Perspectives of Parents of Children With Autism Spectrum Disorder on a Community-Based Parent Education Program

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Abstract

In 2012 a community-based agency that oversees Intensive Behaviour Intervention services for young children diagnosed with Autism Spectrum Disorder (ASD) began delivering newly developed curricula to parents of eligible children. The curricula’s intent was to inform parents about ASD and Applied Behaviour Analysis, to increase their awareness of available community resources, and assist them to be active and engaged in their child’s learning. This mixed-method study used a program-specific survey and focus groups to explore the perspectives parents had on their involvement in these education sessions. Through constant comparison analysis 4 major and 3 minor themes emerged. In general, parents acknowledged that this parent education program included relevant content and a favourable delivery format. The study summarized a number of well-articulated, practical suggestions parents provided. Implications for practice would be applicable to educators interested in providing quality group-based education to parents of young children with ASD.
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Table of Contents

Abstract .................................................................................................................. ii
Acknowledgements ............................................................................................... iii
List of Tables .......................................................................................................... vi
List of Figures ......................................................................................................... vii

CHAPTER ONE: INTRODUCTION ....................................................................... 1
  Purpose of Study ..................................................................................................... 2
  Research Questions ............................................................................................... 3
  Rationale .................................................................................................................. 3
  Importance of the Study ....................................................................................... 4
  Personal Perspective ............................................................................................... 5
  Limitations of the Study ....................................................................................... 6

CHAPTER TWO: LITERATURE REVIEW ............................................................ 7
  Defining Autism Spectrum Disorder ...................................................................... 7
  ASD—A Trip Down Memory Lane ........................................................................ 10
  Applied Behaviour Analysis—A Promising Treatment ........................................ 14
  Impact of ASD on Parents .................................................................................... 20
  Education for Parents of Children With ASD ...................................................... 24
  Chapter Summary .................................................................................................. 29

CHAPTER THREE: METHODOLOGY ................................................................. 30
  Background ............................................................................................................ 30
  Content of Parent Education Sessions ................................................................ 37
  Research Methodology and Design .................................................................... 40
  Participants ............................................................................................................ 41
  Recruitment .......................................................................................................... 44
  Data Sources .......................................................................................................... 46
  Methodological Limitations .................................................................................. 60
  Chapter Summary .................................................................................................. 61

CHAPTER FOUR: RESULTS ................................................................................ 63
  Quantitative Results .............................................................................................. 63
  Qualitative Results ............................................................................................... 75
  Research Questions Revisited ............................................................................. 97
  Chapter Summary .................................................................................................. 102

CHAPTER FIVE: DISCUSSION ............................................................................ 104
  Implications for Theory ....................................................................................... 104
  Implications for Practice ...................................................................................... 106
  Implications for Future Research ........................................................................ 118
## List of Tables

<table>
<thead>
<tr>
<th>Table</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Focus Group Attendance by Quadrant</td>
<td>47</td>
</tr>
<tr>
<td>2. Thematic Definitions</td>
<td>54</td>
</tr>
<tr>
<td>3. Participant Eligibility by Quadrant</td>
<td>59</td>
</tr>
<tr>
<td>Figure</td>
<td>Page</td>
</tr>
<tr>
<td>-----------------------------------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>1. The Parent Education Pathway</td>
<td>32</td>
</tr>
<tr>
<td>2. Breakdown of Eligible Participants by Quadrant</td>
<td>43</td>
</tr>
<tr>
<td>3. Parent Responses Specific to Connectability.ca</td>
<td>64</td>
</tr>
<tr>
<td>4. Parent Responses Specific to Parent Lending Library</td>
<td>66</td>
</tr>
<tr>
<td>5. Parent Responses Specific to Respiteservices.com</td>
<td>67</td>
</tr>
<tr>
<td>6. Parent Responses Specific to the Family Learning Plan</td>
<td>69</td>
</tr>
<tr>
<td>7. Parent Responses Specific to Triad of Impairments Visual</td>
<td>70</td>
</tr>
<tr>
<td>8. Parent Responses Specific to How to be an Advocate Visual</td>
<td>72</td>
</tr>
<tr>
<td>9. Parent Responses Specific to ABC Approach Visual</td>
<td>73</td>
</tr>
<tr>
<td>10. Parent Responses Specific to the Resource Table</td>
<td>74</td>
</tr>
</tbody>
</table>
CHAPTER ONE INTRODUCTION

This study explored the perspective parents had on the education sessions offered to them through a community-based agency that provides Intensive Behaviour Intervention (IBI) to children with a diagnosis of Autism Spectrum Disorder (ASD). The program that provided these education sessions was called Parent Education and Support Services. Specifically, this study used a mixed methods research design to seek parent perspectives on the framework of the Parent Education Pathway, the content included within the education sessions, and whether their participation in these education sessions had an impact on how they approached parenting their child with ASD.

ASD is a neuro-developmental disorder characterized by marked deficits in the areas of social interaction, communication, and behaviour (Matson, 2011). Stemming from these child impairments, parents of young children with ASD often report increased levels of stress and a lower sense of self-efficacy as compared to parents of children with other developmental disabilities.

Currently, “behavioural interventions have become the predominant treatment approach for promoting the social, adaptive, and behavioral functioning of children and adults with ASD” (Larsson, 2013, p. 1). These interventions utilize the principles of Applied Behavior Analysis (ABA) as their primary teaching methodology. ABA is the application of behavioural principles, such as reinforcement and punishment, to address socially significant behaviours of interest. (Miller, 2006) and are widely implemented across the province of Ontario.

IBI is an evidence-based treatment used to educate, and ideally, improve the developmental trajectory for young children with ASD. This treatment intensively applies
behavioural principles to increase “language, imitation, social behavior and self-care skills as well as address disruptive behavior” (Matson, 2011, p. 29). A significant body of research has demonstrated the benefits of including educational opportunities for parents as a component of well-designed, quality IBI programs. The rationale supporting the inclusion of parent education in behavioural treatment programs for young children with ASD will be elaborated on and explored further in chapter 2 of this document.

**Purpose of the Study**

The intention of this study was to gather parents’ perspectives on their experience participating in the education sessions provided through a community-based, parent education and support program, specifically, assessing how they perceived the framework and content included in this program. The content of this parent education program focused on informing parents about common traits associated with ASD, increasing their awareness of ABA and other community resources while enabling them to be active and engaged in their child’s learning; therefore parents’ perspectives on each of these areas will be examined for parent satisfaction and possible suggestions for modification.

Parents were also asked questions regarding their overall impressions of this parent education program and whether they felt they approached parenting their child with ASD differently as a result of their participation in this parent education program.

This study gathered input from parents who had completed “core” education sessions offered through this parent education program. Parents were invited to complete a program-specific survey as well as participate in focus group discussions. This qualitative methodology was selected as it promoted group discussion and had been used
by other researchers assessing parent impressions of ASD-related materials (Mulligan, Steel, Macculloch, & Nicholas, 2010).

**Research Questions**

This study is designed to answer the following research questions:

1. How do parents of children with ASD who have participated in education sessions offered through *Parent Education and Support* perceive the framework of this program?

2. Do parents of children with ASD who have participated in education sessions offered through *Parent Education and Support* perceive this program as being successful achieving its goal of assisting parents to be increasingly informed, aware, and involved in their child’s learning?

3. Do parents report a change in how they approach parenting their child with ASD as a result of their participation in education sessions offered through *Parent Education and Support Services*?

**Rationale**

A number of recent studies have recommended that further investigation be carried out on the content of parent education sessions available to families raising a child with ASD prior to their child beginning IBI. It appears that the demand for programs of this nature will increase as reports by the National Epidemiologic Database for the Study of ASD in Canada suggest the prevalence of ASDs increased in all age groups (2–4 years, 5–9 years, 10–14 years) in all regions between the years 2003 and 2010 (Ouellette-Kuntz et al., 2012). Estimates drawn from data collected for children aged 6 to 9 suggest that 1 in 94 children in Canada are diagnosed with ASD. In the Southeastern region of
Ontario alone, the number of children diagnosed with an ASD between the years 2003 and 2010 increased by 108%, from 1 in 190 to 1 in 77 (Ouellette-Kuntz et al., 2012). A 2013 report published by the Office of the Auditor General of Ontario (OAGO) estimated that approximately 30,000 to 35,000 children with ASD were living in Ontario at the time their report was published (OAGO, 2013). Drawing from this increasing statistic coupled with the growing body of literature supporting that effective education for parents of children with ASD should address the high stress levels and low sense of self-efficacy experienced by this population, the primary investigator of this study wished to gain insight on how parents perceive their experience participating in recently redesigned education sessions offered through this parent education program.

**Importance of the Study**

Evaluating the education sessions delivered through this parent education and support program is beneficial on a number of levels. The literature strongly supports that parent education is an essential component of quality IBI treatment (Fava et al., 2012). Additionally, the senior management of the community-based agency that provides this education program to parents has invested significant resources to develop and deliver education for the families eligible to receive services. These education sessions were developed and sequenced with the goal of assisting parents to be informed, aware, active, and engaged with their child’s ongoing learning. Providing parents the opportunity to relay their experiences by participating in this parent education program, specifically their perceptions of the framework of this program, the role of parent education in general, and their overall impressions will be extremely useful for future program direction. Information gathered from parents may be used to inform the future programming
direction which, from an organizational perspective, is highly advantageous. As this was newly developed and delivered curricula, at the time this investigation began no input had been obtained from parents on their perceptions of the effectiveness of the content.

If this study demonstrates that parents perceive the education sessions developed and delivered through this program as successful in achieving the objectives of increasing parents’ ability to be informed, aware, active, and engaged in their child’s learning as well as impacting their feelings of stress, potential low self-efficacy, and possible feelings of isolation, other agencies who provide IBI to young children with ASD may look to offer similar content to families in their geographic location. It is common practice for not-for-profit service providers to share resources as a cost-saving measure.

**Personal Perspective**

As the primary investigator of this study I have been actively involved in researching parent perspectives, content development, delivery, staff training, and overall program management of this program since it began. I see great benefit in seeking first-hand information from the parents who attended education sessions offered through this program, as I value the time and effort that parents expend to attend these sessions (e.g., travel, childcare) and want to ensure that parents perceive their participation as a meaningful practice. It is necessary to disclose to the reader that in this investigative pursuit I have held dual roles; both as the content developer and as the program evaluator. However, as explicitly detailed in the following chapters, a number of thoughtful processes were intentionally put in place to prevent any perceived conflict and bias.
Limitations of the Study

As this investigation was narrow in focus, primarily concerned with parents’ perceptions of recently developed curricula offered through a community-based program in an urban city in Ontario, results should not be broadly interpreted to represent parent perceptions regarding parent education in general. The parents who participated in this investigation attended a minimum of four education sessions, equaling approximately 8 hours of education provided through this program; because of these criteria the results of this study should not be generalized to reflect perspectives and experiences of all parents of children with ASD. The families who participated in this study resided in an urban community in Ontario and results may not be representative of families receiving behavioural services through other regional providers throughout the province of Ontario. This study elicited parent input specific to the education sessions attended through this program and did not gather parent input on their attitudes or personal feelings on general topics such as the diagnosis of ASD.
CHAPTER TWO: LITERATURE REVIEW

The topic of ASD is broad and multifaceted. There is an extensive body of literature available on diagnostic features of ASD as well as available treatment approaches. This literature review will highlight recent revisions made by noteworthy professionals in the ASD community on diagnostic criteria for ASD. Also included is an overview of literary reports on the impact ASD has on families as well as the benefits of education for parents of young children with ASD.

Defining Autism Spectrum Disorder

The behavioural characteristics an individual must demonstrate in order to receive a diagnosis of ASD are outlined in the diagnostic manual published by the American Psychological Association. Up until May 2013, medical practitioners diagnosed ASD based on the behavioural descriptors included in the Diagnostic and Statistical Manual—Fourth Edition (DSM-IV) released in 1994 with a Text Revision (DSM-IV–TR) released in 2000. During this period this manual was the primary tool used by clinicians to evaluate and assess Pervasive Developmental Disorders (PDD), which the DSM-IV used as an umbrella term to describe a range of neuro-developmental disorders such as Autistic Disorder, Pervasive Developmental Disorder—Not Otherwise Specified (PDD-NOS), Asperger’s Disorder, Childhood Disintegrative Disorder, and Rett’s Disorder. Medical practitioners could assign one of these diagnostic labels to an individual based on the number and severity of symptoms they observed in three main areas: social interaction; communication; and restricted, repetitive, and stereotyped patterns of behaviour (i.e., repetitive movements, and vocalizations). These three areas of impairment assessed under the DSM-IV were often referred to as the “triad of impairments” (Wing,
1981, p. 33) and presented visually in the form of a triangle with each of the vertices labeled with one area of impairment.

Under the DSM-IV, some of the behavioural characteristics indicative of impaired social interaction were the absence or delay in nonverbal signs of showing interest and pleasure from being with another person (Wing, Gould, & Gillberg, 2011). Indicators of impaired social interaction frequently observed in young children with ASD are lack of eye contact, failure to initiate, or respond to smiles or social interactions. Other common symptoms of impaired social interaction are less frequent waving, bringing, or showing items of interest to others. The DSM-IV listed a number of descriptors of communication impairments, including difficulty sharing attention, initiating interactions, and establishing or maintaining conversations. Additional behavioural characteristics of impaired communication could have included atypical posture, facial expressions, as well as less frequent use of gestures such as pointing and reaching (Kupfer & Regier, 2012). The DSM-IV included restricted, repetitive patterns of behaviour as a third area of development often impacted by ASD. Criteria listed in this area include the presence of stereotypic speech, motor movements or object manipulation. In order to qualify as a symptom of ASD, these repetitive patterns of behaviour had to be abnormal in their intensity and focus. Excessively adhering to routines and showing extreme resistance to change could be another indicator of individual demonstrating repetitive and restricted patterns of behaviour (Kupfer & Regier, 2012).

In May 2013, a revised edition of the DSM was released. This version no longer uses Roman numerals in its title and is referred to simply as DSM 5. One of the most notable differences between this and earlier editions of this diagnostic manual is that the
DSM 5 eliminated the umbrella term Pervasive Developmental Disorder and the sub-classifications of Autistic Disorder, PDD–NOS, Asperger’s Disorder, and Childhood Disintegrative Disorder and replaced them with the general term ASD. This change reflects a shift from viewing these disorders as separate and distinct to conceptualizing them as a single condition with different levels of symptom severity. Under the revised diagnostic criteria included in the DSM 5, medical practitioners and assessors can specify a Level 1, 2, or 3 indicating the amount of support an individual would need based on their symptoms. The rationale for eliminating the variety of PDD sub-types and merging them into one diagnostic label came about mainly because many medical and behavioural practitioners in the field of ASD questioned the reliability of diagnoses across the range of sub-types previously available under the umbrella term PDD (Volkmar & McPartland, 2014).

Another noteworthy difference between the DSM 5 and earlier editions of this manual relates to how areas of impairment are organized. Up to and including the DSM-IV, three domains—social interaction, communication, and repetitive and restricted patterns of behaviour—were individually evaluated with a specific number of characteristics required in each domain in order to provide a confirmed diagnosis. The DSM 5 reorganized this triad of impairments into two domains by amalgamating social interaction and communication into one domain, labeled social-communication (Volkmar & McPartland, 2014). Behavioural descriptors for a new disorder, social-communication disorder, are included for the first time in the DSM 5. Individuals would qualify for this diagnosis if they present with social-communication difficulties similar to ASD but do not exhibit the same restricted interests and repetitive behaviours. The DSM 5 also removed
the previous PDD sub-type of Rett’s Disorder due to its genetic etiology. The resulting adjustments to the diagnostic criteria for ASD included in the DSM 5 came from more than 10 years of research and field-testing led by the Neuro-Developmental Disorders Work Group (Kupfer & Reigier 2012). It is anticipated that the elimination of the umbrella term PDD and its sub-types and the use of a single term, ASD, will decrease variability in diagnostic practices and avoid possible confusion among parents, practitioners, and educators.

**ASD—A Trip Down Memory Lane**

Although the criteria for diagnosing and assessing ASD has gone through considerable revisions over time, the primary affected areas of interest are strikingly similar to those noted by the early investigators of this disorder. Dr. Leo Kanner was the first individual to describe ASD, then called infantile autism. In 1943, his observations of eight boys and three girls were published in the journal *Nervous Child* under the title “Autistic Disturbances of Affective Contact.” Kanner outlined specific descriptions of each of the 11 children, acknowledging individual differences as well as common characteristics. Kanner concluded that the clients he observed over a 3-year period were limited in their genuine interest in people. Kanner based the word *autistic* on the Greek *autos* (meaning self) as he was truly intrigued by the intensity of the children’s self-absorption, questioning to what extent patient disinterest contributed to their disorder (Jepsen, 2007).

Kanner’s article also included general descriptions of his observations on the personalities of his patients’ parents, and noted these parents to be “cold, bookish, formal, introverted, disdainful of frivolity, humorless, detached, and highly, even excessively,
ration and objective” (Offit, 2008, p. 2). These descriptors foreshadow how parents of children with ASD would be perceived over the next few decades. Kanner saw little benefit to any form of remediation as he determined that it was a family’s fate or destiny to bear a child with ASD.

Bruno Bettleheim, a philosopher from the University of Chicago with strong psychoanalytic influences, extended Kanner’s earlier work. Bettleheim believed that children were not born with ASD; rather these young children sensed early on, sometimes days after birth, that their mothers were withholding love from them. In response to the lack of intimacy and closeness, the affected children retreated into themselves, resulting in regression and the presentation of autistic behaviours.

Unlike Kanner, Bettleheim believed there was a cure for infantile autism. His proposed treatment, called a “parentectomy” involved removing children from the home-setting for a long period of time and placing them in an institutionalized setting where they could be surrounded by teachers and therapists who he thought to be positive role models (Durbin & Mandas, 2010; Jepsen, 2007). Bettleheim was one of the loudest proponents of the belief that the coldness of the mother was responsible for the child’s condition. Bettleheim’s rationale for prohibiting parent contact was to prevent the young child from drinking the mother’s “black milk” and to allow them time to “thaw out” (Jepsen, 2007, p. 3). This belief solidified into the *Refrigerator Mother Theory* and guided diagnosis and treatment of ASD for many years. In *The Empty Fortress*, Bettleheim (1967) frequently restated his belief that “the precipitating factor in infantile ASD is the parent’s wish that his child should not exist” (p. 5).
Stemming from Kanner and Bettleheim’s etiology of infantile autism, this disorder was categorized as an emotional disturbance along with other psychiatric illnesses. However, this categorization of infantile autism would soon be determined inaccurate. In the early 1960s, the medical community began to question the classification and interventions attached to infantile autism. Bettleheim’s claim that he had successfully treated over 40 children at his Orthogenic School in Chicago was proven fraudulent. In 1964, Dr. Bernard Rimland, an experimental psychologist and father of a child diagnosed with infantile autism, published *Infantile ASD: The Syndrome and Its Implications for a Neural Theory of Behavior*. The book encouraged the medical community to move away from past practices of assessing and treating infantile autism as an emotional disturbance caused by unloving parent–child relationships and move towards accepting it as a neurological disorder pervasively effecting development.

