August 2016

Role of Advocacy Organizations in Promoting Inclusive Education Policies for Students with Rare Chronic Health Conditions: Insights for Education Leaders

Jennifer Flinn
The University of Western Ontario

Supervisor
Dr. Gus Riveros
The University of Western Ontario

Graduate Program in Education

A thesis submitted in partial fulfillment of the requirements for the degree in Doctor of Education

© Jennifer Flinn 2016

Recommended Citation

Flinn, Jennifer, "Role of Advocacy Organizations in Promoting Inclusive Education Policies for Students with Rare Chronic Health Conditions: Insights for Education Leaders" (2016). *Electronic Thesis and Dissertation Repository*. 3934.
https://ir.lib.uwo.ca/etd/3934

Abstract

This qualitative study investigated how advocacy groups for rare chronic health conditions understood their relation to, and interaction with, educational leadership and policy. This study adopted a critical research orientation and framed inclusion as an equity and social justice issue. Semi structured interviews were conducted with advocates representing various rare chronic health conditions, and a policy review of Ontario's inclusion policy, as well as relevant health policies were conducted. The analysis revealed that there was tension in participants' understanding of inclusion, and participants did not always support full inclusion for students with rare chronic health conditions. There is a lack of knowledge and understanding on the part of the education system about rare chronic health conditions, and a lack of connection between the medical and educational systems. A lack of policy to address the needs of children with rare chronic health conditions was identified, as well as diversity in policy enactment between school boards and schools. Recommendations were made, including further examining current inclusion policy in Ontario and elsewhere for potential policy gaps for including students with rare chronic health conditions, better leveraging advocacy organizations to act as knowledge brokers for education systems, creating better connections between education systems advocacy organizations, and re-examining both the allocation and the role of educational assistants in promoting inclusive classrooms for students with rare chronic health conditions. Future research directions are suggested, including further examination of inclusive schooling, evaluating the ways in which barriers exist for inclusion of students with rare chronic health conditions, and further understanding parent, educator and educational leader perspectives on inclusion for students with rare chronic health conditions.

Key Words

Inclusion, rare chronic health conditions, social justice, educational leadership

Acknowledgements

Table of Contents

List of Tables

Introduction

The Research Problem

With current models of inclusion in Ontario classrooms (Edmunds, Macmillan, Specht, Nowicki, & Edmunds, 2009; Ontario Ministry of Education, 2005) and with advances in medical science, teachers today are likely to teach students with a variety of exceptionalities, including chronic health conditions (Asprey & Nash, 2006; Nabors, Little, Akin-Little, & Iobst, 2008; Olson, Seidler, Goodman, Gaelic & Nordgren, 2004). However, a lack of connection and partnership between the education field and the medical field to support the inclusion of students with rare chronic health conditions has been reported in the literature (Nabors, et al., 2008; Olson, et al., 2004; Asprey & Nash, 2006). Despite official inclusion policies, researchers have highlighted an important difference in practice between integration and inclusion (Paliokosta & Blandford, 2010; Bourke & Carrington, 2007). Integration is related to physical placements in mainstream classrooms (Artiles, Harris-Murri & Rostenberg, 2006), while the idea of inclusion goes beyond that, and takes into account issues of belonging and all members of diverse communities being authentically included (DeLuca, 2013; Edmunds, et al., 2009; Schmidt & Venet, 2012).

Historically, advocacy organizations have been responsible in large part for the inclusion movement (Trainor, 2010). Advocacy organizations representing people with rare chronic health conditions have a unique perspective on this group of students, and what the barriers to their inclusion in society may be. This unexplored perspective would be valuable for educational leaders and policy makers to help them understand the barriers and challenges to inclusion for students with chronic health conditions. Creating better connections between advocacy groups, educational leaders and policy makers may facilitate addressing some of

these challenges, as important questions arise about how educational leaders at the school,

district, and ministry levels support the work of advocacy organizations for children with rare

chronic health conditions.

This study aims to investigate how advocacy organizations perceive the role of

educational organizations and their leaders at the school, district and ministry levels, in order

to stimulate partnerships or collaborations to support inclusive practices for this group of

students. Through this research, investigators, administrators, advocates and policymakers

would be able to understand the challenges to these collaborations, and obtain insights on

how to address their common goal of supporting this population. The education sector could

make use of the insights, knowledge and expertise, revealed through this study in advocacy

organizations, to better support inclusion for students with rare chronic health conditions.

Finally, this thesis will offer useful insights that educational leaders could use to improve

their practice.

This research adopts both a critical policy analysis approach and a critical leadership

approach. Critical policy analysis seeks to understand policy contextually and in a

sociologically grounded way (Winton & Brewer, 2014; Taylor, 1997). In traditional policy

analysis, policy is understood in a static orientation, while in critical policy analysis, policy is

understood to be context specific and subject to interpretation (Diem et al., 2014).

Critical policy analysis seeks to actively identify areas of exclusion and inequity in

policies and their enactment in contexts of practice (Diem et al., 2014). Similarly, critical

views on leadership are concerned with examining and understanding power relationships

and seeking sources of inequity (Gunter, 2001). Leadership from this point of view is

understood not as an individual skill, style, attribute or position, but as the relationships

between people, and the power dynamics in these relationships. Using a critical perspective,

power inequities can be examined in leadership practices, policy and its enactment, and the

contextual and situational factors that could be seen as sources of inequity. The current study

adopts a critical perspective in examining leadership and policy. This perspective is

appropriate in order to recognize the marginalization of students who have exceptionalities

(Ryan, 2012) and to understand the complexities faced by those who work to serve this

population. It is hoped that using this perspective for analysis will allow for the identification

of some areas of potential exclusion and inequity for students with rare chronic health

conditions.

Significance

In Ontario classrooms, inclusion of students with exceptionalities has become

the policy and widespread practice (Ontario Ministry of Education, 2005). The first choice of

placement in Ontario according to the Ministry of Education is the regular classroom for all

students who have exceptionalities (Ontario Ministry of Education, 2009). At the same

time, advances in medical technology and health sciences have led to a dramatic increase in

the life expectancy of many children with a variety of chronic health conditions (Mukherjee,

Lightfoot & Sloper, 2000). Thus, classroom teachers today are likely to see a variety of

students in their classrooms who may have chronic health conditions, and as a result, may fall

into some category of exceptionality (Olson, et al., 2004). The Ontario Ministry of Education

(2011) in Ontario defines exceptionality narrowly as students who are identified in one of

five categories (communication, behaviour, intellectual, physical and multiple). This

definition relies on a medical, deficit model of disability, in which students are understood as

deficient or lacking in some way, and thus are categorized as having an exceptionality (Slee,

2001; Paliokosta & Blandford, 2010). In this study, "exceptionality" is understood as students

who may have challenges fitting into existing school structures, cultures and curriculums, due

to differences in academic functioning, behavioural functioning, social functioning or

medical and physical differences. DeLuca (2013) notes that school systems are not well

designed to accommodate the diversity of students in school systems. This view recognizes

wider issues of diversity and how those issues are in schools.

  With inclusive policies, students with chronic health conditions spend most of their

day in regular classrooms (Asprey & Nash, 2006; Nabors, et al., 2008; Mukherjee, Lightfoot

& Sloper, 2000). However, despite inclusive policies, these students and their families

experience significant challenges to their successful inclusion in schools. Martinez

and Ercikan (2009) note that educational outcomes are significantly impacted by chronic

health conditions. These effects can include impacts on academic achievement and social

adjustment (West, Denzer, Wilder & Anhalt, 2013), communication, and general school

experience (Wideman-Johnson, 2011), challenges due to chronic absenteeism (Mukherjee,

Lightfoot & Sloper, 2000), a lack of information and understanding from educators about

chronic health conditions and their impacts on students (West et al., 2013) and overall quality

of school experience (Martinez & Erickan, 2009).

  In order to address some of these challenges, inclusion policy at the Ministry, district

and school levels may need to be developed to support this group of students. Specifically,

policies addressing the potential impacts of chronic health conditions may help improve the

inclusive school experience, by addressing specific areas, such as chronic absenteeism, social

adjustment, knowledge and understanding in the education sector, and better connections

between organizations such as health care, advocacy groups and the education sector, may

positively impact inclusion of students with rare chronic health conditions.

Inclusion can be framed as a social justice issue, in which all students are entitled to

not only an education, but to equal, full participation in society as a basic human right

(DeLuca, 2013). The understanding of inclusion that guides this study recognizes inclusion as

a diversity and equity issue that may impact many groups of students. For the purposes of this

study, inclusion as it relates to students who have rare chronic health conditions will be the

focus. This view of inclusion as a social justice issue acknowledges the historic and

contemporary marginalization of students with exceptionalities within the school system

(Artiles, et al., 2006; Valeo, 2009; Ryan, 2012). Viewing inclusive education in this way,

barriers to full inclusion are sought as social and systemically constructed obstacles to be

addressed (DeLuca, 2013).

The significance of this study resides in its examination of the under researched

perspective of advocacy groups, and how they may contribute and ultimately have an impact

in educational leadership and policy for the inclusion of students with rare chronic health

conditions. In the context of Ontario, little is known about how advocacy organizations might

influence the policies and practices that promote the inclusion of students with rare chronic

health conditions, and, as noted in the literature review, there is a lack of specific policy

about the inclusion of students with rare chronic health conditions. It is possible that some

specific policy could support the inclusion of this group of students. For example, it is

possible that some specific issues experienced by this group, such as chronic absenteeism

(West et al., 2013), or lack of a category of exceptionality that fits for these students, could be

addressed with specific policies to address and bring focus to these issues for educational

organizations. This study has the potential to help leaders and policy makers better

understand some barriers and challenges to the full inclusion of students with rare chronic

health conditions from a social justice perspective.

Purpose of the study

This study offers insights on how advocacy groups for students with rare chronic

health conditions understand their relations with the education sector. In particular, what

collaborations and partnerships currently exist, what are the challenges for greater

collaboration between these groups and educational ministries, districts, and schools; and

how advocacy groups perceive the role of educational leadership at institutions such as

Ministries, districts and schools

The review of the literature reveals that the actual and potential interactions between

advocacy groups and the education sector have not been investigated in the Ontario context.

As noted above, much research about advocacy for chronic health conditions exists mostly

from a medical perspective (Asprey & Nash, 2006). While leadership for inclusive schooling

and exceptional students exists in the literature (see for example Ryan, 2005), no studies or

reviews could be found in the literature examining the work of advocacy groups for rare

chronic health conditions and their relevance for educational institutions. It is hoped that this

project can be a beginning to understanding some of these complex issues for the benefit of

students with rare chronic health conditions in mainstream schools.

Research Questions

The research questions for this study are:

1. How do advocacy groups perceive the role of educational organizations in achieving
   their mission of advocating for students with chronic health conditions?

2. How could the work of advocacy organizations inform or improve current practices

   and policies on inclusion for students with rare chronic health conditions in schools.

3. How can the collaboration and communication between schools, school districts,

   ministries and advocacy organizations be improved to support the wellbeing of

   students with chronic rare health conditions?

This study hopes to fill some gaps in the literature regarding the connections and possible

collaboration between advocacy organizations and educational organizations, to support the

educational inclusion of students with chronic rare health conditions.

Definition of Key Terms

Some important terms must be considered before these questions can be examined in

a meaningful way. These terms will be briefly introduced here, and elaborated on in later

sections of the literature review.

Definitions of *chronic health conditions* can vary widely (Wideman-Johnston, 2011).

For the purposes of this study, a broad definition of a chronic health condition will be in line

with Nabors, et al.'s (2008) definition, and will be understood as a condition that lasts for a

considerable amount of time, and can include both congenital conditions such cerebral palsy,

and diseases such as cancer and diabetes. The focus of this study will be on chronic health

conditions that are considered to be rare. Health Canada defines rare conditions as those

occurring in less than one in two thousand (Heath Canada, 2012).

Advocacy can be defined as "the act of speaking and acting on behalf of another

person or group of people to address their preferences, strengths and needs" (Trainor, 2010,

p. 35). Advocacy can be the work of parents interacting with multiple levels within the school

system (Trainor, 2010), or advocacy groups working at various governmental levels

(Delcourt, 2003). Young and Everitt (2010) note that advocacy groups can include what they call interest groups, which are those organizations that seek to influence policy for their own, or their members, gain, and advocacy groups who work to influence the government to "do something they believe in" (p. 5). These authors broadly define advocacy groups as "*any organization that seeks to influence government policy, but not to govern*" (Young & Everitt, 2010, p. 5). This definition will be used in this study to examine the work of advocacy groups.

Although the focus of the current study is on advocacy groups, at times throughout the study the reader will notice parent voice emerging. This mixing of voice and perspective is a result of the unique position many of the participants in the current study occupy. The participants in the current study are not simply advocates because they have a cause they believe in; rather, they are advocates because their lived experiences relate to the advocacy organization for which they speak. The participants are either diagnosed with the rare chronic health condition for which they advocate, or are parents of children who are diagnosed with the rare chronic heath condition for which they advocate. This puts participants in a position of speaking from personal experience, as well as from the experience of an advocacy organization. Although the focus of this research is advocacy organizations, these voices sometimes mix in this study.

The central concept that will guide and inform this research is *inclusion*. Inclusion refers to the idea, reflected in policies, according to which students with a variety of exceptionalities should be educated in a regular, mainstream classroom (DeLuca, 2013; Edmunds, et al., 2009; Bennett, Dworet & Weber, 2008). Inclusion "fundamentally it refers to supporting and accepting a full range of diversities within a learning context to promote

equitable education for a more cohesive society" (DeLuca, 2012, p. 551). Our conception of

inclusion is broad, and sees diversity and equity as key issues for education systems.

Although the current study focuses on inclusion issues for students who have chronic health

conditions, this broader understanding of inclusion as an equity and diversity issue for

education guides this research.

Inclusion policy has been developing worldwide for the past three decades

(UNESCO, 2009). These policies are based on the idea that all children should have access to

education. Despite global and local policy developments, there continues to be confusion and

debate about what inclusion is, and how it should be implemented (Ainscow, 2007;

Paliokosta & Blandford, 2010; DeLuca, 2013). In part, various understandings of inclusion

relate to how ability, and by extension disability, are conceptualized. According to Thornton

and Underwood (2013), disability can be understood as inherent in an individual (medical

model of disability) or as a socially constructed and mediated process, whereby barriers have

prevented the full participation of various groups in mainstream education.

Ainscow (2007) refers to what he calls an inclusive turn, within which inclusive

discourse "moves away from explanations of educational failure that concentrate on the

characteristics of individual children and their families towards an analysis of the barriers to

participation and learning experienced by students within school systems" (p. 3). Further to

this understanding that focuses not just on individuals, but also on systemic issues that may

be potential barriers to full participation, many authors contend that inclusion must go far

beyond physical placement in a physical setting in a mainstream school for exceptional

students (Schmidt & Venet, 2012; DeLuca, 2013; Artiles, et al., 2006). Ryan (2010) states

that the "goal of inclusion is to see that everyone is included in social processes common to

communities and schools" (p. 8). Similarly, Ainscow (2007) states that the aim of inclusion

"is to eliminate social exclusion that is a consequence of attitudes and responses to diversity

in race, social class, ethnicity, religion, gender and ability" (p. 3).

There is a distinction within the literature between the idea of inclusion and the idea

of integration. Integration focuses on more narrow understandings of inclusivity as the

physical placement of exceptional students with their age mates (Artiles, et al., 2006); while

inclusion focuses on the idea that these students are fully included in the classroom, and have

access to the social and educational benefits of the educational setting (DeLuca, 2013;

Schmidt & Venet, 2012). For the purposes of this study, an understanding of inclusion will be

in line with these and other authors' conception that inclusion is not mere physical placement,

but rather as a diversity and equity issue, that allows for the full participation of exceptional

students in the educational environment with their age mates, within their neighbourhood

schools.

Overview of Methodology and Methods

This research adopted a qualitative research perspective in line with the interpretive

paradigm in education research (Gay, Mills & Airasian, 2009). Semi-structured interviews of

key informants from several advocacy groups were conducted. Advocacy groups were

selected on the basis of their advocacy for people with rare chronic health concerns.

Interviews were recorded and transcribed for later analysis to identify emerging themes and

patterns. In addition to these interviews, a policy review of the Province of Ontario's

inclusion policy, and health policy as they relate to education, was conducted.

Assumptions and Positionality

The current research study evolved through a personal journey as a parent of a child with a rare chronic health condition, Tuberous Sclerosis Complex, which has far reaching educational, developmental and health implications. Maxwell (2012) suggests that researchers should not shy away from personal lived experiences to inform their research, methodological and conceptual framework choices. Building upon the understanding that narrative, lived, personal experience can shape and inform a direction for research, an idea to examine the impact of chronic health conditions on inclusion, policy and leadership practices emerged. From this perspective, this research project developed as I reflected on the various roles that I play as a mother, advocate, and educator. As a mother of a child with a rare chronic health condition, I have personally seen the lack of policy to address her unique challenges in terms of health issues, as well as the lack of information available for her educators, except for the information I provide to the schools. Some challenges to her full inclusion have been the lack of available supports and lack of specific policy around rare chronic health conditions.

As an educator, I have worked in classrooms that were inclusive, and have worked with students who have rare chronic health conditions. In these cases, I have experienced the lack of information and the lack of supports from educational leaders to successfully include them into my classroom. As an advocate for a rare disease group, I have seen many families who feel their child's inclusion is challenged by a lack of supports in inclusive classrooms, and the lack of policy specific to their particular and unique challenges with rare chronic health conditions. Thus this research project was undertaken from the perspective of an

educational researcher, advocate for a rare chronic health condition, educator, and as a

mother of a child who has a rare chronic health condition.

Challenges of Design

One initial challenge was the difficulty in finding participants. Although invitations

were sent out to seventeen different advocacy groups, only participants from five groups

agreed to participate. One key limitation of this study relates to the grouping of multiple rare

chronic health conditions into one study. It is possible that some health conditions will have

very specific challenges associated to their participation in school systems, as well as

challenges associated to leadership practice and policy that can encourage or present

additional barriers to this process. By having the study open to diverse advocacy groups of

children with any rare condition, some important and specific issues related to specific

conditions may be missed. Alternatively, some challenges related to certain conditions but

not to other conditions may be over represented. The study was broad in order to increase the

possibility of attracting enough participation to reach data saturation, but this may create

issues in identifying key themes that are common across conditions.

Another possible limitation of this study is that the focus is specifically on Ontario

inclusion policy, while some participants were from national advocacy organizations. They

may not have had specific knowledge of Ontario policy. However, as will be noted in the

literature review, much inclusion policy in Ontario follows international, global policy trends

towards inclusive schooling. The other provincial policies that participants may have been

familiar with, such as Alberta and British Columbia, follow very similar principles when it

comes to inclusive schooling.

Organization of this Thesis

To address the aforementioned research questions, this thesis begins with a review of the literature. The main topics covered in the literature review are inclusion policies in Ontario, and their connection with some Canadian and global trends. Next, the literature on inclusion, advocacy in general, advocacy in education, special education advocacy, and rare chronic health conditions in inclusive education are examined. The literature review is followed by an examination of the theoretical framework that guided this research. Key concepts in the theoretical framework are educational leadership, critical social justice perspective, and critical policy analysis.

In chapter four, the methods that were used in this research are explained with a detailed description of the qualitative methodology and data collection, including the semi structured interview process. The analysis used in this research is also explained in detail in this chapter.

Chapter five is an analysis and findings chapter, and it details the results of the study. The main themes and subthemes are presented as well as an analysis of how this study fits in with the existing literature on this topic.

Chapter six summarizes the study and offers conclusions and a reflection on how the research questions were addressed throughout this study. Recommendations based on the current research are also offered.

Literature Review

This literature review begins with a discussion of the search method used to identify

relevant research about the problem of practice, followed by a discussion of current inclusion

policies in Ontario, and their connection with some Canadian and global trends. The review

focuses on the literature on inclusion, inclusion policy in Ontario, advocacy, advocacy in

education, special education advocacy, and rare chronic health conditions in inclusive

education.

Search Method

Several areas of educational literature were examined to address the research

questions. First, the literature that conceptualizes inclusion in education was examined, as

inclusion is a key concept in this study. Second, the research on the inclusion of students with

chronic health conditions in regular classrooms was examined. Third, the literature on

leadership for inclusion was scrutinized. Fourth, literature on advocacy in special education,

and advocacy for rare chronic health conditions was reviewed. Fifth, research on advocacy

groups, and advocacy for students with chronic health conditions was reviewed, and sixth,

literature on policy analysis was explored. The purpose of this review was to gain a deeper

understanding of the ways in which advocacy groups interact with the educational policy

context in Ontario.

Although considerable research exists about special education and accommodating

students with exceptionalities in general (see for example Bennett, Dworet & Weber, 2008),

there is little research on the interactions between advocacy groups and educational

organizations to support the goals of the former. Due to the lack of research on this topic, a

wide date range was accepted for literature to inform this literature review. Due to

contemporary policy shifts around inclusion for students with exceptionalities, it was decided

that the literature search should focus on any papers or sources from 2000 onward, in order to

reflect current Ontario policy developments.

Several search terms were used in ProQuest education database. Search terms that did

not yield many results included: "children with rare diseases", "children with rare

conditions", "rare diseases in the classroom", "rare exceptionalities in the classroom",

"integrating rare disorders". When the search term was altered to include "chronic

illness" instead of "disease" or "rare condition", more results appeared. Specific conditions

such as "epilepsy" and "genetic conditions" were combined with terms such as "classroom",

"inclusion", "special education", "exceptional students and teachers' perceptions". Searching

for "teacher perception and chronic illness" and "students with chronic illness" yielded the

most relevant results. "Leadership and inclusion"; "leadership for inclusive practices"; and

"leadership and knowledge mobilization" were also searched. Terms such as advocacy in

education, advocacy and special education, advocacy and inclusion were also investigated.

Advocacy groups and advocacy organizations, as well as advocacy for health conditions, and

parent advocates for special education were also searched. The search was repeated using

Google Scholar and Western University's PsychInfo Database.

To gain some understanding of the policy in Ontario surrounding inclusionary

practices, The Ontario Ministry of Education's website was searched, as were the terms

"inclusion of students in Ontario", "exceptional students in Ontario", and "special education

Ontario" on Google Scholar. Some of the participants were more familiar with policy in

British Columbia and Alberta, so special education policy and inclusion policy was searched

with those two provinces as well. Since the theoretical orientation that will guide the

proposed study is critical and inclusion as social justice, "social justice and inclusion";

"social justice leadership"; "critical policy analysis and "critical leadership" were also

searched.

One limitation of this search was that only sources in English were included. A

challenge was the difficulty in selecting search terms that yielded relevant results. Despite

many attempts at using various combinations of search terms, few relevant studies about

children with chronic health conditions in school were located. It is possible that some

additional search term that was not identified in the current review may have yielded more

relevant results. Some of the research that was found comes from outside of educational

research, from fields such as psychology and nursing. This is somewhat of a limitation on the

current literature review, however, it also speaks to the fact that more research may be needed

in this area from an educational leadership perspective.

Policy Context

Provincial education policy context.   Table 1 outlines the education and health

policies that were reviewed in this policy analysis. The table is followed by analysis of the

policy context in Ontario and Alberta and British Columbia.

Table 1

Policies Reviewed

Policy	Year	Origin
Ontario Regulation 181/98, Education Act	1990	Ontario Ministry of Education
Standards for school boards' special education plans	2000	Ontario Ministry of Education
The Report of the Expert Panel on Literacy and Numeracy Instruction for Students With Special Education Needs,	2005	Ontario Ministry of Education

Kindergarten to Grade 6

Ontario's Equity and Inclusive Education Strategy	2009	Ontario Ministry of Education
Categories of exceptionality	2011	Ontario Ministry of Education
Achieving Excellence: A Renewed Vision for Education in Ontario	2014	Ontario Ministry of Education
Canada's healthcare system	2010	Health Canada
The Canadian Charter of Rights and Freedoms; Section 15 – Equality Rights	2013	Government of Canada
Provincial/territorial role in health	2015	Government of Canada
Ontarians with Disabilities Act, 2001	2015	Government of Canada
Special education services: A manual of policies, procedures and guidelines	2013	British Columbia Ministry of Education
Guide to Education, ECS to grade 12	2015	Alberta Education

DeLuca (2013) notes that the global movement towards inclusion has evolved from a mostly segregated parallel system, to a mainstream system, with exceptional students being placed with their age mates where possible. According to Harpell and Andrews (2010), across Canada the preferred service delivery model is to include exceptional students in mainstream classes. This shift in policy can be seen as a movement towards what Harpell and Andrews (2010) term the normalization of disability.

Special education policy in the province of Ontario has evolved over the past fifty years. Historically, students with exceptionalities would only be educated within self contained programs or institutions, if at all (Gidney, 1999). The inclusion model was not an accepted model of practice, so students with exceptionalities would have received any limited services within self contained programs and classrooms. Many of these students lived in

institutions and received limited to no education at all (Ontario Ministry of Community and

Social Services, 2012). In 1982 the Canadian Charter of Rights and Freedoms was signed,

granting people with disabilities access to an education, and guaranteeing the same rights and

privileges as their nondisabled counterparts (Ontario Ministry of Education, 2005).

Zegarac et al. (2008) note that special education in Ontario had its' beginnings in the

1950's with the Report of the Royal Commission on Education in Ontario (known as the

Hope Report), and was finally the subject of legislation with passing of The Amendment to

the Education act in 1980, known as Bill 82. With the passing of this amendment, special

education became the responsibility of the school boards to provide for students (Ontario

Ministry of Education, 2014). Currently, in the province of Ontario, children with

exceptionalities are included in mainstream classrooms where possible (Ontario Ministry of

Education, 2005). The Ontario Ministry of Education defines inclusive education as

"Education that is based on the principles of acceptance and inclusion of all students.

Students see themselves reflected in their curriculum, their physical surroundings, and the

broader environment, in which diversity is honoured and all individuals are respected"

(Ontario Ministry of Education, 2009).

As part of Bill 82, school boards are required to establish Special Education Advisory

Committee (SEAC) to act as an advisory committee in the area of special education and the

provision of services (Bennett, Dworet & Weber, 2008). The committee is made up of parent

groups and other members from the community. Although the first choice for placement for

all students in Ontario is full inclusion into the community school, the policy allows for

special placements when it is deemed appropriate (Bennett & Wynne, 2006).

