PARENT/GUARDIAN VOICES:

EXPERIENCES AND PERSPECTIVES OF

PARENTS OF CHILDREN WITH EXCEPTIONALITIES

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By

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Krista Kay Marie McMillen, candidate for the degree of Master of Education in Curriculum & Instruction, has presented a thesis titled, *Parent/Guardian Voices: Experiences And Perspectives Of Parents Of Children With Exceptionalities*, in an oral examination held on March 18, 2019. The following committee members have found the thesis acceptable in form and content, and that the candidate demonstrated satisfactory knowledge of the subject material.

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Abstract

In this constructivist grounded theory thesis, I explore the experiences and perspectives of parents and guardians of children with exceptionalities in Saskatchewan. As a classroom teacher and student services teacher for over twenty years, my goal was to better understand the experiences, concerns and opinions of participants. Additionally, I wanted to learn whether or not participants valued inclusion, and find out what their opinions were regarding effective strategies for teaching their children. I interviewed seventeen participants with a total of twenty-one children with exceptionalities among them. I found that most participants did indeed value inclusion. Additional categories that frequently arose included: high intensity parenting, navigating systems, home-school communication, socialization, importance of a strengths-based approach, shared responsibilities between school professionals and parents/guardians, and appreciation for teachers and other school professionals. In addition, I address the importance of teacher professional development, collaboration, parent engagement, social emotional factors, marginalization and challenges within systems. I encourage policy-makers, school division leaders and educators to commit to working towards furthering the state of inclusive education in Saskatchewan and listening to the voices of parents and guardians with children who have exceptionalities.

Key Terms: Inclusion, exceptionalities, parent/guardian engagement, strengths-based approach, special education
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Dedication

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Contents

Abstract ........................................................................................................................................... i
Acknowledgments ........................................................................................................................ ii
Dedication ...................................................................................................................................... iii

Chapter One: Introduction .................................................................................................................. 1
  Terminology ................................................................................................................................... 2
  Rationale for Study ......................................................................................................................... 3

Chapter Two: Literature Review ......................................................................................................... 6
  Table 1: Categories Within the Literature Reviewed ....................................................................... 7
  Inclusion ........................................................................................................................................ 8
  Teacher views about inclusion ......................................................................................................... 13
  Inclusive pedagogies ...................................................................................................................... 15
  Teacher professional development (pre-service and in-service) ..................................................... 18
  Collaboration ................................................................................................................................. 19
  Parent Engagement ........................................................................................................................ 20
  Parents/guardians as partners and resources ................................................................................ 21
  Home and school communication ................................................................................................... 22
  Parents/guardians as agents of change .......................................................................................... 22
  Partnership models ......................................................................................................................... 23
  Perspectives of partnerships ........................................................................................................... 24
  Daily Life for Parents/Guardians ................................................................................................... 25
    Easing their world ........................................................................................................................ 27
  Potential ......................................................................................................................................... 28
  Socialization in Schools .................................................................................................................. 30
  Marginalization, Loneliness, and Difference ............................................................................... 31
  Systems .......................................................................................................................................... 34
  Summary ....................................................................................................................................... 36

Chapter Three: Methodology ............................................................................................................ 38
  Theoretical Framework ................................................................................................................... 38
  Method .......................................................................................................................................... 39
    Participant Selection Process ...................................................................................................... 39
    Data Collection ............................................................................................................................ 41
Chapter Four: Findings ................................................................. 47
Section I: Participant Profiles ................................................... 47
Terminology ................................................................................. 55
Section II: Findings .................................................................. 56
  Table 2: Categories Constructed from the Participant Data .......... 57
  High Intensity Parenting .......................................................... 59
  Navigating Systems ................................................................. 68
  Inclusion .................................................................................. 78
  Communication between Home and School ............................. 88
  Socialization ........................................................................... 96
  Strength-based Approach or Being a Believer: The Importance of Believing in Potential ................................................. 97
  Responsibilities and Roles of Teachers and Parents/Guardians .............................................................................. 99
  Accolades and Appreciation .................................................... 100
Summary ...................................................................................... 101

Chapter Five: Discussion .............................................................. 102
Making Connections between the Data and the Literature ............ 102
Conclusions ................................................................................. 103
  Table 3: Conclusions discovered in the data and literature ....... 103
My Learning .................................................................................. 108
Answering the Research Questions ........................................... 110
Answering “So what?” ................................................................. 110
Contributions and Implications .................................................. 111
Implications for Myself: My Commitment Moving Forward ....... 112
Implications for Schools, Policy-Makers and Community Supports ............................................................................. 113
Directions for Future Research .................................................. 116
Conclusion .................................................................................... 117
References.................................................................................................................................................. 118

Appendices.................................................................................................................................................. 130
Chapter One: Introduction

As a mother, I understand the joys and challenges of raising a child. There is nothing more important to me than the well-being of my children. I know that other parents and guardians feel the same way. Individuals who care for children who have disabilities or other exceptionalities experience even more significant challenges in raising and educating their children (Anaby, Hand, Bradley, DiRezze, Forhan, DiGiacomo and Law, 2013). It is crucial that their voices be heard, and their concerns be addressed. As an educator, I also experience the joys and challenges of teaching other people’s children. As both a classroom teacher and student services teacher throughout twenty years, I have learned a great deal from the parents/guardians of the students I teach. I have always found them to be a crucial resource for successfully teaching their children. Over the years, I have heard many stories from families and found them to be inspiring. I believe there is value in sharing these stories with others. I also believe there is value in taking a closer look at the issues concerning these parents. By doing so, we would perhaps better understand how some families can overcome significant obstacles to see their children grow and succeed beyond their highest expectations, and how teachers might assist in that endeavour.

Historically, students with exceptionalities were educated in separate schools or programs. However, in recent decades there has been a movement to inclusive settings, where all students of the same age learn together in their neighbourhood school. The Saskatchewan Ministry of Education (2017) states, “Inclusion is an attitude, a belief and an approach that supports a commitment to welcome, accept, value and educate every individual as a contributing member of the school community” (p. 2). The document goes on to say that the Ministry “encourages the creation of education settings where
students are engaged in authentic inclusion learning experiences with age-appropriate peers in their home communities. Collaborative teams work together with the end goal of inclusive educational experiences for all” (p. 4). Although school divisions in Saskatchewan and around the world have attempted various models to include children with exceptionalities in regular neighbourhood schools with same-age peers, effective inclusion continues to be a challenge. Many school divisions in Saskatchewan have congregated programs which take students with exceptionalities away from their community and peers. Although I have always strongly believed in inclusion, there have been times when I have doubted or questioned myself and the research around inclusion. I wanted to learn more. And I wanted to hear from parents/guardians of children with exceptionalities in Saskatchewan. What are their perspectives? Do they value inclusion for their children? What practices and experiences are they seeking for their children in school and in the community? What does the extant literature reveal about evidence-based practices for students with exceptionalities and challenges? What does the literature reveal about the experiences of parents/guardians of children with exceptionalities and challenges? What can I do as an educator? This study attempts to answer these questions.

Terminology

Using labels and terms to describe children, their abilities and their situations can be problematic. There is debate about whether and how labels are useful (DeLuca, 2013). In this study, I am required to use words to describe experiences, diagnoses, findings, roles and, concepts. I have chosen terms that I feel are most respectful and most useful in clarifying my messages. I want to address some of the terminologies I have used in this study. I have applied the hyphenation of “parents/guardians,” when referring
to participants, in order to include biological parents, adoptive parents, step-parents, foster parents, relatives and any other person who legally supports or cares for a child (Merriam-Webster, 2018). I selected the term “exceptionalities” to refer to children who have been diagnosed with developmental, physical or cognitive disabilities, autism, learning disabilities or attention deficit disorder, as it is currently the term most commonly used in academic writing (Winzer, 2005). I decided on the term “regular classroom” to refer to a classroom in which all children residing in the same neighbourhood of a certain chronological age attend, regardless of their ability (Jordan, 2007). Occasionally, I have also used the term “mainstream” to refer to regular classrooms, as this term is used in the literature (Lei and Meyers, 2011). I have also chosen to use the terms “congregated setting” or “congregated classroom” to describe a classroom in which students who have similar exceptionalities are brought together to learn (Saskatchewan Ministry of Education, 2001). At times I have also employed the terms “special education” or “segregation” to describe congregated settings or models (Jordan, 2007). I have used person-first language by referring to the person before the exceptionality they are diagnosed with (Saskatchewan Ministry of Education, 2001). Person-first language may not sound as concise to every reader as putting the description of the diagnosis first. However, it is considered more respectful.

Rationale for Study

The rationale for this constructivist grounded theory study was to gain insight into the experiences and views of Saskatchewan parents/guardians of children with exceptionalities. One of the goals of the research was to provide participants with an opportunity to speak about the challenges and successes that mattered to them. Another goal of the research was to learn about participants’ views as they pertain to inclusion at
The research is intended to gain information that can be applied in practice, my personal practice as well as for the teaching community in general, especially in Saskatchewan, in order to serve student needs more effectively. The research questions guiding this study were:

1) What are the experiences of participants in Saskatchewan schools and the community?

2) How do parents/guardians in Saskatchewan advocate for services and inclusive education for their children?

3) According to participants, what are best practices for inclusion? How can educators in Saskatchewan provide for students with exceptionalities in their classrooms?

Charmaz (2005) encourages “applying grounded theory methods to the substantive area of social justice” (p. 507). This area has been historically influenced by Feagin (1999) who explains that inquiry in social justice assumes focusing on and furthering the equitable distribution of resources, fairness, and the eradication of oppression. As individuals with specific exceptionalities make up a marginalized group I have also considered issues of power around this topic. This study has implications for school and school division personnel, parents/guardians, post-secondary institutions, policy-makers, community agency personnel, and of course, students in Saskatchewan.

It is important to note that I have chosen to write this study from the first-person point of view. Saldaña and Omasta (2018) state, “Qualitative research reports have generally adopted the first-person voice to personalize the author and to connect more with readers” (p. 308). This approach will enable me to personalize myself as an author,
as well as the participants and their views. Saldaña and Omasta (2018) explain further that using the pronoun I “does not lessen one’s credibility as a researcher” (p. 308). I have been able to reflect my findings in a professional manner while maintaining a relationship with my reader.

I have organized this thesis into five chapters. Chapter one is the introduction, the beginning, where I come to the questions asked in this study. In chapter two I review the literature relevant to this research. The literature reviewed was based on categories that came about during interviews with participants. The categories include: inclusion; marginalization of individuals with exceptionalities; engagement of parents/guardians; socialization in schools; stress and challenges for parents/guardians of children with exceptionalities; home and school communication; and research on potential. Little research has been conducted on the views of individuals themselves or of the parents/guardians of children who have exceptionalities, especially in Saskatchewan. In chapter three I describe the methodology I used in order to complete this research. In chapter four I will introduce the participants and outline the major findings from the interviews conducted. In chapter five I connect the literature and the data, as well as identify possible implications for myself, personally as well as for schools, community supports and policy-makers.
Chapter Two: Literature Review

The purpose of this chapter is to review the relevant literature related to the research questions of this study, which are:

1) What are the experiences and perspectives of parents/guardians of children with exceptionalities?
2) How do parents/guardians advocate for their children who have exceptionalities?
3) What are the best teaching practices for inclusion, according to parents/guardians and the extant literature?

Both the research questions and participant interviews served to direct my focus on eight categories of inquiry within the literature. The table below provides an overview of those categories.

It was difficult to review all the literature in any of the eight categories due to the high number of broad topics. My study encompasses many expansive areas of research and my curiosity could lead me in a variety of directions. Additionally, since the available research is always growing, it is challenging to stay completely up-to-date. I have read extensively on these subjects, and I believe that this has added to my understanding of the issues, as well as my ability to address potential implications of my research. However, at some point, a researcher must decide to submit their findings. As a result, I have presented what I have found to be most relevant and useful for this study and the research questions. These findings will be further connected and analyzed along with the data in chapter five.
Lichtman (2013) encourages researchers to be upfront about how their personal perspectives influence the process and findings of a literature review. She explains that one purpose of a literature review in qualitative research can be the use of “expert witnesses to provide support or give counterevidence” to one’s findings (p. 173).

However, both Lichtman and Charmaz (2014) discuss some important issues regarding literature reviews in qualitative studies. For example, there is some debate about at what point in the research a literature review should be done at, and even whether one should be done at all. I agree with both Charmaz and Lichtman that a literature review is important and provides a depth of knowledge to qualitative research. A few years ago, I reviewed some of the literature in these categories for a project on the same topic in a university class on action research. I minimally reviewed some of the literature while collecting data. However, I reviewed the bulk of my literature after I had collected the data and analyzed, categorized and summarized my findings. The following is a summary of categories within the literature I reviewed.

Table 1: Categories Within the Literature Reviewed

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<thead>
<tr>
<th>Category</th>
<th>Sub-Category</th>
<th>Specific Frameworks</th>
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<tbody>
<tr>
<td>Inclusion</td>
<td>Teacher views about inclusion Inclusive pedagogies</td>
<td>Universal design for learning (UDL)</td>
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<td></td>
<td>Teacher professional development</td>
<td>Differentiated Instruction (DI)</td>
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<td>Collaboration</td>
<td>Response to Intervention (RtI)</td>
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<td>Parent</td>
<td>Parents/guardians as partners and resources</td>
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<td>Engagement</td>
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<td>Partnership models</td>
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<td>Daily Life for Parents/Guardians</td>
<td>Perspectives of partnership</td>
<td>Physical comfort and sensory issues Social-Emotional development and mental health care</td>
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<td>Potential</td>
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**Inclusion**

The history of education as it applies to inclusion, and the current state of inclusive education in Saskatchewan and Canada, provides important background information for my study. Historically, individuals with cognitive and/or physical disabilities were segregated into institutions for care, for education, or for both. Changes in special education and the treatment of people with disabilities did not occur until the 1970s (DeLuca, 2013). DeLuca writes about “a general shift from segregation to academic integration to inclusion” (p. 309). That shift was largely precipitated by the United Nations’ *Declaration of Rights of Disabled Persons* (1975), which states that people with disabilities have the same rights as all other human beings. Amendments to *The Canadian Human Rights Act* (1977) and the *Canadian Charter of Rights and Freedoms* (1982) made Canada the first country to guarantee rights for people with disabilities in its constitution, which served to advance schooling in Canada to a more integrated model. Timmons (2006) explains that 1981 was declared the International Year of Disabled Persons and “had a catalytic role in raising awareness and prompting action across Canada” (p. 470). Bunch (2015) states that the terms “mainstreaming” and “integration” were commonly used terms in Canada at that time and that children with
disabilities were more likely to be placed in regular schools, but not necessarily in regular
classrooms or included in the activities of the classroom. Bunch also explains how
Marsha Forest and her husband Jack Pearpoint coined the term inclusion at a meeting in
continued to encourage the inclusion of all students, as did the UN Convention on the

The definition of inclusion for the purposes of this study is the definition used by
the Saskatchewan Ministry of Education (2001) in their guiding principles of inclusion:
“the education of all students in age-appropriate regular education classrooms in
neighborhood schools; systematic arrangement of general education settings, personal
support and instructional adaptations; and embedded teaching of basic life skills within
general education activities” (p. 12). A similar definition is provided in the Ministry’s
document “Inclusive Education” (2017) where it states:

Inclusive education creates environments where students feel accepted, valued,
confident and safe to engage in learning and where school personnel, families,
students and community agencies from collaborative teams that are committed to
a shared vision to support students in reaching their full potential. (p. 2)

The document later states, “Inclusive education provides students with an opportunity to
learn with age-appropriate peers within schools in their home communities. An inclusive
environment is welcoming and accepting of student interests, backgrounds, and life
experiences” (p. 2). It is important to note that the Ministry provides an advisory role for
school divisions only.
After reviewing Saskatchewan school division websites, I found one school division that had eight congregated programs for elementary students and nine for high school students. Another school division had three congregated programs and one congregated school. Others appeared to have no congregated programs at all. The situation across Canada is similar. Most provinces still have some form of congregated programs, although the three territories are much more inclusive (Timmons, 2006).

According to Timmons:

The areas in Canada that have seemed to make considerable strides in inclusive education appear to be those that are more rural than urban. This may be because it is difficult in sparsely populated areas to acquire a critical mass of a specific population to develop and set up segregated services. (p. 471)

Timmons (2006) also explains that, of all the provinces, Prince Edward Island (PEI) has had the greatest success at becoming inclusive. Timmons credits collaboration as the main reason for PEI’s success. However, New Brunswick paved the way in 1986 by changing their policies to ensure that all students were included in regular classrooms (Fleiger, 2012).

The Saskatchewan Ministry of Education’s recommendation for inclusion for all is supported by decades of research on inclusion, which has repeatedly found that it is the most beneficial approach for all children. Lyons, Thompson, and Timmons (2016) state:

In cases where people with disabilities have been authentically included in their schools…researchers have found significant (and positive) economic, social, and psychological benefits. Interestingly, students both with disabilities and without
do as well or even better than their counterparts who are educated separately. (p. 879)

However, there continues to be confusion and debate around defining inclusion, how to best implement it, who should be included, and even whether it is beneficial. That such a debate exists is puzzling to academics such as Swedeen (2009) who states, “I am still amazed that a debate exists on whether inclusion is a good idea” (p.3). Researchers have begun using the terms “authentic inclusion” and “genuine inclusion” in order to differentiate between settings that are labeled as fully inclusive and those that actually meet the criteria to be fully inclusive. Swedeen (2009) describes the signs of an authentically inclusive school to be:

Intentional planning, teamwork and team planning time, interactive and hands-on ways of exploring subject content, a truly flexible curriculum, and commitment from the school leadership to support staff with the time, resources, training and vision necessary to implement inclusive practices. Leadership for high quality and continuous professional development is also critical. Most importantly, students with and without disabilities need opportunities to participate together, interact, and contribute across school environments. (p. 3)

Swedeen also states that “authentic inclusion requires as much focus on communication, interaction, and relationship building as it does on curriculum modifications and accommodations” (p. 3).

Other researchers have created criteria to determine whether a setting is indeed inclusive. Florian (2014) proposes using *The Inclusive Pedagogical Approach in Action (IPAA) Framework* to analyze settings for their inclusiveness, and describes inclusive
pedagogy as, “an approach to teaching and learning that supports teachers to respond to individual differences between learners, but avoids the marginalization that can occur when some students are treated differently” (p. 289). Bunch (2015) offers questions for reflective educators to ask in order to ensure that they are applying “pedagogy for all.” In their research, Lyons, Thompson and Timmons (2016) found three central themes related to values and practices: learning and relationships, strong commitment to inclusion, and a team approach. In related research, Timmons and Thompson (2017) found that innovative pedagogy and the valuing of diversity were connected to inclusion. Timmons and Thompson (2017) conducted focus groups in three preschools, four elementary schools, one secondary school and three places of employment. These organizations were referred to them as reflecting strong inclusive practices. Timmons and Thompson applied the principles of appreciative inquiry, which is described as a “search for the best in people, organizations and communities” (p. 4). Their findings show that in schools and workplaces that exemplify inclusive practices: teaching and learning are valued; relationships are valued; visionary leadership is evident; professionals demonstrate individual commitment and contribution to inclusion; the team contributes to implementing the inclusive vision; structures and spaces which support inclusion exist; inclusion is apparent as “true belonging;” and inclusion is viewed as a road to establishing the individual apart from a disability. I found these resources useful in better understanding how I might evaluate an environment for inclusivity, or work towards making an environment more inclusive.

Some educators seem to claim benefits to congrigated programs. Jordan (2007) describes the advantages of congrigated classes: the teachers are trained in special
education; teachers can draw on a variety of instructional methods, curricula and motivational strategies; and individual progress can be monitored. However, she follows up by listing numerous disadvantages for the students, the teachers, and the school, including: students being isolated from their non-disabled peers; students lacking role models; students often lacking a sense of belonging; and, non-disabled students missing the opportunity to get to know students with disabilities. Although I searched for further literature in support of congregated settings, I was unsuccessful. Even articles which appeared, by their title, to be in support of congregated programs, such as Lupart’s “Setting Right the Delusion of Inclusion: Implications for Canadian Schools” (1998) turned out to reveal that inclusion is best, after all. For example, Lupart states, “In this time of major school reform and school restructuring it seems clear that educators in special education and general education must work together to forge a fundamentally different educational framework … based on principles of inclusion” (p. 252). This research has quelled my doubts about inclusion and confirmed my belief that it is important for me, as an educator, to continue to work towards more inclusive settings where I can do so. My ability to be successful at inclusive education is related to my view that inclusion is important. I will demonstrate that this is true for all educators in the next section, where I address literature regarding teacher views about inclusion.

**Teacher views about inclusion.**

In this section, I review the literature regarding teacher perceptions and attitudes towards inclusion and how this affects the inclusiveness of schools and school systems.

Avramidas and Norwich (2002) state that:

A key element in the successful implementation of the policy (of inclusion) is the views of the personnel who have the major responsibility for implementing it, that
is teachers. It is argued that teachers’ beliefs and attitudes are critical to ensuring the success of inclusive practices since teachers’ acceptance of the policy of inclusion is likely to affect their commitment to implementing it. (p. 130)

In their review article, Avramidis and Norwich (2002) explain that although teachers generally stated they had a positive philosophy towards inclusion, they did not actually have an attitude that supported the idea of including everyone. The authors conclude that teachers based their assessment about whether a child should be included in their classroom on the nature and severity of the child’s disability. Teachers were more likely to include students with mild physical or sensory (hearing or vision loss) disabilities. When the students’ needs were more severe teachers were more likely to have a negative attitude about inclusion. Students who had emotional and behavioural difficulties were least likely to be favoured for inclusion. Avramidis and Norwich also found that teachers’ attitudes towards inclusion became more positive when they were provided training on how to do it, as well as sufficient supports and resources, both human and material. Additionally, the researchers found that in school divisions where a policy of “no choice” full inclusion is adopted, teachers are more supportive about inclusion.

