a sampling of the artifacts I had been gathering. For example, I showed them the most recent community centre flyers from their own municipality and asked if they had ever seen, read or used them to find activities for their children. I also showed them flyers from their local libraries. The parents were familiar with their local community centre brochures and had registered their children for various activities in the
centres over the years. Joanna spoke about the exclusion she felt based on her child’s disabilities, saying, "So I did look at community centre brochures and they just weren't for us because I know he can't attend without me paying double really, paying for someone to be with him" (personal communication, April 2, 2014). Joanna explained that, instead, she tended to select specialized programs offered by organizations that catered to children with the same diagnoses as her child. However, she experienced long waiting lists and age restrictions for these types of programs. I also noted that these specialized programs were not promoted within any of the community texts, and thought it likely they are only promoted to members of specific organizations. Cindy, mother to 2-year-old Lulu, used her local community centre flyer to find activities for her daughter.

We looked up activities in the community leisure guide and actually I was on the phone with my friend, we went to sign up for our kids and we try to communicate and from my perspective of looking over that leisure guide is that things are not really for kids on the spectrum so we're just signing up for things that she potentially could be interested in. So our daughter used to be more severe, on the spectrum, and I think now when you put her in a class you don't really notice that she has a problem, so she could sort of blend in, and we just keep in mind that some classes she might like, some classes she doesn't like, then we think it out ourselves… but the guide is totally not, not specifically saying anything like “for children with needs” or anything… actually I don't see any. (Cindy, personal communication, June 4, 2014)

Laura agreed by saying that, although she looks at all the flyers from her local centre, she never sees anything that indicates intentional inclusion:

Well I don't know if there's anything - like that's the thing - like I don't know - I've never seen anything where it says "this is for...." Really, it’s not anything for special needs - I
don't see anything in flyers and I look through them. Any classes I put her in, I just put her in as a typical child and I'm there watching. (Laura, personal communication, June 9, 2014)

Finally, Anna, mother to 4-year-old Andy, recognized her local community centre flyer when I showed it to her but then said she did not really look at them because “it’s too much information.” She went on to say that she was more interested in finding a “proper program” for Andy; she explained that she only wanted programs targeted to his needs and she relied on her child’s developmental consultant to make referrals for them (personal communication, April 28, 2014).

Although the families in this study made regular use of their local libraries or their children’s school libraries, none had seen the specific flyers I showed them from their own libraries. In Chapter 6, I report on families’ experiences in and with public libraries.

In summary, although they used their community centres to find activities for their children, the parents had not noticed anything specific about inclusion for children with disabilities in the early learning programs promoted in the texts from their community centre nor did they expect it.

For-Profit Domain

In the 52 web, print and photograph artifacts gathered from commercial places and spaces such as enrichment programs, toy stores, book stores, and magazines aimed at parents, the texts directed at parents focused on product or program promotion and were uniformly vague in considering of the needs of children with disabilities. I chose to elaborate on those texts from artifacts in this commercial/for-profit domain that were most closely related to aspects of the conversations I had with parents about their children’s activities and opportunities for early
learning in general, as well as more specific early literacy-focused activities and opportunities. In Chapter 1, I defined early literacy and early learning broadly and included activities that encompassed physical development such as gymnastics and bicycling, mainly due to the inherent communication and language aspects of these skills (i.e., vocabulary). I was also curious about whether programs that focus on physical development would present different access issues than programs that focus on cognitive/language/literacy development.

**Enrichment programs & classes.** The collection included web or print artifacts from nine different privately-owned entities that offered programs for young children, ranging from mathematics to bicycling. In ways that were similar to the community centre program descriptions, these for-profit entities claimed various benefits for children who attended their programs. Six of these entities (a fine arts preschool program; a literature and art program; two different music programs; a mathematics program; and a baby massage program) did not have any information about inclusion, inclusion policies, or how they might welcome or accommodate children with disabilities. Three programs (two different gymnastics programs and one bicycling program) provided information about how children with disabilities could participate on their FAQ pages but not on their main pages.

For example, a segment of text found on the website of a gymnastics program for young children mentioned their special needs services that included an additional program fee that essentially amounted to double what children without disabilities would pay. In the FAQ section of another gymnastics program the question “DO YOU WELCOME CHILDREN WITH SPECIAL NEEDS” was followed by an answer that said “Yes! We are a family centered program and would love to work with you to develop an IGP (Individualized Gymnastics Plan)
to ensure that your child has everything they need to thrive in our classes.” I followed up with an emailed inquiry about what this might entail and the company responded by saying:

Children with special needs are welcome; however, we do require that prior to enrolling they submit a physiotherapist’s assessment of their abilities and/or limitations. This serves as a guide for coaches which helps them to achieve maximum success in their classes and keep the atmosphere fun and upbeat. We also require the child has an aid worker with them during classes. (Gymnastics, personal communication, May 15, 2015)

Similarly, in the website FAQ section of a popular bicycling program the company simply advised parents of children with special needs to send their child to bike camp with a person who could act as personal assistant without offering any other information.

**Parent interpretations / experiences of enrichment classes.** When we discussed these websites and flyers, none of the parents I spoke to were surprised at either the vagueness of the language about special needs (if there was any) and reiterated that they rarely, if ever, saw promotions that included invitations for children with special needs from businesses catering to young children’s learning. Similar to the way they assessed other programs, the parents tended to try things out and see how they went. I found that the existence of information about serving children with disabilities did not necessarily correlate with parents’ experiences of inclusion. For example, the private institution that offered arts and literature programming for children ages 2 and older made no mention of accommodating special needs on their website or in their flyer, even though many of their activities would likely appeal to many children with a variety of disabilities and could be adapted to suit their needs relatively easily (i.e., adding visual supports for steps in an art activity). However, Elizabeth, who has a daughter with a physical disability, told me that she had been sending her daughter to programs at this same place for years because
they were quickly able to reassure her over the phone that the fact that her child used a wheelchair was not a barrier:

Exactly, so there's such a relief when you find an ad for something that looks fun, and you call and some places really hedge and they're like, “oh well no we can't really support someone - do you have a nanny that will come with her?” And I'm like "No, I don't have a nanny!" and there's other places where you call and you explain and they say, “Oh yeah, yeah great, yeah no problem!” and I'm just like “I love you guys and we're going to be with you forever!” (Elizabeth, personal communication, May 20, 2014)

**Magazines for parents.** I analyzed several issues of three different free magazines *(Westcoast Families* (8 issues), *Urban Baby & Toddler* (3 issues), and *BC Parent Magazine* (4 issues)) aimed at parents and looked at one issue of *Today’s Parent* and one issue of *Parents* magazine (borrowed from the public library and selected because their covers featured children with disabilities). Much of the editorial content from the free magazines was also available on each of the magazine company websites. As someone who was familiar with these magazines before I began the study, I knew that from time to time, they featured editorial content about various aspects of parenting children with special needs. However, the only item I came across in the search just described was an article on the website of one of the magazines that was about camps for children with disabilities:

Each summer parents sit down with their children and look at all their options for summer camp – should they go to a sports camp, an arts camp, a science camp? – there are so many options. But if you have a child with a physical or mental disability, you quickly realize that your child won’t be able to attend these camps. The camps aren’t
accessible, they don’t have specialized medical care and the staff aren’t qualified to care for a child with special needs. (Blatchford, 2014)

The article then described a program of special camps where children are provided with the necessary supports to enjoy a camp experience with their peers. The author went on to say that children with disabilities at these camps have the opportunity to make friends with children who might share some of their challenges.

*Today’s Parent* is a parenting magazine published in Canada. Many public libraries have subscriptions to this magazine for patrons to borrow and this is where I came across the single issue that I examined. The cover story caught my eye as it was called “My Daughter has Down Syndrome and I Wouldn’t Change a Thing.” The cover photo showed two young children, a toddler girl who appeared to have Down syndrome and a slightly older boy who did not appear to have Down syndrome. They were identified as the daughter and son of the author of the article. The article was about the mother’s acceptance and celebration of her daughter’s uniqueness and did not include any specific advice or content about supporting her child’s early learning. However, the same issue of *Today’s Parent* also included a cover article called “The Ultimate Guide to Reading” and I analyzed this using the same processes as the other early learning texts. The article offered advice to parents about how to “turn your kids into little bookworms” (p. 55) and provided a list of five easy things parents can do to encourage their children to love books (e.g., keeping books and magazines available to read at all times; reading favourite books over and over again; letting children see their parents read too; letting kids choose their own books even if it is fluff; starting book clubs). They also solicited advice from parents who offered tips like playing word games, putting captions on while watching TV, making kids read cookie boxes before allowing them to eat any cookies, and reading road signs
while out on neighbourhood walks. The section also included information about finding books with strong female characters. The rest of the section was taken up by lists of recommended children’s books. There were no specific references to children with disabilities in this piece.

Another article in the same issue provided information about preschool printing skills, describing various aspects of fine motor skills that young children need in order to learn to print and identified specific ages by which specific skills should have emerged:

…at three years old, your child should be able to draw horizontal and vertical lines, cut with scissors and remove lids from small containers; at four, draw horizontal and vertical lines that cross, snip a straight line and lace with string; by five, trace lines, copy a square and cut out a circle. (Gagne, 2014, p. 48)

Similar to the parent advice offered in the Ready, Set, Learn guide from the government domain, this piece advised parents to “talk to your doctor” if there were concerns about a child’s fine motor development but did not offer parents of children with physical disabilities any advice about how to support their children.

**Parent interpretations of magazines.** Most of the parents I interviewed were familiar with several of the magazines aimed at parents of young children that I showed them. While Andy’s mother, Anna, acknowledged that she occasionally saw things in Westcoast Families, BC Parent and Urban Baby & Toddler that applied to her experience as a parent of a child with a disability (personal communication, April 28, 2014), the general consensus was that the parents found that their children’s needs were rarely represented in these free magazines. Jessa, mother to 2-year-old Benjamin, noted, “I find that there's not really anything for kids with disabilities...they're all geared towards the neuro-typical child (Jessa, personal communication, June 6, 2014). Richard, whose son Bobby has autism, commented:
When we first had Bobby, we had a subscription to *Today's Parent* magazine and that kind of thing but as his development diverged, it became much less kind of useful…so, no I don't see a lot of special needs children represented in media in general from just walking around. (Richard, personal communication, June 2, 2014)

Richard also said that although he got most of his information from online news alerts targeted to parents of children with autism, when he did read what he referred to as more “generic” sources, he tended towards adapting some of the parenting advice to suit his child’s developmental stage, not necessarily his chronological age.

I find that a lot of literature *is* useful as his development may be delayed but there are still very typical types of things that happen and it’s just that it might be at a different age appropriate section of the article. So, for my son, I might read some of the things that are still applying to toddlers even though he's now seven but then I might find some kind of advice there for something that we might be facing at that time. Like right now, he just recently started stalling for bedtime which is a completely new development.

(Richard, personal communication, June 2, 2014)

As far as inclusive representations of children with disabilities in this domain, only the February 2013 issue (specifically, vol. 88, no. 2) of one US parent magazine called *Parents* (found at a public library) showed a child with a physical disability on its cover, without any accompanying information about children with special needs. While I found no other relevant early learning texts to analyze in that issue of the magazine, Elizabeth, whose 6-year-old daughter had a physical disability, commented on how her daughter reacted to magazine covers that featured children with mobility equipment similar to her own:
I know my daughter, when she sees a kid on the front of a magazine for example who’s in a walker or in wheelchair, she notices right away and she says “that girl looks just like me!” and she really likes that… and they are not an issue about special needs - that’s just the kid they’ve chosen to do the craft or whatever and so I'm really, really thankful for that because you know everyone wants to see themselves…(Elizabeth, personal communication, May 20, 2014)

**Toy store and children’s book store.** During the year in which I conducted the study, I visited a large chain toy store a number of times, as well as a children’s bookstore. In each location, I took pictures and looked for print material such as catalogues and flyers. I gathered 13 photo artifacts and 2 print artifacts from the toy store and 9 photographic artifacts from the bookstore. I did not gather any or digital artifacts from either store. The toy store contained displays of two different companies’ electronic tablet reading systems designed for very young readers. One of these companies displayed a LeapFrog™ Leap Reader Junior which was geared to very young children (ages 1-3 years) and contained letter/sound activities, as well as uppercase and lowercase letter activities. The product package had a claim that the device could “build basic reading skills in a flash!” The other company’s products made similar claims about giving young children “a head start in learning.” I did not find anything in the toy store that was described as designed for, or suitable for, children with disabilities. None of the child models who appeared on any product appeared to have a disability, either. The children’s book store had thematic displays linked to concepts such as pets, shapes, and seasons, as well as a display of books about beginning kindergarten. The books about children with disabilities were shelved separately from the other picture books, along with parent resources about raising children with special needs and memoirs written by people with disabilities about their own childhoods. The
shelf was labelled “Special Needs” which was adjacent to shelves labelled with things like “Behaviour,” “Death,” and “Divorce.”

Due to time constraints, I decided not to discuss the toy store or book store artifacts with any of my parent interviewees so I do not have any of any parents’ interpretations of what I found in any toy stores or book stores.

Summary

Parent advice texts originating from the government domain were reflective of school-readiness goals that are thought to be accomplished by providing specific and strongly predictive early literacy experiences such as reading aloud, opportunities to scribble and write, and oral language activities. If the parent advice texts included advice aimed at parents of children with disabilities, parents were advised to seek and acquire specialist help. None of the parent advice texts included adaptations that parents of children with disabilities might apply to the advice offered. Texts taken from community-based early learning tended to focus on the fun of participating in various activities and, on occasion, extended qualified offers of support so that children with disabilities could participate in some of the activities with their peers. Commercial businesses that offered enrichment programs such as gymnastics sometimes invited the participation of children with special needs, but frequently added extra fees for this addition of support. Parent magazines were, for the most part, found to be strikingly homogenous in their presentations of normative childhood. On the relatively rare occasions that it appeared at all, information about children with disabilities in parent magazines pointed parents towards specialized services and programs just for children with disabilities. The toy store promoted products that promised early starts with reading, implying that such a thing is both possible and desirable for (presumably typically developing) preschoolers. The book store shelved books
about children with disabilities separately from books about children (and other characters such as anthropomorphized animals) without disabilities. Overall, the collection of artifacts and texts analyzed presented consistently narrow views of early childhood learning, employing common refrains such as referring to parents as their children’s “first and most important teacher” and consistently presented disability topics as “separate” from other early learning topics across all three domains. Parents were familiar with texts from the government domain only through their encounters with the StrongStart program, which they found most inclusive of their children, except when crowdedness was an issue. Most did not recall how they had heard about StrongStart or why they decided to go. They used their community centre flyers and private businesses that offer programs to young children to varying degrees but did not find, nor expect to find, invitations for their children to participate alongside age peers. One parent knew that the programs were not able to accommodate her child without her paying someone to go with him, while others tried things out to see how they went, with easy accommodations found in some instances and not others.

Discussion

Canada ratified the United Nations Convention on the Rights of the Child in 1991 (Canadian Children's Rights Council, 2014; United Nations, 1989) and the United Nations Convention on the Rights of Persons with Disabilities in 2010 (United Nations, 2006; Walker, 2013). Also, British Columbia recently adopted an initiative called Accessibility 2024 that seeks to make it the most “progressive province for people with disabilities by 2024” (British Columbia, 2015). Despite these progressive and ambitious inclusion policies and goals, there was little evidence of progress toward ensuring inclusion for children with disabilities in early learning opportunities. The artifacts from government, community and commercial domains
mainly presented childhood and early learning within a narrow, homogenous, and normative framework. Specifically, the early literacy advice offered by both government sources and public libraries focused mainly on print literacy and oral language development, suggesting a strong orientation towards the type of school-readiness skills promoted by the National Early Literacy Panel (Shanahan & Lonigan, 2008) which “set out to establish which early skills or abilities could be said to be the precursors of later literacy achievement” (p. 280). This panel identified the following skills and knowledge as having moderate to large predictive relations with later literacy development: alphabet knowledge; phonological awareness; rapid automatized naming of letters/digits; rapid automatized naming of objects/colors; writing/writing name; phonological memory; concepts about print; print knowledge; reading readiness; oral language; and visual processing (Shanahan & Lonigan, 2008, pp. 280-281). The report does not include information about children with disabilities, nor anything about what early skills or abilities might predict disabled children’s later literacy achievement.

Turning back to a specific text analyzed for this study, the Ready, Set, Learn booklet (ReadNowBC, 2009) reflected this normative view of childhood literacy learning, despite the fact that this resource is meant to be universal and is provided free of charge to all British Columbian families with young children. If the booklet is meant to be universal, then its content and advice should reflect the developmental diversity of families, and include representations of a much broader repertoire of practices and strategies for families of children who have disabilities. Children with disabilities in this province should be provided with print literacy experiences (among many other experiences) before they go to school and they should be supported in their spoken and/or symbolic language development and fine motor skills. And importantly, their parents should be able to confidently draw on resources that are intended to be
universal, with consideration of disabled children’s learning needs evident within advice texts aimed at all other parents. Similar to the research about parent advice critiqued in Chapter 2, the advice offered to parents in the *Ready, Set, Learn* guide frequently mentioned speech and oral language skills as avenues to literacy success (in addition to print activities such as reading and colouring). However, as discussed in in Chapter 2, children with a range of significant disabilities often have delayed language and speech (Kliewer, 2008b, p. 118). Moreover, otherwise typically developing children can lag behind their age peers in speech; they may stutter or have articulation difficulties. Parents of children for whom speech and language does not progress at a typical rate may find this advice less applicable.

Research suggests that there are other ways to develop language and literacy knowledge in nonverbal and preverbal children that do not require the child to actually talk (Kliewer, 2008a). I concluded that the *Ready, Set, Learn* guide was written from a macrosocial standpoint that did not consider the needs that parents of disabled children might have with regards to early literacy information and resources. Whether this was intentional or not is not known, but I speculated that the producers of this resource considered the needs of children with disabilities to be separate from their non-disabled age peers, thereby necessitating the statement about children with special needs “having goals that are appropriate to the needs and abilities,” implying that they must be different from the goals of non-disabled children (ReadNowBC, 2009, p. 1). This guide is intended as a “universal” resource meant for all young children’s caregivers across the province of British Columbia. This population would logically include families whose children have disabilities, currently thought to be anywhere between 5% and 15% of young children. Instead of including information about early learning that is applicable to children with a broad
range of developmental needs, this guide stated that parents of children who are not developing as expected should seek a specialist.

This separation of advice suggested that these parents would not be able to confidently draw upon the advice that is offered to a general audience of families of young children in BC. The implied suggestion that children with disabilities need to be prepared for school separately from their peers runs counter to the goals of inclusive education in which diverse children are grouped together and provided with accommodations and supports appropriate to their individual needs in the same setting. This separation of advice was also seen in the children’s book store as books about disabilities were displayed on a separate shelf, near other shelves about topics like death and divorce. In these ways, caregiver advice about early childhood learning and development reflected prevailing, medicalized, often negative, and sometimes fearful views about disability in early childhood.

Despite the apparent lack of inclusive advice and inclusive invitations to participate in community programs, several parents told me about some of the activities they chose for their children via some of these artifacts such as community centre flyers. It turned out that their children benefited from participating in the same kinds of activities as their age peers without disabilities, which is consistent with research about children with disabilities and their participation in their communities (Anaby et al., 2014; P. J. Beckman, Wayne, Day, Chatelanat, & Martini-Willemin, 2004; Bedell et al., 2013). Jessa’s narrative about Benjamin quietly observing the circle-time activities and then demonstrating his new knowledge by singing the songs at home showed that inclusive and developmentally beneficial language and literacy experiences for young children with disabilities are available in this large urban community. However, the almost complete absence of representations of children with disabilities in early
learning discourse (including the advertisements that promote programs like StrongStart) pointed to implicit exclusion from activities to which others are routinely invited. I was somewhat surprised by the fact that many of the parent participants were determined to try mainstream programs, even without assurances of inclusiveness. However, I also believe there is a risk of exclusion due to absence of both invitations to, and representation of, children with disabilities in early learning discourse aimed at parents. Understandably, some parents of children with disabilities may believe that typical development is an implied pre-requisite for participation in many settings and choose not to bring their children at all.

The current study included 17 artifacts from public libraries (web, print and photograph) The focus on oral language skills and print literacy skills there was consistent with the data gathered from other similar studies of family literacy and library websites (J. Anderson et al., 2008; J. Anderson et al., 2007; Prendergast, 2013). As discussed in Chapter 2, the involvement of libraries in the provision of early literacy advice to parents, particularly since Every Child Ready to Read (American Library Association, 2011) was published, has increased considerably in North America (Ghoting & Martin-Diaz, 2006; Ghoting & Martin-Diaz, 2013; McKend, 2010; Peterson, 2012). However, this refocusing of children’s library work on early literacy skill development and school readiness has received some criticism. Stooke and McKenzie (2011) questioned “the children’s services community’s uncritical adoption of recommendations derived from studies that frame research and literacy so narrowly” (p. 23). They argued that “the narrow framing of research in children’s services professional discourse could undermine the public library’s ability to achieve important goals with respect to social inclusion (p. 24). Similarly, in a scan of public library web sites in Canada, Prendergast (2013) found that early literacy was conceptualized as a set of skills to be developed prior to school entry and that libraries were
mainly intent on encouraging participation in story time and borrowing books to read at home in pursuit of school-readiness skills. The artifacts from the public libraries in the present study focused on the same set of practices (specifically, singing, talking, reading, writing, and playing) that are promoted as being the best ways to build the skills (phonological awareness, letter knowledge, vocabulary, print awareness, print motivation, and narrative skills) needed for learning to read in school. However, as Prendergast (2013) also found, none of the public library early literacy texts included any information about supporting literacy growth for children with disabilities.