Simultaneously with the shift in causality, family involvement in educational practices for young children with disabilities evolved considerably. Earlier time periods viewed the parents as the root cause of the disability with interventions primarily expert driven and deficit focused with little regard for improving family functioning (Wehman, 1998). During the 1980s and 1990s national and international government policy and legislation were beginning to reflect the changing concept of disabilities and recognize the pivotal role parents played in planning and delivering treatment for their child. The *American Handicapped Act* was one of the first government documents to amend their definition of the client from the child alone to include the family unit. This act included several provisions promoting the likelihood those services were individualized now allowing families to select and prioritize goals and coordinate services for themselves.
Concurrently, similar policy changes were occurring at a provincial and national level in Ontario and Canada. In 1982, the Canadian Charter of Rights and Freedoms was adopted. The charter required that all individuals regardless of race, religion, colour, origin, sex, age, and mental or physical disability had equal representation and protection under the law (Schlosser, 2009). This overarching charter influenced a variety of provincial legislation, such as the Ontario Disabilities Act, which was passed in May 1996. This piece of legislation aimed to improve accessibility for individuals and families affected by a disability in the areas of customer service, information and communications, employment, transportation, and built environment (Ontario Ministry of the Attorney General, 2005). During the 1990s, the provincial regulations and policies guiding services specific to ASD in the province of Ontario continued to broaden and become better organized.

In the year 2000, the Ontario Ministry of Children and Youth Services (OMCYS) provided funding to lead agencies in nine geographic regions to begin planning and delivering an intervention program for young children diagnosed with moderate to severe ASD. The initial service provided through these agencies was IBI, a systematic teaching method to improve language, social, play, and self-help skills in young children with ASD (OMCYS, 2006). The goal of this treatment was to improve the developmental trajectory for children with ASD so it could more closely match that of their same age, typically developing peers. Very quickly this treatment option became highly sought after by families, leading to significant wait-times before their child could begin IBI. As quantified by a recent media survey, wait-times for IBI in the province of Ontario ranged from 1 to 4 years (Gordon, 2012) and in 2013, the Auditor General of Ontario further supported the
need for this intervention, noting that more children with ASD are currently waiting to receive government-funded services than those currently receiving them (OAGO, 2013).

In the start-up years of the IBI program organized through these partnered, community-based agencies, eclectic, inconsistent, parent involvement opportunities were available. Parent education opportunities were provided through some, but not all, of the agencies with some parents possibly receiving child-specific training; however there were no group-based education sessions available to parents on broad topics associated with ASD. Additionally, during this initial start-up period, there was no organized, systematic database to track and record the education opportunities parents had attended. In 2010, the senior staff of these community-based, partnered agencies surveyed parents and clinicians in an attempt to quantify the amount and types of parent involvement being offered and attended by families of children receiving IBI. Based on the results of these surveys, the clinical directors and senior managers felt that there was room to improve in the organization, content, and delivery of parent education offered for families of children eligible for and waiting to receive IBI through this partnership.

This shift in the importance and role the family should play in their child’s treatment is reflected in the current program explored in this research investigation. The primary investigator of this investigation and the staff employed in this program recognize that children will engage with their parents for the majority of their early-life interactions and learning experiences.

**Applied Behaviour Analysis—A Promising Treatment**

As medical practitioners moved away from classifying ASD as an emotional disturbance and moved towards accepting that this disorder had a neurological etiology,
treatment approaches also changed. During the 1970s, Dr. Ivar Lovaas and his team of graduate students began exploring the effects of behaviour analysis on the repertoires of young children with ASD. Lovaas’s lab setting was referred to as the Young ASD Project and was housed in the University of California, Los Angeles. The focus of the Young ASD Project was to assess whether principles of operant conditioning previously demonstrated by earlier psychologists such as B. F. Skinner had an impact on the behavioural repertoires of young children with ASD.

**ABA Theory**

B. F. Skinner’s experimental analysis of behaviour (Matson, 2011), carried out primarily with pigeons and rats, demonstrated that behaviours could be increased or decreased depending on the environmental variables that preceded or followed. Specifically, Skinner demonstrated that frequency of lever pressing could be increased when followed by a positive reinforcer or decreased when followed by an aversive stimulus. Skinner’s experiments also demonstrated that satiation and deprivation impacted the occurrence or non-occurrence of specific actions. Skinner labelled the environmental events that occurred prior to behaviour as antecedents and the events that followed a response as consequences. Skinner referred to the manipulation of antecedents and consequences to effect behaviour as operant conditioning. When operant conditioning is used to address socially significant behaviours, such as increasing language or social skills or reducing self-injurious behaviours as found in some individuals with ASD, it is referred to as Applied Behaviour Analysis (ABA).

Practitioners apply a three-term contingency when analyzing behaviour through an ABA lens. This contingency involves *antecedents*, which are the events that precede
the *behaviour* to be increased or decreased as well as *consequences* which are the events that immediately follow the behaviour. When these three events—an antecedent, behaviour, and a consequence—occur in close temporal proximity to one another a dependent, contingent relationship is formed. *Prompts* are antecedent events that can be conceptualized as additional forms of assistance that are commonly used when teaching young children with ASD new skills. Prompts such as gestures and physical guidance are antecedents that serve as a signal for a particular behaviour to occur. When a therapist or parent is providing prompts they are said to be *prompting* (Matson, 2011).

Following the occurrence of a particular behaviour a consequent event can either be added or removed. Events that are added to an individual’s environment are labelled *positive* and events that are removed following a behaviour are referred to as *negative*. Consequent events can be further categorized based on their effect on the future occurrence of a particular behaviour. Positive or negative events that increase the future likelihood of a behaviour are labelled *reinforcers* and events that decrease the future likelihood of a behaviour are labelled punishers. The procedure of delivering a reinforcer is called *reinforcement*, with *punishment* being the procedure of providing a punisher. Typically ABA applies the principle of reinforcement to increase socially significant behaviours (Kearney, 2008). A review of current research studies for parent training for children with ASD shows that almost three quarters of these studies include operant conditioning procedures in their content (Matson, 2011). This figure lends further support to the importance of these components in contemporary parent training models for this population. The topics of prompting and reinforcement are the main operant procedures discussed during the education sessions delivered as part of this program. Educating
parents on the components of the three-term contingency and how they can apply it when trying to understand their child’s behaviour is the primary problem-solving approach used in this curriculum.

**ABA in Practice**

In 1987, Lovaas and his students published an article titled “Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children” in the *Journal of Consulting and Clinical Psychology*. This article presented the results of a controlled trial investigating the intensive application of behavioural intervention on young children with ASD. It was Lovaas’s hypothesis that “construction of a special, intense, and comprehensive learning environment for very young autistic children would allow some of them to catch up with their normal peers by Grade One” (p. 4). The investigators of these initial ABA-based treatments began to recognize the important role that parents could play in their child’s intervention. Lovaas stated that parents played an integral role in promoting the generalization of skills their child learned in the treatment setting to other environments. Lovaas required that treatment be delivered for “most of a child’s waking hours” (p. 5). The magnitude of treatment provided led to an increased emphasis placed on the importance of parents with Lovaas noting that parents were “extensively trained in the treatment procedure” (p. 5). A parent’s role in these early behavioural treatment programs was to extend the therapeutic approaches carried out during treatment to home routines. Parents were trained to be therapists and were required to deliver therapy to their children. While this wasn’t an ideal or natural role for the parent, this type of parent involvement was an improvement from the passive observer role prescribed to parents earlier. Lovaas’s study reported very favourable
outcomes for approximately half of the children who participated, with nine of 19 children successfully completing the regular Grade One curriculum without support. Following publication, many researchers heavily criticized Lovaas’s study and his results. These critiques stemmed from methodological weaknesses with his research design. Despite these criticisms, this study is one of the primary references for the efficacy of behavioural therapies for young children with ASD. Additionally, Lovaas’s publication is one of the inaugural, large-scale investigations demonstrating the positive impact parent involvement had on the outcomes for young children with ASD.

Following Lovaas’s publication, interventions based on ABA became more widely practiced with results pertaining to young children with ASD more frequently evaluated. The widespread use of ABA-based treatments initiated in the United States of America. In 1996, the New York State Department of Health published Clinical Practice Guidelines for ASD/ Pervasive Developmental Disorders. These guidelines were written by an expert panel comprised of medical doctors, researchers, and noteworthy practitioners in the field of ASD. The Clinical Practice Guidelines recommended that the principles of ABA be included as important elements in any intervention program for young children with ASD (New York State Department of Health, 2011).

ABA in Ontario

Following the United States of America’s adoption of ABA-based services for young children with ASD, Canada, and more specifically Ontario, began to follow suit, beginning with the IBI program initiated in 2000. The term IBI is used to describe the intense, behaviour analytic treatment used to improve the behavioural repertoires of young children with ASD (OMCYS, 2006). This treatment is typically provided by
trained therapists with one therapist assigned to work directly with one child. Children usually receive in excess of 20 hours per week of intervention with the primary goal being to increase the developmental trajectory for children with ASD to more closely match their same-age, typically developing peers (OMCYS, 2006).

In addition to the IBI treatment program, the province of Ontario provides additional ABA-based service options for children with ASD and their families. In May 2007, the Ontario Ministry of Education (OME) created Policy and Program Memorandum No. 140 (PPM 140) titled, *Incorporating Methods of Applied Behaviour Analysis into Programs for Students with ASD*. This document requires publicly funded schools in the province of Ontario to use ABA teaching methods for children with ASD (where appropriate). The principles of ABA programming listed in PPM 140 include, where appropriate: individualized programs, incorporating positive reinforcement and collecting and analyzing data (OME, 2007). In July 2011, the OMCYS once again expanded ABA-based services and supports available for children with ASD by providing funding for short-term, group-based intervention. This service provides group-based treatment targeting behaviour management, communication, social, and daily-living skills. This service option is available to all children 0-18 years of age, with a confirmed diagnosis of ASD, living in the province of Ontario (OMCYS, 2011).

These initiatives based exclusively on the principles of ABA demonstrated the province of Ontario’s commitment to providing a variety of quality, effective services for children and youth with ASD and their families. While diverse applications in the delivery of teaching based on ABA exist, it is apparent that researchers of almost all existing behavioural programs for children with ASD emphasize the centrality of parental
involvement (Silverman & Brosco, 2007). As parents hold a fundamental and important role in their child’s ABA-based treatment, gaining first-hand input on their perceptions of an education program that was developed to promote their active involvement is a relevant and meaningful task carried out through this investigation.

**Impact of ASD on Parents**

Receiving a diagnosis of ASD for their child is a life-changing event for parents and families. Parents report spending an average of 3.4 years and visiting with four to five clinicians between the time of their first concern and receiving a confirmed diagnosis of ASD (Goin-Kochel, Mackintosh, & Myers, 2006). This lengthy, arduous process to obtain a diagnosis is one of the initial stressors parents report. Casey et al. (2012) demonstrated the profound impact receiving this diagnosis had on some families. In this investigation researchers asked parents to reflect on the time their child received a confirmed diagnosis of ASD and respond to a series of questions regarding stress level. Results of this survey indicate 20% of parents met diagnostic criteria for Post-Traumatic Stress Symptoms. These parents reported exposure to a traumatic event and experiencing symptoms such as intrusive recollections, avoidant symptoms, and hyper-arousal that negatively affected their lives.

Stressors such as strain on the marital relationship, increased financial obligations, social isolation, and difficulty arranging educational placements are common to parents of children with disabilities in general. However, there are characteristics unique to ASD that lead these parents to report experiencing higher stress levels than parents of children with other developmental disabilities. Norton and Drew (1994) identified communication deficits, difficulty with mother-child bonding during the infant
years, erratic sleep patterns, challenging behaviour, and the presence of splinter skills (demonstrating unique talents or skills at a level disproportionate to their overall functioning) as adding to the stress profile of parents of children with ASD. Recent investigations identified that guilt associated with spending more time with their child with ASD than their siblings was an additional factor that contributed to the stress profile of mothers of children with ASD (Pisula, 2011). These findings appear to be representative of the sentiments of Ontario families. In a 2014 Interim report drafted by the Legislative Assembly of Ontario’s Select Committee on Developmental Services (Select Committee), parents expressed feeling socially isolated, cut off from friends, extended families, and communities. Some parents added that caregiving responsibilities meant they had little free time to spend with their children (Select Committee, 2014). In a 2013 meta-analysis, Hayes and Watson compared stress measures in parents of children with ASD to parents of children with other developmental disabilities, as well as parents of typically developing children. After assessing for possible publication bias, these researchers concluded that there was a significant difference between the stress experienced by parents of children with ASD when compared to parents of children with other developmental disabilities as well as parents of typically developing children and recommended that further attention should be paid to parenting stress in families including a child with ASD (Hayes & Watson, 2013).

The stressful experiences of parenting a child with ASD were further highlighted by Myers, Mackintosh, and Goin-Kocheet (2009). These investigators asked 350 parents of children with ASD “How has your child in the autism spectrum affected your life and your family’s life?” (pg. 670). Stress was the most reported theme in these open-ended
responses, with 70% of parent answers mentioning stress in some manner. Parents often reported their stress to be painful and constant. This evidence is consistent with Steiner, Koegel, Koegel, and Ence’s (2012) description of the stress profile for mothers of children with ASD. Steiner refers to this stress profile as severe, consistent, across cultural, geographical areas, maternal age, and child functioning.

Self Efficacy

Studies show that self-efficacy is also impacted in many parents of children with ASD. This social learning concept, developed by Albert Bandura, describes individuals’ beliefs about their capabilities to achieve performance levels and influence events that affect their lives. Individuals’ sense of self-efficacy will determine how much effort they will expend and how long they will persist in the face of obstacles. Self-efficacy is not discrete but rather can be conceptualized as a continuum from high to low (Bandura, 1977).

Recently, the concept of self-efficacy was expanded to include parental self-efficacy. This term is defined as individuals’ thoughts or cognitions about their ability to perform competently and effectively as a parent (Jones & Prinz, 2005). Parents’ sense of parental self-efficacy is influenced by direct feedback from interactions with their child (Donovan, Leavitt, & Walsh, 1990). Parents of children with ASD frequently report a lower sense of parental self-efficacy, partly due to the increased difficulty they report in understanding their child’s behaviour (Kuhn & Carter, 2006). Parents of children with ASD report quantitative and qualitative differences in the positive social interactions they experience with their children as compared to parents of typically developing children. Experiencing fewer positive social interactions could have a significant impact on how effective and competent a parent feels in the parenting role. Another potential contributor
to the low sense of parental self-efficacy reported by some parents of children with ASD is that this group receives less positive appraisal statements for their parenting efforts (Raj & Kumar, 2009). Perceiving oneself as having a low sense of self-efficacy or parental self-efficacy can lead to a number of adverse outcomes. Individuals with these perceptions would tend to avoid difficult tasks viewing them as a personal threat, have low aspirations, and a weak commitment to their goals. Additionally, an individual with a low sense of self-efficacy or parental self-efficacy is likely to focus on personal deficits and be slow to recover from challenges or setbacks (Jones & Prinz, 2005). Behaviours of this type could be counter-productive to parents participating in education sessions as they may interpret these events to be a threat to their current parenting style. Parents of children with ASD may be reluctant to practice new techniques during the session or express that they don’t have the knowledge to acquire new skills. For these reasons it is necessary for professionals planning and delivering education sessions for parents of children with ASD to consider the impact a potentially low sense of self-efficacy may have.

While a number of parents and research articles report on the negative impact raising a child with ASD had on their family, this is not reflective of all parent experiences. Myers et al. (2009) report approximately 10% of parents surveyed provided positive responses to the online question “How has your child in the autism spectrum affected your life?” Positive parent responses included statements referring to how their child with ASD has “made them a better parent and appreciate the unique features of their child’s behaviour” (p. 673). In addition to these specific comments, this article included positive themes describing overall parent comments. Theme clusters included enriching our lives, taught positive emotions, learned to slow down, enrich spiritual and
marital life, and provide balance to the often negative impact commonly discussed in the literature and emphasized by parents. This study highlights the rich, substantial insight parents of children with ASD are able to provide when given the opportunity.

**Education for Parents of Children With ASD**

One way parents of children with ASD can be involved in treatment for their child is through participation in education sessions. The term *parent education* is broad and can be widely applied to a variety of settings or events. Common to most parent education opportunities is the intention to provide parents with information or to teach them skills. The specific nature of the content addressed through parent education varies greatly. However, a prevalent focus of parent education is to enhance or facilitate parent behaviours that will influence positive developmental outcomes in their children (Shultz, Schmidt, & Stichter, 2011; Steiner et al., 2012).

In 2001, the National Research Council, an independent organization responsible for reviewing evidence for potential treatments, stated it was their position that across primary preschool programs for young children with ASD there is a very strong consensus that the inclusion of a family component, including parent training is critical (National Research Council, 2001). The National Research Council recognized that children diagnosed with ASD had specific skill deficits and difficulty with learning, making targeted parent education particularly acute for this group of parents (National Research Council, 2001).

There is a consensus that the momentum for parent involvement in ASD treatment is growing (Matson, Mahan, & LoVullo, 2009) with the number of studies investigating parent education for children with ASD expanding to over 30 published studies between
1987 and 2007. From this growing body of literature the potential benefits parents can experience as a result of participating in education sessions became more apparent. In general, parent education has been shown to be an effective strategy to teach parents behavioural skills to use with their child. Parents have demonstrated that following parent education they were able to implement these techniques with a high degree of fidelity (Ingersoll & Dvortcsak, 2010). By applying the expertise gained from participating in education sessions parents had been able to successfully reduce their child’s maladaptive behaviour, improve communication, and social skills. Parents who participate in education sessions report improved parent-child interactions with their child with a diagnosis as well as other children, when applicable.

There are a number of training methods available that led to favourable parent outcomes. Parent coaching is a commonly used education strategy and is often included in education packages for young children with ASD. Ingersoll and Dvortcsak (2010) developed a parent implemented intervention titled “Improving Parents as Communication Teachers (Project ImPACT ®). This treatment program uses parent coaching as its primary method of instruction. Coaching sessions are typically one-on-one with a therapist and parent with therapists using discussion, demonstration, practice, and feedback to assist parents to achieve skills in a variety of areas.

While one-on-one parent-coaching has been shown to be an effective teaching method to assist families to acquire a vast number of skills, the resources and staffing requirements are sometimes difficult for not-for-profit agencies to arrange. Agencies of this nature frequently use group-based training as it is less time intensive for the trainers and more cost-effective for the agency (Ingersoll & Dvortcsak, 2010). In addition to
financial resources, the content focus and anticipated outcomes of the education session may also impact the delivery format selected. Education programs that focus on attempting to reduce the high-stress levels reported in parents of children with disabilities and/or ASD are often provided in a group format rather than in a one-to-one setting (Tongee et al., 2006). This group-based learning environment was favoured as the opportunity to share and network with other families of children with ASD has been shown to lead to improvements in the well-being of both the child and their family (Crinic & Stormshak, 1997).

As research moved toward determining the ideal format in which to deliver parent education focused on reducing stress, it also uncovered key content items that should be included. Researchers such as Hedderly, Baird, and McConachie (2003) reported that it is necessary for educators who develop and deliver education sessions for parents of children with ASD to include a problem-solving element into their curriculum and developers of parent education should prioritize including knowledge specific to their child's disability in the education session. It is crucial that parent educators place considerable emphasis on providing parents with accurate knowledge on the diagnostic features of ASD, as well as training and assistance on how to evaluate sources of information and reported treatment outcomes. Chowdhury, Drummond, Fleming, and Neufeld (2002) demonstrated that parents are likely to come across unsubstantiated or incorrect information, supporting that quality and accuracy of ASD-related information included in these websites varies greatly. A 2010 Google search on the word ASD returned 19,900,000 hits. This abundance of easily accessible information, likely of varying quality and accuracy, highlights the need for parents to develop a skill-set in
vetting sources of information. The findings reported in Mackintosh, Myers, and Goin-Kochel (2007) further demonstrate the need for educators to provide parents of children with ASD up-to-date, accurate information on this disorder as these researchers determined that 86% of the 498 parents surveyed obtained a considerable amount of their ASD related information from web pages, and email list-serves.