Similarly to Avramidas and Norwich, Mooney and Lashewicz (2015) found that teachers believed that the child who was involved in the study belonged in the classroom “only to a degree.” Mooney and Lashewicz found that the teachers and educational assistants in their study were confused about their roles and how they could provide for the needs of the child in their care. Further, the researchers report on inconsistent approaches between teachers, the absence of a common plan, and a lack of commitment towards educational planning.
Sokal and Sharma (2017) conducted a quantitative study of teachers’ views on inclusion. The teachers involved in their research were of three groups: (a) pre-service teachers with coursework about inclusive education, but limited experience in inclusive settings; (b) in-service teachers with experience in inclusive settings, but no coursework; and (c) in-service teachers with inclusive teaching experience as well as coursework in inclusion. The attitudes, efficacy, and concerns of the three groups of teachers were compared. They found that both experience and coursework enabled teachers to feel more confident in their ability to teach inclusively.

Mulholland and O’Connor (2016) examine views of collaboration for inclusion in Ireland. Their study found that teachers who participated in some form of collaboration believed that collaborative practices benefitted them professionally. Further, the teacher participants felt collaboration could both inform school practice and improve outcomes for students with exceptionalities. Overall, the teachers found that team-teaching was a valuable method for progressing inclusive practices. However, they did note that insufficient time for collaborative planning was a barrier to effective practice. As well, they noted that developing teachers’ familiarity with team teaching philosophy and approaches was necessary. This research demonstrates that it is vital for universities and school divisions to provide education around how to include students with severe disabilities and behavioural difficulties, for educators as well as educational assistants. In the next section I investigate best practices for inclusion.

**Inclusive pedagogies.**

Inclusive pedagogies enable educators to teach diverse learners. Various frameworks have evolved over the past few decades that provide direction for school
systems and educators on how to develop more inclusive settings. Universal Design, Differentiated Learning, and Response to Intervention are three such frameworks.

**Universal Design for Learning (UDL).**

Allen (2007) describes the framework of UDL as a method of teacher planning that allows all learners to benefit from the strategies and materials provided. The concept of UDL evolved from Universal Design (UD), an architectural practice developed to improve the accessibility of built environments, especially for people with physical disabilities (Gordon, Meyer and Rose, 2014). UDL developed as an extension to UD and, as Tomlinson (2014) summarizes, “UDL provides an approach for designing learning environments that support high expectations for all learners” (p. 19). Gordon et al. (2014) further explain that “Universal Design for Learning (UDL) drew upon neuroscience and education research, and leveraged the flexibility of digital technology to design learning environments that from the outset offered options for diverse learner needs” (p. 5).

The three core principles of UDL are (1) providing multiple means of engagement; (2) providing multiple means of representations; and (3) providing multiple means of action and expression. Educators must be informed and experienced in these principles in order to include all students. Additionally, since the use of technology as a means of engagement, representation and expression is critical, teachers must be knowledgeable about ever-developing technologies available to their students.

Katz (2012) makes valuable contributions to the understanding and application of UDL through her work, particularly *The Three-Block Model of Universal Design*. Katz proposes understanding UDL by using a concept of three “blocks”: social and emotional
learning, inclusive instructional practices, and systems and structures. Katz (2013) also contributes ideas on the role of resource teachers in the implementation of UDL. Through her work, she encourages the use of cooperative learning and multiple intelligences and also provides learner profile templates to better understand learners.

Like Katz, Jordan (2007) provides blocks or modules for educators to follow in order to learn about UDL and how to apply it in the classroom. Both authors provide excellent resources that can be used by teachers in their daily work, as well as by school leaders for professional development. I discuss, Differentiated Instruction, another inclusive pedagogy in the next section.

**Differentiated instruction (DI).**

Tomlinson explains that differentiation is “a teacher’s proactive response to learner needs to be shaped by mindset, guided by an environment that encourages and supports all learning, quality curriculum, assessment that informs teaching and learning, instruction that responds to student variance that leads students and manages routines” (p. 425). She provides valuable ideas on how educators can differentiate in order to reach all learners. She describes educators who differentiate as “teachers who strive to do whatever it takes” to ensure that all learners grow as much as possible each day and throughout the school year (p. 137). There are four areas in which teachers can differentiate: content, process, product and affect/environment. Educators modify these areas based on student readiness, interest and learning profile. Differentiating teachers use a variety of instructional strategies to create an inclusive environment, including: learning/interest centres, graphic organizers, scaffolded reading/writing, intelligence preferences, tiered assignments, learning contracts, menus, tic-tac-toe, complex
instruction, independent projects, expression options, and small group instruction. Tomlinson’s resources can be used for professional development by educators and school leaders. In the next section I discuss Response to Intervention, another inclusive framework.

**Response to intervention (RtI).**

RtI is a framework to guide educators as they respond to the needs of children in the classroom. The Saskatchewan Ministry of Education’s (2015) Intervention First Diagram lists the continuum of services at each of three tiers: tier one is classroom-based/school-wide instruction; tier two is targeted, group interventions; and tier three is intensive individual supports. The tiered approach and response to intervention are intended to provide direction for educators to ensure that students can remain included in a regular classroom. If congregated programs are an option in a school division there are procedures, criteria, and policies guiding the process of placing a child in said programs. Principals, in collaboration with special education or student services teachers and the school division team, are responsible for adhering to this process. UDL DI, and RtI are crucial pedagogical frameworks that improve the ability of educators to provide for the needs of all their students. In the next section, I discuss the importance of teacher professional development, according to the literature.

**Teacher professional development (pre-service and in-service).**

Teachers must receive appropriate pre-service instruction in order to effectively meet the needs of all learners and to work closely with caregivers and agencies. In addition, the attitudes of teachers about inclusion and collaboration affect whether they teach in an inclusive manner at all as well as their effectiveness in doing so.
Forlin, Loreman, Sharma, and Earle (2009) conducted a quantitative study to learn whether pre-service teachers’ views would change due to a course in inclusive education. The researchers demonstrated the need for pre-service teachers to receive training in diversity and inclusive teaching approaches to be able to further inclusion. Likewise, Killoran, Woronko, and Zaretzky (2013) also studied whether pre-service teachers’ views could be changed due to education. They found that the course provided did have a positive impact on the teachers’ views.

Epstein (2011) explains that teachers and administrators are not well prepared in approaches that facilitate inclusion or partnerships. To that end, Lupart (1998) notes that radical transformation of teacher preparation is necessary. To do so, “practical applications proved to be successful in separate special education settings should be woven into the instructional expertise of all classroom teachers” (p. 261). School principals have a crucial role in furthering teacher preparation. The Saskatchewan Ministry of Education (2002) encourages school principals to provide leadership regarding welcoming and inclusive approaches and to facilitate staff development opportunities.

The research I read on teacher professional development corresponds with my personal experiences. I have found it necessary to start conversations with my colleagues about inclusive pedagogies on a regular basis. I believe this means that ongoing collaboration between student service teachers and classroom teachers is crucial. I discuss collaboration in the following section.

**Collaboration.**

Collaboration between teachers and other professionals is critical in developing inclusive practices. Timmons (2006), reporting a survey of educators in Prince Edward
Island, found that one of the factors for success with inclusive practices is a school-wide approach that includes informal consultation with colleagues. As she asserts, successful teachers are masters of collaboration. Likewise, in their research to better understand how schools achieve successful inclusive practices, Timmons and Thompson (2017) and Lyons et al. (2016) state that “collective agency” (the actions of a group of people toward a common goal) or “collective efficacy,” strong relationships; and a team approach are all vitally important.

Mulholland and O’Connor (2016) studied the movement towards inclusive practices through collaboration in Ireland. They found that close collaboration between classroom teachers and special education teachers, and familiarity with positive collaborative practices, have a significant impact on a school’s ability to implement inclusive practices. They also demonstrate the importance of collaboration between agencies, schools, and parents/guardians. Schwean and Rodger (2013), Timmons (2006), and Katz (2016) all address the importance of these same partners working together. Timmons (2006) describes this as a multi-pronged approach. Schwean and Rodger (2013) call it systems of care. Katz’s (2012) integrates the partners into her three block-model, which is described above in the section on UDL. As an educator, I could use any of these collaborative models to improve my own practice, and the practice of my colleagues. Working with parents is also critical for inclusive practices. I address parent engagement in the next section.

**Parent Engagement**

Parent engagement is crucial to student success. As Valencia (2010) explains, “an abundant corpus of literature documents the positive relation between the degree of parents/guardians’ participation in education and their children’s educational
achievements, particularly improving students’ academic performance, lowering dropout rates, and promoting positive attitudes towards the learning process” (p. 131).

The literature on parent engagement is vast and includes several sub-topics. To best summarize my findings I’ve divided the resources I reviewed into five sub-categories. Those sub-categories are: parents/guardians as partners and resources; home-school communication; parents/guardians as agents of change; partnership models; and perspectives of partnerships.

**Parents/guardians as partners and resources.** Pushor and Murphy (2004) advocate for parent engagement and challenge assumptions that parents/guardians are being given a voice or allowed to participate in meaningful ways. They explain that according to McGilp and Michael, the roles commonly given to parents/guardians are “audience, spectators, fundraisers, aides and organizers” (p. 222). Drawing from her own professional experiences, Pushor states: “I became convinced that establishing communication with the home and accessing a parents/guardians’ knowledge about their child were critical elements in my teaching practice” (p.228).

Wilgosh and Scorgie (2006) surveyed parents/guardians of children with disabilities using The Life Management Survey, which they designed. They extend their findings as recommendations for teacher-parent collaboration. They argue that educators must value the child; allow parents/guardians equal power in decision making; allow parents/guardians to advocate as an expert on their children; value the parent as a competent collaborator and team member; and focus on parent strengths. Tomlinson also (1985) asserts the importance of parental partnerships. Additionally, Gonzalez, Moll, Amanti and Neff (1992) introduce “funds of knowledge” as a key resource in developing
parental partnerships. The authors define funds of knowledge as historically developed skills, abilities, practices or ideas that have accumulated in families. They propose that teachers become researchers to discover the funds of knowledge that exist in their school community, in order to engage families and foster connections with the school.

**Home and school communication.**
In the literature I noted different strategies for fostering communication between home and school. For example, Staples and Diliberto (2010) provide suggestions for communicating with families. Their recommendations include:

1) Daily journals that communicate the child’s performance on tasks in positive, constructive ways;
2) Weekly newsletters for all parents/guardians;
3) Monthly toolkits that include activities to do at home; and
4) Monthly telephone calls or face-to-face meetings.

Another strategy, explained by Hall, Wolfe and Bollig (2003), is the use of a Home-to-School Notebook. The authors recommend using the notebook as a place to write positive information, while being consistent with daily communication and focusing on factual information and data based on the student’s goals, rather than recording personal opinions. They also explain that this notebook could be used to analyze behaviour patterns as well as academic, behavioural and social growth. They provide specific, practical recommendations for setting up routines for the notebook in order to simplify and maintain communication.

**Parents/guardians as agents of change.**
Lyons et al. (2016) define human agency as “a social cognitive theory in which people are seen as the producers as well as the products of social systems. Human
agency is conceptualized as intentional actions aimed at producing a desired result” (p. 892). The authors also discuss collective agency, which is “the shared knowledge, skills and synergy among members” (p. 892). Carter, Swedeen, Cooney, Walter, and Moss (2012) note that community conversations (which are potential incubators of collective agency) could be opportunities for parents/guardians to serve as agents of change. They encourage regular formal meetings where parents/guardians lead the way in recommending for the needs in the school and community. Additionally, they explain that meetings such as these could pave the way for large-scale school reform and improve life for families and individuals in the community. They provide practical solutions and strategies to give parents/guardians the platform they need to become agents of change. In addition, they identify that “the avenues through which parents/guardians might lead grassroots efforts are understudied” (p. 10).

These frameworks are vital to my research and my work as an educator. In my professional role, I can plan community conversations where parents/guardians have the opportunity to be agents of change. Additionally, through my literature review, I discovered other useful partnership models which I describe below.

**Partnership models.**
A variety of partnership models exist. Each model provides different opportunities and challenges. The value of each depends on its purpose and the community it’s utilized in. Three specific examples of partnership models follow.

The first model, known as The World Café, involves parent-led community conversations (Carter, 2012). Through involvement in the conversations, this model allows parents/guardians to serve as “agents of change in their local communities” (p. 12). The second model is known as an Action Team for Partnerships or ATP (Epstein,
ATPs are school committees that are dedicated to improving the plans and practices of involvement by community and family. Setting up a committee to focus on this goal certainly demonstrates a high level of dedication and value placed on community and family involvement. The third model, which is encouraged by the Saskatchewan Ministry of Education (2001), is the Multi-Action-Planning-System (MAPS). This third model is a framework for meeting with all partners involved in a child’s education in order to decide on goals and strategies to meet the child’s needs. This model is designed to focus on the “maintenance of social relationships.” Any of these three models can be implemented by schools in order to manage and focus on building and maintaining parent-school-agency partnerships.

**Perspectives of partnerships.**
In addition to partnership models, there are partnership perspectives: ways of viewing partnerships that can be positive or negative and more or less beneficial. There are three different ways of thinking about perspectives regarding parent-school-agency partnerships. First, O’Connor (2008) describes three different levels of partnership: expert, consumer, partnership. At the expert level the professionals have the greatest decision-making power; at the consumer level, the power of parents/guardians increases somewhat; and finally, at the partnership level, parents/guardians have an equal or greater amount of decision-making power as the professional. This perspective is useful in thinking about how educators and administrators view the power of parents/guardians. Second, Epstein (2011) describes three perspectives of responsibility between parents/guardians and schools: separate, shared, and sequential. Epstein also proposes a new—third—perspective (dubbed the “life course perspective”) that takes into
consideration a student’s history and development as well as the influences that schools and families have on one another.

It is important to reflect on the responsibilities held by each of the stakeholders and how perceptions regarding responsibilities might affect the success of the child. Each of these perspective models provides valuable insights into how schools can improve their practices to increase the involvement of parents/guardians and thereby expand the democratic participation of the parents/guardians themselves, as well as their children. Parent engagement is an area of great importance which I will address in the section on implications; however, first I will examine the challenges that parents/guardians of children with exceptionalities experience, as addressed in the literature.

**Daily Life for Parents/Guardians**

Several researchers have documented and categorized the daily stressors and challenges faced by families who have children with disabilities. In their review of the literature, Anaby et al. (2013) studied the effect of environment on participation for children and youth with exceptionalities. They found that families face unique barriers related to time, such as planning ahead, negotiating the environment, and experiencing a different pace or rhythm in their daily activities. The authors suggest that professionals can assist families by helping students and parents/guardians learn skills to manage these issues.

Scorgie and Wilgosh (2004, 2008) studied effective life-management strategies of parents/guardians of children with disabilities. The researchers constructed nine themes around three research questions. They found that parents/guardians had (or developed) common personal traits, attributes, and abilities that made them able to effectively
manage their daily lives. They discovered that parents/guardians reframed their thinking, accepted the child’s diagnosis, discovered a sense of purpose in their child’s diagnosis, developed the ability to live with undeterminacy, maintained balance in their personal and professional roles and identity, and developed the ability to locate resources effectively.

Fox, Vaughn, Wyatte and Dunlap (2002) studied families with children who had problem behaviour and the ways in which that behaviour affected the families’ lifestyle. The problem behaviours noted were property destruction, loud vocalizations, repetitive behaviours, and physical aggression. The authors constructed three themes:

1) Something is Not Right, which is an account of parents/guardians’ journey of coming to terms with their child’s disability;

2) A Shoulder to Lean on, which describes the families’ need for support and encouragement from helpful professionals: and

3) It’s a 24 Hour, 7-Day Involvement, which describes the intensity of these parents/guardians’ daily lives and parenting.

Cole (2007) studied home-school relations. She contends that the term “parent,” as a blanket term, masks the different gendered reality and experiences of mothers and fathers. She noted that mothers often felt frustrated and helpless when dealing with professionals and held back so as not to upset the professional dealing with their child. My own research corresponds to Cole’s conclusions. As I explain in the findings section, many of the mothers I interviewed identified experiences in which they felt frustrated and helpless. In these situations, mothers found that involving the children’s fathers was necessary in order to achieve their goals. Cole’s work is important and relevant to my
study. However, I chose to focus on other areas of research that I felt I had greater control over—in particular, one sub-category within “Daily life for parents/guardians”: “Easing their world.”

**Easing their world.**

The concept of easing their world came from an interview with one of the participants in this study, Alice. In order to review literature of this category, I categorized it into two areas: (a) the physical comfort of the child, including sensory issues, and (b) the social-emotional development of the child and mental health care. School professionals can ease a child’s world through careful planning and in-the-moment intervention, which tangentially serves to ease the world of the child’s parents/guardians as well.

**Physical comfort and sensory issues.**

Puteh, Che Ahmad, Mohamad, Adnan and Ibrahim (2015) found that physical factors such as classroom and school design, seating, room temperature, ventilation, and lighting impact student learning, and should be given careful attention. Additionally, Kranowitz (2006) described sensory issues as an ineffective central nervous system which affects children’s daily lives and the ability to perform tasks. Children with autism spectrum disorder, attention deficit disorder, and other diagnoses often experience sensory processing difficulties. Kranowitz explained that children are best able to learn when these sensory needs are met through breaks, food and drink, and physical activities such as pushing, pulling, lifting and jumping.

**Social-emotional development and mental health care.**

Katz (2012) discusses the link between social and emotional development and academic success and explains that “a loving community and support network can protect
both children and adults from the negative effects of crises and illness” (p. 29). In all of her resources (2012, 2013, 2018), Katz addresses the importance of learning communities where adults demonstrate care and love for the children and where they address mental health. Similarly, Mooney and Lashewicz (2015) refers to Paulo Freire’s “courage to love” and “love of the child” as being the key to emancipatory pedagogy. Also, Schwean and Rodger (2013) conducted research to demonstrate systems of care. They found that school-based mental health systems were highly effective.

Additionally, Holley and Steiner (2005) surveyed the views of post-graduate university students regarding safety in the classroom. Their participants stated that they were able to learn more in a safe space. Participants noted that characteristics of the instructor, their peers, and the physical environment affected their feelings of safety and their ability to take risks, which impacted their ability to learn new concepts in the classroom. Other characteristics of safe classroom spaces include unbiased, non-judgmental, and caring instructors; proper seating; appropriate room size; and good lighting. Although this study is about university students, these findings could relate to easing the world of younger students as well. In the next section I address the category of potential, including strength-based approaches and the concept of being a believer.

**Potential**

The concept of professionals as “believers” evolved through many of the interviews I conducted. It was one of my participants, Ann, who used the term believer when speaking of professionals who helped her child in an exceptional way. This concept excites me but it was challenging to find sources about human potential and the concept of being a believer. Many of the resources I found were about future employability or the idea of the self-fulfilling prophecy, also known as the Pygmalion
effect, where the opposite is called the Gollem effect. There was also a great deal of reference to having an asset-based approach, focusing on student strengths, rather than having a deficit-based approach. Rosenthal and Jacobson (1968) demonstrate that teachers’ suppositions about pupils’ learning potential, even if incorrect, had a more significant impact on student performance than did actual ability. Many researchers, including Stebbins (1975), have supported these findings.

Hutchinson (2010) advocates for a new framework, away from a discrepancy model towards an appreciative model, that recognizes students’ abilities to learn when provided with the appropriate accommodations. Valencia (2010) provides practical solutions for educators to focus on student and family strengths, rather than deficits. He organizes his suggestions according to five areas: pre-service teacher education, parental engagement in education, educational leadership, social justice and ethnography of schools. Although Valencia’s work is focused on dismantling deficit thinking around race and poverty, his suggestions are relevant to other marginalized groups, such as those with exceptionalities. His discussion around social justice is particularly important since he makes suggestions for changing the way we think about differences and labelling in schools. He proposes that principals implement four strategies. First, he suggests devoting time to marginalized students’ achievement. He also recommends strengthening staff capacity through professional development. Further, he argues that strengthening school culture and community would be beneficial. Finally, he advocates improving the structure of schools by (a) de-tracking; (b) providing full inclusion; (c) arranging greater access to advanced courses; (d) completing informal portfolio assessment; and (e) challenging teachers’ deficit thinking. Valencia argues that the
implementation of these strategies would transform schools towards an appreciative model.

Coleman (1988) studied the effects of social capital on high school graduation rates. He explains that “human capital is created by changes in persons that bring about skills and capabilities that make them able to act in new ways. Social capital, however, comes about through changes in the relations among persons that facilitate actions” (p. S100). He identifies three forms of social capital: obligations and expectations (dependant on trustworthiness); information-flow capability of the social structure; and norms accompanied by sanctions. Coleman found that “social capital in the family and social capital outside of it, in the adult community surrounding the school, showed evidence of considerable value in reducing the probability of dropping out of high school” (p. S119).

As these studies show, professionals who believe in students increase their academic success. Through my personal experience, the interviews in this thesis, and the literature reviewed, I have come to understand that it is crucial for educators to believe in the potential of the children in their care. In the next section I discuss the category of Socialization in schools.

**Socialization in Schools**

Socialization came up frequently in participant interviews. Specht (2013), Avramidas and Norwich (2010), and Wotherspoon (2009) agree that socialization is a role of the school. However, among these authors and others, there is some debate about specific issues around socialization. That debate swirls around issues such as the purposes of socialization and the ways in which children are socialized both intentionally
and unintentionally, through the hidden curriculum, or as Apple (2004) puts it: “the tacit teaching of social and economic norms and expectations to students in schools” (p.42).