Consistent with other research reviewed in Chapter 2, I found that across the three domains, the texts positioned parents as needing expert advice to help them understand their role in supporting their children’s development. Additionally, in this collection of texts, only an article about selecting summer camps for children with disabilities (Blatchford, 2014) presented information for parents of children with disabilities and it discussed a separate program, not an inclusive one. The author of the article claimed that children with disabilities “won’t be able to attend” other types of camp, because they aren’t “accessible,” and that they lack specialized medical staff who can provide adequate care, implying that all children with disabilities require constant specialized medical support, thereby explaining why regular camps cannot accommodate them. However, most children with disabilities are not medically fragile (Statistics Canada, 2006), and while they may need accommodations to thrive at a summer camp, many would benefit from regular camps with the addition of supports suited to their developmental needs. While all of the positive aspects of the specialized camp may be true (e.g., opportunities to make lasting friendships with peers who also have disabilities), the implied inability of every
other type of camp to accommodate children with special needs may perpetuate the belief that special camps are the only place for disabled children.

**Limitations and Significance**

The collection of artifacts analyzed in this study was not a comprehensive collection of all early learning artifacts across this large urban community. As described in Chapter 3, I gathered artifacts on my way around several communities and I followed up on statements made by families about early learning opportunities they had pursued for their children with disabilities. Therefore, the critiques are limited to the scope of the texts found within the artifacts I gathered, the interpretations made by families of some of the texts, as well as any additional resources the families mentioned to me. It cannot be assumed that other artifacts in this large urban community do not contain texts that better reflect the needs and experiences of families of children with disabilities. However, the degree to which the artefactual content and the parents’ interpretations of the content aligned with the work of others who have examined early learning discourse (Nichols et al., 2012; Penner, 2015; Stooke & McKenzie, 2011) suggests with some confidence that the texts analyzed in this study are representative of some of the early learning discourse that parents of children with disabilities (and indeed all parents) might encounter in this large urban community. The parents in the study did not seem surprised that they rarely or never saw children with disabilities represented in the texts we discussed. Maggie’s reaction to seeing girls who look like her in some magazines points to the importance of children with disabilities being able to see themselves reflected in discourse about young children. I also suggest that there remain many other unexplored consequences for parents of children with
disabilities as they navigate this overwhelmingly normative early learning discourse while they raise their children in this region of Canada.

**Recommendations**

This chapter examined a collection of artifacts that contained texts about early learning aimed at parents of young children. In order address some of the issues identified in my findings, I make the following recommendations.

**Research about Representations of Normativity and its Implications for Families**

More research should be conducted that examines ways in which diverse children are represented in early learning discourse. This research should also examine images (i.e., photographs) of children within such discourse. Additionally, research should attempt to find out more about how parents of children with disabilities interpret early learning discourses as they raise their young children. My study showed that parents are generally unsurprised that their children are not represented in early learning discourse in general but that they employ various strategies to navigate the normative world of early learning. More research needs to explore why parents of children with disabilities do not expect their children to be represented in their own communities’ early learning promotions, and it would be valuable to expand what is known about how parents of disabled children respond to representations of normativity in early learning.

**Early Learning Promotions, Initiatives and Advice Texts**

Producers of texts such as the ones I analyzed in this study (i.e., websites, enrichment programs, storytimes, etc.) should consider doing reviews of their material with the aim to update texts (and images if there are any) in more inclusive ways to ensure that all children are represented. For instance, advice texts aimed at parents and caregivers should include clear
examples of how to adapt specific activities to suit a wide range of children’s development, e.g., “Speak or sign back to your child when they make an attempt to communicate with you. Add more complex vocabulary to what they tell you.” Producers of early learning texts should consider the needs of, and commit to learning about, families of children with disabilities and consider ways that families might be involved in program planning and promotion. Producers of early learning texts across contexts should learn about the different ways that disability and ableism can and does impact the lives of children and families and then seek ways to represent, invite, encourage, and ensure disabled children’s access and participation.

Conclusion

I speculate that the relative invisibility of children with disabilities in the analyzed data points to enduring exclusionary practices with regards to children (indeed all people) with disabilities, and that it reflected what Devlin and Pothier (2006a) referred to as “a system of deep structural economic, social, political, legal, and cultural inequality” (p. 1). Overall, this study revealed what appear to be enduring beliefs about children, and more specifically children’s early learning, that idealize what is commonly referred to as “typical” development. Typically developing children were present in all the texts and their accompanying images (for brevity, an in-depth image analysis was not undertaken for this study but photographs of assumed-to-be typical children were noted as prevalent across all domains) and advice to parents assumed that they were seeking or in need of advice about typical children.

Early learning discourse that idealizes one type of child (i.e., the “typical child”) over another type of child (i.e., one that has disabilities) effectively privileges the typical child and discriminates against the disabled child, whether this discrimination is intentional or not. The well-represented child (i.e., non-disabled, with typical, normative development), therefore,
becomes the intended recipient of the invitation to participate in whatever early learning opportunity is on offer while parents of children with disabilities hope that their children might be able to blend in, ask for accommodations that may or may not be provided, or opt to have their children not participate at all. The findings of this study suggest that there remain prevalent beliefs that children with disabilities are incapable of participating alongside their age peers so their exclusion is, therefore, implied and the status quo normative homogeneity is maintained. This is the effect of ableism on the lives of children with disabilities and their families, including those who participated in this study.

As children with disability labels are estimated to make up at least 5% to 15% of the population of children in our communities (Canada Office for Disability Issues, 2003; Statistics Canada, 2006), the fact that so few of the materials analyzed demonstrated intentional inclusivity should be cause for concern for both researchers and practitioners who work with families in various settings. Reconsidering how children with disabilities are positioned in early learning discourse may also help to advance a much needed counter-narrative about their opportunities for participation. Kliewer et al. (2006) contended that a “seismic shift” (p. 186) in how people with disabilities are understood must take place in society as a whole before they are afforded equal access. I believe that many more overt messages about welcoming children with disabilities and supporting their participation in a range of inclusive early learning experiences and opportunities for all children are of critical importance.
CHAPTER FIVE: CAUGHT IN BETWEEN: PARENTAL EXPLORATIONS OF THEIR CHILDREN WITH DISABILITIES EARLY LITERACY LEARNING IN THEIR HOMES AND COMMUNITIES

Introduction

In the Western world, the movement towards inclusive education has helped to promote the notion that children with disabilities should be given opportunities to develop language and literacy skills alongside their age peers (Kliewer, 2008b; Koppenhaver, Coleman, Kalman, & Yoder, 1991; Lawson et al., 2012; Mock & Hildenbrand, 2013). However, the literacy research community as a whole still leaves topics concerning children with disabilities “relatively under attended” (Pressley, 2007, p. 7). For example, in the International Handbook of Research on Children’s Literacy, Learning and Culture (Hall, 2013) that claims to offer scholars an international perspective on recognizing and anticipating increasing diversity in literacy, there are no chapters solely dedicated to children with learning or other disabilities. Indeed, the terms “disability,” “special needs,” “learning disabilities,” or “ableism” do not appear in the index. “Dyslexia” appears in the index and is discussed briefly on only one page of this 580-page volume. The SAGE Handbook of Early Childhood Literacy (Larson & Marsh, 2013) includes one chapter about early childhood disability and inclusive early literacy (Mock & Hildenbrand, 2013) and the index has 14 other references to children with disabilities in the other 36 chapters. Furthermore, the research about early literacy and children with disabilities reveals little about parents’ perceptions of, and experiences, with their children’s early literacy lives. This chapter’s exploration of parents’ experiences of their children’s early learning
opportunities and activities aims to fill a gap in the literature on parents’ roles in the literacy development of children with disabilities.

The limited research available about early literacy in the lives of children with disabilities suggests that these children and their families frequently experience complexities such as multiple therapies, appointments, and medical procedures that may impact how early literacy learning opportunities are taken up (Koppenhaver et al., 1991). Also, transitioning children to formal schooling may present additional challenges for these families (Janus, Hughes, & Duku, 2010; Janus et al., 2007). In alignment with Bronfenbrenner’s ecological systems theory explained in Chapter 2, the focus in this chapter is on how their parents interpret the children’s opportunities for early literacy learning within the microsystems of the home and in the community. I undertook this case study (part of a multiple case design study as explained in Chapter 3) to discover more about the lives of families of children labelled with disabilities and to learn about how their children participate in early literacy opportunities in their daily lives. The goal was to document the challenges that children with disabilities and their families encounter, as well as the opportunities available to them, in terms of early literacy learning.

My critical stance in this case study is informed both by my experience in providing children’s library services, as well as my experience as a parent of a child with disabilities. As described in Chapter 3, in this study, parents were asked to document their children’s daily routines, interactions, and activities that support their learning. Then, during interviews, they were asked to discuss their child’s opportunities for engagement in early learning opportunities in the community, as well as instances of when their child’s disability status may have hindered his or her participation. I analyzed the data through a
critical lens that questions taken-for-granted assumptions about developmental normativity as a pre-requisite for participation. While the parents and I discussed the children’s literacy learning at home, I paid close attention to those that take place in the community. The rationale for this aspect of the study stems from my belief that the expansion of our knowledge of how parents of children with disabilities participate or do not participate in community early learning may lead to more inclusive practices.

**Research Questions**

1. For families of young children with disabilities, what routines and activities of their daily lives influence how their children participate in early literacy learning both inside and outside the home?
2. Specifically, what resources do their children access and what activities do they participate in both at home and in the community that may support early literacy learning?
3. In what ways do parents interpret how their children’s disabilities influence their ability to participate in, or not participate in, early literacy learning?
4. How do parents respond to any perceived challenges and barriers for accessing early literacy learning (at home and in the community) for their children?

**The Participants**

Thirteen families participated in the study. I conducted interviews with 11 mothers by themselves, one father by himself and one couple, a mother and a father, for a total of 14 parents. The focal children in these families, (five girls and eight boys), ranged in age from 2 to 8 years of age. Six of these children had siblings or, in one case, step-siblings, ranging in age from one
year to 20 years living in their homes with them. The families lived in five different municipalities in a large urban community in British Columbia, Canada. The parents ranged in age from the early 30s to mid-40s and were working either full-time or part-time in public service, education and business sectors. Eleven of the participant families had biological children and two had adopted children. See Table 3.1. Parent Participants for more information about the participants.

**Findings**

In the following sections, I start with a brief review of how I considered and incorporated data from the child activity logs in the study. Then, I present the findings that include selected parents’ narratives that align with Bronfenbrenner’s framework as discussed in Chapter 2. First, I explore the participants’ children within the home **microsystem** (the child within a specific setting), and present three themes: print literacy practices; digital literacy tools; and heritage language strategies. Secondly, I explore **mesosystem** (two or more microsystems interacting) influences on their lives and present findings regarding participant families’ interactions with their children’s therapists, as well as attendance at specialized and mainstream group early learning activities with age peers. Thirdly, drawing on conversations I had with parents about both opportunities and barriers they have encountered for their children’s participation in early learning, I explore the **macrosystem** (broader social and cultural mores and practices) influence on these families’ daily lives by exploring the themes of inclusion, ableism and parent advocacy.

**Child Activity Log Findings**

As explained in Chapter 3, I asked participants to complete a log of their children’s daily activities for one week (See Appendix F). The logs were intended to serve as an elicitation device for parent interviews, wherein I would ask them to tell me more about various activities
that they had noted in the log. Once I had gathered the 13 completed logs, I compiled the children’s logs to present their activities as a group (Appendix I) and I found that the compiled data pointed to themes regarding the children’s daily schedules and routines that I report below. Gathering data (via parent report) in this presents some reliability issues, however. In a study that examined parent-child reading, Hofferth (2006) suggested that parents will over-report activities that they know are good for children via whatever reporting process has been used in order to be “viewed as good parents” (p. 302). Other researchers have used a variety of parent-reporting tools to learn about Western cultural and family life, typically employing mixed methods, such as follow-up interviews with parents (e.g., Harkness et al. (2011) DeCaro and Worthman (2007)). In terms of reliability for this study, I asked the parents to briefly record elements of their children’s day. They were instructed to spend only 5 to 10 minutes per day recording what their child did, where, and with whom. Since they already knew I would be asking them about some of the information provided in the logs, I anticipated that these directions would prompt parents to record only things that actually took place and the frequency with which they took place, and would have an opportunity to discuss specific activities in more detail when we met for the interviews. I acknowledge that the log instructions provided some examples (i.e., appointments, therapies, classes and activities, playing, watching media, playing with iPad apps, spending time with family members and friends), and it is possible that participants over-reported these while under-reporting things that I did not specifically mention in the instructions. This caution notwithstanding, I found a great deal of similarity between the parents’ logs of their children’s daily routines and many aspects of my own experience raising a child with a disability. This similarity suggested to me that the log data were fairly reliable in terms of the patterns in the range of activities reported. In terms of addressing the research questions, the log
data showed that the children in this study spent considerable amounts of time going to therapy appointments, while the subsequent interviews shed light on the amount of advocacy parents undertook so that their children could participate in non-therapeutic activities with age peers. The activities recorded in the child activity logs and the subsequent discussions about these activities were similar to many of the things I remember doing with both my children. The main difference of course, was the fact that I had no need to take my child without disabilities to any therapy appointments, nor did I have to advocate for her inclusion in activities like I did for my disabled son.

**Microsystem: Processes Surrounding Children’s Early Literacy Learning at Home**

**Print literacy practices.** To recap briefly, in the interviews, I used data from each child activity log to elicit parents’ responses about their children’s daily lives in order to address the research questions. I transcribed the interviews and also coded the data using a constant comparative coding strategy (Freeman, 2005). The families included children ages 2 to 8 years old of both genders and were from a range of cultural and linguistic backgrounds similar to the general population found in this region of Canada.

As expected, the children’s early literacy routines and activities differed somewhat from child to child, with some differences accounted for by the different ages and abilities of the children. For example, the parents of younger children reported reading aloud to them more often than to the older children, who were more likely to be reported to read by themselves. The parent reports via their children’s activity logs and the interview data revealed that within the microsystem of each child’s home, the children had many opportunities to interact with objects (i.e., toys, iPads and so forth), symbols (i.e., reading materials, printing activities, etc.) and people (i.e., parents and grandparents) to support learning and development in enjoyable ways. I
found that the participants discussed literacy activities as they were woven into their daily lives but did not necessarily link them to their children’s current or future success at reading, nor did I get the sense that they were doing these activities for school-readiness or to teach their children to read. Rather, I speculated that the participants’ home literacy practices were mainly geared towards the children’s interests and enjoyment. I speculated that the parents were positively oriented towards various early literacy activities and provided them to their children on a regular basis for their intrinsic and/or cultural value, which I acknowledge would have been influenced by the parents’ own cultural and educational beliefs. While the literacy activities they reported on aligned with the literacy practices of Western schooling, I was not given the impression that they were provided as deliberate strategies to “teach” literacy in preparation for school literacy (Taylor, 1981, 1983); however, I assumed that parents’ own experiences with learning to read would have influenced what literacy activities they provided (and sometimes adapted) for their children. For instance, the children were given regular opportunities to colour with crayons and pens, cut with scissors, and make crafts. They also baked and listened to audiobooks, danced to music, and read together. As mentioned, some of the children had already learned to read but parents still recalled their pre-reading time. When we talked about home reading routines, Annie, mother to Michael (age 6), who has a diagnosis of autism spectrum disorder, recalled her early literacy-influenced strategy for toilet training her son a few years ago:

I would plop him on the toilet and I sat opposite him and I would keep reading the whole time because it’s a double whammy for me! I think because it took him that much longer to get toilet trained and well, otherwise I would be sitting there and bored - he’d be bored - he would want to get out so what I did was I would take a stack of books from the
library and I would read to him and that's part of his early literacy I guess! (Annie, personal communication, May 27, 2014)

Books were a source of pleasure and engagement for Michael, who was happy to remain in the bathroom as long as his mom stayed to read to him. She said that because of his disability, mastering independence in the bathroom took longer than it did for her other child (a daughter who does not have autism), but this approach helped both Michael and his mother get through the time together. Annie added that Michael now reads independently at grade level proficiency, and books remain part of his daily routine where he reads alone or someone else reads with or to him at least once a day.

Laura described her 6-year-old daughter, Blossom (diagnosed with learning disabilities), as a very active child who loved going to swimming and skating lessons in the evenings. Laura also talked about her daughter’s routine at bedtime that always included being read to by a parent, usually her father. She felt that a calming wind-down at bedtime was crucial to Blossom’s ability to settle to sleep and she saw Blossom’s love of being read as helpful, in that regard:

She gets read to every night - she likes us to read to her - she has tons of books and she likes to go to the library and get books out and at school they do that every week and they let them take as many as they want…she doesn't have a lot of homework - she's supposed to be doing her reading and her sight words - with her it depends on what it is and it’s hard - I hate homework to tell you the truth - it’s hard because she's got stuff at nighttime and especially for kids like this the day is long enough – it is really hard for her to get her focussed at the end - but by the time you're doing it - they go to bed at 7 o'clock you know - and by the time she gets home it’s 3 o’clock and then she would have swimming
or skating or something usually so it just is hard. But, the reading before bed, I love - it
unwinds her and it’s her routine. (Laura, personal communication, June 9, 2014)

Laura differentiated between what she perceived to be the busywork of her daughter’s grade one
homework and the benefits of close, one-to-one reading time that Blossom spends each night
with one of her parents. She indicated that Blossom is an enthusiastic participant in the early
literacy activities that take place at home (art activities, baking, etc.) and she is also learning to
read at school in an inclusive grade one classroom setting (personal communication, June 9,
2014).

Only 8-year-old Mark’s mother Mary discussed her concern about his lack of progress
when compared to his classmates at school, and said that she wished he had more help with his
academic learning (personal communication, April 23, 2014). The rest of the parents did not
mention particular concerns about their children’s current or future academic achievement nor
did they discuss any anxiety they felt about their children being able to learn to read. When some
of them mentioned their children’s homework, like Laura, they tended to frame it as a sometimes
boring or even unpleasant but necessary task. I speculated that because they were already
providing lots of reading times and other literacy activities, they found the busywork of spelling
words and worksheets of secondary importance. Moreover, I speculated that it was also possible
that the children themselves resisted these decontextualized tasks because they were challenging
and/or frustrating for them.

**Digital literacy tools.** The activity logs of most children showed that all but one child
had daily access to digital devices. I wanted to find out about families’ approaches to digital
media and explore how it might have been used in their daily activities, i.e., whether it had a
therapeutic, educational, or entertainment role, or a combination. I was also curious about any
use of Skype and Facetime to connect with family and friends, as these were tools that were not available to me when my children were younger. The logs indicated that during the week in which parents recorded activities, three children communicated with extended family via Skype or Facetime at least once. The most common use of digital media for entertainment was watching children’s television shows such as Curious George™, Caillou™, and Max & Ruby™. Four-year-old Natalie strongly preferred to watch home movies and digital slide shows. Her mother Leslie said:

That's all she watches - my stepdad has been videotaping her since she was a baby and he makes us DVDs and so that's what she watches and then we also have one from the daycare - they made a slide show and so she'll choose…but we've tried other things, like I put on like Curious George the other day and she's just like - she'll watch it but - she would rather watch the people she knows, including herself, yeah… (Leslie, personal communication, June 5, 2014)

At the time of our interview, Leslie told me her daughter was using picture symbols for communication (American Speech-Language-Hearing Association) but that they were moving to a communication app on an iPad soon. Eight-year-old Evan’s mother, Amy, said that they had first gotten him an iPad for communication purposes when he was about 5, as he was nonverbal then. He had since learned to talk, so he now uses it for reading apps and watching videos (personal communication, May 17, 2014).

In contrast, 2-year-old Lulu’s parents, Steve and Cindy, talked about why they did not allow Lulu, who has autism spectrum disorder, any access to digital media, apart from occasional Skype calls to her extended family. Steve said:
So before she got the diagnosis, we would show her some cartoons on the computer or we had some apps for her on the phone and she liked to play with it...when she was one, she could already, if we showed her an app, after if she didn't like it, she could already exit it and choose another one and we always thought that she was very intelligent and then after she got the diagnosis, we were advised that we should cut her back on the electronic stuff and actually she gets very addicted to it...so the doctors told us that it's easy for this type of children to get very good at it because they can focus and they can be at it for hours without getting tired but it takes them away from interacting with other people so we stopped doing that...So now she actually gets no TV, no iPad, no iPhone. (Steve, personal communication, June 4, 2014)

Steve and Cindy explained that, although they were aware that other children might need digital technology to learn to talk, Lulu was already highly verbal and they believed that the risks of addiction and disengagement from face-to-face social interactions were not worth the entertainment value of digital technology at this point. They anticipated that Lulu will be able to interact with digital technology as a learning tool, once she is older and able to understand the guidelines for using it within reasonable limits (personal communication, June 4, 2014).

Another perspective on digital media came from Nicolas’s mother, Joanna, when she talked about her son’s use of his iPad. She explained that, as a child with autism, Nicolas finds social relationships difficult and although he has a few friends and he plays with his siblings, school is challenging for him. After school, he tends to want to spend time alone with his iPad at home. Joanna said:

I have found his reading has really developed by himself by reading the games - he has to read the instructions and that in itself has sort of pushed him - because he can read better.
I've found he's reading more other stuff, not just on the iPad…I still think he spends too much time on the iPad and I still have that worry but there have been some benefits to using it - in lieu of any of these other things that he is not able to do...I think for him it’s part of his early literacy and communication because if he learns these games - other kids have it - all of sudden he's able to talk about something that the other kids know about and he's got an in, he's got an in with what the other kids are doing, and he didn't have that before. (Joanna, personal communication, April 2, 2014)

While acknowledging that she still felt ambivalent about the amount of time her son spends on his iPad, in this response, Joanna focused on its benefits for Nicolas: his reading improved because he was motivated to read the instructions for playing games he enjoyed and he was better able to participate in some of the conversations about these games with his social peers at school.