In the province of Ontario, inclusion of exceptional students into mainstream

classrooms is the policy for preferred placement of children with exceptionalities (Bennett,

2009). Despite this policy, implementation of inclusion practices varies across Ontario and

Canada, and tends to be school board specific (Bennett & Gallagher, 2013). For example, the

Supreme Court of Canada, in a landmark decision, upheld one school district's decision to

place a child who had cerebral palsy in a segregated school against her parent's wishes. The

parents had desired for their child, Emily Eaton, to attend the neighbourhood school in an

inclusive environment, but the Supreme Court of Canada agreed with the Brant County

School Board that the child's best interests could be better served in a segregated special

education environment (Rioux, 1999). The Supreme Court's decision was based on the

argument that this was not a form of discrimination such as discrimination based on race or

sex, because the disability was an actual difference, whereas in the other cases, those were

just stereotypes (Rioux, 1999). Rioux (1999) argues that this is part of the backlash to not

only inclusivity in schools but to equality itself.

In contrast, in another landmark case, Moore v British Columbia (Ministry of

Education), the Supreme Court of British Columbia ruled that access to special education

supports were not an added service, but foundational to the human rights of an individual if

they allowed that individual to access education (British Columbia Ministry of Education,

2012). According to the Council of Canadian with Disabilities (2012), Jeffery Moore was

denied special education supports due to budget cutbacks. He has significant learning

challenges, and required special education supports in order to access the education system.

The Supreme Court of British Columbia ruled that access to special education supports was a

right, and compared it to needing an interpreter in order to access education. The case is

significant, in that it aligns with the understanding of inclusion as an equity and diversity

issue, rather than framing special education services as optional for districts to provide.

In all three provinces from which participants for this particular study resided

(Ontario, Alberta, and British Columbia), inclusive education is described in policy as the

goal for special education students. In Alberta, the policy states that

> Alberta's education system is built on a values based approach to accepting
>
> responsibility for all children and students. Inclusion is a way of thinking and acting
>
> that demonstrates universal acceptance of, and belonging for, all children and
>
> students.
>
> To support children and students in attaining the goals as stated in the Ministerial
>
> Order on Student Learning, school authorities must ensure that all children and
>
> students (Kindergarten to Grade 12), regardless of race, religious belief, colour,
>
> gender, gender identity, gender expression, physical disability, mental disability,
>
> family status or sexual orientation, or any other factor(s), have access to meaningful
>
> and relevant learning experiences that include appropriate instructional supports.
>
> (Alberta Education, 2004, p. 25).

British Columbia states in their inclusion policy that

> British Columbia promotes an inclusive education system in which students with
>
> special needs are fully participating members of a community of learners. Inclusion
>
> describes the principle that all students are entitled to equitable access to learning,
>
> achievement and the pursuit of excellence in all aspects of their educational programs.
>
> (British Columbia Ministry of Education, 2013, p. 2).

Despite widespread policy, there remain different interpretations and understandings

of what this policy means in practice. For example, the Ontario Ministry of Education (2009)

reported that as of 2009, only around half of Ontario school boards had an equity policy in

place. Because education in Canada falls under provincial jurisdiction, there is no unified

policy in Canada with regard to how inclusion is implemented for exceptional students

(Harpell & Andrews, 2010; Bennett & Gallagher, 2013). In Alberta, although the policy is in

support of inclusion, it states that although policies "are mandatory; however, those

responsible for implementing these policies have some flexibility in choosing the methods of

implementation". (Alberta Education, 2004, p. 25). Thus the enactment of their inclusive

policy is left open the interpretations of different stakeholders. In British Columbia, the

inclusion policy states that the "practice of inclusion is not necessarily synonymous with full

integration in regular classrooms, and goes beyond placement to include meaningful

participation and the promotion of interaction with others". (British Columbia Ministry of

Education, 2013, p. 2). Thus in British Columbia the policy does not clearly state what sorts

of classroom placements, ranging from fully integrated to fully segregated, 'inclusion'

dictates. This is a surprising formulation of the idea 'inclusion', in that it seems to focus more

on the interactions students might have with others rather then their placement in inclusive

environments.

In the Province of Ontario, regulation 181/98 outlines the process by which students

are identified and placed in special education (Ontario Ministry of Education, 1990). Students

are only entitled to the provision of special education supports, although mandated by policy,

if they have been formally identified as exceptional through the Individual Placement and

Review Committee (IPRC) process (Cobb, 2016). This identification process then can act as

"a powerful gatekeeper in the province" (Cobb, 2016, p. 53). According to Cobb (2016)

students who "do not go through the process can certainly access special education support

on an informal basis, any support these students receive – such as the above mentioned

strategies – is purely discretionary. It is at the discretion of school professionals, such as

school board consultants, school principals, and classroom teachers. Moreover, non-identified

learners who access support may lose it at any time. In Ontario, identification is the key to

formal support"(Cobb, 2016, p. 53).

In order to formally qualify for special education support, students must be evaluated

and can be identified in one of five categories: behaviour, communication, intellectual,

physical and multiple (Ontario Ministry of Education, 2011). The formal process of

identification in order to access formal special education supports can present barriers to

students. Cobb (2016) identifies three key barriers to this: either-or scenarios, where at

multiple points along the assessment and identification process parents are presented with

either-or decisions; assessment quagmire where assessments are conducted based on many

assumptions about intelligence and the ability to measure it; and the label-stigma dilemma

whereby students who are formally identified are now also labeled, and as such, face possible

stigmatization due to their identification.

Paliokosta and Blandford (2010) note that the lack of a clear understanding about

what inclusion means presents a barrier to its success. These authors suggest that the

terminology associated with inclusion policy is inconsistent, and causes feelings of tension

and inadequacy in educators. DeLuca (2013) further points out that there continues to be

ambiguity in Canada over how inclusion should be implemented and practiced. DeLuca

(2013) posits that educators receive contradictory messages regarding inclusion in part due to

the various sub-disciplines that inclusion discourses have developed from, including special

education, multicultural and antiracist, gender studies, sexual orientation studies and poverty

discourses. He calls for a unified framework uniting the various discourses of inclusive

education.

There is much variability in how special education policy is enacted across the

province of Ontario. A report by People for Education (2015) indicates that there are wide

differences between school boards in how special education and inclusion is enacted. In some

school boards in Ontario all students are served in inclusive classrooms, while in others four

percent of students are served in segregated classrooms (People for Education, 2015).

Global policy trends have an impact on both the development and enactment of policy at

local levels (Ball, 1998). Ball (1998) notes that the educational policy trends globally have

followed a market driven, managerial, neoliberal agenda, that may not equally benefit all

groups. Ryan (2012) points to neoliberal shifts in education policy as exclusive to

disadvantaged groups such as students who have exceptionalities. Bagley and Woods (1998)

note that "competitive pressures are encouraging not only a sharpening of academic focus,

but a *privileging of the academic* over other aspects of schooling" (p. 781) that the authors

maintain are key to students with exceptionalities' success in school. In the Canadian context,

policy in Ontario has also followed this accountability move, as can be seen in the

implementation of EQAO testing, and the focus on results of these tests. The most recent

priority document from Ontario, called *Achieving Excellence: A Renewed Vision for*

Education in Ontario (Ontario Ministry of Education, 2014), focuses on "achieving

excellence" (p. 3) through academic achievement, and "closing gaps" (p. 9) for all students

with exceptionalities. This can be seen as a move away from the social justice imperative of

inclusion and more towards an accountability system, where success is measured strictly in standardized test outcomes. Academic achievement is privileged in the Province of Ontario.

Health Canada policy for rare diseases. Many countries have specific policies to deal with disorders that are considered to be rare, because of unique challenges for this group of people. For example, Europe has a specific policy dealing with funding and treatments for rare diseases (EURORDIS, nd). Lee and Wong (2014) contend that Canada is one of the few developed countries that do not have a specific policy about rare diseases. According to Canadian Organization for Rare Disorders (CORD, 2015), a rare disease strategy is needed for people who have rare conditions, because treatments and medications for rare diseases are more expensive than treatments for other conditions, and are often inaccessible due to costs. Despite the rarity of rare chronic health conditions (one in 2000), collectively, one in twelve people in Canada suffers from a rare chronic condition (CORD, 2015). Two thirds of Canadians who suffer from rare conditions are children (CORD, 2015). The lack of specific policy to address rare chronic health conditions in Canada then, impacts many Canadian school age children.

Health care in Canada is shared between the federal government and the individual provinces and territories (Health Canada, 2010). Health Canada sets guidelines and frameworks, but individual provinces and territories are responsible for administering health care to residents (Health Canada, 2010). Because of the provincial responsibility for administering health care services, differences in services and health care coverage exist from one area of the country to another (Government of Canada, 2015).

Chronic health conditions

Chronic health conditions can have multiple definitions (Wideman-Johnston, 2011).

For the purposes of this study, a broad definition of a chronic health condition will be in line

with Nabors, et al.'s (2008) definition, and will be understood as a condition that lasts for a

considerable amount of time, and can include both inherited conditions and acquired ones.

Chronic health conditions are not uncommon in the pediatric population, with estimates

ranging from ten percent (Asprey & Nash, 2006) to thirty percent (Martinez & Ercikan,

2009) of children having a chronic health condition, depending on the criteria for health

condition. The focus of this study is on conditions that are considered rare, less than one in

two thousand (Health Canada, 2012). The Canadian Organization for Rare Diseases (CORD,

2015) also defines rare chronic health conditions as those occurring in less then one in two

thousand. This could include (but is not limited to) Spinal bifida, cancer, genetic syndromes,

etc.

Chronic health conditions impact the educational outcomes of students (Martinez

& Ercikan, 2009). Absenteeism can be a challenge for students with chronic health conditions

(Mukherjee, Lightfoot, & Sloper, 2000). Academic achievement and social adjustment can

also be affected by chronic illness (West, et al., 2013). Wideman-Johnson (2011) further

elaborates on the impacts that chronic health conditions can have on children, including

impacts on "communication, day-to-day living, self-care, academic abilities, and motor skills.

The social repercussions include: social skills, familial dynamics, school experiences, and

relationships with medical and psychological support" (Wideman-Johnson, 2011, p. 127). In

inclusive classrooms, teachers are primarily responsible for dealing with health concerns and

accommodations for students with chronic health conditions (West et al., 2013). Schooling

can be an important determinant of normalcy for children with chronic health conditions, and

for "'children with life-threatening illnesses schooling is a manifestation of normality in a life

otherwise largely caught up with an agenda of illness: symbolically it offers a ray of

optimism" (Asprey & Nash, 2006, p. 10).

Inclusion in education

Inclusion refers to the full participation of students who have exceptionalities within

regular, mainstream classes with their age mates (DeLuca, 2013; Bennett, Dworet, & Weber,

2008). The inclusion movement has been an evolving trend globally over the past number of

decades (Paliokosta & Blandford, 2010). Despite policy and global trends, the concept of full

inclusion is not universally supported (Hess, Molina, & Kozleski, 2006). Parents of children

with exceptionalities also have differing opinions about whether full inclusion or other

classroom placements are most appropriate for their children, depending on a variety of

factors such as severity of exceptionality and age of their child (Leysera & Kirk, 2004).

Runswick-Cole (2008) suggests that parents may be more in favour of inclusion if they frame

their child's disability in a social model-viewing the barriers as existing within structures and

schools rather than within the child. In contrast, she found that parents tended to be more in

favour of segregated placements for children with exceptionalities if they held a medical

model of disability-viewing the challenges to learning and functioning within the school

system as residing within the child.

Paliokosta and Blandford (2010) report a lack of clear understanding and

definitions of inclusion to be one of the barriers in its successful practice. Erten and Savage

(2012) contended that "[i]nclusive education is seen as a 'contested territory with competing

definitions" (p. 221). DeLuca (2013) further found that in the Canadian context,

teachers often receive mixed signals about what inclusion is and what it should look like.

Models of disability that frame the individual as deficient in some way dominate

some discourses and some ways of thinking about inclusion (Thornton & Underwood, 2013;

Slee, 2001). Slee (2001) points out that these conceptions of disability and inclusion lead to

thinking that nothing can be done to further include these groups of marginalized students. In

contrast, Slee (2001) suggests inclusion must be understood as a political and social issue that

involves relationships and institutions. These various views of inclusion and special

education impact the perception of inclusion, "On one hand, inclusion presumes that children

with disabilities will be in the regular classroom unconditionally. On the other hand,

inclusion is a privilege for children with disabilities, whom educators may view as

transgressing normative boundaries" (Thornton & Underwood, 2013, p. 60). In

practice, inclusion can "range from mere placement of students with disabilities in a general

education classroom to the transformation of the philosophy, values, and practices of entire

educational systems" (Artiles, et al., 2006, p. 260).

In the special education discourse, difficulty arises from the contrast between

integration and inclusion (DeLuca, 2013). Schmidt and Venet (2011) also note the distinction

between the terms integration and inclusion. According to these authors, inclusion implies a

philosophy where all students are educated within a regular classroom, and supports are

provided to ensure success. Integration, on the other hand, implies that exceptional students

may be placed with their age-mates in a regular classroom, so long as they are deemed to not

be intruding on the rights of other students. Thus under an integration policy, students may

still be segregated if that is deemed to be a better setting for them.

Erten and Savage (2012) also highlight the difference between integration (which they call special education) and inclusion. They contend that in order to develop an inclusion model, schools "should develop their practices according to the 'ecology of inclusion'. The ecology of inclusion is a fundamental notion that explains the main difference between special education and inclusive education. This notion indicates that schools are responsible for examining environmental factors such as regular classroom dynamics rather than focusing merely on the deficits of individual students" (Erten & Savage, 2012, p. 222).

Bourke and Carrington (2007) note that integration models focus on making students with exceptionalities fit into existing structures and curriculum to "accommodate" them, but do nothing to empower exceptional students and others to challenge the actual structures that exclude them. By contrast, Bourke and Carrington (2007) point out that inclusive models require a "fundamental paradigm shift because it is a social movement against structural, cultural and educational exclusion, and these problems are endemic to education as a whole" (p. 17). Artiles, et al., (2006) further argue that the creation of dual track, segregated programs for exceptional students perpetuates the "mainstream educational systems refusal to work with a wider range of human abilities [...] and prevents systemic changes to make education responsive to an increasingly diverse society" (p. 261).

In inclusive education, tension also arises around the role of educational supports, such as educational assistants, who may be assigned to classes to assist students who have exceptionalities (Giangreco, Sutter & Doyle, 2010). Educational assistants (EAs) often play an "increasingly prominent role in the instruction of students with disabilities" (Ghere & York-Barr, 2007, p. 21). They are often highly involved in planning and implementing the Individual Education Plan (IEP), and may also be the primary contact person for parents of

children who have exceptionalities (Conley, Gould & Levine, 2009). However, some authors

have argued that the use of EAs in special education can sometimes appear to be an easy fix

solution, which does not necessarily address the learning needs of exceptional students. For

example, Giangreco and Doyle (2002) point out that often students who have exceptionalities

receive the majority of their instruction from the least qualified personnel in the school. They

highlight the important role that EAs can play in the inclusion of students who have

exceptionalities, but they point out that EAs are often used as a substitute to specialized

instruction from a qualified teacher. Using EAs in this way does not address larger,

underlying systemic issues of dual track systems, which do not allow for diversity. Students

who have exceptionalities receive separate programs designed, delivered and evaluated by

EAs. This suggests that how EAs are utilized in the inclusion of students who have

exceptionalities may need to be reconsidered.

Advocacy

Advocacy "refers to the notion that one or more individuals believe in a particular

cause and are willing to support it in multiple ways". (Delcourt, 2003, p. 26). Kidder (2000)

suggests that parents become advocates for a variety of reasons, and work either on their

own, or as part of an advocacy group. All parents to some degree act as advocates for their

children, but for parents of children with exceptionalities, the advocacy occurs more

frequently and to a higher degree of complexity (Ryan & Runswick-Cole, 2009). Ryan and

Runswick-Cole (2009) suggest that this may be in part due to the large number of

professionals, including educational professionals, that parents of these children must interact

with. Zaretsky (2004) points to challenges to meaningful, democratic interaction between

school leaders and parent advocates. Some of these challenges stem from historically

hierarchically organized education systems, and differences in power between school leaders

and parent advocates, as well as from neo-liberal pressures on schools to perform on

standardized testing and operate within economic constraints.

Differing understandings about what disability and inclusion are also contribute to

difficulties collaborating between parent advocates and school leaders (Zaretsky, 2004).

Trainor (2010) notes that parents act as advocates in four different ways: as intuitive

advocates, as strategists, as disability experts, and as agents for systemic change. Mothers of

disabled children can preform advocacy independently but also often join groups with other

parents of children who have similar conditions or general disabilities (Ryan & Runswick

Cole, 2009). Opportunities to participate in these groups offer mothers of children with

exceptionalities opportunities to feel valued, in the "social field of the self-help group, the

mother of a disabled child enters a social domain where she has valued capital" (Ryan &

Runswick Cole, 2009, p. 46).

Although all parents may advocate for their child in the school system at some point,

it "has historically been a key responsibility of parents of children with disabilities who have

sought to provide their children with appropriate and inclusive educational opportunities"

(Trainor, 2010, p. 35). Erten and Savage (2012) also note that advocacy "efforts of parents of

children with disabilities were amongst the most crucial steps in influencing legislation and

rights of children with disabilities". (p. 222). Young and Everitt (2010) posit that advocacy

groups play an important role in Canadian democratic processes, by allowing citizens to be

involved in governance decisions. Winton and Evans (2016) also note "ongoing examination

and critique of policy by ordinary citizens is essential to democracy" (Winton & Evans, 2016,

p. 21). These authors go on to suggest that "Broadening public policy dialogues about

education by increasing the number and diversity of perspectives represented and by

challenging dominant policy discourses also contribute to enhanced democracy" (Winton &

Evans, 2016, p. 21). Young and Everitt (2010) assert that advocacy groups may play an

important role in giving voice to marginalized groups in democratic society.

Young and Everitt (2010) define advocacy groups as those groups who work to

influence policy, but do not wish to govern. These can include interest groups who are

primarily concerned with their own or their members' individual benefit, as well as those

advocacy groups who are interested in influencing policy for the greater good of society

(Young & Everitt, 2010). Advocacy groups also sometimes operate as umbrella organizations

encompassing multiple, smaller advocacy groups. Gormley and Cymrot (2006) note that

advocacy groups may be more likely to form coalitions when they feel their advocacy efforts

are directed at policy makers who are perceived as unsympathetic to the advocacy groups'

cause.

Young and Everitt (2010) note that advocacy groups differ in the extent to which they

give their supporters and members opportunities to participate, and the extent to which they

attempt to be inclusive in their membership. Some advocacy organizations have members

who pay dues, and are allowed opportunities to vote on board members, and participate in

decisions about policy stance for the organization, while other advocacy groups have

supporters who do not have voting rights. In these groups, boards maintain control over the

direction of the advocacy group and its stance on various policies. While some advocacy

groups attempt to be inclusive by ensuring membership and boards are representative of

cultural, linguistic, and ability diversity, other advocacy organizations are not inclusive, and

may be exclusive in their membership. Advocacy groups in a Canadian context experience

some challenges due to the small population, but geographically spread out nature of the

country (Young & Everitt, 2010). Another challenge to advocacy groups is a lack of funds

and resources.

In a study of advocacy efforts for 'gifted' students, Delcourt (2003) found that the

most important determinates of success for advocacy groups at the state policy level were:

passion, preparation, inspiration, perseverance, and serendipity. Gormley and Cymrot (2006)

note the importance of advocacy groups' interactions with what they call "friends and

enemies" (p. 103). 'Enemies' are defined as those individuals, groups and policies that are in

conflict with the advocacy groups, while 'friends' are those whose interests coincide with the

advocacy group. Lobbying to friends means that advocacy groups have access and the

sympathy of the policy maker or leader that the advocacy group is trying to lobby. Trust is

another important component of lobbying to perceived friends. In contrast, lobbying directed

at perceived enemies occurs when advocacy groups have no access, and no relationship to

build on.

Gormley and Cymrot (2006) note that advocacy groups use different strategies to

lobby, depending on whether they are lobbying towards perceived friends or enemies. If they

are lobbying to perceived friends, they tend to use insider strategies, and if lobbying to

enemies, they tend to use outsider strategies to lobby. Insider strategies include those such as

direct discussion with policy makers, providing input into policy, and testifying at

proceedings. Outsider strategies on the other hand involve media campaigns, rallies and letter

writing campaigns. Young and Everitt (2010) note a similar distinction in the actions of

advocacy groups, but they term them formal and informal advocacy strategies. According to

these authors, advocacy groups employ different strategies ranging from formal advocacy to

informal advocacy. Examples of formal advocacy might be meetings with government officials and policy makers, while informal strategies might be rallies, or walks in support of some policy change. Many advocacy groups employ both strategies.

Winton and Evans (2016) contend that "advocacy organizations in education use research in their efforts to influence elite policymakers and their decisions" (p. 7), and that their efforts to use research can be categorized as technical, political and transformational. Technical efforts to use research involve using it to inform policy and plan for the organization. Political use of research is directed at trying to shift power and build the organization's power to influence policy decisions and enactment. Transformative research use is aimed at influencing and changing deeply held beliefs at multiple levels, including the individual, groups, the public, policy makers and policy actors (Winton & Evans, 2016).

Advocacy groups that develop to support patients who have rare chronic health conditions play an important role in terms of contributing to and directing research in the medical field (Hall, 2013). Dunkle, Pies and Saltonstall (2010) note that one of the most important evolutions in rare disease research is in the role of patient advocacy groups. These groups influence research and policy development for the benefit of patients impacted by rare diseases. They explain that "advocacy on behalf of patients with rare diseases is an important element in seeking to assure that federal and worldwide policies address the concerns of these patients, and that policies recognize the unique challenges faced by patients with rare diseases" (Dunkle, Pines, & Saltonstall, 2010, p. 525). In this sense, advocacy groups for rare chronic health conditions engage in democratic processes. They participate in power-mediated knowledge-mobilization processes by influencing how research knowledge is

disseminated to members of the organization and other stakeholders, such as the medical

community, and as noted above, they also influence what gets researched.

Winton and Evans (2016) note that there are always power interactions in any

advocacy work, with one group's benefit impacting other stakeholders' interests. In the case

of rare chronic health condition advocacy groups, they lobby for research and policy change

in relation to their particular disease group, which then has wider impacts on other groups.

Advocacy groups for rare chronic health conditions can interact with the education sector in

the same way, advocating for change in policy to positively impact students affected by a rare

chronic health conditions.

Knowledge mobilization and brokering

It has been reported in the literature that the education system at all levels may not

have enough information and knowledge about rare chronic health conditions and how they

impact students (Asprey & Nash, 2006; West et al., 2013). For this reason, the concepts of

knowledge mobilization and *knowledge brokering* are relevant to the current study. The

extent to which the education system has access to knowledge and information, or takes it up

into practice, as it relates to rare chronic health conditions, is important to the successful

inclusion of these students.

Various definitions and ideas about knowledge mobilization can be found in the

literature, as well as multiple terms, including knowledge transfer, knowledge brokering and

knowledge (see for example Sa´, Li, & Faubert, 2010). For the purposes of this study, the

term knowledge mobilization will be used as it has "gained increasing currency as a way of

thinking about the complex social processes that underpin the cooption, uptake and use

within one sphere of practice of specialised knowledge created in another". (Moss, 2013, p.

237). The word "'mobilization' emphasizes the multi-dimensional, longer-term, purposeful, and interactive nature of the work in comparison to earlier terms that seem to imply a one-directional or linear move from research to practice" (Sa, Li, & Faubert, 2010 p. 503). Levin (2011) defines knowledge mobilization as the uptake of knowledge and research into practice. A key component of knowledge mobilization is that research and knowledge must not simply reach individuals, but rather it must "result in changes in ideas, policies and practices" (Levin, Cooper, Arjomand, & Thompson, 2011, p. 3).

The process of knowledge and research uptake is not a simple or straightforward one (Davies, Nutley, & Walter, 2008). It is a socially mediated process, in which complex organizations and individuals are variables that influence the process (Moss, 2013). Sa, Li, and Faubert, (2011) point to the power relationships inherent in knowledge mobilization. Issues around which research and knowledge gets taken up, and which knowledge does not are involved in this power dynamic (Moss, 2013). As a historically marginalized group (Bourke & Carrington, 2007), students with exceptionalities and chronic health conditions may be further marginalized through this process of prioritizing some research and knowledge over other research.

In addition to knowledge mobilization, an important concept in this research is *knowledge brokering.* Knowledge brokering refers to "people and organizations that move knowledge around and create connections between researchers and their various audiences" (Meyer, 2010, p. 118). Meyer (2010) contends "Knowledge brokering tends to happen in particular locations—in spaces that privilege the brokering of knowledge across boundaries" (p. 119). In the current study, the extent to which the advocacy organizations are sought as knowledge brokers may represent the extent to which their knowledge is valued by

educational organizations. According to Meyer (2010), knowledge brokers not only distribute knowledge, they act on knowledge through "the identification and localization of knowledge, the redistribution and dissemination of knowledge, and the rescaling and transformation of this knowledge. Brokering knowledge thus means far more than simply moving knowledge—it also means transforming knowledge" (p. 120).

Haas (2015) contends that there are three distinct roles in knowledge transfer: boundary spanners, gatekeepers and knowledge brokers. Boundary spanners are those who make contacts outside of their organization, gatekeepers actively decide which knowledge flows into and out of an organization, and operate at the boundary of an organization, and knowledge brokers are involved in knowledge dissemination without actually belonging to either organization (Haas, 2015). In the current study, advocacy organizations can be seen as knowledge brokers in this definition, since they do not belong to either the educational institution or to the health care institution, but have the capacity to disseminate knowledge between the two.