While the parents/guardians I spoke with view socialization from a positive, basic, everyday perspective, the literature goes further to talk about sociological theories, issues, and problems in education. Parents/guardians who spoke about their children going to school to be “socialized” were speaking about their children picking up skills and habits of getting along with others and understanding social rules and norms. They believe this is a positive aspect of schooling and that their child has the same right to this opportunity as other children.

However, Wiener (2004) explains that adult facilitation of friendships within context is more beneficial for socialization than structured social skills programs. There are numerous educational programs designed for educators to assist children in developing friendships, social skills, and self-regulation skills. However, I do not intend to review any of these programs or philosophies, as this topic is too broad and complex for this study. In the following section I address the reality that children with exceptionalities are not receiving the adult facilitation they require in order to develop friendships and relationship skills. Instead, they are often marginalized and lonely (Margalit, 2010).

Marginalization, Loneliness, and Difference
Margalit (1994, 2010), Specht (2013), Bunch (2015), and Wiener (2004) all found that children with exceptionalities were at a higher risk for loneliness, exclusion, and marginalization. Wiener (2004) defined loneliness as “an aversive subjective experience involving sadness, and alienation from the people and things that are important to the individual” (p. 23). Specht (2013) explains that “the need to form connections with other
people is a fundamental need of human beings. People who do not have their belonging needs met are more likely to experience emotional deficits (anxiety, depression, grief, loneliness, etc.)” (p. 44). Specht goes on further to say that inclusive education should be considered “a means to an end,” in that it should create a better quality of life for all as well as a society that is accepting of differences. She also explains that when students with exceptionalities are segregated we lose this opportunity for diversity and to build “social capital” for all students. Specht states: “It seems that disability is the last bastion of inclusion that we are still fighting for...when we say all, we mean ALL.” (p. 46).

The term “Othering” refers to “those groups that are traditionally marginalized in society” (Kumashiro, 2000, p. 24). The literature about Othering is extensive; the works I found most valuable are summarized below. Derrida theorizes about relationships of power and the idea that a dominant group is at the centre while the others are excluded on the outside. Graham and Slee (2013) apply these concepts to the act of excluding those with exceptionalities from classrooms. They encourage educators to reflect on the language we use, explaining that, “there is an implicit centered-ness to the term inclusion, for it discursively privileges notions of the pre-existing by seeking to include the Other into a prefabricated naturalized space” (p. 280). Further, they suggest that we problematize the practice of labelling and categorizing students with the intent to understand where they fit. Gillham (2011) also suggests that we reflect on assumptions that exist in education and the idea of special education, including the role of the psychologist.

DeLuca (2013) encourages educators to not just reflect, but to rethink and reform. He suggests a social-justice driven, interdisciplinary framework of inclusivity which
includes special education, anti-racist education, gender education, and queer studies. In terms of rethinking and reforming, DeLuca suggests getting away from an “analyze and fix them” approach. He proposes working towards an “understand and include them” approach while changing the way we think about ability and what it means to be normal” (p. 312). DeLuca’s framework includes a diagram depicting four progressive conceptions of inclusivity from a unicentric, normative, “be like us” conception, to a concentric, transgressive, heterogenous, social justice pedagogical conception which uses student diversity as a “vehicle for the generation of new knowledge and learning experiences” where “there is no dominant group” and “learning cannot be standardized…because individual differences alter what and how learning takes place” (p. 334). Also in this framework, “labelling of difference is limited; rather the continuum moves towards claiming individual, unique positions of knowing” (p. 334).

Deluca’s description of different ways of knowing is similar to neurodiversity, “a concept where neurological differences are to be recognized and respected as any other human variation” (Jaarsma & Welin, 2011, p. 2). Au (2012) explained that standpoint theory argues that those who are systematically oppressed or marginalized provide the best “starting off thought” for generating “illuminating critical questions that do not arise in thought that begins from the dominant groups lives” (p. 55). Danforth (2006) wrote specifically about disability theory and stated, “a belief is appraised within the specificity of the lived experience of an individual or group. It must be retested and re-evaluated by persons taking action within the contextual features of a given social and historical movement” (p. 340).
All the researchers reviewed in this section raise important points about reflecting on and problematizing our current approaches to education. Their suggestions provide possibilities for reducing the current marginalization, loneliness, exclusion and power relationships that people with differences experience. I will address the systems, in which these power relationships take place in the next section.

**Systems**

Participants frequently spoke about challenges they faced within systems (such as agencies, schools, families and communities) while attempting to meet the needs of their children and include them in regular classrooms. There are many realities in organizations and systems which make the development of authentically inclusive schools challenging. Many of the sources I reviewed provided insights. For example, Mooney and Lashewicz (2015) discuss challenges for administrators in managing the “business” of education with shrinking budgets, fluctuating resources, high expectations and the increasing prevalence of students with disabilities in their schools. Schwean and Rodger (2013) address “systems of care” between schools, agencies and policy-makers by creating a framework. They recommended systemic changes to the mental health system and school systems, which will need to be driven by a concerted effort from policy-makers.

Timmons (2006) describes the success Prince Edward Island has had developing inclusive practices due to a concerted effort from stakeholders and policy-makers. She explains that service-deliverers and policy-makers worked closely to coordinate their approach to serving the needs of children. However, part of the problem in Canada, as Bunch (2015) explains, is that, with the exception of First Nations students, most school-related policies are developed provincially. Instead, Bunch recommends that the federal
government lead the way towards inclusive education by following the examples of the more inclusive provinces and territories. Like Bunch, Lupart (1998) argues that one of the reasons for slow progress of inclusion is that the primary responsibility for education is provincial and not federal.

Thompson and Timmons (2017) provide details about how a province handles that responsibility by focusing on Saskatchewan. In that province, the Saskatchewan Ministry of Education provides a set amount of money to each school division for students with disabilities. School divisions may allocate that funding as they wish. Thompson and Timmons pondered whether the lack of criteria or guidelines for use of the funding is the reason inclusive practices vary from school division to school division.

On an international level, Lei and Myers (2011) discuss the Education for All Fast Track Initiative, established in 2002 to improve the quality of education for children with disabilities worldwide. The authors report that children with exceptionalities are still being largely excluded from mainstream education regardless of whether they reside in low- or high-income countries. Additionally, the authors explain that there is a lack of leadership and commitment on the part of policy-makers towards inclusive education. Ultimately, they identify an urgent need to transform education systems to work towards an inclusive approach.

Mulholland and O’Connor (2016) explain that institutional and systemic shortcomings impede opportunities for professional cooperation, which is beneficial for developing inclusive practices. The authors argue that there must be a shift in educational policy that supports collaboration. Avramidas and Norwich (2002) found that teachers’ “experiences of inclusion” promoted positive attitudes towards inclusion and that
therefore, a “no choice” inclusion policy might be necessary. Katz (2016) and Graham and Slee (2013) recommend disrupting the current discourses around difference and speaking up in order to move towards inclusive practices for all. Katz provides specific recommendations for systemic change towards inclusivity.

Summary

In this chapter, I review much of the current literature on a variety of categories, which were chosen through my interviews with participants. Several key points emerged from this review.

Without question, inclusion is the best approach for all students (Lyons, et al. 2016). Inclusion can be achieved through Universal Design for Learning (Katz, 2012), Differentiated Instruction (Tomlinson, 2014), and Tiered Intervention (Saskatchewan Ministry of Education, 2015). However, there is much room for improvement of inclusive practices in Canadian schools (Specht, 2013).

A review of the perspectives of teachers reveals that teachers generally do not feel comfortable or well-prepared for including students with exceptionalities in regular classrooms (Avramidis and Norwich, 2002). Professional development for pre-service and in-service teachers improves teachers’ abilities and comfort level in providing for students with exceptionalities (Killoran, et al., 2013). Additionally, when teachers are able to collaborate with fellow colleagues and other professionals their own comfort level and ability in inclusive practices increase (Mulholland and O’Connor, 2016).

Further, parent engagement and home-school communication are crucial for successful inclusion and the progress of children with exceptionalities (Valencia, 2010). Parents/guardians can be agents of change (Lyons et al., 2016) but it must be recognized that their daily lives are more intense and require a greater level of organization, patience,
energy, and resourcefulness than those of parents/guardians of children who do not have exceptionalities (Anaby et al., 2013).

A number of other key points emerged through the literature review. First, a teacher’s belief in a student’s ability affects student progress (Rosenthal and Jacobson, 1968). Second, schools have an important role in the socialization of students. Schools can be places where all children learn about diversity as well as places where students with exceptionalities can learn how to make friends and get along with others (Specht, 2013). Third, individuals with exceptionalities are marginalized and Othered within society and within systems (Specht, 2013). Fourth, many realities exist with current systems which affect the development of individuals with exceptionalities (Lei and Myers, 2011). In chapter five I will further analyze the literature and explain how it applies to the categories I constructed from the data. However, first in chapter three, I explain the theoretical framework for this study and the methodologies I used to recruit participants and to collect and analyze data. Additionally, in chapter four, I will explain the findings from participant interviews.
Chapter Three: Methodology

In this chapter, I will explain the ontological and epistemological framework of grounded theory and constructivism. I will describe how these frameworks influenced my research as well as the methods and processes that I used to recruit participants and to collect and analyze data. I will also explain some limitations of my research.

Theoretical Framework

This grounded theory study is based on the inter-related theories of constructivism. Grounded theory is the discovery of theory from data, where the researcher uncovers something that was already there (Glaser and Strauss, 1967). While interviewing participants, the goal of a researcher might be to obtain an emic view of behaviour. However, it is impossible to reproduce the experiences of participants (Charmaz, 2014). From a constructivist perspective, the data collected is a construction of the shared experiences of the participants and the researcher. Additionally, the analyses are social constructions based on how the researcher interprets the data. According to Charmaz (2014), constructivism “brings subjectivity into view and assumes that people, including researchers, construct the realities in which they participate. Constructivist inquiry starts with the experience and asks how members construct it” (p. 342).

Even before I began my research, I knew that parent voices would be my topic. Additionally, I wanted to share how important it is to include children with exceptionalities in regular classrooms. When I learned about grounded theory, I knew this was an excellent fit for the research I wanted to do. As Charmaz (2005) explains, “A social justice researcher can use grounded theory to anchor agendas for future action,
practice, and policies in the *analysis* by making explicit connections between the theorized antecedents, current conditions, and consequences of major processes” (p. 512).

As a researcher, I am aware that my personal world-view, experiences, knowledge, values, culture and belief system affect how I view and construct data. Consequently, my biases affect my research. As Charmaz (2005) states, “No analysis is neutral” (p. 510). As a result, I remained aware of my personal biases and how they influenced my analysis of data. Charmaz deepened my awareness of this influence by stating that “Constructivist grounded theorists take a reflexive stance on modes of knowing and representing studied life. That means giving close attention to empirical realities and our collected renderings of them - and locating oneself in these realities” (p. 509). My background as a white woman who was raised in a middle-class family affects my beliefs and how I view my data. As well, both my experiences as a teacher, which include many successful examples of inclusion of students with exceptionalities, as well as my personal experiences with individuals who have exceptionalities has also influenced my analyses. I documented these experiences in a narrative account during a graduate course in 2015 (Appendix E).

**Method**

In this section I explain how I selected participants, collected and analyzed data, using grounded theory methods.

**Participant Selection Process.**

For this study, I was able to recruit seventeen participants. To begin the process of recruiting, I received permission from the University of Regina as well as from the Regina-Qu’Appelle Health Region. The sampling techniques I used were purposive sampling, multiple case sampling, and snowballing. I applied purposive sampling, which
is also known as selective sampling, when I deliberately selected participants who had children with exceptionalities. Multiple case sampling is well explained by Saldaña (2018): “Multi-case sampling allows researchers to analyze whether particular findings hold true only at a particular site or more broadly” (p. 95). Finally, I applied snowballing, in which participants, or those in a position to work with or know potential participants, refer them to me (Saldaña, 2018).

I created a poster which described the research and which identified criteria for potential participants (see Appendix A). I delivered the poster to four community agencies that agreed to either post it in their offices or email it out to clients they felt might be interested. Additionally, I emailed the poster to six school divisions that agreed to share the poster in various ways among their teachers and parent populations. I also posted it on my personal social media sites and hand-delivered it to individuals who had previously expressed interest in my research. Six individuals self-referred after seeing my poster or receiving it in an email from an agency or school division. Nine of the participants were previously known acquaintances of mine. Those nine had either seen my poster on social media, received a hand-delivered poster from me, or had received a poster from a mutual acquaintance. Two were husbands who were referred by their wives.

The poster requested that any parent/guardian of children with differences, who wanted to share their perspectives and experiences, contact me. I used the word differences in order to leave it open for parents/guardians of children with a variety of exceptionalities. I was willing to interview parents/guardians of children with various exceptionalities, as the issues I was curious about did not have to do with a specific
challenge. Instead, I wanted to find out what obstacles and successes parents/guardians faced in the school system as well as in the broader community. Since I placed no limitations on the type of differences, I interviewed parents/guardians whose children were diagnosed with autism spectrum disorder (10); Down syndrome (2); learning disabilities (2); cognitive disability (1); developmental delay or dyspraxia (2); fetal alcohol spectrum disorder (1); and cerebral palsy (1). Of the seventeen parents/guardians interviewed, fifteen were mothers and two were fathers. One participant had adopted children, another was a step-parent, and the other fifteen spoke of their biological children. However, whether they were adoptive parents, step-parents or biological parents was irrelevant to my research. They all had similar experiences as parents/guardians of children with exceptionalities. Profiles of the participants, with further details, are included in the findings chapter.

Data Collection.

Once a participant had contacted me and agreed to be interviewed, we set a date, time and location for the interview to take place. One of the interviews occurred in my home. Three of the participants kindly invited me to their homes. Four interviews occurred at a room at the University, one was set at a local library and one happened at a restaurant. Two participants requested to be interviewed at their workplace. Two of the interviews were conducted over the phone due to distance and time issues. And two of the participants chose to respond by email.

Before we began the interview, I reviewed the informed consent form (See Appendix C), questions were answered and the participant signed the form. I had created a list of guiding questions, based on Charmaz’s (2014) guidelines (See Appendix D). The interviews were semi-structured, allowing for the participant to take the lead. I
found that it was best to encourage the participant to basically tell the story of their child’s life, while I listened, only asking the occasional clarifying question. My body language was significant, showing that I was fully engaged in the conversation and that I wanted to hear what they had to say. Participants readily shared their experiences and opinions. Some became emotional at some points when remembering a difficult time. However, the emotions did not stop them from continuing to share their story. The interviews ranged in length from forty-five minutes to two hours. I completed the seventeen interviews within the span of four months. In the following section I explain how I analyzed the data.

**Data Analysis.**

I recorded each interview and had them transcribed. I then analyzed them using the three-phase process proposed by Charmaz (2014) – initial coding, focused coding, and theoretical coding. I began with line-by-line coding of each interview transcript. By using line-by-line coding and focusing on actions, I was able to immerse myself in the data and begin to categorize and label these actions. After the first three interviews, I began engaging with the transcripts and co-constructing some initial codes and categories. The categories continued to be quite consistent throughout this process. Participants had similar messages, within their unique stories. I was aware of my biases while trying to also be aware of the participants’ world-views, and think critically about what they had to say. As Charmaz (2014) states:

> Line-by-line coding prompts you to look at the data anew. Initial codes help you to separate data into categories and to see processes. Line-by-line coding frees you from becoming so immersed in your research participants’ world-views that you accept them without question. (p.127)
During the initial coding, I noticed some *in vivo* codes. “In vivo codes are characteristics of social worlds and organizational settings” (Charmaz, 2014, p.135). For example, the parents/guardians who had children with autism used many of the same terms and phrases to do with autism, such as “desensitize”, “stimming”, “fixates”, and so on. Once I had done an initial coding of all the transcripts, I began the process of focused coding. Charmaz states, “Focused coding means using the most significant and/or frequent earlier codes to sift through and analyze large amounts of data. Focused coding requires decisions about which initial codes make the most analytic sense to categorize your data incisively and completely” (2014, p. 138). Focused coding allowed me to compare participants’ statements within the same interview, as well as to other interviews. I compared and labeled, categorized, organized and re-organized, as I tried to make sense of what participants were saying. I constructed core categories and realized that they were interrelated.

Additionally, I documented my thoughts through memo-writing. Charmaz (2014) explains, “Memo-writing is the pivotal intermediate step between data collection and reading drafts of papers. Memo-writing constitutes a crucial method in grounded theory because it prompts you to analyze your data and codes early in the research process” (p. 162). I made notes about my categories and reflected on them.

At this point, I was also referred to NVivo software. I attended a workshop on how to use NVivo and had it downloaded onto my computer. I entered my data into NVivo and began the process of using it to assist me in analyzing my data. However, in the end, I found it much more beneficial to simply use the hard copies of my data to
continue my analysis. I am glad to have had the experience of using this software, and learning that I personally prefer to simply use pencil and paper.

Theoretical coding is the next step in the coding process. It was Glaser who introduced theoretical coding, which allows the researcher to conceptualize, “how the substantive codes may relate to each other as hypotheses to be integrated into a theory…they weave the fractured story together again” (Glaser, 1978, p. 72). Glaser outlined eighteen code families. However, I did not believe that my codes easily fit these code families. It is important to point out that another researcher may see my data with a slightly different slant. Also, due to the variance of topics within my research, there are various directions for researchers to pursue or further analyze. Further research into this topic is welcomed.

**Delimitations.**

Throughout the process of this constructivist grounded theory I remained aware of the limits of this research. The conclusions rely on my shared experiences with my participants, my worldview and my interpretations and is situated in a certain time, place, culture and situation (Charmaz, 2014). My experiences as a white, middle-class female affected the conclusions of my research. Participants were self-referred. All participants had forms of financial, educational, and human resources available to them. They were all generally confident about speaking with me and sharing their experiences, as they obviously had the confidence and comfort to contact me. I did not speak to any individuals who may or may not have seen my poster and did not contact me. As a result, I can only speculate on reasons why my sample was not more diverse or how this study may have been different if it had been. Additionally, my topic was intentionally quite broad. As a result, the findings address a range of issues. This is representative of how
complex it is caring for and advocating for children with exceptionalities. However, it did limit my ability to research some of the specific topics in a more in-depth manner.

Validity.

A variety of perspectives exist among qualitative researchers regarding the idea of validity. McNiff and Whitehead (2011) explained that once a researcher has gathered evidence, they must then show its authenticity, seek validity for the claims to knowledge and legitimacy for the account. They explained that essentially, validity refers to trustworthiness. Guba and Lincoln (2005) compared validity to an ethical relationship. They also stated that, “the way in which we know is most assuredly tied up with both what we know and our relationships with our research participants” (p. 123). As a result, researcher bias must be addressed with reflexivity. Guba and Lincoln also explain that qualitative inquiry builds capacity in the research participants for positive social change and for action towards social justice in the community.

Johnson (1997) describes three types of validity: descriptive, interpretive and theoretical. Descriptive validity is the manner in which the researcher presents factual accuracy and whether the experiences of the participants took place. Interpretive validity is the researchers’ ability to accurately interpret the meaning of the topic attached by participants. Guba and Lincoln (1997) explain that according to postmodernism, there is no “ultimate truth;” that all views of reality are constructed, and therefore encourage researchers to be “interpretively rigorous.” Additionally, Johnson (1997) states that low inference descriptors such as direct quotations from the participants enable the reader to experience the participant's descriptions on their own which maintains the researchers’ interpretations as authentic. Theoretical validity refers to the degree that the explanation fits with the data provided, making the conclusions credible and defensible.
Additionally, researchers look for cases that oppose or contradict their conclusions, in order to address the concern that data were selected only to support the researchers’ conclusions.

In this study, I was rigorous in seeking participants and learning about their experiences. I conducted a thorough literature review and considered many possible points of view. I maintained ethical relationships with participants throughout my interviews, listened intently, clarified often and showed interest and concern throughout the relationship. I constantly engaged in critical thinking and reflected upon my own beliefs, biases, and interpretations. Additionally, I constantly reflected on statements made by the participants. The process of memo-writing assisted me in making connections as I went. I actively sought out a variety of views that may even have opposed my conclusions in both the literature review and in conversations with participants. As well, I continued to speak about social justice issues of exclusion, marginalization and unfair treatment for individuals with exceptionalities.

**Summary**

In this chapter, I described the constructivist grounded theory framework I applied. I described the methods I utilized to gather data, code and categorize data. and finally, using the framework, I described how I constructed meaning around my topic. I wrote about some of the limitations of my study. Additionally, I explained how I ensured validity within my study. In chapter four I introduce the participants in my study and describe the findings that I constructed after analyzing the interview transcripts.
Chapter Four: Findings

In this chapter, I begin to relay the participants’ stories of their journey as a parent of a child with exceptionalities and explore the categories I constructed using the data. First, I will describe the participant profiles. Second, I will describe the categories that arose repeatedly during my conversations with participants.

Section I: Participant Profiles

There were seventeen participants involved in sixteen interviews, as one couple chose to be interviewed together. Another couple chose to be interviewed separately. This means there were fifteen families and a total of twenty-one children with exceptionalities involved in the study. At the time of the interviews, all families resided in Saskatchewan, except one family who resided in Alberta. Ten families lived in urban settings and five in rural settings. In order to help protect the confidentiality of participants, the size of their community of residence will not be specified.

The ages of the children in these families at the time of the interview ranged from six to nineteen, with one exception of a twenty-nine-year-old. The diagnosed exceptionality or differences of the children included autism spectrum disorder (10); Down syndrome (2); learning disabilities (2); cognitive disability (1); developmental delay or dyspraxia (2); fetal alcohol spectrum disorder (1); and cerebral palsy (1). Two of the children were undiagnosed at the time of the interviews. Additionally, three of the children were diagnosed comorbidly with attention deficit disorder, obsessive-compulsive disorder, a medical condition or a combination of diagnoses already listed.