Except for Lulu’s family, who had followed the advice of a specialist to stop using digital technology (except for Skype video calls) with their daughter, the families used digital technology for a range of purposes that they determined to be suited to each child’s needs and abilities. I speculated that the parents were both aware of digital tools’ affordances and wary of the risks, and chose strategies such as time limits for managing the latter.

**Heritage language strategies.** Eight of the parents spoke languages other than English. Since my definition of early literacy includes what I refer to in Chapter 1 as the “broad range of experiences that young children have within their cultural contexts,” I thought that exploring how families approached their children’s heritage language development would offer some insight into their early literacy lives. I drew on the activity log to inquire about heritage language usage within the family. Depending on the age of the children and the resources at their disposal
(i.e., grandparents who speak to the children in their heritage languages, etc.), the participants shared some of their approaches to their family’s heritage languages. One of the most interesting examples came from Anna, whose 4-year-old son Andy had both language and motor delays. Anna spoke Mandarin as her first language. She told me that she had spoken to Andy in Mandarin until he was diagnosed with delays and began speech language therapy as well as other early intervention therapies that were all delivered in English:

Because his language was so delayed, he started speaking when he was three and when he went to preschool and even when we talked to him in Chinese, he only picked up a few words and not sentences at all but now he speaks English more…Yeah, we did try to reintroduce Chinese back but he seems not very interested - even when I read some Chinese books with him he wants to close the book - he doesn’t want to read that, yeah he likes English books. (Anna, personal communication, April 28, 2014)

As English-speaking practitioners provided the therapies, Anna felt it necessary to speak to Andy only in English, her second language, believing it was less confusing to him if he had to deal with just one language. She told me he was beginning to speak English in short phrases and interact with his English-speaking peers at preschool.

Lulu’s parents Steve and Cindy each spoke a different first language (one spoke a European language that I have not identified to protect the family’s identity and one spoke Mandarin). They used English as their common language to speak to each other. Before Lulu was diagnosed with autism, they each spoke to her in their own first languages and assumed Lulu would grow up to be trilingual. Then, they began to have concerns about her lack of eye contact and lack of speech and sought help from a specialist who diagnosed her with autism. After Lulu’s diagnosis, Steve and Cindy elected to speak to her only in English. As her therapies were
also provided in English, they believed focusing on one language had already helped Lulu make significant progress in her oral language development. Because of Lulu’s social communication issues due to her autism, the parents planned to continue speaking only English to her (personal communication, June 4, 2014).

Other multilingual parents persisted in speaking their heritage languages with their children with disabilities at home because they hoped that their children would become familiar enough with the non-English language that they would eventually be able to communicate with or understand their extended family members who do not speak English well. For example, Abigail hoped her son Thomas would become fluent enough in his heritage language of Tagalog to be able to travel independently to the Philippines one day (Abigail, personal communication, May 15, 2014). Diane’s daughter, Jane, who had cerebral palsy with fine motor delays, understood her heritage language Arabic but did not yet know how to write in that language. Diane said she was not concerned with that at all; as long as Jane could understand the spoken language of her family, she would be very happy (Diane, personal communication, May 30, 2014). Jessa, whose family was Taiwanese, had recently obtained a Mandarin language kit to share with her two-year old son Benjamin. She thought he responded positively to the tiger character and was happy with his engagement in Mandarin, because she wanted him to eventually be able to speak it. Similar to Diane, Jessa was not concerned about Benjamin learning the language’s written form; as long as he could speak it with his extended family members, she would be content:

I am trying to speak Mandarin because I'm the only link that would keep him learning it… like it's something I can try to teach him as much as I can myself—and I think if he
travels in the future, he'd get more enjoyment if he went to a country that spoke that language. (Jessa, personal communication, June 6, 2014)

As noted, families who decided to forego their heritage languages in favour of English did so because the children’s therapists delivered their services in English. I speculated that in addition to trying not to confuse their children with more than one language, parents were also being given advice about how to support their children in English (i.e., phrases to use to explain things to their children, etc.) so they may have found it simpler to stick to those strategies in one language only. I considered the interactions between the parents and their children’s therapists to be constitutive of the mesosystem which is explored in more detail next.

**Mesosystem: Contexts, Processes and Supports for Early Literacy Learning**

**Interactions with therapists.** The child-activity logs showed that the children attended various therapy appointments on average about three times per week. Overall, therapy appointments took up at least 3 or 4 hours each week, but a few of the younger children with autism diagnoses had 2 hours of behaviour therapy each day. During the interviews, I asked parents to describe their child’s therapy sessions, whether they themselves are involved, and if so, how.

Leslie, whose 4-year old daughter Natalie has global developmental delays, described what typically happened at Natalie’s speech therapy appointments.

We're there every other week most of the time and the speech pathologist will have kind of a visual plan of what we're going to do. It's evolved to be more of Natalie's interests because earlier on, we were trying to get her to understand how to follow somebody else's lead through the session and we would just lose her so now we are doing things more based on her interests. So, there's always a book and then there's usually an activity
that is somehow related to the book. So, it's basically using what is motivating to her and trying to encourage her to communicate in whichever ways she can. (Leslie, personal communication, June 5, 2014)

Amy, whose 7-year-old son Evan has autism, told me about a time his behaviour therapist helped them work out a strategy to stop a negative behaviour:

So, when we have been driving in the car and my husband and I are talking, Evan was constantly kicking the seat and he wanted attention so we had to have a lovely long session where our consultant came and we spoke about general behavioural issues and rewards and reinforcers and giving him regular small rewards. Like for the behaviour in the car: so he loves the iPad and now he reads all the street signs so with the chair kicking we said “Okay if you can sit quietly and behave nicely and you don't kick the seat until we get to such and such a street you can have the iPad.” Because we’re teaching him to stay calm for a short period of time and so next time it is a little further distance and so he reads the street sign and gets the iPad. (Amy, personal communication, May 17, 2014)

In both of these examples, literacy was woven into how the therapist and the parents approached the children’s learning. For Natalie, communication goals were built around her engagement with a book, whereas for Evan, behavioural change on car trips was motivated by his desire to play on the iPad and was enacted because he had recently learned to read by himself: Instead of kicking the seat for attention, he was asked to read the street signs for a specific length of time, after which he was given the iPad for the remainder of the trip. I understand the mesosystem in these examples to be constituted in the ways that the parents adopt and apply the strategies offered by the children’s therapists, who have expertise for addressing learning goals for their children that the parents do not have.
Sometimes, children went to community activities with their therapists acting as caregivers. For example, Abigail’s son Thomas attended a local playgroup with his behaviour interventionist, so I asked her to tell me about it:

In the beginning, I was like there and I always feel that if I have to leave the intervention sessions, I need to know what they are doing so I can apply the things - but they [program facilitators] said that “you really need to take some time for yourself!” …I did tell them that his interventionist will be there and they said, "it doesn't matter what he has, come and join..." and when he does have a meltdown or situations we talk to them about that and we just explain why he does it and maybe they can incorporate something to help him out…They've been very open. (Abigail, personal communication, May 15, 2014)

In this example, I understood the mesosystem to be made up of interactions between Abigail, her son’s behaviour therapist, and the playgroup facilitators. The behaviour therapist had already shared strategies with Abigail for helping Thomas; in turn, she was able to offer the playgroup facilitators some tips on how to help him too. Another mesosystem influence was found in the way the playgroup facilitator reassured Abigail that they welcomed Thomas no matter what disability he had. As a result of this interaction, Thomas was able to access the learning inherent in a community playgroup that included typically developing age peers.

Andy’s activity log indicated that he had six appointments with therapists that week. During our interview, his mother Anna told me he had shown lots of improvement in his language and motor skills. However, she also said she was anxious about him being ready for kindergarten where he would be surrounded by other children. She said that, even though therapy was helping him, she wanted him exposed to typical age peers, and that this was the reason she took him to story time at the library on the weekend:
I just want him more exposed to this kind of environment because he's so great with one-on-one sessions - he's able to, he learns very fast, every time when I hear from the program therapist, "oh he's doing great one-on-one, one-on-one” but the you know the reality is not always one-on-one right? He needs to learn how to handle those kinds of distractions in the groups that he attends so that is the reason I brought him there. But because I know my son is motivated by peers, if they have typical kids around it would be best, I know some kids with a similar disability are maybe running away and maybe causing more distraction. (Anna, personal communication, April 28, 2014)

Earlier on in the interview, Anna had told me about another play program that other children with disabilities attended, some of whom were not listening and running away from the instructor. She hoped that a program like a story time would be attended mainly by children whose behaviour Andy could positively emulate in preparation for kindergarten (personal communication, April 28, 2014). This conversation helped to illuminate an inherent tension in these families’ lives: their children need therapy to help address their impairments but they also need to learn alongside age peers. How families went about finding and providing those experiences, in light of their children’s therapy schedules, was one of the most interesting aspects of this study which I discuss in more detail next.

**Mainstream and specialized group programs.** The families’ experiences in their communities, particularly with regard to their children’s participation in informal early learning activities such as those offered at community centres and libraries, took up a considerable portion of the interviews. The interview data revealed that although the children needed to spend much of their time in therapy sessions, they also participated in regular, mainstream programs
alongside age peers without disabilities. They also spent time in specialized early learning programs for children with disabilities.

I was curious about how parents decided what programs (mainstream or specialized) to take their children to. When I noticed that a child had attended a specific program or class in their log, I asked about why they had signed up. Leslie told me that her daughter Natalie, age 4, had global developmental delays. Also, Natalie was mostly nonverbal and used a picture symbol system in a binder to help her communicate with others. When asked how she went about deciding what programs to put her in, Leslie said she selected activities based on Natalie’s needs, abilities and preferences:

I feel like it’s up to the parent to make that decision of whether or not you think your kid’s going to be able to handle it and go and see if it's okay but I also choose very wisely because I know her and what she can do…so I kind of do a lot of research before going, knowing who she is, versus, waiting for someone to say "any child of any need would be welcome...” (Leslie, personal communication, June 5, 2014)

Leslie also mentioned that she sometimes took Natalie to mainstream programs geared toward toddlers because her daughter’s global delays might be less noticeable among them, rather than typical four-year-olds who are usually able to sit in a circle and to respond verbally to others (personal communication, June 5, 2014). I wondered about the notion that Natalie could or should blend in more easily with children two years younger than her, but agreed with Leslie that most program facilitators of mainstream early learning programs would expect four-year-olds to be verbal and would likely find it difficult to engage her without prior knowledge of, and assistance with, the picture communication system she used. Leslie did not mention that she ever discussed Natalie’s developmental delays with the program facilitators, so it was hard to say
whether the mesosystem entailed bi-directional communication (meaning, did the program instructor learn about Natalie’s needs and adjust the program in any way to help accommodate them). However, the program content that Leslie and Natalie learned together and later did at home (i.e., a song or story) would constitute the mesosystem as the interaction between them and the program leader led to learning something new.

Laura, 6-year old Blossom’s mother, was familiar with some strategies that she thought helped children like hers (i.e., those with attention and learning difficulties) focus. She mentioned the importance of the following strategies: making eye contact; repetition of key information; visual cues; and sensory items. However, she added that she often saw missed opportunities for getting children with disabilities more engaged:

You can see when you go to different play groups and different things and when they sit down at the circle-time they run off… I found all the kids who had special needs or ADHD could not sit in that circle – it's too much! So you almost have to give them two things so if you gave them a stress ball or something like that or when they're waiting for the bubbles - if they know what comes next - and I think that’s how you have to do it, is to prepare them “we're going to do this”… so first of all this is what we're going to focus on and then it’s short and then okay we're going to move to this because then you have their attention span you know you just have to - it can't be like – “here's our book”… they don't allow for special needs…you have to just slightly adjust your teaching - and the other kids wouldn't know - it's not going to affect them at all, in fact it's going to help everybody. (Laura, personal communication, June 9, 2014)

Laura also found it worrisome that sometimes, Blossom’s program instructors just let her go through a class without checking to see if she had learned anything. Laura said she sometimes
gave instructors pointers on how to engage her daughter and make sure she was learning but she also worried that once she identified her as a child with a learning disability, they would lower their expectations of Blossom and just not try to teach her anything (personal communication, June 9, 2014). In Laura’s example, the mesosystem could be seen to either support or hinder her child’s access to learning. If instructors were open to suggestions to help Blossom learn (i.e., offering two-step instructions) then she would likely learn more. If they ignored Laura’s input and/or lowered their expectations of Blossom, she would likely not learn to her potential.

Annie’s son Michael was 6 years old with autism. She said she struggled to find appropriate mainstream programs for him and also took advantage of special programs for children with disabilities. However, she did so with a degree of ambivalence due to her doubts about how much Michael benefitted from them. She believed that his cognitive development was more advanced than most of the other participants in such programs. She said:

For me, I feel like I am caught in between. I cannot put him into the regular programs because he is "special needs" but when I put him in the special needs programs he's not learning much at all...he's spending time but he's not learning - that is how I feel - I mean I wish the special needs programs would also take in regular kids to make it, like you know, just like society would be in general. (Annie, personal communication, May 27, 2014)

In Annie’s example, the way that the mesosystem was able to benefit her son was dependent on how well each program was able to meet his developmental level. In the special needs programs, Annie thought it unlikely that Michael would learn much if his peers were developmentally behind him, as she supposed that the program leaders would prioritize their needs over Michael’s. However, she was also frustrated by the lack of accommodation he was offered at
regular programs where the mesosystem interactions between Michael’s mother and the program leaders resulted in hindering his access to what she supposed would otherwise be a beneficial experience with his intellectual age peers without disabilities, because the program leaders decided against letting him attend due to his extra support needs. Annie was a persistent advocate for her son’s inclusion in community programs and told me she had given up her career to spend the time this advocacy took. At school, Michael’s extra support needs were accommodated and he was thriving and learning alongside his age peers. Annie found that informal community programs did not have the same kinds of systemic structures in place to offer Michael the support he needed, reflecting the influence of the macrosystem. That is, the lack of support for children with disabilities in mainstream community programs reflects broader social and cultural beliefs and practices as explored previously. I next consider the effect of the macrosystem on the families and children.

**Macrosystem: Inclusion, Ableism and Advocacy**

The influence of the macrosystem on the lives of the families was apparent throughout all three of the cases, but was most apparent in the parents’ narratives about their children’s activities outside of their homes, schools, and daycares (each school-age child and the preschool-aged children in formal childcare or preschool had been given the support they needed to participate fully alongside their classmates). As explored in the previous chapter about early learning discourse, Western society in general holds prevalent notions about early childhood and these notions have filtered into daily life (Cooper, 2013). The notion that young children should be able to participate in developmentally beneficial activities is a strongly held cultural value in the Western world (Khetani, Graham, & Alvord, 2013) and it is one that I think greatly influenced the families’ efforts to find group, early learning programs for their disabled children.
The next section explores some of the macrosystemic influences on their daily lives, particularly with regard to their children’s participation in early learning opportunities that took place outside of their homes and outside of their formal educational environments (i.e., schools and daycares).

**Families experiencing inclusive programs.** Steve and Cindy’s 2-year-old Lulu, who had autism and was too young to be registered in a formal preschool education program, had daily behaviour intervention sessions lasting up to 3 hours, but she also participated in various informal parent-child programs in the community. Her favourite activity at the time of the interview was a ballet class. Lulu’s parents explained that, although Lulu’s autism had been more noticeable before her therapies began, her development had progressed to the point that they thought she could blend in with other toddlers at the ballet class:

> With the ABA therapy, that she's used to getting adult's attention - she's turning sort of into a teacher's pet so she’s always trying to get teacher's attention and the teacher likes her because she smiles and she follows the directions and in the ballet class I think you cannot notice anything different in her except that she likes the class a lot - so we are now on the basis that we don't tell - if they figure out, they figure out - then we'll tell, right – but it’s not like "Hi!" during the first class, "My name is so and so - this is my daughter and she's on the spectrum..." we're not like that. (Cindy, personal communication, June 4, 2017)

The ballet class involved parent-participation and Lulu enjoyed the activities. Even though the instructor was not aware that Lulu had autism, she did not need any accommodations so they all experienced ballet class as an inclusive place where Lulu’s interests and needs were being met with a group of her age peers. It seemed likely that because the group was quite small and each child had a parent or caregiver with them, the program was already inclusive of a wide range of
children. Although I did not ask at the time, I speculated that Steve and Cindy were concerned that the instructor might have a negative reaction to the news that Lulu was autistic, so they opted not to tell.

In another example of inclusion, Diane explained that when her daughter Jane was 4, the family moved to Canada from a Middle Eastern nation where there was little social acceptance of, or accommodations for, people with disabilities. When Diane came to Canada, she was struck by how welcoming her community was of her daughter, who has cerebral palsy and uses a wheelchair for mobility:

I registered her in a preschool and in the preschool my daughter was really happy and I was happy about it because doing the circle-time and dress-up and cooking together and so she was really developing socially and incredibly and she was really happy and I could see that, yes, she's learning how to talk, she's learning how to - like she's not shy anymore, she's not afraid of talking anymore. (Diane, personal communication, May 30, 2014)

In contrast, Diane said that their annual trips back to their home country to visit family were stressful because she was never sure if they would be able to get Jane, with her mobility aides, to wherever they needed to go. She also mentioned that in her home country, the prevailing practice was that people who have disabilities like Jane were generally kept hidden, and not welcomed to participate in community life (personal communication, May 30, 2014). Diane’s experiences point to the differential influence of the macrosystems of the two nations on her family’s life, and it was easy to see that, compared to the Middle Eastern nation from where she came, Canadian culture reflects the notion that children with physical disabilities should be able to access community programs.
Ableism in action. Annie told me that her autistic son Michael was bright and verbal, and that his physical development was similar to his age peers. However, she still felt scrutinized by staff and other program attendees when her son’s behaviour (because of his disability) did not align with expectations for children his age. She recalled a recent trip to a nature-themed program at her local library:

I had to deal with…how we were being looked at - how you feel you are being judged by everybody else: the kids look at you like – “what are you doing?” – “why are you doing this?” or “why are you not doing this?” It doesn't make you feel that good - so I kind of told myself after spring break I am not going to try for regular programs anymore…because it just too hard - I came back feeling completely drained from the whole experience. I think the problem might get bigger as he gets older because people will really see he's different than kids his age - he will be bigger and by the time you are nine, kids behave a certain way and he will behave like someone younger and his behaviour will be that much more different. (Annie, personal communication, May 27, 2014)

Michael’s disability affected his behaviour and Annie learned that behavioural differences set him apart from his age peers, as well as cast her in what she understandably experienced as a very negative light as a parent seen to be unable to control her child.

Cindy and Steve told me that Lulu’s therapy had helped her so much that they thought her disability would go unnoticed by her ballet teacher, and they had opted not to tell her about Lulu’s diagnosis. I took this to mean that they assumed she could now “pass” (Devlin & Pothier, 2006b) as a child without a disability. Additionally, since the program content suited Lulu just fine, they did not see the need for any accommodations to be made by the teacher. Their decision
to not share her diagnosis seemed reasonable to me, and, mostly, I was happy to hear they were finding Lulu’s class inclusive and fun. However, later in the interview, I explored an unexpected aspect of the macrosystemic impact of ableism in Lulu’s family when her parents elaborated on why they were choosing not to share their daughter’s diagnosis: Cindy said that, on the advice of a psychologist, they had stopped telling anyone that Lulu has autism, except for a few friends. Steve elaborated that they did not tell anyone else because they did not want to discourage any potential playmates, implying that they assumed that parents of children without disabilities would prefer not to arrange playdates with them if they knew their daughter had autism. This family’s negotiations with other people regarding their daughter’s autism diagnosis demonstrated one of the ways that Lulu’s ecological systems were intermeshed with society’s predominantly negative view of disability (D. J. Gallagher et al., 2014; Hosking, 2008; Watson, 2012). Although I felt sad about it, I understood why Lulu’s parents simply avoided talking about her label in order to minimize ableism’s effect on her.

**Advocacy.** Many times, situations encountered by the families called for parental advocacy to help dismantle or mitigate some of ableism’s impact on their children’s lives. At the time of our interview, Elizabeth’s daughter Maggie, who has cerebral palsy that requires her to use a wheelchair and other mobility equipment, was in a kindergarten class in a public school that was fundraising for a new playground. Elizabeth was on the fund-raising committee and they were working on a proposal that would ensure that the playground would be wheelchair accessible. She was discouraged because the financial decision-makers on this project balked at the significant price difference between woodchips and wheelchair-accessible surfacing and one of them questioned whether it was worth it for “just one kid.” Elizabeth explained to me how she had responded to him:
It’s just kind of like people think it’s a good idea but then when it comes down to money they don't want to spend that extra bit of money, so I said - "I want you who is saying “no” to come down to our school. We'll line up all the kids - I want you to look each one in the face and say "You can play" and "You can play" and "No, I'm sorry - you can’t play" and you look them in the face because I'm not willing to do that and that's exactly what you are saying... Like why don't you come and help me take my child to a playground where there are woodchips and she gets stuck…it’s heartbreaking for her to stay on the side and then she just wants to go home…” (Elizabeth, personal communication, May 20, 2014)

The creation of programs and environments that work only for able-bodied people is by definition ableist and while playgrounds are qualitatively different from organized community activities, I thought this example of ableism reflected a core issue of exclusion: It is often the case that children with disabilities do not have their needs met because of how much it will cost to meet their needs. Whether they need wheelchair accessible playground surfacing and play equipment or better adult-child ratios in programs, the impact of ableism is the same: they are excluded.