Knowledge brokers act is three distinct ways according to Meyers (2010). They can act as managers of knowledge, "linkage agents (between producers and users of knowledge), or capacity builders (through enhancing access to knowledge)" (Meyers, 2010, p. 121). Meyers (2010) argues that knowledge brokers are in between worlds, and can thus be seen as living on the periphery. This is a useful conception for the current study, as the participants in the study are on the boundary between institutions-medical and education. They are on the periphery of education, and not members, and are also on the periphery of health care, but not members of this institution. They act as knowledge brokers between these two institutions. Meyers (2010) uses the term "double peripherality" to describe the position. According to

Meyers (2010), knowledge brokers have the capacity to disseminate more useful knowledge through the "production of a new kind of knowledge—what we could call brokered knowledge. Brokered knowledge is knowledge made more robust, more accountable, more usable; knowledge that "serves locally" at a given time; knowledge that has been de- and reassembled". (Meyers, 2010, p. 123).

In the current Neoliberal context of schooling, the accountability movement has had significant impacts on school priorities (Hursh, 2000). Moss (2013) highlights the effects that the accountability movement has had on what is researched, and what research actually gets mobilized. This can be seen as a potential source of marginalization for students with exceptionalities, as it has the potential to shift focus and resources away from special education and towards improving scores and rankings (Apple, 2001). For teachers and others trying to mobilize and broker knowledge for the successful inclusion of students with chronic health conditions, these competing priorities within schools and districts may act as additional barriers.

Given the policy context in Ontario and other provinces in Canada, inclusion is the preferred placement for students who have exceptionalities (Ontario Ministry of Education 2009). However, there is still much debate and tension in the literature as to what inclusion should look like, and how it should be practiced (DeLuca, 2013). Policy in Ontario has the potential to be exclusive to certain groups of students (Cobb, 2015), and this may be the case for students who have rare chronic health conditions. Advocacy groups have a potentially important role to play in terms of democratizing policy process (Winton & Evans, 2016). In terms of rare chronic health conditions, advocacy groups have played a key role in terms of research and how it becomes mobilized (Dunkle, Pines & Saltonstall, 2010). In addition to

mobilizing knowledge, advocacy groups for rare chronic heath conditions may have the

potential to become knowledge brokers (Meyers, 2010).

Theoretical Framework

Educational Leadership Perspective

The term leadership in schools can be understood in a variety of ways. Eacott (2013) notes that the very ubiquitousness of the term "leadership" has the potential to render the term itself meaningless. Similarly, Blackmore (2013) contends that leadership "is discursively overworked and theoretically underdone in policy and in much of the literature" (p. 140). Eacott (2013) contests both the ideas of attributism (Higham, Hopkins, & Matthews, 2009), where leadership is understood as a list of personal attributes, and the idea of leadership as a list of specific behaviours as fully capturing what leadership means. Eacott (2013) suggests instead that notions of leadership must be understood within a social context and relationally. He views the school as a field, within which social players perform within external constraints (such as policy, social pressure, economic pressures), and that this field constitutes leadership.

Leadership, for Eacott (2013), is understood as a social construct at the important intersection of social and situational factors, carried out and influenced by key players. The field, which Eacott (2013) views as a school or group of schools, remains somewhat autonomous. Although this field is influenced strongly by outside factors such as policy, the key players within the school maintain a degree of independent functioning within their field. Gunter (2005) also highlights the relational aspect of leadership, noting: "educational leadership is a social practice, is about the interplay between agency and structure" (Gunter, 2005, p. 177).

Using a situated sociologically grounded notion of leadership, the current problem of practice views leadership as the social interactions of key players in the inclusion of students

with rare chronic health conditions. Who these key players are could encompass a variety of

individuals. These could include principals, vice-principals, district leaders, ministry leaders,

policy, and members of advocacy organizations who act within the field of the school, school

district or province, facilitating and supporting inclusion or presenting barriers to it. The

environment these players act within is mediated and influenced by constraints such as

provincial policy, school board policy, economics, social pressures from community, and

other stakeholders within the field (Eacott, 2013).

A key element in leadership practice is the idea of power relationships. Blackmore

(2013) contends that leadership must be understood in a situated way that is "shaped by the

cultural, organizational, structural constraints of place and time" (p. 150). Power then, is an

essential part of understanding leadership practice: power that is politicized and understood

relationally. Examining how power is exercised and manifested, and how political spaces are

created between and among leaders and individuals, as well as institutions, policies and

society, is an important consideration in leadership practice (Rottmann, 2007). This broad

understanding of leadership encompasses the actions and practices of formal and

informal leaders, such as principals, district leaders, Ministry leaders, teachers, and

advocates. This perspective includes a view of leadership as an activity practiced through

policy.

Schmidt and Venet (2012) note that "school administrators set the tone for inclusion in

their schools" (p. 221). The attitude that administrators have towards inclusion impacts the

success of inclusion in schools (Harpell & Andrews, 2010). Leadership at multiple levels has

a key role to play in the success of inclusionary practices (Bennett, 2009). Ryan (2010)

contends that "inclusive efforts, no matter how well intentioned, will not succeed or sustain

themselves if they are not entrenched in the accompanying leadership arrangements" (p. 8).

The process by which leadership impacts inclusive practices is likely not a simple,

straightforward one. Schmidt and Venet (2012) suggest that "the success of inclusion is

thought to be associated with administrators' planning and will, as well as the essential factor

their values, beliefs, and their positive attitude constitute in creating a favourable climate in

which all students in the school can be accepted" (p. 221).

Leadership practice can range from individualistic, based on hierarchical structures, to

more distributed, cooperative practices (Sheppard, Brown, & Dibbon, 2009; Harris & Muijs,

2003; Spillane, 2005). Ryan (2010) discusses the idea of inclusive leadership as leadership in

which multiple people are included in a variety of ways in leadership practice through having

voice in policy and decision-making. Paliokosta and Blandford (2010) contend that

leadership structures can influence the extent that inclusionary practices are implemented.

They suggest that less hierarchically structured leadership can promote inclusionary practices

for students. Pazey and Cole (2012) note that inclusive leaders "engender democratic decision

making and replace hierarchical structures with participatory structures and team based

practices…these leaders believe in the democratic ideals of sharing power and distributing

responsibility so that all members of their educational community have a common

understanding and commitment to serve all students" (p. 259).

Billingsley (2007) examined the role that classroom teachers play in special education

leadership. Billingsley notes that a focus on distributed leadership practice is largely absent

from the literature on inclusive education. Special education teachers (resource teachers)

were found to have an important influence in confronting barriers to successful inclusion

(Billingsley, 2007). York-Barr et al. (2005) frame the work of resource teachers as

leadership. They point to the important "horizontal channels of influence and relationship, as opposed to the vertical channels of hierarchy and positional power" (p. 211) that special education teachers leverage. Framing their work as leadership leads to more collaboration between resource teachers and general education teachers. Collaboration between teachers has been found to be an effective component of successful inclusion for student learning (Bennett & Gallagher, 2013).

AuCoin and Porter (2014) further suggest that resource teachers must act as leaders in order to successfully support exceptional student learners. They found that the role of the resource teacher has shifted from that of a professional working with students directly, to a leadership role where the resource teacher supports general education teachers. This supports the notion that leadership practice that is shared among multiple levels of leadership may be important for special education. Harpell and Andrews (2010) point to teacher empowerment, and involving teachers in important decisions, as an important determinant of the success of inclusion in a school. This focus on empowerment can be understood as distributed leadership practice (Spillane, 2005) in which teachers have voice in important school decisions.

Towards a critical social justice perspective in educational leadership. Research on leadership exists in the literature from a variety of viewpoints. Gunter (2001) argues that the field of educational leadership can be divided into four main approaches: instrumental (reduces leadership to prescribed activities or behaviours), scientific (views leadership success in terms of measurable outcomes and benchmarks), humanistic (concerned with lived narratives of leaders), and critical. Critical perspectives, according to Gunter (2001), are concerned with examining and understanding power relationships. Rather than focusing on

leadership as a position or an individual, critical perspectives focus instead on the

relationship between people, and how power operates in these relationships. The power

relationships that can be examined in a critical perspective include policy, contextual factors,

cultural and other potential sources of inequity or injustice.

For the current study, the conceptual framework that will guide the understanding of

inclusion will be a critical and social justice perspective. In a critical lens in education,

solutions to systemic exclusionary practices are actively sought. Given the historical and

contemporary marginalization of students who have exceptionalities (see for example Valeo,

2010; Ryan, 2012), using a critical framework to examine inclusionary practices for students

with chronic health conditions may have value in identifying barriers to their inclusion in

education. For example, Ryan (2012) highlights the current neoliberal policy shift towards

accountability and market driven forces in education as contributing to the exclusion of

exceptional students. Pazey and Cole (2012) also highlight the difficulty that limited

resources and competing priorities that current educational reform movements create for

leaders even when they are inclusive minded. Slee (2013) notes that while "the volume of

inclusive education discourse is loud, it is inaudible when located amid more strident

educational discourses" (p. 6). He points to standards, accountability and choice discourses as

overshadowing inclusion discourses despite international policy directives towards inclusion.

Within the critical perspective on educational leadership, many researchers also

identify with a social justice aim (Ryan & Rottamann, 2007). Ryan (2013) defines social

justice in inclusion as being "about legitimacy, fairness and welfare" (p. 3). Artiles, et al.,

(2006) note that the view of inclusion as social justice stems in part from the understanding

that students with exceptionalities have been historically marginalized and excluded from a

regular education, and thus implementing change to allow them to be included within

mainstream education is a step towards restoring social justice for those students. Hattam,

Brennan, Zipin and Comber (2009) contend that "media and community discourses tend

toward deficit views" (p. 306) of less advantaged student groups. Bourke and Carrington

(2007) highlight the importance of a paradigm shift that recognizes 'disability' as existing not

just within an individual, but as a construct that is understood and "influenced by the

conventions of social expectations and interactions" (p. 15).

Paliokosta and Blandford (2010) contend that the lack of knowledge and exposure to

various types of exceptionalities as leading educators to revert to medical models of

disability. Slee (2013) notes that the use of experts to diagnose students with disabilities

perpetuates "corresponding belief amongst teachers in regular schools that children

diagnosed with disabilities are best served by expert special educators and therapists" (Slee,

2013, p. 9). DeLuca (2013) points to an important shift in inclusionary environments from a

medical model of disability to what he terms a "social model" of special education, which

recognizes not only the rights and benefits of students with exceptionalities participating in

regular classrooms, but the wider benefits to all students of including and embracing multiple

diverse learners in the classroom. In terms of social justice, DeLuca (2013) notes that this

form of inclusion recognizes inclusive environments as basic human rights for all

individuals. In his framework for inclusivity, DeLuca (2013) advocates for what he terms a

social justice pedagogy that recognizes diversity from multiple sources and actively seeks

sources of exclusion for all students, "reframing the inclusive discourse as a socially

constructed condition" (p. 335).

Importantly, Paliokosta and Blandford (2010) note that schools can be one of the key

areas for promoting social justice within society. Ryan (2013) also highlights the idea that

inclusion can be "one way to promote social justice" (p. 3). Blackmore (2013) argues that

schools "are not separate from society, but constitute a key site in which democratic

citizenship is understood and practiced. Inclusive schooling requires inclusive leadership in

which diversity in and of leader- ship based on democratic processes and practices is a central

aspect of education" (p.148).

Critical Policy Analysis

For the purposes of this study, policy will be understood as "texts and 'things'

(legislation and national strategies) but also as discursive processes that are complexly

configured, contextually mediated and institutionally rendered" (Ball, Maguire, & Braun,

2012, p. 3). Ball (2015) draws a distinction between policy as discourse and policy as text.

He notes that on the one hand "policies are 'contested', mediated and differentially

represented by different actors in different contexts (policy as text), but on the other hand, at

the same time produced and formed by taken-for-granted and implicit knowledges and

assumptions about the world and ourselves (policy as discourse)" (Ball, 2015, p. 311).

Discourses, according to Ball (2015) refer to the implicit, often unarticulated (and sometimes

un-articulable) understandings and ways of being that are taken for grated assumptions

underlying our everyday lives and understandings of truth. Policy as discourse goes far

deeper than the actual words and directives contained in policy documents, but speaks to the

underlying assumptions and understandings of truth that are contained within policy.

Ball, Maguire and Braun (2012) refer to policy enactment rather than policy

implementation. The term enactment reflects the complex, messy process whereby policy is

interpreted and acted upon (or not acted upon), by social actors in specific contexts. This

view of policy as being 'enacted' will guide the interpretations in this research. Policy will be understood as something that lives not only in text form, but that is acted upon in different ways, in a socially mediated, context specific way.

Critical policy analysis, sometimes referred to as CPA, draws on discourse theory and policy analysis; however, it is more contextually and sociologically grounded than policy analysis (Taylor, 1997). Policy analysis has historically been less concerned with methodological issues, and more concerned with theoretical frameworks (Taylor, 1997). Taylor (1997) notes a "growing awareness of methodological issues in education policy work, with an increasing emphasis on issues to do with meaning and, related, a shift towards exploring the effects of policy rather than on policy intentions" (Taylor, 1997, p. 24).

In contrast to traditional policy analysis, which according to Diem, et al. (2014) reflects a positivist orientation, critical policy analysis is context specific and acknowledges the importance of subjective, group specific, time dependent understandings (Diem et al., 2014). Policy is understood not as a static entity, but as a contested space (Winton & Brewer, 2014). Taylor (1997) notes that one distinct feature of critical policy analysis is the extent to which it is considered contextually, in relation to "theoretical frameworks are used to place cultural forms within broader patterns of social inequity and relations of social dominations" (Taylor, 1997, p. 32). Winton and Brewer (2014) note that understandings of policy must be situated in context, that "all policy problems are co-constructions of a historically situated, social world" (p. 1093). Winton and Evans (2016) contend that "policy also includes the discourses, contexts (political, historical, social, economic), texts, groups, and individuals who shape policy decisions (intentionally or otherwise), as well as the actions of individuals who interpret and enact policy in their practice" (Winton & Evans, 2016, p.5). Diem et al.

(2014) point to the shift in global policies towards increased centralized control and

accountability measures in education as a coinciding shift to the trend for policy analysis

researchers to take on a critical theoretical framework.

Critical policy analysis is concerned with issues of power and the relationships

between a given policy and how it might affect a marginalized or silenced group (Diem et al.,

2014). Critical Policy Analysis "aims to understand how policy processes challenge and/or

perpetuate inequities" (Winton & Brewer, 2014, p. 1106). According to Young and Diem

(2014), one "of the main goals of CPA is to shed light on how everyday policies, structures,

and processes perpetuate and reproduce systems of domination and oppression" (p. 1065).

Diem et al. (2014) note that what distinguishes critical policy analysis from other forms of

policy analysis is the focus on action and positively affecting groups of students through the

critical examination of policy. The focus on the possibility of affecting change is a common

theme in critical policy analysis (Taylor, 1997; Diem et al., 2014). This perspective seems

most appropriate for the current research project, as students with exceptionalities are a

historically marginalized group (Valeo, 2009), and continue to be marginalized by neoliberal

trends that privilege marketization, competition and accountability in policy, both globally

and locally (Ryan, 2012).

Another important concept in policy enactment is that of street level bureaucrats.

Lipsky (1993) defines street level bureaucrats as those workers who directly interact with

public policy through their work, and thus have important impacts on the way in which

policy is implemented. Lipsky (1993) contends that street level bureaucrats are important

policy actors in the ways in which policy is lived out and enacted at local levels. Hupe and

Hill (2007) note the importance of the many layers that exist within institutions, and how

policy is lived out at these various levels. Street level bureaucrats have a certain degree of

professional autonomy, and this is an important way in which they interact with policy. Street

level bureaucrats, through their public role, work to enact policy and influence policy

enactment.

This concept of street level bureaucrats relates to the educational leaders and other

educators that work with students who have rare chronic health conditions in the current

study. Educational leaders and other actors can be seen as important policy actors who enact

policy in their specific contexts, and thus act as street level bureaucrats through their

enactment of policy.

Framing the work of advocacy groups and their intersection with educational

leadership and policy for students with rare chronic health conditions within a critical policy

analysis orientation would allow administrators, policy makers and researchers to identify

gaps in policy and improve service for this underserved group. Taylor (1997) notes that

critical policy analysis can be useful not only for researchers and policy makers, but also for

other groups concerned with issues in education policy. As such, this orientation to research

hopes to include the participants (advocacy groups for rare chronic health conditions) in

authentic ways in the active discourse in educational policy issues that may affect children

with rare chronic health conditions within the education system. Thus this research effort

reframes the participants in this project as partners in the research, and advances an

emancipatory research end. Diem et al. (2014) highlight the collaborative nature of critical

policy analysis, and enlisting participants as active social actors who may be empowered by

examining the power differences inherent in educational policy.

This theoretical framework will help to answer the research questions by focusing the analysis on sources of inequity and exclusion for this group. Understanding the connections between advocacy groups for rare chronic health conditions and educational organizations will help identify to what extent these organizations work together, and what the interactions between them are. Looking to understand how policy impacts the inclusion of students with rare chronic health conditions in a contextually, sociologically grounded and situated perspective will allow for some understanding of what the barriers for inclusion might be, and how educational leaders, organizations and policies could be potential sources of exclusion and inequality.

Methodology

In this chapter, the research design and procedures are described. This study utilized a qualitative research methodology. Semi-structured interviews were conducted, transcribed and then analyzed through 2-level coding for themes. Themes were then analyzed in relation to the literature review and the theoretical framework. A policy analysis of Ontario, British Columbia and Alberta special education policy, and Health Canada policy was conducted.

Ethics

This study received ethics approval from Western University's Ethics Review Board. See Appendix A for a copy of the ethics approval form. Informed consent was obtained from participants through a letter of information and consent. In the letter of information and consent, it was explained that participation was being sought to participate in a semi-structured interview about how participants understood their relation to the education sector, and how they might influence policy for the inclusion of students with rare chronic health conditions. Participants were given contact information directing them to whom they might contact should they have any additional questions or concerns. See Appendix C for a copy of the letter of information and consent. The study and interview procedure was explained to participants in detail prior to the interview commencing, and all questions were answered. The steps taken to maintain anonymity were also explained to participants. In order to maintain participant anonymity, it was important that organizations for which participants advocated were not revealed, and pseudonyms were used. This was due to the rarity of the conditions for which the participants were advocating. Revealing the organizations may have allowed the reader to identify individuals who participated in the study.

Qualitative Research Approach

To gain some in depth understanding of how advocacy groups interact with

educational organizations in a context in which identities and relationships are constantly

shifting and developing, a qualitative research methodology was selected. Lincoln (1995)

highlights the value in using qualitative methods to unravel some of the complex, messy

nature of human experience. Education is a multi-layered environment. A qualitative

approach can help to gain insight into how advocacy groups interact with educational leaders

to support their advocacy goals, and how this interaction is situated within a complex system

with multiple layers of leadership and influence. Quantitative methods can be useful for

clarifying causal or correlational relationships, but as Lincoln (1995) notes, human stories

and narrative are rarely simple and rarely have straightforward cause-effect relationships.

Qualitative research methods acknowledge that there is not one 'reality' that can be

objectively understood, and challenge realist views with more socially constructed

understandings about the world (Lee, 2012).

Research Methods

This study adopts a qualitative research perspective in line with the interpretive

paradigm in education research (Gay, Mills & Airasian, 2009). Interpretive research "focuses

on understanding (interpreting) the meanings, purposes, and intentions (interpretations)

people give to their own actions and interactions with others" (Smith, 2008, p. 459).

Interpretive research posits that reality cannot be understood in an objective sense, but rather

only in a constructed sense that is inextricably related to the researcher's and the participants' subjective realities (Smith, 2008). The goal of interpretive research is understanding (Bhattacharya, 2008). Individual research methods are not prescribed as mandatory within the interpretive paradigm, but rather the focus is on building understanding of constructed realities (Smith, 2008). In the current study, semi-structured interviews were used to uncover and understand the participants' constructed and context specific realities. Through this data collection method, it was possible to investigate how members of advocacy organizations, interact with educational leaders and policy. This was an appropriate choice, since the focus of this research was to understand participants' perspectives. "Member-checking", namely, sharing the transcribed interviews with the participants, was used to ensure that participants' descriptions of their realities were captured in a way that they wanted them to be portrayed.

Participants

The participants for this study were members of advocacy organizations who advocate for people with rare chronic health conditions. Advocacy organizations can advocate for rare conditions in general, or can be specific to a particular chronic health condition, such as, but not limited to: cancer, epilepsy, genetic syndromes (for example: Tuberous Sclerosis Complex, Spinal Bifida, Neurofibromatosis 1, hemophilia), congenital syndromes (for example: Spinal Bifida, Type 1 diabetes, Cerebral Palsy), and acquired conditions such as AIDS/HIV, as they would all meet the criteria established for this study as rare chronic health conditions. Participants could be paid staff of advocacy organizations or volunteer members.

Participation for this study was sought through email invitations that were sent to email addresses accessed on publically available websites. The email invitation can be seen

in Appendix B. Seventeen different advocacy organizations were approached to participate.

Participants from five different organizations agreed to participate in the study. The

participants for this study were eight members of advocacy organizations for rare chronic

health conditions. All participants were given pseudonyms to protect their anonymity. For

this study, three participants were men and five were women. Participant ages ranged from

30 years old to late 60s. The short biographies that follow are provided to give the reader

some context about the participants for this study. Pseudonyms are used, and organization

names are removed to protect the participants' anonymity.

Although it would be easier for the reader to know which specific conditions were

represented in this study, because of confidentiality concerns, it was felt that identifying

specific conditions may lead to the ability to identify specific organizations and participants,

due to the rarity of conditions that the participants represented. According to the Tri Council

Policy Statement, TCPS2 (Government of Canada, 2014), information that could indirectly

lead a reader to identify individuals must not be identified in a study. In the current study, the

unique and rare nature of the conditions represented by the advocacy groups may

compromise the confidentiality of participants if revealed.

Participants' Profiles

Amy has her own business, and is a parent of a teenaged child with a rare chronic

health condition. She volunteers as co-chair of a small, all-volunteer advocacy organization,

which she has been involved with for over ten years.

Sandra is involved as co-chair for a small advocacy organization, and as an executive

of a larger national umbrella advocacy organization. She has an adult child who has a rare

chronic health condition. She has been involved with advocacy for over twenty-five years,

and was one of the founders the advocacy organization, which she co-chairs. Sandra works in education.

Carolyn has a teenaged child with a rare chronic health condition, and she works in the home to care for her needs. She volunteers for a small advocacy organization.

Bob volunteers for a small advocacy organization, as well as a larger, national advocacy organization that focuses on policy change. He is himself diagnosed with a rare chronic health condition. Bob works as a university professor.

Steve is also a university professor. He has an adult daughter who is diagnosed with a rare chronic health condition. Steve volunteers and co-founded a national advocacy organization that is not condition specific, but rather works to support families of people diagnosed with rare chronic health conditions.

Sarah works full time in city planning, and is a parent of a young child with a rare chronic health condition. She volunteers on the board of directors for a small volunteer advocacy group.

Henry is retired from the business industry. He is himself diagnosed with a rare chronic health condition. He is involved as president of a small volunteer advocacy organization.

Tracy is educated in the field of education. She currently serves on the executive for a national advocacy organization focused on policy change. Tracy is herself diagnosed with a rare chronic health condition.

Data Collection Instruments and Procedures

Semi structured interviews. Semi-structured interviews were selected to capture the richness of the participants understanding. In this type of interview, there is a list of pre-

determined topics or questions, but the interviewer is allowed to ask follow up questions and request clarifications from the participant. In this sense, the questions "are allowed to evolve as the interview progresses" (Barlow, 2010, p. 499). Interview is an appropriate data collection strategy when "depth of meaning is important and the research is primarily focused in gaining insight and understanding" (Newton, 2010, p. 1). For this research study, semi-structured interviews gave the flexibility to be responsive during interviews and allowed for probing questions to evolve during the course of the discussions with participants.

Barlow (2010) suggests semi structured interviews are effective for researchers who are already familiar with the topic under investigation. As an insider in the topic under investigation, I am familiar with many aspects of it, and used that insider information to help me guide the interview to gain insight into how the participants understood how their organizations interact with education systems.

Semi-structured interviews were conducted with members of advocacy organizations until data saturation occurred. Saturation is "the point in data collection when no new or relevant information emerges" (Saumure & Given, 2008, p. 196). The goal of the research was to interview between six and twelve participants, in the hope that that would be sufficient to reach the data saturation point to analyze themes and trends. After eight interviews, data saturation was achieved.

Interviews were recorded and transcribed. Recording interviews is important, as it allows the researcher to fully capture everything that was said, but does not distract the researcher from being reflexive in the moment during the interview (Firmin, 2008). Since this research was interpretive, the recording of actual words was very important to ensure participants' portrayals of reality were accurately portrayed. Firmin (2008) notes "Words are of utmost

importance to qualitative researchers. Not only are the general ideas salient, but also the

richness in word choices, metaphors, and even slang is salient" (p. 191). The semi-structured

interview questions can be seen in Appendix D.

Document analysis. A critical policy analysis of the Ontario Ministry of Education's

policies for inclusion was conducted to gain a more broad level of understanding of the

current context of inclusion in Ontario. Since not all participants resided in Ontario, inclusion

policy in the provinces of Alberta and British Columbia were also examined. Health

Canada's policy for rare chronic health conditions was also examined to give context to the

examination of challenges to inclusion for this group.

The critical policy analysis was conducted by reading policies several times, and

taking notes on the relevant portions. Policies were examined in order to gain an

understanding of inclusion in Ontario, and other provinces, and to look for areas of tension

and potential areas of exclusion for students with rare chronic health conditions. Health care

policy was examined in relation to rare chronic health conditions in Canada, as well as in

relation to the relationship between provincial and federal bodies in health care. Policy was

examined in relation to the literature review, and then in relation to the findings from

participant interviews.

Establishing trustworthiness. In qualitative research, Lincoln and Guba (1986)

suggest concepts of reliability and validity be replaced with understandings of

trustworthiness. Lincoln and Guba (1986) suggest four criteria for evaluating trustworthiness:

credibility, transferability, dependability and confirmability.