All, but one of these families were two-parent households. There is one exception, in which the parents/guardians were divorced and lived in different cities. Also, all of the parents/guardians were employed either full or part-time, in or out of their
home, with the exception of one couple who were retired. Every parent had post-secondary education of some description. All these families had family and friendship supports. In addition to the children’s ages, family unit descriptions and diagnosis, I will relay some of their interests and characteristics as described by their parents/guardians.

All participants were self-referred. The participant profiles are written in the present tense, reflecting details as they were at the time of the interviews. In order to help protect the confidentiality of participants, pseudonyms have been used.

**Alice and Peter**

Peter is ten years old and lives in an urban setting. Alice is his mother. The family unit consists of Peter, his mother, father, and one sister. Peter is bright, energetic and inquisitive. He loves being read to. He attends French Immersion and has learned French easily. Peter plays piano and the entire family is very musical. He has also been involved in soccer, coding club, and a cross country team. Alice explained that she frequently sets up playdates for Peter and that he has many friendships. Peter is diagnosed with autism spectrum disorder, attention deficit disorder and a learning disability. Peter lived in another province previously, where he was diagnosed. Peter is in a regular classroom at his neighborhood school. Alice was interviewed at her place of work, after work hours.

**Ann and Andrew**

Andrew is nine years old and lives in an urban setting with his mother, Ann, as well as his father and his brother. Andrew is creative, has an excellent memory and enjoys Minecraft, coding, video games, playing outside, swimming, boating and water sports, puzzles, reading, and drawing. Andrew has many interests and goes through
phases when he is interested in different topics such as architecture. Andrew is diagnosed with autism spectrum disorder. At first, his diagnosis was considered low functioning, but due to teachings at home and at school his diagnosis is now considered high functioning autism. Andrew is in a regular classroom at his neighborhood school. Ann was interviewed in her home.

**Anna, Daniel, and Elyse**

Daniel and Elyse live with their mother, Anna, and their father and their baby brother in an urban setting. Daniel is nine and likes reading, parkour, swimming, soccer, water slides, amusement parks, YouTube videos about Minecraft and Roblox and playing with his younger brother. His mother describes him as sweet and docile usually, although he can be argumentative and rigid. He is very inquisitive, asking a lot of questions with a need to understand “why.” Elyse is six and likes art, swimming, playing with her dolls and her younger brother. Her mother describes her as quiet and shy for the most part but she can be stubborn. Elyse will often play on her own when she is at daycare or at home. The family goes on frequent outings, activities, and trips as Anna likes to keep them busy. Both children attend a French school in regular classrooms. Elyse and Daniel are both diagnosed with autism spectrum disorder. Anna was interviewed at the University of Regina.

**Annie and Miles**

Miles is fourteen years old and lives in an urban setting with his mother, Annie, as well as with his step-dad and his six siblings. Miles has an excellent memory, enjoys reading, and, as his mother describes him, is a “great defender of justice”. Miles is diagnosed with autism spectrum disorder. He attends a specialized program in a high
school in the city, where he is integrated into some regular classes. Prior to high school Miles attended his neighbourhood elementary school in regular classrooms. Miles exhibits stimming behaviours such as hand flapping, pacing and vocalizing when he is bored. Annie explained Miles’ description of having “two worlds:” the “real world” and his “autism world,” which he prefers, where he goes to imagine scenarios when he is bored. Annie explained that she believes Miles has developed greater flexibility due to his large family than he would have had if he had been part of a smaller family. I interviewed Annie in my home.

Dawn and Walter

Walter is sixteen years old and lives in a rural setting with his father and sister. Dawn is his mother who lives in an urban setting. Walter likes music, maps, bowling, and drama class. He enjoys going to the movies, as well as for drives and for walks, and he especially enjoys exploring new areas. He has a fascination with "forks in the road." He is an outgoing person who likes to talk, especially about his topic of interests. He loves helping people, especially when it involves his topic of interest. He has dreams of living on his own, having a job, and doing the things he loves to do in his free time. He would like to work in a place where he can help people find where they are going and help with places and directions. He loves spending time with his sister and his adult buddies. He attends a specialized congregated program at the local high school where he is integrated into some classes. Prior to high school, Walter attended his neighborhood elementary school in a regular classroom. He is diagnosed with autism spectrum disorder, with a comorbid diagnosis of obsessive-compulsive disorder. Currently, Walter has a difficult time relating to kids his age and prefers the company of adults. Walter has
a photographic memory and often “fixates” on specific topics of interest for him, such as
time zones, and verbally repeats lists of his knowledge of those topics, especially when
he is tired. I interviewed Dawn at the University of Regina.

**Dianne and Samantha**

Samantha is nineteen years old and lives with her mother, Dianne, as well as with
her father and her older brother in a rural setting. Samantha participates in volleyball,
drama, acting classes, singing lessons, dance, and track and field. She enjoys swimming,
bowling, dancing and preparing food. Dianne describes Samantha as being loving and
compassionate, with a quirky sense of humour. Samantha also loves movies, especially
Disney films, and dreams of going to Disney World someday. Samantha has graduated
from high school, but she attended elementary in regular classrooms and high school in a
specialized program, where she was integrated into some classes. Samantha is diagnosed
with Down syndrome. Dianne chose to correspond over email.

**Elsa, Sven, and Olaf**

Olaf is fifteen years old and lives in an urban area with her parents/guardians,
Elsa and Sven, and her older brother. Olaf attends a specialized program at a high school
in her city. Previously she attended elementary school in regular classrooms at her
neighborhood school, and then at a private elementary school. Olaf’s parents/guardians
describe her as happy, outgoing and funny. She likes cross-fit, writing and baking. She
currently competes in speed skating and kayaking, while she participated in extra-
curricular band in the past. Olaf is great with kids. She is diagnosed with developmental
delays, which affect her speech and language, as well as her fine and gross motor
coordination. She also has had health problems from the time of birth, including
difficulty with breathing, low energy, low immunity, and celiac disease. I interviewed Elsa and Sven in their home.

**Jocelyn, Todd, Jill, and Jane**

Jill and Jane live in an urban area with their parents/guardians Todd and Jocelyn. Jill is six and Jane is nine. Both girls are energetic, outgoing, friendly and imaginative. Jill loves Lego and has attended a Lego day camp. Jane loves sports and is involved in flag football and skating. They both attend their neighbourhood school in regular classrooms. Jill is diagnosed with autism spectrum disorder and attention deficit disorder. Jane is undiagnosed but has significant difficulty with math, reading, writing, and spelling. Jocelyn and Todd were interviewed separately. I interviewed Jocelyn at a public library and Todd at his place of work.

**Lora, Christena, Maurice, and Leo**

Christena, Maurice, and Leo live in a rural area, close to a larger centre with their mother, Lora, and their father. Christena and Leo are ten-year-old twins and Maurice is eleven. Christena likes being outdoors, wall-climbing, swimming, jumping on her trampoline, and walking on her treadmill. She is good natured and happy, despite all of her challenges. She is funny and affectionate and loves to be around people. Her mother says she will sneak cookies if they are not put away. Christena is diagnosed with autism spectrum disorder as well as with a severe cognitive delay and apraxia. She is considered non-verbal, although she does have a vocabulary of a few words.

Leo is very social, athletic, hard-working and kind. He makes friends easily. He is highly protective of his sister and already helps to care for her. He was previously
diagnosed with autism but no longer shows signs of it. Lora believes that this progress is due to successful ABA (Applied Behaviour Analysis) therapy.

Maurice is smart and funny. He is a voracious reader who can remember an amazing amount of facts and loves to share them. He is emotional, sensitive and compassionate. Maurice is diagnosed with autism and also has Still’s disease, a chronic auto-inflammatory disease, which can cause flare-ups of joint pain, fever, rashes, and other, potentially life-threatening, symptoms. Maurice and Leo attend a private school, whereas Christena is home-schooled. I conducted the interview with Lora over the phone.

**Lorraine, Tom, and Olly**

Tom is ten years old and his brother, Olly, is thirteen. The boys live in a rural setting with their mother, Lorraine, and their father. Both boys attend the local school and are in regular classrooms. Tom loves singing in the school choir while Olly is outgoing and likes public speaking. Tom is diagnosed with autism spectrum disorder, attention deficit disorder, and dyspraxia. Olly is undiagnosed but has significant difficulty with reading, writing, and spelling. Lorraine chose to correspond over email.

**Lynn and Paul**

Paul is sixteen and lives with his mother, Lynn, his older sister and his father in an urban setting. Paul generally relates better to younger children or adults but has begun to develop same-age friendships. Paul loves to write and play video games. He participates in the school band program, competes on a special Olympic speed swimming team, and was taking driver’s education courses at the time of the interview. Paul is diagnosed with autism spectrum disorder. He has the ability to “hyper-focus” or fixate on a task or topic
Paul attended his neighborhood elementary school in regular classes and now attends a specialized program in high school where he is integrated into some regular classes, including some advanced placement courses. At the time of diagnosis, Paul was considered to be on the low functioning end of the spectrum, whereas now, he falls on the high functioning end. I interviewed Lynn at the University of Regina.

**Misha and Jack**

Jack is six years old and lives in an urban centre with his step-mother, Misha, his father, and his baby sister. Jack is unofficially diagnosed with childhood apraxia of speech and he exhibits tendencies of attention deficit disorder, although he was considered too young to be diagnosed at the time of assessment. He attended a specialized, integrated program prior to starting Kindergarten. He now attends Grade One at his neighborhood school in a regular classroom. I interviewed Misha in her home.

**Nina and Amy**

Amy is a twenty-nine-year-old woman who lives in a group home in a rural area. Her mom, Nina, her father, and her three younger siblings live in their home in the same town. Nina describes Amy as fun-loving, with a “contagious giggle” and a wonderful sense of humour. Amy likes to hang out with friends, enjoy the outdoors, and having her nails and make-up done. Diagnosed with cerebral palsy, Amy is non-verbal and non-mobile. She requires a wheelchair and is completely dependent on others. She understands when others speak to her, but is only able to speak about twelve words, including “yes” and “no.” Amy attended her neighborhood elementary school in regular classrooms, followed by a specialized program for high school. Her family moved to
another province while Amy was in high school in order to ensure that she would get the best care they could find. I conducted the interview with Nina over the phone.

**Tina’s Mom and Tina**

Tina is a nineteen-year-old university student who lives in an urban setting with her parents. Tina is an inquisitive, determined, hard-working young woman. She attended French Immersion at her neighborhood elementary and high school. Tina was diagnosed with a learning disability in Grade Twelve. I conducted the interview with Tina’s mom at a restaurant.

**Lulu, Beno, and Soap**

Beno and Soap are sisters who are fifteen and thirteen years old respectively. They live in a rural area with their adoptive father and adoptive mother, Lulu. There are three other adopted children in the home and the parents/guardians take in foster children as well. In addition, Lulu and her husband have grown children who live outside the home, and who are part of Beno and Soap’s extended family. Soap takes piano lessons and enjoys art, photography, and cooking. She is diagnosed with fetal alcohol spectrum disorder. Beno participates in a religious-based girls’ group. She is diagnosed with Down syndrome. Both girls attend local schools in regular classrooms. I interviewed Lulu at the University of Regina.

**Terminology**

Using labels and terms to describe children and their situations can be problematic. There is debate about whether and how labels are useful (DeLuca, 2013). In this study, I am required to use words to describe experiences, findings, and concepts. I have chosen terms that I feel are most respectful and most useful in helping readers understand my messages. I want to note that the parents/guardians interviewed used a
variety of terms to describe their children’s situations, which may or may not be the terms I have chosen to use consistently in writing this study. These terms are the ever-changing everyday language used by parents/guardians and professionals at various times, in-vivo codes that are used to communicate information about individuals for a variety of purposes. I respected the terms used by parents/guardians. I did not ask them to use specific terms but instead listened for their messages.

I also asked each participant if they agreed to the use of the term exceptionality in this study to describe their child’s diagnosis. They all agreed to that term. However, one participant also expressed her preference for the term challenges when speaking about her child. I debated using that term as a result. Ultimately, I decided that the term exceptionality would work best to describe the various diagnoses of each child. The remainder of this chapter describes the categories I found in the data.

**Section II: Findings**

In this section, I will describe the categories constructed from interviews with the participants. These categories are inter-related and overlap. There are eight overarching categories that emerged during the interviews, as well as various sub-categories and dimensions. All are organized in the table below and are described in detail on the following pages.
Table 2: Categories Constructed from the Participant Data

<table>
<thead>
<tr>
<th>Category</th>
<th>Sub-Category</th>
<th>Dimensions</th>
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<tbody>
<tr>
<td>High Intensity Parenting</td>
<td>Coming to terms</td>
<td>Labelling</td>
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<td></td>
<td>Daily life</td>
<td>Routines and structures</td>
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<td>Behavioural challenges</td>
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<td>Parents/guardians supporting children at school</td>
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<td>Effects on work and finances</td>
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<td>Effects on health and relationships</td>
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<td>Easing the child’s world</td>
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<td>Effects on siblings</td>
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<td>Navigating systems</td>
<td>Marginalization and loneliness</td>
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<td>Societal Judgment</td>
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<td>Navigating agencies</td>
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<td>Navigating school systems</td>
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<td>Situation-specific contexts</td>
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<td>Inclusion</td>
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<td>congregated settings</td>
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<td>Inclusion is for everyone</td>
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<td>neighborhood schools</td>
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<td>Clumsy inclusion</td>
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<td>Accommodations</td>
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<td>Educational assistants</td>
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<td>Communicating between home and</td>
<td>More communication, more positivity</td>
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<td>school</td>
<td>Initiating communication</td>
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<td>Being heard</td>
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<td>Feeling like a “bad kid”</td>
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<td>Requests to deal with behaviour</td>
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<td>at school and communicate constructively</td>
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<td>“Holding it in” versus “easing their world”</td>
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<td>Meeting, reporting and engaging</td>
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<td>Partnership</td>
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<td>Socialization</td>
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<td>Strengths-based approach or being a believer</td>
<td>Realistic expectations</td>
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<td>Responsibilities and roles</td>
<td>Misconceptions</td>
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<td>Accolades and appreciation</td>
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High Intensity Parenting
Participants frequently spoke about their belief that there is another level of intensity when parenting children with exceptionalities. As Alice stated, “There is another layer of intensity that happens when you have a child that has, you know, autism and ADHD. And it’s not at all the same level of, like, what you need in terms of energy and patience and wisdom.” This category consists of two sub-categories: Coming to Terms and Daily life.

Coming to Terms.
Nearly all the parents/guardians spoke of the need to come to terms with their children’s exceptionalities. Dianne described her initial experience as such: “In the first few months of her life, there was a roller coaster of emotions: grief, sadness, confusion, excitement, frustration, etcetera. Along with feeling overwhelmed with all the information and things I needed to learn about.” Participants explained that they experienced the stages of grief upon initially learning their children had exceptionalities. Further, they explained that they worked through different stages of grief as they came to terms with the diagnosis, and as the children grew into each new age and stage. Alice explained, “You just need time as a parent, and as a child, to come to terms with the diagnoses. And you revisit that over time, like what that means. And it comes to mean different things as they get older.” Some participants told me that they experienced denial and had difficulty accepting that their children had exceptionalities. Dawn said, “we were in denial and took the approach that he must be misunderstood.” Misha also explained, “at that time my husband was not even coping with the diagnosis, let alone anything else…not every parent has accepted that their child has needs.”
Other participants explained that they knew there was something different about their children even when those children were still babies. Nina told me, “we knew right from the beginning that there was something wrong.” Sven explained that his daughter, at the time of her birth, “came out sick.” Also, Annie described her experience with her son, “with the two (siblings) born before Miles, they just did things differently…like their disposition, their pattern of sleep … he was able to focus on something and it kept him content. Most newborns are not that focused.” Participants also described coming to terms with labelling their child, as I have explained in further detail below.

**Labelling.**

Participants also described their need to come to terms with “labelling” their children and the ways in which labels can be seen as both a hindrance and a benefit. Lynn described how she came to terms with her son’s label this way: “Well, either they know he’s autistic, or they think he’s just the bad kid. He’s gonna be labeled either way.” Lorraine said, “It felt like such a relief to me to finally have a concrete answer … At the same time, it was very overwhelming with all the information and things I needed to learn about.” Participants also spoke of how they, and others around them, try to understand how and why the children’s exceptionalities came to be. Lynn said, “with autism, everyone wants to know how that happened.” And Anna stated, “I’m sure it’s genetics.” Participants spoke about the need for compassion and understanding for parents/guardians as they go through their unique, personal journey of acceptance, at each stage. Misha explained, “I think the understanding isn’t always there. And it’s important for teachers to understand what families are going through.” I describe the next sub-category, Daily Life, below.
Daily Life.

Participants also noted that the intensity of their daily parenting lives is different in many ways from that of parents/guardians with typically-developing children. They described long days, high emotions, and physical exhaustion. Lora said, “I mean, it’s all-consuming. Some parents can’t even go to the grocery store, right? And there’s no respite services.” Misha told me, “when you have a child with special needs at home, your day isn’t easy and every night is hard. I don’t ever get to just have a chill night.”

Daily Life consists of seven dimensions: (1) routines and structures; (2) behavioural Challenges; (3) parents/guardians supporting children at school; (4) effects on work and finances; (5) effects on health and relationships; (6) easing the child’s world and (7) effects on siblings.

Routines and structures.

Participants told me that they felt they needed to be more structured, following a set routine, than parents of typically-developing children. As Jocelyn explained, “We learned really quickly, scheduling is a must. We have to follow a schedule.” Anna told me, “there’s no break, there’s no respite. And the other thing is we have to keep our family crazy busy because it has to be structured at all times.”

Even seemingly simple tasks like going grocery shopping become more difficult with a child who has exceptionalities. Nina explained, “I did not have a wheelchair accessible vehicle….so can you imagine, in the winter, packing up three toddlers in their winter clothing and Amy in her wheelchair…driving a block to the grocery store, unloading everybody and the wheelchair, and then at the end of the shopping trip, loading everybody back up again.” As another example of a simple task that can be more
difficult when a family has a child with a exceptionality is mealtime. Jocelyn said, “you try to get her to the table for lunch or whatever, even a snack, and she would just fall to the ground into a full meltdown.” Ann explained, “Family didn’t always understand…[why] my child [is] running from the Christmas table as if the house is on fire.”

Jocelyn also explained that she must work harder with her children to maintain a sense of calm in the home and to ensure that her children learn age-appropriate life skills. Ann told me that she felt the need to push her son, to get him out of his comfort zone so that he would develop those life skills that children often develop naturally. She and other participants described situations in which they would “plan organized meltdowns” in public places to develop their children’s flexibility and coping skills, instead of avoiding all situations that caused their child to melt down. “I did push him and I guess what I should add is that it was emotionally exhausting because you’re giving so much of yourself every day.”

In addition, children with exceptionalities and their parents/guardians frequently have hours of daily exercises to do, such as speech and language practice or occupational therapy. Often, this work begins when a child is still a toddler. Ann told me that she spent thirty to forty hours a week doing speech and language homework, as well as working on social skills, with Andrew. Misha said, “at eighteen months we were working on vowel sounds…five minutes, five times a day. Then we progressed to consonant-vowels, and then consonant-vowel-consonants. And now we’re working on sounds within words.” Participants also told me they would spend time creating materials for their children to use at school to increase their chances of success. Ann
said, “I actually ended up making a lot of the visuals, and I made a lot of our task boards.” Ann also described the work she would do with her son over the summer. “I did a lot of work with him that summer again. We focused on him packing lunches and taught him to physically put a lunch in his backpack, how to throw away his garbage and put lids back on and put it away.”

**Behavioural challenges.**

Participants also explained that, due to the increased or different behavioural needs of their children, discipline could be challenging. It can also have different considerations than the discipline for children who are typically-abled. Sven explained, “one of the hardest things to do is when you have a child who is unwell it’s very hard to be strict and consistent. It’s heartbreaking. It’s hard enough when someone is well but when they are not well you just want to cave into everything.” Ann explained that “there were times when the easier thing to do would have been to give in.” Participants expressed the need to be consistent. Ann said, “It wasn’t always easy, but the thing is consistency. It’s the most important thing. We can’t be tired or have an off day if you want them to learn and make that connection.”

**Parents/guardians supporting children at school.**

Another topic that came up at times was parents/guardians coming to the school at recess, or staying after school when picking up their children, in order to observe their children at play or teach social skills. Ann, Jocelyn, Todd, Nina, and Lynn all described some of their experiences. Ann explained that when her husband picks Andrew up from school each day, sometimes he will stick around with some of the other parents/guardians to let their children play tag or other games together. They will watch for conflicts when
the children play and then intervene to teach skills such as, “no tag backs”, or “no endless
time outs”, or, “no tagging the same person repeatedly”. Ann and her husband have also
taught their son how to take deep breaths when he becomes angry and how to know when
it’s time to request the assistance of a supervisor.

Jocelyn explained that she will drive to the school at recess times to observe her
child from across the street. She explained to school staff that she will be doing this and
subsequently talked to school staff about some of the incidents she observed. She
explained two incidents where she noted Jill attempting, unsuccessfully, to initiate play
with other children. She realized that Jill was not understanding that the other children
did not want to play the game or the fantasy play that she was trying to engage them in.
Jill would continue to attempt to engage them and eventually the encounter would result
in conflict. Jocelyn used these observations to better understand how to help Jill learn
important social skills and to have a more positive experience on the playground. She
then shared that information with school staff so that they might do the same.