Parents report information specific to diagnostic criteria, treatment options, characteristics of the disability, and specific disability-related concerns (i.e., sleep patterns, social skills) as helpful (Tongee et al., 2006). It is interesting to note that it is not necessarily the amount of knowledge a parent acquires specific to their child’s disability that has an impact but rather their perception that they acquired new knowledge. Luthra and Perry (2011) explored perceived and actual parent knowledge as a possible factor influencing outcomes for parents of children with ASD. Their results showed that perceived knowledge on the part of the parent was a significant predictor of positive impact. Parents’ perception of how much they knew about their child’s disability as opposed to actual knowledge acted as a positive force in overall parent outcomes. This study suggested the need for improved parent education and training to target parents’ sense of self-efficacy and confidence in their ability to help their child. Those individuals who develop education sessions for parents of young children with ASD need to recognize the challenges and unique experiences exclusive to this group and be aware of the high levels of stress and low sense of self-efficacy often reported.

Equally as important as the content of parent education is the timing in which it is delivered, relative to intensive service. It is essential that parents of young children with ASD have education sessions available to them prior to their child commencing IBI.
Educating parents while their child is on the waitlist for more intensive services may enable parents to be more involved in their child’s treatment, as they have a familiarity with commonly used terms and teaching approaches (Ingersoll & Dvortcsak, 2010). Arranging education opportunities for parents before their child begins IBI is also beneficial for the service provider. Employees involved in the provision of IBI treatment need to be aware of the stress levels of parents prior to their child beginning treatment and education opportunities provided are a suitable way to gain this insight. Having prior knowledge of the potential stress levels parents are experiencing could have an impact on how IBI is administered. Shine and Perry (2010) demonstrated a trend where children whose parents had somewhat higher parental distress scores at Intake, which is the beginning of IBI, achieved fewer gains in the developmental domains targeted through IBI.

It is apparent that many researchers are focused on determining the ideal conditions to maximize the effectiveness of educational sessions for parents of young children with ASD. Currently, the literature supports a group-based learning environment that includes problem solving and knowledge components. Additionally, literature recommends that education opportunities be available for families prior to their child beginning IBI. While IBI is a direct, one-on-one child-focused intervention, treating a child on the spectrum involves more than just the individual therapy and should actively include the family and others who spend time with the child (Burrell & Borrego, 2012). The demonstrated need for educational sessions for parents of young children with ASD to include problem solving, information specific to autism spectrum disorder, and ABA was incorporated into the curricula under investigation. As this content was delivered to a considerable number of families, the onset of this investigation was an ideal time to seek
parent input and assess their perspectives on a number of questions related to their experience participating in this program.

**Chapter Summary**

The shift from ASD being classified as an emotional disturbance caused by poorly developed mother–child relations to our current understanding of a disorder with a neurological etiology had a significant impact on the role that parents of children with ASD play in their child’s education. Historically, parents of children with ASD played a passive, observer role in their child’s treatment and education, however, researchers such as Ivar Lovaas demonstrated that active parent involvement in ABA-based intervention programs, currently widely available in the province of Ontario, can significantly improve treatment gains for children with ASD. In addition to describing the changing role of parents in treatment programs for children with ASD, researchers also investigated the impact having a child with ASD had on parents’ well-being. A number of published studies concluded that parents of children with ASD often presented as highly stressed with a low sense of self-efficacy. Clinicians who plan and oversee well-designed IBI programs often recommend parent education as an essential component to their treatment plan as a wealth of potential benefits, such as improved stress levels and increased knowledge about their child’s disorder are available to parents who participate in these education opportunities.

The remainder of this document outlines the process the researcher undertook to gather input from parents of young children with ASD who participated in education sessions offered through a community-based agency that provides behavioural intervention. The results and implications of this investigation are presented in chapters 4 and 5.
CHAPTER THREE: METHODOLOGY

In order to appreciate the anticipated outcomes of this study, it is helpful for the reader to have a working understanding of the overarching, community-based program that oversees the education sessions currently under investigation. This chapter presents a brief description of this service including the staff involved as well as a succinct description of the curricula provided.

Background

In January 2011, a partnership of agencies overseeing IBI in an urban area of Ontario expanded the services available to parents of children with ASD to include Parent Education and Support Services, a complementary program focused on supporting parents of children with ASD eligible to receive IBI. Through this program a range of services was offered to families, such as service co-ordination, assistance with registration for community programs, and group-based parent education. The focus of this investigation was to gain input from parents who had participated in the education sessions offered as part of Parent Education and Support Services; therefore, service co-ordination and individualized assistance were not evaluated. The education component of this program consists of a series of group-based, sequenced sessions captured under the umbrella-term the Parent Education Pathway (Figure 1).

The Parent Education Pathway

Education sessions carried out under the Parent Education Pathway ranged in length, lasting between 1.5 and 2 hours and often took place in small meeting rooms equipped with necessary items required for teaching; large presentation screen, computer, and LCD projector with light refreshments typically provided. Education sessions were
facilitated by one or two Family Support Coaches—individuals employed by one of the partnering agencies, with a background implementing IBI who had received additional training in basic presentation skills and adult education learning theories.

The *Parent Education Pathway* is organized into four phases which roughly align with the various stages a child and family will pass through during their involvement with the community-based IBI provider: eligible and waiting, preparing to begin IBI service, active in IBI service, and transitioning from IBI service into future learning environments. The *Parent Education Pathway* and the sequence of sessions it included makeup the framework of this education program and the focus of the first research question guiding this investigation. During focus group discussions parents were asked to specifically provide their input and perceptions of the *Parent Education Pathway*. The results of this discussion will be presented in the subsequent chapter.

**Phase 1: Getting started.** Once a child and family were deemed eligible to receive IBI services, that child’s name was added to the bottom of the program waitlist. Family Support Coaches would call eligible parents within 6 weeks of their child being added to the waitlist to invite them to attend the initial education session provided through this program. Parents began their involvement with the *Parent Education Pathway* at Phase 1, which was divided into two sections: *Getting Started* and *A Behavioural Approach to Parenting*. *Getting Started* included two education sessions; the first session *An Orientation to Autism Services*, included a detailed overview of the model of service adopted by the community-based agencies. Family Support Coaches spent the majority of this 2-hour session discussing the range of benefits available to parents who participate in education opportunities.
### Figure 1. The Parent Education Pathway.

<table>
<thead>
<tr>
<th>Phase 1: Getting Started Mandatory</th>
<th>Phase 2: Preparing for IBI</th>
<th>Phase 3: Partnering for Success in IBI</th>
<th>Phase 4: Preparing for School and Beyond</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Following eligibility:</strong></td>
<td>Special Topics Session(s)</td>
<td>During IBI Service</td>
<td>Transition</td>
</tr>
<tr>
<td>1. Getting Started</td>
<td>• Toileting</td>
<td>Parent education provided through</td>
<td>Introduction to</td>
</tr>
<tr>
<td><strong>Part One:</strong> Introduction to Autism Services</td>
<td>• Communication</td>
<td>clinical team</td>
<td>Connections for Students</td>
</tr>
<tr>
<td><strong>Part Two:</strong> Intro to ASD</td>
<td>• Nutrition and Autism</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. A Behavioural Approach to Parenting</td>
<td>• Play/Social Skills</td>
<td></td>
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</tr>
<tr>
<td><strong>Part One:</strong> ABA Key Terms</td>
<td>• Daily Living Skills</td>
<td></td>
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<tr>
<td><strong>Part Two:</strong> Building ABA into Family Routines</td>
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<tr>
<td><strong>Part Three:</strong> Prevention and Redirection</td>
<td>Parent Introduction to Intensive Behaviour Intervention</td>
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As part of this session parents were provided with a Family Learning Plan, a hard-cover booklet that assisted them in planning and tracking the future education sessions they would attend. When presenting the second education session, *An Introduction to Autism Spectrum Disorder*, Family Support Coaches placed considerable attention on explaining the common areas of development impacted by a diagnosis of ASD as well as highlighting theories of causation currently being investigated.

Following completion of *Orientation to Autism Services* and *An Introduction to Autism Spectrum Disorder* parents enrolled in a three-part *Behavioural Approach to Parenting* series which included three education sessions: *ABA Key Terms*, *Building ABA into Family Routines*, and *Prevention and Redirection*. *ABA Key Terms* introduced parents to words and concepts they would continue to hear in future education sessions offered through this program, as well as throughout their various stages of IBI service.

Parents participated in large and small group discussions as Family Support Coaches explained and defined the terms ABA, prompting, reinforcement, and task analysis. The content included in this session was a prerequisite to all other sessions in the *Parent Education Pathway*. During the second session *Building ABA into Family Routines*, Family Support Coaches highlighted the importance of being active and engaged in their child’s learning and assisted parents to identify teachable moments, objectively define suitable skills to teach, and develop plans to reinforce.

The sessions described above—*An Orientation to Autism Services*, *An Introduction to Autism Spectrum Disorder*, *ABA Key Terms*, and *Building ABA into Family Routines*—made up the core education sessions of the *Parent Education Pathway* and the main focus of this investigation.
During the third session in the *Behavioural Approach to Parenting* series, *Prevention and Redirection*, Family Support Coaches exposed parents to behavioural terms used within the IBI program to assess, prevent, and redirect behaviours that may interfere with their child’s learning and discussed how parents could adopt a functional approach to reducing problematic behaviour.

**Phase 2: Preparing for IBI.** The second phase of the *Parent Education Pathway*, *Preparing for Intensive Behaviour Intervention* included five elective, special-topic sessions: toileting, communication, nutrition and ASD, play and social skills, and daily living skills. These topic areas were included as they represented skill areas that are often delayed or affected by a diagnosis of ASD. Additionally, phase 2 included a *Parent Introduction to Intensive Behaviour Intervention* which informed parents on key elements related literature noted should be included in quality comprehensive IBI programs, specifically stressing the importance of active parent involvement with clinicians during treatment.

**Phase 3: Partnering for success.** This phase of the *Parent Education Pathway* begins when a child starts IBI direct service, anywhere between 18 and 24 months after joining the waitlist. During this phase, the provision of parent education shifts from the Family Support Coach to the child’s core clinical team consisting of; a clinical supervisor, supervising therapist, and several instructor therapists. The roles and responsibilities associated with these clinical positions are described in detail in the OMCYS’s *ASD Intervention Program Guidelines*. The guidelines included in this public document “govern the delivery of intensive behavioural intervention and associated
services to children with autism by the Regional Program Providers delivering the Autism Intervention Program” (OMCYS, 2007, p. 4).

A clinical supervisor is responsible for overseeing, monitoring, and evaluating the overall quality and consistency of a child's behavioural program (OMCYS, 2007). Ideally, a clinical supervisor would have a doctoral degree in Psychology and be a Board Certified Behavior Analyst. However, due to the limited number of clinicians meeting these qualifications in the province of Ontario, clinical supervisors often possess a Master’s degree plus extensive relevant experience. Within this community-based IBI program, a clinical supervisor could oversee between two and four treatment teams.

One supervising therapist is assigned to each IBI team in this community-based IBI partnership. A supervising therapist performs a number of clinical and administrative responsibilities such as; implementing the clinical recommendations provided by the clinical supervisor, staffing, scheduling, training, and supervision.

Typically, an IBI treatment team is comprised of eight to nine children, each assigned one primary instructor therapist. An instructor therapist’s primary responsibility is to deliver one-on-one or group instruction to the clients on their caseload. Additional tasks included within the instructor therapist role are; making necessary program materials, maintaining their primary client’s programming binder, data collection, graphing, and program revisions.

While a child is in active IBI, the education provided to parents is tailored to build on the knowledge gained through participation in the education sessions currently being investigated, as well as align with the specific goals and skills targeted within the child’s individualized curriculum.
Phase 4: Preparing for school and beyond. The final phase of the Parent Education Pathway is titled Preparing for School and Beyond. Currently, this phase includes one group-based education session titled An Introduction to Connections for Students. During this session Family Support Coaches explain the details of Connections for Students; a program jointly offered through the OME and the OMCYS to assist children and families transitioning from the Autism Intervention Program to a publicly funded school board.

In addition to the education sessions offered through the various phases of the Parent Education and Pathway, parents were provided additional educational opportunities to learn about other community agencies and supports that may provide additional resources to their family. These information sessions included topics, such as financial planning, Parks and Recreation, registering for school, and respite options. The goal of these sessions was to increase parent awareness on how to access relevant community resources.

The intention of the education sessions offered through the Parent Education Pathway was to provide parents with content that was relevant and applicable to the questions and concerns they may have had at this early stage in their acceptance of receiving a diagnosis and moving forward with parenting a young child with ASD. These sessions did not attempt to address all possible age groups and topic areas. Adopting a narrow focus to parent education aligned with the findings of a number of published studies as several researchers stated that a recurring problem in the area of educating parents of children with developmental disabilities and ASD was not the availability of teaching methods with supporting research, but making this information available to families in a
timely, acceptable, user-friendly manner (Hudson et al, 2003; Sanders et al., 1999). As previously discussed, there is an emerging body of literature guiding parent educators on items to include as well as ideal training format when designing education for parents of young children with ASD. The content included in the education sessions offered through this program covered topics relevant to parents of young children with ASD such as: information on diagnostic criteria of ASD, effective ABA-based teaching methods, as well as information on common areas of parent concern such as (e.g., toileting, nutrition, and communication). The Family Support Coaches who facilitated these sessions hoped that through their attendance parents of children with ASD would be active and involved in their child’s learning and have an increased awareness of additional available community programs and resource material (books, DVDs) that could promote their continued learning. Family Support Coaches anticipated that involvement in these sessions would assist parents to incorporate behavioural strategies into home and community routines so parents could be active and engaged in their child’s learning.

The Family Support Coaches involved in the development and delivery of these parent education sessions intended to reduce the potentially high levels of stress these families may be experiencing by providing them with in-depth knowledge about their child’s disability and the evidence-based treatment options available to them. It is necessary to evaluate whether parents who participated in these sessions perceived this program as being effective in achieving this goal.

**Content of Parent Education Sessions**

The sessions delivered through this program were not carried out as part of a standard, manualized curriculum but were developed by the researcher based on
consultation with the clinical staff of the community-based IBI program, as well as a thorough investigation of the literature on common questions and concerns reported by parents of young children with ASD. The dual roles assumed by the primary investigator was disclosed as a potential limitation of this investigation in chapter 1 and the number of activities employed to prevent any potential for researcher bias are presented at the conclusion of chapter 3. The potential for a non-manualized education program to achieve favourable outcomes is possible based on recent findings. Kaminski, Valle, Filene, and Boyle (2008) demonstrated through a meta-analysis on components associated with parent training program effectiveness that manualized, standardized curricula did not produce a significant effect size when compared to programs without standardized curriculum.

The researcher of this study adopted a unique approach when organizing and developing the content for this parent education program, identifying key parent attributes targeted for increase. These attributes were represented by four words—*Informed, Aware, Active, and Engaged*—and were included in the learning objectives as well as mentioned frequently by the Family Support Coaches throughout the education sessions. Included within each of these attributes were specific outcomes staff in this program hoped parents would acquire.

**Informed**

A main objective of this parent education program was to provide parents of children with ASD up-to-date, well-researched information specific to ASD, ABA, and general parenting practices. The Family Support Coaches assisted parents to understand
and effectively implement commonly used strategies such as prompting and reinforcement.

**Aware**

Through participation in the education sessions offered as part of the *Parent Education Pathway*, Family Support Coaches anticipated that parents would become familiar with other community resources and agencies available to provide service and support to their child with ASD and their family as a whole. The Family Support Coaches were deeply committed to assisting parents to recognize the importance of ongoing, active, community involvement for their child with ASD, siblings, and the family as a whole.

**Active and Engaged**

All sessions delivered through the *Parent Education Pathway* included role play, small and large group activities, and other opportunities for active parent involvement. The Family Support Coaches facilitating these sessions felt that by providing parents with the opportunity to practice and receive feedback on their ability to implement behavioural teaching methods during the training sessions they would have increased confidence and competence when implementing behavioural teaching strategies during their home routines.

As this is a newly developed curriculum carried out under a redesigned framework, the *Parent Education Pathway*, the primary researcher of this investigation devised research questions that would explicitly address parents’ experiences participating in redesigned education sessions as well as their input on the framework that guides this curriculum.

The sessions included in the *Parent Education Pathway* were offered continually, on an ongoing basis. As parents completed one session they became eligible to participate
in the subsequent session. Parents completed these core education sessions across varying lengths of time, with some parents choosing to attend a session every 2 to 3 weeks whereas other parents may have longer intervals (i.e., several months) between education sessions. Family Support Coaches informed parents of the dates, times, and locations of upcoming sessions which they were eligible to attend. The senior management of the agencies affiliated with this parent education program did not make participation in these education sessions a mandatory component of the services they provide. Family Support Coaches encouraged and recommended that parents participate in these sessions prior to their child beginning IBI treatment as it was anticipated that exposure to the topics addressed in these education sessions prior to their child beginning IBI treatment would assist parents in being more knowledgeable about ASD, ABA, and the parameters of IBI service.

**Research Methodology and Design**

This is a mixed-method study involving both qualitative and quantitative research. Research of this nature applies at least one quantitative and one qualitative approach to the collection and analysis of data (Evans, Coon, & Ume, 2011; Greene, Caracelli, & Graham, 1989). In recent years published, mixed-methods studies have increased in number and breadth, becoming increasingly popular in the fields of education, social, behavioural, and health sciences (Evans et al., 2011; Tashakkori & Teddle, 1998). These areas of study are sometimes referred to as practice fields and can have “messy, confusing problems of interest that defy rigorous technical problem solving” (Evans et al., 2011, p. 276). Researchers who employ this methodology, often referred to as pragmatists, typically consider all research methods as viable options to best understand the current research problem. Employing a pragmatic approach to data collection allows a
researcher to acquire new knowledge within these uncertain and sometimes unstable environments (Evans et al., 2011). These outlined characteristics of a pragmatic researcher reflected the perspectives the primary researcher held towards conceptualizing, designing, and carrying out research studies and are indicative of my worldview. Creswell (2012) characterized worldviews as the “broad philosophical assumptions researchers use when conducting studies” (p. 357). In order to be true to the subtle, idiosyncratic differences that make mixed-method research unique, Johnson and Christensen (2004) stated that it is essential that researchers appreciate the fundamental principle of this methodology when conducting research designs of this nature. Adopting this fundamental principle requires that researchers who use a mixed-method approach “collect data in such a way that the resulting mixture had complementary strengths and non-overlapping weaknesses” (Johnson & Christensen, 2004, p. 411). As the goal of this program evaluation was to gain practical input from a broad sample of parents who had participated in education sessions offered through this program a mixed-methods approach was fitting. This study included a program-specific survey intended to obtain objective input from parents on key elements included in these education sessions as well as in-depth, content-rich insight obtained through focus group discussions. It is my hope that by utilizing a mixed method research design a more holistic understanding of the perspectives of parents who completed core education sessions through this program could be obtained.

Participants

Purposeful sampling as outlined by Creswell (2012) is used to describe a researcher’s intentional selection of specific participants to help learn or better understand a central
phenomenon. For this study, the sole source of participants was parents or caregivers of a child with ASD who had been deemed eligible to receive IBI through a community-based service provider. At the time this study began participants may have had a child who was waiting to receive, or already participating in IBI services. In addition, eligible parents must have completed the first four core education sessions (*Introduction to Autism Services, Introduction to ASD, ABA Key Terms, and Building ABA into Family Routines*) offered through this parent education program. This criterion for inclusion was selected because parents who had completed these sessions would have been familiar with the aspects of the program currently under investigation, and its content, delivery style, and messaging.