In terms of *credibility*, data triangulation and member checking were used in the

current study. Data triangulation involved looking at data from multiple sources in order to

ensure the consistency of data collected (Morse, 2015). There are four main types of

triangulation: investigator, data, methodological, and theoretical triangulation (Wolfram Cox

& Hassard, 2010). Investigator triangulation involves multiple investigators looking at the

data and analysis, to ensure consistency and robustness of conclusions and analysis. Data

triangulation involves looking at multiple data points to ensure credibility of data and

conclusions. Methodological data triangulation involves using multiple methodologies as a

way to ensure credibility of data and conclusions, and theoretical triangulation involves

analyzing data from different theoretical perspectives to ensure a well-rounded and robust

understanding of the data emerges. In the current study, methodological, investigator and data

triangulation were used. Data triangulation involved conducting multiple interviews to

contrast themes between participants. Methodological triangulation involved the combination

of data sources from policies and participant interviews. Investigator triangulation was also

used in the current study. All interviews, themes and analysis were reviewed and discussed

with the thesis supervisor to ensure robustness of data and consistency of analysis. Using

these three different forms of triangulation added credibility to the current study.

Member checking was also used to enhance credibility. Sandelowski (2008) explains

member checking as a technique in which participants are offered a transcript of their

interviews to ensure they agree with how they portrayed their messages, and to give

participants opportunities to add or clarify their interview. Member checking means that "the

participants add credibility to the qualitative study by having a chance to react to both the

data and the final narrative" (Creswell & Miller, 2000, p. 127). In the current study, all

participants were sent a copy of their verbatim interview transcript and given the opportunity

to comment, expand, alter or refute what had been captured during their interview. Only one participant chose to elaborate and add to her interview transcript.

One method to ensure *confirmability* is through researcher reflexivity. Creswell and Miller (2000) define researcher reflexivity as an important component of critical research, wherein the researcher reflects on their own biases, positioning and perspective, and brackets that perspective throughout the process. Throughout this research study, I have been conducting research as an insider (as a member of an advocacy organization, and as a parent of a child who has a rare chronic health condition). This positioning was not withheld from participants, and was used to help guide questioning.

Although this research aims to understand the reality of the participants, as they see it, it is fully acknowledged that the research is necessarily influenced and guided by the researcher's own personal perspective and bias. In critical research, participants are seen as partners in research, and in this case, being from the same world as the participants (parent of child with health condition and member of advocacy organization) helped to establish this partner perspective, and addressed some power differences inherent in research between researcher and researched (Duncombe & Jessop, 2012). Throughout the research process, the researcher reflected on the various roles that were lived; researcher, parent, advocate, and how these various roles influenced and impacted the research.

Transferability refers to the extent that an outsider can see how the findings of a study can be applied to other times, settings and places (Cohen & Crabtree, 2006). One way to achieve transferability is through thick description (Lincoln & Guba, 1986). In order to ensure the results of this study are transferable, thick, robust description was used. The

interviews that were conducted for the current study are described in chapter five in detail,

with thick description and heavy use of participants' own words.

Dependability refers to the extent to which the analysis is consistent to an outsider to

the research, so he or she would analyze the data and arrive at the findings in a similar way

(Lincon & Guba, 1986). To ensure dependability, throughout the research process the thesis

supervisor acted as an external audit, examining data, ongoing and evolving analysis and

interpretation. In this way the entire process of research has been subject to audit to ensure

dependability.

Data Analysis

Analysis proceeded throughout the data collection process. Constant comparison

analysis was used to identify themes in the data as interviews progressed (Leech &

Onwuegbuzie, 2007). This technique comes from grounded theory (Miles, Huberman &

Salanda, 2014) where the analysis of themes is conducted through inductive procedures.

Patton (2014) suggests that the analysis for themes and coding should be ongoing throughout

the research process, so that questions and follow up probing questions can be continually

refined to look for new and emerging trends in the data. Using this process helped to ensure

that data collected related to the research questions, and that new findings could be explored

with participants as the data collection progressed.

Interviews were transcribed verbatim, and then read multiple times to begin looking

for codes. Codes were decided upon, first deductively in relation to the theoretical framework

and literature review, and then, inductively based on the participants' responses. Interview

transcripts were then placed in a two-column table and codes were colour coded. Once all the

interviews were coded, the codes were organized into broader codes, and redundant codes

were combined and eliminated in a process Miles, Huberman and Saldana (2014) call

subsuming. Coding of data was divided into first and second level coding (Miles, Huberman

& Saldana, 2014). In first level coding, the raw data from interview transcripts were

examined and codes were created. Next, in second level coding, the codes were refined, and

categories were created from the codes identified in the first level. These second level codes

were then distilled and combined into broader themes (Litchman, 2006). Once data were fully

coded and combined into themes, narratives were created for each theme. The narratives

presented the main themes with quotations and ideas from participants. The narratives were

then analyzed in relation to the literature review and the theoretical framework, and were

considered in relation to the research questions. Finally, conclusions were drawn and

recommendations were made.

Analysis

This qualitative study explored complex relationships between advocacy groups for rare

chronic health conditions and educational leadership and policy. The focus of the study was

on inclusion, and how advocacy organizations saw themselves impacting inclusive schooling.

Semi-structured interviews were conducted with members of advocacy organizations for rare

chronic health conditions.

Samure and Given (2008) note that data saturation can be reached more quickly when

a sample is cohesive, and drawn from the same population, rather than from a random

population. In the case of this research study, saturation was reached relatively quickly, since

the participants for the study were all members of advocacy groups for rare chronic health

conditions. Data saturation was achieved after eight interviews. The point of saturation was

determined by examining the emerging themes, field notes, and interview transcripts, and

determining that no new themes or information was emerging.

Coding for the current study was done both inductively and deductively. Miles,

Huberman and Saldana (2014) note that deductive coding involves creating a list of potential

codes on the basis of the literature review before fieldwork is conducted. The deductive codes

developed for this study prior to collecting interviews were: inclusion, advocacy, leadership,

policy and knowledge mobilization. Inductive coding takes place after interviews are

conducted, and involves determining codes based on analysis of the data (Miles, Huberman

& Saldana, 2014). The codes that emerged in this study through inductive coding were:

connecting stakeholders, parents as advocates, advocacy strategies, and the tensions in

understanding inclusion. Once all the interviews were transcribed, they were coded to

identify emerging themes. Themes were identified on the basis of the literature review,

theoretical framework, and on the basis of the ideas that the participants brought up that were

pertinent to issues of inclusion, leadership and policy. Once the main themes were identified,

they were combined and recoded to search for areas overlap, redundancy, and salient

categorical themes.

This chapter is organized around the following themes and subthemes:

- Inclusion
    o *Tensions between understandings of inclusion*
    o *Identified barriers to full inclusion*
- Policy
    o *Policy frameworks for rare diseases*
    o *Inconsistencies in policies*
    o *Narrowness of policies*
    o *Funding challenges*
- Advocacy
    o *Parents as advocates*
    o *Advocacy strategies*
    o *Barriers to advocacy-burdens on parents, time and funding*
- Leadership
    o *Educational leaders as gatekeepers*
- Knowledge Mobilization and Connecting Stakeholders
    o *Knowledge mobilization as mission of organization*
    o *Lack of information*
    o *Roles and responsibilities in knowledge mobilization*
    o *Barriers to knowledge mobilization*
    o *Connecting stakeholders*

Decisions about subthemes and themes were made based on the frequency of

participant responses, the importance of the ideas from the perspective of the participants and

the degree to which the responses support or are in tension with the literature review and

theoretical framework. The selected perspective for analysis was Critical Policy Analysis,

which aims to locate sources of inequity and exclusion within policy and its enactment (Diem

et al., 2014). Blackmore (2013) contends that schools are key places in which democratic

ideals of society can be lived out through inclusion. Thus schools are not apart from society,

but rather are society, and should thus reflect the diversity therein. Paliokosta and Blandford

(2010) posit that schools can be important sources of social justice within society. Likewise,

advocacy groups can be framed as important sources of democratic participation in the

policies formed and enacted by governments and other social actors (Young & Everit, 2010;

Winton & Evans, 2016). In the current study, the themes will be examined from a critical

policy analysis and social justice framework.

Theme 1: Inclusion

Inclusion can be understood in multiple ways (Paliokosta & Blandford, 2010). Many

scholars from the critical perspective view inclusion as a much broader and deeper issue than

just physically placing students who have exceptionalities in classrooms with their age mates

(Schmidt & Venet, 2011). Critical understandings of inclusion characterize it as involving not

only physical placement, but also addressing the societal and systemic barriers to full

participation of diverse people in schools (Artiles, et al., 2006; Erten & Savage, 2012;

Schmidt & Venet, 2011). Authors such as Ryan (2012), DeLuca (2013) and Slee (2001)

challenge prevailing views of inclusion to suggest that until systemic issues are critically

examined and challenged, students who have exceptionalities are likely to experience

exclusion from full participation in mainstream schools.

Participants in this study had different views of inclusion and what it meant, as well

as different opinions about whether or not full inclusion was valuable or desirable for all

students. Some participants felt that full inclusion should always be the goal. Others felt that

there should be more choice of placement for children, depending on their particular needs,

which may include segregation or partial segregation. Some participants felt that full

inclusion was the best placement only if supports were in place to support students. This

theme includes subthemes about the tensions in understanding inclusion and perceived

barriers to inclusion.

Tensions between understandings of inclusion. Participants generally supported

the concept of inclusion, but their views on full inclusion varied. This is supported in

literature that has found parents of children who have exceptionalities have differing opinions

of inclusion (Hess, Molina & Kozleski, 2006; Runswick-Cole, 2008; Leysera & Kirk, 2004).

Participants in this study understood inclusion as students with exceptionalities being

included in mainstream classes with their age mates. In this sense, participants seemed to

understand inclusion more as integration, as in physical placement of students with their age

mates (Artiles, et al., 2006). This is in contrast to ideas of inclusion, which can be understood

as belonging and being fully included within all aspects of schooling (Erten & Savage, 2012;

Bourke & Carrington, 2007), with an examination of systemic barriers to full participation

(DeLuca, 2013; Schmidt & Venet, 2012). Importantlyly, when discussing the wider

implications of inclusion, and the social justice aspects of inclusion, participants seemed to

understand the concept more as inclusion than as integration.

Some participants supported full inclusion. For example, Henry commented that his

organization sometimes heard that "kids are segregated from their friends because they have

this disease and there's fear from the staff that something is going to happen and it will upset

the class. That's the worst thing we can do, I think, is to segregate them from their friends".

Tracy supported the idea of inclusion, saying, "I think it's really important, I think I've seen

it work really successfully". Sandra said, "I believe in inclusion whole heartedly; I know a lot

about it, I know some of the problems that happen with it". Bob differentiated between the

placement of students in inclusive settings and the extent to which they were effectively

included. He said, "school systems are going to eventually need to recognize that while they

are inclusive already, that is we no longer isolate and deny students with rare conditions an

opportunity to be in school, nevertheless we don't know how to integrate them well into the

classroom". Carolyn highlighted a difference between inclusion at a school level and at a

classroom level. She said "I have not experienced any child being denied access to a

'mainstream school', but I am quite experienced with children being denied access to 'full

inclusion classrooms'". These examples again seem to relate to the difference between

inclusion and integration. These comments are consistent with findings that mere classroom

placement is not synonymous with inclusive schooling (Thornton & Underwood, 2013;

Antiles, et al., 2006).

Some participants felt segregated class placements were important options to serve

the needs of diverse children with rare chronic health conditions. Sandra said "I think that a

total inclusion model or a total segregated model are two ends of the spectrum, and I think

you have to find somewhere in the middle that meets the specific needs of the specific

students". Carolyn felt that the placement of a child with a rare chronic health condition in a

full inclusion or segregated class might depend of the type of impacts of the health condition

she/he had. She noted that if the child's challenges were primarily physical, then a fully

inclusive placement would likely be best, but that "might not be the best fit for a

disabled child who also has severe developmental delays or behavioural issues. It would

depend on what types of placements the local school board offers and how much support is

available in a full inclusion classroom". Sandra expanded on the idea of classroom placement

options being tailored to student needs specifically. She stated: "So as much as I believe in

integration, it doesn't meet the needs for every single individual. I think it has to be

balanced". This supports work done by Leysera and Kirk (2004) who found that the extent of impairment influenced the extent to which full inclusion was supported for students with exceptionalities.

Sandra felt that the idea of inclusion need not be limited to academic subjects, saying "if it can't be in math and language arts, then maybe it could be phys-ed or maybe it can be out in the community or maybe it can be all kinds of different things". She felt that the complex learning challenges and needs could sometimes make full inclusion problematic. She noted that in fully inclusive classrooms, students with extremely complex learning needs may not get their needs met without individual supports such as educational assistants (EAs).

Steve felt that full inclusion should be an option as long as students were benefiting in terms of their education. His thoughts about inclusion were focused on what the academic benefit to the students might be. As he put it, "I think where it is appropriate, and where the kids benefit, then I think it is appropriate to have them included, but I think it is necessary to articulate how the kids are benefiting, and making sure that is actually being accomplished". Steve went on to explain that he felt that the decision about whether or not to have a child in an inclusive environment was a complex one, and that the goals and benefits of inclusion should be examined. Steve stated: "I think it's useful to reassess the expectations of having kids, particularly kids with neurological developments in classrooms, but simply saying they don't belong there isn't the answer either". These comments reflect some of the complexities of inclusive placements. While Steve felt students shouldn't be excluded, he questioned the goals of full inclusion. Some authors, such as Antiles, et al. (2006) suggest that inclusive schooling must be aimed at creating educational environments that are responsive to diverse

students. Thus these and other authors might suggest that the question should not be how

students are benefiting academically, but rather how the system is altering to ensure students

who have exceptionalities reach their potential (see Bourke & Carrington, 2007; Erten &

Savage, 2012).

Steve felt that the socialization opportunities of inclusive classrooms were extremely

important to students, and so if they were in segregated classes, then the socialization piece

would need to be addressed elsewhere. This was echoed by Carolyn who said one benefit of

inclusion is "the whole social aspect and, yes it's much better to be integrated into a regular

classroom and get a lot more exposure to regular peers but school is also supposed to be

about learning". Amy saw the options for class placements as too narrow. She felt that there

were situations when a student might have minor learning challenges "but they not be able to

function in a full mainstream class-yes they can be integrated in some classes, however then

they are still put into a smaller classroom that might not be the right fit for them". The lack of

options for placements was seen as a challenge to having student needs met.

Most participants pointed out the value of inclusion of students with rare chronic

health conditions for non-exceptional students. As Sandra put it, "Other people in the

community need to learn about people with special needs and diversity, you can't learn about

it if you are not exposed to it… it's the value to society". Sandra pointed out that "people

who have special medical needs, or special learning needs are not a drain on society". She

summed up by saying "Education is not only to meet the special needs of the special needs

child, its also to teach the rest of the children what a diverse society looks like". Sarah also

expressed a belief that inclusion was important for students in the class who do not have

special needs. She noted, "I think inclusion is a great thing, both for the individual that has

the rare disorder as well as for the other children in the class, because they can learn and it just gives them a lot more exposure to disabilities and I think that's a good thing". Steve echoed this thought saying "I also think there is a benefit to other kids to have kids with chronic conditions and disabilities in classrooms, for kids who don't have those, I think there is a social value to that".

The idea that inclusive school is beneficial for all students is supported by Hess, Molina and Kozleski, (2006) who contend: "inclusive education promotes all students' social growth and does not negatively impact the academic growth of students without disabilities". (Hess, Molina & Kozleski, 2006, p. 150). DeLuca (2013) also contends inclusion has wider social benefits to both students who have exceptionalities as well as students who do not.

The idea of inclusion extended beyond schooling and into general life. Participants felt that inclusion was a larger issue, and that people with rare chronic health conditions may need to contend with inclusion in many areas of life. As Carolyn noted, "The inclusion piece isn't just in the classroom, it follows them all through life… that inclusion/exclusion question comes up again, in fact it comes up in everything". This broader understanding of inclusion fits into the social justice perspective on inclusion. Rioux (1999) posits that "[i]nclusive education, like other issues related to disability, is a barometer. It reflects the degree to which there has been a fundamental movement towards a recognition of human rights. The backlash we feel is not just the backlash towards inclusive education but a statement of the level of resistance to equality more generally" (Rioux, 1999, p. 97). Students with exceptionalities have been a historically marginalized group, and this is one reason using a social justice analysis has value for understanding the barriers to full inclusion for this group (Valeo, 2010; Artiles, et al., 2006; Ryan, 2013). In the next section, an examination of why the participants

in this study supported inclusion in principle but not necessarily in practice will be framed in

a critical policy analysis, seeking potential areas of exclusion and barriers to full inclusion for

these students.

Participants in this study held differing views about inclusive classroom placement for

students with rare chronic health concerns. From a philosophical standpoint, participants

were supportive of inclusion, however from a pragmatic viewpoint, they did not always

support inclusive placements for students with rare chronic health conditions. This is

consistent with findings from Leysera and Kirk (2004), who found that parents of exceptional

children "gave strong support to the inclusion concept from a legal and philosophical

standpoint. They identified social and emotional outcomes as benefits of inclusion, yet were

concerned about possible social isolation, negative attitudes, the quality of instruction,

teacher training and skills, and support from teachers and from other parents" (Leysera &

Kirk, 2004, p. 271). Some participants in this study cited worries that children with

significant impairments may not benefit academically from inclusive placements.

The participants identified themselves in two ways. Some identified as adult rare

disease patients, while some identified as parents of children with rare diseases. Within the

participants who identified as parents, some described their children as more significantly

cognitively impacted by their health condition, and some were less cognitively impacted.

This distinction seemed to impact how participants framed their responses and their opinions

about inclusion. The parents in the study who described their children as more significantly

cognitively impacted were less inclined to be supportive of fully inclusive classroom

placements, while those participants who were parents of children with less significant

cognitive impacts, or who were themselves diagnosed with a rare chronic health condition,

were more supportive of full inclusion. This is consistent with Leysera and Kirk (2004) who

found parents of children who had milder impairments were more likely to support full

inclusion.

It is possible that the participants who were not in favour of inclusive placements may

not have seen examples of successful inclusion, or may not have access to the appropriate

supports in place to facilitate inclusion. Runswick-Cole (2008) has noted that some

researchers feel parents of children with special needs may not be in favour of full inclusion

because "they lack experience of seeing children with special educational needs positively

included in mainstream schools and the wider community" (Runswick-Cole, 2008, p. 76).

She however, favours an analysis based whether parents hold a deficit or a social model of

disability. Disability can be framed as residing within the individual as a deficit (Thornton &

Underwood, 2013), or as residing in socially constructed norms that prevent full participation

due to societal barriers (Ainscow, 2007). Most special education discourses are framed

around a deficit model; for example, according to Cobb (2016) in the province of Ontario,

exceptionality falls within the deficit model of disability. This is in contrast to Erten and

Savage's (2012) assertion that inclusive education is best framed in an ecological model,

whereby systemic and environmental factors that prevent the full participation of diverse

students are examined. This conception of inclusion focuses less on individual, within student

factors and more on systemic constraints.

If the participants' feelings about inclusion or segregation are analyzed in this way, it

is possible to argue that those who supported full inclusion may be viewing inclusion from a

social, ecological model, and those who did not support full inclusion may have been viewing

inclusion from a deficit model. It is possible that the participants in the current study are more

likely to frame their children's disability in this deficit perspective given that the source of

any educational challenges is a medical condition. The frequency with which parents and

adults diagnosed with rare chronic health concerns in this group must deal with professionals

in the medical field may predispose them to frame everything about exceptional children in

terms of a medical model of disability.

Identified barriers to full inclusion. One barrier to full inclusion identified by most

of the participants was the lack of resources. As Sarah put it, "the inclusion needs to be

backed up with additional support in the actual classroom and that requires time, it requires

resources, which you know without policies in place and clear guidelines and implementation

and resources I think that it is more of a challenge". For Sarah, "the resources need to be

there in order to make inclusion successful". Tracy noted that inclusion "has to be paired

with good education and good communication with the people that you're working with, the

other students and teachers, the staff at the school, and it only works when everyone's on

board". Steve said "there just don't seem to be enough resources around, and so often

students and families don't feel that their kids are getting adequate support". This sentiment

was supported by almost all the participants, who felt that lack of resources to support

students was a barrier to their inclusion.

The lack of resources often centred around the allocation of educational assistants

(EAs). Participants felt that there were not enough educational assistants at times to facilitate

full inclusion. Tracy said, "there's just not the money out there to give those kids help that

they need. You know, if they need an assistant and they've cut back on a lot of those

programs and that makes inclusion even more difficult". The lack of EA support was seen to

be an additional burden on inclusion for teachers as well, Tracy explained "you can't

overburden the teacher… the problem is that you're not giving the teacher any support to deal

with the special needs of that child, and I think that's really difficult". The importance of

having educational assistants as part of an education team is documented in the literature

(Mounsteven, 2010).

Amy pointed out that supports offered by EAs may not always be academic supports.

She noted that an EA may be allocated to support the medical needs of a child who has a

chronic health condition, but not the learning needs that may be associated with that

condition. Amy felt that when students were in inclusive placements, any EA support

allocated to the classroom would end up going to students who had behavioral needs rather

than the academic needs of students with rare chronic health conditions. Amy went on to

explain that in order for inclusion to be successful, students need to "have the proper

assistance that they need in the classroom, to develop, to grow, and to be able to have the

same opportunities as any other students who might not have any type of challenges or

medical issues". This is an important perspective, and relates to literature citing lack of

clarity in the role of EAs is sometimes problematic to their work in inclusive settings

(Giangreco, Suter & Doyle, 2010). Educational assistants are often overused as a Band Aid

fix approach to solve special education dilemmas (Mueller, 2003). This can lead to the

'Velcro effect' in which students are attached to an educational assistant as a means of

including them in the classroom. Educational assistants often end up being primarily

responsible for programing and evaluating students' academic programs, which are different

from their classmates (Conley, Gould & Levine, 2009; Giangreco & Doyle, 2002).

Giangreco, Yuan, McKenzie, Cameron and Fialka (2005) posit that "parents seeking

inclusive education through the assignment of an individual, full-time paraprofessional may

be working at cross-purposes with themselves" (Giangreco et al., 2005, p. 29). While they

seek educational assistants as a way to access inclusive classrooms, the assignment of

individual educational assistants to individual students may be a source of marginalization

and segregation, as it separates and stigmatizes students from their peers, limits the amount of

time students spend with teachers, and delays altering educational systems to better

differentiate for diverse learners (Giangreco et al, 2005). Most participants saw the lack of

EAs as a potential barrier to inclusion, rather then looking for systemic barriers to inclusion

within schools. Seeing an EA as the only possible solution to inclusive schooling does not

address inclusion as a diversity issue, in which many diverse learners are accommodated

within the classroom.

Tracy discussed the challenge of rare chronic health conditions not always being

stable in terms of the educational supports needed. Tracy pointed out that many rare chronic

health conditions can be cyclical, so children may require differing levels of support during

different times in their illness. As Tracy put it, "inclusion has to look at the cycle of the

disease. You have to understand that it's not straight line, the kid or child or teenager is going

to have a lot of needs at some point and then there's a period where they don't have as many

needs. You've got to be able to have the flexibility". Steve echoed this need for flexibility

saying "the need for support is variable with some of these kids, the issues are not necessarily

consistent over time, you know they can vary, so what they need for several months may not

necessarily be what they need several months later, depending on flare ups on the conditions

or something like that". The identification process does not allow for flexible levels of

support, and this lack of flexibility in educational supports was seen as a barrier to inclusion.

This notion that supports may need to be flexible to follow fluctuations in rare chronic health

concerns challenges prevailing views of exceptionality as stable, permanent deficiencies

residing within a student (Slee, 2001). It is interesting that this deficit perspective comes from

a medical model of disability, and yet, in this case, a medical diagnosis may not lead to

stable, permanent needs for supports for students diagnosed with these conditions.

One challenge to inclusion noted by participants in the current study was attendance

issues experienced by students with rare chronic health conditions. Participants reported that

it was difficult for students to experience academic success when they had to miss school for

appointments and hospitalizations. This is documented in the literature as a challenge for

students with chronic health conditions (Mukherjee, Lightfoot, & Sloper, 2000; West et al.,

2013). Participants suggested this was an area where effective communication, as well as

school level policy could be helpful to facilitate the inclusion of these students. Especially in

cases where chronic absenteeism was somewhat regular, it was suggested that this could be a

policy gap that could be addressed to facilitate inclusion for these students.

Participants in this study noted some potential barriers to full inclusion for students

with rare chronic health conditions. One of the barriers identified was a lack of funding for

supports for students. Another was a lack of flexibility in the supports available. Chronic

absenteeism was also a potential challenge for students with rare chronic health concerns in

inclusive classrooms.

Theme 2: Policy

A key question in this research was how can the work of advocacy organizations

inform or improve current practices and policies on inclusion for students with rare chronic

health conditions in schools? This theme addresses this question by highlighting areas of

policy that intersect with the work of the advocacy organizations represented in this study.

Participants saw policy as a key issue in inclusive schooling for students with rare chronic

health conditions: inconsistency of policies, as well as the variability in policy enactment,

were both seen as important issues for students with rare chronic health conditions, both in

terms of health care and education.

Overall, participants felt there was a lack of specific policy that addressed students

with rare chronic health conditions. There was also a feeling that there was inconsistency of

policy at the school board level and inconsistency of application of provincial policy at

school boards. Some policy, for example policies around identification of exceptionality,

were seen as too narrow to allow for students to access supports that may be necessary to

their successful inclusion. Policy itself varied, as did what Ball, Maguire and Braun (2012)

term "policy enactment"; that is the way that policy is interpreted, translated and acted upon

by various stakeholders in their specific contexts. According to Winton and Brewer (2014),

policy is not a fixed and constant thing, but rather policy is a contested space that is created

and recreated based on contextual and time and place dependent variables (Diem, et al.,

2014). Participants in the current study felt that textual policy itself, as well as policy

enactment, was important to students with rare chronic health conditions.

Critical policy analysis looks for ways that policies and structures can perpetuate

exclusion (Young & Diem, 2014). By examining how policy may impact inclusive practices

for this group of students, advocacy organizations may be able to influence positive policy

change, as well as policy enactment, for inclusive practices for students with rare chronic

health conditions. In order to tease out the nuances of this complex theme, it is divided into

subthemes of policy framework for rare diseases, inconsistencies in policies, narrow policy

and funding challenges.