Annie also spent a great deal of time researching and advocating for additional supports and program options for her 6-year-old son Michael because she wanted him to attend community programs without her:

My days are spent doing these kind of things - looking through the websites and seeing what's available, what's not, what other parents are talking about - and putting more work into watching over his academics, his school work, training him… so it is a lot more work. (Annie, personal communication, May 27, 2014)
Even with the advocacy work she performed on a regular basis, she had recently been turned down by a program she wanted Michael to attend over spring break:

I mean I understand if he had medical issues - if he had tubes and stuff that he had to have a specialized medical professional or somebody who knows what's going on to watch over him in case something happens, I get that. However, Michael is not like that. He is physically fine - he can run, he just needs more guidance, he needs to be watched because he might walk off…I went into a lot of negotiation but at the end of the day it was still "no." It kind of hurt because what you thought would happen didn't happen and it’s part of life, however when you get that kind of everywhere you turn to, the door is closed on you - it doesn't make you feel too good. (Annie, personal communication, May 27, 2014)

The community program that Annie wanted Michael to attend, excluded him because they were not able to provide him with the supervision he needed to ensure his safety and maximize his participation. It was not because he could not do the program activities alongside his age peers. I speculated that macrosystemic, taken-for-granted assumptions about children’s development that I discussed in Chapter 4 meant that children’s programs are usually planned with only the needs and abilities of children without disabilities in mind.

Discussion

Within the microsystems of the children’s homes, the literacy routines and activities reflected Western, mainstream notions about early literacy, the most obvious being parent-child book reading. This finding was consistent with other studies about home literacy practices of young children with and without disabilities, which often indicate that shared book-reading occurs on a regular basis (Bus, Belsky, van Ijzendoorn, & Crnic, 1997; Bus & van Ijzendoorn,
1995; DesJardin, 2010; Weigel, Martin, & Bennet, 2010). However, this finding should be interpreted cautiously because the recruitment flyer clearly indicated that this study was about early literacy, and may have contributed to respondents’ bias in favour of book reading. Western early literacy discourses (Eagle, 2012; Nichols, 2011; Nichols, Nixon, & Rowsell, 2009; Teichert & Prendergast, 2014) privilege books and shared reading as the best ways to develop early literacy skills in young children. The participants have likely received many messages about the importance of reading to children, and this may have contributed to the frequent appearance of parent-child book reading in the data. Additionally, I found that other literacy practices in participant families’ homes aligned with Western notions of early literacy skills (e.g., drawing, and cutting paper with scissors), similar to those skills noted in Chapter 4. These activities suggest that this particular group of families, to varying degrees, were cognizant of the benefits of books and other literacy-linked activities for their children. Examined through the theoretical lens as presented in Chapter 2, I thought it likely that the parents were influenced by omnipresent messages about the value and importance of reading to children. These broad cultural messages, constitutive of the macrosystem, in turn influenced the processes that took place in these individual families, within each child’s home microsystem.

All but one of the families in this study made use of a variety of digital literacy tools for early literacy learning and entertainment. Also, three families made regular video calls to extended family using digital tools. Parents whose children have autism mentioned that their iPads were paid for through government funding and were used to help their children learn letters and words, listen to stories, and play educational games. Other than Steve and Cindy, who had, on the advice of their child’s specialist, decided to no longer allow their child to have access to digital media, this group of families used digital resources for their children’s learning and
entertainment in ways that reflect what is known about media use in the lives of all children, not just those with disabilities (Aronin & Floyd, 2013; Chai et al., 2015; Liebeskind, Piotrowski, Lapierre, & Linebarger, 2013; Marsh, 2004, 2005; More & Travers, 2013; Stephen, Stevenson, & Adey, 2013; Wooldridge, 2016). Interestingly, while Wooldridge (2016) found that children’s use of digital devices was often to distract a child so that the their parent could attend to another task, I was unable to make such a determination. I was more interested in the content of what they watched or played with or who they interacted with using such tools, not whether their parents had been able to get anything done while their children were occupied with their iPads or watching television. Most parents indicated that they were in favour of their children’s judicious use of media (Donohue, 2015), whether they paid for the tools themselves or they were purchased with government funding, to enhance learning and to provide entertainment.

While seven parents spoke heritage languages, they were all bilingual and sufficiently fluent in English to participate in the study. Not much is known about how children with disabilities from linguistically diverse families in the Western world fare in terms of learning their heritage languages (Yu, 2013). Anne, Mary, Steve and Cindy had stopped even speaking their heritage languages at home and spoke English because it was the language that their children’s therapists used and they said they wanted to avoid confusing their children. Research suggests that multilingualism has many cognitive benefits, and that children with disabilities can learn more than one language at a time (Bialystok, 2016; Guān & Cheatham, 2016). Moreover, Canadian culture (macrosystem) values both multilingualism and multiculturalism. Multiculturalism is enshrined in Canada’s constitution, with linguistic heritage emphasized as an important aspect of Canada’s cultural life (Guardado, 2002; Tierney, 2007). Because of this cultural value, immigrant parents are more likely to be encouraged to continue speaking to their
children in the language they know best (A. Anderson, Anderson, Hare, McTavish, & Prendergast, 2016; Bialystok, 2011; Guardado, 2002). In my work as a public librarian, I have reassured many immigrant and refugee parents that their children will learn English in their communities (i.e., library, preschool, friends, popular media etc.) while I also encouraged them to maintain their heritage languages. In this study, however, I speculated (and some parents confirmed) that the heritage language development of their disabled children was forestalled because they needed to participate in therapeutic activities delivered in English and they thought that continuing to speak in their heritage languages would confuse their children, which is consistent with what Yu (2013) found as well. These children with disabilities were not given the same opportunities to become bilingual and biliterate as children without disabilities. Moreover, children with disabilities whose parents had forestalled speaking to them in their heritage languages may have been hearing and learning non-fluent English, instead of a fluent first language from their parents, and this may have further limited children’s acquisition of both vocabulary and fluency in either English or their heritage language (Tabors & Snow, 2001). Any lack of progress in vocabulary and fluency might later be attributed to their disability rather than a lack of exposure to fluent spoken language in the home. This factor might also contribute to lowered expectations for children’s early literacy development once they arrive at school, as they may not yet be fluent in either their heritage language or English. At least some children with disabilities are at risk of not having access to the linguistic, cultural, and cognitive benefits of bilingualism (Guān & Cheatham, 2016) or even fluency in any language. This lack of exposure to fluent language would impact their literacy development. Since language is closely linked to culture and early literacy is enmeshed in children’s cultural contexts (Hamer, 2005), I believe this finding points to a critical need for more research in this area, echoing similar calls from
other scholars (Bruce, Meggitt, & Grenier, 2010; Lund, Kohlmeier, & Durán, 2017; Marinova-Todd, Colozzo, Mirenda, & Stahl, 2016; Yu, 2013).

In terms of mesosystem influences on the lives of the children in this study, the findings are consistent with other research with children with disabilities that points out the significant time children with disabilities usually spend in therapeutic activities (Dolezal-Sams, Nordquist, & Twardosz, 2009; Harry, 1995; Koppenhaver et al., 1991). In Bronfenbrenner’s framework, the time spent in therapeutic settings (each one a separate microsystem) could both advance and/or hinder different aspects of development. For example, learning how to do a step-by-step task in a behavioural intervention program may result in learning an important life skill. On the other hand, the time needed to attend weekly therapies, no doubt deemed necessary by specialists and parents alike, may hinder children’s opportunities for participating in other activities that their age peers without disabilities engage in. Research about early literacy participation and recreational activities suggests that children with disabilities participate to a lesser degree than their non-disabled peers for a number of reasons (Anaby et al., 2014; Paula J. Beckman et al., 1998; P. J. Beckman et al., 2004; Bedell et al., 2013; Katims, 1994; Koppenhaver et al., 1991). In this study, I found that the schedules of the younger children were dominated by one-to-one therapy sessions oriented to improving developmental/learning outcomes. Even though parents acknowledged the importance of their child spending time with other (preferably typical) children, four to five therapy appointments a week may have limited their efforts. Additionally, the notion of one-on-one therapeutic activities versus group social activities sets up another conundrum for the parents. As Andy’s mother explained, the children tended to do well in therapeutic scenarios where they worked one-on-one with another adult, but they were not as successful interacting appropriately with their age peers in group programs. Knowing the
limitations of therapy sessions to teach their children how to play and socialize with other children meant having to find other programs and activities to fit into their already busy schedules. This finding suggests that many parents of children with disabilities struggle with providing a balance between the benefits of various therapies targeting specific disabilities and the benefits of regular, social interactions with age peers. Understanding the challenges faced by parents of young children with disabilities as they navigate therapies as well as early learning opportunities represents an important area for future research.

For the most part, parents who attended mainstream programs like ballet, music, or story time with their young children did so without revealing their child’s disability label. For children with visible disabilities, such as Natalie, who communicates with a picture symbol book, and Maggie, who uses a wheelchair, explaining their disabilities might be unnecessary as program facilitators can see for themselves that the children’s development differs from other children’s. However, I speculated that when parents decide not to explain either visible or invisible disabilities to program facilitators, this might leave unsaid critical information about how to best accommodate and include the children. Laurie had seen that sometimes program facilitators used the knowledge of Blossom’s learning disabilities as an excuse to not try to teach her, whereas Jessa and Leslie had no expectation that regular program facilitators would know how to engage their children, and so did not say anything about their children’s disabilities. I thought this phenomenon to be consistent with the findings from the early literacy scan reported in the previous chapter, in that children with disabilities are so under-represented that even their parents do not expect community programs to be able to anticipate and plan for their participation. I was left with the impression that mesosystem interactions between program facilitators (i.e., music, dance, story time etc.) were minimal due in part to the reasonable assumptions made by parents
that program facilitators would be either unwilling or unable to accommodate their children’s needs. However, the families in this study had also found inclusive programs and experiences. For example, Abigail’s experience at the family centre drop-in, (where the facilitators not only welcomed her autistic son but were open to learning some of the strategies used to help him during meltdowns) demonstrated to me how mesosystem interactions can result in a child’s inclusion.

From a critical standpoint, I view ableism, both overt and subtle, to stem from a macrosystem that values normativity and perpetuates a medical model approach to disabilities in society, including early learning contexts (Ferri & Bacon, 2011; Goodley, 2014; Lyons, 2013). In this study, the effects of ableism were experienced as exclusion from activities and opportunities that parents of non-disabled children can take for granted. When Lulu’s parents avoided telling potential playmate’s parents about Lulu’s autism, they were doing so in order to avoid the impact of ableism on their daughter’s social life. I was not sure whether Lulu had already been rebuffed for having autism or this was their agreed-upon strategy to avoid future rejection. However, the idea that parents of non-disabled toddlers would discourage their children’s friendship with Lulu weighed on me heavily at the time (and still does) but Steve and Cindy seemed unfazed, as if they expected their daughter’s social peers’ parents to have ableist attitudes. Other researchers have explored children’s social exclusion as an outcome of ableist attitudes (e.g., Pearce (2009); Slater (2013)), but I was not sure to what extent parents of children without disabilities actually go to avoid having their children build relationships with children with disabilities. This would be an important area of future study, particularly as current research has explored peer play between children with and without disabilities in early childhood settings such as preschools and

I heard many examples of parents’ advocacy, which is reflected in other research about children with disabilities (Algood et al., 2013; Goddard et al., 2000; Lalvani, 2008; Lalvani & Polvere, 2013; Purdue, Ballard, & MacArthur, 2001). Both Annie’s and Elizabeth’s efforts were particularly intense and time-consuming and were not always successful. Annie’s efforts to have her son included in mainstream programs at her local public library and community centre were unsuccessful, due to an apparent lack of funding for extra paid staff people to attend to and support children with disabilities. This lack of support remains the case in many public libraries and community centres, including the library I work at now. On a more positive note, after our initial interview, I learned that Elizabeth’s daughter Maggie’s school playground received adequate funding to ensure that it was built to be fully inclusive and accessible for children who use wheelchairs and other mobility equipment (personal communication, June 28, 2017).

In this study, I found that, while many parents had to advocate for their children to participate in early learning to some degree, those whose children were of school-age and had cognitive disabilities were least successful. This was likely due to the need for these children to have dedicated support in the form of human resources, not just equipment, furniture, or the appropriate physical environment. As Elizabeth’s story about her playground advocacy work pointed out, woodchip surfaces in playgrounds represent serious barriers to children like Maggie who have physical disabilities. On the other hand, all kinds of (inclusive and non-inclusive) physical environments may be physically accessible to children like Michael, who has no physical disabilities but who has autism. However, without adequate support, those who have
needs such as Michael (due to cognitive disabilities) might be barred from participating in informal community early literacy program settings altogether.

**Limitations and Significance**

Thirteen families participated in this study and the relatively small number necessitates caution in interpreting the results. Furthermore, and although diverse in terms of linguistic heritage, the families were fairly homogenous in terms of socioeconomic status, and it would be imprudent to generalize from their experiences and narratives about their children’s early literacy learning. However, the small sample size, and the homogeneity notwithstanding, the range of narratives about their children’s participation in therapies (Goddard et al., 2000), how they are engaging in both formal and informal learning opportunities (Nind, Flewitt, & Payler, 2011), how they are navigating barriers and advocating for their children’s participation (Goddard et al., 2000; Harry, 2002) reflect many of the same themes in studies about children with disabilities. Overall, the literature about parents and children with disabilities suggests a certain degree of commonality in Western parents’ experiences raising children with disabilities today. While more research about the inclusion of children with disabilities in informal early literacy learning settings is necessary, the findings suggest that the common experiences around exclusion in particular are likely due to both subtle and overt but very persistent, negative social responses to disability in Western society in general (Lyons, 2013; Titchkosky, 2014). Like other qualitative research that draws on the lived experiences of a small number of people, the aim of this study was to point out general themes, not absolute truths. Many experiences (e.g., frequent therapy appointments) were shared across the participant group. Other experiences were divergent, as some children blended into their community’s programs while others were faced with the need for more specific, specialized programs and services. Parents’ general attitudes about inclusion
were diverse with some very satisfied with their community experience and others having experienced frustration and rejection. This diversity of experiences is likely to exist across larger samples as well, suggesting that family characteristics, as well as the social and cultural capital (Schultz, Corman, Noonan, & Reichman, 2009; Stehlik & Chenoweth, 2004) variation that exists in broader communities also impact families who face extraordinary circumstances in their children’s early years.

**Recommendations**

This chapter explored parents’ interpretations of their children’s early learning lives. In order to address some of the issues identified in my findings, the following are recommendations for the field of early childhood learning in general.

**Research about Heritage Languages and Children with Disabilities**

Parents’ decision-making about heritage language maintenance needs more investigation. Although not the focus of this study, I found the different decisions that the families made about their heritage languages very interesting. Because the social, cultural, and linguistic benefits of bilingualism are well-established (Bialystok, 2011, 2016), it is critical that a better understanding of the implications of English-only environments for disabled children who have multi-lingual families is needed, particularly those whose parents speak English as a non-heritage language. I recommend that more research about the heritage language approaches of multilingual families of children with disabilities be conducted. This research is needed to ensure that families who want to maintain their heritage languages are provided with supports that meet their children’s developmental needs.
Research about Parents’ Roles as Advocates in Early Learning

Existing research about parents of children with disabilities confirms that their lives are complex, often requiring parents to act as advocates, in addition to fulfilling the roles of their children’s first teachers. More research with parents that explores their lived experiences as advocates for their disabled children as they also take up early literacy support roles, may help to build a body of knowledge that I believe is needed to for policy-makers, educators, and others to begin to alleviate the inordinate pressures that ableist society currently places on parents of children with disabilities. Learning more about how parents navigate and juggle their roles may help in the creation of early literacy learning opportunities that are more responsive to parents and more inclusive of children with disabilities.

Community Early Learning Programs Accommodating Practices

Parents’ narratives about their children pointed to some issues that warrant further investigation and action in order to help them access the kinds of early learning activities that best suit their children’s needs and interests. Providers of children’s early learning activities should consider examining the participation rates of children with disabilities in their services, and then seek ways to increase disabled children’s inclusion and participation. Providers should also consider revising program descriptions to ensure that parents and caregivers receive explicit invitations for children with disabilities to participate, which may help alleviate some of parents’ advocacy burden. When running programs, facilitators should expressly invite all participating families to share their ideas about how to make the program activities as inclusive as possible. Participant feedback should be sought that addresses how well the program was able to include and accommodate those participants with extra support needs. Additionally, to promote inclusion, and to recognize that some families may struggle to find opportunities for their
children to socialize with peers without disabilities, providers of specialized programs should consider inviting some children without disabilities to participate in group activities. Finally, children with disabilities should not have to pay any additional registration fees for any support provided.

**Conclusion**

Throughout the study, I have focused on early literacy in the lives of children with disabilities. However, I would argue (and a large body of research in early childhood suggests) that all kinds of experiences, from free play to more structured programs such as story time, are important for children’s development. Additionally, as I pointed out in Chapter 4, Canada has ratified two major human rights documents: The United Nations Convention on the Rights of the Child and the United Nations Convention on the Rights of Persons with Disabilities (Canadian Children's Rights Council, 2014; United Nations, 2006; Walker, 2013). Both conventions purport to advance a notion of a unified childhood, one in which children with disabilities are able to participate alongside their age peers without barriers. However, the findings from this study show that children’s rights to access appropriate supports and to have accommodations made for them across various contexts were not always provided. Echoing others who have written about persistent barriers to inclusion, I suggest that changes need to take place at a macrosystem level (Gunn et al., 2004; Kliewer, 1998; Purdue, Gordon-Burns, Rarere-Briggs, Stark, & Turnock, 2011) that go beyond signing idealistic and non-binding global documents. The fact that parents continue to have to do advocacy work indicates that inclusion often remains an elusive goal. This study explored the experiences of families as they navigated a society in which their children’s inclusion was not always guaranteed. By sharing their perspectives, I hope to contribute to the
disruption of some of the macrosystem factors that continue to perpetuate exclusion based on children’s abilities.
CHAPTER SIX: MAKE IT WORK: CHILDREN’S LIBRARIANS’ AND PARENTS’
EXPLORE EARLY LITERACY AND INCLUSION AT THE PUBLIC LIBRARY

Introduction

This chapter explores the intersections of children’s librarianship and early literacy in the lives of children with disabilities. As described in Chapter 3, I conducted semi-structured interviews with 11 children’s librarians’ about how they were prepared in their librarianship programs at University and through ongoing professional development for providing early literacy resources and support for children with disabilities and how they actually provided support and resources. In another set of semi-structured interviews, I asked the 14 parents discussed in Chapter 5 about their experiences with public libraries when seeking early literacy resources for their young children with disabilities.

The field of early literacy research presents a rich array of evidence from various disciplines and theoretical perspectives that point to the importance of a childhood that includes experiences with literacy (Flewitt, Messer, & Kucirkova, 2014; Hamer, 2005; Hamer & Adams, 2003; Lonigan et al., 2009; Neuman, Copple, Bredekamp, & 2000; Roskos et al., 2003; Saracho, 2017a; Shanahan & Lonigan, 2010; Teale, 1999). Because of heightened interest in early child development in general and early literacy specifically, the past few decades have seen a proliferation of discourse about the importance of early learning (American Library Association, 2011; Quirke, 2006; Saracho, 2017b; Wall, 2010). This discourse often includes messages for parents about early literacy, pointing out information about typical language and literacy developmental milestones, as well as school-readiness skills and invitations to participate in community early literacy learning opportunities. Many of these messages mention the public library as a key resource for the provision of early literacy resources and experiences for all
children (Lopez, Caspe, & McWilliams, 2016; Neuman & Celano, 2012; Rankin, 2016; Sirinides, Fink, & DuBois, 2016).

As discussed in Chapter 2, a review of the professional literature in children’s librarianship revealed that providing library services that meet the needs of children with disabilities is a topic of considerable concern (Akin, 2004; Association for Library Service to Children, 2015; Baldassari-Hackstaff et al., 2014; Banks, 2004; Banks, Feinberg, Jordan, Deerr, & Langa, 2014; Farmer, 2013; Grassi et al., 2013; Kaeding & Prendergast, 2017; Klipper, 2014; Wray, 2013). However, in a review of the research literature in library and information studies (LIS), I found only a few studies have addressed this issue (Adkins & Bushman, 2015; Barker, 2011; Kaeding, 2015; Koulikourdi, 2008; Poulson, 1994; Prendergast, 2013; Ross & Akin, 2002; Rovenger, 1987). For example, Subramaniam, Rodriguez-Mori, Jaeger, and Hill (2012) investigated the extent to which dissertations in the field of library and information studies completed in the years 2000-2009 focused on issues of diversity and inclusion. Within the many aspects of diversity that they noted (i.e., race, gender identity, and so forth), they found that topics pertaining to libraries and people with disabilities of any age accounted for less than 3% of all dissertations, and less than 1% focused on parents of children with disabilities. Also, while researchers have investigated the home and preschool literacy experiences of young children with significant disabilities (Craig, 1996; DesJardin, 2010; Dynia, Lawton, Logan, & Justice, 2014; Flewitt et al., 2009; Hadadian & Weikle, 2003; Justice et al., 2016; Kliewer et al., 2004; Marvin & Mirenda, 1993; Ricci, 2011), very little is known about whether families of young children with disabilities choose to participate in early literacy learning opportunities offered at public libraries, nor of the nature of their experiences when they do participate. Better understanding of how, and to what extent, children’s librarians in public libraries provide
responsive early literacy programs and resources to parents of children with disabilities and how these programs and resources in libraries are taken up by families, may help with the creation of more inclusive and appropriate resources across the field of children’s library services, as well as contribute to the field of early literacy in general.

As described in Chapters 2 and 3, by exploring three linked cases (i.e., discourse, parents and librarians) my aim was to map the early literacy ecology of children with disabilities including the particular cultural context of the public library. In previous chapters, I reported how children with disabilities are represented in the discourse about early learning (Chapter 4) and how parents respond to and interact with early literacy resources for and with their children (Chapter 5). In this chapter I explore the issue of providing early literacy for children with disabilities from the viewpoint of practitioners, as well as the perspectives of parents as they reflect on the early literacy resources available in public libraries to their children with disabilities.