Nina noted that, since the family’s backyard looked onto the school playground,
she was able to watch Amy at play during school hours. Nina said that when Amy was in
kindergarten Nina was not used to having someone else care for Amy and was, “just so
worried about her.” Being able to observe Amy happily interacting with the other
children at recess helped her feel confident that Amy was being well cared for at school.

Lynn explained that she volunteered in Paul’s classroom in order to be involved
and observe what it was like for Paul there. Other parents, like Jocelyn, also explained
that they would like to come into the classroom at times to observe their children and
subsequently help school staff better understand their children’s needs.
Effects on work and finances.

Parents/guardians shared that taking their children to appointments frequently and the difficulty of finding appropriate childcare caused them to miss work; and, in some cases, even quit their jobs to care for their children full time. Lynn explained that she reduced her work hours. Jocelyn told me, “I’ve changed my whole life. I quit my job. I’m running a daycare…so my personal finances have dwindled.” Anna worried that frequently missing work might cause her to lose her job.

Participants also explained that frequent appointments, assessments, and activities placed a strain on their finances. Anna said, “We did pay consistently for social skills groups, I paid for speech, I paid for psychology, I paid for OT (Occupational Therapy). So I’m paying for most of these things out of my pocket. And it’s thousands.” Alice described a similar experience, “We sought out, we paid for our own private therapy. And we sought out all the diagnosis and organized all that. It was really on us. It was not through the school.”

Effects on health and relationships.

Parents/guardians also discussed how their own health and relationships were impacted by having children with exceptionalities. Lynn, for instance, said that the stress caused her to have “migraines every day, it was affecting my health so bad that, um, I couldn’t do anything.” Ann explained the effects of stress on her emotions and told me, “if you need to cry, cry in the shower for five minutes and move on, because that’s a productive time to do it.”

Sufficient sleep is also an issue. Parents/guardians explained that they were not able to get enough sleep, as their children were not sleeping well. Jocelyn explained that
her daughter would wake up with tantrums in the night and told me that, “as a parent, you’re still sleep deprived, right? And you’re just like, “This isn’t my life. This isn’t supposed to be my life.”

The stress, emotional toll, and lack of sleep can have an effect on personal relationships. For instance, Lynn explained her perspective on spousal relationships when the family has a child or children with exceptionalities:

These people are tired. Some of them will have two or three kids (with challenges). They don’t sleep. They can’t work. They’re financially and emotionally broken….a lot of divorces happen because of stress and disagreements on how to handle things. ‘Cause when do you have the time?

In addition to strained spousal relationships, participants explained that their other family relationships may be affected, they have fewer friendships, and they often feel isolated. Ann told me, “we didn’t have a ton of support. I actually lost friendships because I had to commit a lot of time to my son and some people didn’t understand….and family, family didn’t always understand.” Ann went on to explain that the sacrifices she and the other participants make are worth it for their children: “You do have to sacrifice a whole lot and you need to keep in mind that this is a short-term sacrifice for long-term gain.”

Ann also expressed the value of spending time and energy to ensure the very best for her child: “it’s a lot of work to get there but how do you put a price on your time? There is no price on time.”

**Easing the child’s world.**

Participants also spoke, directly and indirectly, about stressors on their children. It is important to note that often challenges for parents/guardians stem from their children
experiencing stress. When parents/guardians spoke of frequent “meltdowns,” for example, the meltdowns were stressful for the children. Alice explained, “He doesn’t do tantrums in public, he does that at home…it’s that sense of stress…a chance to finally release that stress…all kinds of stressors that build up.” Some participants spoke of how they had learned to comfort their children or found ways to accommodate their children. Alice went on to say, “So there were a lot of sensory things that, once we kind of understood them…we were able to kind of ease his world a little bit.” Annie explained that, “I really admire [Miles] because the world doesn’t adjust for him so that he has to adjust for the world. And he says sometimes it’s frustrating.”

**Effects on siblings.**

Participants also spoke about stress on the siblings of the children with exceptionalities. Parents/guardians explained that siblings often had to take on responsibilities in terms helping out with the children with exceptionalities, or that the siblings received less of the parents/guardians’ time and energy. Dawn and Lynn both spoke about how their daughters each took on responsibilities of caring for their siblings at school, in public and at family events: ensuring their comfort and safety, and standing up for them when a peer made fun of them or said something that was inappropriate or hurtful. Ann also explained that, to ensure that she actually did so, she scheduled time to spend with her typically-developed child. Annie described how Miles was positively affected by having numerous siblings, all of whom understood how to tease Miles while still remaining respectful of his unique needs, such as having his own space and not having certain possessions touched or moved. Lynn explained that she felt her typically-
developed daughter has a greater capacity for sympathy and a better understanding of diversity from growing up with a brother with autism.

**Navigating Systems**

Participants frequently spoke about a variety of issues relating to navigating social systems. Parents/guardians spoke about dealing with challenges such as judgment from family, friends, professionals, and strangers. They also discussed the marginalization, isolation, and loneliness experienced by their children and as a result, by the entire family.

Participants also spoke about challenges in navigating through agencies to acquire supports and services, as well as navigating through school systems in order to access the best possible education for their children. Participants often expressed their belief that these challenges are systemic. These topics directed my focus on eight subcategories: (1) marginalization and loneliness; (2) societal judgement; (3) navigating agencies; (4) navigating school systems; (5) advocacy; (6) sympathizing; (7) systems; and (8) situation-specific contexts.

**Marginalization and loneliness.**

Concerns about loneliness and isolation were raised numerous times. Dawn told me:

He’s never had a friend, like somebody that comes over and plays. He’s never had a birthday party with kids….He has asked how come his sister has all these friends and goes out with her friends and…gets to sleep over at friends’ houses.

Annie explained, “Miles never really had friends, like come over and play, he was a very solitary kid.” Lynn shared that, “Paul never had friends… he didn’t call friends, he didn’t invite friends over.” Dawn also explained, “Up until then (her child entering school) we
had lived a life of exclusion.” These were sometimes emotional moments, as the topic was difficult for parents/guardians to talk about. Marginalization and loneliness were also addressed in the literature review and will be addressed again in later sections.

**Societal judgment.**

Participants frequently explained that they experienced judgment from family, friends, professionals and complete strangers in public places. Participants often observed that this judgment likely came from a lack of understanding about their children’s challenges. Alice told me, “I remember Peter having a lot of tantrums in the grocery store or on walks, public places like that. And people just like constantly offering advice, or judging you, or like trailing you (laughs).” Later, she went on to say, “I feel like there is more judgment a lot of times from adults. And I think as a parent you get a lot of that from people you don’t know and from people you do know…. I have heard people talk about a parent or a child with autism and say, “Well you know where that comes from” or “why this behaviour is there.” And I just think, “you have no idea.”

Lulu described an incident in which she was at the grocery store with her child who has Down syndrome, and was approached by a complete stranger who told her: “You should know better than to have a kid at your age.” Lulu explained to the stranger that her child was adopted, but that regardless, this question was highly offensive to any parent and child. Lynn explained, “When we were in public people would be just awful…..so then I made a decision…I said, ‘I just have to forgive everybody before I even walk out the door.’” Ann also described situations in which she had lost friendships or there was conflict with family members as a result of judgment about her child’s exceptionalities. Ann explained her early fears regarding this judgment by saying that, “This world is cruel
and judgmental and other people might make it harder for him or misunderstand him because sometimes different means less to others.” Annie also told me, “We, like in the sense of everybody in society, we’re not educated enough…and we don’t want to educate ourselves…it’s easier to stay ignorant for people, so they’d rather be ignorant than have to educate themselves.”

Some participants told me that they felt their parenting was being judged or blamed for their children’s exceptionalities, even by professionals in community agencies. Anna used the word “condescending” when speaking about a bad experience she had.

**Navigating agencies.**

Frequently, participants reported challenges in navigating agencies in order to have their children assessed and diagnosed and then to receive the recommended services and treatments. Dianne explained:

I felt and still feel, that the biggest challenge is navigating a system I knew nothing about. Trying to keep all the information organized in my head and on paper, going to meetings and feeling very intimidated by a lot of educated professionals who greatly outnumber us, being heard and understood by all those professionals.

Annie expressed frustration in the diagnostic process. She told me that, “It was a long process ... they make it really hard for kids to get diagnosed.” Participants explained that there is not enough funding in our province for services that they require for their children. Lora told me, “We realized very quickly that we couldn’t get the treatment that
was recommended in any quality or at the diagnosed intensity. There’s no funding … so we actually started looking in the States for a provider.”

Participants expressed feeling confused and uncertain about exactly how to access services or which services to access. They felt there was a lack of direction and guidance for them. Elsa explained, “We were just sorting out how do we approach everything? Lots of discussion. ‘Wanna try this?’ ‘Okay, let’s do that’ … and it sure wasn’t guided by anybody.” Lynn, Todd, and Anna all mentioned that they wished that someone had given them a “map” to help them figure out the processes and next steps of their journey.

Navigating school systems.

Participants also spoke about a variety of challenges once their children entered the school system. Some of these issues will be dealt with in upcoming sections. However, there were some topics that stood out as being related specifically to navigating school systems, and thus will be addressed in this section. Many of the participants expressed feeling that schools were too traditional and had not kept up with the changing times. Annie told me:

Okay, so I think the whole education system, with the classrooms, I think that’s all screwed up anyway. Like, one teacher with thirty-two students is crazy … and I think we’re still stuck on like, everybody sits in your desk … if you were to put some round tables in there, and … lower your numbers … let children learn from other children … like, a science experiment, instead of learning everything from a book … they’re not learning anything anyway, because most of the time they’re bored.
Another challenge in navigating school systems that was noted by parents/guardian is in regards to technology. Tina’s mom and Dawn both explained frustration over the reluctance of many school professionals in regards to allowing use of technology as an accommodation or as general learning tool.

Participants also explained that they felt the need to advocate strongly, or “fight,” for services within school systems. Dawn stated that, “It was fight mode for the first couple years. We were always defending and trying to educate the educators.” Lynn shared a story of a time when she went to meet with school division professionals to advocate for Paul:

And I think one of the people on the panel said, “You’re such a good mom.” And I said, “I am. I love this child. But I’m not a good teacher, and I’m not a good psychologist, and I’m not a good speech therapist…I have no idea how to deliver that to my child…it’s sitting here all in this room and I still don’t have access to you.” … And I said, “I need your help. I need you.”

Another challenge that parents/guardians discussed was the lack of knowledge among school personnel about the challenges facing their children as well as a lack of knowledge regarding the strategies and approaches that would be most beneficial. Alice explained, “I think a lot of parents/guardians would assume that teachers would know the strategies for working with a child with ADHD, and like, in actual fact, hardly anybody knew.” Annie told me:

Well, I had to explain it to [the school staff]. … The thing is, I don’t think that they educate teachers enough on autism. I think that they, the school, the school board, the education system, they lack the understanding of how important it is to
educate teachers [about children] on the spectrum, … And it upsets me because it means you’re being ignorant because it’s out there.

Lulu also felt that there was not enough training for educational assistants. She told me that, “The lack of education that some of the EAs have…if you’re actually going to have someone in there that is going to be like a second teacher for that child, there needs to be some education.”

Participants understood that the schools are overwhelmed and that financial constraints and budget cuts affected schools and their ability to provide services for their children. Lora explained it as: “like teachers are stretched beyond belief…And without someone in a position to make some changes and increase funding, it’s never going to change. … It’s a system that’s designed to fail.” And Lulu told me, “So you can keep cutting back but …well that’s your future…I mean, we might have bigger problems down the line.”

**Advocacy.**

Often, participants felt that they needed to advocate strongly for the community services their children required. They frequently used the words “fight”, “battle”, and “barriers.” Elsa explained, “We even had to fight and battle every step of the way. … [I]t can be a nightmare…. But it’s all about advocating. Boy, do you learn to be an advocate.” Lynn explained that she is, “still fightin’, still trying to advocate.” To that end, over the years she has written letters to her member of legislative assembly and has had meetings with individuals at the ministry of health. Tina’s mom noted that, “We have actually hired someone to help us navigate this (technological tools for University accommodations).” Lora stated that at times she felt that she was treated in a
“confrontational” manner. Nearly all participants expressed frustration with time and effort it took to have their children diagnosed and to continue to get the services they require to progress and function.

Parents/guardians also expressed frustration that, even when they do advocate, often services simply are not available. The system is overloaded and there are not enough qualified individuals to provide the services required. As well, there is a great amount of turnover and movement of individuals providing services. And finally, the services continue to be cut further. Lora, Lynn, Anna, and Ann all told me of their concerns regarding turnover of staff in various agencies. They also expressed concerns over long wait times. Anna told me:

There’s the frustration of trying to access services and appointments, get diagnosed and wait…the wait time…they seem overwhelmed with the amount of clients they have. And just the money and time, and the frustrations and the little things that add up.

Lynn explained, “I was on a two- to ten-year wait list for services...This makes no sense. Like you could go to a doctor, get a diagnosis (if you are sick) you get help, you get medicine….But something else is wrong here. There’s a disconnect.” Lynn went on to say:

There’s a lot of cutbacks and stuff; there’s a lot of programs that are not running anymore. And I think it’s an absolute shame…because there’s nowhere else for them to go. And I don’t know if people realize that...these children have a right to adequate health care. This is not a choice the government gets to make. This is a right, a constitutional right.
Misha expressed similar sentiments about this being a “human right’s issue.”

Lora, Todd, Ann, and Dawn all explained that they felt like some of the challenges are caused because agencies do not work together, but rather “in silos” as Dawn described it. They also explained that they had had difficulty in transitioning from one agency or ministry to another as their children aged and grew.

Lulu expressed that she felt teachers benefited from professional development such as conferences. She explained her experience with a teacher who worked with her daughter: “that learning resource teacher went to a conference on down syndrome … and she said she probably learned a lot more than she would have just reading it in a textbook”.

Frequently, participants used phrases such as “fight mode”, or “we really had to fight that year”, or “that was a real battle” when referring to advocacy within the school system as well. Ann described a situation in which she felt she was verbally attacked at a school meeting, when the principal yelled at her. However, she remained calm and continued to advocate for her child. Ann told me, “It was hard for me [that year] because there was a lot of resistance, and it seemed unnecessarily so.” The feeling of needing to “fight” was particularly strong, according to parents/guardians, when first coming into a school. Participants also expressed their sympathy for other families in similar circumstances, as I describe in the following section.

**Sympathizing.**

In our conversations, parents/guardians frequently spoke of what it must be like for others who may not have the resources they possess, such as finances, family and friend supports, education, privilege, and so on. They had great sympathy for others and
theorized that if things were difficult in their situation, it would be even harder without
the resources and supports they had. Sven said, “If Elsa didn’t know what she knows
[because of her line of work], if it was just two people like myself, it would have been
even worse. I mean ‘cause how do you even know what’s available?” Anna noted that,
“I think if I didn’t know what to do [given her education and line of work] how does a
random parent know what to do?”

**Systems.**

Lynn told me that, “…it’s just sad because the system has always been broken.
It’s been scattered, very difficult to navigate.” Lora explained, “…it’s nothing but
barriers…and I’m pretty savvy now, but these poor new parents … they’re trying to help
their kids, but the system is broken. We’re really not getting anywhere. It’s a systemic
problem.” Dawn, speaking both as a parent/guardian of a child with autism and as an
employee of an agency that focuses on people with autism, said that, “Now, in my work
in the field, I understand how the ministries work. They work in silos, really. Like, you
go from one ministry to the other. [One agency] looks after services until they’re school
age, and then education picks that up. And then adulthood is, well, “That’s it, we’re
done” (mimics dusting her hands off).

Participants expressed frustration with recent budget cuts to agency and school
programs that provide services to children with exceptionalities. Lynn stated, “…there’s
a lot of cutbacks and stuff, there’s a lot of programs that are not running anymore. And I
think it’s an absolute shame. It’s just really awful.” Misha echoed that statement:

Unfortunately, those classrooms are now cut, the program is cut. I actually cried a
lot of tears over that program when it ended, because I just can’t even imagine
that these children won’t have the same opportunity as Jack. Because of that
decision, really and truly, those children may never speak as typical adults.

Some of the concerns expressed by participants were due to situation-specific contexts, as
I explain in the next section.

**Situation-specific contexts.**

Some concerns were specific to certain participants’ contexts. Female participants explained that they found they had more success getting services when their husbands became involved. Jocelyn explained, “I pulled my husband into the appointment with our physician…and finally, the ball got rolling…” Nina also shared some stories of not feeling like she was being heard by her doctor when she felt something was not right at the end of her pregnancy. And Dianne shared her experiences of receiving difficult news about her daughter’s diagnosis, immediately following the birth, without her husband present.

Participants living in rural areas felt that they had greater challenges getting services than those living in urban settings. Dawn explained, “…there was nobody in our city that could diagnose him, ‘cause that’s what happens when you live in rural Saskatchewan.” Dianne, Lorraine, Nina, and Lulu all expressed frustration with lack of services in rural areas and hardships of having to come to the city for services.

Participants with children who were non-verbal and immobile expressed concerns for potential abuses in adult group homes and other settings. Nina shared a story about Amy receiving an injury during a fall, which was not reported. Lora also shared worries about her daughter’s vulnerability.
Jocelyn, Todd, and Anna expressed a lack understanding about diagnosis and services for girls who have attention deficit disorder or are on the autism spectrum. Jocelyn told me that, “There aren’t many professionals…who understand girls on the spectrum….So it’s a constant fight for people to see and understand girls on the spectrum.”

The situation-specific concerns described in this section could be researched further. As an educator I have become more aware of these concerns because of this research.

**Inclusion**

As described in the introductory section, The Saskatchewan Ministry of Education (2017) defines inclusion as, “an attitude, a belief and an approach that supports a commitment to welcome, accept, value and educate every individual as a contributing member of the school community”. Inclusion consisted of eight subcategories: (1) benefits of inclusion versus congregate settings; (2) inclusion is for everyone; (3) congregate settings are detrimental; (4) neighborhood schools; (5) Clumsy Inclusion; (6) Accommodations; (7) designed for some, of benefit to all; and (8) educational assistants.

**Benefits of inclusion versus congregate settings.**

All but one of the participants in this study strongly support inclusion. They spoke of their experiences and the reasons why they feel that inclusive environments were critical for their children’s overall development. Ann passionately explained, “I think it would have been catastrophic if he hadn’t been [included in the regular classroom]. Catastrophic! He would not be anywhere near where he is today. Catastrophic! As in, I would be caring for my son until I die.” Ann went on to say, “Integration, I think, is the most crucial thing that you can offer any child who has a
disability. Every child deserves to be integrated in whatever capacity they have.” Lynn had very similar beliefs about her son’s development. “I think if he would have been put in a program in elementary school, it would have stopped everything.”

The parents/guardians claimed that the most important reason for including their children is social development due to socialization with their peers. Ann explained:

If modeling peer behaviour was one of the key components and he was with all special needs children all day or most of his day, um, where would he have the opportunity to learn those skills with his peers? Because I am not his peer. I’m his mom. I am not the same age as him. And you can only provide so many opportunities to do that.

Lynn also described similar reasons for wanting her son, Paul, in a mainstream classroom:

Putting Paul in the mainstream really wasn’t about academics…it was about teaching him to function with people, how to move from thing to thing, how to get your mind to work that way … Everybody else’s kids are there to practice their ABCs and 123s and mine’s there to practice how to function and get desensitized.

Lynn explained that for Paul, academic progress came later, when Paul made great gains academically in Grade Six and onward. Dawn also discussed a similar experience with Walter.

Nina’s daughter, Amy was also in a mainstream classroom throughout her elementary school years, despite being non-verbal and non-mobile. Nina described Amy’s experience as, “some of the best elementary schooling, for a person in her
situation that she could ever have possibly received … I think she really felt she was just kind of one of the group. And that was a good thing.” Nina described Amy’s experience further:

She was integrated into a regular kindergarten classroom and that was wonderful for her. Just the social dynamic. So one of the students, even in kindergarten, you know, five-year-olds, would wheel her down with the attendance. And so, every day somebody else was her helper…So those kinds of things, I think are really how they got everyone to get to know Amy…and it almost became like a treat…so she became someone everybody wanted to be around. Oh, it just melted my heart.

**Inclusion is for everyone.**

Through their experiences, these parents/guardians observed that inclusion also benefits the typically-developed students in the room, in the school, and in society as a whole. As Dawn stated, “Inclusion is for everybody.” Dawn went further to say:

I think it’s important that we treat people with disability like everyone else ... We have expectations of them, accommodate for them and learn more about each other too. That learning about each other and realizing that there’s not just one way of doing something is good for everybody … I think the benefit of inclusive classrooms is hopefully the foreshadowing of an inclusive world.

Ann shared similar thoughts on the benefits of inclusion for everyone, stating that, “Their peers have also learned to become more compassionate, more flexible, more understanding. It brings out the best in everybody when you have integration.” Lorraine agreed when she said, “…this is his model for the greater world and how he will
ultimately figure out how to get by and for others to learn to be inclusive.” Dianne stated her belief that, “How kids are treated in school carries over to life outside of school. If the teacher doesn’t accept and include all students, then the students will do the same. Inclusion benefits ALL students.” Further, Lulu said:

A kid with a disability provides a lot to a classroom ... I think kids need to see that there are other children in the world, I think it’s a big thing to be able to sit in a classroom and accept that somebody else...that people are different, they’re gonna learn differently. You don’t have to laugh at them because they don’t get something or their education has to be different. But they contribute something to the classroom.

Many of the participants had similar comments about the critical importance of inclusiveness. Only one parent/guardian had concerns about inclusive schooling. Lora stated that her daughter, Christena, should not be in a regular classroom because she felt it was unsafe for her. Instead, Lora homeschools Christena.