Policy framework for rare diseases. Several participants mentioned the lack of a

rare disease framework policy in Canada, and highlighted the fact that Canada is the one of

the only developed countries without a rare disease policy (Lee & Wong, 2014). Some of the

participants are involved in advocacy work for a national advocacy organization whose

mandate is to lobby for a national policy, so it is not surprising that they highlighted the

importance of this lack of policy as a key issue for people with rare diseases.

Sandra said "[our organization] has really been lately involved in advocating for a

rare disease framework. All developed countries, other then Canada, have a rare disease

framework and an orphan drug policy". Bob explained, "we've been trying to work for a

national rare disease strategy, at the federal level…establishing a framework whereby all of

the provinces could begin to tie in". Tracy said, "We are looking for a framework for rare

diseases from health Canada. We were promised in 2012, and we still don't have it. Canada is

the only developed country who doesn't have a rare disease framework [or] a special policy

to deal with rare diseases". These participants felt that the lack of a rare disease framework in

Canada was a serious issue for people with rare chronic health conditions.

This vacuum was seen to impact access, not only to treatments, but also educational

opportunities for this population. Sarah felt that there was a lack of policies in general to

address the needs of students with rare chronic health conditions. She felt that advocacy

organizations "need to lobby the government to raise awareness, but also to promote the need

for, I guess, overarching policies, to ensure that those children with rare disorders are safe in

school. I think that's really important". She felt that the lack of policies had the potential to impact student safety as well as what services they had access to.

The lack of a rare disease framework in Canada, and specific education policy, were seen as a serious barrier to equitable access to medical services, treatments, and education services. Health care falls under provincial policy in a similar way to education. There is a federal Health Canada body that regulates some aspects of health care in Canada (Health Canada, 2010). In education, although policy is provincial, the provinces' policies must comply with federal policy imperatives such as section 15 of the Canadian Charter of Rights and Freedoms, which guarantees equal rights and prohibits discrimination based on mental or physical disability (Government of Canada, 2013). In the same way that there is no federal level rare disease policy, there is no federal inclusion policy or specific federal policy pertaining to the inclusion of students with rare chronic health conditions. This lack of unifying policy, which confirms findings from other studies (DeLuca, 2012), has been highlighted as a potential barrier to inclusion in Canada.

Each province sets their own educational policies and interprets the Canadian Charter of Rights and Freedoms how they see appropriate. This interaction between provincial and federal policy can be seen in examples such as Eaton vs. Brant County School Board (School Advocacy Hamilton, 2006) in which a family wished for their child, Emily Eaton, to have an inclusive school placement, but the Supreme Court of Canada determined that a segregated classroom was in her best interest. This overturned an earlier provincial court decision that ruled in the parents favor granting their child an inclusive placement. This decision is seen by some (see for example Rioux, 1999) as a discriminatory move against inclusion and against social justice. In the current study, not all participants felt that inclusive school placements

were always the best placement for students with rare chronic health conditions. However, all

participants supported the idea of inclusion from a social justice perspective. It is possible

that having clearer, unified federal policy around inclusion could be helpful to students with

chronic health conditions. However, these federal policies would only be beneficial for

students with rare chronic health conditions if they were in support of inclusion and inclusive

placements, and if inclusive placements were the desired placement for families of children

with rare chronic health conditions. It is possible that once parents of children who have rare

chronic health conditions are exposed to inclusion from an equity and diversity perspective,

their views on inclusion for their child in school may align more closely with their views of

inclusion philosophically.

Inconsistencies in policies. Participants in the study noted that inconsistency in

policies impacted people with rare chronic health conditions. Inconsistency of policy from

province to province, or region to region, impacted the care of individuals with rare chronic

health conditions. Sandra and Tracy highlighted the parallels between diversity of health care

policy and education policy. Sarah felt that there seemed to be "a lack of overarching policies

that deal with these illnesses, so it just leads to very different levels of support". The majority

of the participants felt there was diversity of inclusion policies for rare health conditions from

school board to school board.

In addition to inconsistency of policy, participants felt that the application of policy

could vary between schools, leading to differing amounts of supports and access to inclusive

classrooms. Sandra used the term 'postal code lottery' referring to the fact that depending on

where you live, your services and access to supports will vary. As she explains, "there is a lot

of advocacy around changing policy at the federal government level, at the provincial

government levels with the drug plan managers, that kind of thing, to try and bring some

consistency across the county for a) treatment, and b) access to medications, because of what

they call the 'Postal Code lottery'. Depending of what province you live in and what disease

you happen to get, depends on the treatments you can get and if you can access medication

for it" She noted a parallel in the education system, highlighting the variation in policy for

special education. She explained special education is seen as "too costly, each person who

has special needs costs more then the regular students … it may be more expensive to

provide some services to students in education when they have special needs" Henry also felt

that where you live might impact what you have access to. He explained: "it's a crapshoot on

who you end up having to deal with, on your success rate, what school board you are in, what

province you are in. What rules there are in place and what the attitude there is in any given

school".

Carolyn felt that there was variability between types of schools, especially between

the public and Catholic school boards. She pointed out: "not all the rules apply across all the

school boards, and not all the same rules apply across the types of schools. Here in Ontario

there are small placement classrooms in some boards, I don't know if all boards have them or

not". In contrast, she felt the "Catholic system does not believe in small placement

classrooms. All of the Catholic boards that I am familiar with, none of them have small

placement classrooms. They believe in 100% inclusion, that may or may not be a good thing,

depending on whether or not they are financially able to support those kids in full inclusion".

Sarah echoed this difference between school boards and their policies around inclusion and

resource allocation: "Without an overarching policy, school boards and even schools within

those school boards manage these children very differently and provide varying levels of

support, and so I think my one message is to get together with organizations, get information,

and develop policies".

These finding are consistent with the People for Education's (2015) findings that

there is much diversity between school boards in how they enact special education policy.

Ball, Maguire and Braun (2012) discuss an important dimension in policy is not only the

policy itself as it lives in textual form, but the enactment of policy in contextual ways by

actors who interpret and act on policy. The diversity of policy between schools can be seen as

this diversity in enactment. Although the Ministry of Ontario (2005) clearly states special

education services will be offered to students, the structure of special education services

varies from district to district (People for Education, 2015). For some districts, this might

mean they offer segregated classes as potential placements, while other districts may only

offer full inclusion placements. This inconsistency in application of policy also speaks to the

various understandings of what inclusion is, and what it should look like (Bennett &

Gallagher, 2013). This diversity of policy enactment can impact inclusion of students with

rare chronic health conditions in terms of the placements they may have access to as well as

the supports that are available to them within inclusive environments.

These differences in both policy and the application and enactment of policy from

school board to school board and from school to school were seen as a potential barrier to

accessing inclusive environments and the supports needed for successful inclusion.

Participants in this study felt there was a need to develop rare disease frameworks and

policies, and to build consensus around these policies. There are potentially broader issues of

inequality and systemic barriers to full inclusion for this group of students. Critical policy

analysis perspectives suggest looking for systemic sources of inequality and exclusion when

examining policy (Young & Diem, 2014). The inconsistency of policy and its enactment

identified in the current study is an example of a potential systemic source of exclusion.

Narrowness of policies. Some participants felt that the policies in place to receive

supports for exceptional students are too narrow. Often students with rare chronic health

conditions do not fit into the Ontario Ministry of Education's (Ontario Ministry of Education,

2011) categories of exceptionality, and may not be identified as exceptional. The official

identification as an exceptional student is often required in order to access special education

supports, such as educational assistants (EAs). In Ontario, the provision of formal special

education support is provided on the basis of identification in the IPRC (Identification,

Placement and Review Committee) process (Ontario Ministry of Education, 1990).

Identification is based on five categories: behavior, communication, intellectual, physical,

and multiple (Ontario Ministry of education, 2011). Any students falling outside of these

particular categories do not qualify for formal special education supports, such as educational

assistants, special equipment, additional programs, coaches and special education teachers.

Cobb (2016) contends that the identification process is itself a barrier to special education,

and "until the present policy and funding model changes, identification is a powerful

gatekeeper in the province". (Cobb, 2016, p. 53).

Carolyn explained it this way: "If you don't fit into a narrow box, you can't get the

support you might need. There are only certain categories of exceptionality, and you might

meet criteria in several of them, but not enough to be in that category, so you may not qualify

for support". Steve pointed out that the lack of specific diagnoses could also act as a barrier

since policy for supports were narrow. As he put it "the notion of having a diagnosis is one of

those bottle necks that are difficult to get through and it becomes one of those ways of

screening who should and who shouldn't receive services". Steve went on to discus the

importance of having a clear idea of what the actual needs of students were instead of broad

categories in terms of supporting inclusion and the allocation of resources. He said "having a

clearer picture of what the actual populations are that school boards are working with would

be useful. I think it is done on a simple category by category need rather then asking what are

the particular needs in each of the classrooms". Sarah felt that this was an area where

advocacy organizations had the potential to influence policies for students with rare chronic

health conditions. She noted "patient organizations can have a lot of influence on this and,

you know, lobby and work with the government to make policies that actually support the

needs of those with rare disorders." Steve came back to the idea of focusing on actual

student needs rather than diagnoses later in the interview, saying

> if you are labeling rare disease kids as rare disease kids, you are looking at the
>
> disease, rather than their functional needs, and this is the major problem… usually
>
> school boards require a diagnosis, they require something from the doctor with a
>
> diagnosis, and the focus is on the diagnosis, not on what the functional needs are.

Amy also found the policies around placement, as well as the options for placement were far

too narrow. She felt that the placements were either fully inclusive classrooms, where the

student may not get supports that are needed such as educational assistants, or segregated

classrooms that might have children with much higher needs. She felt there was nothing in

between those two extremes, and so there may not be an appropriate placement that might fit

the needs of a child with minor impairments. Carolyn pointed to the complex interaction

between funding, policy and placement. She noted:

> the right placement and right amount of support to ensure any child with any
>
> disability is learning as much as they can is often compromised due to a lack of
>
> funding. Having a child with a rare chronic health condition identified by their school
>
> board might not help in obtaining additional educational funds since the government
>
> rules for funding are rather rigid.

This idea that funding and supports are allocated based on Ministry policy that defines

exceptionalities as specific categories that students with rare chronic health conditions may or

may not fit into was seen as a barrier to successful inclusion.

The need for formal identification by experts in the psychology and medical fields

perpetuates notions of disability as residing within students, and being the jurisdiction of

experts to both diagnose and treat. As Slee (2013) notes, "Over time, expert knowledge about

childhood disorders and disabilities has driven a corresponding belief amongst teachers in

regular schools that children diagnosed with disabilities are best served by expert special

educators and therapists. Regular children are the business of regular teachers" (Slee, 2013, p.

9). The categorical nature of the identification process in Ontario represents a

medical/deficient view of students with special education needs. It perpetuates the view that

students with exceptionalities are outside of what is considered normal, and are deficient in

some way (Erten & Savage, 2012; Thornton & Underwood, 2013).

Slee (2013) contends that the "discourse of inclusion has insinuated itself into the

vocabulary and texts of education jurisdictions, but the language shields long-standing views

of normality and abnormality and of the roles of special and regular education. The discourse

of special education has not been dislodged by inclusive education". (Slee, 2013, p. 9). If

students are not formally identified, they may not be able to access inclusive classrooms.

Cobb (2016) points out, "If special education support is provided to offer an equitable and

inclusive atmosphere in schools, then non- identification is ultimately an issue of access and

inclusion" (Cobb, 2016, p. 54). For students with rare chronic health conditions, it would

seem that this identification dilemma was a particular barrier to their ability to access

supports. Having a rare chronic health condition would not guarantee qualification under one

of the Ministry of Education's definitions of exceptionality, thus this is a potential source of

exclusion from inclusive schooling for these students.

The language in the Ontario Ministry of Education's policy is supportive of the ideals

of inclusion, defining it as: "Education that is based on the principles of acceptance and

inclusion of all students. Students see themselves reflected in their curriculum, their physical

surroundings, and the broader environment, in which diversity is honoured and all individuals

are respected" (Ontario Ministry of Education, 2009). However, its enactment in practice,

due to diversity of policy application, funding challenges, challenges to access supports due

to a medical disability model categorical identification processes, can be a source exclusion.

As Slee notes "The language of inclusion is often deployed to shield the practice of

exclusion" (Slee, 2013, p. 14). The inclusion discourses contained within policies in Ontario

and elsewhere do not guarantee corresponding inclusive experiences for students.

Funding challenges. The majority of participants saw funding as a major barrier to

successful inclusion. The lack of funding was seen to lead to a lack of support personnel such

as educational assistants (EAs), as well as budgetary cuts that lead to larger class sizes that

may be an additional challenge to inclusion. Participants also felt there was a lack of

placement options for students with rare chronic health conditions. This speaks to the lack of

models of inclusion that address systemic sources of exclusion. Parents may not feel

segregated class options are necessary if systemic issues are addressed to be inclusive of all

diverse learners. This tension between wanting inclusion and wanting segregated class

placements may be an artifact of students with rare chronic health conditions not currently

having their needs met within the mainstream classroom. This is again the tension between

integration and inclusion (Erten & Savage, 2012).

Carolyn explained the importance of understanding funding in advocacy work:

"another piece of advocating for the right help is understanding the dollars and the dollar

flows, understanding who has the money, and what they can or cannot do with the money

they have". Carolyn explained that children could "generate funds" for the school because of

mixed diagnoses, but that "other kids who don't have the same mix, and may or may not

generate the funds to support the needs that they have. So that's another system that is rather

flawed". Carolyn explained that the identification process itself was expensive and time

consuming, which could be a barrier to accessing funding for special education services. She

noted that "there could be children who are identified but are coping well, and there could be

children who are not identified who do not cope". Most participants mentioned funding as a

barrier to inclusion.

Participants in this study highlighted the idea that funding itself and the relation

between policy and funding were barriers to successful inclusion. Funding challenges were

seen to lead to a lack of resources that could facilitate inclusion such as educational assistants

(EAs). Policy associated with the identification process was identified as a barrier, as students

with rare chronic health conditions did not always qualify for funding supports, and funding

challenges caused longer wait times to access identification processes.

Participants in this study felt that funding for special education services and supports

were a major challenge to inclusive schooling for students with rare chronic health

conditions. Neoliberal competition for resources is seen by some researchers (see for

example, Ryan, 2012; Pazey & Cole, 2012) as decreasing attention and resources towards

special education. For example, some researchers (see for example, Ryan, 2012) contend that

resources that could potentially support students with exceptionalities are funneled towards

raising scores on standardized tests. The focus becomes those students who are seen as

potentially being able to achieve the desired outcome on standardized tests rather than on

those students who are exceptional, and may not achieve a desired score on standardized

tests, even with intervention. As Slee (2013) notes, "inclusive education is reduced to a battle

to secure additional resources, often in the form of a teaching assistant, a special teaching

room or an alternative placement" (Slee, 2013, p. 9). The lack of funding was felt to be a

policy issue at multiple levels of the school system. Participants felt this reflected Ministry

funding of special education, as well as district and school level policy decisions about

special education resource allocation.

Participants saw policy as an important determinant of the success of inclusion in

terms of access to funding and supports, as well as to access to various classroom placements.

Inconsistency of policy, and its enactment, was also an important factor identified by

participants in this study. Participants in this study highlighted complex interactions between

policy, leadership at multiple levels, and advocacy groups for people with rare chronic health

conditions.

Theme 3: Advocacy

In the context of this study, advocacy organizations are defined as groups wishing to

influence government but not to govern (Young & Everitt, 2010). However, given the

overlapping roles of some participants as both advocacy organization members and parents of

children with rare chronic health conditions, some aspects of this theme reflect the identities

of participants as parents and as advocates. This theme of advocacy addresses part of the

research question, how can the work of advocacy organizations inform or improve current

practices and policies on inclusion for students with rare chronic health conditions in

schools? This theme is divided into subsections about parents as advocates, advocacy

strategies and barriers to advocacy work.

Parents as advocates. Parents were seen as a crucial first point of contact in terms of

advocacy and knowledge mobilization. This is consistent with the literature, which has found

that parents acting as advocates had a vital role in influencing inclusion policy (Erten &

Savage, 2012). As Carolyn put it: "All families should prepare, in advance, adequate

information about their child's health condition so that they can educate all staff and possibly

even classroom peers about the condition so that the child is more readily accepted and their

condition understood". Participants felt that parents must have a role in advocacy with

educational organizations.

Most participants highlighted an important aspect of their advocacy organization's

work as training parents to take on an advocacy role within the school system for their child.

Amy said "I think as far as advocacy for our organization, we do our best to do that by giving

information to our families, our supporters, I would say it is important to ensure that our

supporters know that it is constant advocacy with the boards and the schools". Carolyn felt

that advocacy organizations had a key role in helping families by "providing materials that

enable families to advocate for the appropriate education of their child with a rare chronic

health condition". Sandra also highlighted a key mission of her organization as teaching

advocacy. She said "We've been doing these expert patient training sessions and mentoring

them". Carolyn spoke about her advocacy group bringing in guest speakers to train parents

how to advocate within the school system. The session focused on "the IEP, and talking

about the IPRC [Individual Placement and Review Committee] and talking about how you

approach the different levels of education if you feel that your child's needs are not being met

adequately in the classroom". Steve also spoke about the importance of providing advocacy

training to parents to enable them to engage with the education of their child. His

organization also provides training to parents, and part of the training focused on what to

expect during meetings about Individual Education Plans (IEPs), as well as for following up

on them, as he felt "in some schools, its seen as an activity that is done once a year, maybe

twice a year, but there is very little monitoring that is done over the course of time in between

the formal sessions".

Carolyn felt that advocacy organizations who have a "strong provincial presence may

be able to assist families of a child with a rare chronic health condition in obtaining

the educational placement they want and/or to educate the local school and board about a

condition. However, many health charities lack the funding and/or staff to provide these services". Bob spoke about how training patients to be advocates was often an effective way to allow those within their own advocacy organizations to engage in their own advocacy work. He explained "by providing resources and training for members of these individual groups, [they] become, in a sense, ambassadors for their particular organization". Tracy echoed this idea, saying "we let our disease groups do that work…we train patient advocates where we teach them the system and what you need to be an advocate, what knowledge you need, so we train basically expert patients". Training members of advocacy groups to act as advocates was seen by many participants as an important function and an important way to engage with the field of education.

Training members of advocacy organizations to act as advocates can be seen as increasing the democratization of education policy for students with rare chronic health conditions (Young & Everitt, 2010; Winton & Evans, 2016). Advocacy groups in the current study relied on a larger, umbrella organization, as well as outside experts to help in training members to act as advocates. Part of this process was teaching members how education policy worked, and what to advocate for during formal meetings such as IPRCs. This allows more people to engage with policy application directly, increasing the democratic participation of members.

Advocacy strategies. Although the focus of the current study is on advocacy organizations, many of the participants also referred to their own personal work as parent advocates, as well as advocates acting on behalf of organizations. These roles often merged during the interviews. There were many advocacy strategies employed by participants in this

study. Table 2 shows an overview of strategies, followed by a description of the strategies

used by participants in this study.

Table 2

Advocacy Strategies used by Participants

Advocacy Strategy	Description	Example of Advocacy Strategy	Reference
Intuitive Advocacy	Advocacy based on intuitive understanding of what is needed.	Participants advocating for particular school placement for their own child	Trainor (2010)
Strategist	Advocacy based on understanding of special education procedures and policies	Training members, such as parents, to work as advocates	Trainor (2010)
Disability Expert	Advocacy based on expert knowledge	Participants mobilizing knowledge about the chronic health condition for which they advocate	Trainor (2010)
Agent of Change	Advocating for systemic change as a strategy	Participants advocating for policy change, such as a rare disease framework	Trainor (2010)
Insider Advocacy also known as Informal Advocacy	Advocacy directed towards perceived 'friends'; advocacy is based on relationship and communication	Participants advocating at local school directly with educational leader	Gormley and Cymrot (2006); Young and Everitt (2010)
Outsider Advocacy also known as Formal Advocacy	Advocacy directed towards perceived 'enemies'; advocacy is based on there not being pre-existing relationships	Participants participating in rallies, media campaigns and information campaigns	Gormley and Cymrot (2006); Young and Everitt (2010)

Trainor (2010) suggests that parents can act as advocates in four different ways: as intuitive advocates, as strategists, as disability experts and as agents of change. The participants in this study acted as advocates in all of these roles, depending on the situation. They acted as intuitive advocates when they focused on what placements they felt were best for their own children, and for their members' children. They acted as disability experts in their efforts to mobilize knowledge about their conditions for educational leaders and the public. They acted as strategists when appealing directly to educational leaders to effect change, or to gain supports for their child, or their members' children, in the education system. They also act as strategists when they train their members to advocate on behalf of their children in the education system. Finally, the participants in this study act as agents of change when they lobby governments and ministries to enact policies on behalf of people affected by rare chronic health conditions. This can be seen in the current study through the actions of advocacy groups to lobby the federal government to enact a rare disease policy framework.

Gormley and Cymrot (2006) note that advocacy groups direct their advocacy towards perceived "friends" or "enemies", and this influences how they advocate, using insider and outsider strategies. Working directly with school leaders, and emphasizing relationship and communication is an example of advocating using an insider approach. In contrast, advocating for changes in policy directed at the government through media campaigns and policy briefs is an example of outsider advocacy. The extent to which insider or outsider advocacy strategies are used in the current study reflects the purpose of the advocacy. The participants tended to use insider strategies when advocating for their own child within the

school system, and training other parents to act on behalf of their children. An example of

this is when participants spoke of the importance of building relationships and

communicating with school staff on an ongoing basis. Outsider strategies were used when

advocating for policy and systemic changes. An example of the use of outsider strategies can

be seen in participants' discussions about lobbying the government for rare disease policies

and when participants worked to influence policy change. Most participants in this study used

both advocacy strategies in their advocacy work.

Barriers to advocacy-burdens on parents, time and funding. One of the main

barriers identified by participants was a lack of time and energy to do their advocacy work.

The participants were all volunteers with their advocacy originations. Some worked full time

outside of the home, some stayed home to care for children who had rare chronic health

conditions and one was retired. All mentioned the difficulty of finding enough time and

energy to volunteer in their advocacy efforts. For participants who were also parents of

children with rare chronic health conditions, the burdens of parenting a child with rare

chronic health conditions was another major barrier to their advocacy. They felt that their

parenting role involved advocacy for every aspect of their child's life, including broader

inclusion in society, friendships, securing services and leisure activities. The challenge of

parenting a child with a chronic health condition is well documented in the literature (Miller

et. al, 2009; Asprey & Nash, 2006), so it is not surprising that this surfaced as a barrier to

advocacy. School districts may need to consider the burdens faced by these parents when

engaging with them to include their children in inclusive schools.

One participant noted that with such limited resources, it was important to prioritize advocacy efforts. Currently many participants felt the biggest need was to advocate for a rare disease framework policy within Canada to help people with rare diseases access medications and care, and to equalize access across the provinces. Education was seen as very important, but with limited resources, concentrated advocacy for education was seen as something that would have to come after a rare disease framework policy was in place. One participant felt that federal policy aimed at inclusion for students with rare chronic health conditions could be modeled after a federal rare disease strategy was enacted.

Advocacy was seen as something that happened in many aspects of life, not just education. Amy said "I think that anything that has to do with children with chronic health conditions, there is always advocacy work that has to be done, whether it is medical, education, life skills". Sandra similarly stated that everything a parent did for their child who has special needs was advocacy, noting:

> When you are doing advocacy and you have a special needs child, you are not only doing advocacy for education, you are doing advocacy for treatment, you are doing advocacy for services, you are doing advocacy for community things, you have to advocate to have kids to come to a birthday party, every single thing to do with a special needs child has to be advocated for!

Henry also saw time as a major barrier to doing advocacy work. Since the advocacy organizations in this study are volunteer-based, time and funds often prevent their advocacy work. He said "When you are dealing with a volunteer organization, you have a finite amount of resources, both financial and human resources, and we're a very, very small charity group because of the rarity of the disease".

Steve felt that the burdens on parents were compounded by structural and institutional

factors of schools and other institutions such as health care. He felt that " many of the

problems that parents face are not disease specific, they really have to do with the kinds of

institutions that families have to deal with". Steve felt that families had difficulty when they

were unsure of what to advocate for and how to work with Individual Education Plans, and

schools were unsure "what the needs of the family are…almost all of these weaknesses in the

system are issues that have to be dealt with by the parents for lack of the institutional

resources, so that compounds the burdens on parents in addition to dealing with the medical

issues themselves". This supports Zaretsky's (2004) assertion that challenges of lack of

understanding can contribute to difficulties for parents of exceptional children working with

school leaders. Carolyn also felt that advocacy put a large burden on families. She explained,

"it is sad that families have to advocate so strongly and often fight to obtain the education

that their child legally is entitled to. The process does not stop there either. Many families

have to fight for post secondary opportunities, job placements, acceptance in society". Ryan

and Runswick-Cole (2009) further suggest that parents of children who have exceptionalities

must deal with large numbers of professionals, and this can further add to the burdens for this

group. The burdens of advocacy were compounded in the current study by the burdens of

parenting children with rare chronic health conditions for many participants.

Some participants felt that the term advocacy itself could be a barrier to engaging in

advocacy work. For example, Sandra felt that sometimes misperceptions about the word

advocacy itself could serve as a barrier. She felt there "is a barrier there around perception

and around what people think is advocating and what people actually perceive it to be too".

This was seen as a potential barrier to engaging in advocacy work, as other people might

have a negative understanding of advocacy work. This is consistent with Young and Everitt's

(2010) finding that advocacy groups were sometime viewed in a negative light, as narrow

interest groups, and that the term advocacy could sometimes be used pejoratively.

Some of the barriers to advocacy identified in this study were the lack of resources in

terms of time and funding. The burdens of parenting a child with a rare chronic health

conditions was seen as a barrier in engaging in advocacy work. Misconceptions about the

meaning of advocacy was also seen as a potential barrier to advocacy.