**Research Questions**

1. What are children’s librarians’ experiences with, and perspectives of, serving children with disabilities in their communities?
2. What do parents of young children with disabilities say about their experiences with early literacy resources of the public library?
3. What are professional children’s librarians’ reports about any training they have received and their thoughts about training they believe they need to receive for providing early literacy programs, services, and collections that meet the needs of children with disabilities?
The Participants

**Librarian participants.** As described in Chapter 3, I recruited 11 librarians with master’s degrees in librarianship who worked at four different public library systems to participate in a semi-structured interview of 45 to 60 minutes. These participants all worked in early literacy resource provision in their libraries for at least part of their current work-day, conducting story times, developing literature collections, and performing advisory services for young children and their parents and caregivers.

**Parent participants.** I described the parent participants in Chapters 3 and Chapter 5; all of these respondents were raising young children who had disability labels.

Findings

As I explain in Chapter 3, the dual perspective aspect of this study, which attempted to capture the experiences and perspectives of children’s librarians and parents, presented some challenges in terms of how to identify and communicate what seemed to be the most salient findings across the data set. I had two different participant groups, with two different interview protocols. While both groups talked about libraries, one group was coming to this topic from the practitioner perspective and the other from the parent perspective, while I was a member of both groups simultaneously. Also, the parents and librarians were not known to one another. Moreover, I did not expect that parents would have any prior knowledge of librarians’ professional training and the work that they do, nor did I expect that librarians had any specific knowledge about raising a disabled child. When the parents spoke about librarians they had encountered, or the librarians who spoke about parents they encountered, I made no efforts to identify who they spoke about, nor did I know whether any of the parents and librarians actually knew each other through interactions in public libraries. Through my conversations with
Accommodating Environments

During the interviews, I asked the children’s librarians their thoughts on how their library was doing with regards to access for people with disabilities, particularly children with disabilities and their families. All 11 librarians thought that children using wheelchairs would be able to access the physical space of their libraries, likely due to the fact that all the workplaces had been built to meet current building codes which include accessible routes and entrances (British Columbia Office of Housing and Construction Standards, 2014). However, when they considered the children’s areas of the library, most librarians conceded that computer tables, shelving, and other furniture arrangements might make negotiating the space with a wheelchair or walker difficult, but perhaps not impossible. Lana, a children’s librarian in a busy urban branch, described her library’s children’s area:
I would describe the space as pretty tight for people to move around even with the regular sized strollers! It's a small space and, quite realistically, getting in there with a larger stroller or wheelchair would be quite a challenge, I am sure of that. (Lana, personal communication, May 23, 2014)

Children’s librarians Molly and Piper worked in very new libraries that had been built less than 3 years before our interviews and both were confident that anyone using mobility equipment could access the space without difficulty, again likely due to improvements in building codes over the years. None of the librarians I interviewed were aware of any families of children with physical disabilities who used their libraries on a regular basis, so their assessments of accessibility were based on their knowledge of the physical layout and its potential to accommodate mobility equipment, not from feedback from disabled users.

Two of the participating families had children with physical disabilities who used wheelchairs and they expressed no complaints about their respective libraries’ physical accessibility. Moreover, both these parents said that they found library staff to be consistently welcoming and accommodating. Elizabeth, mother to 5-year-old Maggie, said this about her local library branch:

It's great - the bathrooms are big enough, the doorways are big enough- there's buttons on the doors so that they open and then the little chairs and the little table are at great height so I take her out of her wheelchair - she likes to sit. (Elizabeth, personal communication, May 20, 2014)

Next, I asked each participant to consider how well their libraries were able to accommodate and support families of children who have behavioural and/or cognitive disabilities, and in various ways they all indicated that it would depend on who was working at
the time and how familiar staff members were with patrons’ individual needs. By way of offering some positive examples, both Sandy and Sophia described how their libraries welcome and accommodate groups of young adults with disabilities who visit their locations on a regular, sometimes daily basis. In both cases, the young adults have developed relationships with all the library staff, not just the librarians. Sophia said “they're very comfortable, they all know the staff – staff know them - and it's just a very comfortable relationship” (personal communication, May 10, 2014).

However, many of the librarians said that they were concerned about how well some of their colleagues would be able to provide consistently caring support and accommodations. While Sandy described the “really great relationships” she and coworkers had with their regular patrons who have disabilities, she still worried about how accommodating they might be to patrons and families whose needs are unknown to them:

I think the difficult thing is when maybe new families or new patrons come in that live with different abilities and are not as much known to us, I think depending on who is working at the time - it could be a welcoming experience but it could also be kind of awful...I worry about how much is dependent on staff in terms of how they [patrons with disabilities] feel welcomed. (Sandy, personal communication, May 12, 2014)

Similarly, Piper had this to say:

Honestly, sometimes I think it might depend on the person that's working. If you have a child who can't help but have outbursts or be loud or disruptive there will people [staff members] sometimes that go over and scold them quite rudely, to be blunt...and other times it wouldn't be an issue or it might be an issue but the approach would be much
more friendly and sort of getting a sense of what's going on and trying to maybe mitigate
the situation… (Piper, personal communication, April 17, 2014)

Lana admitted that she and her coworkers were not always “equipped to recognize what is going
on sometimes” (personal communication, May 23, 2014). Robert described some of his recent
interactions with families:

I don't feel like I've been given training so I kind of have to rely upon politeness and
empathy… I'm going from my limited experience and just what makes sense as a human
being - I still felt underprepared even if it went okay. (Robert, personal communication,
April 15, 2014)

Confirming the point that Piper made about patrons with disabilities not always being welcomed,
Joanna, whose son, Nicolas, has autism spectrum disorder, described past experiences at the
public library where she said she felt scrutinized for her son’s behaviour, as he tended to run
around and frequently went behind the circulation desk to investigate the checkout machinery.

They thought he was just badly behaved basically and that I was just not really interested
in teaching him the proper behaviour in the library and then I just didn't want to get into it
with them so I just stopped going there. (Joanna, personal communication, April 2, 2014)

Although she eventually enlisted the aid of Nicholas’s behaviour interventionist to help him
learn how to behave in the library, she did not recall ever being approached by a children’s
librarian or any other library staff member with an offer to help collaborate on strategies that
might have helped Nicolas learn how to do so. She added that because of how she was made to
feel at the first branch, the family actually switched branches and found that the staff at the
second branch was “really quite relaxed” (personal communication, April 2, 2014) about her
son’s behaviour, although she did not discuss his needs with the librarian there either. Her son’s
eventual success (he regularly visits the second branch library without any behaviour issues) was accomplished without support from the children’s librarians at either location.

**Inclusion in Story time**

The libraries in which the participants worked all provided story time as part of their programming for young children. The librarians all emphasized their commitment to including children of all abilities in story time programs but said that only rarely did children with obvious disabilities attend. Each of them described a variety of strategies they employed to foster inclusion based on what they perceived to be the individual needs of children, sometimes by consulting with parents and caregivers, and sometimes just using what they called their “common sense.” Piper, who had 10 years of experience as a children’s librarian, said:

> It’s trial and error and if you make an error it might be a while before you get to have another trial! And I also worry that I have nothing that might help with what they need...you know, we have no materials so I don't want to embarrass myself either. (Piper, personal communication, April 17, 2014)

Piper then shared a story about a young girl with a complex disability whose caregiver accompanied her to story time:

> I did have one girl come regularly to story time with her caregiver and she was 4 or 5, and I don't know exactly what her disability actually was, but she had physical and mental disabilities, and she was in a special stroller - and the caregiver talked to me first before they started coming, she's like "Can I bring her to the story time?" I said, "Of course!" She said, "I'm a little bit worried that she might be disruptive." and I told her "It's not a problem…it’s fine!" And so she spent the first story time on one side of the room and she was really kind of having a hard time focusing so the next time I said,
"Why don't you try the other side of the room because there's a window there so if she
doesn't want to listen you can just turn her around and she can look outside," so that
worked really well and by the end of the story time session, she was able to almost focus
for the whole story time which was wonderful. And she didn't want stamps at the start
and she wanted stamps at the end - and that's like any kid – they get more comfortable as
they come into story time and get to know you. (Piper, personal communication, April
17, 2014)

Piper was able to see that the child had obvious disabilities and her caregiver had approached
Piper beforehand to discuss her attendance at story time. In noticing the girl’s distress the first
time (as the caregiver had predicted), she offered a solution to the caregiver that involved
distracting the child, without removing her completely. Piper’s interest was in keeping the child
in the program long enough for her to get used to the goings-on and to begin to pay attention and
ultimately enjoy the story time activities. Working with the caregiver, Piper offered a scaffolded
approach to building the child’s engagement over the course of several months and she noted
with satisfaction that it had worked out well. However, other librarians, Sally, Annika and April,
each spoke about some instances where there were otherwise “typical” looking children at story
time who were behaving in ways that made them think that perhaps they might have had
disabilities. They said they were unsure about broaching the topic with the children’s parents.
They wanted to find out if there were ways they could make story time more successful for the
children but they all worried that if they talked to the parents about their child’s behaviour, the
parents would be embarrassed and choose not to return. For example, Annika was
understandably frustrated by a young story time attendee who used to pinch her during her
programs. She suspected he had a disability but did not feel she could approach his elderly
caregiver (who she assumed was the boy’s grandparent) about it and did not want them to stop coming but needed the pinching to stop. Somewhat by chance, Annika met an early childhood educator who worked in a community family drop-in program who also knew this boy as he attended the same family drop-in program. The educator noticed the same kind of behaviour at the program she worked in, and was able to then approach the child’s mother about getting the child some behavioural support. Annika said that the child’s mother then began bringing him to her story time and she and Annika started working together on setting up expectations for him, to which he responded well. Annika concluded by saying that he was “a totally different child” after that (personal communication, April 22, 2014). While this particular story had a positive outcome, it was only a mutual acquaintance with expertise in early child development that made this possible, pointing to the precariousness of interactions and relationships between families of children with disabilities and children’s librarians who want to help them but may not know how. Natasha offered an interesting rationale for her decision to not invite a family (who came into the library for books on a regular basis) to also join her story time programs.

I have a family that's been coming to the library for years and they have a daughter who’s been diagnosed with autism and she does not bring her to story time - and I've never said, “Oh you should bring her" because it’s like she's already made the decision and it would be too loud for her and she wouldn't be happy at all, so I think my programs are loud and they're full and they're not inviting to parents of kids with disabilities so they just don't come - even if I were to invite them they wouldn't come - because it would just be too loud and upsetting. (Natasha, personal communication, April 14, 2014)

One of the parents, Abigail, described her and her son Thomas’s experience in story time at the local library, which, like the ones Natasha mentioned, was also noisy and crowded:
I had to stop taking him to story time because they tell you if your child is upset you maybe have to take him out and then I didn't know he had autism at the time. I didn’t know what sort of interventions I could do so I stopped taking him […] I didn't know what he had then, but if it was smaller, then he would have had more space and I could have actually reached him but there wasn't any space - the noise was also bothersome to him so I think if it was a bit smaller and not so crowded. I don't think the kids enjoy it anyway because it is superhot in there and it’s crowded. (Abigail, personal communication, May 15, 2014)

When I asked her whether she had ever discussed Thomas’s difficulties at story time with the children’s librarian who led the program, Abigail conceded that she had not. Likewise, the librarian had not approached her with any suggestions for making things better for them. Based on what the librarians told me about not knowing what to say to parents about specific children’s behaviour and being worried about scaring them away, it seems possible that the librarian had noticed Thomas’s behaviour but was reluctant to approach Abigail about it. Another possibility is that the librarian had noticed Thomas’s difficulties and, like Natasha, they knew they were not able to offer less crowded programs so they chose not to approach Abigail as they had no solutions to offer her. Similar to Abigail, parents Richard (Bobby), Annie (Michael) and Amy (Evan) also tried story time when their children were very young but stopped going as they too found that their children ended up being upset and/or disruptive. Even though they both used their libraries for books to read to their children, Joanna, mother to Nicolas, and Laura, mother to Blossom, both said they never bothered with story time at the library. Laura said, “She [Blossom] was too busy and wouldn't sit still” (personal communication, June 9, 2014). However, Steve and Cindy told me they took their 2-year-old daughter to the library twice a
week and she loved it, even when it was crowded. They reported that she was learning a lot of songs that they enjoy singing together at home (personal communication, June 4, 2014).

When children with disabilities found a good fit with a story time program, the librarians tended to see the parents and caregivers as being more likely to keep bringing them, even if things got difficult from time to time. For example, Sandy, a children’s librarian at a busy urban branch, described recent interactions with a family at her weekly story time programs. She had begun offering an afternoon timeslot, and a mother with a little girl with a disability began to attend then, instead of the typically crowded morning program. Sandy thought this might be because the afternoon program had fewer attendees, sometimes just one or two other families:

It resulted in really intimate programming and it was really lovely and it allowed us to just sit at a table which was a bit different for my story times because the girl was a little bit older and I think it enabled us all to focus a bit better - I mean I have no idea but I do think the mum felt more comfortable just because there were less kids (sic) and the daughter would often do a lot of exclaiming loudly or real crying if we moved on to something else - there were lots of tears around the transitions between different activities but it just really didn't matter because it was so small… some parts of it were really nice interactions and I feel like that mum feels really comfortable in that space and greets me really warmly when I've seen her out walking around near the branch and when I've seen her in the branch too. (Sandy, personal communication, May 12, 2014)

None of parents whose children had disabilities that affected their behaviour were able to share any experiences where they engaged with a children’s librarian to support their children’s participation in story time. None had ever been approached by the librarians who led the story time programs about their children’s extra support needs either. However, both parents of
children with physical disabilities (who may have just needed the library staff to make room for their wheelchairs in the story time area) talked about their very positive experiences at story time at their local libraries. Diane, an immigrant whose 8-year-old daughter, Jane, has cerebral palsy, has been making regular visits to their library for story time and other programs since their arrival in Canada 4 years ago when Jane was still a preschooer.

   We don't have a public library in my home country so I came here and then we saw the public library and the programs and all the books and the story times and I was so happy because I thought she was really engaged in the community and she is getting more socialized so these programs -- anytime we heard about any program in the library we used to go to that program and one time they did this fairy program and she was all dressed up and she went in her little wheelchair and everyone was taking pictures and she was so happy! (Diane, personal communication, May 30, 2014).

Maggie’s mother, Elizabeth, was pleased when her local public librarian was also at her daughter’s school for their Welcome to Kindergarten day. She said, “It was the same librarian from story time, so Maggie whipped in there in her wheelchair and they were ‘chat, chat, chat’ about this book and that book, she was very engaged so that was great!” (personal communication, May 20, 2014).

   These examples provide some insight into the range of experiences that children with disabilities and their families can have at their public library story times; however, hearing more from parents about what librarians can do to make story times more inclusive is important.

**Community Outreach**

   The librarians talked about what might be contributing to the relative rarity of seeing families of disabled children in the library, and attending programs such as story time. As Piper
mentioned earlier, they sometimes worried that they were not able to provide enough of the most appropriate resources and support for early language and literacy learning for families of children with disabilities. They also thought that effective community outreach was an important and largely untapped strategy for finding out what families of children with disabilities needed from them. This would entail finding out where and when service providers who support families of children with disabilities are conducting group programs, and then offering to visit them, or host them in the library, in the same way as they would visit or host other parenting groups in their community. Lana had some questions about how to do this outreach:

You know - how do we even find organizations that support the parents? Assist the families, you know - therapists that work with them? So how do we even get to them? I understand that it’s pretty overwhelming perhaps for families but if we're taking ourselves to able-bodied parents and babies and health unit drop-ins maybe we can take ourselves to the drop-in units for kids who have challenges - why not? (Lana, personal communication, May 23, 2014)

The librarians were aware that without an ongoing, trusting relationship with the child’s parent or caregiver, learning about how best to accommodate an individual child’s needs would be difficult. As mentioned, the librarians all said they were willing to hear from, and work with, families of children who need accommodations or extra supports, but only Piper could recall being approached by a caregiver to plan for a child’s inclusion, while Sandy made ad hoc adjustments to her programming to help accommodate a young girl and Robert adapted his program processes to help a young participant feel more comfortable. However, none of these interactions stemmed from intentional outreach to families of children with disabilities. Furthermore, Annika pondered the possibility that traditional community outreach where
librarians go out to other programs such as their local health departments’ newborn baby clinics to promote the library was just not sufficient:

Maybe we're not reaching the right people. Maybe families that have kids with specific needs are so immersed in their child's own therapies or behaviour classes or whatever resources they are already accessing - are we redundant? Or is there a place we can go?

(Annika, personal communication, April 22, 2014)

Also, since few children with obvious disabilities attended the early literacy programs at the libraries or were seen there with their families to choose books, the question loomed large about how to find them and how to attract them to the library. Lana elaborated about the time constraints that prevented her from conducting such outreach:

The business of making those connections is actually something that is kind of like growing a little pea, you know, you have to plant it, you have to love it, you have to water it, you have to give it sun - and then it will grow - meaning, you need time, you need time to make it happen [...] It's actually cold-calling, introducing yourself, trying to get a meeting, trying to talk to people, it takes time to build that [...] the way my week runs, I don't know how to sprout that pea, I just don't want it to die, really! (Lana, personal communication, May 23, 2014)

She went on to describe her current workload and the problem she faced with regards to dedicating sufficient time to build community relationships with service providers who work with children with disabilities and their families. Belle elaborated on what she thinks is important for herself and her peers with regards to finding out what parents of children with disabilities need from librarians:
Bring the community in - have conversations like - we're all about community-led programming and all of these kinds of things but I don't see it - whether it's because of a time issue or funding issue. We need community conversations where you invite parents of children with disabilities in to talk about what it is that they need - and that's part of what we need. (Belle, personal communication, June 10, 2014)

Since none of the parents interviewed had approached a librarian about their child’s special needs, even when difficulties were apparent, it seemed easy to conclude that the word is just not getting out about librarians’ willingness to work with these families to make the library a positive experience for them and their children. The next section focuses on input from parents about how libraries could improve with regards to families of children with disabilities.

Parents’ Input

The parents’ interviews included a question about what they wished the library could do for them. Answers varied and included general statements like “more story times” so that the current ones were not so crowded, and suggestions to limit attendance at programs by implementing ticket systems. The parents needed encouragement to think about what kinds of things they would be comfortable asking for help with. I understood from this that they preferred to interact at a distance from the children’s librarians in their communities. Given Joanna’s negative experience, as well as many of the librarians’ doubts about some of their colleagues’ public service approaches, I thought this might be due to parents wishing to avoid their children’s behaviour (and by extension their parenting abilities) being scrutinized by unsympathetic staff. However, Cindy and Steve talked about their daughter Lulu’s current attachment to “her favorite librarian” whose program she attended regularly and they were satisfied with their experiences there, except for the fact that it was quite crowded sometimes
(personal communication, June 4, 2014). As mentioned, Joanna admitted that she had not approached the children’s librarian to ask for help when she and her son’s behavioural interventionist worked together on a behaviour support plan for Nicolas. This plan included the creation of a simple “social story” which is an individualized booklet (usually made with printed PowerPoint slides) about the steps involved in the behaviour that is being taught and the new experience that is being introduced (Halvorson, 2006). The children’s librarian did not approach her either and Joanna felt that it would have been nice to have been approached with an offer to help at the time. Laura shared an idea that was similar to what Belle had said about inviting parents of children with disabilities into the library. However, Laura’s idea included the notion that parents would come to the library to gather information about coping with their child’s disability. Laura has extensive knowledge of community resources due to her years of advocacy for all three of her children, each of whom has a learning challenge. She thought that libraries could play an important role in helping to distribute the kind of information she finds herself called upon to share in her informal social network, where she frequently meets parents of children who are newly diagnosed:

They need a place to go where their child is looked after and somebody who knows what they are doing and recognizes that there are challenges and embraces that rather than everybody turning their nose up and they don't get the help and they go deeper and deeper down... Parents need information and there should be information where you can go to the library... it would be nice if parents could go... because I am sure there's tons of information at the library that they could be utilizing and they don't even know and if you don't know you can't get it... And you wouldn't even think about that - most people don't think because everybody is online now - nobody thinks about going to the library to get
information...and they have it at the gym where you can drop your kids off at the daycare
and go and workout, like why don't they have it for when you want to read about your
child's disability? (Laura, personal communication, June 9, 2014)

Both Belle and Laura touched on the importance of parents and librarians interacting: the parents
can hear from librarians what the library has for them and the librarians can hear from parents
what else they need from libraries.

Annie, who indicated she spends most of her time looking for programs suitable for her
son, wanted the library’s programs for school-age children to be made accessible to children like
her son Michael, who has autism. She had come up against access barriers recently as the
library’s school-age (i.e., 6-12 year) programs would not provide him with a support person so
he could attend, without her. She said she could not afford to pay someone else to go with him so
he did not attend at all. She thought that having teenagers available to act as one-to-one
volunteers for children like hers, who need a bit of extra support in informal school-age library
programs, would help.

Children’s Librarians’ Training

To reiterate, the interviews with the librarians were not meant to be judgmental about the
quality of their master’s degrees or their individual skill sets. However, I wanted to elicit
information about their academic preparation in terms of serving young children with disabilities
and their families, specifically regarding early literacy resources and support. Generally
speaking, the librarians recalled that their master’s degree programs made them aware that public
librarianship meant being ready to serve the whole spectrum of human diversity. However, they
indicated that their training in how to accomplish this was minimal; they instead had to learn on
the job, via mentorship or just “trial and error.” Of the 11 children’s librarians, four (Natasha,
Molly, Annika and April) said that they had not taken any children’s library services courses in library school because they had planned to work in other areas of librarianship. Nevertheless, they found themselves working as children’s librarians and subsequently learned on the job. Natasha and Molly explained that they had been mentored by experienced colleagues, and Annika and April said they had attended professional development workshops and conferences that helped prepare them for children’s library work. Since these four had not taken any children’s services courses in their LIS programs, they were only able to comment on what they recalled from courses that touched on community diversity and working with the public. They each remembered having some class discussions and occasionally course assignments about working with adults with disabilities. The other seven librarians had taken one or more children’s library services courses and three of them had taken a course focused on library services for young children and their families. Six of these librarians could not recall having learned much specific information about disability or inclusion in their children’s library coursework. As mentioned earlier, Robert thought he still needed and wanted more training in the area of inclusive library services, but he was also the only children’s librarian who emphasized that the children’s librarianship courses he took all included frequent references to how to consider the needs of children with disabilities in children’s library work, which he was able to enact in a digital literacy program he had recently worked on.