**Negative effects of congregated settings.**

Tangential to their notes about inclusion, parents/guardians stated that having their children in a congregated setting can actually be detrimental for the children. Anna explained:

If I take him to someplace with lots of kids with needs, he starts to mirror behaviour and then we have way more problems with him. So, it’s better for me sometimes, to not put him in those situations, and just keep him in a neurotypical environment.
Dawn also felt that congregated settings had negative aspects: “When you have a bunch of autistic kids together, it’s great because they’re kind of speaking the same language and they get each other. But nobody knows how to behave in a social situation. So that awkward stuff continues, right?” Nina also explained Amy’s unique experience of starting out early in life in a fully integrated school setting, then moving to a semi-segregated program for high school, and then into a group home in adulthood:

I don’t really have a tactful way of saying this…but Amy is uncomfortable around people with special needs ... We’re so thankful we’re so lucky that we can communicate with her and she’s got an amazing sense of humour. You know, she’s just full of life. And her two roommates (in the group home) … they don’t understand, you can’t speak with them the same way. That’s hard for Amy because she wants to interact. I think you know back to her formative years…she became so social with everybody…So now it’s hard for her to be around people with special needs that interact with her maybe in a way that she doesn’t want them to. I mean she likes her own personal space. She doesn’t like her wheelchair being touched unless it’s simply to get her somewhere ... And sometimes people with special needs don’t necessarily understand physical boundaries. So, if someone comes up to her and wants to hug her or touch her head or something, she gets upset. Because it’s not [typical] social behaviour. Additionally, Ann explained her belief that it is morally wrong to label and limit a child at a young age:

You cannot decide for the rest of a child’s life at age five … and I think it is unfair and irresponsible of any educator to make that decision [for a congregated
program placement] … to deprive him of a high school diploma one day because [his education] looks different.

**Neighbourhood schools.**

Connected to their thoughts about inclusion and congregated settings, some parents/guardians told me that it was important for their children to attend the neighborhood school if at all possible. Annie explained that there were different benefits to having her son Miles attend the local high school. For example, he would be able to walk there, and he would also have friends that live nearby and that he could socialize with after school. She revealed that when Miles found out he had to attend a program at a school in a different area of the city he was “very distraught…he had his heart set on going to the local high school.”

**Clumsy inclusion.**

In my conversations with participants regarding inclusion, I noticed an interesting common sentiment. Many of the participants spoke about the difference between integration and inclusion. They had observed that even when children were simply integrated, and not included particularly well, the most important benefits of inclusion were still noticeable, and their children showed progress regardless. I began to think of this as “clumsy inclusion”. Ann explained clumsy inclusion well when she said:

Set the bar high. Push him. Because he will grow. And the teachers who have done that … actually, even the teachers who didn’t do that, he still grew … Even if it wasn’t 100%, [his teachers] still showed up and everyone has contributed to his growth. Whether it was something they did or something they didn’t do, it still contributed to his growth.
Clumsy inclusion is not to be confused with “dangerous inclusion,” in which a child might be at a higher risk of injury or potential discrimination or abuse. Also, authentic inclusion is certainly an ideal that educators should aspire to. However, we might consider that when we are learning anything new, we usually go through a period of time when we are not very skilled at it, but are clumsy, before we get to a stage where we begin to excel.

**Accommodations.**

All participants felt that there is a general lack of understanding and knowledge among school-based professionals regarding the cognitive learning needs of their children specifically and of children with exceptionalities in general. Alice told me,

Sometimes those pieces could be a little bit better…like we’re talking about executive functioning skills like he just doesn’t have them. There’s nothing you can do about that … So, if you would not expect a grade one to do that, then it’s not really fair to (expect that of) him. And then he’s in trouble.

All participants expressed that they felt there was a general need for an increase and improvement in the quantity and quality of accommodations being made for their children. They felt that often their children’s teachers did not have a full understanding of why their children required a certain accommodation, or that the accommodation was unnecessary. Lulu stated:

I find some teachers are a lot better at adapting things, so they’re included in the classroom…it’s that whole thought of it – being able to do things like other people and you don’t necessarily have to be at the same level as them.
Jocelyn explained that it was important, “Just (for teachers) to understand how to simply accommodate, and how to get the right approach when something is going wrong.” Lorraine stated, “I appreciate teachers who make attempts to understand diversity and adapt how they approach different learning needs, who see the individual needs and don’t just focus on managing problems.” Elsa and Sven described what school is like for their daughter, Olaf: “You just sit and suffer … They’re supposed to (adapt). But they don’t. So we spend hours and hours sometimes doing (home)work. But there are no adaptations made.” Ann described a situation in which a teacher would use trampoline time, which was recommended as a self-regulation accommodation, as a reward. Ann explained, “the trampoline is like oxygen to him ... He needs it to regulate himself. And if he’s having a bad day, if you give him the trampoline, he’ll actually work more effectively for you.”

Jocelyn and Todd spoke about the lack of understanding that they have experienced for Jill’s attention deficit disorder. They stated that Jane was often punished for not paying attention or not understanding social cues, even though those are both characteristics of her exceptionalities. Alice described similar frustrations regarding her perception of the lack of understanding about attention deficit disorder in schools. Lulu described her belief that school staff do not fully understand fetal alcohol syndrome or Down syndrome and, as a result, had expectations of both girls that were unrealistic.

Tina and her mom described various times in her education in which her teachers did not realize that Tina had a learning disability and needed accommodations for spelling, reading, and writing. They knew that technology could be a great
accommodation for Tina. Tina’s mom expressed her frustration at the lack of adaptations her daughter received:

Personally, as a parent, I’m very disappointed in the K to twelve school system because I believe that that’s part of moving a student ahead. It’s not purely the education and academics. It’s how to make them an individual who can function in society. And, I must say that I’ve had to pick up a lot of that personally and financially. And thank goodness, she has such a strong desire to learn that she will figure all these things out on her own. But it’s been a tremendous struggle.

Parents/guardians also frequently gave examples of adaptations that were being made in extracurricular or community activities so that their children could participate. For example, Lynn spoke about Paul’s involvement in speed swimming, explaining that his coaches worked very well with Paul and never hesitated to include him. Dianne also spoke about Samantha’s involvement in the school volleyball team and a community drama program, saying that the coach and the instructor, respectively, were able to involve Samantha and let her individual talents shine. Elsa explained that Olaf spent time with trainers at a local fitness centre instead of doing physiotherapy or occupational therapy exercises. Her trainers were able to adapt and tailor her training for her while making it fun and interesting. These examples provide some insight into improving the quality of accommodations in school settings, which I will discuss in later sections.

Tina and Tina’s mom also provided some insight through their experiences of accommodations at the university level. They described the difficult process of receiving documentation from a psychologist for Tina to receive specific accommodations and having these passed through the proper channels at the University. However, they have
encountered ongoing challenges in which Tina has had to advocate to receive these recommended accommodations. Tina has also encountered a lack of understanding with her peers, who have made comments such as, “well I could get grades just as good as you if I had accommodations too.” Tina’s experiences at university demonstrates a lack of acceptance and understanding in the general population.

**Designed for some, of benefit to all.**

Participants also shared their observations that many of the accommodations and strategies that are helpful for their children are beneficial for all children. Annie explained this well when she said, “An autistic kid is different because of the way they think…but we’re all different in the way we think … So like anything that I could suggest for Miles, is really anything that I could suggest for any child.”

All of the participants shared examples of strategies and approaches that were beneficial for their children’s learning and development that were beneficial for all children, regardless of ability. Annie spoke of using visuals in order to assist with daily routines and completing tasks, as well as allowing children to move around the room, to have group discussions and participate in interest-based-learning. Todd and Tina’s mom mentioned using kinesthetic, active strategies such as pacing, connecting gestures to new learning, or making up a song to remember concepts. Ann spoke about movement and exercise breaks, such as jumping on a trampoline. Lorraine spoke about a calm approach to dealing conflict and providing a safe space for children when they are overwhelmed. All of these are excellent examples of strategies and approaches that work for children with exceptionalities and are also beneficial strategies and approaches for people of all ages.
Educational assistants.

Participants also frequently spoke about their experiences with educational assistants who worked with their children. All participants felt that educational assistants can be a critical piece of their children’s inclusive education if they are utilizing beneficial approaches and have training. Because of that critical role, many parents/guardians spoke of their disappointment in cuts to funding for educational assistants over the years.

Communication between Home and School

A topic that came up with every participant, sometimes multiple times, was communication between home and school. Communication consisted of eight sub-categories which I address on the following pages: (1) more communication, more positivity; (2) initiating communication; (3) being heard; (4) feeling like a “bad kid;” (5) dealing with behaviour at school and communicating constructively; (6) holding it in versus “easing their world;” (7) meeting, reporting and engaging, and (8) partnership.

More communication, more positivity.

Parents/guardians repeatedly stressed the importance of communication. They stated that they needed more frequent communication and more positive communication, in addition to an increase in transparency and openness and more input into their children’s education. Misha told me, “Communication with parents and caregivers is the most important thing that you can do for a child. Communication with parents is everything, and if it can’t be positive communication then how can there be any type of positive change?” Alice explained, “I sat at parent seminars…and basically, everybody in the room was completely frustrated with the schools…and they felt like the only time they heard from the school was when there was a problem, and that they heard about the
problem day after day.” Lorraine told me that what she needed from the school was, “as much communication as possible…to know that they are paying attention and trying to understand him.” Elsa stated, “We felt out of the loop…and we hear that from a lot of parents … If communication was better it would work in both favours…and I think assumptions are made sometimes.” One issue with communication that parents/guardians noted was inconsistency among school-based professionals and across schools. Dawn observed that: “Our communication with the school was better some years than others, and a lot of it would have to do with who the classroom teacher was.”

Some parents/guardians relayed their thoughts about the impact of negative communication from the school. Misha told me about an experience where she was receiving negative daily communication in a notebook that came home each day. The notebook was intended for the parents and also for the child. Misha explained that it was “very challenging” because Jack would have daily tantrums at home since he was so upset by the communication book.

However, some of the observations that parents/guardians shared focussed on the positive aspects of communication from the school. Ann shared that she had observed a direct connection between daily communication and her son’s progress: “He’s had the highest success rates when we have daily communication.” Nina also relayed positive experiences. She said that some teachers, “really reached out to me on a regular basis and said. ‘Hey, we’re thinking about this. What do you think?’ And it was obvious they were putting in the extra effort and they were thinking about it and reaching out to me and bouncing ideas off me.” Elsa also shared a positive experience: “She [a previous
principal] was the one who communicated with us. And it was always positive. ‘Look what she did today!’ And that’s amazing. Like you just don’t see that from people.”

**Initiating communication.**

Parents/guardians frequently expressed that they felt they had to be the ones to initiate communication. Todd explained that they have yearly meetings with the school, “but that’s only been because we’ve asked for it…the access to those meetings seems fairly difficult.” Alice also noted that she was the one who had to initiate meetings and conversations about Peter’s progress:

I find in most cases I was the first one to notice that there’s a problem. Like I was the first one to say, ‘Oh, you know what? I don’t think he’s quite understanding this math concept.’ …We’ve never had a time where we went to the school…that they took the lead.

**Being heard.**

Participants frequently expressed that they did not feel like what they had to say was being taken seriously, that they were being heard by the school. Misha told me: “That was hard because we didn’t feel heard, we didn’t feel like there was going to be a solution.” Alice explained that she wished educators would more often, “actually [take] a moment to listen to the concern and like just maybe [think], ‘Is there something more at the bottom of this?’” Jocelyn noted that she often felt she was dismissed as the “crazy parent” and like she was given an “eye roll.” It was very clear in the interviews that these parents/guardians felt like they were not being heard often enough.

**Feeling like a “bad kid.”**
Many of the parents/guardians brought up concerns about their children frequently getting into trouble for their behaviour and subsequently always feeling like a “bad kid.” Alice explained:

I think his [Peter’s] life is, and a lot of parents I’ve talked to, their lives are their kids getting into trouble. Their kids get into trouble every day, multiple times a day ... we didn’t want him to develop the idea for himself that he is not bright, that he’s lazy, that he’s a bad kid.

Additionally, Dawn told me about Walter’s experience at the age of three, where he was ‘kicked out’ of preschool on the first day due to his behaviour. She explained that after that experience she went to a meeting to get him into a pre-kindergarten program at the local school and asked what would get him kicked out there. She remembered being extremely relieved, and even crying, when the school-based professionals she spoke to told her that would not happen in their program, but they would work with him to improve his behaviour.

**Dealing with behaviour at school and communicating constructively.**

Participants often had very strong beliefs about how behaviour should be dealt with in schools. The messages about their children’s behaviour and communication from the schools were very much intertwined, and at times I found those messages contradictory. Initially, I was hearing that parents/guardians wanted a lot of communication, but they didn’t want to hear everything their children did. However, soon enough I realized that the points the parents/guardians made were extremely consistent and made sense. Participants repeatedly explained that they wanted the school to be able to deal with their children’s behaviours on their own, in a positive manner.
Parents/guardians wanted the school to assist the children to progress in their abilities to get along with others and follow rules. Further, participants wanted school staff to communicate with them about their children’s behaviour in a positive and timely manner. Participants didn’t want to hear “every little thing” their children did all day long. They wanted the highlights and the useful pieces of information and they wanted to be contacted during the school day only when absolutely necessary. Participants wanted long term and solution-focused thinking. They wanted partnerships—a “what are we going to do about this?” approach—instead of a “what are you going to do about this?” approach. They wanted school staff to be able to deal with their children’s behaviours and begin to teach them social skills and academics.

Lulu discussed the experience of her daughter being suspended. Lulu stated that suspension is an inappropriate and futile way to deal with behaviour in children with exceptionalities. She explained that her daughter often did not understand what she had done wrong and needed immediate feedback in order to learn from her mistakes. Participants had strong beliefs and valid reasoning about how their children’s behaviour should be dealt with at school.

“Holding it in” versus “easing their world.”

There were also many discussions about the children having to “hold it in” at school and subsequently releasing all their emotions when they got home. Alice stated, “I think he holds it in a lot in his day and so when he gets home to me…(her facial expression showed that it was not easy when he got home).” Todd also explained, “I really get the sense where she struggles to keep it together, keep calm and happy at school, and then when she gets home she just needs downtime.”
Often participants told me that they wished that their children felt safer at school or had a strategy to release the stress they experience there in some way, or even that they wished that the school staff could see the tantrums their children have at home, so the staff might better understand their children. Anna told me, “He’s just having such a hard time holding it together at school, that he’s melting down as soon as I pick him up.” Anna continued, “I still get the behaviour at home, but I think maybe if they were giving a heavy work break or something at school, we might not have this pent-up anger at home.” And Jocelyn explained:

I wish they would see my child on her worst day. But on the flip side, parents are saying, “I know my kid is doing a good job at school, but come home, they are just in full-blown melt-down. [At school] they are just suppressing, suppressing, suppressing and blowing up in the safe zone, at home. Where’s the carry-over?

Dawn insightfully noted:

It wouldn’t surprise me to see the growth in the achievement of his goals in correlation with classroom teachers who were compassionate, to say the least, and maybe just had a better way of understanding the communication barriers better. So they were adapting themselves to him rather than expecting him to adapt to them, right?

The concept of easing the child’s world became critical to me, as an educator through these conversations.

Meetings, reporting and engaging.

Participants also discussed their views about Inclusion and Intervention Plans (IIPs). An IIP is a document required in schools for children with exceptionalities, who
require school and outside agency supports. Parents/guardians frequently expressed that they did not feel like their input was valued at IIP meetings and also that there was a lack of follow through in the plans that were created at these meetings. Sven and Elsa told me:

We don’t feel like we ever get anywhere [in IIP meetings]. We sort of talk about things but nothing ever comes of it. We were told her goals a lot. And the goals that were set were awful, we didn’t agree with them. But it didn’t matter. There were a lot of people around the table. We just kind of let things happen after a while.

When asked how they would have liked to be involved in these meetings, Elsa’s response was, “way ahead of time. More consistently. Not so many people around the table. I think the questions need to be different and more functional for families.” Sven added that he would like to see more realistic goals set and better follow through for those goals. Dianne expressed similar sentiments.

Parents/guardians frequently described feeling intimidated at meetings or feeling like they had to be extremely careful not to offend school personnel. Todd explained, “I find it fairly exhausting to taper the message you want ... I don’t want to go into a meeting telling the principal who has been in education for thirty years or the teacher who’s been doing this for ten years… ‘this is how you do it.’ Alice, Dianne, Misha, and Lynn also expressed similar concerns about needing to be careful about when and how they approached school staff. Lulu said that she has become very determined about speaking up and advocating for her child when it is required: “If I don’t agree or I don’t like it, I guess I’m one to be there to say, ‘Okay, I don’t agree and I don’t like it.’” All of
these parents/guardians have become quite skilled at advocating for their children, as discussed in other sections of this study. However, they still expressed this as a concern.

In addition, participants noted that the information provided in report cards was usually not very beneficial for them. Their perception was that it gave them very little information about what their children could actually do. Also, they felt that their children were often at school to learn social skills and for other reasons, aside from academics. As a result, the report card, with its focus on academic work, was really not relevant or helpful. Assessment and reporting for students with exceptionalities vary for each school division and for each school.

**Partnership.**

During interviews, I usually asked whether participants felt like they are a “partner” in their children’s education. While all of the participants expressed that they did feel like a partner, there were some hesitations. Ann explained, “I do feel like we have been considered a partner. But I think it’s partly because we’ve demonstrated that we’re willing to work really, really hard to help him be successful… I think we’ve had to show up and show that consistently. And I do feel like we have had to pave the road a little bit to get there, prove ourselves.” Many of the participants echoed this sentiment about needing to work hard in order to be seen as a valued partner in their children’s education. It seems to me that their sense of being a partner came, in part, from their decision to be an active partner and their determination to do so.

As described in the sections on navigating systems, many of the participants expressed that they had a great deal of sympathy for other parents/guardians who may not have the same resources they did. They discussed how very difficult advocating for
children with exceptionalities must be when resources are lacking. And, further, they noted that perhaps that lack of resources resulted in an inability to do the work that is required to feel like a valued partner in their children’s education. The topics that came up regarding communication between school and home were complex and thought-provoking for me.

Socialization

All of the participants believed that socialization of all students is a responsibility of the school system. Dawn spoke of the school as “foreshadowing” our future world and “a reflection of society”. Lynn stated, “School is where children spend the majority of their time. This is the perfect place for kids to learn how to socialize.” I referred to socialization in the section on inclusion, where I explained that, for many of the parents/guardians, socialization was the primary reason for their children to attend school, with academics coming second or later. In the inclusion section, I also referred to participants valuing diversity and the idea that inclusion is for everyone so that, as a society, we may become more inclusive as a whole. Participants viewed diversity education as a vital responsibility for schools.

Parents/guardians often stated their belief that school is an ideal place to work towards reducing social stigma, marginalization, and loneliness for their children and for other individuals with exceptionalities. They felt that school could and should be a place for their children to experience joy and a sense of belonging. Todd mentioned that, “Every day, if [my daughters] come home and say, ‘I like school’ … ‘school was good,’ well, then the teacher did her job.” Parents/guardians spoke about “easing the child’s world” at home and their hopes that their children could feel that school was a safe space where they could express themselves and the school staff could also “ease their world.”
Additionally, parents/guardians spoke about school as a place to help prepare their children for citizenship in society as adults. Lulu stated, “For me, it’s always been, ‘Eventually, you’ve got to be part of society…you can’t just take, you have to be able to contribute too.’” Alice concurred, saying, “the way it is, he has to learn to be ready for the wider community.” And Tina’s mom also spoke about her belief that one purpose of school is to prepare individuals how to function in society.

Overall, parents/guardians of children with exceptionalities want the same things that all parents want for their children. As Dianne stated, her hopes for her daughter Samantha include, “a purposeful, fulfilling and happy life, working at a job she likes, having access to leisure activities she enjoys and having a circle of friends to do it all with.”

**Strength-based Approach or Being a Believer: The Importance of Believing in Potential**

Frequently participants shared stories about professionals who came into their lives for a specific role in assessing, diagnosing, teaching or providing service or assistance for their children, and who made an important difference. These individuals were occupational therapists, psychologists, speech and language therapists, principals and teachers. Each participant used different words to describe these exceptional people. Ann used the words “believer” and “godsend.” Sven described one individual as “the one with the magic dust, there was a magic way about her.” Dawn called one, “the angel in our life” and also spoke of “our saving grace.” Nina explained that, “it takes that special person.” Lorraine stated that, “Every once in a while, you stumble upon a teacher who just feels like magic.” And, when speaking to me about Jack, Misha described a speech and language therapist who, “just changed his life, his entire life.”
Using Ann’s words, I began to call this, “being a believer.” I realized that participants were expressing how important it is for professionals to avoid placing preconceived limits on children, but instead believing in their potential and having high expectations of what they can achieve over time. Lynn stated, “If people could see the potential in other people, they would nurture this.” Ann said, “The sky is the limit with [Andrew] … Just think if all those gifts were wasted because nobody had thought to push him or give him an opportunity or give him the tools.” Alice noted that Peter’s teachers, “always believed in him. Like that was a big thing.” Dawn mentioned a teacher who was the first person to help her to see what her son was capable of. She realized, “Wow, like you know, this kid has (Dawn began crying) all kinds of potential.’ And that was the first time that I really saw it.”