Theme 4: Leadership

Participants identified a connection between educational leaders and their work as

advocates. The participants in this study felt that school leaders were very important to the

inclusive school experience of students with rare chronic health conditions. This is not

surprising, given previous reports of school leaders' importance to the success of inclusion

(Schmidt & Venet, 2012; Harpell & Andrews, 2010; Bennett, 2009). Eacott (2013) contends

that leadership is best understood as socially situated, as various social actors relate to one

another. In the current study, participants spoke of the importance of relationships with

leaders in education for the successful schooling of students with rare chronic health

conditions. Communication with educational leaders was also noted by participants in the

current study as very important, which is in line with Miller, et. al.'s (2009) work which

found that a lack communication with the school could be a barrier to students' success in the

school system.

Participants felt that educational leaders had much power over how inclusion policy

was enacted. Leaders were seen to mediate policy within the structure of the school system.

So, for example, some participants felt that the principal could have great influence over the allocation of educational supports such as educational assistants. Another participant spoke of the ability of principals to strictly adhere to, or to bend, policy in order to better accommodate students. This is an example of how policy actors enact policy (Ball, Maguire & Braun, 2012). For Ball, Maguire and Braun (2012), policy enactment refers to the complex process in which policy is interpreted and acted upon in context by social actors. Thus policy enactment is an interpretive, messy process that is mediated by contextual factors. Critical perspectives focus on power relationships when looking at leadership (Gunter, 2001). The relationships identified in the current study often related to the school principal, who was seen to have great influence in terms of enacting policy. This is consistent with critical policy analysis, which highlights power of the social actors involved in policy enactment (Diem, et al., 2014; Winton & Evans, 2016). The Ministry level of leadership was seen by some participants as an important determinant of inclusive policy, and thus an important target of advocacy activities, while other participants felt that the principal was an important mediator of policy, and thus should be a target of advocacy efforts.

Developing effective partnerships and connections between advocacy organizations and multiple levels of educational leadership is likely the best way to achieve effective policies to support the inclusion of students with rare chronic health conditions. Since policy lives in both texts and in contextual, situationally dependant fields (Winton & Brewet, 2014; Taylor, 1997; Ball, 2015), targeting advocacy at Ministry levels of leadership to develop textual policy, as well as at local school leadership levels to impact the enactment of those policies is potentially the most effective strategy.

In the current study, participants referred to principals as school leaders. They had

several different ideas about what the interaction between educational leaders and advocacy

groups might be. Sarah felt that communication and willingness to learn on the part of

principals was an important factor to the success of inclusion. She stated that inclusion could

be successful "as long as teachers and principals are willing to learn and develop an IEP

[Individual Educational Plan], specific to that child, and have a more individualized care

plan". Sarah also saw a role for principals in terms of ensuring information about conditions

was sought out and that resources were allocated to support students with rare chronic health

conditions. She saw an important role for advocacy organizations as being key resources that

principals could seek out for current information and knowledge. As will be noted in the next

chapter (Ch. 6), advocacy organizations have the potential to become "knowledge brokers"

where greater partnerships could be created between advocacy organizations and school

leaders.

Henry felt that in order to influence policy change, it was important to specifically

engage with leaders in education. He said "there's no point in wasting your time chasing

smoke with individuals who don't have any authority and have no influence with the decision

maker. You have to find out, in the system, who can make a decision, or who can influence a

decision". Henry felt that change could be initiated most effectively by targeting leaders at

every level in education, but most importantly at the Ministry level, in order to mobilize the

organization's agenda. He elaborated on this idea, stating that directing advocacy work

"school board by school board or school by school, that just isn't going to happen. We have

to do it at the ministry level in every province". This view that multiple levels of leadership

play an important role in inclusive schooling is consistent with the literature, which has found

that school leaders are very important for the inclusive practices in their schools, and that

multiple levels of school leadership structure contribute to this (Pazey & Cole, 2012; Ryan,

2010). Overall, participants had differing views of how their roles interacted with educational

leaders at multiple levels, but many felt there was an important interaction between their

work and educational leaders' work.

       Educational leaders as 'gatekeepers'. Participants identified several barriers to

engaging with educational leaders at multiple levels. Bob highlighted the fact that school

systems and leaders are often overburdened, and may not be open to additional demands in

accommodating for students with rare chronic health conditions. However, he saw the

importance of partnering with leaders, and offering assistance as a way to encourage leaders

to be onside with the needs of students. Competing demands on school systems have been

noted as potential barriers to inclusion (Pazey & Cole, 2012). Neoliberal accountability

pressures place additional pressures on school systems in terms of achievement and

measurable student outcomes. (Ryan, 2012; Pazey & Cole, 2012; Ball, 1998). Slee (2013)

notes that inclusive discourses, although represented in textual policy, are overshadowed by

other discourses such as accountability and standardization pressures. In the current study,

participants felt that getting their message to educational leaders was sometimes challenging

because the school system seemed to be overburdened already with competing demands.

       Carolyn pointed out that while education leaders at different levels might have

knowledge and understanding about a child's rare chronic health condition, this information

does not always make it from leaders to teachers who are working with students. Leaders,

then, are seen as potential gatekeepers of knowledge. She said, "I'm not sure who needs to be

taking the initiative to have the school boards more aware. And sometimes just because the

school board is aware, doesn't mean the information is going to float down to the other

levels". This also relates to how knowledge is mobilized, which is examined in a later section.

Steve felt that an important barrier to inclusion is the leaders' potential lack of information and misunderstanding about the impact of rare diseases. He felt that "starting simply at the top gets you only so far because again there is not an understanding of what the particular needs are, and again, I think often the particular actual needs are not appreciated and are over generalized". Steve felt that one important step would be to "begin with the people on the front lines to get them to identify what the systemic constraints are, and then working with supervisory personnel to deal with those". This relates to the idea of how what Lipsky (1993) terms street level bureaucrats. The educators working on the front lines as Steve notes, are important enactors of policy in action, and thus may be an important starting point in terms of identifying potential barriers to inclusive practices in schools for students with rare chronic health conditions.

Henry also felt that principals had a lot of power in terms of inclusive practices, and saw them as gatekeepers in terms of which policies were strictly adhered to or not. He explains, "Because the principal has a massive amount of authority, … you'll have some who will just knock themselves out, and do everything in their power and even go against the rules to try and figure out what's best for the child and those who just follow the rules". This idea also relates to the extent to which school leaders acted as gatekeepers in terms of the enactment of inclusion policies.

Some participants felt that although teachers might be open to the idea of inclusion, one of the barriers was reluctance of teachers to accommodate students with rare chronic health concerns. As Steve explained "I think systems are not particularly well designed to

accommodate individualized needs, and so there's an assumption that a kid with any problem is going to involve a whole range of issues that often is not necessarily the case". Educational leaders may not know the potential impacts of a diagnosis of a rare chronic health condition, and this may impact their ability to accommodate for students with rare chronic health conditions. This is in line with West et al. (2013) who found very little understanding on the part of school personnel about rare chronic health conditions.

Sandra also felt there was sometimes reluctance on the part of educators to accommodate rare chronic health conditions. She explains, "You are asking teachers or educational assistants or admins, school secretaries to become experts in medication and then because of the legal and litigious side of that, there is a lot of angst around that". Steve echoed this idea, and discussed how sometimes simple diagnoses were not the best way for teachers to understand the actual demands of the child with rare chronic conditions. The feeling was that an overestimation of what the demands of a condition may be could cause anxiety on the part of educators. Focusing on diagnoses may not be the most useful way to understand the needs of individual students in inclusive classrooms.

Participants identified several ways in which educational leaders acted as potential gatekeepers. Educational leaders at the school level could act as gatekeepers by deciding on what priorities for the school were. As one participant pointed out, educational systems are already overburdened, so deciding to engage with advocacy groups about rare chronic health conditions would be an additional burden to take on for leaders. They may decide they do not have the time or resources to devote to an issue that may affect only a small number of students. School leaders also acted as gatekeepers when they did not ensure information about rare chronic health conditions was spread to multiple levels of the organization. In this

way, they were gatekeepers of information. Finally, leaders sometimes misunderstood or over

or under estimated the impacts of a rare chronic health condition, and would decide not to

engage due to misunderstandings of what the potential impacts could be. If inclusion is

framed as a diversity and equity issue, then the understanding of educational leaders has the

potential to move more towards focusing on individual student needs, whether they are health

related or otherwise, rather then focusing on categorical diagnoses.

Theme 5: Knowledge Mobilization and Connecting Stakeholders

One of the main research questions in this study was: how can the collaboration and

communication between schools, school districts, ministries and advocacy organizations be

improved to support the wellbeing of students with chronic rare health conditions? This

theme addresses how collaboration and communication between schools, school districts,

ministries and advocacy organizations be improved to support the wellbeing of students with

rare chronic health conditions by addressing some areas of knowledge mobilization and

connections about rare chronic health conditions.

The process of knowledge and research uptake is not a simple or straightforward one

(Davies, Nutley & Walter, 2008). It is a socially mediated process, in which complex

organizations and individuals are variables that influence the process (Moss, 2013). Sa, Li,

and Faubert, (2011) point to the power relationships inherent in knowledge mobilization.

Issues around which research and knowledge gets taken up, and which knowledge does not

are involved in this power dynamic (Moss, 2013).

The importance of knowledge mobilization for advocacy groups surfaced in the study

in several respects. Participants spoke of the importance of knowledge mobilization to their

role as an advocacy organization. They saw knowledge mobilization as an important function

in terms of the medical community; in terms of building understanding among medical

professional, as well as in education. Most felt that the education field did not have enough

information and understanding about rare chronic health conditions. Some participants felt

that policy around knowledge mobilization was lacking.

In terms of connections, participants spoke of the importance of creating connections

between parents of children with rare chronic health conditions. They saw creating

connections as an important part of their role as advocacy organizations. Another way

connections came up was in relation to creating connections between health organizations

and school systems, which participants saw as lacking. Finally participants saw creating

partnerships, and the loss of partnerships, between various agencies such as schools, school

nurses and occupational therapists were challenges to successful inclusion for students with

rare health conditions.

Knowledge mobilization as mission of organization. Most participants pointed to

knowledge mobilization as central to their mission as an advocacy organization. For example,

Amy said, "I think our biggest mission as an organization is raising awareness". Other

participants also described raising awareness and educating about their disorder as a key

mission of their advocacy organization. Knowledge mobilization is a socially mediated

process, with various stakeholders interacting to mobilize knowledge (Moss, 2013). In this

sense, the advocacy groups who participated in this study felt it was central to their role to act

as an agent of knowledge mobilization. This is consistent with research findings that

advocacy groups for rare chronic health conditions play an important role in directing and

disseminating research about their conditions (Hall, 2013; Dunkle, Pies & Saltonstall, 2010).

Lack of information. Most participants felt that schools systems didn't have enough

information about rare diseases in general. For example, Tracy said, "There's very little

understanding of rare diseases, I mean if you've got a child in your class who is diabetic, you

are probably going to get some training, you'll get someone from the Diabetes society,

there's pamphlets". She felt that with more common health conditions, people may have

some background knowledge, or know someone who has the condition, but by contrast, "with

rare diseases, no one knows what to do with those kids and you know if there's no advocacy

group that's producing a kit for schools then you're really in trouble". Sandra said "they

don't know what they don't know! And yet, if they knew some of it, I think it would help

them a lot. It would help them, it would help the kids". Sarah felt that educators needed to be

well informed about health conditions that students have. She felt that "if they know that they

have a student in that school with some type of medical condition, they need to get better

with learning and understanding that medical condition. I realize they are not doctors, but

they do need to understand what is going with those kids". She felt that schools "have a

responsibility to understand what their student needs are and they need to get that

information. Whether it is from the health sector or from patient organizations." Amy also

felt that leaders at a school had a responsibility to understand the needs of students with rare

chronic health conditions in their school. She felt that whether "it's a principal understanding,

whether it's a teacher, …there needs to be experts as well amongst our teachers that are

knowledgeable on the different conditions that are out there, .. it should be mandatory for

information to be given to those teachers, they should become experts". Amy felt this was an

important role for advocacy organizations, stating "I think they need to have current

information and seek out advice from ptient organizations and get that education and training

in order to be able to truly understand what each individual student needs." This lack of

understanding and knowledge about chronic health conditions has been reported as a

challenge in the literature (Asprey & Nash, 2006; West, et al., 2013).

Participants felt there was a lack of knowledge and understanding in general about

rare chronic health conditions in the education field. This was seen by participants as

something the education system needed to improve at in order to better meet the needs of

students with rare chronic health conditions.

Roles and responsibilities in knowledge mobilization. Although participants in this

study felt that there was a lack of information and knowledge about rare chronic health

conditions, they were unsure how knowledge might best be mobilized to address this issue in

education. There was lack of clarity from advocacy groups about whose responsibility it

should be to seek out information about rare diseases. Sarah said, "I think they have a

responsibility to have current information about the disorder and seek advice about the

disorder. Seek out maybe some education and training about the disorder. I think, I mean, I

don't know really whose responsibility would be, whether it would be the agency kind of

reaching out to the school board, on behalf of an individual with [the condition] or whether or

not it's a school board that would be responsible". This lack of clarity about roles was seen as

a barrier.

Tracy felt that the rarity "of a condition may impede families in obtaining the best education for their child because school boards often rely on their psychologists and staff in assessing what a child is capable of - and yet they might not be well versed in the condition the child has". She further pointed to a lack of understanding about health conditions as potentially impacting understanding of what challenges a student is experiencing. She noted "Certain physical conditions can also mimic developmental impairment, for example, seizures can affect focus, mobility issues can affect the child's ability to work at the same speed at their peers". A lack of understanding some of the impacts of a condition in this case may impact how educators interpret what is happening with the child.

Participants felt that there needed to be awareness and understanding among teachers and leaders about specific conditions. Sarah felt that there should perhaps be a policy in place for training about the medical conditions students have. Overall, participants in this study felt that there should be more knowledge mobilization about rare chronic health conditions, but were unsure whose responsibility this should be. This is an area where advocacy groups may have great value in acting as brokers of knowledge. Knowledge brokers, according to Meyers (2010), are individuals who are outside of the institutions, but can help to bring knowledge from one world to another. They bridge the gap between institutions (Haas, 2015).

Barriers to knowledge mobilization. One of the barriers to knowledge mobilization was a lack of access to resources and information. Amy said, "There is so little I think resources available for educators themselves". Sandra pointed out "there's not a lot of resources for that kind of training". Carolyn noted that "part of that is because of the fact that [health condition] is considered a rare disorder, so there is a huge disconnect of the education

system understanding what having [health condition] means for a child in school". The rarity

of rare chronic health conditions presented an additional barrier to knowledge mobilization.

One of the key ideas in knowledge mobilization is not only access to information, but

also its dissemination to the proper people and its use in practice (Moss, 2010). As Carolyn

pointed out "I think the school boards across the province don't know enough about the

medical conditions. I'm not sure who needs to be taking the initiative to have the school

boards more aware. And sometimes just because the school board is aware, doesn't mean the

information is going to float down to the other levels". Knowledge mobilization is a process

that is mediated by power relationships (Sa, Li, & Faubert, 2011). Educational leaders have

the power to decide which knowledge gets taken up and brought to the educators who will be

working with the students directly. In this example, Carolyn is discussing the idea that

although knowledge might be present at the district level, it does not necessarily get

mobilized down to the classroom level.

In the current study, advocacy groups for chronic health conditions must work hard in

a crowded educational landscape to raise awareness of their particular condition. Zaretsky

(2004) highlights competing pressures from Neoliberal agendas and accountability discourses

as a barrier for parent advocates of students with special needs working effectively with

educational leaders. Advocacy groups for rare chronic health conditions have been shown to

have a key role in mobilizing knowledge and influencing both research and policy (Dunkle,

Pines & Saltonstall, 2010). Advocacy organizations, through "research mediation and

translation help democratize research and policy by making research accessible to a broader

range of individuals who in turn can participate more knowledgably in policy processes and

make decisions based on a broader range of information" (Winton & Evans, 2016, p. 22).

Advocacy groups can influence policy due to their "capacity to collect, interpret, and utilize

education research in policy processes" (Winton & Evans, 2016, p. 5). The participants in

this study worked as advocates to influence policy development for a rare disease strategy.

They also influenced how knowledge is taken up through their interactions with both medical

professionals and with educational leaders.

Respondents also reported that not all parents of children with chronic health

conditions were comfortable sharing information about rare chronic health condition

diagnoses with the school system for fear of stigmatization, and that this was a potential

barrier to the child's full inclusion. For example, Henry felt that parents sometimes "want to

be really protective and don't want to share that information widely because of variety

reasons…But I think that parents have to become educated first of all and then they have to

be willing to talk to the teachers and to identify certain things that happened to them". Henry

went on to state that it was important for parents to keep educators informed about health

conditions, as "you anticipate the worst but you, and you plan for that, but on the other hand

you hope that life can go on as normal as possible." Bob also felt there was sometimes a

reluctance on the part of parents to share in formation. He also thought hesitation of parents

to share too much information was due to fear of stigmatization. Cobb (2016) has highlighted

what he calls the non-identification dilemma, where many students are unidentified by the

formal IPRC process, and thus do not qualify for special education supports. By setting up

what Cobb (2016) calls an either/or paradigm of exceptional/normal, the policy and process

to formally identify students in order to qualify for special education supports is not

supportive of true inclusion. Fear of stigmatization and labels is one of the barriers to the

formal IPRC process (Cobb, 2016). In the current study, this was seen as a barrier to fully

accessing special education supports and thus fully accessing education in mainstream

classrooms.

Parents needed to balance worries about stigmatization with a need to share important

information about chronic health conditions. Barriers to knowledge mobilization in the

current study were seen as lack of resources, rarity of the conditions and parents' hesitation to

share information.

Connecting stakeholders. The participants in this study felt that making connections

between parents of children with rare chronic health conditions was an important part of their

mission. Steve said "what we try to do is get families together so that they can learn from

other families about strategies to deal with these various institutions". Similarly, Sarah felt

that organizing opportunities for families to get together was very important as "it just gives

people the opportunity to meet and talk with others that are going through the same thing,

especially when it's a rare disorder, its priceless to meet others" She felt creating these

connections gave parents opportunities to "get a sense of what's going on with them in terms

of school, you see what kind of support they're getting, you see what kind of challenges they

have". Most participants felt that creating connections between families who are affected by a

rare chronic health condition was a key aspect of the advocacy organization's role.

Ryan and Runswick-Cole (2009) note that for mothers of children with disabilities,

advocacy groups give them opportunities to feel valued and to gain support from one another.

Within the advocacy groups, Ryan and Runswick-Cole (2009) suggest that mothers of

children with disabilities have opportunities to have valued social capital within the group.

Hall (2013) notes the importance of advocates forming together in groups to learn from each

other, allowing groups "that have just started out together with more experienced groups so

they can learn about organisation, priorities, means of communication, and what works and

doesn't work"(Hall, 2013, p. 1021). In the current study, the national umbrella organization

of which several of the smaller groups were members, acted as a resource to smaller groups

and individuals, teaching them how to advocate for their disease group. The creation of

connections between families was also important in terms of empowering family members to

take on an advocacy role within the school system.

Connections were also seen as important in terms of a lack of partnerships between

various agencies and the education system. Henry felt that there were not very strong

connections between the advocacy organizations and the education system. As he put it "I

think they could do a lot there. I think both sides could do a lot there. I don't think we can put

all the onus on the education system". Amy felt that there was a lack of connections between

the Ministry of education and advocacy groups for rare chronic health conditions. She felt

"there could be better communication between organizations, and I'm not just saying [our

organization], I think organizations in general, as far as the community, I think that definitely

they have a huge role… there is lack of communication". Sarah also felt creating better

connections between education and health care would be important for students with rare

chronic health conditions. She felt it was challenging to work with school boards, but that it

was important to work together "as a partner to help the school board develop clear policies

and guidelines to support students with rare disorders. I guess it's just more the willingness of

both the organization and education board to work together". She also mentioned the

important role advocacy organizations could play in providing information to education

systems if they had better connections. This again suggests an important role for advocacy

organizations as knowledge brokers (Meyers, 2010). This lack of communication and

connection was seen by participants in this study as a challenge for students with rare chronic

health conditions.

Several participants felt that community partnerships with other professionals such as

nurses and therapists had decreased in recent years, and that this was a barrier for inclusion of

students with rare chronic health concerns. Sandra felt that partnerships had decreased over

the years as funding decreased. She felt this was a strain on inclusive environments. She

noted that school systems had multiple partnerships with health care as well as various

services providers, but that " Those partnerships have really taken a strain too with the lack of

resources, and that's everybody, I mean it's not just the education system but its the health

care system is resource challenged and all those associated services as well…but the

connections are key". Tracy agreed with that sentiment, pointing out that "years ago there

were nurses in the schools!" Henry also felt the lack of school nurses was a barrier for

students with rare chronic health conditions. He felt that the lack of school nurses is a "major

failure of the system when it comes to rare diseases. I mean, is that nurse going to be an

expert in all rare diseases, no, but they can become knowledgeable about the rare diseases for

the children in that school". Henry wondered if the nurse had been taken away due to

funding cuts. Tracy also felt that the lack of communication and partnerships was in part due

to funding cut backs. She said "There's very little communication with the healthcare field

now, I find, There's just not much, the services are so cut back so I think that's really

unfortunate". Greater connections between health care and education is a need that has been

documented in the literature (Asprey & Nash, 2006; Nabors, et al., 2008; Olson et. al., 2004).

Steve felt that there was no one tasked with coordinating services for families in Canada, and that lack of service coordination was a barrier to inclusive environments. He said "But there doesn't seem to be anyone in a position to do the coordination of, other then the parents, at least in Canadian systems". The lack of a person or policy attached to care and service coordination is a potential barrier to accessing services (Miller et al., 2009). The lack of connections between health care and education was seen by participants in this study to be a challenge and potential barrier to inclusion for students with rare health conditions.

A lack of connections between the education system and the medical field is well documented in the literature for students with chronic health conditions (Asprey & Nash, 2006; Nabors, et al., 2008; Olson, et. al., 2004). Miller et al. (2009) found that the complex services, including health care and education, that families of children with rare chronic health conditions need to navigate are not well coordinated. Advocacy groups contain much specialized expertise about their particular rare chronic health condition. Within the current study, several participants noted that their group acted as a source of expertise for doctors and other members of the medical fields. This knowledge and expertise is underutilized by the education sector. It is possible that advocacy groups for rare chronic health conditions could act as an important intermediary, or knowledge broker, between the medical and educational institutions.

Summary and Conclusion

This qualitative study investigated how advocacy groups for students with rare

chronic health conditions understand their relations with the education sector. In order to

address the research questions, semi structured interviews were conducted with participants

who were members of these advocacy groups. This chapter summarizes the findings in terms

of the main themes identified in the research. The main findings from this study can be

divided into five key themes: inclusion, policy, advocacy, leadership and knowledge

mobilization/connecting stakeholders. The chapter will examine how those themes addressed

the research questions. Recommendations based on the findings from this study, as well as

future research directions, are also suggested.

Inclusion surfaced as a main theme in this research study. Tensions around

participants' understanding of inclusion emerged, in that all participants supported a broader,

social justice oriented view of inclusion, but not all participants viewed inclusive school

settings as the best placements for students with rare chronic health conditions. This tension

reflected the various understandings of inclusion, ranging from integration to full inclusion

(Artiles, Harris-Murri & Rostenberg, 2006). Possible reasons for this tension between

participants' views of inclusion may be influenced by several factors, such as lack of funding

for supports for students with rare chronic health conditions, narrow policies and

identification processes for students, and lack of exposure to models of full inclusion for

students with exceptionalities. Also, tensions result from a desire to have appropriate

supports in place and a worry of being 'labelled' as deviant and not normal.

Participants felt some barriers to inclusion were lack of funding for supports, lack of

understanding about what the students' with rare chronic health conditions needs are, and

concomitant issues such as chronic absenteeism. This study identified much complexity in

the inclusion of students with rare chronic health conditions from the perspective of the

advocates for this population.

The impacts of policy on inclusion for students with rare chronic health concerns was

a strong theme in the current study. Participants felt that policy, or the lack of it, impacted

inclusion of students with rare chronic health concerns. Indeed, the lack of policy specific to

this group in both the health care and the educational fields was a concern shared by the

participants. They also felt existing policies were too narrow, and that in the particular case of

the Ontario Ministry of Education (2011), the identification policy was restrictive, and in

itself, a source of exclusion. Students with rare chronic health concerns were not always able

to access appropriate supports, as they did not always qualify as "exceptional" under the

policy. Inconsistency of policies and inconsistency in policy enactment were also seen as

ways policy presented potential barriers to inclusion for students with rare chronic health

concerns. For example, there was variation in inclusive policy from school district to school

district, and even from school to school within districts. The extent to which educational

leaders, such as principals, enacted inclusion policy varied greatly from school to school,

impacting the inclusive experience for students, depending on what school they might attend.

From a critical policy analysis perspective (Diam et. al, 2014), the impacts of policy

on inclusion for students with rare chronic health conditions was seen as a barrier to access,

and a source of exclusion. Policy in Ontario specifies a formal identification process (IPRC)

that students must go through in order to formally qualify for special education supports. This

formal identification process perpetuates a medical/deficit view of students with

exceptionalities, and itself poses challenges for true inclusionary environments that would see

a broader acceptance of diversity and would challenge prevailing views of normalcy that are

deeply entrenched in the educational domain. Although policy rhetoric is supportive of

inclusion, other competing policies such as those focused on accountability and

standardization are challenges to inclusion of diverse students. From a social justice

perspective, if school systems are in fact a reflection of society, they should reflect the

diversity that exists within society, and systemic barriers to the full inclusion of students with

rare chronic health conditions should be addressed.

Advocacy was an important theme in the current study. Participants employed

different advocacy strategies depending on the purpose and context of their advocacy.