I have a boy who does have unique learning challenges - he's told me for example that when we are doing role playing exercises or acting that he said "I can't do this" and it wasn't just because he was shy because that's normal and lots of kids said that, but he said "my words just get too tangled up and I can't tell stories..." and again I could list the things that I observed that made me wonder if there was something I could do, but again I
don't really know what it is - all I know is that he gets obsessed on certain subjects but
listening to him I can tell has meant a great deal to him - but there are certain types of
learning that he isn't comfortable with but he was able to express that to me and I was
able to adjust what I put in front of him. (Robert, personal communication, April 15, 2014)

Another librarian, Belle, who graduated 2 years before the interview and had taken a course in
children’s library services, as well as other public service courses, was adamant that the topic of
serving people with disabilities of any age had never come up at all, saying, “Nothing - and I can
say that with certainty - that was specifically targeting or including topics of children with
disabilities - absolutely none…” (personal communication, June 10, 2014). When I asked if her
course content included any exploration of diversity, she elaborated, “We'd have to do, you
know, environmental scans of certain library areas and the focus was on looking at socio-
economic differences or characteristics of the community, as well as linguistic and cultural
heritage, those kinds of things…” (personal communication, June 10, 2014). She was
disappointed that her library degree did not offer any courses that included disability topics,
believing that knowledge of disability is critical for children’s librarians working in public
libraries. When asked how she was going about filling this perceived gap in her training, Belle
said that she was currently taking a six-week online professional development course offered
through the Association of Library Services to Children on the topic of library services for
children with disabilities that she paid for herself on her own time after work (personal
communication, June 10, 2014).

Library and information studies graduate program courses. The participants attended
three different master’s programs over the span of two decades. It was difficult to discern how
much, the topics of early literacy and disability were covered in their degrees or in other LIS master’s programs. To explore if and how current LIS programs are addressing these topics in their course offerings, I undertook a scan and analysis of course content from a random sample of 20 different American Library Association accredited library degree programs in the United States and Canada. At the time I undertook this scan (late 2014), out of 53 course descriptions from 20 programs, I found one course at one LIS program that was devoted to serving children with disabilities. It was described as including “strategies for planning library programs and services that are inclusive of the information needs of PK-12th grade students with disabilities” and remains on this school’s calendar of regular course offerings (R. F. Hill, 2017). I found one other course about serving adults with disabilities from another program, which was described as covering “the historical and philosophical context of the concept of disability” and “the practicalities of equal provision of service to populations designated as special needs” (Adams, 2013). There were only two courses devoted to early childhood literacy in the sample, one called “Early Childhood and Public Libraries” (Higgins, 2017), the other called “Services for Families and Early Literacy in the Preschool Years” (Taylor-McBride, 2017). This finding does not mean that early literacy and disability topics were not covered in other courses, just that there were few courses dedicated to these aspects of public librarianship. Furthermore, when they were available, the descriptions for other courses infrequently included these topics in their overall course content.

During the final segment of the interviews with librarians, I invited them to offer ideas for how to address any of their perceived knowledge gaps and the kinds of training they thought would work well for all children’s librarians. While none of the librarians intended to go back to library school, they agreed that the topic of disabilities should be covered a great deal more
deliberately and intensively in library program course offerings than currently is the case. In terms of how to accomplish this, there were some differences of opinion. Sophia thought that an entire course on disability was warranted in LIS master’s programs, mostly to help allay some of the fears and discomfort she believes that many people feel when they encounter people with disabilities:

I think courses where they talk about different people with different types of disabilities - because there are very specific types - I mean I don't think you would ever understand all of them - you would always encounter things that you didn't necessarily understand - but if you had enough - if you had some basic knowledge about how you approach some people with some of the disabilities…some basic skill sets and just an understanding of the barriers and what tools we have to assist them going around those barriers and overcoming them. (Sophia, personal communication, May 10, 2014)

In contrast, Belle thought that disability issues should be touched on in all courses, to normalize the notion that people with disabilities of all ages are part of the communities we serve and that disability should not be treated as a separate topic at all.

It needs to be introduced in an MLIS program, not as an elective specialty course on patrons with disabilities - because that is just perpetuating this kind of isolationist and segregationist view of the topic - it needs to be woven into the core courses, that's the only way that it actually is going to happen - that's how I think, a powerful sort of change-making core. (Belle, personal communication, June 10, 2014)

**Professional development opportunities.** Whether or not library schools add courses that include coverage of early/family literacy and services for people with disabilities, interviewees agreed that they both wanted and needed more training in this area. I also asked the
librarians about professional development that they had taken after graduation that dealt with early literacy and/or disability topics. The longer they had been working as children’s librarians, the more likely it was that they had attended workshops and conferences that included some type of early literacy training. Since Every Child Ready to Read® (American Library Association, 2011) workshops have been offered at Canadian and American library conferences for over a decade, with free webinars also available from time to time, all 11 interviewees had at least introductory training in the ECRR® program’s basic tenets. There were, however, mixed opinions on whether or not ECRR® resources were inclusive of children with disabilities and their families. Robert, a recent graduate, mentioned that the webinar he took on this program included considerations for children with disabilities, while Lana thought it was directed at a fairly “homogenous” group of children. Most of the librarians recalled that ECRR® professional development training did not address early literacy for children with disabilities and their families. However, Sophia talked about how she regularly adapted the content in ECRR® to meet the needs of the vulnerable families that she worked with in her community outreach role, describing some of her strategies for describing the five ECRR® practices of singing, talking, reading, playing and writing like this:

So when you are encouraging for example, drawing or writing or manipulating a pencil, I encourage scribbling right? ECRR® encourages things that develop the skills that have not yet been formed yet and it recognizes that they are emerging at many different levels and I think that it really simplifies the process for parents… the kids are doing something but the parents might not have recognized that it's part of that skill development… and all you have to is just say those five things and point out a couple of skills around each one of those words - it does work and this is all the stuff I mean about
“before they start reading”… that falls into place and then it all makes sense. (Sophia, personal communication, May 10, 2014)

In discussing professional development opportunities, several librarians identified the Parent-Child Mother Goose Program® (PCMGP®)\(^5\) (BC Council for Families, 2008) facilitator training and the Mother Goose On the Loose® (MGOL®)\(^6\) workshop as having content that was applicable and/or easily transferable to situations where parents of children with disabilities might attend story times. Sophia, who has over a decade of experience working in communities with vulnerable families, said she recently attended the MGOL® workshop:

> I love what was emphasized at the end in the Mother Goose on the Loose® program about talking to the parents and just telling them that it was all okay and just reassuring them that everything that is happening is okay and while there were different experiences that was okay too. (Sophia, personal communication, May 10, 2014)

Natasha, who had also attended this workshop, said that she liked that the workshop facilitator emphasized how important it was to make “people feel comfortable and want to come back” (personal communication, April 14, 2014). I thought about how some of the families I interviewed were sometimes scrutinized by staff and other families because of their children’s behaviour. A program facilitator who cultivated (and trained people how to cultivate) an inclusive atmosphere might help create more comfort and inclusiveness for parents of children with disabilities.

\(^{5}\) Parent-Child Mother Goose is an early literacy program developed in Canada that focusses on oral language play between parents and their babies.

\(^{6}\) Mother Goose on the Loose is an early literacy program that draws on early brain development and was created an American children’s librarian and early learning consultant, Dr. Betsy Diamant-Cohen.
Another issue arose when discussing institutional support for pursuing professional development. Not surprisingly, it was preferable that training be offered as part of regular paid work, with tuition fees covered by the institution. Both Belle and Molly, who were taking online or evening courses, said they were paying their own fees and doing the course work during their free time, which neither thought was sustainable or ideal; both said that they would be happy when their courses were over.

When considering professional development opportunities for themselves, the librarians all emphasized the importance of hearing directly from disability experts, as opposed to a class that focused on research on disability topics which they would expect in a graduate course. Lana thought it important that she learn “a little bit more about the actual difficulties and barriers of children with disabilities” (personal communication, May 23, 2014). Molly wanted more training in child development but did not want to take a course outside of work time either (personal communication, May 14, 2014). Finally, Piper sympathized with staff members who might be reluctant to approach families with children who had disabilities, and she thought training on how to make initial contacts positive for everyone was very important for all library workers, not just professional librarians:

I think people need to know. Just in general, people can get scared about how to approach a family that has children with disabilities so instead people avoid – “I'm just going to go to the back room right now!” So just maybe being aware of what different, like someone with autism, what you might need to know about that and just techniques - I guess awareness in general is what people need, then build that comfort level. (Piper, personal communication, April 17, 2014)
Overall, the librarians agreed that while professional development in this area was important to them, none were clear on what different opportunities were available to them. Some had heard about a new training toolkit in the province and others occasionally attended conference programs on disability themes, but most indicated that they rarely heard about free or low-cost online or face-to-face learning opportunities on disabilities topics for library professionals serving any age group. As described in Chapter 3, I conducted a scan of professional learning opportunities throughout the study year of 2014. I looked at professional development course offerings aimed at librarians working in early literacy and tried to find those that included content about serving children or people of any age with disabilities. The scan revealed an array of mainly online learning opportunities, most of which were webinars conducted by librarians who worked in the United States who presented their own program models aimed at serving people with disabilities. Except for the aforementioned Mother Goose on the Loose©, Parent-Child Mother Goose©, and the online course called Serving Children with Disabilities in the Library offered by the Association of Library Service to Children, none of the librarians I interviewed had taken any other professional development course in working with patrons with disabilities in early literacy.

Discussion

My findings with regard to accommodating environments explored the impact of both the physical environment as well as the experiential environment that families of children with disabilities might encounter at the library. I found there was little research in this area. H. Hill (2013) suggested that the passage of the Americans with Disabilities Act (ADA) (Bertot & Jaeger, 2015) may have accounted for the lack of research about people with physical disabilities and libraries, in that it would be easy to assume that libraries must be accessible by being
compliant with the law. However, Copeland (2011) interviewed library users with physical
disabilities (who were also LIS professionals) and found that tight spaces (such as the ones some
of the librarians in this study were worried about) and other physical access barriers, were still an
issue for them as adults who used mobility equipment. Canada does not have a corollary to the
ADA, but does have building codes that make accommodations for people using mobility aids
such as wheelchairs. Although only two parents in this study had children with physical
disabilities, neither had encountered barriers to access in the libraries, but more research in
Canadian public libraries would be needed to see whether their positive experiences are the norm
or the exception. When considering how well public libraries are able to accommodate children
with cognitive or behavioural disabilities, the judgement from library staff felt by parents like
Joanna and Annie in particular has been discussed by Kaeding (2014, 2015); Kaeding et al.
(2017). Other researchers have pointed out the importance of disability awareness training for
staff. For example, Kaeding et al. (2017) identified training as a key aspect of their proposed
“inclusive library model” and emphasized that training needs to be at all staffing levels. As Todd
(2014) stated, “Staff development is a good way to ensure that all workers respond with a
positive attitude” (p. 27).

Research about public library story time and children with disabilities is sparse. However,
in their questionnaires and interviews with 18 librarians from Canada and the United States,
Kaeding et al. (2017) found that 50% of respondents believed that “library programmes do not
cater for children with disabilities” while 44% pointed out issues with the library’s physical
environment, such as noise and poor lighting, as barriers to program access. This assessment of
story time is congruent with that of both parents and librarians in this current study who also
noted some of the ways that story times are not accessible for some children with disabilities, a
view reflected in the professional literature as well (e.g., Grassi et al. (2013), Jarombek and Leon (2010); Leon (2011). Interestingly, in her study of caregiver perceptions of early literacy at the library, Clark (2016) reported that some caregivers did not see any problems with large groups at story time, while others criticized the crowdedness of story times as being chaotic. As Clark noted:

If the program size becomes too large for the librarian to interact, transmit information, and make attachments with children, then the goals of emergent literacy programming are lost (p. 165).

Clark did not mention whether any of the parents she interviewed had children with disabilities.

The topic of outreach and partnership appears in the research literature in ways that confirm my librarian participants’ assertions about the importance of conducting effective outreach and forming strong partnerships with organizations that serve families of children with disabilities. For example, in their study of inclusion in libraries, Kaeding et al. (2017) found that 94% of libraries that were providing inclusive services and programs to families had conducted outreach and developed enduring partnerships with other community organizations that served families. Kumbier and Starkey (2016) stressed the importance of outreach to disabled people as a way “to understand why they are not already users and how the library may become accessible for them” (p. 483).

Prior library research paid scant attention to the views of parents, and extant studies have not focused on the experiences of those whose children have disabilities in a way that could confirm or contradict my findings. Mainly, parents have been given questionnaires or interviewed to provide feedback about library programs for children, such as the study by Clark
(2016) mentioned above and another study by Sensenig (2012) that explored both librarians’ and parents’ perspectives of early literacy learning in the library.

The findings from interviews with 11 librarians and 14 adults from 13 families of children with disabilities revealed that the children’s librarians can and do interact with families whose children have disabilities in positive ways, but that service gaps still exist for this group of children. Viewed through Bronfenbrenner’s framework, these gaps can be construed as impediments to development within individual children’s microsystems of support. Some of these gaps may be due to attitudinal barriers on the part of parents who may assume their children are either not welcome or not able to be accommodated in the library, and some may be due to library staff’s lack of preparation for serving this group of people in inclusive ways (Kaeding et al. (2017). Moreover, the lack of attention paid to disability topics relative to the prevalence of disability in society (Katz, 2009; Subramaniam et al., 2012) is consistent with the perspectives of the librarians I interviewed and with my analysis of library program curricula. This lack of attention suggests that macrosocial, ableist, and exclusionary responses to people with disabilities still exert considerable, negative influence on the lives of people with disabilities. The interviews also suggested that, despite the prevalence of ableism in society, children’s librarians who are willing to offer responsive, inclusive services and parents who want and need such services rarely encountered each other, but when they did, the benefits of such interactions were obvious, especially when viewed through Bronfenbrenner’s bioecological systems framework (Goodson, 2011; Hayes et al., 2017). In these interactions, parents and librarians working together can be seen to contribute to more positive experiences for the child. For example, Sandy’s narrative about her interactions with the child and the child’s mother in the comfortable, less crowded, more intimate context allowed the girl repeated opportunities to
experience literacy in more meaningful ways than she would have been able to in the crowded morning program. Moreover, Sandy’s effort to build a trusting relationship with the mother seemed to have resulted in her sustained interest in coming to the library for programs and for materials for her child. Less accommodating experiences, such as feeling scrutinized when her child cried, may have left this mother feeling reluctant to return, as her daughter’s frequent emotional responses may have seemed too difficult to manage. This example shows that a children’s librarian can exert a positive influence on the child’s ability to experience and interact with “persons, objects, and symbols” (Bronfenbrenner & Evans, 2000) and support her literacy learning and development.

However, echoing Rovenger (1987), these interviews also suggest that librarians, with their expertise in encouraging early literacy development in young children, may remain underutilized resources in the lives of families whose children have disabilities. Unless librarians receive further training to learn how best to accommodate children’s differential developmental trajectories and adapt resources and advice offered to parents, as well as undertaking intensive community outreach to engage such families, they are likely to remain under-utilized. In Chapter 5, I stressed the burden of advocacy roles that parents of children with disabilities have to take up for their children’s participation. Disability research literature frequently mentions parents’ roles as advocates for their children (Campito, 2007; Goddard et al., 2000; Kelly, 2005; Kliwer et al., 2006; Trainor, 2010). However, in this study, except for Annie who tried unsuccessfully to register her 6-year-old son with autism in an after-school library program (he was turned away because they did not feel they could ensure his safety with the staffing they had planned for this particular program as he requires more supervision than other children his age), I did not find evidence of parental advocacy within libraries. The professional literature has many examples of
how libraries have responded to parents’ requests for special story times and I thought it curious that none of the families I interviewed had advocated for their child’s inclusion at story time or asked for special programs. That being said, from the stance of critical disability theory, I believe that the responsibility for addressing barriers within children’s library services should fall on the institutions and personnel, not on the people who are facing barriers to participation. I found that while they were willing to offer positive and welcoming settings, the librarians rarely encountered families whose children might need extra support. On the occasions when they did so, they tended to rely on common sense and instinct to try to make the interactions as productive and positive as possible. This suggests that librarians are already ideally placed in communities to offer inclusive support to families because the nature of their work already requires of them interpersonal skills that can be tailored to meet the needs of each family. It seemed that many were striving to do just this, even without specific training. However, the librarians I interviewed felt underprepared, due to their general lack of familiarity with disability issues and a lack of knowledge about how to reach families and how to adapt early literacy resources for children with disabilities. Moreover, as Natasha expressed in her assessment of her own story time programs as not being welcoming to families of children with disabilities, the ways in which librarians’ work is organized can impose barriers to inclusion. Presenting story times is only one of many duties in a typical librarian’s workday and the option of offering additional story times to decrease group size cannot be assumed as a viable solution. Within their institutions, librarians need agency and resources to help determine, with input from families, the best ways to meet the early literacy needs of children of the families in their communities, and these need to be adaptable and scalable to suit different situations. Inclusion aims need to be viewed as worthy of significant investment that go beyond mission statements and positive attitudes. I believe this
needed shift in children’s librarianship is reflected by Kumbier and Starkey (2016) in which they stated:

When we bring the framework of collective access into conversations with conventional library understandings of access, one of the biggest shifts we make is from thinking about accessibility as a matter of problem solving at the “tick-box” level to accessibility as part of a larger project to dismantle ableism in our libraries. When we conceptualize access in this way, we are asking libraries to understand it as an ongoing project, one that will transform our profession and organizations in ways we cannot anticipate. (p. 485)

In Bronfenbrenner’s framework, these internal institutional practices are identified part of the “exosystem”, which exerts indirect influence on the developing person. Understanding how exosystem influences (and ableism) impact a disabled child’s access to early literacy resources should be investigated in future research.

**Limitations and Significance**

This case study involved 11 librarians and 13 families of children with disabilities and examined 20 North American LIS programs. Given the sample sizes, findings need to be interpreted cautiously. The interviews were co-constructions of moments in time within the fluid social worlds of my participants. Even with my shared identities of parent and practitioner, I only had a partial view of participants’ insights and what I gleaned from them is not complete. Nevertheless, several themes in the findings suggest ways that libraries and librarians can improve services to children with disabilities and their families. As discussed in Chapter 2 and earlier in this chapter, in the Western world, there is heightened interest in early years education at the macrosocial level. Consequently, children’s librarians are likely to continue to be professionals who have expanding expertise in early childhood literacy. This study intended to
highlight the possibilities inherent in considering, as well as expanding, the potential contribution of librarians within the early literacy ecologies of young children with disabilities and their families.

**Recommendations**

The following recommendations are meant to be seen as opportunities for the field of children’s librarianship to improve the ways in which families are able to access and benefit from the significant early literacy resources of the public library.

**Inclusive Early Childhood Education Research**

There is a fairly extensive research literature in the area of inclusive early childhood education and professional resources that offer practitioners effective strategies for including children who have disabilities (Barton, Reichow, Wolery, & Chen, 2011; Brug, Van der Putten, & Vlaskamp, 2013; Conn-Powers, Cross, Traub, & Hutter-Pishgahi, 2006; Dennis, Lynch, & Stockall, 2012; Vakil, Welton, O’Connor, & Kline, 2009), as well as how to work supportively and collaboratively with their families (P. A. Gallagher, Fialka, Rhodes, & Arceneaux, 2002; Harry, 2002; Ray, Pewitt-Kinder, & George, 2009). I believe that drawing on existing knowledge about inclusive early literacy will build capacity in children’s librarians’ abilities to work more effectively with children with disabilities, and especially those with cognitive and behavioural disabilities. Librarians working with parents (and sometimes therapists and others) would exemplify Bronfenbrenner’s notion of the mesosystem where different agents within a child’s Microsystems interact in support of that child. Working with individual families to meet their children’s needs represents a significant way that children’s librarians can ensure that children with disabilities have equitable access to the early literacy resources available at the library. This is the foundation of inclusive practice. While the kinds of improvisations enacted by the
participants in the current study offer insights into how libraries can be organized for inclusion, greater shifts in how professional librarians approach, develop, promote, and deliver inclusive early literacy programs resources to all children and their families are needed.

**Expand LIS Studies Curriculum**

Library and information studies graduate programs should assess course content concerned with early literacy to make sure it includes information about engaging with families whose children have disabilities and ensure that graduates have the necessary knowledge and skills to provide inclusive early literacy resources in public libraries. Additionally, content about serving people with disabilities of all ages who need accommodations to access the library should receive more attention in all courses focused on user experiences in every type of library.

**Professional Development for Library Practitioners**

Library leaders should both encourage and provide professional development opportunities in the areas of inclusive early literacy and serving people with disabilities for staff at all levels (including paraprofessional and support staff). Library workers who interact with the public need to have knowledge about working with families whose children have various disabilities. Librarians and other library workers need to be supported in learning how to plan for these children’s participation in library services as a whole. Library leaders should also encourage and enable ongoing professional mentoring relationships so that more experienced, knowledgeable staff members work with their less experienced colleagues to develop their knowledge around inclusive library services.