Participants with children now in high school or beyond shared that they have been amazed at the progress their children have made over the years. Sven noted that, “You never would have guessed that [Olaf] would be able to do all this when she was younger.” Lynn, Dawn, and Ann shared that they would not have thought, when their sons were younger, that the boys could have achieved what they did. Those three participants also strongly believed that without those crucial professionals in their sons’ lives—people who went the extra mile, did not put limits on their children, and focused on their children’s strengths—their sons could not have made those strides. As Nina said:

It definitely takes people that are willing…that really have it within themselves to go above and beyond… Many of [Amy’s] teachers throughout the years, and her
EA, they wanted Amy to be happy and they wanted Amy to be included. Not because the school board told them to, but because they wanted to. There was one sub-category within Being a Believer, Realistic Expectations.

**Realistic expectations.**

While compiling my findings I felt I needed to reconcile the concept of being a believer with participants’ frequent requests for realistic expectations for their children. Participants expressed both of these views simultaneously. And I believe it is possible for school-based professionals to fulfill both roles. That is, professionals can provide accommodations and supports, and have realistic expectations of a child, while also allowing them space to grow into their potential, without limiting them, which is what it means to be a believer.

**Responsibilities and Roles of Teachers and Parents/Guardians**

Throughout the discussions, participants frequently indicated the importance of clearly defined roles and responsibilities for parents/guardians and school personnel. Alice explained, “I really hope that the partnership will develop…having a clear understanding between parents and teachers of what each job is, is really crucial.” Many of the roles and responsibilities participants discussed have already been addressed in previous sections. Participants expect that educators will include their children, accommodate them, provide opportunities for children to socialize at school and believe in their children’s potential while also communicating with parents/guardians regarding the progress of their children. However, participants expressed the belief that teachers often had some misconceptions about their children. They believed that it is a responsibility of school staff to educate themselves regarding the research regarding exceptional children.
Misconceptions.

Participants expressed their feelings that there were often misconceptions and a lack of understanding about why their children behaved the way they did. Alice explained, “usually if [Peter]’s not behaving there’s something wrong. Either he’s anxious or he doesn’t understand…or it’s a new situation…it’s a trigger.” Annie stated, “A lot of times they say, ‘Well this kid’s being bad,’ or, ‘This kid’s disruptive,’ or, ‘This kid’s misbehaving,’ or, ‘This kid’s just trying to get me upset.’ And really, no, this child has autism or ADHD.” Misha, Jocelyn, and others expressed similar thoughts about their children’s behaviour being misunderstood. Despite their feelings around these misconceptions, parents/guardians often expressed appreciation for their children’s teachers.

Accolades and Appreciation

It is important to note that many participants expressed sympathy and appreciation for the work done by teachers and other school personnel. There were many stories of successes and wonderful experiences with beloved teachers. Participants understood the constraints and challenges professionals face in the school systems. Dianne noted, “Our teachers have multiple grade classrooms and multiple subjects and they work very hard. I know they are challenged every day in their work. I value all their efforts.” Elsa explained that, “Over the years [Olaf]’s been surrounded by a lot of great people and we’ve been so blessed for that…all those meetings and stuff…we know how much effort gets put into those things.” Nina said, “The school system Amy was involved in from K to eight was fantastic. I could not have asked for anything better. They went above and beyond. We had some pretty amazing teachers and experiences.” Ann stated, “teachers are important, they are very important.” Lynn stated:
I really hope [school employees] get support because quite honestly, it’s gonna be so much stress on teachers and EAs...like, being a teacher, I can’t believe how much more complicated being a teacher is than when I was young... You put so much time into my kid...it just floors me. You know as a parent, I’m so thankful for that.

Participants appreciate teachers and want to have positive relationships with school personnel, especially because it is in the best interest of their children.

Summary
This chapter provides an overview of the categories that I constructed to illustrate participants’ experiences and views regarding their children with exceptionalities, and how their lives are affected by those experiences. I describe the profiles of the participants and their children, in order to allow my readers “get to know” them. I also include a table in order to summarize the categories, sub-categories and dimensions expressed by parents/guardians. In chapter five, I will discuss how I analyzed these findings and the literature in order to come to conclusions regarding this study. I will also discuss what my findings mean for me as a professional, as well as the implications for schools, community supports and policy-makers.
Chapter Five: Discussion

In this chapter, I connect and analyze the literature and the data. I also discuss the implications for me as an educator, as well as for schools, families, school divisions, community supports, and policy-makers. I explain what I learned personally and professionally from the experience of completing this study. Additionally, I will take a closer look at what this study contributes to the field of education. Charmaz (2014) states, “we construct research processes and products, but these constructions occur under pre-existing structural conditions, arise in emergent situations, and are influenced by the researcher’s perspectives, privileges, positions, interactions, and geographical locations” (p. 240). The research I have constructed is based on my perspectives as well as those of my participants and the authors of the literature I read, within our current time and setting.

Making Connections between the Data and the Literature

Charmaz (2014) explains that, “any field contains fundamental concerns and contested ideas, whether or not they have been theorized” (p. 246). I have studied a broad range of categories throughout this research, and I could potentially analyze any of these areas. In the table below, I have compiled common categories and concerns that came out of the data and the literature review to consider for further analysis. Each of these categories and concerns is important and further research in any of these areas could provide valuable contributions to the field of education. Additionally, I could view my research through different perspectives such as parent, educator or agency employee. The conclusions could differ, depending on which lens I chose. As it is most beneficial for me as a professional, I have chosen to view my work through the lens of an educator for the final pieces of my analysis.
Conclusions
When I compared the data from participant interviews with what I learned from the literature, I was able to discover and construct twenty-one conclusions within ten categories. I have compiled my conclusions in the table below. These may not be new conclusions in the field of education. Additionally, other researchers may come to other conclusions that I might not have found as of yet. However, for me, as a researcher and an educator, these are important conclusions that I have constructed at this time. Admittedly, there are many conclusions here. As a researcher, I felt a need to narrow my focus when referring to my personal commitment. I explained how I went about narrowing my focus in further discussion, later in this chapter.

Table 3: Conclusions discovered in the data and literature

<table>
<thead>
<tr>
<th>Category</th>
<th>Conclusions, Connections to the literature</th>
<th>Connections to Participant statements</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Intensity parenting</td>
<td>Parents/guardians of children with exceptionalities experience a high intensity of parenting. (Anaby et al., 2013).</td>
<td>Alice: “There is another layer of intensity that happens when you have a child that has, you know, autism and ADHD. And it’s not at all the same level of, like, what you need in terms of energy and patience and wisdom.”</td>
</tr>
<tr>
<td></td>
<td>When families have a child with challenging behaviour, the families’ lifestyle is affected (Fox, et al., 2002).</td>
<td>Ann: “I did push him, and I guess what I should add is that it was emotionally exhausting because you’re giving so much of yourself every day.”</td>
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<td></td>
<td></td>
<td>Jocelyn: “I know my kid is doing a good job at school, but come home, they are just in full-blown melt-down (at school). They are just suppressing, suppressing, suppressing and blowing up in the safe zone, at home. Where’s the carry-over?”</td>
</tr>
<tr>
<td>Inclusion</td>
<td>Full inclusion is best for all children and can create a more inclusive, tolerant society (Lyons et al., 2016, Specht, 2012).</td>
<td>Dawn: “I think it’s important that we treat people with disability like everyone else ... We have expectations of them, accommodate for them and learn more about each other too. That learning about each other and realizing that there’s not just one way of doing something is good for everybody … I think the benefit of inclusive classrooms is hopefully the foreshadowing of an inclusive world.”</td>
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<tr>
<td></td>
<td>Educators who are able to implement inclusive pedagogies can effectively include children with diverse abilities (Katz, 2012).</td>
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</table>

Parents/guardians of children with exceptionalities spend a lot of time, energy and finances advocating and navigating systems in order to meet the needs of their child (Anaby et al., 2013). Dianne: “I felt and still feel, that the biggest challenge is navigating a system I knew nothing about. Trying to keep all the information organized in my head and on paper, going to meetings and feeling very intimidated by a lot of educated professionals who greatly outnumber us, being heard and understood by all those professionals.” Tina’s mom: “It’s not purely the education and academics. It’s how to make them an individual who can function in society. And, I must say that I’ve had to pick up a lot of that personally and financially.”
<table>
<thead>
<tr>
<th>Professional Development</th>
<th>When educators receive professional development in the area of inclusive pedagogies, they feel more confident in their ability to teach students with exceptionalities (Forlin et al., 2009).</th>
<th>Lulu: “that learning resource teacher went to a conference on down syndrome … and she said she probably learned a lot more than she would have just reading it in a textbook.”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collaboration</td>
<td>When educators and other professionals are able to collaborate and are focused on inclusive pedagogies, there are positive academic and social-emotional outcomes for students. (Mulholland and O’Connor, 2016).</td>
<td>Dawn: “Now, in my work in the field, I understand how the ministries work. They work in silos, really. Like, you go from one ministry to the other. (One agency) looks after services until they’re school age, and then education picks that up. And then adulthood is, well, “That’s it, we’re done” (mimics, dusting her hands off).</td>
</tr>
<tr>
<td>Parent Engagement</td>
<td>Parents/guardians want to be involved and engaged in their child’s education and work with professionals. (Pushor and Murphy, 2004). Parent engagement has positive effects for the child’s learning. (Valencia, 2010)</td>
<td>Lynn: “And I think one of the people on the panel said, “You’re such a good mom.” And I said, “I am. I love this child. But I’m not a good teacher, and I’m not a good psychologist, and I’m not a good speech therapist…I have no idea how to deliver that to my child…it’s sitting here all in this room and I still don’t have access to you.”…And I said, “I need your help. I need you.”</td>
</tr>
<tr>
<td></td>
<td>Parents/guardians can be a valuable resource for educators teaching their child (Pushor and Murphy, 2004).</td>
<td>Nina: “those are the ones (teachers) that really reached out to me on a regular basis and said. “Hey, we’re thinking about this. What do you think?” And it was obvious they were putting in the extra effort and they were thinking about it</td>
</tr>
</tbody>
</table>
When educators and parents/guardians communicate on a regular basis and have clear roles, children are happier and more academically successful at school (Pushor and Murphy, 2004).

Parents/guardians and educators can work together as agents of change (Lyons et al., 2016).

Potential

When educators maintain an asset-based approach, student performance and success improves (Hutchinson, 2010).

and reaching out to me and bouncing ideas off me.”
Dawn: “We were always … trying to educate the educators.”

Misha: “Communication with parents and caregivers is the most important thing that you can do for a child. Communication with parents is everything, and if it can’t be positive communication then how can there be any type of positive change?”

Ann: “he’s had the highest success rates when we have daily communication.”

Alice: “I really hope that the partnership will develop…having a clear understanding between parents and teachers of what each job is, is really crucial.”

Lora: “teachers are stretched beyond belief…And without someone in a position to make some changes and increase funding, it’s never going to change….It’s a system that’s designed to fail.”

Alice: “His teachers always believed in him. Like that was a big thing.”
Ann:“(Now)The sky is the limit with him… Just think if all those gifts were wasted because nobody had thought to push him or give him an opportunity or give him the tools.”
<table>
<thead>
<tr>
<th>Socialization in schools</th>
<th>Schools are social systems where children learn how to socialize with others. (Specht, 2013).</th>
<th>Lynn: “school is where children spend the majority of their time. This is the perfect place for kids to learn how to socialize.”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social-Emotional Factors</td>
<td>When children and adults feel comfortable and safe, they are better able to learn (Puteh, et al., 2015).</td>
<td>Todd: “Every day, if they (his daughters) come home and say, “I like school” … “school was good”, well, then the teacher did her job.”</td>
</tr>
<tr>
<td></td>
<td>When children and adults have their social-emotional needs met, they are better able to learn (Katz, 2018).</td>
<td>Dawn: “It wouldn’t surprise me to see the growth in the achievement of his goals in correlation with classroom teachers who were compassionate, to say the least, and maybe just had a better way of understanding the communication barriers better. So they were adapting themselves to him rather than expecting him to adapt to them, right?”</td>
</tr>
<tr>
<td></td>
<td>When children and adults have their sensory needs met, they are better able to learn (Kranowitz, 2006).</td>
<td>Anna: “I still get the behaviour at home, but I think maybe if they were giving a heavy work break or something at school, we might not have this pent-up anger at home.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Alice: “So there were a lot of sensory things that, once we kind of understood them…we were able to kind of ease his world a little bit.”</td>
</tr>
<tr>
<td>Marginalization</td>
<td>Children with exceptionalities are more likely to feel lonely. (Bunch, 2015).</td>
<td>Annie: “Miles never really had friends, like come over and play, he was a very solitary kid.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lynn: “Paul never had friends… he didn’t call friends, he didn’t invite friends over.”</td>
</tr>
</tbody>
</table>
Individuals with exceptionalities are marginalized (DeLuca, 2013).

If you want to know what is best for individuals with exceptionalities, it is important to ask them (Danforth, 2006).

Dawn: “up until then (her child entering school) we had lived a life of exclusion”.

Lynn: “When we were in public people would be just awful….so then I made a decision…I said, “I just have to forgive everybody before I even walk out the door.”

Ann: “this world is cruel and judgmental, and other people might make it harder for him or misunderstand him because sometimes different means less to others.”

Annie: “We, like in the sense of everybody in society, we’re not educated enough…and we don’t want to educate ourselves…it’s easier to stay ignorant for people, so they’d rather be ignorant than have to educate themselves.”

Challenges exist in societal systems (schools, the medical system, the social care system, government policies) which negatively affect individuals with exceptionalities (Lei and Myers, 2011, Katz, 2018).

Lynn: “It’s just sad because the system has always been broken. It’s been scattered, very difficult to navigate.”

Lora: “It’s nothing but barriers … the system is broken. We’re really not getting anywhere. It’s a systemic problem.”

**My Learning**

Throughout the process of my research, I have reflected not only as a researcher but also as a mother and as a teacher. As a mother, I have experienced times when I had to advocate for the needs of my children. In my own way, I was able to relate when participants spoke about how difficult and stressful it was to find the right words to speak up. I know the deep emotions experienced when your child’s well-being is at stake.
Additionally, I value inclusivity. My childhood experiences with individuals with exceptionalities helped me to construct the belief that we all belong and that, with a little creativity, we can knock down barriers—barriers which I wish did not exist in the first place—so that we can find a way to include everyone. I carried this belief into my career and had learned continually about ways to include students with exceptionalities in my classroom. As a learning resource teacher, I have experienced varying degrees of success while assisting other teachers in including their students. I have been frustrated by the slow progress of the inclusion movement. In these ways, this research has been a very personal experience for me. Throughout the process of this research, it has been challenging for me to balance my roles as a mother, educator, wife, friend, sister, daughter and student researcher. When the research became overwhelming for me, what kept me going were statements from my participants that I would replay in my head, such as Ann saying, “we can’t be tired or have an off day” or, “if you need to cry, cry in the shower for five minutes and move on, because that’s a productive time to do it.” These statements brought me back to my original purpose and kept me going.

In many ways, this research confirmed what I already believed, or quelled doubts that I had. Existing knowledge became deeper or I learned an entirely new concept. For example, this research confirmed for me that inclusion benefits everyone. I gained a deeper understanding of parent perspectives and experiences with their children’s behaviour at school. I developed the concepts of being a believer and of easing the children’s and the parents/guardians’ worlds. Additionally, I gained a deeper understanding of UDL and other inclusive practices. I find myself wondering, even more
now than before, why I do not see more of these practices in my daily work. I will be able to apply all of this learning in my role of educator.

**Answering the Research Questions**

The research questions for this study were:

1) What are the experiences of parents/guardians in Saskatchewan in schools and the community?

2) How do parents/guardians in Saskatchewan advocate for services and inclusive education for their children?

3) According to parents/guardians, what are best practices for inclusion? How can educators in Saskatchewan provide for students with exceptionalities in their classrooms?

Charmaz (2014) describes grounded theory as “social actions that researchers construct in concert with others in particular places and times” (p. 234). With the help of my participants, I constructed categories, concepts and conclusions regarding the education of children with exceptionalities. I found answers to the research questions. I found that parents/guardians of children with exceptionalities experience a high level of intensity in parenting, and that individuals with exceptionalities are marginalized in society. However, when parents/guardians continue to advocate for their children, when they are resourceful and persistent, they can help achieve positive outcomes for their children. Additionally, I found that DI and UDL are excellent inclusive frameworks for educators.

**Answering “So what?”**

Charmaz (2014) states that, “writers must address the ‘so what?’ question” (p. 292). Why did I undertake this research in the first place? Why does my research
matter? After I completed the interview with Alice, she hugged me and said, “What you are doing here is really important.” The question, however, is why it is important. I believe there is value in listening to and validating individuals who feel they are not being heard. There is value in sharing what I have learned with other professionals and other parents/guardians on their journey. There is value for me professionally. I will be better able to serve students and parents/guardians and work with colleagues in my role as a learning resource teacher as a result of this research. I will also share what I have learned with the educational community, other professionals and policy-makers. I will explain how I plan to do so in the Contributions and Implications sections.

**Contributions and Implications**

I have concluded that I have not created original theory through this research, but that I have contributed to the field of education, nonetheless. Perhaps part of my contribution is in mining “an overlooked or under-analyzed area” (Charmaz, 2014, p. 289), namely, the perspectives and experiences of parents/guardians who have children with exceptionalities in Saskatchewan. I believe that the conclusions I have come to can have an impact on education and services in Saskatchewan. I will explain more about the implications later in this chapter. An additional contribution of this study is sharing how participants are actively working to change the system and to make it work for them and for other parents/guardians on a similar journey. Charmaz (2014) states:

> Structures exist and persist, but some individuals may resist, circumvent or ignore the constraints or use them for their own purposes. Institutionalized values and practices precede and constrain individuals and set the conditions for possible actions, although how they respond to these conditions can vary. (p. 269)
Participants were challenging systems by constantly advocating, writing letters and emails, showing up to protests, and continually learning about their children’s exceptionalities in order to provide for them as best they can. They persist in the face of challenges and hardships. It is possible that through their advocation these systems could change in the future, which would potentially improve the lives of individuals with exceptionalities in many ways.

**Implications for Myself: My Commitment Moving Forward**

Ultimately, as an educator, I have some control over the daily teaching of students in my care. As a result, I have chosen to focus on parent engagement as well as utilizing DI and UDL in my role as learning resource teacher. I have set several goals. My first goal is to create a brochure regarding my findings to be distributed to schools and other organizations. The brochure is meant to be a friendly, quick, easy way to get the message across to teachers and others in a position to make a difference for families.

Additionally, I will create a website as a place where individuals can go to access more information and resources. Through a grant with the McDowell Foundation, I will also be presenting on this topic in the future. Perhaps I can partner with parents/guardians to continue to speak out about these issues. Additionally, I have become a member of the Manitoba Alliance for Universal Design for Learning (MAUDeL) and hope to create a chapter of this organization here in Saskatchewan.

As a member of a school division, I intend to continue to spread information about UDL and DI both informally and formally, in our school division’s communities of practice, and at other professional learning opportunities. I intend to speak openly about my belief that UDL is a better alternative to congregated settings. I also intend to encourage my colleagues to use DI and UDL in the school where I work as a learning
resource teacher. I have found the work of Jennifer Katz (2012, 2013, 2018) to be particularly useful and will encourage the use of these resources with my colleagues. In addition, I plan to begin a family engagement committee at my school and hold community conversations to provide an opportunity for families to speak to the issues that are important to them. I also plan to write letters and emails to stakeholders to encourage change. Additionally, I would consider continuing future action research as an educator in the area of inclusivity, perhaps using the work of Jennifer Katz as a guide.

**Implications for Schools, Policy-Makers and Community Supports**

In Table Three I displayed the conclusions I made through participant statements and the literature I reviewed. I concluded that there is a need to work towards improvements in education and services for children with exceptionalities in Saskatchewan. Within the literature as well as through conversations with participants, I found possible directions for improving the quality of life, academic outcomes and long-term productivity for individuals with exceptionalities, their families and their communities within the province of Saskatchewan. These improvements involve the combined responsibility and commitment of leaders at the federal, provincial, agency, school division, and school levels.

The literature I reviewed is extremely valuable in this section. Lei and Meyers (2011) identify an urgent need to transform education systems to work towards an inclusive approach. Katz (2012) recommends tighter policy on inclusive education in every province and territory, improvement in teacher training, curricular improvements and reduction of standardized testing. She states, “I suggest that the money invested in developing, implementing and marking assessments instead be put into professional development for teachers” (p. 163). Katz goes on to recommend community partnerships
between teachers and parents/guardians and utilizing a “strengths-based approach.” She recommends parent and community education and states, “If we really want policy and practice to change, we must educate the public – because they vote, and the politicians will follow.” Katz recommends that school divisions create “a vision for inclusion. She uses research-based criteria as a basis to develop six steps for successful change in school divisions:

An uncompromising commitment to and belief in inclusion, perceive differences among students and staff as a resource, encourage teaming and a collaborative interaction style among staff and children, nurture a willingness of staff to struggle to sustain practice, ensure inclusion is understood as a social/political and academic issue and demonstrate a commitment to inclusive ideals that is communicated across the school and into the community (2012, p. 166).

I agree with Bunch (2015), who recommends that the federal government lead the way in developing policies towards inclusive education, and follow the examples of those provinces and territories that seem to be more inclusive. Avramidas and Norwich’s (2002) recommendation for a “no choice” inclusion policy might be necessary. I believe stake-holders in Saskatchewan can follow the lead of Prince Edward Island where service deliverers and policy-makers worked closely to coordinate their approach to serving the needs of children (Timmons, 2006). Schwean and Rodger’s (2013) framework for systems of care between schools, agencies and policy-makers can be a useful resource for working towards a coordinated approach.