In total, parents of 141 clients met this criterion. This total group of participants was further categorized into smaller quadrants based on the very large geographic location in which they resided. This quadrant also represented the location of the education sessions attended as well as where their child would receive IBI services. Of the 141 eligible participants, 54 resided in the West quadrant, 39 resided in the East quadrant, 30 resided in the North quadrant, and 18 resided in the South quadrant. The number of participants eligible across the four quadrants differed as a result of the varying number of children eligible for IBI as well as the dissimilarity in the number of education sessions delivered in each quadrant. The parents involved in this study completed the last core education session, *Building ABA into Family Routines* between May 2012 and February 2014. Figure 2 shows a breakdown of eligible participants across the four quadrants.
Figure 2. Breakdown of eligible participants by quadrant.
Recruitment

This study received clearance from Brock University Research Ethics Board (file number: Brock 13-135-MAICH) and the review board affiliated with this community program in January 2014. All participants in this study were recruited through a pre-existing tracking database used across the partnered agencies affiliated with this parent education program. This program-specific database included parent and child names, addresses, and the dates that an education session was attended.

For the purposes of this investigation, eligible participants were identified by an office assistant employed at one of the partnered agencies with no prior relationship or contact with any of the participants who met this study’s inclusion criteria. Eligible parents were those individuals who had a date of attendance for each of the four core education sessions. After compiling a mailing list of the contact information of the eligible participants, the office assistant mailed a one-page flyer labelled Invitation to Participate in Research to the home address of each participant. This mailed document briefly described the details of a focus group, the commitment of the parents, as well as information specific to date, time, and the location of the session. Interested participants were asked to register with the office assistant responsible for the mail-out. Aligning with literature recommendations, focus group attendance was limited to 10 participants (Asbury, 1995). A focus group of this size was selected as it provided a representative sample of the participants within each quadrant while still being manageable for the moderator. None of the scheduled focus groups had registration higher than 10
participants, so no interested parents were turned away. If registration for the focus group was less than six participants 2 weeks prior to the scheduled date, the office assistant contacted families by phone to inquire whether they had received the *Invitation to Participate* in the mail and asked if they wished to attend. This additional recruitment method was required for three of the four scheduled focus groups and was guided by script that was succinct and void of any coercive influence (Appendix A). The number of attendees at each focus group ranged from two to seven with a combined total of 16 parents made up of 11 mothers and five fathers.

In addition to the invitation to participate flyer, a program-specific survey (Appendix B), accompanied by a cover letter (Appendix C), were also mailed to the family home of the 141 clients who were eligible to participate in this investigation. The survey cover letter outlined the purpose of the document as well as explaining that responses would be used for program improvement. The cover letter reiterated that completing the survey was voluntary and that all information would be kept confidential. The first page of the survey included a number of statements specific to the possible uses of the data collected. The introductory paragraphs stipulated that the information provided by the respondent would be used for a thesis, shared with the administrators of the program, and possibly published. Parents agreed to participate by returning their completed surveys.

Parents were asked to return completed surveys in the paid postage envelope provided to the Research Department at the agency overseeing this education program. Neither the program-specific survey nor the accompanying cover letter included a
specific return-by date. Completed surveys that were returned within the 2 months required to complete the focus group discussions were included in data analysis.

Table 1 shows a breakdown of the attendance at each focus group and the status of the family within the community-based IBI program at the time of the focus group. *In-service* refers to a parent of a child who is currently receiving IBI and *waitlist* refers to a parent of a child who is currently eligible and waiting to begin IBI.

**Data Sources**

This investigation included two main data sources: transcribed recordings acquired through focus group discussions, and parents’ responses to statements included in the program-specific survey. The primary researcher anticipated that combined, the results from these two sources of data would provide a complementary, comprehensive overview of the perspectives parents had on their involvement in this program.

**Focus Group**

A focus group is the process of collecting data through interviews with a group of people (Creswell, 2012). Researchers use this data collection method to gain insight into participants’ attitudes, feelings, beliefs, and reactions to experiences or events (Gibb, 1997). Literature included several examples of the effectiveness of focus groups as a suitable research methodology to gain insight specifically from parents of children with ASD. For example, Mulligan et al. (2010) carried out an investigation based in Ontario that included two focus groups to gather parent impressions on a recently developed ASD resource. The researchers selected focus group methodology as it “invited optimum group reflection and a dynamic interchange of ideas in yielding a range of perceptions related to a specific topic of inquiry or evaluation” (p. 116). As the intent of this investigation was
to gain parent perspectives specific to their participation in recently redesigned education sessions, focus groups were a valid data collection method.
Table 1

*Focus Group Attendance by Quadrant*

<table>
<thead>
<tr>
<th>Quadrant</th>
<th>Mother</th>
<th>Father</th>
<th>In-service</th>
<th>Waitlist</th>
</tr>
</thead>
<tbody>
<tr>
<td>North</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>West</td>
<td>4</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>East</td>
<td>3</td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>North (2)</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>11</td>
<td>5</td>
<td>8</td>
<td>5</td>
</tr>
</tbody>
</table>

*Note.* One mother and father couple attended West focus group.
Additionally, Patterson and Smith (2011) conducted 2-hour focus groups to complement data obtained during individual interviews with parents/caregivers of a child with ASD exploring their experiences participating in a Canadian-developed, parent-implemented, language intervention program comprised of group-based education sessions and in-home coaching called More Than Words.

Focus group discussions have yielded useful information and have been broadly implemented for a range of purposes. Program evaluation is one type of research that commonly relies on focus groups as a primary method of data collection (Bamberger, 2012). Market researchers and social scientists often use focus groups as a method of inquiry with the role and intent of the focus group varying between these disciplines. Race, Hotch, and Packer (1994) highlighted that market researchers typically use focus group discussions as a tool for consumers to provide information on specific behaviours such as buying, brand-usage, and attitudes towards products, behaviours that typically had little value to the individuals participating in the focus group. On the other hand, social scientists use focus groups to investigate behaviours that are likely to be important to the participating individuals, such as perceptions and personal experiences. Often the topics explored through focus groups carried out under a social science lens are relevant to the participating individuals who report feeling a sense of empowerment because of their involvement in the focus group process. As a primary goal of this parent education program is to promote parents’ sense of feeling informed, aware, active, and engaged in their child’s learning, enhancing feelings of empowerment compliment these other attributes targeted for increase, lending further support to the usage of focus groups as a suitable qualitative data collection method for this investigation.
For this study, four focus groups were held. The researcher intended to hold a focus group in each quadrant of this urban setting; however, due to low registration the focus group originally scheduled for the south quadrant was relocated to the north quadrant with eligible south quadrant families invited to attend this relocated session. Focus groups were held in meeting rooms within agencies affiliated with the community-based IBI program. All participating families were familiar with the focus group site, as education sessions were often held at these locations. Participants sat around a large, round table as it was anticipated that this room set-up would promote facilitation and group discussion as well assist with even acoustics for recording. Present at each focus group were a moderator and co-facilitator. Both these individuals were employed in the Research and Evaluation Department at an agency affiliated with this community-based IBI program, had no prior relationship with the focus group participants and had previous experience leading and assisting with focus groups. For the purpose of this investigation, the moderator posed questions to the group, encouraged participation from each member, and ensured discussions stayed on track (Asbury, 1995; Creswell, 2012). The co-facilitator assisted with registration and preliminary transcription, and noted any non-verbal behaviours that would not be captured through the audio recording. Digital recording of each focus group commenced following the consent signing process.

The first 15 minutes of each focus group were allocated to obtaining free and informed consent. The moderator reviewed the *Consent To Participate Form* with each participant. This document provided participants with information on the scope of this research project, processes for data analysis and storage, as well as reminded them that their involvement was voluntary. Prior to beginning the formal focus group questions,
participants read and signed the consent form as well as indicating whether they would like to receive a summary of the research results upon study completion. Each participant was given a copy of their signed consent form for their records and the Research and Evaluation department also retained a copy.

Focus group discussions were guided by a flexible script (Appendix D) structured to promote discussion on three main areas of interest: the content and organization of the four core education sessions included in the Parent Education Pathway, the overall goals of the program (Informed, Aware, Active, and Engaged) and whether parents felt their attendance had helped them parent their child with ASD. In addition to the main questions, sub-questions, commonly referred to as probes (Creswell, 2012) were also included in this script. These additional points of inquiry allowed to moderator to explore the topic of discussion further as well as assist participants to expand on their ideas (Creswell, 2012). Following completion of the formal questions, the moderator provided parents an opportunity to provide input on any aspect of this parent education program or any education sessions included in the Parent Education Pathway.

Focus groups ranged in length from 1 hour and 10 minutes to 2 hours and 15 minutes. In order to minimize the likelihood of a perceived conflict of interest and to ensure the trustworthiness of the data, the primary researcher of this study was not present at the location during the scheduled focus group and had no involvement in the recruitment or delivery of the focus groups.

Following each focus group, the co-facilitator provided feedback to the moderator on maintaining objectivity and consistency across all focus groups. This debriefing strategy was put in place to prevent moderator bias and potential drift from the focus
group script. Additionally, the co-facilitator reviewed the verbatim transcripts to verify that transcriptions were an accurate reflection of the discussions that occurred during each focus group.

Following the final focus group, the researcher listened to the audio recordings and used a PC laptop to type the discussions verbatim into text files. This technique, commonly referred to as transcription, is defined by Creswell (2012) as the process of converting audio recordings into text data (p. 239). The total amount of time to transcribe the audio recordings was 13 hours, with the time to complete individual transcriptions ranging between 2 to 4 hours.

Creswell (2012) referred to qualitative computer programs as programs that store, organize, and enable the researcher to assign codes to data. For the purposes of this investigation transcribed data were uploaded to a qualitative data analysis computer program titled Dedoose® (Lieber, 2009). Dedoose was easy to navigate, appropriate for a novice user, accepted a variety of text formats, located key words quickly in documents, and permitted other file types (i.e., SPSS, Excel Spreadsheets) to be imported or exported. This computer program expedited the analysis of the textual data by allowing the researcher to conveniently access and simultaneously analyzes large text files from multiple focus groups.

The researcher followed the analysis process detailed in Creswell (2012) beginning with conducting an initial, preliminary, exploratory analysis of the text files. This initial step in the qualitative data analysis process allowed the researcher to become familiar with the text as a whole, as well as note any initial observations or points of interest. Following this preliminary review of the data the researcher began a more
detailed process of segmenting and labeling the transcribed text using a specific word or words to describe the identified segments. The format of this software program enabled the researcher to attach, modify, and revise codes to identified segments of text with ease. A number of steps were completed during this qualitative, coding process: the large text files were divided into segments, segments were then labeled with codes, codes were examined for similarities, differences and redundancies, culminating with a number of coded segments being grouped and collapsed into broad themes (Creswell, 2012). A unique feature of Dedoose was its ability to list codes in a hierarchical order based on the frequency of occurrence. This feature enabled the researcher to provide quantitative descriptions including frequency and percentage of the qualitative data (Lieber, 2009). The process of segmenting and coding textual data permitted the researcher to disregard unnecessary data and attend only to data that supported the identified themes. The initial coding of the textual data for this study included in vivo codes, terms used directly by the focus group participants, as well as emergent terms selected by the researcher.

For this investigation, the number of segments of text coded in each focus group ranged from 25 to 70 with a total of 206 segments of text coded by the researcher. Following qualitative analysis procedures, identified codes were listed and reviewed to check for redundancy with overlapping codes grouped together into themes. As Creswell (2012) stated, themes emerged from text through “refining, collapsing, and merging codes into related concepts to form a major idea” (p. 245). Creswell defined major themes as those that represent the major ideas and minor themes as the secondary ideas in the data set. For the purposes of this study, a theme was labelled “major” if it was discussed in all four focus groups and had at least 20 segments of text labelled with that
code. A theme was labelled “minor” if it was discussed in three focus groups and/or had at least 15 segments of text labelled with that code. Through this process the researcher was able to identify four major themes and three minor themes. Creswell recommended a researcher should end up with no more than five to seven themes as the goal is to be able to provide a deeper level of detailed analysis as opposed to short, general statements on many themes.

The final focus group provided no new major or unique codes therefore no further focus groups were required, given theme saturation. The researcher followed a grounded theory method of inquiry when analyzing the transcribed, coded data. As outlined by Given (2008), this mode of inquiry included a set of systematic, yet flexible guidelines for qualitative analysis, with an end goal of theory construction. The themes that emerged from the transcribed data are defined in Table 2.

**Program-Specific Survey**

Survey research is an effective method to acquire information from a group of people about their characteristics, opinions, attitudes, or previous experiences (Leedy & Ormrod, 2010). Quantitative survey methods are defined as a “set of scientific procedures for collecting information and making quantitative inferences about populations” (McColl et al., 2001, p. 3). This method was a suitable component to the current investigation as the researcher was interested in gathering information on parents’ opinions on the usefulness of specific resources and visuals included in education sessions offered through this program. Quantifiable information on whether parents had used resource material made available to them or whether they plan to in the future was also obtained.
Table 2

*Thematic Definitions*

<table>
<thead>
<tr>
<th>Themes</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major themes</td>
<td></td>
</tr>
<tr>
<td>This is great, but something is missing</td>
<td>Any positive praise statements regarding this parent education program as well as any factor related to resources and/or supports sought after by the parents, not addressed through these education sessions, i.e., additional expertise in the community, assistance for siblings.</td>
</tr>
<tr>
<td>Don’t just tell us…show us</td>
<td>Any factor related to application, alternative training methods, i.e., videos or additional coaching.</td>
</tr>
<tr>
<td>We need more</td>
<td>Any factor related to parents wanting more from the existing education sessions. This definition included reference to more information, more opportunity to ask questions and more opportunity to talk with each other.</td>
</tr>
<tr>
<td>A parent’s perspective is worth a thousand words</td>
<td>Any factor related to parents wanting information, assistance or resources directly from other parents. This definition included discussion around hearing from a seasoned parent.</td>
</tr>
<tr>
<td>Minor themes</td>
<td></td>
</tr>
<tr>
<td>Advocacy, it isn’t that simple</td>
<td>Any factor related to advocacy and advocating for his or her child.</td>
</tr>
<tr>
<td>Lead us in the right direction</td>
<td>Any factor related to seeking validation from professionals or wanting vetted material.</td>
</tr>
<tr>
<td>Don’t forget the finer details</td>
<td>Any factor related to the process of delivering parent education sessions; elements to consider such as room set-up, handouts.</td>
</tr>
</tbody>
</table>
Prior to the decision to develop a tool specifically for this investigation, the researcher considered a number of previously validated tools (Bloomfield & Kendall, 2005; Reitman, Currier, & Stickle, 2002). After determining that a survey did not exist that would accurately measure the variables this study was looking to assess the decision was made to create a program-specific survey. As the focus of this research was to assess program outcomes for newly developed and delivered curricula, for which no assessment tools currently existed, this decision was logical. This survey was a one-time assessment of the perspectives parents had on resources and visual aids included in the parent education sessions, as such it represented a cross-sectional survey design (Creswell, 2012).

The mailed, program-specific survey required 15 minutes to complete and included 35 first-person statements surrounding three resources, four visuals, and the resource table present at each education session. This survey used language common to the parent education and support program with the phrasing of questions being sensitive to families for whom English is not their first language. This mailed-survey included questions that required parents to select “yes” or “no” to indicate whether or not they had received information about specific resources through this program’s education sessions, whether they knew about these resources prior to hearing about them through this program, if they had visited websites affiliated with these resources, whether they had used any materials from these resources or whether they plan to use these resources in the future.

In addition to statements pertaining to specific resources, this survey also included closed-ended statements about four specific tools used during parent education sessions: the Family Learning Plan, The Triad of Impairments visual, The ABC Approach visual, and How to be an Advocate visual. Survey questions specific to these resources, required
parents to respond either “yes,” “no,” or “not applicable” to statements such as “I have seen this visual in parent education sessions,” “I found this visual helpful,” and “I use this visual in my parenting.”

Prior to producing and mailing the program-specific survey the researcher consulted relevant literature for recommendations and suggestions on survey formatting and design. McColl et al. (2001) determined that postal surveys were the most common way to administer self-completed questionnaires as this method allowed researchers to investigate a wider number of individuals as well as capture the opinions and perspectives of individuals who may be reluctant to participate in face-to-face focus groups but would still appreciate the opportunity to participate in research. This program-specific survey was colour-printed, single-sided, stapled through the spine, and compiled into a booklet format. This presentation format was selected as it was easier for respondents to read, reduced the risk of losing pages, and appeared more professional (McColl et al., 2001). Surveys were printed on different coloured paper (white, purple, beige, and yellow) with participants in each quadrant receiving similarly coloured surveys. This strategy allowed the researcher to determine whether parent opinions on the resources included in education sessions differed depending on the quadrant their service was provided in.

Sixty-one of the 141 surveys mailed were completed and returned to the Research and Evaluation Department of the lead community-based agency at affiliated with this investigation, for a return rate of 43%. Hager, Wilson, Pollak, and Rooney (2003) reported that return rates of 25% to 50% are typical for mail surveys carried out by non-profit organizations; based on these figures, the response rate for this investigation falls
near the high end of the range reported for mail surveys. It is necessary to note that the response rate for this investigation was attained with no pre-notification or follow-up procedures. Creswell (2012) encourages researchers who are using mail surveys as a primary data collection method to mail a second survey out to the non-responders 2 weeks after the initial mail out as well as mail a post card as a final reminder. The time commitment and resources required to perform these follow-up procedures were not available at the time of this study.

The returned surveys were kept in a locked file cabinet in the researcher’s office for the duration of the data entry and analysis process. Following the completion of data entry and analysis surveys were moved to a locked cabinet in the Research and Ethics Department of the lead agency. The raw data from the survey responses were entered into a Microsoft Excel Spreadsheet by a research assistant employed at the lead agency. As part of this agency’s mandatory training and documentation protocols this staff was required to sign a document indicating they adhere to the agency’s confidentiality practices. Following the initial entry, the research assistant and researcher reviewed the data to identify any data entry errors or missing information. Any questions, for which data were not provided, because the participant did not supply it, were removed from the data analysis. Following this inspection of the data set, descriptive statistics were run through Microsoft Excel. Survey results report only on the number of respondents who answered each question.

In addition to questions specific to resources and visuals, the survey also included a few demographic questions. Participants were asked to indicate who completed the survey (mother, father, or other caregiver), whether English was their first language, and
if Internet access was available in the home. These questions were included to help determine if having convenient internet access impacted whether the respondent accessed the website resources referred to in the survey. No other identifying information such as parent or child name was obtained. The majority of the surveys, 86% (n=51) were completed by mothers with the remaining 14% (n=10) completed by fathers. As a primary focus of this survey was to determine whether families who attended sessions offered through this parent education program accessed resources, questions related to home internet and English as a first language were included. When asked, “Do you have internet access at home?” 92% (n=56) of the parents who completed the survey responded “yes.” Table 3 shows a breakdown of the number of participants who were eligible to complete the survey within each quadrant as well as the quadrant-specific and total response rate.