Gormley and Cymrot (2006) note a distinction between insider advocacies strategies, which

are advocacy strategies directed towards perceived friends, and outsider advocacy strategies

that are directed towards perceived enemies. Insider advocacy could involve discussions with

policy makers and participating in policy proceedings, while outsider strategies involve

things like media campaigns, letter writing, and demonstrations. Young and Everitt (2010)

note a similar distinction in advocacy strategy, but use the terms formal and informal

advocacy strategies. When advocating for their own children, they often used insider

advocacy and emphasized relationship and communication. They worked as intuitive

advocates, relying on what they intuitively felt was necessary to advocate for. When

advocating for larger, systemic and policy changes, such as a rare disease policy framework,

advocacy organizations utilized outsider advocacy, and acted as strategists and agents of

change, focusing their advocacy in more formal ways. One important strategy that emerged

was to teach parent members of organizations to act as advocates within the school system. In

this way, advocacy organizations enabled individuals to employ insider advocacy by

developing relationships and communication with educational leaders while advocating for

appropriate supports and placements for their children.

Advocacy must occur at multiple levels-from parents acting as advocates with school

leaders, to advocacy organizations interacting with districts and ministries. The specific

advocacy strategies used in these various interactions vary, but advocacy at these multiple

levels is essential. Given the situational, context specific enactment and interpretation of

policy, communication on a local scale has the potential to influence the enactment of policy

for specific schools and districts. Larger scale advocacy, such as that conducted by advocacy

groups in this study who were working to advocate for a rare disease strategy, has the

potential to influence textual policy that then can be enacted at local levels. This highlights

the importance of doing advocacy at multiple levels of the system.

Several barriers to advocacy work surfaced in this study. A lack of time and energy

for advocacy work was identified as a challenge, as all the participants were volunteers with

their respective organizations. Competing demands from other causes, and from neoliberal

demands on educational systems, such as accountability movements, efficiency discourses,

and standardized testing regimes, was another barrier to advocacy work. A final barrier

identified by participants to engaging in advocacy work was the additional burden of being a

parent of a child with a rare chronic health condition. Parents of children who have chronic

health conditions need to engage in advocacy work in many contexts, not just in the

education field, and so may feel already overburdened with the additional demands placed on

them from the medical conditions their children have. They have additional demands in the

care of their children in terms of their health care, which may cause additional burdens on

this parent population.

In terms of educational leadership, participants felt there were important ways that educational leaders impacted the schooling of children with rare chronic health conditions in terms of their allocation of resources and enactment of policy. Participants saw leaders as potentially important mediators of policy, as well as potential brokers of knowledge. Principals, as educational leaders, have much influence over how inclusive policy is enacted within their school. Participants felt that this can happen through the allocation of resources and supports such as educational assistants. However, there are deeper systemic issues that educational leaders can also have much influence over in terms of inclusive policy. Although much inclusive policy in Ontario and other provinces appears to respect and encourage diversity within the classroom, in practice inclusion policies, such as the Ministry of Ontario's (2011) identification of exceptionality policy, serve to be sources of exclusion and stigmatization, rather than inclusion. Simply increasing funding towards education supports will not address systemic issues of inequity and diversity in education. Increasing the number of educational assistants is not necessarily an effective solution, and is often viewed as a Band Aid solution to larger systemic issues (Giangreco, & Doyle, 2002). Only by addressing educational systems and looking for ways to live out policies that espouse inclusion and acceptance of diversity within the classroom, can leaders encourage inclusive practices.

The final theme that emerged in this study was that of knowledge mobilization/connections with stakeholders. Creating connections was seen as an important activity for advocacy organizations. Connections that were seen as important were those created between parents of children with rare chronic health conditions, and between various health and educational agencies. There was a lack of connections in general between the medical and educational spheres, and this was a potential barrier to inclusion. Overall,

participants felt there was not enough knowledge and understanding about rare chronic health

conditions in the education system. This knowledge mobilization is a power-mediated

process, whereby information deemed important becomes mobilized, while information that

is deemed less important may not become mobilized. In this way, a lack of knowledge

mobilization was a potential source of exclusion for these students.

Advocacy groups have the potential to act as important knowledge brokers to fill the

void between the medical and educational spheres. Creating better connections between these

two fields could be helpful for the inclusion of students with rare chronic health conditions.

These connections may facilitate knowledge mobilization about these conditions and about

supports needed for students. Advocacy groups for rare chronic health conditions represent

an underutilized source of expertise that could be better leveraged by the education system.

They could act as an important intermediary between the medical and educational fields.

The themes identified in the study address the research questions. In the following

section, each research question is presented, along with a description of how the questions

were answered through this study.

**How do advocacy groups perceive the role of educational organizations in achieving
their mission of advocating for students with chronic health conditions?**

In this study, the participants felt that educational leaders at multiple levels had a role

in achieving the goals of their organizations. Most participants identified knowledge

mobilization as a key goal of their organization. Although participants felt there was not

enough knowledge and information in school systems about rare chronic health conditions,

they felt that school leaders had a role, and in fact a responsibility, to mobilize knowledge

about rare chronic health conditions to help facilitate inclusion of students. In this way,

educational organizations could support one of the key roles of advocacy organizations,

which is knowledge mobilization.

Advocacy organizations for rare chronic health conditions have important knowledge

and information about the rare conditions they advocate for, and thus are important sources of

information for school systems. Young and Everitt (2010) note that one important function of

advocacy groups in Canada is to help make informed policy decisions based on expertise

contained within the group, that may not be understood by the policy maker, or policy

enactor. In the current study, one of the key missions of the advocacy groups was to effect

policy change to better support students with rare chronic health conditions. Educational

organizations and policy makers, then, can support the goals of advocacy organizations by

seeking out important expertise contained within advocacy organizations when making

policy decisions and when enacting policy that impacts students with rare chronic health

conditions.

Another important function of advocacy groups according to Young and Everitt

(2010) is to "make governments more responsive to citizens by informing them of views of

segments of the population affected by a policy" (Young & Everitt, 2010, p. 21). In this

sense, advocacy organizations can help governments and policy makers understand some of

the issues that affect students with rare chronic health conditions, and how policies impact

their inclusion.

Not all participants in this study felt that inclusive placements were the best

placements for all students with rare chronic health conditions. Many participants felt there

were not enough placement options for students with rare chronic health conditions, or felt

that placements in inclusive classrooms were not well supported. The extent to which

ministry policy and school districts offered a variety of placements, and supports such as

educational assistants (EAs) for those placements, was seen as an important way educational

organizations could support the work of advocacy organizations. However, providing

additional funding for educational supports, such as EAs, is not necessarily the solution to

creating inclusive schools (Giangreco, Sutter & Doyle, 2010). As Giangreco and Doyle

(2002) have pointed out, providing funding for additional EAs may actually serve to

contribute to exclusion and segregation, by separating students from their classmates. It can

also prevent an examination of the systemic structures, such as school structure, curriculum

and pedagogy, that are barriers to full inclusion (Giangreco, et al., 2005). This suggests what

may be needed is an examination of systemic and socially constructed factors that are acting

as barriers to full inclusion for these students, rather than simply additional funding and

educational assistants.

A policy gap in terms of accommodating the unique challenges of students with rare

chronic health conditions was identified: First, in terms of a lack of specific policy, and

second, in terms of the current identification process (Ontario Ministry of Education, 2011).

The identification process was seen as a barrier to inclusion, as its lack of flexibility limits the

access to educational supports that might facilitate inclusion of this population. The

categorical nature of identification also perpetuates a medical/deficit model of exceptionality

(Cobb, 2016). In this sense, the educational organizations do not always support the goals of

advocacy organizations in this study. Educational organizations could potentially better

support the goals of advocacy organizations by reexamining the identification process and the

lack of specific policy for students with rare chronic health conditions.

How could the work of advocacy organizations inform or improve current practices and policies on inclusion for students with rare chronic health conditions in schools?

The participants in this study identified several challenges to inclusion for students with rare chronic health conditions. The identification of these challenges could lead to the development of clearer policies and improved practices to facilitate the inclusion of this group of students. Participants identified a lack of specific policy about rare chronic health conditions. Developing policies for this group has the potential to facilitate their inclusion in inclusive schools. Participants also felt there was a lack of placement options for students. They felt there were often only full inclusion or full segregation, and that these two options didn't always meet the needs of students with rare chronic health conditions. Identifying this perceived lack of options suggests that perhaps the placement options offered by school districts need to be examined closely. It also highlights the need to fully evaluate inclusive settings. Are they truly inclusive in the sense that they address systemic and social barriers to full participation for students? Or are they examples of integration, where students are merely accommodated to fit into existing school structures?

Advocacy groups have the potential to improve current practices by acting as experts in specific chronic health conditions. Educational leaders could benefit from the specific knowledge that advocacy organizations have accumulated about specific health conditions. This knowledge could help to inform practices that would facilitate inclusion of students with rare chronic health conditions. Advocacy groups also have the potential to act as an intermediary between the health care field and education, bridging knowledge from one institution to the other.

The various advocacy strategies used by participants in this study have the potential to

improve practices in education for this group of students. When advocates act using what

Gormley and Cymrot (2006) term insider strategies, they have the potential to influence the

enactment of policy, which Ball (2015) contends is a socially mediated process that is

specific to each school and/or district. Advocacy efforts that are directed at local school

leaders have the potential to impact the interpretation and enactment of inclusion policies by

education leaders. Young and Everitt (2010) term these strategies informal advocacy

strategies. In this study, participants identified training parents to act as advocates to be a key

strategy in their advocacy efforts. This training of local parent advocates has the potential to

influence policy enactment for students with rare chronic health conditions.

When advocates work towards advocating for policy change at the ministry level,

they utilize what Gormley and Cymrot (2006) term "outsider advocacy techniques". Using

outsider advocacy techniques and lobbying for policy change has the potential to address

some of the identified barriers in this study. Young and Everitt (2010) call these advocacy

strategies formal advocacy strategies. Advocating for more specific policies for rare chronic

health conditions has the potential to help develop strategies to address the unique challenges

of this group.

**How can the collaboration and communication between schools, school districts,
ministries and advocacy organizations be improved to support the wellbeing of students
with chronic rare health conditions?**

In this study, participants felt there were not sufficient connections between health

care and education, as well as between advocacy groups and the education system. Better

connections between these various agencies were seen as important to facilitating the

inclusion of students with rare chronic health conditions. Barriers such as lack of time and

funding were cited as challenges to creating better connections. It is possible that the

development of specific policies and procedures for accessing knowledge and understanding

about rare chronic health conditions could contribute to better connections being formed.

Some participants suggested that policies about accessing information, and staff

becoming informed about certain conditions could help in the inclusion of these students. If

there were policy in place around mobilizing knowledge about rare chronic health conditions

that affect students, this could facilitate better connections. A policy such as this could

mandate that educational leaders (principals, resource teachers, school board personnel) find

information about rare chronic health conditions to provide this information to teachers and

resource staff who will be educating these students. Part of this role could be to seek out

connections with advocacy groups who are likely in possession of such specialized

knowledge. Young and Everitt (2010) posit that one essential function of advocacy groups is

to provide information for policy makers, and this could be an example of leveraging

advocacy groups to do just that. The participants in the current study all felt there were not

currently good connections between their groups and educational institutions, which suggests

this role of seeking out information, and making connections with advocacy groups, is not in

existence at this time in the Province of Ontario.

The many institutions that are involved in the care of children with rare chronic health

conditions are fragmented (Miller et al., 2009). Advocacy groups may be an underutilized

resource that could help to bridge the gap between the health care fields and the education

field. Educational leaders who need information about specific rare chronic health conditions

could reach out to advocacy groups to provide much needed insight into what the impacts of

a condition may be. In this way, advocacy organizations could act as knowledge brokers,

since they are on the periphery of both organizations (Meyer, 2010). Brokering knowledge is

a key role in bridging gaps between diverse fields of practice. In this case, bridging the gap

between education and medicine has the potential to increase inclusion for this group of

students. Advocacy organizations have the potential to play a unique role here as knowledge

brokers. This could greatly impact the wellbeing of students, as their needs may be better met

if there is more understanding of what some of their challenges might be.

Some participants felt that the lack of knowledge and understanding sometimes

caused educators to overestimate and overgeneralize the impacts of rare chronic health

conditions. Creating better communication and connection between advocacy organizations

and the education system could help to dispel misconceptions and anxiety on the part of the

education system.

Recommendations

Policy gaps. One important finding in this study is a gap in policy about rare chronic

health conditions. There is currently no specific policy about rare chronic health conditions in

either the health care field or the education field. Developing specific policy has the potential

to help better serve the needs of this group of students.

Another gap in policy identified in this study is in the categorical nature of

identification of exceptionality (Ontario Ministry of Education, 2011). Students with rare

chronic health conditions may not fit into the five categories of exceptionality, but may

benefit from educational supports and services nonetheless.

There are broader issues of exclusion embedded within the identification process.

Identification as exceptional in effect perpetuates a medical/deficit model of disability (Cobb,

2016). It speaks to long held notions of what is normal and what is outside of normal, thus

serving to 'other' people with exceptionalities. This categorical identification process can act

as a gatekeeper in several ways. To begin, students may not meet the criteria laid out in the

definitions. The identification process itself can be long and expensive, and there can be

waiting lists to access testing, which must be done by educational psychologists and doctors.

This further serves to perpetuate a deficit model. Parents may not want to have their child

formally identified for fear of stigmatization, and this can then be a barrier to accessing

education supports. By creating a policy that requires formal identification, students who

have exceptionalities are further excluded.

The entire formal identification process in Ontario may need to be revaluated to

examine these sources of exclusion. Broader, systemic sources of inequity are inherent

within this system, in that it perpetuates the understanding that learners who do not conform

to an accepted version of normal need something that is different, special, and outside of the

regular education system. By contrast, reframing education discourses to understand that

learners are diverse, and that each student should be able to access education that moves them

forward in their own learning removes the need for stigmatization and exclusion. Critical

scholars, such as DeLuca (2013), call for a broader acceptance of diversity within

classrooms. A focus on teaching students, rather than strictly adhering to curriculum targets

for the 'average' student can address broader diversity within the classroom.

Better connections between advocacy groups and education systems. There is a

lack of communication and connections between various sectors, such as health care, and

education (Miller, et al., 2009). One potential recommendation is leveraging the expertise

contained within advocacy groups to better mobilize knowledge about students with rare

chronic health conditions. Advocacy organizations could have an important role to play as

intermediaries between the health care system and the education systems. Advocacy groups

for rare chronic health conditions are likely underutilized sources of information about rare

chronic health conditions and their potential impact on students with rare chronic health

conditions in schools.

Advocacy groups have the potential to act as knowledge brokers between the

education system and the health care systems. As Haas (2015) notes, knowledge brokers

transform knowledge that they share between institutions, making it useable and relevant for

the institution they are brokering it to. Advocacy groups for rare chronic health conditions are

in a privileged position to perform this transformation of knowledge. They have very health-

condition specific knowledge, and can take that medical knowledge and transform it into

knowledge that is useable for the education system.

It was unclear in the current study whose role it should be to seek out knowledge and

understanding about rare chronic health conditions. Educational leaders may have an

important role to play in the mediation and brokering of knowledge about rare chronic health

conditions. As leaders in their schools, principals could initiate contact between advocacy

groups and resource teachers or classroom teachers to start the knowledge mobilization

process. School board leaders could also operate in this capacity, seeking out contacts from

advocacy groups and making connections with the appropriate teams who would benefit from

the information.

Re-examination of classroom placement options. In this study, not all participants

favored inclusive classroom placements for all students with exceptionalities. The important

question arising from this finding is why did the participants feel this way? The options for

placement of students with rare chronic health conditions may need to be reexamined. Are

there sufficient options to allow students to reach their educational goals? Do inclusive

classroom placements support the educational development of these students? Are the current

inclusive classrooms really representative of the broader social ideals of inclusion, or are they

more representative of integrated classrooms, where students with exceptionalities are

physically in the room, but are not truly included? These are important considerations that

merit more research and investigation.

       Re-examination of funding allocation for educational supports. Participants in this

study felt that educational supports for students with rare chronic health conditions were

lacking. They felt that funding for supports such as educational assistants (EAs) was often

insufficient, and that this negatively impacted the inclusion of students with rare chronic

health conditions. The results from this study suggest that the allocation of educational

supports may not always work to support the needs of students with rare chronic health

conditions: if students with rare chronic health conditions are not formally identified as

exceptional, are they able to access educational supports in all districts? This suggests that the

role of educational supports may need to be re-examined. Are educational assistants the only

educational supports that can help exceptional students reach their potential? Or are there

other ways that classrooms, curriculum, and pedagogy could be re-imagined to better include

students with rare chronic health conditions? Some authors (see for example Schmidt &

Venet, 2012; Artiles, et al., 2006; Ainscow, 2007) suggest that inclusive schools are places

where the needs of all diverse learners are met in authentic ways. DeLuca (2013) suggests

educational discourses must be reframed to allow for this diversity. Schools are important

places that social justice can be promoted and realized (Blackmore, 2013; Paliokosta &

Blandford, 2010; Ryan, 2013).

The inclusion of students with rare chronic health conditions is a complex and under

researched area (Olsen, et. al., 2004; Asprey & Nash, 2006). With inclusion policies in the

province of Ontario (Ontario Ministry of Education, 2009) and elsewhere, students with rare

chronic health conditions are likely to spend most of their time in inclusive classrooms.

Advocacy organizations have played a key role in the development of inclusive policy

(Trainor, 2010). This study aimed to examine the intersection of advocacy organizations and

inclusion of students with rare chronic health conditions.

The value of this study resides in its examination of the under researched perspective

of advocacy groups for rare chronic health conditions and their work in relation to

educational leaders and policy. Looking at how advocacy organizations for people with rare

chronic health conditions understand their relations with the education sector is one way of

examining many issues in inclusion, exclusion, policy, and policy enactment. This study

adopted a critical, social justice perspective. Since students with exceptionalities are a

marginalized group, this perspective has value, as it is aimed at identifying areas of exclusion

in policy and its enactment. This study highlighted some challenges for this group and some

potential areas where there are gaps in policy. Further research on this topic would help to

flesh out the complex and subtle relationships and how these advocacy organizations work

for change in inclusive schooling.

Future Directions

Some future research directions emerge as a result of this study. It would be interesting to further investigate the parent perspective for children with rare chronic health conditions, and how they understand inclusion for their children. Although the parent perspective emerged in this study in some cases, it was not the focus of the research. Specifically looking at the parent perspective may add some clarity to this issue. Another perspective that would have added to the current research is the voice of educators and educational leaders. It would have been interesting to investigate the dynamics and interaction between educators, educational leaders and parents as well in terms of framing inclusion for this group of students.

In the current study, much tension emerged in terms of what inclusivity means. Participants vacillated back and forth between broader conceptions of inclusivity as a basic right to narrower ideas of inclusivity as classroom placement. Further research into why these tensions exist, and what it means for students, is warranted.

As DeLuca (2012) and others suggest, in order to be inclusive, environments and systemic constraints must be carefully examined. Further delineating what aspects of school and inclusion are problematic for students with rare chronic health conditions may be an important step in better including this student group in school in meaningful ways.

References

Ainscow, M. (2007). Taking an inclusive turn. *Journal of Research in Special*

  Educational Needs, 7(1), 3-7.

Alberta Education (2015). Guide to Education, ECS to grade 12, 2015-2016.

  https://education.alberta.ca/media/1626501/guide_to_ed_school_act_2015-june-4-

  with-active-links.pdf Alberta.

  AuCoin, A. & Porter, G. L. (2013). The role of the resource teacher in an inclusive setting:

  A time-use inquiry in New Brunswick schools. *Education Canada,* Retrieved from:

  http://www.cea-ace.ca/education-canada/article/role-resource-teacher-inclusive-

  setting

Apple, M. (2001). Comparing neo-liberal projects and inequality in education. *Comparative*

  Education, 37(4), 409-423.

Artiles, A. J., Harris-Murri, N., & Rostenberg, D. (2006). Inclusion as social justice: Critical

  notes on discourses, assumptions and the road ahead. *Theory Into Practice, 45*(3),

  260- 268.

Asprey, A., & Nash, T. (2006). The importance of awareness and communication for the

  inclusion of young people with life-limiting and life-threatening conditions in

  mainstream schools and colleges. *British Journal of Special Education, 33*(1), 10-

  18. https://www.lib.uwo.ca/cgi-

  bin/ezpauthn.cgi/docview/62088663?accountid=15115.

Bagley, C. & Woods, P. A. (1998). School choice, markets and special educational

  needs**.** *Disability & Society, 13*(5), 763-783.

Ball, S. J. (2015). What is policy? 21 years later: reflections on the possibilities of policy

    research. *Discourse: Studies in the Cultural Politics of Education, 36*(3), 306–

    313. http://dx.doi.org/10.1080/01596306.2015.1015279

Ball, S. J. (1998). Big policies/Small world: An introduction to international

    perspectives in education policy *Comparative Education, 34*(2), 119-130.

Ball, S. J., Maguire, M., & Braun, A. (2012). Doing enactment research. In: *How

    Schools do Policy: Policy Enactment in Secondary Schools*. (pp. 1-19).

    Routledge, NY, NY.

Barlow, C. A. (2010). Interviews. In A. J. Mills, G. Durepos & E. Weibe (Ed.), *The

    encyclopedia of case study research.* (pp. 496-500). Thousand Oaks, CA: Sage

    Publications, Inc. doi: http://dx.doi.org/10.4135/9781412957397.n182

Baxter, P. & Jack, S. (2008). Qualitative case study methodology: Study design and

    implementation for novice researchers. *The Qualitative Report, 13*(4), 544-559.

Bennett S. (2009). Including students with exceptionalities: Research Monograph 16.

    Literacy and Numeracy Secretariat, Queens Printer, Ontario.

    http://www.edu.gov.on.ca/eng/literacynumeracy/inspire/research/bennett.pdf

Bennett, S. & Dworet, D., with Weber K. (2008) *Special Education in Ontario Schools.* Sixth

    Edition. Highland Press.

Bennett, S. M. & Gallagher, T. L. (2013). High school students with intellectual disabilities

    in   the school and workplace: Multiple perspectives on inclusion. *Canadian

    Journal of Education, 369*(10), 96-124.

Bennett, S. M. & Wynn K. (2006). Special education transformation. *The report of the co-*

chairs with the recommendations of the working table on special education.

Toronto: Ontario Ministry of Education.

Bhattacharya, H. (2008). Interpretive research. In L. M. Given (Ed.), *The SAGE*

encyclopedia of qualitative research methods (pp. 465-467). Thousand Oaks, CA:

SAGE Publications Ltd. http://dx.doi.org10.4135/9781412963909.n235

Billingsley, B. S. (2007). Recognizing and supporting the crucial roles of teachers in special

education leadership. *Exceptionality, 15*(3), 163-176.

Bourke, P. & Carrington, S. (2007). Inclusive education reform: Implications for teacher

aides. *Australasian Journal of Special Education, 31*(1), 15-24.

Blackmore, J. (2013). A feminist critical perspective on educational leadership. *International*

Journal of Leadership in Education, 16(2), 139-154. Retrieved from

http://www.tandfonline.com.proxy1.lib.uwo.ca/doi/abs/10.1080/13603124.2012.7

54057.

British Columbia Ministry of Education. (2013). *Special education services: A manual of*

policies, procedures and guidelines.

http://www.bced.gov.bc.ca/specialed/special_ed_policy_manual.pdf

Canadian Organization for Rare Disorders (2016). Retrieved from:

https://www.raredisorders.ca/

Cobb, C. (2016). You can't loose what you never had. *International Journal of Inclusive*

Education, 20(1), 52–66.

Cohen, D. J., & Crabtree, B. F. (2006). Evaluative Criteria for Qualitative Research in Health

Care: Controversies and Recommendations. *Annals of Family Medicine,* 6(4), 331-

339. doi:10.1370/afm.818.

Conley, S., Gould, J. & Levine, H. (2010). Support personnel in schools: Characteristics and

importance. *Journal of Educational Administration, 48*(3), 309-326.

Council of Canadians with Disabilities. (2012). *The Moore case: Summary of key points.*

http://www.ccdonline.ca/en/humanrights/litigation/Moore-Case-Key-Findings-

9Nov2012

Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative

inquiry. *Theory into Practice, 39*(3), 124-130. doi:10.1207/s15430421tip3903_2

Davies, H., Nutley, S., Walter, I. (2008). Why "knowledge transfer" is misconceived for

applied social research. *Journal of Health Service Research Policy, 13*(2), 188-

191.

Delcourt, M. A. B. (2003). Five ingredients for success: Two cases of advocacy at the state

level. *Gifted Child Quarterly, 47*(1), 26-37.

DeLuca, C. (2012). Promoting inclusivity through and within teacher education

programmes. *Journal of Education for Teaching, 38*(5), 551–569.

DeLuca, C. (2013). Toward an interdisciplinary framework for educational inclusivity.

Canadian Journal of Education, 36(1), 305-348.

Diem, S., Young, M. D., Welton, A. D., Mansfield, K. C., & Lee, P-L. (2014). The

intellectual landscape of critical policy analysis. *International Journal of*

Qualitative Studies in Education, 27(9), 1068–1090,

http://dx.doi.org/10.1080/09518398.2014.916007

Duggan, D. D., Medway, F. J., & Bunke, V. L. (2004). Training educators to address the

needs and issues of students with chronic illnesses: Examining their knowledge,

confidence levels and perceptions. *Canadian Journal of School Psychology,*

19(1/2), 149-165.

Duncombe, J, & Jessop, J. (2012). Knowing responsibly: Ethics, feminist epistemologies

and methodologies. In T. Miller, M. Birch, M. Mauthner, & J. Jessop (Eds.),

Ethics in qualitative research (2nd ed., pp. 122-139). Thousand Oaks, CA:

Sage.

Dunkle, M., Pines, W., & Saltonstall, P. L. (2010). Advocacy groups and their role in rare

disease research. In M. P. de la Paz & S. C. Groft (Eds.) *Rare Disease*

Epidemiology. (pp. 515-525). Netherlands: Springer, doi: 10.1007/978-90-481-

9485-8_28.

Eacott, S. (2013). Towards a theory of school leadership practice: A Bourdieusian

perspective. *Journal of Educational Administration and History, 45*(2), 174-188.

Retrieved from

http://www.tandfonline.com.proxy1.lib.uwo.ca/doi/abs/10.1080/00220620.2013.7

68966

Edmunds, A. L., Macmillan, R. B., Specht, J., Nowicki, E. A. & G. Edmunds, G. (2009).