Additionally, Katz (2012) states that, “A division that is truly dedicated to inclusive education will close down segregated classes and provide support through
professional development, public education, budgeting, staffing, and resources to make inclusive education work” (p. 166). Katz also makes recommendations for budgeting in school divisions and explains that segregated classrooms are, “expensive economically, socially and emotionally” (p. 168). Her suggestions include redistributing funds from busing to staffing and technology, reassigning staff from segregated programs to school-based or division-based positions in UDL, reducing educational assistants and increasing team teaching partnerships, and allowing individual schools to create their own plans for professional development. Katz also identifies leadership and vision as important. She describes four synthesized categories of characteristics of leaders who move their schools towards inclusion: cultural and wise leadership, organizational leadership and management, curriculum and pedagogical leadership, and political and community leadership. Katz also states that, “it all boils down to unwavering commitment” (p. 180).

I realize these recommendations may seem daunting to leaders in school divisions where congregated settings still exist. However, I believe I provide a compelling argument for change through conclusions I made by using the literature and the data in this study. These implications are overwhelming as they involve transforming systems and attitudes. I am realistic about the possibility of immediate change in these areas and my limited ability to have an impact. However, I will continue to speak up, along with the participants of this study, because I am passionate about increasing inclusivity in my community. If these recommendations were implemented it would ease the worlds of parents/guardians who have children with exceptionalities, and the worlds of the children themselves, which, in the words of Dawn, could be “the foreshadowing of an inclusive world.”
Directions for Future Research

Because one of the main purposes of this study was to provide an opportunity for participants to tell me what was important to them and then follow their lead, numerous and diverse topics were covered. Therefore, there are some directions for future research. Two topics that came up most frequently were inclusion and parent engagement. The idea of easing the child’s world—or in other terms, supporting social and emotional well-being within the community, home and school—was also important in this study. Those three topics came together in the findings. There was a great deal of discussion about how best to include children with exceptionalities. As Thompson and Timmons (2017) said, “In some ways, this research (about inclusion) feels unnecessary” (p. 80). Indeed, there is an abundance of literature from researchers who state that inclusion is best for all. However, segregated settings continue to be common in Saskatchewan and worldwide. As long as this remains true, educational researchers need to continue to further this research.

Additionally, there were discoveries within my study regarding feminist theory that could be researched further, such as reasons why participants sometimes felt they needed to bring their husbands into meetings in order to have their perspectives heard. Research regarding administrator and teacher workload as well as class size and their effects on student academic outcomes could be integrated (Mooney and Lashewicz, 2015). The concept of agency as described by Lyons et al. (2016) could also be studied further. Parents/guardians and teachers can be agents of change and together they can be even stronger. The concepts of standpoint theory (Au, 2012) and disability theory (Danforth, 2006) confirm that the voices of marginalized and oppressed groups, such as the families of children with exceptionalities, need to be heard. Additionally, DeLuca’s
(2013) multidisciplinary framework for educational inclusivity as well as Katz’s (2018) three-block model provide possible directions for future research. The work of Pushor (2004) and Carter et al. (2012) provide guidance on how best to engage families. I believe it is important that research in Saskatchewan include the idea of inclusivity so that it can move us toward a more tolerant society that celebrates every aspect of diversity.

Conclusion
Throughout the process of this research, I grew as an educator. I felt privileged to be invited to hear the stories of these families and to describe their experiences and concerns in their own words. I found this research to be one of the most challenging and gratifying experiences of my life. I have grown personally and professionally, and I look forward to applying what I have learned in the context of my work as I speak about inclusion and create opportunities for parent engagement within the schools where I work. I also know I will continue to learn as I move forward on my personal and professional journey.
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Appendices
Appendix A

*Parent and Caregiver Voices:*
*Research Exploring the Experiences of Parents and Caregivers Regarding the Education of their Child*

Would you like to share your experiences and perspectives as a parent or caregiver of a child with differences and challenges in school?

If so, please contact me:
Krista McMillen
deck12@uregina.ca
306-520-7223
Inquiries welcomed.
Or contact Marc Spooner (advisor)
marc.spooner@uregina.ca 306-585-4538

**What is involved?:**
- A 60-90 minute interview with me
- Talking about your experiences and perspectives with your child
- Full access to the final research (expected to be completed by June 2018).

**Who am I?**
A Learning Resource Teacher in Regina, with 20 years of experience, a mother of 2 and a Master’s of Education student with the UofR.

**What is the purpose of the research?:**
- To inform practices in schools
- To learn how to better collaborate and partner with parents
- Simply to provide an opportunity for parents to have a voice

**How will the research be used?:**
- The interviews will be the main focus of a *written thesis*
- Findings will be shared in *presentations* to other teachers
- Findings will also be shared on a *[website](http://example.com)*

**REB (Research Ethics Boards) Approvals:**
University of Regina
Regina Qu’Appelle Health
School Divisions: Regina Public Schools, Regina Catholic Schools
Appendix B

Initial Codes and Categories:

1  High level of intensity of parenting (and high levels of stress for child also)
   1.1 Coming to Terms
   1.2 Daily Life

2  Navigating Systems
   2.1 Systemic Issues (including Marginalization, loneliness)
   2.2 Advocating for agency services or government support
   2.3 Advocating for School supports (includes inclusive practices, technology in school, specific programs or strategies)
       2.3.1 Advocating for an increase in teacher PD/education

3. Inclusion vs Congregation-
   (includes instruction, DI, UDL, Accommodating, Assessment, person-first philosophy, "clumsy inclusion")

4. Communication between home and school
   Kids holding it in at school all day and then letting it out at home
   Children always feeling like “bad kids”
   Accolades and Appreciation

5. Socialization
   (Including joy, diversity, citizenship, reducing social stigmatization and marginalization)
   Autism and 2 Different Worlds

6. Believing in potential/ Strengths based Approach

7. Responsibilities and Roles
   (partnerships, caregiver voices, caregiver engagement)
Appendix C

Participants

(All names are Pseudonyms)

<table>
<thead>
<tr>
<th>Participant</th>
<th>Child/ren &amp; Age (at time of interview)</th>
<th>Challenge/s</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alice</td>
<td>Peter, 8</td>
<td>Autism, ADHD, LD</td>
</tr>
<tr>
<td>Ann</td>
<td>Andrew, 9</td>
<td>Autism</td>
</tr>
<tr>
<td>Anna</td>
<td>Daniel, 8, Elyse, 6</td>
<td>Autism</td>
</tr>
<tr>
<td>Annie</td>
<td>Miles, 14</td>
<td>Autism</td>
</tr>
<tr>
<td>Dawn</td>
<td>Walter, 16</td>
<td>Autism, OCD</td>
</tr>
<tr>
<td>Dianne</td>
<td>Samantha, 19</td>
<td>Down syndrome</td>
</tr>
<tr>
<td>Elsa and Sven</td>
<td>Olaf, 16</td>
<td>Developmental delays, health condition</td>
</tr>
<tr>
<td>Jocelyn and Todd</td>
<td>Jill, 6, Jane, 9</td>
<td>Autism, ADHD, Undiagnosed</td>
</tr>
<tr>
<td>Lora</td>
<td>Christena, 10, Leo, 10, Maurice, 11</td>
<td>Autism, apraxia, severe cognitive disorder</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Previously Autism, no longer shows characteristics of it</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Autism, Still’s Disease</td>
</tr>
<tr>
<td>Lorraine</td>
<td>Tom, 10, Olly, 13</td>
<td>Autism</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Undiagnosed</td>
</tr>
<tr>
<td>Lynn</td>
<td>Paul, 16</td>
<td>Autism</td>
</tr>
<tr>
<td>Lulu</td>
<td>Beno, 15, Soap, 13</td>
<td>Down syndrome, FASD</td>
</tr>
<tr>
<td>Misha</td>
<td>Jack, 6</td>
<td>Unconfirmed Apraxia of speech</td>
</tr>
<tr>
<td>Nina</td>
<td>Amy, 29</td>
<td>Cerebral Palsy</td>
</tr>
<tr>
<td>Tina’s Mom</td>
<td>Tina, 19</td>
<td>Learning Disability</td>
</tr>
</tbody>
</table>

38 people in total involved in these interviews, 21 kids, 15 moms, 2 dads, 11 w autism (inc 1 with ADHD also) 2 w Down syndrome, 2 w a LD, 3 with developmental delays/dyspraxia and/or health condition, 2 with physical disabilities, 1 w FASD

Challenges:
- Autism
- ADHD
- Down syndrome
- Learning Disabilities
- Developmental Delays
- Dyspraxia
- Health condition
- Cerebral Palsy
- FASD
Appendix D

**Participant Consent Form**

**Project Title:**
Parent and Caregiver Voices: Exploring the Experiences of Parents and Caregivers Regarding the Education of their Child

**Researcher:**
Krista McMillen, Graduate Student, Faculty of Education, University of Regina, (email and phone number removed)

**Supervisor:** Marc Spooner, Professor, Faculty of Education, University of Regina, (email and phone number removed)

**Purpose(s) and Objective(s) of the Research:**
- You will be interviewed by the researcher and asked to share about your experiences, hopes and preferences about services provided by schools and agencies. You will be asked to share your opinions about your child’s greatest successes and greatest challenges.
- The researcher will use the results of the study to share with colleagues through a thesis, a published work, at workshops, conferences and possibly journal articles.
- The researcher hopes to learn ways to further inclusive practices in schools, as well as ways to increase collaboration and partnerships with parents/guardians.

**Procedures:**
- We will meet at a mutually agreed upon location and time, I will conduct an interview, which will take between 60-90 minutes, with planned but flexible questions, a recording device will be used to record the interview, the recordings will later be transcribed. I will use the transcriptions to gain further insight into my practice as a learning resource teacher and to attempt to generalize this insight for colleagues.
- Please feel free to ask any questions regarding the procedures and goals of the study or your role.

**Funded by:** I am receiving a Grant from the McDowell Foundation.

**Potential Risks:**
- There are potential emotional risks of this research for the participant.
- **Risks will be addressed by:** providing the name and phone number of a local counsellor willing to provide service to the participant if requested.
- The participant’s confidentiality will be protected. The only circumstance where information shared will not be kept confidential is in the case of a disclosure of actual or potential harm to the participant, the participant’s child or any other person. In this case, the interview would be concluded and the participant would be notified that the researcher would contact relevant agencies and assistance would be offered to the interviewer if requested. The recording would not be transcribed or used for research in this case.

**Potential Benefits:**
• The insight gained by the researcher will be shared with other professionals in hopes of developing awareness of the issues discussed and possible implications regarding authentic inclusion in Saskatchewan.

Confidentiality:
• Electronic recordings will be deleted (overwritten and erased with eraser software) after transcription. Transcriptions will be destroyed after five years. The recording device will be stored in a locked cabinet and all electronic documents will be password protected.
• Pseudonyms will be used.
  Participant 1 pseudonym: _____________________
  Participant 2 Pseudonym: _____________________
  Child Pseudonym: _____________________________

Right to Withdraw:
• Your participation is voluntary and you can answer only those questions that you are comfortable with. You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort.
• Whether you choose to participate or not will have no effect on you (e.g. access to services) or how you will be treated.
• Should you wish to withdraw, any recordings or written information will be deleted or destroyed.
• “Your right to withdraw data from the study will apply until March 30, 2018. After this date, it is possible that some results have been analyzed, written up and/or presented and it may not be possible to withdraw your data”.

Follow up:
• Would you like to have a written report of the results of this research mailed to you once completed? ___ yes ___ no
  Please provide an address where they can be mailed or alternate arrangements for receiving the report:
• Would you agree to having the results posted to a website created by the researcher? ___ yes ___ no

Questions or Concerns:
• Contact the researcher(s) using the information at the top of page 1;
• This project has been approved on ethical grounds by the UofR Research Ethics Board on June 29, 2017. Any questions regarding your rights as a participant may be addressed to the committee at (email and phone number removed). Out of town participants may call collect.

Consent
Your signature below indicates that you have read and understand the description provided; I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

__________________________________  ___________________________________  _______________________
Name of Participant                  Signature                      Date

__________________________________  ___________________________
Student Researcher Signature        Date
Appendix E

Parent and Caregiver Voices:
Research Exploring the Experiences of Parents and Caregivers Regarding the Education of their Child

Interview Question Guide

1. Tell me all about your child/children (their interests, personalities, talents).
2. Does your child have a specific diagnosis? If so, can you tell me about it?
3. Tell me about your child’s current school environment. (And past school environments).
4. What do you consider to be the best possible learning environment/situation for your child? Why?
5. Does your child use technology at school? For what purposes? How often? Which devices and applications or programs does he/she use? How has this been helpful for your child?
6. What are some of the frustrations and challenges you encounter as a parent/caregiver of your child?
7. What are your beliefs about inclusive environments? Do you believe there is value in segregated/congregated programs or settings (segregated school or preschool programs, independent living facilities, and so on)?
8. What qualities do you value in your child’s teacher/s?
9. Do you consider yourself a partner in your child’s education? Why or why not?
10. Tell me about your experiences with community agencies regarding diagnosis and treatment for your child (Medical Doctors and specialists, Child and Youth Services, Wascana Rehabilitation Centre, and so on)?
11. What are your thoughts on perceptions in our society about people with disabilities and differences?
12. Can you tell me about some of your experiences (positive or negative) in the community regarding interactions with your child?
13. Can you tell me about some times when your child has had particular success in school. What do you think were the reasons for their success in those situations?
14. Have you heard of Universal Design for Learning? If so, what are your thoughts about it as an inclusive approach for your child? (If not, show caregiver the video https://www.youtube.com/watch?v=MOUdmzaZrc and ask their thoughts after.)
15. What are your hopes for your child’s future?
16. Is there anything else you would like to tell me about that we haven’t discussed?
Appendix F

Narrative: How did I become passionate about advocating for inclusivity for people with challenges?

How did I become interested and passionate about advocating for inclusion for people with disabilities and other challenges? Looking back over my life, I can see many experiences that shaped me as a person and developed in me some essential beliefs about human rights, respect, dignity and equality.

From about the age of eight, one of my closest friends had a sister with a disability. However, as a child, I don’t remember ever really thinking about her as having a disability. I saw her as a person, a friend. She would often be involved with our group of friends and be a part of whatever we were doing in any way we could include her. We treated her in the same manner as the rest of the friends in the group, including affectionately teasing her at times. She has physical disabilities which limit her mobility. So, at times, we would have to involve her in our play in a different way. For example, if we were dancing, she would be a judge, or a central part of the dance so that she would stay in one place. When we went out in public together, we would take turns assisting her walking. We naturally found ways to include her. We did not want her to be left out. We enjoyed being with her and we knew she had contributions to make to our play. She made us laugh and gave great ideas that added to our activities. We were all better because she was part of our group.

This friend of mine also had an uncle who had a severe disability. He required a wheelchair and was non-verbal. He had little control over his body and was spastic at times. He would make loud, random vocalizations. On a few occasions I had the privilege of visiting my friend’s grandparent’s farm where her uncle lived. I remember at first, being somewhat unsure or perhaps
even a little fearful of her uncle. But once I spent some time with the family I began to feel quite
comfortable around her uncle. I observed that although he had severely limited mobility and
communication, the family would make an effort to involve him in whatever was happening.
They would talk to him and understand his responses. They would joke with him and tease
occasionally. They would spin him and he would laugh and express a great deal of joy. They
would hug him and show affection. He was part of the family. Again, the family was better
because of him. He brought joy to the family.

At the same time in my life, at school there was a specialized classroom where there were
about ten children with special needs. These children had both physical and cognitive challenges.
Those of us in typical classrooms only saw the children in this class at recess or in the hallways.
Unfortunately, these children were often ostracized, teased and called names. They were not
included in our play. We did not really get to know them. We did not make an effort to talk to
them. That would not have been a popular thing to do. As a result, we missed out on learning
what they could have contributed to our play, our learning and our development as young people
and the joy they might have brought to our classrooms. I wonder what school was like for these
children and their families.

When I went to University, I volunteered for a program here in Regina called Night
Flight. It was a recreational program for people with severe physical disabilities. Volunteers
were needed to take these individuals out for high risk activities that required one on one
attention. I especially remember taking the group swimming. I remember the other volunteers
began to splash the participants of the group and I was quite shocked for a moment, thinking that
these people were fragile and vulnerable and that it was mean to splash them! However,
immediately, I could see the participants begin to laugh uncontrollably. They were having so
much fun. There was so much joy. So I gently began to participate in the splashing myself. In
talking with another volunteer after and explaining my observations, she shared with me that she had felt the same way her first time. And then she realized that the participants in this program had the same needs we all had. They wanted to have fun and get a little crazy sometimes. They wanted to participate in the world around them. Don’t we all need to let lose sometimes?? She also shared with me that she had initially felt sorry for the participants; that they would never have a “normal” typical, independent life. And then she realized that they still had the ability to feel joy and be happy and could contribute in their own way and that they really didn’t want anyone’s pity.

While attending University, I also worked as an assistant to a child with a severe disability. This ten-year-old little girl was home schooled. Her parents were dissatisfied with the school divisions and the options provided them. They were in dispute with the public-school division to get a placement for their daughter in a regular classroom in the neighborhood school. They believed this was best for their child and would accept no less. I assisted the little girl with eating lunch, I took her for walks and I worked with her on academic tasks. In the time that I worked with her she learned letter names and sounds and some basic words. Although she had very little language, I found ways to assess her knowledge and to teach her new things. She was quite a capable learner. She was full of joy and I looked forward to my time with her. I even began to recognize times when she was teasing me and playing little pranks on me. She had a lot of personality and was quite a jokester! How much fun could she have brought to a classroom full of children?!

During University I was also able to take all six classes that were needed at that time to receive a certification in Special Education, at that time. I learned a great deal in those classes and credit this learning with an increased confidence in my ability to serve the needs of children with disabilities and challenges to a greater degree than I would have been able to otherwise. I
have always believed that what I learned in those six classes should be required learning for all pre-service teachers.

I also remember writing an essay on *Home Visits* during my time as an undergraduate student. I realize that working with families has always been important to me.

Over the years as a classroom teacher and a learning resource teacher I have had numerous experiences teaching children with challenges. One of the students I worked with early in my career was a little girl who was in a wheel chair and was non-verbal. This little girl attended her neighborhood school from Kindergarten to grade 8. She was fully included with her peers in a regular classroom. She had the same full time Educational Assistant for all those nine years. Her peers knew her well. They would take turns pushing her wheel chair around the school and outside at recess. They knew how to make her laugh and they could communicate with her quite well. She was part of the school community. Everyone knew her and spoke to her in the hallway. One particular event stands out for me. When she started grade 8 her new teacher was a little reluctant and unsure of how to prepare for her and her needs. I assured him that it would be fine; that I would help him find ways to teach her and that her peers and her EA would assist him as he went along. It was only about a month later when this teacher came to me to say that he now understood. He understood why it was important that this child was in the regular classroom and how he could provide for her quite easily. He saw how she contributed to the classroom environment and to everyone who worked with her. He said that, as a teacher, until you have a child in your classroom with challenges, you really don’t fully understand how they add to our experiences and that teaching them is really not as complicated as we sometimes believe.
I have learned a great deal through teaching children who had attentional challenges. One child, in particular stands out. He so badly wanted to make me, his teacher, happy. He tried to pay attention and get to work and stay on task. However, his mind would wander frequently. He could not seem to control speaking out whatever was on his mind, whenever he was thinking it. He was constantly interrupting and blurting out and of course, that made it very difficult to get through lessons, instructions and to help other students. Keeping my patience was easier on some days than on others. I knew he was motivated to pay attention, follow rules and learn. It was a matter of finding out how to help him learn how to do that. He would complete a self-evaluation at the end of each day, allowing him to self-reflect and problem solve after the fact, in order to learn more positive choices for the next time. I was in close contact with his mom. We were consistent and supportive of one another. I also communicated with his medical doctor about medications and with Child and Youth services who were working with the family. By the end of the year, he had made tremendous progress academically and behaviourally. I believe it was these relationships, along with his own self reflections that made all the difference for this boy that school year.

Early in my career I learned to use a meeting process called MAPS (Multi-Action Planning System). This process focused on specific questions and involved the entire team of professionals who were involved with the child, including, and most importantly, parents. The process included only seven questions and it was required that parents respond to these questions first. After only a few of these meetings I realized just how purposeful they were designed. They were not simply a way of gathering information and making plans. They were also, and more importantly, a method of developing positive relationships, trust, and giving an equal voice to all stakeholders, especially to parents or caregivers.
I have had some amazing mentors along the way also. They have taught me effective practices for working with children with various challenges and challenges. We celebrated diversity together. I was inspired by their passion and their abilities to get things done! I wouldn’t be who I am, professionally or personally, without the mentors I have been lucky enough to have in my life.

The children I teach make me a better teacher and a better person. They challenge me to be creative. I continue to learn that positivity, listening and understanding go a very long way. Students and families are much more willing to cooperate and work with schools and school staff when they feel they are heard and can place their trust in the school and community.

My experiences with natural inclusivity have shaped me and stayed with me in powerful ways. I believe that people with challenges are all around us to teach us. The individuals whose stories I have told have inspired me; they have become a part of who I am. I believe that if we segregate and remove individuals with challenges, we are removing experiences with an important population in our society. These experiences have the potential to make us better, more satisfied and complete. If we remove individuals with challenges, we take away opportunities for children to have these experiences; to develop compassion; in some cases, to learn how to be a caregiver; to see that everyone, no matter what their abilities or their challenges, has a unique contribution to make; to know many important aspects of what it means to be human. I continue to be inspired by the joy and the spirit I see in the eyes of individuals who face immense daily challenges. I know I have more to learn. I know my future holds more stories to be a part of and to learn from. As a result of these experiences, I am always learning and looking for ways to improve my own work.
The University of Regina Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol, consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS
In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: http://www.uregina.ca/research/for-faculty-staff/ethics-compliance/human/forms1/ethics-forms.html.
Dr. Katherine Robinson  
Chair, Research Ethics Board

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