Of the 60 respondents who replied to the question “Is English your first language?” 47% (n=28) indicated “no” with 53% (n=32%) replying “yes.” Fifty-seven participants responded to the question “Do you need materials in another language?” Of those who replied, very few, 21% (n=12) indicated that resources in another language is required. Nine surveys indicated that materials in the following languages were required: Eighen, Chinese, Mandarin, Bengali, Tamil, and Spanish, mentioned four times. It is necessary that these results are considered in a broader context. No data are available for the 56% (n=80) of the parents who did not respond to this survey. It is plausible that the level of English required to complete the survey was a barrier to some families. Gaining a true sense of whether families require resources in languages other than English are best carried out in-person and approached in a very sensitive and respectful manner.
<table>
<thead>
<tr>
<th>Quadrant</th>
<th>Number of parents eligible</th>
<th>Number of parents who responded</th>
<th>Response rate percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>North</td>
<td>30</td>
<td>22</td>
<td>73</td>
</tr>
<tr>
<td>South</td>
<td>18</td>
<td>5</td>
<td>28</td>
</tr>
<tr>
<td>East</td>
<td>39</td>
<td>13</td>
<td>33</td>
</tr>
<tr>
<td>West</td>
<td>54</td>
<td>21</td>
<td>39</td>
</tr>
<tr>
<td>Total</td>
<td>141</td>
<td>61</td>
<td>43</td>
</tr>
</tbody>
</table>
Methodological Limitations

It is necessary for the researcher to attempt to address the methodological weaknesses associated with the current study that may impact the generalizability of the results. One potential limitation of the current investigation is the small sample of parents who participated in the focus group discussions. Sixteen parents of a possible 141, equating to 11%, participated in four focus group discussions. The researcher did not engage in any follow-up measures to identify any potential barriers that prevented some parents from participating. It is also necessary to note that the 16 participating parents were not equally distributed across the four focus groups. The West focus group had a larger number of attendees than the other three discussions, resulting in lengthier discussion and a greater proportion of the coded text analyzed.

There are a few methodological limitations with respect to the program-specific survey that may alter how the results of that data source are interpreted. This program-specific survey was administered to assist the researcher to gain targeted insight specifically on the usefulness of visuals and resources referred to throughout this parent education program with limited space to provide in-depth responses. Including some of the broader questions posed by the moderator during the focus group discussions into the program-specific survey may have enabled more parents to share general perspectives on this education program and possibly further supported the emergent themes. The level of English proficiency a parent required to accurately read and understand the mailed survey potentially prevented some parents from responding. Again, the researcher did not initiate any follow-up practices to uncover possible reasons preventing 80 parents from completing and returning the survey. Another possible factor that could affect how these
results are interpreted is the larger amount of surveys that were returned by parents in the North quadrant. The researcher did not explore any potential factors that contributed to a greater number of responses from North quadrant families. After consulting a number of previously implemented survey tools, the researcher determined that these would not adequately address the research questions of interest and logically decided to develop a survey for the purposes of this investigation, which may also be considered a methodological weakness. As no prior investigations utilized this program-specific survey there is no available information on its psychometric properties such as validity and reliability.

The last potential methodological limitation is the potential for a perceived conflict of interest based on the researcher’s active role in developing the content and curriculum currently being investigated. A detailed description explaining the nature of the researcher’s involvement in this parent education program was well articulated in the two ethics proposals that were granted clearance through Brock University and the community-based agency affiliated with this program. The researcher intentionally embedded a number of processes in procedures related to how participants were recruited, focus groups delivered and data analyzed.

**Chapter Summary**

This investigation employed a mixed-method research design to gain insight on the perspectives parents of children with ASD had on education sessions provided through a community-based program. These education sessions were part of a comprehensive curriculum that focused on assisting parents to be informed, aware, active, and engaged in their child’s learning. The two main data sources for this
investigation were focus group discussions and a program-specific survey. Following transcription, text files were uploaded to Dedoose, a web-based software program for thematic analysis. Parent responses to the questions included in the program-specific survey were entered into a Microsoft Excel spreadsheet that assisted with compiling descriptive statistics. These data will be presented and analyzed further in the subsequent chapters.
CHAPTER FOUR: RESULTS

This investigation included two data sources—a program-specific survey and transcribed text compiled from four focus groups discussions—to explore the perspectives that parents of children with ASD had on education sessions delivered through a parent education program in a metropolitan region of Ontario. This section includes the summarized results from the program-specific survey, presents the emergent themes that evolved from the coded text, and answers the research questions that were used to guide this investigation.

Quantitative Results

The program-specific survey that was mailed to the 141 clients who met this investigation’s inclusion criterion included statements regarding three specific resources discussed during education sessions offered through this program. The first set of statements were specific to Connectability.ca, a web-based resource that provided parents of children with an intellectual disability links to audio workshops, relevant websites, visuals, and articles.

A second resource discussed frequently by Family Support Coaches during education sessions was the Parent Lending Library. This library, located at the main site of the lead agency affiliated with this education program housed a range of books, videos, and DVD’s that covered a variety of ASD-related topics suitable for parents, children, and professionals.

Figure 3 presents a summary of the responses parents provided regarding Connectability.ca.
Figure 3. Parent responses specific to Connectability.ca.
*Respiteservices.com* is a web-based resource that provides families with a child with a developmental disability information on a range of respite options available in this metropolitan area of Ontario. The Family Support Coaches involved with this education program often suggest to parents that they learn about respite and explore suitable options based on their family’s needs.

Overall, parents reported that the majority of these resources were unfamiliar to them prior to attending the sessions offered through this education program. Of the 57 parents who replied to the statement “I knew about Connectability.ca prior to hearing about it through Parent Education and Support,” more than half of the parents, 64% (n=36) responded “no.” Additionally, 86% of the 54 parents who responded to a similar statement specific to the Parent Lending Library indicated they did not know about this resource prior to hearing about it through this program. While a larger portion of families (55%) were familiar with Respiteservices.com before hearing about it through these education sessions, this program introduced 45% of families to this valuable resource. Figure 4 shows the responses of parents provided to statements about the parent lending library, while Figure 5 shows the results of the parent responses to statements pertaining to Respiteservices.com.

In addition to questions regarding resources presented during education sessions offered through this program, the program-specific survey also included statements about specific visuals and materials provided to parents. This booklet included the titles of all education sessions delivered as part of this program as well as space to write the date and location of completed sessions.
Figure 4. Parent responses specific to the Parent Lending Library.
Figure 5. Parent responses specific to Respiteservices.com.
Three visuals were included in the core education sessions of this program: the Triad of Impairments, How to be an Advocate, and the ABC Approach. Parents were asked to respond to a series of statements pertaining to each visual when completing the program-specific survey. The vast majority (96%) of the 58 respondents agreed with the statement “This visual helps me identify strengths in my child.” Additionally, 100% of the 59 respondents said “yes” to the statement “This visual helps me identify and describe areas I could work on with my child.” These favourable responses speak to the usefulness of the Triad of Impairments visual. Figure 6 presents parent responses to statements specific to the Family Learning Plan; Figure 7 presents parent responses to statements specific to the Triad of Impairments visual.

The researcher of this study created and incorporated a visual (Appendix E) into education sessions offered as part of this program. This visual was intended to help parents recognize the variety of advocacy related activities they could engage in. This visual was adapted from Areva Martin’s (2010) approach to advocacy as described in The Everyday Advocate. This broad approach to advocacy includes seven sub-principles divided into activities an advocate performs and a description of what an advocate can become:

1. Take Responsibility: Be a leader
2. Learn: Be an expert
3. Think Critically: Be discerning
4. Speak with Authority: Be pro-active
5. Document: Be prepared
6. Collaborate: Be a team builder
7. Educate: Be a voice for your child
Figure 6. Parent responses specific to the Family Learning Plan.
Figure 7. Parent responses specific to Triad of Impairments visual.
Overall, it appears that the visual that this parent education program chose to use as a tool to inform parents about advocacy was effective, as 85% of parents surveyed indicated that this picture helped them understand the importance of advocacy and 80% of parents reported that this visual reminded them of various ways they can advocate. Figure 8 presents a summary of the responses parents provided to statements included in the survey specific to the topic of advocacy.

The ABC Approach is another visual that was referred to often during parent education sessions. Survey results support that a large proportion (93%, n=59) of parents found this visual useful in helping them organize their approach to teaching. Equally favourable was the high level of confidence parents report having with the ABC approach. Of the 57 parents who responded to the statement “I feel confident using this approach,” 53 (93%) indicated “yes.”

The final question included in the program-specific survey asked parents to provide input on the contents included on the resource table that was present at each education session. This table was organized by Family Support Coaches prior to the beginning of an education session, was clearly visible to the parents, and included general, quadrant-specific brochures related to upcoming family events (i.e., events at local libraries and community centres), as well as magazine articles on general parenting topics.

From the responses parents provided to the statements regarding the resource table, it appears that this is a worthwhile addition to the education sessions offered through this program. Almost all parents indicated they have taken materials from the resource table and that the materials helped connect them to other community resources. Figure 9 summarizes parent responses to statements specific to the ABC Approach visual; Figure 10 presents the results of statements specific to the resource table.
Figure 8. Parent responses specific to How to be an Advocate visual.
Figure 9. Parent responses specific to the ABC Approach visual.
Figure 10. Parent responses specific to the resource table.
Qualitative Results

This investigation included four focus group discussions that resulted in 206 segments of coded text which were collapsed into four major and three themes depending on the frequency of occurrence during focus group discussions.

Major Theme 1: This Is Great, but Something Is Missing

The moderator in each focus group posed questions to the participants about the resources included and the structure of the parent education sessions. Participant 2 from the West focus group stated “I was very pleasantly surprised with how much information was given to us.” Participant 6 from the same focus group reported that the Parent Education Pathway was “put together really well.” Participant 4 from the first North focus group describes how she had high expectations of this program when she was first made aware of it:

I had an expectation of learning a lot, of being able to pick what I thought I could potentially implement and also to hear from other parents. That was the expectation I had, and it ended up being better than what I thought.

Parents were also asked to share with the moderator how they would describe these education sessions to families who had not yet participated in the program. Participant 4 from the first North focus group provided a very positive overview of this program:

I felt it was very informative. The facilitators were all very good, easy to talk to, they explained things clearly. It was a good experience. Also, you were not alone. You know what I mean. You had a room full of parents who were in the same situation that you are in. It just made you feel better. It gets you used to this is
your life. So it [these education sessions] gives you that kick-start in the right direction.

Participants 6, 9, and 5 from the West focus group all would recommend this program to parents of newly eligible children. This sentiment was repeated by Participant 1 from the East focus group who replied “I think it is great, to be honest with you,” when asked how she would describe this parent education program. Participant 2 from the second North focus group said that the education sessions carried out as part of this more comprehensive parent education program is “something that new families should look forward to.”

While the overall sentiment towards this parent education program was very positive, reflecting on this program led some parents to identify resource and information gaps that existed outside the scope of this program. The theme *This Is Great, but Something Is Missing* was the most frequently coded with 22% (n=46) segments of text forming this theme. Participants were overwhelmingly in support of the framework and resources brought forward through this education program. However, the expanded discussion about resources that have helped at this stage in their autism journey led some parents to highlight the inadequacy or lack of certain resources available throughout the larger community.

In each focus group parents highlighted a number of specific resources and services they felt were currently not available, most frequently commenting on the absence of support groups. Participant 1 from the East focus group described her feelings on the importance of parent support:

As parents there are not a lot of people who understand what we are going through, like our personal friends, they can’t begin to understand what we are
going through, they say they do but they don’t, family members, they pretend that they do, but they really don’t have any idea. That is where the parent support comes in.

Parents described in great detail the intention and focus that these parent support sessions should have. Participant 2 from the West focus group stated that she would like, “somewhere where we can just go talk and laugh.” Participant 3 from the East focus group suggested, “we just need casual conversations, it’s very important. That’s what we need.” There was deep discussion regarding the absence of parent support during the East focus group. One participant in this session outlined how the current parent education program being investigated could assist with arranging informal parent support:

In these sessions that you do, you might have like a sheet where parents could put their name and their emails and it could be like a support group of families and at each group you could just talk about it…if you need support or to speak to other parents here is a list of parents and its voluntary where you don’t have to put your name on it but if you want to you can and the names and the email would be available to other parents.

When this idea was brought up at subsequent focus groups all parents in attendance were in support of this.

Another noteworthy gap for parents pertained to resources for the siblings of the child with ASD. This topic was discussed in three of the four focus groups. During the West focus group Participant 2 described the stress that parents experience because resources for siblings are not available:

I think if you add a session about siblings. I know not everyone has siblings but
we have two older daughters and that has been a struggle trying to help them understand what is going on with their brother and why and how to deal with him. And later on how to deal with other kids who are maybe taunting him or teasing him or making fun of him. …How do you explain what is going on with him. I know it is not in the context of ABA and stuff…but if the onus is on us to help our child then let’s include the whole family.

Participant 4 from the first North focus group explained that sibling support is necessary even for older children:

My children were old enough to understand, but they’re also at the age where it’s going to affect them differently, they weren’t small children so you need that support because they are also semi-caregivers too. So, to help them to understand. They might not understand the higher level like the parents do…so you do need more resources for the other parts of the family.

This participant later added how this focus group discussion has led her to recognize this resource gap: “I don’t think there is enough resources for the family as a whole or the siblings. So there are resources missing I think. So this [focus group discussion] has made me aware of what’s missing.”

Participant 3 from the East focus group described how she is accessing sibling support: “I have been sending my other two to get some practice at the center where he [child with ASD] used to go. She is training my other two how to socialize with him. Even for this I have to pay.”

Participant 5 openly shared a personal account lending support to the reality that parents struggle with feeling whether they spend adequate time with all their children: “I
know our eldest is fine, our youngest has autism but the middle child, is kind of stuck in the middle and we are kind of feeling that maybe she is not getting much attention as she should.”

During two focus groups the discussion about resources for siblings extended to include resources, education, and training for other members of the family. Participant 1 in the first North focus group suggested: “More resources for the family as a whole because it affects the whole family and it can cause a lot of issues.” Participant 9 in the West discussion was visibly upset when she recounted the difficulty explaining her son’s ASD to her parents:

I kind of feel the same way because my son sometimes he screams just for no reason (all other participants nodding in agreement) and then my dad is like, why is he screaming? And then I’m like okay, how do I say this to my dad…that that’s just the way he is dad. My mom understands more, so I say that’s the Autism.

Participant 5 described a similar situation and the need for guidance on how to educate his immediate family:

We had our child at an event at Christmas and a family member said Oh he wasn’t very well behaved. Would you say that about a kid with Down Syndrome…like he’s disabled, he has autism, this isn’t just misbehaving. He has a disability! But I just don’t know how to make her see that.

During the West focus group, Participant 2 suggested: “Maybe classes of teaching others, outside of here, like our family and their siblings, and the community that is going to be in contact with them. A class on teaching others about ABA is a good idea.”
The results from the program-specific survey support that parents generally feel more aware on the availability of resources included in the education sessions carried out under this program. Further discussion on the topic of resources led many parents to identify specific resources such as parent support groups, support for siblings and tools that would assist them with educating their extended family would be beneficial to them.

**Major Theme 2: Don’t Just Tell Us—Show Us**

A second major theme that emerged from the data analysis was parents’ emphasis on visuals, videos, increased use of real-life examples, and the opportunity to receive more individualized coaching during the education sessions. These segments were coded and collapsed under the theme *Don’t Just Tell Us—Show Us* and were included in 17% (n=36) of the coded text. Participant 2 from the West focus group mentioned:

The one thing I would change probably was if there were more videos of application of what they are presenting. Like okay, here is this student and this is how we work with them to do, I don’t know, this is how ABA is applied in a classroom setting, to actually physically see it.

The notion of increased video footage was mentioned consistently across all four focus groups. Participant 4 from the North focus group thought increased use of videos would assist those parents whose first language was not English:

So add more visuals yeah, most people are visual so you hear it and you see it. Yeah, it gets more quickly reinforce. And even people like you said with the language barrier they might get a better understanding if they could see it.

During the West focus group, Participant 5 indicated that the video examples could be very brief:
Just a 10-second clip, like this is a prompt, and a therapist engaging a child and seeing what that looks like. Would really… like not only do we get the material, and we’re talking about, but we’re visually seeing it being done.

In addition to videos, parents also had suggestions regarding the types of examples they would like to see used in education sessions. Participant 5 from the West focus group detailed how an increased use of real-life examples would have helped,

It would have been nice, this is one thing that I remember, is we all share certain struggles, I mean all our children are different but there are certain struggles we all share so, if maybe during one of the classes if someone gives an example of something that they are struggling with at home, whether it’s brushing your teeth or something like that and then the instructors could have said these are the terms as they are applied to that situation and how you would, address those issues, so what’s the function of that behaviour, what’s the antecedent, use all those terms in a real life context example that we all kind of have experienced. Then those words would sort have come to life.

Many parents also reported that they would like more opportunity to receive feedback on their experiences trying the strategies discussed. Participant 3 from the East focus group explains the importance of additional sessions dedicated to follow-up; she mentions that these are needed “so we can share the actual reality with them, they tell us to do like this, but the actual reality of what we see at home, we should have a chance to discuss it later.”

When asked whether any of the terms discussed during the sessions were challenging to understand, Participant 2 from the East focus group is quoted as saying,
“No, they were hard to apply at home but not to understand.” Participant 3 agreed with this comment, replying, “Applying is the challenge!”

Participant 1 from the second North quadrant focus group recommended that this program include additional “feedback sessions for parents to tell how implementation is going specifically with your own child.” The purpose behind the feedback sessions was elaborated on by Participant 2 during the East focus group:

We need these [extra sessions] so we can share the actual reality with them, they tell us to do like this, but the actual reality of what we see at home, we should have a chance to discuss it later.

Participant 4 expanded on the idea of individualized support, reporting:

I got the information I needed but I did not have any follow up. Instead of asking me if I heard you, instead, let’s set a goal with parents and say how are you with your goals? Are you following the steps? Do you need more information? I understood, but need to put it in practice with support and with follow up. The more you learn, the more you work at home and practice, you are doing it at home, but you need feedback and help and support.

Participants from the West focus group commented that they would like to see the coaching and individual check-ins have a personal touch. Participant 2 suggested:

It would have been nice if they checked in with people every week or so... I know it’s a lot of their time, but just like, Hey how is it going? How are you applying some of these concepts in your daily life with your child?

Participant 5 agreed that “it would be a nice touch to have someone to call you once in a while.”
Through the focus group discussions it is very apparent that parents participating in education sessions find videos, visuals, and real-life examples to be useful learning tools. Additionally, many parents reported that more frequent, individualized contact from facilitators would be beneficial.

**Major Theme 3: We Need More**

Through this study the researcher wished to gain insight on parents’ perspectives specific to the information included within education sessions. Information pertains to specific visuals included within the education sessions as well as specific topics (i.e., prompting and reinforcement, etc.).

The topic of approaching teaching using the *ABC Approach* was brought up during the focus group discussions. A few parents shared their positive thoughts on this teaching technique. Participant 1 from the second North focus group explained, “The ABC was very important to me, for example my son, he cries, *why*? There is always a reason. Learning to stop and see what he is doing. The ABC is very helpful.”

Participant 1 from the first North focus group session supported the usefulness of the ABC approach and visual: “I found that (ABC) simple and easy to implement. It is more relaxed than IBI. That’s real life; I am implementing it in real life. And it has been pretty effective for the most part.”

During the West focus group, when asked “What has been the helpful tool to assist with parenting?” Participant 5 added, “Just the ABC, I use it all the time, it has just become second nature. It has become part of everything; it is an easy concept to teach my other children.”

While a large proportion of the parents indicated through the program-specific
survey and focus group discussions that the information included within the parent education program was useful and helped them in parenting their child with ASD, a common sentiment shared by many of the parents who attended the focus group discussions was the idea of requiring more out of the sessions they attended. Parents used the term “more” when referencing the need for more information, more time to ask questions and more time to talk to each other. This theme was mentioned in 16% (n=34) of the segments coded.

Parents had a significant number of comments specific to the length of the education sessions. During the second focus group in the North quadrant, Participant 1 commented, “2 hours was too short, I would love a full day course or a weekend.” Participant 3 from the East focus group commented, “Time wasn’t enough, when parents start asking questions and they start answering, and then the time was up. It happens every time with every topic.” During the same focus group Participant 2 explained, “Every time in the comments I used to write, it would have been good if they extended, not time but two sessions for the same topic, two or three.”