**Disability-focused Research Agenda in LIS**

LIS faculty should conduct more critical research, such as that undertaken by Kumbier and Starkey (2016) that aims to dismantle ableism in libraries and explores the intersections
between the disability experience and library services. Librarians who work in all types of libraries should similarly be willing to participate in research that probes for a better understanding of how well libraries are able to accommodate the needs of people with disabilities. Overall the field of librarianship needs to develop strategies that help make inclusive libraries a reality for all, beginning in the early years and continuing across the lifespan.

Conclusion

Children’s librarians are skilled professionals who may have a great deal to offer in terms of early literacy learning to families whose children have disabilities. The librarians in this study provided insights based on their own experiences that suggested that when they encountered families whose children have disabilities, they tried to be supportive in terms of helping the children get the most out of their experience at the library. Parents reported that they had mainly positive experiences at libraries. There were exceptions, including attending crowded, noisy story times, as well as sometimes feeling scrutinized by library staff and other members of the public when attending with children who have disabilities that impacted their behaviour. As I noted in Chapter 1, after two decades in the profession, I maintain that we are likely not seeing many of our communities’ children with disabilities in our libraries. Conducting this study has shed some light on why that might be the case and it has also illuminated the potential for children’s librarians to help facilitate the early literacy development of children with disabilities. While there must be a commitment from the profession as a whole to eliminate macrosystemic barriers, particularly the persistent social stigma associated with disability in general, children’s librarians should continue to be recognized for their already significant roles in providing early literacy programs and resources in diverse communities while concerted attention is paid to the
remaining gaps in how well they are able to meet the needs of children with disabilities and their families today.

By considering Bronfenbrenner’s bioecological systems framework, I propose that more frequent interactions with the early literacy resources (including the people who facilitate access to such resources) of the public library could represent a positive force for individual children’s early literacy development, in much the same way as regular home reading and opportunities to engage in interactive play with peers might support early literacy growth. By the same token, fewer, or less successful interactions in the library context could inhibit literacy growth because of lost opportunities to engage with the resources that are available there. This study has begun to uncover some of the ways in which libraries and librarians may be more effectively enmeshed within the early literacy ecologies of children with disabilities and their families, and has proposed some ways of moving forward towards meeting inclusion aims in public libraries.
CHAPTER SEVEN: CONCLUSION TO THE STUDY

This study aimed to explore how children with disabilities are enmeshed within early literacy learning ecologies, with their families and other community resources and people. By first considering prevalent early literacy discourse found in their communities, I speculated that the under-representation of children with disabilities in early literacy discourse renders them invisible and contributes to their inevitable exclusion from opportunities. By hearing from families about their daily lives, I concluded that children’s therapy schedules impinged on their opportunities to participate in inclusive early literacy experiences. I also heard from parents that they sometimes struggled to find a balance between therapeutic and non-therapeutic activities for their children and that they often needed to advocate for their children’s inclusion in mainstream early literacy learning programs. I found that children with physical disabilities were accommodated into programs such as those offered at community centres and public libraries. However, I found that children with cognitive disabilities were sometimes excluded from community early literacy programs, or their parents found that such programs were not able to accommodate their needs so they stopped attending. Parents of preschool-age children with disabilities tended not to inform early literacy program facilitators about their children’s development or needs, nor did they expect program facilitators to know how to work with their disabled children. While most parents used libraries to borrow books and sometimes to attend story time and other literacy programs, they tended not to discuss their children’s needs with librarians. Librarians indicated that were rarely consulted by parents of children with disabilities and they noted that they seldom saw children with disabilities in the library. They also maintained their philosophical and professional commitment to inclusive practice but some
struggled to find ongoing professional development that would help them best meet the early literacy needs of children with disabilities.

**Mainstream vs. Inclusive**

As mentioned earlier, disability is not an umbrella term, but rather, in this study, it is used primarily to point out social responses to people’s perceived impairments. While I attempted to build a rationale for inclusive early literacy in which children with disabilities can participate alongside their age peers in so-called “mainstream” or regular programs, I acknowledge that no single setting can possibly be inclusive of all children at all times. For example, a setting in which the variable needs of children with sensory, cognitive and physical differences are constantly accommodated might not be realistic or even desirable and there remains a rationale for separate programs for children with the same disability sometimes. However, based on the results of this study and the perspectives in the extant literature, I argue that we can do much better in making more community based early literacy programs more accessible to many more children and their families than is presently the case.

**Revisiting the Theoretical framework**

This study drew on critical disability theory and Bronfenbrenner’s bioecological systems theory. Using a critical disability lens allowed me to examine the societal/macro influences on the lives of children and families. I aimed to expose taken-for-granted assumptions and explore the impact of positioning children with disabilities as separate from their non-disabled age peers. I listened to parents’ own narratives about their experiences supporting and advocating for their children’s inclusion and I reflected on other critical literature about the impact of ableism on the lives of children with disabilities and their families.
Using Bronfenbrenner’s bioecological systems theory helped me to consider the systems of developmental support for the children both in their homes and their communities. I was able to explore their many interactions with “objects, symbols and people” as they went about their daily lives, enacting routines and participating in activities. This systemic view allowed me to identify developmental barriers, as well as opportunities. When looking at the role of public libraries and librarians in particular, the bioecological lens assisted in an exploration of the role of children’s librarians in the mesosystem of children with disabilities as well as think about the impact of the exosystem in terms of current institutional practices in libraries. I believe that Bronfenbrenner’s bioecological systems theory can contribute to conceptualizing a research agenda for future research about children and libraries.

Blending critical disability theory and Bronfenbrenner’s bioecological systems theory allowed me to develop more nuanced understandings of participants’ experiences across contexts and settings and to present findings that reflected their lived experiences as well as the social and discursive contexts which families with children with disabilities navigate. These lenses also contributed to my understanding of the way in which normative discourse and ableism influence institutional practices that result in barriers to access for some children.

Throughout this study, by using this theoretical framework, I engaged in critical self-reflection including how and why I came to this particular study. I brought my lived experience as a parent of a child with disabilities, and my professional work as a children’s librarian in a public library, to the ever-expanding body of scholarly knowledge of early literacy research.

I believe that these theories and analytic stances allowed me to explore various influences on the participants’ children’s developmental opportunities across settings and contexts. By re-storying parents’ narratives, I was able to emphasize some of the most important influences,
especially macrosystem influences that contributed to the perpetuation of practices that effectively excluded some children. I synthesized librarians’ perspectives in ways that pointed to the need to build opportunities for enhancing their mesosystem roles when working with children with disabilities and their families.

**Limitations of the Study**

As indicated earlier, given the relatively small sample sizes in each of the cases, some caution is called for in interpreting my findings. Nevertheless, the findings reported across all three segments of this study indicated robust patterns indicating the dominance of ableist assumptions in much of the discourse about children’s early literacy learning, the struggles of families of children with disabilities to participate in early literacy programs and opportunities at libraries and other public spaces in their communities, and a strong desire on the part of many children’s librarians to create inclusive spaces so that all children can participate.

**Significance**

Although other researchers (e.g., Ramaekers and Suissa (2012) Nichols, Nixon, et al. (2009)) have examined and critiqued the normative ways that childhood is presented in discourses that deal with parenting, education, and early learning, this is the first study that I am aware of that examined how parents of children with disabilities perceive this discourse. As expected, the parents reported that, except in rare instances, they do not see their children represented, and interestingly, they indicated they do not expect to see such representation. Thus, this study contributes to the literature that critically examines these dominant discourses. By illuminating the perspectives of families of children with disabilities, and how they are relatively invisible in invitations to, advertisements for, and promotions of community based early learning opportunities, the study also contributes to the literature about inclusion. Furthermore, the study
identified some of the barriers that families encounter in publically sponsored programs and resources that are, ostensibly, open and freely available to all. The study also contributes to the literature on public libraries’ increasing roles in providing early learning programs, as well as guidance to families about early literacy. There is a dearth of studies that have examined how families of disabled children avail of or do not avail of these services, how librarians perceive how they provide opportunities for these families, and how librarians perceive the degree to which their university programs and professional development opportunities prepared them to work on insuring the inclusion of children with disabilities and their families. Thus, the study contributes to filling several gaps in the research literature and has implications for both practice and policy.

A great deal of research about children with disabilities confirms that they still face barriers to full inclusion (Goodley & Runswick-Cole, 2010; Kliewer et al., 2006; Purdue, 2009; Purdue et al., 2011) and my study adds to this body of work. The continued invisibility and exclusion of children with disabilities should be considered unacceptable in our society and I hope that this study contributes to a much-needed change.

**Closing Thoughts**

I believe that the experience of having a child with a disability has been a transformative one for me. Before having my son, I had never considered the extent to which the world is made for non-disabled people. We soon found that the parenting world is also created only with the needs of parents raising non-disabled children in mind. Parents like us quickly learn that navigating an ableist system adds many complexities to our lives. In my introduction, I shared some of the complexities my husband and I faced as we learned about our son’s impairments and how to support his development. I also shared that, despite very dire predictions about his overall
academic potential, Calum learned to read quite well by the end of Grade One. I speculated that his success was due to the fact that as a children’s librarian, I provided him a childhood that was particularly rich in early literacy and that his learning outside the home was characterized by its inclusiveness. I believe these were important factors in overcoming any difficulties with literacy that his disability may have caused. Now, as I reflect on Calum’s childhood and adolescence, I am happy that he has been able to sustain his interest in reading. He still reads for pleasure and for information, preferring non-fiction, mysteries, and true crime topics. I am very proud of him and all that he has accomplished thus far. However, we still have to navigate a very exclusionary world and are currently flummoxed by how difficult it is for him to find meaningful paid employment. In our frequent conversations about his work potential, I ask my husband, “Who is out there who is ready to help us?” We have gone down several different routes but are still finding we have to do the lion’s share of the advocacy work to help our son find a meaningful paid job. We just do not seem to have the insider knowledge to do this work so we will likely have to wait an inordinate amount of time until it is his turn to receive the services of a qualified job coach, who (we hope) will connect him and his skillset to a good employer. I realize now, as I write the final words of my conclusion, that when I was the parent of a young child with a disability, I had the insider knowledge and the skillset to support his early literacy. I was a resource to myself because I knew about early literacy. I had access to almost unlimited resources at work and I practiced (and sometimes adapted) the advice I gave other parents of young children in the library. But what if I weren’t a children’s librarian? Who would have been ready to help me? Who would have helped me see that, despite his obvious developmental differences, Calum was fully engaged in early literacy even as a mostly nonverbal toddler? Who would have reassured me that he was learning literacy in his own way and that it was okay? Who
would have been ready to suggest that we keep building on his love of fire trucks and ambulances to help him learn more words and about how sentences work? In addition to being his mother, I played the supporting role of children’s librarian with early literacy expertise in my own son’s early literacy ecology. With the inclusivity already built-in to his preschool and early elementary school program, I had only to continue what I was doing at home, as his teachers ensured his inclusion in his classes’ early literacy activities. Not every child with a disability can be assured of having what my son had, somewhat by chance. In fact, my research suggests that parents of children with disabilities, while they do take up advocacy roles in various contexts and for various reasons, are less likely to advocate for their children to participate in the resources of their public libraries. As I acknowledged earlier, this was a relatively small study, and it is difficult to draw conclusions about the extent to which children’s librarians interact in what Bronfenbrenner and Ceci (1994) refer to as the mesosystem in the lives of children with disabilities. However, my experiences with ableism are consistent with the experiences that participants shared. I believed that my participants were all wonderful parents who were doing their utmost to help their children reach their potential, but I also knew that not all of them had the same kind of insider knowledge that I had about early literacy. That is what led me to this study: how can children’s librarians take up the role that I played in my own son’s life? I recently read about an organization that serves families of children with autism that has opened their own library (CBC News British Columbia, 2017). Reminiscent of the ways some of my participants’ own experiences at a library, as well as those offered by Kaeding et al. (2017), the article refers to the judgement parents feel when taking their autistic children to public libraries, and presents this specialized library as an “inclusive” place. While I do not argue with the unfortunate fact that families face judgement from others, I do disagree with the article’s determination that this
special library, as valuable as it may be, is actually inclusive. However, its existence does point out that many families of children with autism (and, I would assume, many other disability labels) have not found public libraries to be inclusive either. I hope my work contributes to a better understanding of what inclusion in children’s libraries and other community spaces really means. I came to this study with a strong belief in the role that children’s librarians in particular can play in the early literacy ecology of children with disabilities. My doctoral work has only served to strengthen my belief in the potential of children’s librarianship to contribute to the dismantling of ableism and its effects on the lives of children with disabilities.
REFERENCES


Public Library InterLINK. Public Library InterLINK. Retrieved June 12, 2015 from http://www.interlinklibraries.ca/


ARE YOU THE PARENT/GUARDIAN OF A

YOUNG CHILD (0-8 YEARS OLD)

WHO HAS DISABILITIES?

I am an early literacy researcher from UBC who is seeking Lower Mainland, BC families (birth/adoptive/foster parents and legal guardians) to participate in a
study about early literacy learning for children who have been diagnosed or labelled with a significant disability, or multiple disabilities, in any areas of their development (i.e., physical, sensory, cognitive). This study has received approval from the Ethics Review Board at UBC.

**Parent/Guardian Participant Activities:**

- 1 child activity log: you will fill out a simple form to tell me what your child does, and with whom, in a typical week. This should only take 5 to 10 minutes per day for 7 days (total: 35 to 70 minutes) and can be done by hand or on a computer.
- 1 informal in-person interview lasting about 1 hour: we will talk about early learning opportunities in your community and your family’s use (if any) of your local public library for early literacy resources for your child with a disability.

**Remuneration:** All participating families will be offered $40 gift cards for the local children’s bookstore Vancouver Kidsbooks to thank them for their contribution to this research study. (Vancouver Kidsbooks is a children’s book store with locations in Vancouver, North Vancouver and Surrey and a website)

Your real names will not be used, nor anything else that could identify your family. Your participation is voluntary, and you may withdraw from this study at any time in the process. As parents/caregivers of young children labelled with disabilities, your input about early literacy learning is extremely important for researchers and others as we work towards creating inclusive early literacy
learning opportunities and experiences for young children in our communities. Please consider helping by contacting the researcher using the contact info on the attached business cards below. If you have any concerns or wish to learn more about this study please contact the study’s principal investigator Dr. Jim Anderson at XXX-XXX-XXXX. Thank you for your consideration.

Business card text will read and will be provided with the poster (box of cards):

Early Literacy Study Call for
Parent/Guardian Participants

Please contact the researcher

Tess Prendergast

Phone or text: XXX-XXX-XXXX

Email: XXXXXXX@XXXXXX.XX
Appendix B Third Party Recruitment Letter

Third Party Family Service Agency Recruitment Letter

March 7, 2014

Dear Sir/Madam,

My name is Tess Prendergast. I have been working on my doctorate in early literacy since the fall of 2011. I am now beginning the study for my dissertation project which has just received approval from the UBC Ethics Review Board. I am doing my doctoral dissertation within the Department of Language and Literacy Education, University of British Columbia under the supervision of Dr. Jim Anderson. If you have any questions or concerns you may reach him at XXX-XXX-XXXX.

As my research involves families and early literacy, I am requesting your help to find parents of young children labelled with developmental disabilities / special needs who may be willing to participate in my study. Through a short child activity-log assignment (about 5-10 minutes/day for 1 week) followed by a one-hour interview, I will be exploring parents’ encounters with opportunities for their children’s early learning experiences in their home communities.

My background is as a children’s librarian so I am especially interested in the experiences, if any, that they have with their local public libraries. The time commitment will not be onerous and the activity log and interview will be done at times that suit their schedules.

After the interview I may need to contact participants by phone or email to clarify something that was said. I will also ask participants to read a draft of what I have written about them to make sure I have accurately captured their thoughts.

Throughout this research, participant families will not be required to reveal anything that they do not wish to about their child’s condition, diagnosis or any other personal information. They will be asked to pick aliases for themselves and their children and all identifying information, including specifics about their child’s diagnosis/condition will be left out of the study, including the names of the cities they live in, their service providers and the names of the places they go to with their children.
I would appreciate the opportunity to come to one of your programs to speak to the parents in person about my project and invite them to consider volunteering for this study. After explaining the study, I will leave the attached participant recruitment flyer. If they decide to do so, they can simply call, text or email me at their convenience so that I can explain the steps and send them the consent forms and child activity log to fill out. For you information, I have attached copies of the child activity log as well as a sample interview script.

Please let me know at your earliest convenience by if I may be permitted to visit your program and have a short time slot (about 10 minutes) to speak to parents to extend this invitation to them in person.

Also, I would very much appreciate your direct referral of any families who you think might consider this request. Please feel free to give out the enclosed participant recruitment flyer and encourage parents to contact me for more information. Also, please reassure everyone that their participation is completely voluntary and that they may withdraw from the study at any time.

Let me know if you have further questions. Thank you very much for your consideration of this request.

Sincerely,

Tess Prendergast
Doctoral Candidate
Department of Language and Literacy Education
University of British Columbia
xxxxxxx@xxxxxx.xx
XXX-XXX-XXXX
Appendix C Consent Forms

Consent Forms (Parents and Librarians)

The University of British Columbia

Behavioural Research Ethics Board

Office of Research Services
Suite 102, 6190 Agronomy Road
Vancouver, B.C. V6T 1Z3
Phone: (604) 827-5112, Fax: (604) 822-5093

CONSENT FORM

Parent Participant Consent Form

Early Literacy in the Lives of Children with Disabilities: Exploring the Experiences and Perspectives of Parents and Public Library Children’s Librarians

DATE

Principal Investigator: Dr. Jim Anderson, Department of Language and Literacy Education XXX-XXX-XXXX

Co-Investigator(s): Teresa (Tess) Prendergast, Doctoral Candidate, Department of Language and Literacy Education XXX-XXX-XXXX

This study will contribute to this candidate’s dissertation project as well as one or more journal articles and one or more conference presentations.

Purpose:
This study seeks to explore the experiences of parents with young children labelled with disabilities and how they respond to the mainstream messages about early literacy that they encounter and if and how they and their children are able to participate in early literacy activities and resources, particularly those of the public library.

**Study Procedures:**
Parents will be asked to keep a brief log of all of their child’s activities (routines, appointments, classes, playtimes etc.) for a one week period. They will be asked to send completed logs to the researcher a few days before meeting for interviews. The semi-structured interview will cover topics about their daily life with their child, their encounters with early literacy texts/messages in their communities and whether or not they have participated in any early literacy resources (such as story time) at their public library. The total amount of time that participants are asked to contribute to this study is not expected to exceed three hours.

**Potential Risks:**
This study carries minimal risk. Even so, there is a small risk of psychological impact. Having a child who has a disability can cause emotional upset and stress for parents. While no participant will be compelled to discuss painful experiences, there is the risk that some topics about their children will cause them some distress. The researcher will minimize the risk of harm by reassuring participants that they need not discuss topics that are painful to them. Also they will be reminded that they may withdraw from the study at any time in the process.
**Potential Benefits:**

There is a recognized gap in the research concerning the early literacy development of children with disabilities. Not much is known about how parents interpret and act upon early literacy messages in their communities, nor about their experiences with the early literacy resources of the public library. The outcomes of this study will contribute to the early literacy research about children with disabilities as well as the research about children’s library services.

**Confidentiality:**

Participants’ identity will be kept confidential throughout this study. Participants will be invited to choose aliases/pseudonyms for themselves and their children at the beginning of the program. All identifying information will be left out of the final study documents, including locations. All data from this study will be kept on a password protected laptop computer, with back-up files stored securely in a separate location.

**Contact for information about this study:**

The researcher, Tess Prendergast is available to answer your questions and discuss your concerns about this study at any time. You may contact her anytime by telephone.
Contact for concerns about the rights of research subjects:

If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598 or, if long-distance, email to RSIL@ors.ubc.ca

Consent:

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without jeopardy to yourself or family.

Your signature below indicates that you have received a COPY of this consent form for own records. Please sign two copies and return one copy to the researcher.

The aim of this study is to learn from parents about how they interpret and act on early literacy messages, the routines of their daily lives with their children who have disabilities, and if and how they have participated in any early literacy resource of the public library.

I consent/I do not consent (please circle one) to my participation in this study.
Librarian Participant Consent Form

Study Name, Date

**Principal Investigator:** Dr. Jim Anderson, Department of Language and Literacy Education XXX-XXX-XXXX

**Co-Investigator(s):** Teresa (Tess) Prendergast, Doctoral Candidate, Department of Language and Literacy Education XXX-XXX-XXXX

This study will contribute to this candidate’s dissertation project as well as one or more journal articles and one or more conference presentations.

**Purpose:**

This study seeks to explore the perspectives of children’s librarians who provide early literacy activities and resources in public libraries. In semi-structured interviews, the researcher will explore with participants’ their thoughts about how their libraries provide early literacy resources appropriate for children with disabilities as well as their thoughts on the training they have received thus far as well as any training that they perceive they need to provide inclusive early literacy resources.
**Study Procedures:**

Potential participants who are children’s librarians will receive an invitation to participate in this study either by email, poster, word-of-mouth, and/or over social media such as Facebook and Twitter. Those librarians who wish to do so will contact the researcher who will confirm their eligibility to participate. The researcher will then provide them with a description of the study and answer any questions they might have before signing this consent form and proceeding. Participants will then be asked to choose a time to be interviewed. These semi-structured interviews will last approximately 45 minutes and will take place during a time and location of the participant’s choosing and convenience.