Principals and inclusive schools: Insight into practice. *EAF Journal, 20*(1), 1-I,

https://www.lib.uwo.ca/cgi-

bin/ezpauthn.cgi/docview/214080806?accountid=15115

Erten, O. & Savage, R. S. (2012). Moving forward in inclusive education research.

International Journal of Inclusive Education, 12(2), 221-233.

Eurordis (nd). *Rare disease policy.* http://www.eurordis.org/eu-rare-disease-policy#tabs-2

Firmin, M. (2008). Data collection. In L. Given (Ed.), *The SAGE encyclopaedia of qualitative*

research methods. (pp. 191-193). Thousand Oaks, CA: Sage Publications, Inc.

doi: http://dx.doi.org.proxy1.lib.uwo.ca/10.4135/9781412963909.n96

Gay, L. R., Mills, G. E., & Airasian, P. (2012). *Educational research: Competencies for*

analysis and applications (10th ed.). Upper Saddle River, NJ: Pearson Merrill.

Ghere, G. & York-Barr, J. (2007). Paraprofessional turnover and retention in inclusive

programs: Hidden costs and promising practices. *Remedial and Special*

Education, 28(1), 21-32.

Gidney, R. D. (1999). *From Hope to Harris: The reshaping of Ontario's schools*. Toronto:

University of Toronto Press.

Giangreco, M. F. & Doyle, M. B. (2002). Students with disabilities and paraprofessional

supports: Benefits, balance, and bandaids. *Focus on Exceptional Children, 37*(7),

1-12.

Giangreco, M. F., Suter, J. C., & Doyle, M. B. (2010). Paraprofessionals in inclusive

schools: A review of recent research. *Journal of Educational and Psychological*

Consultation, 20(1), 41-57. doi:10.1080/10474410903535356

Giangreco, M. F.,Yuan, S., McKenzie, B., Cameron, P., & Fialka, J. (2005). "Be careful

what you wish for ...": Five reasons to be concerned about the assignment of

individual paraprofessionals. *Teaching Exceptional Children, 37*(5), 28-34.

Gormley, W. T. & Cymrot, H. (2006). The strategic choices of child advocacy groups.

Nonprofit and Voluntary Sector Quarterly 35(1) 102-122.

Government of Canada. (2013). *The Canadian Charter of Rights and Freedoms; Section 15 –*

Equality Rights. http://www.pch.gc.ca/eng/1355929397607/1355929510108

Government of Canada. (2014). Tri-Council Policy Statement for Ethical Conduct for

Research Involving Humans. http://www.pre.ethics.gc.ca/pdf/eng/tcps2-

2014/TCPS_2_FINAL_Web.pdf

Government of Canada. (2015). *Provincial/territorial role in health.* Retrieved from:

http://healthycanadians.gc.ca/health-system-systeme-sante/cards-cartes/health-

role-sante-eng.php

Government of Ontario. (2015). Ontarians with Disabilities Act, 2001. Retrieved from:

http://www.ontario.ca/laws/statute/01o32

Gunter, H. (2001). Critical approaches to leadership in education. *Journal of Educational*

Enquiry, 2(2), 94-108. Retrieved from

http://www.ojs.unisa.edu.au/index.php/EDEQ/article/viewFile/583/455

Gunter, H. (2005). Conceptualizing research in educational leadership. *Educational*

Administration Abstracts, 40(3). Retrieved from

http://ema.sagepub.com.proxy1.lib.uwo.ca/content/33/2/165.refs

Hall, J. G. (2013). The role of patient advocacy/parent support groups. *Ethical, Psychosocial*

and Anthropological, 103(12), 1020-1022.

Harris, A. & Muijs, D. (2003). Teacher leadership: Principles and practice. *National College*

For School Leadership. Institute of Education, University of Warwick.

Harpell, J. V. & Andrews, J. J. W. (2010). Administrative leadership in the age of inclusion:

Promoting best practices and teacher empowerment. *The Journal of Educational*

Thought, 44(2), 189-210.

Haas, A. (2015). Crowding at the frontier: boundary spanners, gatekeepers and

knowledge brokers. *Journal of Knowledge Management, 19*(5), 1029 – 1047.

http://dx.doi.org/10.1108/JKM-01-2015-0036

Hattam, R., Brennan, M., Zipin L., & Comber, B. (2009). Researching for social justice:

Contextual, conceptual and methodological challenges. *Discourse: Studies in the*

Cultural Politics of Education, 30(3), 303-316.

Health Canada (2010). *Canada's healthcare system.* Retrieved from: http://hc-sc.gc.ca/hcs-

sss/medi-   assur/index-eng.php

Health Canada (2012). Orphanet-Canada. Retrieved from: http://www.hc-sc.gc.ca/ahc-

asc/media/nrcp/_2012/2012-147b-eng.php

Hess, R. S., Molina, A. M., & Kozleski, E. B. (2006). Until somebody hears me: Parent voice

and advocacy in special education decision making. *British Journal of Special*

Education, 33(3), 148-157.

Higham, R., Hopkins, D., & Matthews, P. (2009). *System leadership in practice.* Berkshire,

England: Open University Press.

Hupe, P., & Hill, M. (2007). Street-level bureaucracy and public accountability. *Public*

Administration, 85(2), 279-299.

Hursh, D. (2000). Neo-liberalism and the control of teachers, students, and learning: The rise

of standards, standardization, and accountability. *Cultural logic, 4*(1). Retrieved

from http://clogic.eserver.org/4-1/hursh.html

Kidder, A. (2000). Parent advocates: Who are they and why do they do it? *Education Today,*

12(8). Retrieved from:

http://search.proquest.com.proxy1.lib.uwo.ca/docview/218612458?pq-

origsite=summon&accountid=15115

Leech, N. & Onwuegbuzie, A. J. (2007). An array of qualitative data analysis tools: A

call for data analysis triangulation. *School Psychology Quarterly, 22*(4), 557–584.

Leysera, Y. & Kirk, R. (2004). Evaluating Inclusion: an examination of parent views

and factors influencing their perspectives. *International Journal of Disability,

Development and Education 5* (3), 271-285.

Levin, B. (2011). Mobilising research in education. *London Review of Education 9*(1), 15-26.

Levin, B., Cooper, A., Arjomand, S., & Thompson, K. (2011). Can simple interventions

increase research use in schools? *Canadian Journal of Educational

Administration and Policy, 126*.

Lincoln, Y. S. (1995). Revolutions in qualitative research: From just experience to

experiencing justice. *Journal of Thought 40*(4), 25-40.

Lincoln, YS. & Guba, EG. (1985). Naturalistic Inquiry. Newbury Park, CA: Sage

Publications.

Lichtman, M. (2006). Making Sense of your Data. In: *Qualitative Research in Education: A

Users Guide.* Thousand Oaks: Sage Publications.

Lipsky, M. (1993). Street-level bureaucracy: An introduction. (pp. 393-403). In: Micheal Hill

(Ed.) *The Policy Process: A Reader (2nd Edition).* New York: Routledge.

Martinez, Y. J. & Ercikan, K. (2009). Chronic illnesses in Canadian children: What is the

effect of illness on academic achievement, and anxiety and emotional disorders?

Child: care, health and development, 35(3), 391-401.

Maxwell, J. (2012). Conceptual framework; What do you think is going on? In *Qualitative*

research design: An interactive approach (pp. 39-72). Los Angeles: Sage.

Meuller, P. H. (2003). The paraeducator paradox. *NERRC Hot Topics, Exceptional Parent,* 1-

6. Retrieved from: http://www.uvm.edu/~cdci/parasupport/reviews/HotTopics.pdf

Meyer, M. (2010). The rise of the knowledge broker. *Science Communication, 32*(1), 118-

127. DOI: 10.1177/1075547009359797

Miles, M. H., Huberman, A. M., & Saldana, J. (2014). *Qualitative Data Analysis: A Methods*

Sourcebook, 3rd ed. Los Angeles, Sage.

Miller, A. R., Condin, C. J., McKellin, W. H., Shaw, N., Klassen, A. F., & Sheps, S. (2009).

Continuity of care for children with complex chronic health conditions: Parents'

perspectives. *BMC Heath Services Research, 9,* 252-241.

Moore v. British Columbia (Ministry of Education) (2012). SCC 61. Retrieved from:

https://www.canlii.org/en/ca/scc/doc/2012/2012scc61/2012scc61.pdf

Morse, J. M. (2015). Critical analysis strategies for determining rigor in qualitative

inquiry. *Qualitative Health Research 25*(9) 1212–1222.

Moss, G. (2013). Research, policy and knowledge flows in education: What counts in

knowledge mobilisation? *Contemporary Social Science, 8*(3), 237-248.

Mounsteven, J. M. (2010). *Roles and responsibilities of educational assistants in Ontario*

schools: Implications for practice (Order No. NR64926). Available from Education

Database; ProQuest Dissertations & Theses Global. (748286870). Retrieved from

https://www.lib.uwo.ca/cgibin/ezpauthn.cgi?url=http://search.proquest.com/docview/

748286870?accountid=15115

Mukherjee, S., Lightfoot, J., & Sloper, P. (2000). The inclusion of pupils with a chronic

health condition in mainstream school: What does it mean for teachers?

Educational Research 42(1): 59-72,

https://www.lib.uwo.ca/cgibin/ezpauthn.cgi/docview/62426793?accountid=15115

. Nabors, L. A., Little, S. G., Akin-Little, A., & Iobst. (2008). Teacher knowledge of and

confidence in meeting the needs of children with chronic medical conditions:

Pediatric psychology's contribution to education. *Psychology in the Schools.*

45(3), 217- 226.

Newton, N. (2010). The use of semi-structured interviews in qualitative

research: strengths and weaknesses. Paper submitted in part

completion of the requirements of the degree of Doctor of Philosophy,

University of Bristol. Retrieved from:

http://www.academia.edu/1561689/The_use_of_semi-

structured_interviews_in_qualitative_research_strengths_and_weakne   sses

Olson, A. L., Seidler, A. B., Goodman, D., Gaelic, S. & Nordgren, R. (2004). School

professionals' perceptions about the impact of chronic illness in children.

Archives of Pediatric and Adolescent Medicine. 158, 53-58.

Ontario Ministry of Community and Social Services. (2012). *From institutional to community

living: A history of developmental services in Ontario.* Retrieved from:

http://www.mcss.gov.on.ca/en/dshistory/index.aspx

Ontario Ministry of Education. (1990). *Ontario Regulation 181/98, Education Act*. Retrieved

from: https://www.ontario.ca/laws/regulation/980181 .

Ontario Ministry of Education. (2000). *Standards for school boards' special education*

plans. Queen's Printer for Ontario.

Ontario Ministry of Education, (2005). *The Report of the Expert Panel on Literacy and*

Numeracy   Instruction for Students With Special Education Needs, Kindergarten

to Grade 6. Queens Printer, Ontario.

Ontario Ministry of Education. (2009). *Ontario's Equity and Inclusive Education Strategy*.

Queens Printer, Ontario.

Ontario Ministry of Education, (2011). *Categories of exceptionality.* Retrieved from:

http://www.edu.gov.on.ca/eng/general/elemsec/speced/2011CategoryException.p

df

Ontario Ministry of Education (2014). *Achieving Excellence: A Renewed Vision for*

Education in Ontario. Retrieved from:

http://www.edu.gov.on.ca/eng/about/renewedVision.pdf

Paliokosta, P. & Blandford, S. (2010). Inclusion in school: A policy, ideology or lived

experience? Similar findings in diverse school cultures. *British Journal of*

Learning Support 25(4), 179-186.

Patton, M. Q. (2015). Qualitative analysis and interpretations. In M. Q. Patton (Ed.),

Qualitative research and evaluation methods: Integrating theory and practice (4th

Ed.) (pp. 520-651). San Francisco, CA: SAGE Publications.

Patton, M. Q. (1999). Enhancing the quality and credibility of qualitative analysis. *Health*

Services Research, *34*(5 Pt 2), 1189–1208

Pazy, B. L. & Cole, H. A. (2012). The role of special education training in the development

of socially just leaders building an equity consciousness in educational leadership

programs. *Educational Administration Quarterly, 49*(2), 243-271.

People for Education (2015). *Ontario's schools: The gap between policy and reality*; *Annual

report on Ontario's publicly funded schools 2015*. Toronto: People for

Education. Retrieved from: https://www.peopleforeducation.ca/wp-

content/uploads/2015/06/P4E-Annual-Report-2015.pdf

Rioux, M. (1999). Inclusive education in Canada: A piece in the equality puzzle. (pp. 87-

99). In F. Armstrong & L. Barton (Eds.), *Disability, Human Rights And

Education: Cross Cultural Perspectives.* Sheffield, UK, Open University Press.

Rottamann, C. (2007). Leadership for change and social justice: Mapping conceptual

terrain. *Journal of Education Administration and Foundation. 18*(1/2), 9-23.

Runswick-Cole, K. (2008). Between a rock and a hard place" Parents' attitudes to the

inclusion of children with special educational needs in mainstream and special

schools. *British Journal of Special Education, 35*(3), 173-180.

Ryan, J. (2005). What is leadership? In W. Hare & J. Portelli (Eds.) *Key Questions for

Educators* (pp. 22-25). Halifax: Edphil Books.

Ryan, J. (2010). Establishing inclusion in a new school: The role of principal leadership.

Exceptionality Education International, 20(2), 6-24.

Ryan, J. (2012). The exclusive neoliberal context of education. In J. Ryan (Ed.), *Struggling*

    for inclusion: Educational leadership in a neoliberal world (pp. 19-34).

    Charlotte, NC: Information Age Publishing.

Ryan, J. (2013). Promoting inclusive leadership in diverse schools. In I. Bogotch and C.

    Shields (Eds.), *International handbook of educational leadership and social*

    (in)justice (pp. 359-380). Dordrecht, NL: Springer.

Ryan, J. & Rottamann, C. (2007). Educational leadership and policy approaches to critical

    social justice. *Journal of Education Administration and Foundation, 18*(1/2), 9-

    23.

Ryan, S. & Runswick Cole, K. (2009). From advocate to activist? Mapping the

    experiences of mothers of children on the autism spectrum. *Journal of Applied*

    Research in Intellectual Disabilities, 22, 43–53.

Sa, C. M., Li, S. X. & Faubert, B. (2011). Faculties of education and institutional strategies

    for knowledge mobilization: An exploratory study. *Higher Education, 61*, 501–

    512.

Sandelowski, M. (2008). Member check. In L. Given (Ed.), *The SAGE encyclopedia of*

    qualitative research methods. (pp. 502-503). Thousand Oaks, CA: SAGE

    Publications, Inc. doi:

    http://dx.doi.org.proxy1.lib.uwo.ca/10.4135/9781412963909.n257

Saumure, K.& Given, L. (2008). Data saturation. In L. Given (Ed.), *The SAGE encyclopaedia*

    of qualitative research methods. (pp. 196-197). Thousand Oaks, CA: SAGE

    Publications, Inc. doi:

    http://dx.doi.org.proxy1.lib.uwo.ca/10.4135/9781412963909.n99

School Advocacy Hamilton (2006). *The Canadian Charter of Rights and Freedoms.*

Retrieved from: http://www.schooladvocacy.ca/left_level3/rights_freedom.html

Schmidt, S. & Venet, M. (2012). Principals facing inclusive schooling or integration.

Canadian Journal of Education. 35(1), 217-238.

Schwandt, T. A., Lincoln, Y. S., & Guba, E. G. (2007). Judging interpretations: But is it

rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New*

Directions for Evaluation, 114, 11-25. doi:10.1002/ev.223

Sheppard, B., Brown, J. & Dibbon, D. (2009). *School district leadership matters*. New

York: Springer.

Shiu, S. (2004). Positive interventions for children with chronic illness: Parents' and teachers'

concerns and recommendations. *Australian Journal of Education 48*(3) (11): 239-252.

Slee, R. (2013). Meeting some challenges of inclusive education in an age of exclusion.

Asian Journal of Inclusive Education, 1(2), 3-17.

Slee, R. (2001). Driven to the Margins: Disabled students, inclusive schooling and the

politics of possibility. *Cambridge Journal of Education, 31* (3), 385-397.

Smith, J. (2008). Interpretive inquiry. In L. M. Given (Ed.),*The SAGE encyclopedia of*

qualitative research methods(pp. 460-461). Thousand Oaks, CA: SAGE

Publications Ltd. doi: 10.4135/9781412963909.n233

Spillane, J. P. (2005). Distributed leadership. *The Educational Forum, 69*(2), 143-150.

Taylor, S. (1997). Critical Policy Analysis: Exploring contexts, texts and consequences.

Discourse: Studies in the Cultural Politics of Education, 18(1) 23-35, DOI;

10.1080/0159630970180102

Thornton, C. & Underwood, K. (2013). Conceptualizations of disability and inclusion:

Perspectives of educators of young children. *Early Years, 33*(1), 59–73.

Trainor, A. A. (2010). Diverse approaches to parent advocacy during special education

home–school interactions; Identification and use of cultural and social capital.

Remedial and Special Education, 31 (1), 34-47.

UNESCO, (2009) *Policy guidelines on inclusion in education.* UNESCO, France.

Valeo, A. (2009). Education's enduring prejudices: Disability at the door. *Learning Inquiry

Journal, 3*(2), 97- 109.

West, A. M., Denzer, A. Q., Wildman, B. G. & Anhalt, K. (2013). Teacher perception of

burden and willingness to accommodate children with chronic health conditions.

Advances in School Mental Health Promotion, 6(1), 35-50.

Wideman-Johnston, T. (2011). Resilience and students with chronic illness: A literature

review of fostering resilience into the lives of students with chronic illness.

Journal of Educational and Developmental Psychology, 1(1), 127-132.

Winton, S. & Brewer, C. A. (2014). People for Education: a critical policy history.

International Journal of Qualitative Studies in Education, 27(9), 1091–1109,

http://dx.doi.org/10.1080/09518398.2014.916005

Winton, S., & Evans, M. P. (2016). Consulting, mediating, conducting, and supporting:

How community- based organizations engage with research to influence policy.

Leadership and Policy in Schools, 15(1), 4-24.

Wolfram Cox, J., & Hassard, J. (2010). Triangulation. In A. Mills, G. Durepos, & E. Wiebe

(Eds.), *Encyclopedia of case study research*. (pp. 945-949). Thousand Oaks, CA:

SAGE Publications, Inc. doi:

http://dx.doi.org.proxy1.lib.uwo.ca/10.4135/9781412957397.n348

Young, M. D. & Diem, S. (2014). Putting critical theoretical perspectives to work in

educational policy. *International Journal of Qualitative Studies in Education, 27*(9),

1063–1067, http://dx.doi.org/10.1080/09518398.2014.916015

Young, L., & Everitt, J. M. (2004). *Advocacy groups*. Vancouver: UBC Press.

York-Barr, J., Sommerness, J., Duke, K., & Ghere, G. (2005). Special educators in inclusive

education programmes: Reframing their work as teacher leadership. *International*

Journal of inclusive Education. 9(2), 193-215.

Zaretsky, L. (2004). Advocacy and administration: From conflict to collaboration

Journal of Educational Administration, 42(2), 270-286.

Zegarac, G. et. al. (2008). Special Education in Ontario "Closing the Gap as the

Overarching Goal: Changing Special Education Practices and Outcomes".

Retrieved from:

http://www.edu.gov.on.ca/eng/research/specEd_AERA_CSSE.pdf

Appendix A Ethics Approval

Western Research

Research Ethics

Western University Non-Medical Research Ethics Board
NMREB Delegated Initial Approval Notice

Principal Investigator: Dr. Augusto Riveros Barrera
Department & Institution: Education, Western University

NMREB File Number: 107418
Study Title: The role of advocacy organizations in promoting inclusive education policies for students with rare health conditions
Sponsor:

NMREB Initial Approval Date: December 15, 2015
NMREB Expiry Date: December 15, 2016

Documents Approved and/or Received for Information:

Document Name	Comments	Version Date
Recruitment Items	Recruitment Email	2015/11/02
Instruments	Interview Protocol	2015/11/30
Western University Protocol		2015/11/30
Letter of Information & Consent		2015/11/30

The Western University Non-Medical Research Ethics Board (NMREB) has reviewed and approved the above named study, as of the NMREB Initial Approval Date noted above.

NMREB approval for this study remains valid until the NMREB Expiry Date noted above, conditional to timely submission and acceptance of NMREB Continuing Ethics Review.

The Western University NMREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the Ontario Personal Health Information Protection Act (PHIPA, 2004), and the applicable laws and regulations of Ontario.

Members of the NMREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000941.

████████████████████████████

Ethics Officer, on behalf of Riley Hinson, NMREB Chair or delegated board member

Ethics Officer to Contact for Further Information: Erika Basile ___ Nicole Kaniki ___ Grace Kelly ___ Mina Mekhail ___ Vikki Tran ___

This is an official document. Please retain the original in your files

Appendix B Letter of Information

Project Title: *The role of advocacy organizations in promoting inclusive education policies for students with rare health conditions*

Principal Investigator

Augusto Riveros-Barrera, PhD, Department of Education, Western University

Additional Research Staff

Jennifer Flinn, Doctoral student, Faculty of Education, Western University

1. **Invitation to Participate**

You are being invited to participate in this research study about 1) how advocacy groups can promote policy change in education in relation to the inclusion of students with rare chronic health conditions; 2) how advocacy organizations interact with educational leadership at multiple levels, including ministry, district, and schools, to encourage knowledge mobilization about students' rare chronic health conditions.

2. **Why is this study being done?**

The purpose of this study is to better understand how advocacy organizations and educational leadership at multiple levels (ministry policy, school district, local school levels) can work together to accommodate and support students with rare chronic health conditions in mainstream schools.

3. **How long will you be in this study?**

It is expected you will be in this study for one 45-60 minute semi-structured interview.

4. **What are the study procedures?**

If you agree to participate, you will be asked to participate in one semi-structured interview. This interview will be scheduled at a mutually convenient time and place, and may be conducted in person or using a telephone or skype [voice only] if distance prevents a face-to-face meeting. You will be asked a series of questions about your work with the advocacy group and your perceptions about the role of the education sector in supporting the goals of your organization. Interviews will be audio recorded.

5. What are the risks and harms of participating in this study?

There are no known or anticipated risks or discomforts associated with participating in this study. Should you experience any discomfort or fatigue at any time, the interview will be paused, stopped or postponed. You are free to withdraw from the study at any time.

6. What are the benefits of participating in this study?

You may benefit directly from participating in this study by having an opportunity to reflect about the opportunities and challenges that the education sector would offer to the achievement of the mission and goals of your organization. Society would benefit by achieving greater understanding of how advocacy organizations and educational organizations interact to support the inclusion of students with rare chronic health conditions in schools.

7. Can participants choose to leave the study?

If you decide to withdraw from the study, you have the right to request withdrawal of information collected about you. If you wish to have your information removed, please let the researcher know.

8. How will participants' information be kept confidential?

While we do our best to protect your information there is no guarantee that we will be able to do so. If data is collected during the project, which may be required to report by law, we have a duty to report. The researcher will keep any personal information about you in a secure and confidential location for a minimum of 5 years. A list linking your study number with your name will be kept by the researcher in a secure place, separate from your study file. If the results of the study are published, your name will not be used, however quotes that are not attached to identifying information may be used.

9. Are participants compensated to be in this study?

You will not be compensated for your participation in this research.

10. What are the rights of participants?

Your participation in this study is voluntary. You may decide not to be in this study. Even if you consent to participate you have the right to not answer individual questions or to withdraw from the study at any time. If you choose not to participate or to leave the study at any time it will have no effect on you.

We will give you new information that is learned during the study that might affect your decision to stay in the study.

You do not waive any legal right by signing this consent form

11. Whom do participants contact for questions?

If you have questions about this research study please contact:

Augusto Riveros-Barrera, PhD, Department of Education, Western University

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Research Ethics

Project Title: Educational Leadership for students with far chronic health conditions-the impact of advocacy organizations on inclusive education

Document Title: Letter of Information and Consent

Principal Investigator

Augusto Riveros-Barrera, PhD, Department of Education, Western University

Additional Research Staff

Jennifer Flinn, Doctoral student, Faculty of Education, Western University

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

I consent to the use of unidentified quotes obtained during the study in the dissemination of this research

☐ **YES** ☐ **NO**

	Signature	Date *(DD-MMM-YYYY)*
Name		

This letter is yours to keep for future reference.

Appendix C Email Script for Recruitment

Western

<u>Subject Line: Invitation to participate in research</u>

You are being invited to participate in a study that we, Dr. Augusto Riveros-Barrera and Doctoral candidate Jennifer Flinn are conducting. Briefly, the study involves participating in one 45-60 minute semi-structured interview about 1) how advocacy groups can promote policy change in education in relation to the inclusion of students with rare chronic health conditions; 2) how advocacy organizations interact with educational leadership at multiple levels, including ministry, district, and schools, to encourage knowledge mobilization about students' rare chronic health conditions.

We have attached a letter of information to this email. If you would like more information or have questions or concerns, please contact the researcher at the contact information given below.

Thank you,

Augusto Riveros-Barrera, PhD,

Department of Education, Western University

Student Contact: Jennifer Flinn, Doctoral student,

Department of Education, Western University

Appendix D Interview Protocol

Interview Protocol

1. Can you tell me a bit about you and your background? Why and how did you get involved

with this advocacy organization?

2. Tell me about this organization, what is its purpose and what kind of initiatives is the

organization involved in?

3. What kind of work do you do with your organization?

4. What is, in your perspective, the role of the education sector (Ministry, school boards,

schools) in supporting the work of your organization?

5. Is your organization interested in influencing changes in the education sector in relation to

policy and/or practice?

6. Do you get questions about education from the population you represent?

7. What do you know about inclusion in education?

8. How do you see chronic health conditions fitting in with inclusion policy? Is there

anything missing? Anything that needs to be added?

9. What would be the challenges to engaging with the education sector?

10. What lessons from your advocacy work could be applied to support of

students with rare chronic health conditions in schools?

11. How do you think you could advocate for education policy change to address the needs of

children with rare diseases?

12. How do you think schools can make better links with the health care field?

13. What are some of your biggest challenges in advocacy work?

14. What would be your message to educational leaders at the Ministry, district and school levels, in relation to their support of the goals of your organization?