Later in the focus group Participant 2 went on to elaborate, that she would appreciate “at least one more session on prompting and reinforcing.” In addition to an increased focus on prompting and reinforcement, participants also had some suggestions for new information that could be provided through the education pathway. During the first North quadrant focus group, Participant 2 suggested, “I think it would be great to keep parents informed on upcoming conferences, special education workshops outside, whether it’s at a cost or not that they may want to attend.”

During each of the focus groups parents alluded to wanting more opportunity to
be able to ask questions. Participant 1 from the second North focus group relayed:

Every case is different, and sometimes parents want to ask questions that are personal and refer to our children and maybe you can extend the time, have those two hours and maybe little more maybe half an hour because there are still a lot of questions.

Also included in this theme was the notion that parents would like more opportunity to speak and share with one another. During the West focus group, Participant 2 shared how parents were having meaningful conversations with each other after the sessions had ended:

What we found is that after each session we would meet the other parents in the parking lot or hallways we would chat for sometimes 20 minutes, half an hour kind of like how are things going? It was more like therapy for us! You don’t feel alone anymore in dealing with whatever you are dealing with that week. I have exchanged phone numbers and emails with some of the parents and just been a support for them.

Participant 3 from the West focus group indicated that she would like “More opportunity for a little bit of interaction between the parents. I mean, it’s supposed to be a venue where you should be exchanging information.”

Results from the program-specific survey demonstrated that parents overwhelmingly support the usefulness of the visuals included in these education sessions. Specifically, parents felt comfortable and confident with teaching their child through an ABC approach. This comfort and confidence was elaborated on with comments from a number of focus groups. While parents vehemently supported the
usefulness of these two visual aids, through comments shared during the focus group discussions parents also mentioned the value of education sessions including more. Parents explicitly mentioned more time was needed for certain topics and more opportunity to share and hear personal examples from other parents.

**Major Theme 4: A Parent’s Perspective Is Worth a Thousand Words**

From the discussion surrounding increased opportunities for parents to speak directly and hear from other parents, another salient theme emerged. Through in-depth focus group discussions it became apparent that the first-hand experiences and guidance from other parents of children with ASD was “worth a thousand words.” In total, 13% (n=26) of the transcribed text included codes that were collapsed to form this theme. Two main areas of focus emerged from discussions related to parents’ perspectives; the first was receiving information directly from other parents and the second was the ability for parents to speak with and hear from “seasoned” parents of children with ASD who have already passed through this IBI program.

Participant 2 from the East focus group explained the basis of the relationship between parents of children with ASD: “Parents just trust each other.” She later added, “When I see reviews on the computer I just don’t feel like believing them, ‘cause it might be right or it might be wrong, but when it comes to parents they always speak the truth.”

When discussing treatment centres and intervention options during the East focus group, Participant 3 expressed: “All the pamphlets I get, I just see reviews that may be true or false on the Internet but the person that is talking is something very different. Parents have experience about correct (meaning good) places.”

During the West focus group, Participant 2 discussed the weight of a parent’s
first-hand experience. She stated: “I am a parent so only a parent can give me the correct information.” Participant 3 elaborated on this point: “Someone who has walked in your shoes, their information is much more valuable than someone who has never had a child with autism who is lecturing to you about what you should be doing.”

During the focus group discussions parents shared the desire to speak and hear from parents of older children with ASD as well as parents who had gone through the IBI program. Participant 3 from the West focus group explains, “it would be valuable to have someone like you [referring to Participant 4, whose child is already in active IBI] come in and speak to us when we haven’t started the program yet.”

The idea of hearing from a parent who was “ahead” was also brought up by Participant 1 during the first North focus group. She mentioned:

What I think would also be great is having someone there [a parent] who has already been through that stage, a parent who has been there so they are a little bit ahead so you could get some insight to get a parent’s perspective. That might help.

Hearing from an experienced parent was really important to Participant 2 from the West focus group. She described an opportunity she had from another education program to hear from a “seasoned parent”:

They [the agency hosting the program] brought a mother in whose child is a lot older now, she had gone through this program and she was very encouraging to listen to and she gave us hope. That is what we all need is a little bit of hope. So, it would be nice if someone that had went through this program came in and said, *my kid went through. This is what to watch for. This is what was great; this is*
what was not great. You know that kind of thing. Just to encourage us that once they go through this program that there will be some positive changes to our lives. I know not necessarily everybody will see the best results, or any results but just some sort of encouragement. Okay, I gotta keep at it because there is a light at the end of the tunnel even though it may be a glimmer right now. That would be nice just to meet someone who has gone through the program.

Focus group discussions highlighted that parents of children with ASD prioritize the experiences of seasoned parents. Through feedback provided during these discussions it is apparent that the perspectives and opinions of parents of older children who passed through similar programs had significant weight and influence on parents at earlier stages in the ASD process.

**Minor Theme 1: Advocacy—It Isn’t That Simple**

The education sessions carried out as part of this parent education program included information on the topic of advocacy and provided parents with the opportunity to discuss their experiences specific to advocating for their child with ASD. Both the survey and the focus groups had questions related to the topic of advocacy. The topic of advocacy was mentioned in three focus groups with a total of 9% (n=18) of the segmented text aligning with this theme. When asked by the moderator what she learned about advocacy through the core sessions offered by the Parent Education program, Participant 2 from the East focus group session shared, “that first and foremost you are the most important. That you have to be the most important ‘cause you’re with your child all the time. You’re the most important advocate, not the teachers, that was the main thing.”

The intention of the advocacy visual seemed to be received by the parents who
attended these education sessions. However, a common sentiment that advocacy is not that simple emerged out of the majority of focus groups. It is plausible that parents’ sentiments on the topic of advocacy are not best captured through the program-specific survey as parents only had the option to respond “yes” or “no” to these statements. Providing parents an open forum to explain their thoughts and experiences on advocacy provided for a much richer understanding. Participant 5 from the West focus group stated, “I can understand that this is what we are supposed to do; research and have knowledge, but it is really hard to be out there and explain your situation and confront these things.”

Participants also shared how the responsibility of advocating for their child placed additional stress on them. Participant 2 from the West focus group described her feelings after being introduced to the topic of advocacy:

I think everyone walked away with a lot of pressure, feeling a lot of pressure. We were already dealing with a challenging situation and on top of that now they are saying it’s your responsibility to take care of all this stuff too. We all felt a lot of stress.

Parents also commented that they were unsure they were equipped at this stage in their autism and ABA knowledge to be an effective advocate for their child. During the West focus group Participant 5 outlined:

I get the actual ideas, I get it, about taking responsibility and all those different things but why do I need to be doing that? I already have this kid I am dealing with and I’m supposed to speak with authority? Like how does that fit? Maybe that’s something good to do later when I’ve got my feet on the ground and I know
where I am going and I kind of understand a bit more.

During the same focus group, Participant 6 shared her feelings that advocacy was not something learned in one session: “It’s very nice in theory and I guess it’s something to aspire to.”

The majority of parents were in agreement that they would like to see the topic of advocacy presented in smaller increments. During the West focus group, Participant 5 discussed how broad the topic of advocacy spans: “[Advocacy] is not just one little topic; there is like six, seven different things. There is a lot there and it is hard to kind of grasp.”

The idea breaking the topic of advocacy down into more manageable parts was supported by Participant 2 during the first North focus group—“If you had separate sessions for each of those, you could really do something”—and expanded on by Participant 6 during the West focus group:

Break it [the topic of advocacy] into parts; don’t throw it all at once in a very short period of time. Pick one for each session and then the next one for the next session. Don’t do it all at once.

During the first North focus group, Participant 2 expanded on her thoughts about the topic of advocacy and how it was presented through the Parent Education program:

I think it’s effective, but maybe that could be a session that is more than one time because there is so many different types of advocacy and at different levels and depending on the age of the child. You’re going to advocate at different times and for different reasons and for different severities of autism and for different needs of the family. So I think having more than one session or a little more in each session would have been better.
Through data obtained through the program-specific survey it appears that parents are in favour of the visual used to facilitate discussions on the topic of advocacy. Expanded feedback gained from the focus group discussions indicates that the topic of advocacy is broad and dynamic. Careful consideration should be paid in determining how best to address this important topic with parents.

**Minor Theme 2: Lead Us in the Right Direction**

A second minor theme that emerged from the transcribed data was the emphasis parents placed on the skills and knowledge of the professional, and parents’ desire for professionals to help lead them in the right direction when it came to navigating and accessing information. Throughout three of the focus groups, parents discussed the need for material that has been vetted by professionals. These sentiments were mentioned in 7% (n=14) of text segments. Parents expressed that they would be appreciate a wide range of vetted material from professionals. Parents commented on the need for assistance in sourcing out professionals in community that were knowledgeable and familiar with clients with ASD.

During the West focus group, Participant 2 recalled conversations from the initial session she attended:

I remember like the first day we were talking about where to go, what centres, or what dentist, or hairdresser or whatever to send our child. The parents were just discussing it, but if you guys could provide…this is a good place…this is a good place.

Participant 3 during the East focus group was concerned that she felt as a parent she was not equipped to evaluate the quality of a treatment centre: “They give us a lot of
pamphlets but how can we judge what is good or not?” Participant 1 expanded on Participant 3’s comments, adding:

You know what I think is important, a list of centres, for parents who are getting direct funding, like the good ones and the bad ones, because you can’t afford to make a mistake and a lot of parents are not aware and you don’t want them to make that mistake and lose a lot of time for their kids and funding, there should be some kind of list to lead [parents] in the right direction.

During the West focus group, Participant 3 described how he would like to hear a professional’s opinion on the most recent Autism and ABA-related evidence: “I think that everyone wants to know the latest research, and sometimes we just want to see what you guys say about it.”

Similarly, during the first North focus group, Participant 2 shared her sentiments about the need for professional guidance specific to navigating the vast amount of reading material and her recognition that not all sources are of the same quality: “Yeah, just to make sure you’re reading or accessing reputable, well researched with supporting evidence, those sites and those books. There is just so much out there that you could be reading the wrong thing.”

Participant 3 from the West focus group recognized that there is potential for parents to come in contact with inaccurate and untrue information. She described her thoughts on how professionals could assist:

Dispelling myths is needed. I know that is tricky, because who decides it’s a myth, but it would be helpful. Having someone go through with a fine tooth comb, all those websites that are out there so parents don’t get confused and read
the wrong information.

When coding text segments for this minor theme, the researcher was made aware that many parents often confused other parent education programs they had participated in through other agencies with the parent education program being explored for the purposes of this investigation. Frequently, parents were describing and recalling details of other programs and labeling them as part of this parent education program. This occurred at least once in every focus group, with some participants spending considerable time describing alternative parent education programs and labeling them as this program.

Participant 3 from the West focus group recalled an example of a video clip that was helpful for him but is not a component of any of the sessions included in the Parent Education Pathway:

I remember one of the sessions watching a video, the parent had a son and making a child sit in the couch, watching and seeing how he progressed the approach was very helpful for us, how to be patient and wait.

Participant 1 from the first North focus group frequently included descriptions of events not included in this education programs into his comments. When discussing his first impressions of this program he explained, “It was like every day, from Monday to Friday, for 6 weeks, I think. …It went on for nearly 2½ months, or 3 months.” This description is not reflective of how the education sessions in this program are planned and delivered as these sessions are stand-alone, single sessions offered to families after their child is eligible to receive IBI. Participant 1 later added, “I had to sign these triplicate sheets like white, yellow, something like that,” again recalling events that did not take place through this education program.
When asked by the moderator to share what had been the most helpful technique provided through this parent education program, Participant 2 from the East focus group shared, “the most effective thing was when we could all three could go together to a session.” Parent training with the child present is not currently offered through this parent education program. Participant 2 is recalling events that occurred through another service.

It is evident through the comments shared during the focus group discussion that parents place significant value on the knowledge and expertise of the facilitators leading the education sessions. During the focus groups some parents confused details of other parent education programs with those of the Parent Education Pathway currently being explored.

**Minor Theme 3: Don’t Forget the Finer Details**

A final minor theme that emerged from the transcribed data related to parents’ comments regarding details such as room set up and supplemental materials provided during the education sessions. Some practitioners may consider these details insignificant; however from parent responses it is clear that considering the room set-up and handouts provided can add significant value to the parent education experience. Comments related to the “finer details” were mentioned during three focus groups and occurred in 8% (n=14) of the segmented text coded.

A few parents suggested that organizers of parent education events consider making social workers and interpreters available. During the first North focus group, Participant 2 explained the emotional state that he and his wife were in at the time they began participating in the Parent Education Pathway. He shared, “there is a lot of panic in
the family during these early days, with what is happening and that kind of stuff. So, there should be somebody, maybe more on the psychological side.” Following this comment, Participant 4 elaborated:

Like a social worker? So, if there was a social worker on site for those parents who were having a tough time that they could, you know, talk to them or... some don't need it, some need it more than others, and that’s a good idea, to have that emotional support.

In addition to having social/psychological support available, participants in the first North focus group felt that assistance with translation should also be considered when organizing parent education.

Participant 2 mentioned that “if you could have a language person there or something like that, that would be fantastic.” Participant 4 agreed and expanded this sentiment, sharing, “that is a good idea, because especially in Toronto, that it’s such a multicultural city… and, it’s true language barriers can be an issue, that’s a really good idea, having interpreters.”

The primary investigator in this study included practical questions specific to room set up and supplemental materials provided to the parents in the focus group script. While these questions do not directly relate to the larger research questions guiding this project, they are important and necessary details to discuss when seeking to create an optimal learning environment for parents.

When asked by the moderator “Do you think you would be able to get as much out of the sessions without the hand out?” all parents who responded to the question disagreed. During the West focus group, Participant 2 expressed that if handouts were not
provided, parents “would have been too busy copying what is on the overhead that [they] would not have got as much out of it.” Parents unanimously agreed that they prefer a handout that contains the same information that is included on the PowerPoint slides with space available to write down personal notes. Participant 4 from the first North focus group explained, “what I found useful was the slides was exactly all the stuff that was shown, so when you are writing you are writing extra things, extra points or things people said, things that caught your attention.” Many parents shared that they kept the handouts following a session. Some parents spoke about how they organized handouts into binders or folders. Participants discussed how they shared the handout material with their spouses who did not attend the education sessions.

In addition to comments specific to the handouts provided, the focus group moderator sought input from parents on the seating arrangement and room set up. In three of the four focus groups, parents shared sentiments about preferred seating style. All comments supported a round table format as opposed to classroom style (rows) or theatre style (horizontal rows with no tables). During the first North focus group, Participant 4 mentioned,

In one session we sat like this [round table]. To me, it’s the best. It’s a more relaxed environment; less structured so people can look at each other and have open dialogue. Then you know if someone is talking, you don’t have to look around to see if someone is raising their hand. You can have a better conversation, like you are around the dinner table.

During the West focus group, Participant 9 shared a similar sentiment, stating, “I like [round table] too. We can talk to each other and hear each other, hear each other’s
Participant 1 from the East focus group liked the personal touch the round table seating arrangement provided. She elaborated: “When you think about it...circle is better because you can look at the person when they are talking. In rows you can’t.”

Through the comments shared by the parents who participated in the focus group discussions, it appears that handout materials and room set-up should be considered by those who plan and deliver parent education. Based on the opinions of these parents, handout material that matches the PowerPoint slides and round table seating arrangements are ideal.

**Research Questions Revisited**

This mixed methods study explored the perspectives parents of children eligible to receive IBI through a community-based program had on education sessions delivered through a Parent Education and Support Services. This investigation was guided by three research questions. To answer these research questions, this study analyzed data from a program-specific survey completed by 61 parents as well as transcribed data gathered from 16 parents across four focus groups totaling over 5 hours of in-depth discussion.

**Research Question 1**

The first research question sought to identify the following: How do parents of children with ASD who have participated in education sessions offered by Parent Education and Support perceive the framework of this program?

This investigation assessed parent perspectives on core education sessions provided through a parent education program in an urban setting of Ontario. These sessions were intentionally sequenced, with the resulting framework titled the Parent Education Pathway. One of the initial questions posed by the moderator during the focus
group sought to gain parent insight on how parents perceived this framework. Parents used words such as “great” and “well put together” to describe their perspectives on how this education program was organized. A focus group participant shared that this education program is “something that parents should look forward to participating in.” These sentiments indicate that parents support the framework of this education program.

After sharing their support for the framework of this education program parents voiced a number of well-articulated suggestions that could potentially enhance this education program. Parents recommended that the developers and organizers of this content consider adding more opportunities for them to speak to directly to one another as well as exploring the possibility of arranging opportunities to hear from parents of older children with ASD. Parents suggested spending more time discussing key subject areas such as prompting and reinforcement, and look to add more real-life, video examples to support the current framework. These suggestions will be explored further in the subsequent chapter.

**Research Question 2**

The second research question sought to answer the following: Do parents of children with ASD who have participated in education sessions offered through Parent Education and Support perceive this program as being successful achieving its goal of assisting parents to be increasingly informed, aware and involved in their child’s learning?

A key focus in this investigation was to determine if parents who had participated in this program’s education sessions perceived this program as being successful achieving its goal of assisting parents to be increasingly informed, aware, and active in
their child’s learning. Organizing content around key attributes targeted for increase was unique to this parent education program. Gathering parent input on the notion of awareness was addressed through both the program-specific survey and the focus group discussions with the main intent of the program-specific survey being to gain precise parent input on visuals and resources common to this program. Parents consistently reported that this education program had made them aware of resources they were not familiar with prior to attending education sessions through this program. Family Support Coaches introduced parents to informative, useful agencies and websites as a strategy to promote ongoing learning and community involvement.

A sizeable number of parents demonstrated being active in their child’s learning by following up and using or planning to use the newly introduced resources. One-third of the parents who responded to the parent-education survey reported accessing the Respiteservices.com website, with 75% planning to access this web-based resource. Almost half of the parents (47%) responded that they had accessed the parent lending library, with the vast majority (90%) planning to access. Almost all of the parents (90%) who responded to this survey had accessed the Connectability.ca website. During the focus group discussions many parents elaborated on their appreciation for being introduced to these resources through this education program. While parents agreed that this program had been very helpful and successful at introducing them to Connectability.ca, the Parent Lending Library, and Respiteservices.com, a broader discussion about resources in general led some parents to identify current resource gaps in the larger community. Most commonly noted during the focus group discussions were
the need for sibling and parent support as well as training on how to educate extended family members about ASD symptoms and ABA strategies.

Family Support Coaches aimed to increase parents’ knowledge on the topic of advocacy and the wide variety of actions this term describes. This program adopted Areva Martin’s (2010) approach to advocacy as outlined in her book *The Everyday Advocate*. Responses from the program-specific survey support that the vast majority of parents agree that the education sessions offered through this program increased their confidence advocating for their child and the *How to be an Advocate* visual was an effective tool to remind parents of different ways they can advocate. When the topic of advocacy was explored further during focus group discussions, the perspectives parents articulated differed slightly from the survey responses. During the focus group discussions parents acknowledged that the topic of advocacy was essential to discuss and supported the approach this program adopted as being relevant and comprehensive; however many of the parents felt that this program could explore revising how and when in the curriculum the elements of advocacy are discussed. Parents suggested addressing one advocacy related topic at a time or providing advocacy related training after parents felt confident in their knowledge of ASD and ABA.

The staff responsible for developing and delivering the content included in this parent education program hoped that through participation parents would feel confident using a behavioural approach to teaching their child. The focus group participants agreed that participation in this program had increased their knowledge and understanding on the key behavioural principles of prompting and reinforcement. However, parents unanimously agreed that in order for them to have increased confidence applying these
principles during home and community routines they would require coaching and child-specific training on how to implement. The perspectives parents had on the necessity of coaching were captured in the major theme *Don’t Just Tell Us—Show Us.* Across all focus groups parents reported that understanding the theoretical components of these terms was not a challenge but applying them in natural settings was. In order to more effectively assist parents with being active and engaged in their child’s learning the organizers of parent education programs should pay closer attention to the importance parent coaching could play.