**Potential Risks:**

This study carries minimal risk. However, some librarian participants may feel uncomfortable or unduly scrutinized when they think about discussing their own or their colleagues’ approaches and practices with regards to early literacy resources for children with disabilities. They may feel embarrassed if they believe they lack the expertise to do this work. Before the interview starts, the researcher will emphasize that this study is **not evaluative** of any individual's work or any specific library's services or overall inclusiveness. It will be explained that this is an exploratory study about ways that children's librarians in public libraries are prepared for, wish they were prepared for, and can and do provide early literacy support for children with disabilities. The researcher will emphasize that their input is highly valuable to the fields of early literacy and children's librarianship.
**Potential Benefits:**

Participating in this study will contribute to the field of children’s librarianship and potentially lead to the development and availability of better professional development opportunities for children's librarians who work in diverse communities. The researcher assumes therefore, that librarians who provide early literacy services within public libraries will be receptive to the opportunity to contribute to the development of targeted training to help them and their colleagues provide more inclusive early literacy resources in their work.

**Confidentiality:**

Participants’ identity will be kept confidential throughout this study. Participants will be invited to choose aliases/pseudonyms for themselves at the beginning of the program. All identifying information will be left out of the final study documents, including the names of the libraries they work in. All data from this study will be kept on a password protected laptop computer, with back-up files stored securely in a separate location.

**Contact for information about this study:**

The researcher, Tess Prendergast is available to answer your questions and discuss your concerns about this study at any time. You may contact her anytime by telephone at XXX-XXX-XXXX or by email at xxxxx@xxxxx.xx. Also you may contact the researcher’s supervisor (and principal investigator on this study) Dr. Jim Anderson at XXX-XXX-XXXX or by email at xxx.xxx@xxx.xx
Contact for concerns about the rights of research subjects:
If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598 or, if long-distance, email to RSIL@ors.ubc.ca

Consent:
Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without jeopardy to yourself.

Your signature below indicates that you have received a COPY of this consent form for your own records.

The aim of this study is to learn from
I consent/I do not consent (please circle one) to my participation in this study.

____________________________________________________________________
Participant’s Signature                                      Date

____________________________________________________________________
Printed Name of the Participant
Dear Library Director (Insert real name here)

I am a doctoral student within the Department of Language and Literacy Education at the University of British Columbia under the supervision of Dr. Jim Anderson. My doctoral research project plan includes interviews with professional children’s librarians on the subject of early literacy resources for children with disabilities. Interviews will be conducted outside of participant librarian’s normal working hours and will last for about 45 minutes to an hour.

Participants will be offered $20 gift cards to Vancouver Kidsbooks to thank them for their contribution to this research. In addition to contributing to my final dissertation project, data from the interviews may also be used in future publications and conference programs. However,
neither the librarian participants, nor the libraries where they work, will be identified in the final printed study or publications or presentations. Participants must provide written consent to participate in this study and they may withdraw their consent at any time.

In order for me to fulfill the requirements of the UBC Ethics Review Board, I am requesting written confirmation of your permission of my request to be allowed to recruit librarian participants from within your library via your staff email list. If permission is granted, I will email you a pdf document that explains the study, its eligibility requirements and how to participate (I have attached a hard copy of this document for your review) and ask that you distribute this pdf to all fulltime, part-time and auxiliary children’s librarians for their consideration.

If you choose to grant this permission, please sign at the bottom of both copies of this letter and return one copy either by email (scanned with electronic signature inserted) to: xxxxxx@xxxx.xx or by post to Tess Prendergast, XXXX XXX St, XXXXXXXXXX, BC, XXX XXX at your earliest convenience.

If you have further questions or would like to learn more about this study, please contact me. I will be happy to answer any questions you have. You may also contact Dr. Jim Anderson, Principal Investigator at XXX-XXX-XXXX

Sincerely,
Tess Prendergast
Library Director Name___________________________________ grants permission for Teresa (Tess) Prendergast to recruit participants for this study from within this organization via one group email and flyers to be distributed to all children’s librarians (full-time, part-time and auxiliary) who work at XXX Public Library who may wish to volunteer their time to be interviewed.
CHILDREN’S LIBRARIANS NEEDED FOR INTERVIEW STUDY ABOUT EARLY LITERACY

Are you a children’s librarian who participates in the provision of early literacy resources at your library? Are you willing to contribute to current academic research about early literacy in the lives of children with disabilities?

I am a doctoral researcher from UBC’s Department of Language and Literacy Education. My dissertation project investigates early literacy in the lives of children with disabilities.

I would like to talk to practicing, professional children’s librarians about their current early literacy work. Individual interviews will be set up at time and place of your choosing. Interviews will last from 45 minutes to 1 hour and you will receive a $20 gift card for Vancouver Kidsbooks to thank you for your time.
If you wish to participate, please contact me at your earliest convenience so that we can set up a time to talk.

Please contact the researcher **Tess Prendergast**

Phone or text: XXX-XXX-XXXX or Email: xxxxxx@xxxxx.xx

This study has received approval from the UBC Ethics Review Board. If you wish to learn more about the scope of this study, please call or email me or call my supervisor and principal investigator of this study, Dr. Jim Anderson at XXX-XXX-XXXX

*Thank you for your time!*
Appendix F Child Activity Log

Child Activity Log

INSTRUCTIONS

Thank you again for agreeing to participate in my study. I would like to hear about your child, and the activities that he or she participates in on a regular basis so I am asking you to keep a brief, daily activity log for one week. This will help me understand how and with whom learning and development takes place in your child’s life. This activity log has 7 blank pages for you to fill out each day for 7 days total. Please take only about 5 or 10 minutes filling out one page each day for one week / 7 days total. Please focus on your child’s regular activities especially things like appointments, therapies, classes and other developmental/learning activities, both formal and informal including things like playing, watching television/dvds/ or any time spent doing activities on a computer or tablet device such as playing with apps on an iPad, visits and time spent with other family members and friends should also be noted. These can be activities that take place in your home or outside your home. Please write down what the activity is, where the activities took place and with whom. You may attach extra pages if you run out of space to write. I will ask you more about some of these activities when we meet for our interview.

Please try to complete this over the course of 7 days straight. If you miss a few days, just continue until you have 7 days total. Please return when you have a total of 7 days. If you choose to fill this out on a computer, just send it back as an attachment to my email or
photograph/scan and send to me by email or pop it in the stamped addressed envelope and mail it to me when you are finished. I will be sending you a reminder email in about 2 weeks to set up a time for an interview. Thank you!

CHILD ACTIVITY LOG

Child’s First Name
____________________________________________________
Parent’s First Name____________________________________________________
Date Chart started on__________________________________________________
Date Chart finished on__________________________________________________

DAY 1

TODAY IS: ___________________________________

<table>
<thead>
<tr>
<th>MORNING</th>
<th>MIDDAY</th>
<th>EARLY AFTERNOON</th>
<th>LATE AFTERNOON</th>
<th>EVENING</th>
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<tbody>
<tr>
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<td>Approximately 1:30-3:30</td>
<td>Approximately 3:30-6:30</td>
<td>Approximately 6:30pm onwards</td>
</tr>
</tbody>
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What?
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DAY 3

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<td>Day 4</td>
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**Who?**

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DAY 5

TODAY IS: ________________________________

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<td>Approximately 3:30-6:30</td>
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| Who? |  |  |  |  |

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<tr>
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<td>Approximately 1:30-3:30</td>
<td>Approximately 3:30-6:30</td>
<td>Approximately 6:30pm onwards</td>
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| Who? | | | | |
| Where? | | | | |
### DAY 7

**TODAY IS: ________________________________**

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<td>Approximately 1:30-3:30</td>
<td>Approximately 3:30-6:30</td>
<td>Approximately 6:30pm onwards</td>
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What?
Who?

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Appendix G Parent Interview Protocol

Parent Interview Protocol

Parent Semi-structured Interview Protocol

Part 1: The first part of the interview will be spent discussing some examples of early literacy discourse. For example, I will show the parents some material culture gathered from their local community and ask if they have seen it or something similar and to talk about what it means to them.

Preamble: As you know, my research project is about early literacy support and resources that are available for families whose children are labelled with disabilities. In my research I have spent a lot of time looking at stuff in the community and online that is about early child development in general and specifically about early literacy. I am wondering, from your perspective as a parent whose child has developmental differences, what interpretations you make of much of this stuff. So, I have some examples and I’d like to spend some time discussing these and perhaps other examples of early literacy learning “stuff”. (Show selected text/image, such as Ready, Set, Learn poster sample in appendix).

- What do you see as the key point or message in this text?
- How useful or relevant is this material for you when you see it?
- Describe what happens, what you think about, what you do when you see/encounter/hear material that pertains to early learning?
- Can you think of any other examples of news stories, flyers, pamphlets, notices, or posters about early learning? How did you respond to it?
Part 2: The second part of the interview will be spent going over the child activity week log. I will ask the parents to elaborate on one or two different activities that are noted in the log.

Preamble: The next part of the interview will be all about your child (name) and what he or she does and with whom over the course of a typical week. I am doing this to get an idea about the kind of regular activities your child participates in. This will help me think about the ways in which he or she is able to access early literacy experiences and also what kinds of social and other supports might be available to you through whatever activities your child participates in.

- Can you tell me about a typical session of (type of) therapy that you attend with your child?
- You wrote that you go to play group at the child development centre: who is this program aimed at? What happens there? What resources do you find are available in this setting that help you support your child’s early literacy? What about social support for yourself? I.e., Have you met other parents there?
- What about technology? Does your child play with digital tools (like a tablet) or watch television/dvds? If so, can you describe what he or she does or watches and what happens when he or she plays with digital tools or watches tv/dvds?

Part 3: The third part of the interview will be concerned specifically with public library experiences related to early literacy development for the child. Some parents may not use the library, others who do may have several critiques about their experiences there, while others may
be making frequent use of the resources (i.e., picturebooks and story times) that are typically found at the public library. All views will be explored.

**Preamble:** You may remember from the description of the study in the letter I sent you, I am a children’s librarian and I work at a public library when I am not doing work related to my doctoral studies. I am very interested in your views about if and how well your public library is able to provide appropriate early literacy resources and/or support for you and your child. By this I mean I want you to tell me about any experiences, good and bad, within the public library. I will not be sharing your feedback with specific libraries so, do not worry about saying anything negative about a specific location – it will not be able to be recognized as specific location.

- Do you utilize the resources at the public library for supporting your child with a disability, I.E., books, story times, referrals and information etc.? If yes, can you talk a bit more about what use you make of the library (e.g., how often? What resources? What programs?)
- (If applicable to this participant)You wrote that you attend a program at the library on Wednesdays. Can you tell me more about that program? What happens there? Do you think the program is beneficial to your child? If no, why not? If yes, how does your child benefit or how does the program help your child’s learning? Do you think that you benefit from the program? If not, why not? If yes, how do you benefit? Are there social opportunities for yourself (i.e., meeting other parents with young children)?
If you do not use the public library for your child (you do not borrow books or other material for her, nor do you take her to age-appropriate story time program offerings) I would like to explore what reasons or thoughts you may have about not using the resources of your public library to help you support your child’s learning.

Whether you use the library or not, can you tell me what you think you would like the library to do (in addition to what it already provides) that would support and benefit your family?
Appendix H Librarian Interview Protocol

Librarian Interview Protocol

Children’s Librarian Semi-structured Interview Protocol Draft

These interviews will be semi-structured and each librarian will be guided through the same set of topics designed to capture their thoughts about work settings and their personal perspectives on supporting early literacy for children with disabilities as well as their thoughts about any training they have (or think they need) in order to prepare and deliver appropriate early literacy support to children labelled with disabilities and their families. I will make it clear to interviewees that my stance in interviewing librarians is one of collaborative problem-solving and exploration of the issues addressed in the research, not one of judgement or evaluation of their practices.

Preamble: My doctoral research is concerned with early literacy in the lives of children with disabilities. Because libraries provide free early literacy resources in the form of collections, services (like outreach) and programs, I am exploring how these resources are able to meet the needs of families with young children with disabilities.

1) How would you describe the physical accessibility of your library and its spaces dedicated to early literacy learning for families whose children with physical disabilities? For example, children who may be using wheel-chairs, walkers and specialized strollers? What about things like acoustics and clear signage?

2) We’ve talked about physical accessibility – now let’s think about other access. How would you describe how well your library is able to accommodate and support families whose children who have cognitive and/or behavioural disabilities?
3) How would you describe your library’s collection of picture books for young children that depict stories about and images of young children with disabilities? Do you have any books in Braille? Audiobooks? Any other kinds of Assistive technology?

4) If there are any families whose young children with disabilities are attending any of your library’s early literacy story time programs describe your impressions of how it is going? What things about this program do you think foster the inclusion of this particular child (or these particular children)? Have any issues or barriers come up? If so, how have you resolved, or attempted to resolve, them?

5) Are you aware of any steps that your library is taking to promote inclusion in your community? In particular, what are they doing to promote the library as a welcoming, inclusive place for families?

6) In your MLIS training, describe any training in any course that you think helped to prepare you to do the work of developing and providing appropriate early literacy resources for young children labelled with disabilities.

7) Describe any subsequent professional development training or any resources (such as articles and books) on the topic of serving children with disabilities that you have taken or used (i.e., webinars, conference sessions, journal articles, books, websites and blogs, etc.)

8) Finally, please elaborate on what you think about the educational and professional development needs of children’s librarians on how to accommodate children with disabilities into the early literacy resources available at the public library?
Appendix I Child Activity Log Compilation

Child Activity Log Compilation

<table>
<thead>
<tr>
<th>Child name (all names are pseudonyms), M/F, age, Disability label as mentioned by parent (not required)</th>
<th>Attending preschool, school or child care program?</th>
<th>Therapy &amp; Medical appointments</th>
<th>*Special group classes &amp; activities (those designated for children with special needs/disabilities only)</th>
<th>**Regular group classes &amp; activities (those open to general population of children) (not including formal childcare, preschool or school time)</th>
<th>Reading Books sessions</th>
<th>Other Media use sessions (time blocks vary in length) per week from 15 to 60 min</th>
<th>Extended family visits &amp; caregiving</th>
<th>Other informal learning/developmental activities &amp; resources mentioned in log</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lulu, F, 2, Autism spectrum disorder (ASD)</td>
<td>N/A</td>
<td>4 total Behaviour interventionist x 3 Medical doctor x 1</td>
<td>None were noted in child activity log for this week</td>
<td>4 total Library story time x 2 (with parents) Strong Start x 1 (with parents) Ballet class x 1</td>
<td>None were noted in child activity log but parents mentioned frequent reading during interview</td>
<td>2 total Skype (to aunt) x 1 CD (music) X 1</td>
<td>2 total Grandparents</td>
<td>Paper, crayons, playing outside</td>
</tr>
<tr>
<td>Benjamin, M, 2, ASD</td>
<td>N/A</td>
<td>5 total Autism specific x 3 Medical doctor x 1 Infant development x 1</td>
<td>1 total Parent-Child Mother Goose for IDP program families</td>
<td>4 total French x 1 (with grandparents) Swimming x 1 (with dad) Birthday x 1 (with family) Gymnastics x 1 (with parent)</td>
<td>11 total Parent/s x 8 Grandparent x 2 Solo x 1</td>
<td>3 total Mandarin learning DVD x 2 Music CDs/MP3s x 1</td>
<td>6 total Grandparents, cousins</td>
<td>Bubbles, LEGO, dolls, play kitchen, trucks, playdough</td>
</tr>
<tr>
<td>Andy, M, 4, Language-motor delays</td>
<td>Licensed preschool</td>
<td>5 total Behaviour interventionist x 4 Speech-language pathologist x 1</td>
<td>None were noted in child activity log for this week</td>
<td>4 total Library story time x 1 (with parents) Community gym x 2 (with parents) Pre-K club x 2 (with Behaviour interventionist)</td>
<td>7 total Parent/s x 7</td>
<td>5 total Youtube videos of favorite children’s songs x 5</td>
<td>6 total Grandparents</td>
<td>Park, playground</td>
</tr>
<tr>
<td>Natalie, F, 4, Global developmental delay</td>
<td>Licensed daycare</td>
<td>2 total Physiotherapist x 1 Speech-language pathologist x 1</td>
<td>None were noted in log</td>
<td>None were noted in child activity log for this week</td>
<td>7 total Parent/s x 7</td>
<td>11 total Home movies x 8 Digital photos x 2 Facetime x 1</td>
<td>None were noted in child activity log for this week</td>
<td>Baking, dancing, library visit, swimming, bicycle trip, walking the dog, playing in park,</td>
</tr>
<tr>
<td>Thomas, M, 4, ASD</td>
<td>Licensed preschool</td>
<td>6 total Behaviour interventionist x 3 Play therapist x 1 Occupational therapist x 2</td>
<td>2 total Play therapy program x 2</td>
<td>1 total Community playgroup (attended with Behaviour interventionist)</td>
<td>15 total Parent/s x 10 Solo x 5</td>
<td>16 total TV show x 9 iPad x 4 Facetime x 2 Skype x 1</td>
<td>1 total Aunt</td>
<td>Colouring, drawing, writing, puzzles, Playmobil, LEGO, playground</td>
</tr>
<tr>
<td>Child name (all names are pseudonyms), M/F, age, Disability label as mentioned by parent (not required)</td>
<td>Attending preschool, school or child care program?</td>
<td>Therapy &amp; Medical appointments</td>
<td>*Special group classes &amp; activities (those designated for children with special needs/disabilities only)</td>
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<td>Reading Books sessions</td>
<td>Other Media use sessions (time blocks vary in length) per week from 15 to 60 min</td>
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<td>Other informal learning/developmental activities &amp; resources mentioned in log</td>
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<tr>
<td>Maggie, F, 5, Cerebral palsy</td>
<td>Public elementary school, Kindergarten</td>
<td>2 total Medical doctor x 1 Therapeutic horseback riding instructor x 1</td>
<td>None were noted in log</td>
<td>1 total Sparks group</td>
<td>14 total Parent/s x 9 Sibling x 2 Grandparent x 1 Solo x 2</td>
<td>6 total Movie x 2 TV show x 1 iPad x 1 Audiobook x 1</td>
<td>2 total Grandmother</td>
<td>Dancing, cutting paper with scissors, colouring, swimming</td>
</tr>
<tr>
<td>Blossom, F, 6, Learning disabilities</td>
<td>Private elementary school, Grade 1</td>
<td>None were noted in log</td>
<td>None were noted in log</td>
<td>1 total Swimming lesson</td>
<td>11 total Parent/s x 10 (including help with homework) Solo x 1</td>
<td>1 total TV show</td>
<td>5 total Grandparents x 3 Cousins x 2</td>
<td>Baking, crafts, drawing, doing homework</td>
</tr>
<tr>
<td>Michael, M, 6, ASD</td>
<td>Public elementary school, Grade 1</td>
<td>1 total Behaviour interventionist</td>
<td>None were noted in log</td>
<td>None were noted in log</td>
<td>4 total Parent/s (including help with homework) Solo x 2</td>
<td>6 total TV shows x 4 Movie theatre x 1 iPad x 1</td>
<td>None were noted in log</td>
<td>Participating in autism research study</td>
</tr>
<tr>
<td>Bobby, M, 7, ASD</td>
<td>Public elementary school, Grade 1 Licensed after-school care</td>
<td>3 total Behaviour interventionist x 2 Speech therapy x 1</td>
<td>None were noted in log</td>
<td>None were noted in log</td>
<td>8 total Parent/s (including help with homework)</td>
<td>1 total Video game</td>
<td>1 total Cousins</td>
<td>Playing with toys, doing homework</td>
</tr>
<tr>
<td>Evan, M, 7, ASD</td>
<td>Public elementary school, Grade 2</td>
<td>6 total Behaviour interventionist x 3 Occupational therapist x 1 Speech therapist x 1 Physiotherapist x 1</td>
<td>None were noted in log</td>
<td>None were noted in log</td>
<td>7 total Parent/s (including help with homework)</td>
<td>11 total TV shows x 9 Home movies x 1 iPad x 1 Photobooth x 1</td>
<td>3 total Grandparents</td>
<td>Playing with toy foods, biking, taking trips on public transit, doing homework</td>
</tr>
<tr>
<td>Mark, M, 7, ASD</td>
<td>Public elementary school, Grade 2 Licensed after-school care</td>
<td>2 total Behaviour interventionist</td>
<td>None were noted in log</td>
<td>None were noted in log</td>
<td>None were noted in log</td>
<td>3 total Videogame x 2 Movie x 1</td>
<td>1 total Aunt</td>
<td>Dancing, writing, playing with LEGO, swimming</td>
</tr>
<tr>
<td>Nicolas, M, 7, ASD</td>
<td>Public elementary school, Grade 2</td>
<td>1 total Behaviour interventionist</td>
<td>None were noted in log</td>
<td>None were noted in log</td>
<td>7 total Parent/s x 5 Solo x 2</td>
<td>19 total iPad x 13 Movie x 3 TV shows x 3</td>
<td>None were noted in the log</td>
<td>Library visit, playing with LEGO, biking</td>
</tr>
<tr>
<td>Child name (all names are pseudonyms), M/F, age, Disability label as mentioned by parent (not required)</td>
<td>Attending preschool, school or child care program?</td>
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</tr>
<tr>
<td>Jane, F, 8, CP</td>
<td>Public elementary school, Grade 2</td>
<td>3 total Occupational therapist x 1 Physiotherapist x 2</td>
<td>None were noted in log</td>
<td>None were noted in log</td>
<td>15 total Parent/s (including help with homework) x 9 Sibling x 4 Solo x 2</td>
<td>6 total TV shows x 5 Computer x 1</td>
<td>None were noted in log</td>
<td>None were noted in log</td>
</tr>
<tr>
<td>Totals</td>
<td>2 children not attending preschool or daycare</td>
<td>2 children attending licensed preschool</td>
<td>1 child attending f/t licensed daycare</td>
<td>7 children attending public elementary schools</td>
<td>2 children attending licensed after-school care also</td>
<td>1 attending private elementary school</td>
<td>All parents report that their children are provided with extra, inclusive supports in these settings due to their disability status</td>
<td>41 therapist appointments noted for 12 children An average of 3 therapy sessions per week per child</td>
</tr>
</tbody>
</table>