**Research Question 3**

The third research question sought to answer the following: Do parents report a change in how they approach parenting their child with ASD as a result of their participation in education sessions offered through *Parent Education and Support* services?

A final area of inquiry this researcher wished to explore was whether parents reported a change in their parenting as a result of their participation in education sessions offered through this program. This research question was answered exclusively through the focus group discussions as this forum provided parents with ample time to provide in-depth responses. Parents were unified in their agreement that the behavioural approach to parenting presented through this education program as well as specific information and techniques discussed had made parenting their child with ASD easier. During the West focus group, Participant 2 shared that these sessions helped her “calm down and be very patient.” During the same discussion, Participant 6 stated that because of her involvement
in these sessions she has “learned to slow down.” Participant 2 from the second North focus group explained the positive impact this program has had on her parenting:

Yes now I know what to do, to have in my mind with what to do for certain behaviours. If she’s screaming or something, I know I have to be calm, say “no” or something like that. I don’t use “no” as often as before, but it has been very very helpful, gives us a guide, gives us a chance to learn and teach our children. It’s been great actually.

When asked specifically to retell topics that had been of particular use, parents frequently referred to the ABC model of teaching that is discussed throughout this parent education program. The effectiveness of the teaching parents how to identify antecedents and consequences through the use of the ABC visual was mentioned in all focus groups. Participant 2 from the initial North session labeled this approach as “helpful and easy to implement.” The program-specific survey responses specific to the ABC visual attest to how useful this strategy was to the families who participated in this program, with 90% of responders agreeing that the manner in which the ABC approach was presented by Family Support Coaches helped them feel confident and organized when teaching their child. It is clear from the program-specific survey responses and the discussions that occurred during the focus groups that parents experienced a positive impact on parenting their child with ASD as a result of participating in education sessions through this parent education program.

**Chapter Summary**

This thesis investigated parents’ perspectives on newly developed curriculum delivered through a parent education and support program. Specifically, this investigation
used both quantitative and qualitative data collection methods to answer three research questions specific to parents’ perspectives on the structure of this program, whether it was effective at achieving its goals, and whether parents reported that their participation impacted their parenting.

Overall, parents responded favourably to the structure of this program. They supported that the type and amount of information provided was manageable. Parents were strongly in agreement that this parent education program had introduced them to new resources and new approaches to being involved in their child’s learning and that this positively impacted their parenting. Through focus group discussions, a deeper understanding of the perspectives of parents was attained. Four major and three minor themes emerged from the 206 segments of transcribed text. The major themes identified were: (a) this is great, but something is missing, (b) don’t just tell us—show us, (c) we need more, (d) a parent’s perspective is worth a thousand words. The three minor themes explored were: (a) advocacy—it isn’t that simple, (b) Lead us in the right direction, and (c) don’t forget the finer details.
CHAPTER FIVE: DISCUSSION

This chapter explores implications for theory, implications for practice, as well as implications for future research. It presents a synthesis of the study’s findings discussing how they align with the current literature on parent education for young children with ASD. Instances where current findings differ from those previously reported in the literature are noted and discussed.

Implications for Theory

The quantitative and qualitative findings from this investigation align with benefits previously reported specific to educating parents of children with ASD on the principles of ABA. Additionally, the results of this investigation cohere with Bandura’s concept of self-efficacy and its extension—parental self-efficacy.

Behavioural Learning Theory

ABA is an extension of operant conditioning, popularized by B.F. Skinner in the early 1950s. This learning theory demonstrated that antecedent events in an organism’s environment could set the occasion for a particular response to occur and the consequent events that followed this behaviour could have an effect on whether the frequency of this behaviour increased or decreased in the future. Skinner’s experiments with pigeons and rats and a seminal investigation by Lovaas paved the way for operant conditioning to be more broadly applied to improve the developmental trajectories for young children with ASD. Lovaas’s (1987) investigation included parents as active members of the treatment team and his results supported the value of educating parents of children with ASD on the principles of ABA. During this investigation parents agreed that they were more informed on prompting and reinforcement as a result of participating in education.
sessions carried out through this program. Responses to the program-specific survey supported that parents feel confident in using an ABC Approach in their home routines.

During focus group discussions many parents commented that learning the three-term contingency was easy and impacted how they parent their young child with ASD. Jang et al. (2012) reported that providing parents education and training on principles and procedures of ABA could assist them in better understanding their child’s intervention program as well as increase the likelihood that parents could carry over behavioural teaching in the home and community. This investigation aligns with literature that demonstrates how valuable it is to provide parents of young children with ASD education on operant learning theory, especially antecedent prompting and positive reinforcement.

Self-Efficacy

Self-efficacy is a social learning concept but forth by Albert Bandura in the late 1970s. Bandura (1977) stated that individuals possess beliefs regarding personal capabilities. Bandura concluded that an individual with a strong sense of efficacy will persevere when faced with personal challenges, as opposed to an individual with a low sense of self-efficacy who may feel personally threatened when faced with challenges or obstacles. More recently, the notion of self-efficacy was extended to include parental self-efficacy, a concept that relates specifically to an individual’s sense of competence and capability in a parenting role. An individual’s sense of self-efficacy or parental self-efficacy is impacted by feedback from others on how competent they are perceived in their role. During the focus group discussions carried out as part of this investigation, many parents requested the opportunity to receive performance-specific feedback on their ability to implement behavioural teaching strategies in the home. Parents referred to this
as the need for increased parent coaching. Parents’ eagerness to receive direct feedback on their competence implementing a behavioural approach to parenting relates to the self-efficacy extension, parental self-efficacy. The parents who participated in this investigation demonstrated that they were willing to carry out actions that may differ from their everyday parenting practices and keen to receive performance specific feedback. It is plausible that the parents of children with ASD who provided input through these focus group discussions are inclined to adjust their feelings of self-efficacy, and initiating parent coaching sessions is a suitable strategy to ameliorate this mindset.

**Implications for Practice**

This section highlights key research findings and present how they could be interpreted to inform the practice of educating parents of children eligible to receive behavioural intervention through community based programming.

**Focus Groups**

This study added further support that focus groups are a suitable research method for parents of children with ASD. Previously, Mulligan et al. (2010) used focus groups as their method of inquiry when seeking to gain parent impressions on a recently developed ASD resource. These researchers selected focus groups as they provided their participants the opportunity to reflect and exchange ideas resulting in a range of perceptions related to a specific topic of inquiry or evaluation.

The present study, exploring perspectives of parents of children with ASD had on education sessions offered through a parent education program, extends a number of research findings pertaining to the benefits of parent education, the stress levels of parents, and the value of parent coaching as a training format. This study uncovered that
there is the potential for parents who are accessing a number of services to confuse the details of these programs. Additionally, through the detailed responses parents provided to questions specific to the topic of parent advocacy, this study demonstrated that if educators wish to assist parents of children with ASD to achieve an established skill-set advocating on their child’s behalf, a concentrated amount of time should be dedicated to discussing and practicing advocacy related activities.

**Content and Structure**

The overall framework of this program was captured under the phrase *Parent Education Pathway*, and was organized in a very deliberate manner with specific objectives. Education sessions carried out under this pathway aimed to make parents increasingly informed, aware, active, and engaged in their child’s learning. Certain key words—-informed, aware, active, and engaged—appeared often throughout the education sessions. When reviewing the literature specific to parent training formats and methods it did not appear that other content developers of education programs for parents of children with ASD had prioritized important parent attributes when organizing their curriculum. When asked to provide input on these attributes, parents agreed that they were suitable terms and appropriate skills to increase. Going forward, those individuals responsible for developing curriculum for parents could look to identify specific areas to address, determine an attribute to describe these areas, and refer to these identified terms frequently throughout the parent education curriculum. Structuring content in this way assists with keeping parents and educators focused on the objectives of the program.

**Knowledge.** A main focus of the core education sessions offered through this program was to accurately inform parents on diagnostic features of ASD as well as
evidence-based treatments, primarily ABA. Through the survey responses and the focus group discussion, parents overwhelmingly agreed that through their participation they felt more knowledgeable about ASD and ABA. There is a considerable amount of literature guiding curriculum developers on what to include in education programs specific for parents of children with ASD. This study lends further support for education programs to include content specific to the core deficits in autism, its etiology, and effective intervention methods.

Assisting parents to gain a better understanding of their child’s diagnosis of ASD and reinforcing that as parents they are knowledgeable and valuable to their child’s education may address the potentially low feelings of parental self-efficacy experienced by many parents of young children with ASD. Parental self-efficacy involves parents’ beliefs in their ability to influence their child and the environment in ways that would foster the child’s development and success (Jones & Prinz, 2005). In a recent study, mothers of children with ASD reported more difficulty understanding their children’s behaviours than mothers of typically developing children (Tunali & Power, 2002). Factual knowledge about ASD may aid parents in attributing their children’s impaired behaviour to the disorder rather than to their parenting. Therefore education programs concerned with addressing potentially low feelings of parental self-efficacy are encouraged to include a knowledge component to their curriculum as having greater autism knowledge may promote feelings of parenting self-efficacy (Kuhn & Carter, 2006).

Problem-solving. The education sessions offered through this program included a number of visual tools. Parents reported one specific tool, the ABC Approach, as being as being very useful for them. This visual is included in a number of education sessions and
is used by the facilitators as a strategy to help parents visualize how the principles of applied behaviour analysis are present in everyday parent-child situations. Parents are encouraged to share a description of a common problematic situation or routine and facilitators write specific actions and events into the respective parts of the ABC sequence: antecedent, behaviour, or consequence. Learning how to break problematic situations down into these smaller units and recognizing the relationship between the antecedent, behaviour, and consequence is a useful problem-solving skill for parents. Survey results demonstrated that the vast majority (93%) of parents found this visual useful in helping them organize their approach to teaching. This study also demonstrated that for the most part, parents are confident in their ability to use the ABC approach. Of the 57 parents who responded to the statement “I feel confident using this approach,” 93% (n=53) indicated “yes.” During the focus group discussions, parents provided lengthy responses supporting the effectiveness of the ABC approach, corroborating the data obtained through the quantitative survey. Parents labelled the ABC approach as important, useful, easy to implement, and part of everything they do. The favourable comments and survey responses specific to this problem-solving approach support the literature findings that suggest parents who feel empowered to problem solve are those who experience less stress (Hedderly et al., 2003).

**Short-Term Education Programs**

The core education sessions offered through this program totaled approximately 7 hours of group-based parent education. This study gained parents’ perspectives on the content and structure of this program, as well as inquired whether parents perceived their participation in this program as having a positive impact on their parenting. During the
focus group discussion, parents unanimously agreed that participating in the education sessions provided through this community-based service’s parent education program made parenting their child with ASD easier. These statements lend further support to Ingersoll and Dvortsak’s (2010) claim included in their training manual Teaching Social Communication to Children With Autism that parents who participate in education sessions report improved parent-child interactions. Analysis of the quantitative data obtained through the program-specific survey as well as the qualitative data gathered through four focus group discussions demonstrate that parents generally support that this program met its objectives of increasing their knowledge on ASD and ABA, furthering their awareness of available community resources and assisting them to be active in their child’s learning.

These findings are similar to those reported by Samadi, McConkey, and Kelly (2012), who demonstrated through a pre-post crossover design a significant improvement in parental ratings of health, stress, and family functioning following parent’s participation in a 10-hour group-based education course.

**Benefits of Parent Education**

This study lends further support to the literature claims that a number of benefits are available to parents of children with ASD who participate in parent education opportunities. In 2001, the National Research Council recommended that preschool programs for children with ASD include a parent training component. The rationale to include parent training was put forward as it was determined that parents who participated in these opportunities reported increased feelings of competence (National Research Council, 2001). Statements shared through focus group discussions for this
investigation support that parents who attended the education sessions offered through this parent education program experienced similar positive outcomes. Crnic and Stormshak (1997) stated that the opportunity for parents who are learning techniques as part of a group to be part of a social network with other families of children with ASD had been shown to have a positive impact on the well-being of the child and their family. While parents had a number of thoughtful suggestions for this program, all parents who participated in the focus group discussions would recommend this program to other parents of children with ASD. As Participant 3 emotionally shared during the West focus group, “it is nice that you have these programs that we can meet other parents that have the same, similar issues, because you feel like you’re the only one who has a problem.” The overall positive, praise statements parents voiced towards this program adds further support to earlier researchers’ claims that short-term, non-manualized curriculum can have a positive impact on parents of young children with ASD.

**Parental Stress**

While this study extends the possible benefits available to parents of children with ASD who choose to participate in education opportunities, it also furthers the stressful and adverse accounts often reported by these parents. During the West focus group, one parent became visibly upset when discussing the difficult time she had experienced parenting a child with ASD. The term “stress” occurred 12 times throughout the transcribed data. Stress was mentioned by mothers and fathers, by parents of children who were on the waitlist for IBI service, as well as by parents of children currently receiving IBI services. This evidence is consistent with Steiner et al.’s (2012) description of the stress profile specific to mothers of children with ASD. Steiner et al. refer to this
stress profile as severe, consistent, across cultural, geographical areas, maternal age, and child functioning. While the sample of fathers included in this focus group was small, the fact that fathers of children with ASD were as likely as mothers to reference stress could extend Steiner et al.’s stress profile to include fathers.

In addition to the stressful and trying experiences parents relayed, the notion that parents of children with ASD lose friendships and social opportunities, as well as encounter difficult situations with family members arose in a few focus groups. These sentiments align with the findings published in the 2014 Interim Report by the Select Committee on Developmental Services. During public hearings held across the province of Ontario between November 2013 and January 2014, caregivers of children, youth, and adults consistently recounted feeling socially isolated, cut off from friends, extended families, and communities. While parent education and parent support have different goals and intentions, organizations whose primary focus is parent education are encouraged to identify and make available contact information for parent support groups.

During the East focus group, one parent suggested that the current parent education program being investigated organize a voluntary, informal contact list with parent email addresses, a strategy to connect parents that would require very little oversight. Statements by parents of children with developmental disabilities included in the Interim Report by the Select Committee on Developmental Services (2014) also spoke to the idea that caregiving responsibilities attached to parenting a child with ASD meant that they had little free time to spend with their other children and grandchildren. Pisula (2011) supported this claim with a detailed account of the likely guilt parents
associated with not spending enough time with other children. Participants in this investigation shared sentiments that aligned with these feelings.

Literature reviews on stress as it relates to parents of children with ASD frequently identify specific child behaviour traits that reportedly contribute to parent stress levels. Parents of children who present with low levels of pro-social behaviour, lower daily living skills, challenging behaviour, regulatory difficulties, and/or sleep problems report higher stress levels (Pisula, 2011). Throughout the four focus group discussions carried out as part of this investigation, parents did not refer to any specific behaviour excesses or deficits their child demonstrates as having a significant impact on their stress. The fact that parents did not allude to any specific actions may indicate that the societal factors—such as lack of key resources in the community, lengthy waitlist for services, challenges explaining ASD to family members, and social isolation—may be more of a contributing factor to parental stress than specific child characteristics.

**Parent Coaching**

This study demonstrated that parents were eager to receive direct child specific feedback on their ability to implement the behavioural strategies discussed through education sessions offered through this program. During the focus group discussions the topic of coaching was included in 17% (n=36) of the coded segments of text. The literature reports highly favourable results when a coaching component is included in parent training. A recent meta-analysis of parent education components found that having parents practice their new skills was associated with larger effects than other programs without these components (Steiner et al., 2012). Additionally coaching can be advantageous as this intervention strategy can be tailored to the child’s needs, provide an
emphasis on “practice with feedback,” and sessions can take place across a variety of settings such as the family home and in the community (Steiner et al., 2012). Parent coaching has been shown to increase the knowledge and confidence of parents of young children with ASD (Ingersoll & Dvortcsak, 2010).

Prior to including coaching into training platforms for parents of children with ASD those individuals responsible for program oversight should consider a few important factors. Firstly, the skill set required to effectively coach parents on their ability to implement behavioural teaching strategies with a high degree of fidelity is different than the skill set required to lead didactic sessions on behavioural teaching. Steiner et al., in their 2012 article discussing issues related to effectively planning and delivering parent education for autism spectrum disorders, specifically mention the “area often ignored, albeit a key area of importance is the specific skills and strategies employed by parent educators” (p. 1222). These researchers elaborate on the necessary skills parent educators should demonstrate, listing: mastery and conceptual understanding of intervention procedures, responsive and collaborative teaching style, fluency in presentation, and providing immediate feedback (i.e., providing feedback immediately after a parent demonstrates a skill, as opposed to the end of the session). Instilling these skills in the repertoire of parent educators would require increased and targeted staff training. Organizations would need to determine if necessary resources were available to assist with developing this skill set in their staff. Coaching parents on their ability to implement behavioural teaching is not often an area of professional development prioritized by behavioural treatment programs. Employees working in these programs are primarily concerned with increasing personal knowledge and understanding of
behavioural concepts. Translating this information into content that is practical and immediately useful for parents as well as being able to respectfully provide in the moment feedback to parents is often overlooked as essential.

Another factor to consider specific to including or increasing parent coaching opportunities is this training format maybe an added expense for organizations to organize and deliver. As discussed, parent coaching is most often delivered in a one-on-one setting, with one parent educator assisting one child and their parent(s) at a time. This dense ratio is essential to the success of the coaching format. However, from a service model perspective, agencies may not be able to serve as many clients through a parent-coaching model as opposed to a group training format.

Given the favourable observations noted in the literature and the frequent mention of coaching during this study’s focus group discussions, it may be in the best interest for this parent education program to explore including parent coaching into its existing parent education pathway.

**Service Organization**

One key finding uncovered through this investigation is the potential for parents who are accessing a variety of services to confuse or overlap the objectives of these programs. At least once during each focus group the researcher noted that parents recalled or described elements of other programs and labeled them as the occurring as part of this education program. Agencies and organizations that focus on assisting children diagnosed with ASD and their families spend a considerable amount of time, energy, and resources developing their specific, programmatic approach. However, from the data obtained through this investigation it appears that some parents are confused
about the details of the variety of programs they are accessing. Practitioners in the fields of autism and parent education could do more to assist parents in organizing and understanding the range of supports available to parents, helping parents to recognize how these programs may be similar as well as identifying key features that may differ. Practitioners in these fields would need to exercise due diligence in increasing their familiarity with other services parents of young children with ASD could be accessing.

Further, parent education programs may look to adopt key messages or simple program-specific descriptions that could be included on printed material (e.g., bookmarks, power point templates, letterhead). This simple branding strategy may assist parents in organizing and recalling the key, unique objectives attached to the various programs and services they access. Assisting parents, especially those with a newly diagnosed child who are just beginning to access services and supports, to establish a system to organize agency and key contact information is strongly suggested.

Hedderly et al. (2003) noted that poorly organized and co-ordinated services (health, education, and social) can actually be a source of parental stress. Communication and clarification between service providers and programs is essential so that parents are not given contradictory advice. One suggestion is that practitioners spend some time at the beginning of their education sessions allowing parents to discuss other programs and services they are currently accessing or have participated in the past. This would be an ideal opportunity to describe the specific objectives attached to the current education program and to point out any resemblances or differences programs may have with each other.
Advocacy

This parent education program included the topic of advocacy throughout the education sessions it offered. The advocacy model discussed was based on a model developed by Martin (2010) and outlined in her book, *The Everyday Advocate*. This broad approach to advocacy included a number of sub-principles divided into activities and was represented in a visual during all core education sessions through this parent education program (Appendix G). Survey results support that parents found this visual helpful in reminding them of the importance of advocacy and the various ways they could advocate for their child. When exploring the topic of advocacy further during the focus group discussions it became more apparent that the current method this parent education program uses to educate parents on the topic of advocacy does not sufficiently instill a strong sense of what specific parent advocacy activities are or devote an adequate amount of time to coaching parents to become skilled advocates. The method currently adopted by this education program would have benefitted from emphasizing practical application as opposed to the current emphasis on theory.

This recognition that advocacy is a comprehensive topic aligns with many literature descriptions. Audrey Trainor (2010) labeled parent advocacy and its expected outcomes—that the educational rights of youth with disabilities are being met—as an enormous responsibility. Many researchers determined that effective parent advocacy requires a very deliberate strategy (Foster, Rude, & Grannan, 2013). The myriad of skills required of an effective parent advocate is broad, spanning a range of complex areas. To be effective advocates, parents must be well organized, functioning as a case manager for their child: managing medical records, school records, evaluations, and history.
Parents should practice taking detailed notes during meetings. Additionally, parents may also need to include knowledge of legislation and policies specific to education and inclusion. Going forward, the staff in this program should look to revisit the current method for addressing the topic of parent advocacy. The curriculum is on the right track by identifying that this topic, while broad and potentially overwhelming, is necessary to be discussed with parents of young children with ASD. However, those who develop and deliver curriculum for parents of young children with ASD need to be sensitive to the comprehensive and complex number of activities this already taxed population is being asked to adopt. Curriculum developers are encouraged to adopt a systematic model that breaks the topic of parent advocacy down into smaller, more manageable tasks. Ample time and frequent opportunities to practice and discuss advocacy-related scenarios should be prioritized.

**Implications for Future Research**

Implications for future research are suggestions made by the primary investigator regarding additional studies that could be carried out based on the results of the present research (Creswell, 2012). The outcomes of this investigation pave the way for topics to be explored further through future research.

This study demonstrated that parents who participated in education sessions offered through this community-based agency had favourable perspectives on the education sessions in which they participated. During the focus group discussions, parents offered a number of valuable suggestions that if implemented would enhance the content offered through this parent education program. A follow-up study of similar design would be an ideal method to assess whether future parents who participate in this
education program have similar points of view to those expressed by the participants included in this investigation.

Another potential area for further exploration would be to investigate whether parent participation in education sessions prior to their child beginning IBI service leads to increased involvement in their child’s treatment. Creating conditions for the highest level of parent involvement possible is an important factor to consider for providers of IBI. This short-term treatment relies heavily on mediators to maintain the gains acquired during treatment.

This study demonstrated that parents feel confident and competent using an ABC approach when teaching their children. It may be of interest to some behaviour analysts to assess the accuracy with which parents are using this behavioural teaching approach in the home and the community.

This study recruited a total of 16 mothers and fathers. Future researchers should strive to take a closer look at factors that prevent a larger, more diverse group of parent turnout. Future research could possibly consider individual interviews as a possible data collection method.

Going forward, this parent education program and possibly other organizations tasked with planning and delivering education opportunities for parents while they are waiting for their child to begin IBI could explore the benefits of a parent advisory group. This parent committee could serve as a potential resource on the content to be included and the delivery format.
Strengths

This study is the first to evaluate the core education sessions included in newly developed curriculum offered through a community-based parent education and support program. Strengths include this study’s mixed-method approach to obtaining both broad and in-depth insight into parents’ perspectives of their involvement in this program. A substantial number of the 141 program-specific surveys mailed to the families who had participated in the core education sessions were returned. At the outset of this investigation the researcher predicted a 10% return rate and at the time of data analysis, 44% (n=61) of surveys were completed and returned without any additional follow-up from the administrative staff assisting with this study. Complementing the data obtained through the program-specific survey, this investigation included more than 5 hours of in-depth discussion gathered from four focus groups. This qualitative data collection method enabled the researcher to gain a deeper understanding of the perspectives parents had on their involvement in a community-based parent education program. This design allowed parent experiences, attitudes, and behaviours to be identified through the use of direct quotations and verbatim transcription (Creswell, 2012).

This in-depth, first-hand account could not have been captured through quantitative methods alone. Focus groups were loosely guided by a pre-developed script. This guiding document was intended to promote moderator consistency across the scheduled focus groups. While adhering to the pre-developed script the moderator and participants still engaged in natural conversations. When necessary the moderator posed additional probe questions, and clarified and summarized parent statements to ensure accuracy in paraphrasing. Another measure that was put in place to strengthen the
integrity of the data was that all four focus groups were moderated and assisted by the same two individuals. Such consistency prevented focus group questions inadvertently being misinterpreted.

Prior to organizing this study’s design, the researcher engaged in an in-depth review of the literature related to ASD, ABA, parents’ experience parenting a child with ASD, and education opportunities for this group. Specifically included in this study was a detailed description of behaviour analytic programs and services in the province of Ontario. Providing this context was a noteworthy strength of this study.

Limitations

Although this study was conceptualized and carried out in a highly rigorous manner, a few limitations were still present. An apparent limitation of this investigation is the perceived potential conflict of interest of the researcher. The researcher of this investigation was actively involved in the design and delivery of the education sessions delivered through this parent education program. A number of safeguards were intentionally put in place throughout this investigation to reduce the likelihood that others would perceive a conflict. Firstly, the researcher had no involvement in the recruitment or registration of participants. These duties were carried out by an office assistant with no prior relationship to the participants. Completed surveys were returned to the attention of the Research Department of the community-based agency affiliated with this investigation. Secondly, parent responses were entered by a data analyst and focus groups were staffed by a research assistant and moderator both with no previous relationship to the parents in attendance. The primary researcher was not on-site during any of the scheduled focus groups. The nature of the researcher’s involvement with this parent
education program was explicitly outlined in the cleared, research ethics board applications for both Brock University and the community-based program affiliated with this investigation. While the potential for perceived conflict of interest is present in this current investigation, the researcher demonstrated due diligence to ensure that there was no actual conflict.

Another potential limitation of this investigation is related to the data collection methods. This study used a program-specific survey to gain perspectives parents had on specific resources and visuals included within education sessions offered through a parent education and support program. The researcher did consider using previously validated measures; however these tools would not have accurately captured this study’s variables of interest. The small number of parents who participated in the focus group discussions could also be viewed as a possible limitation, however the sizeable response rate to the program-specific survey generated equally important information that was confirmed and elaborated on through the meaningful discussions that occurred during the focus groups.

In total 16 parents participated in four focus groups with attendance ranging from two to six parents per session. At the outset of participant registration the researcher anticipated recruiting anywhere from six to 10 parents per focus group. Follow-up phone calls were required for three of the four focus groups. Confirmation calls were completed 1 week prior to each scheduled focus group as well as reminder calls the day before. These procedures did not guarantee focus group attendance. It is of value to note that the attendance rates of the focus groups is similar to the rate of parent turn-out for education sessions. Frequently, the number of parents registered for an education session is significantly higher than the number of parents who actually show up. Low attendance at
parent training sessions is often the most cited impediment in the literature (Ingersoll & Dvorchak, 2010). Additional barriers to attendance are: no child care, conflicting work schedules, transportation, and multiple competing demands of life. Circumventing these obstacles was not an option for this investigation. This parent education program was unable to provide child care and the dates, times, and locations were determined based on staff and room availability. There was no budget to cover transportation costs or provide incentives to the families who did attend. It is also necessary to point out that two focus groups were carried out in the North quadrant as opposed to one being delivered in the South as there was a significantly low number of eligible South quadrant families at the time of recruitment. While the few South quadrant families who were eligible to participate were invited to the North sessions, no South quadrant families participated in the focus group sessions. The relatively low number of parent attendees and the absence of South quadrant families can be viewed as a limitation as a larger group may have yielded even deeper insights and parent perspectives. Moreover, families from the South quadrant of this urban setting may have perspectives on this parent education program that differ from those families who reside in the North, East, and West quadrants.

Conclusion

This study was the first to assess newly developed curriculum offered through a community-based parent education and support program. This study applied a mixed-methods research design that included a program-specific survey and focus group discussion to investigate three meaningful research questions. Participants were parents who had participated in a minimum of four education sessions offered through this program. Careful review of the transcribed conversations uncovered four major and three
minor themes. Many of the themes uncovered in this investigation align with and add to
the experiences of parents of children with ASD previously reported in the literature.
Parents communicated a number of well thought out suggestions to enhance the
curriculum currently provided through this program. Future research could revisit
assessing the perspectives of future participants following implementation of these
recommendations.
References


Appendix A

Follow-up Telephone Script

“Hello (parent’s name). This is __________ (name of office assistant) calling from ______________ (name of agency).

How are you?

I am calling to follow up on a few pieces of mail you recently received from the Parent Education Program. One was a survey to complete and return and the other was an invite to participate in a focus group about the Parent Education program. Did you receive these?

- If the parent says “no” – briefly describe the survey and flyer.

- The survey was asking parents to give feedback on the usefulness of some of the resources and visuals included in their presentation. The survey would take about 5-10 mins to complete. A return address and postage will be provided. Would you like another survey to be mailed to you?

- The focus group is looking for parents who have attended some of the parent education sessions. They’d like to ask you some questions about these sessions. They hope that your feedback could help them to improve the program. The focus group results will also be used for a graduate thesis.
  
  o “Are you interested in attending one of the focus groups?”
    
    - If the parent says “no”, thank them for their time.
    - If the parent says “yes”, provide them with date/time/location of the focus group for their quadrant.

- If the parent says “yes” – briefly describe the flyer and ask them if they are interested in participating:
  
  o “Great... so you know that the Parent Education program and Brock University are looking for parents who have attended some of the parent education sessions. They’d like to ask you some questions about these sessions. They hope that your feedback could help them to improve the parent education program. The focus group results will also be used for a graduate thesis.

  o “Are you interested in attending one of the focus groups?”
    
    - If the parent says “no”, thank them for their time.
    - If the parent says “yes”, provide them with date/time/location of the focus group for their quadrant.
Appendix B

Program-Specific Survey

Parent Education and Support Services

FEEDBACK SURVEY

The staff of this community based parent education and support program would like to hear from parents about the resources and content of our education sessions.

We would like to use your responses to help us improve this program. This information will also be used as part of a thesis for Brock University.

There are no right or wrong answers. We are interested in finding out what works for you and what can be improved.

Your answers will be anonymous. We are not collecting any information from you that would allow us to identify you personally.

The results of this survey will be shared with the administrators of this program, academic supervisors at Brock University, and may also be published.

Please read the following statement and, if you agree with it, complete the survey and return it in the self addressed enclosed envelope.

I understand that by completing and returning this survey I am agreeing to my answers being included in reports, publications, presentations and an academic thesis for Brock University.

Please check one box for each statement

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have internet access at home?</td>
<td></td>
</tr>
<tr>
<td>Is English your first language?</td>
<td></td>
</tr>
<tr>
<td>Who is completing this survey?</td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>Father</td>
</tr>
</tbody>
</table>
Our program aims to increase your awareness of resources available outside of this program to assist with parenting a child with Autism Spectrum Disorder (ASD).

_The following questions refer to specific resources discussed during these education Sessions._

### Resource 1: Connectability.ca

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I received information about Connectability.ca through these education sessions</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I knew about Connectability.ca before hearing about it through this education program</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I have visited the Connectability.ca website</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I have used materials from the Connectability.ca website</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I plan to visit the Connectability.ca website</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

### Resource 2: Parent Lending Library

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I received information about this library through these education sessions</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I knew about this library before hearing about it through these education sessions</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I have signed out items (e.g., books, videos, DVD’s) from this library</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I plan to access this library</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

### Resource 3: RespiteServices.com

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I received information about RespiteServices.com through these education sessions</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I knew about RespiteServices.com before hearing about it through this parent education program</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I have visited the RespiteServices.com website</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I have accessed services through RespiteServices.com</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I plan to use RespiteServices.com</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
The staff in this parent education program hopes that after attending our sessions, you feel better informed on Autism Spectrum Disorder, Applied Behaviour Analysis, and ways you can be active in your child’s learning. The following questions refer to specific tools used during these education sessions.

### Family Learning Plan

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>I received a Family Learning Plan</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>This tool helped me track my progress through the Pathway</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I shared my Family Learning Plan with my child’s clinical team</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I found this tool helpful when meeting with my child’s clinical team</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Triad of Impairments

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have seen this picture in education sessions offered through this parent education program</td>
<td></td>
<td></td>
</tr>
<tr>
<td>This picture helps me remember the areas commonly affected by a diagnosis of ASD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>This picture helps me identify strengths my child may be showing in these areas</td>
<td></td>
<td></td>
</tr>
<tr>
<td>This picture helps me identify and describe areas I could work on with my child</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### How To Be An Advocate

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have seen this picture in these education sessions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>This picture helps me understand how important it is for me to advocate for my child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>This picture reminds me of ways I can advocate for my child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>This parent education program has increased my confidence as an advocate for my child</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The staff in this program hopes that after attending our sessions, you feel better informed on Autism Spectrum Disorder, Applied Behaviour Analysis, and ways you can be active in your child’s learning.

The following questions refer to specific tools used during these education sessions.

<table>
<thead>
<tr>
<th>A-B-C Approach</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have seen this picture in these education sessions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>This picture helps me organize my approach to teaching my child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel confident using the ABC approach to teach my child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I use an ABC approach when teaching my child</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

These questions refer to the materials displayed on the resource table at each education session.

|                                                               | Yes | No |
|                                                               |-----|----|
| I have taken materials from the resource table                 |     |    |
| I have used information from these materials                   |     |    |
| I find these materials helpful                                 |     |    |
| Do you need materials in another language?                    |     |    |
| If yes, what language would be helpful?                       |     |    |
| Overall, I feel these materials helped connect me with other resources in my community |     |    |

Thank you for providing feedback on the visuals and resources included within the education sessions delivered through this community based parent education program.

*Your feedback is greatly appreciated.*
Appendix C

Program-Specific Survey Cover Letter

Dear Sir/Madam,

The staff employed in this community-based parent education and support program, in partnership with Brock University, is inviting you to fill out a survey to help us improve our program. We want to know what works for you and what you think we can improve. This information will also be used by Kelly Alves, the program supervisor, as part of her graduate thesis at Brock University.

We have sent you this survey because your child is eligible for Intensive Behaviour Intervention (IBI) and you have attended the first four sessions of the Parent Education Pathway. These four sessions are:

- Orientation
- Introduction to Autism Spectrum Disorder
- ABA Key Terms
- Building ABA into Family Routines

This survey is voluntary. You do not have to complete it if you don’t want to. Your decision will not affect your access to any services.

Your answers are private. We are not asking you for any information that will identify you personally. We won’t know the names of anyone who completes the survey.

It will take about 15 minutes to finish the survey.

We have given you a stamped envelope. If you complete the survey, please use the envelope to return it to us.

If you have any questions or concerns about this survey, please contact:

Thank you for your time,

Name of Moderator
Address of Lead Agency
Appendix D

Focus Group Script

Hello everyone and welcome. Thank you for taking the time to participate in this focus group. We appreciate your contribution.

My name is____. I will be moderating the focus group this evening. I have worked in the research and evaluation for five years. Part of my job is to help evaluate the clinical and education programs offered through the community based agency affiliated with this education program. This evening, [name] from the research and evaluation department will be joining us. [Name] will be taking notes during the discussions to help me keep track of the feedback we receive from you.

This parent education program has been running for over a year. Now that we have a large group of parents who have attended the four core sessions we are interested in hearing your perspectives on the program. The purpose is to find out how participants in the program feel about:

• what was presented in the four core sessions of the Parent Education Pathway and how it was organized
• the goals of the program
• whether you think your participation has helped you parent your child

<< point to the Parent Education Pathway diagram >>

We are asking you to share your honest and open thoughts with us.

GROUND RULES

1. We would like everyone to participate. I may call on you if I haven’t heard from you in awhile. If you feel uncomfortable responding, it is fine to decline from responding. Although I want to encourage everyone’s participation, we don’t want you to feel uncomfortable.

2. Participants need to be polite and respectful of other people’s opinions. There are no right or wrong answers. Every person's experiences and opinions are important. Speak up whether you agree or disagree with what others have said. We want to hear a wide range of opinions. Remember, we are doing this so we can figure out what is working and what we can improve. Even feedback that may seem negative is important because often, it helps us identify those things that need improvement.

3. What is said in this room stays here. We ask that you respect the privacy of the other participants and agree not to repeat what you’ve heard in this session outside of the focus group.

4. We will be tape recording this session. We do this so we can capture all of the feedback. When we listen to the recording it is just to make sure we haven’t missed anything. We are not interested in identifying the person speaking. We don’t identify anyone by name in our report. You will remain anonymous.

5. One person talks at a time

Please print your name on the place card in front of you. We will use your first name to address you during this focus group, but when we transcribe the recordings, no names or other identifying information will be written down. This way, when we use the transcriptions to compile our report, your responses will all be anonymous.

The Parent Education and Support program and the affiliated agency are committed to respecting your privacy and keeping the details of this discussion confidential. I will review the consent form with you now.
Once you have had a chance to ask any questions you may have about the study, I will ask you to sign the form. We will make a copy of your form for our records and you will keep the original for your records. By signing the consent form, you will be agreeing to keep the details of the focus group discussion confidential.

<< Moderator will go over the consent form with the group, answering any questions they have. >>

Moderator: If you have finished signing the consent form and would like a drink or snack before we begin, please feel free to help yourself to something from the table.

*******

Summary of Focus Group Topics and Questions:

Ice breaker/ Introductory Question:

1) When you signed up for parent education sessions, what were you expecting?

Questions about the structure and content of the program:

2) I want you to think back on the first four sessions of the pathway.
   - Did the order of the sessions make sense?
   - In general, when you think about these four sessions, how did you feel about the amount of information that was presented to you?
   - For those of you who are on the waitlist, are there topics that we included but you don’t think we needed to include?
   - For those of you who have a child in the IBI program now, are there topics that we did not include but you think we should have?

Questions about the goals of the program[informed(3), aware(4), engaged(5), active(6)]:

3) Thinking back over the first four core sessions:
   - Did we help you to better understand ABA terminology (e.g., prompting, reinforcement)?
   - If you don’t have a better understanding of these topics and terms, what do you think we could change to do a better job of helping you?

4) Did we succeed in increasing your awareness?
   - Did we introduce you to resources that you had not been aware of?
   - Did we provide enough information so that you were able to access these resources?
   - What were some of the resources that you found particularly helpful?
   - What was it about those resources that you liked?
   Thinking about where you are in the IBI process at present:
     - What kind of additional resources do you think might help you?

5) Were these effective ways to help you participate in your child's learning?
   - Do you think we spent enough time on these skill areas?
   - If not, where do we need to spend more time?

6) Was there enough discussion about advocacy and the various ways it can be done to help you feel more confident in advocating for your child?
   - If not, what else could we provide to help you feel more confident in advocating for your child?

Questions about the impact of the program on their parenting:

7) Has parenting your child with ASD become easier?
   - What has been most helpful?
- Were there any tools that you will continue to use?

Questions about the PowerPoint handouts distributed during sessions:
8) Do you find it helpful to receive a handout from each parent education session?
   - What do you do with the handout after you have attended?

Concluding Questions:

9) When you look back over the four core sessions, is there any content that would have been helpful to you had you received it earlier?

10) How would you describe this parent education program to parents of children with ASD who have not yet participated in this program?

11) Up to this point, I’ve asked you questions the program supervisor is interested in having your feedback on. Clearly, there are a lot of questions we could have asked, but didn’t. If there is any feedback you’d like to share at this point that you feel has not been captured in our discussion this evening, please feel free to share that with us now.
Appendix E

Advocacy Visual