

Examination of Canadian parents' awareness of early intervention supports for their child  
diagnosed with Autism Spectrum Disorder: A Co-cultural perspective

by  
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We accept the thesis as conforming to the required standard

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### Abstract

Using co-cultural theory, this study compares how a sample of parents in Canada perceive what early intervention supports are available for their child diagnosed with Autism Spectrum Disorder (ASD). Participants consisted of parents of children diagnosed with ASD whom were six years old or younger. Through mixed method design and a co-cultural communication theory lens, nine parents who fit participation criteria answered a self-report questionnaire. Two major findings are (1) parents did not equally perceive availability of early intervention supports; (2) word of mouth is a predominant way for parents to become informed of early intervention services. Demonstrated through the data, the participants engage in multiple communication strategies. These results open the potential to investigate further into how funding agencies can utilize word of mouth methods of communicating to ensure correct information is disseminated to the parents regarding early intervention.

*Keywords:* Autism Spectrum Disorder, early intervention, intercultural communication, parents

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Examination of Canadian parents' awareness of early intervention supports for their child diagnosed with Autism Spectrum Disorder: A Co-cultural perspective

Working in the world of disabilities entitles you a glimpse into the life of parents dealing with stress, confusion, and often a feeling of being overwhelmed. One of my most poignant revelations into the struggles that parents who were navigating the social system for their child diagnosed with Autism Spectrum Disorder (ASD) came in the spring of 2009. I was working intimately with a family from Somalia whose child, Canadian born, was diagnosed with ASD and was deaf. I entered into this family's home to help support them in learning American Sign Language so they would be able to communicate with their child. This family, who had limited social and financial supports, desired to have a community aide helper. A community aide worker would support their child in accessing recreation and community programs. This form of support was available to them although they were not aware they qualified for this type of service. When I approached the government agency to enquire as to financial support for this form of aide, to my disbelief the worker states, "they should know, it's in their contract". From this point forward, I questioned the effectiveness of communications delivered to this specific population.

Limited research has focused on parents' perception of how early intervention services are communicated to them after their child has been diagnosed with Autism Spectrum Disorder (ASD). In practice, it has been observed by colleagues and myself, parents may have difficulty navigating the social system to acquire early intervention services for their child with ASD.

"I had no idea that service was available" or "who should I speak to for support? I need help" are phrases, or generalizations of feelings, expressed by parents heard too often during my career in the field of early intervention. From these personal experiences, I was compelled to

explore if this was a reoccurring theme across Canada and if so, what could be done to simplify and support the process of accessing services.

For the purpose of this paper, the term parent and caregiver are both used. Parent will refer to the relationship in which the adult individual has with a child. Caregiver is used specifically when referring to the social responsibility the parent has for the child.

The need to inform parents regarding early intervention services is crucial based on the research that validates early diagnosis and early intervention as beneficial to the individual, family and society (Corsello, 2005; Daniels & Mandell, 2013; Rogers, 1996). It is imperative that service providers across disciplines provide clear, concise information regarding early intervention services. Although there are a variety of reasons that may influence how information is communicated and received by parents regarding intervention such as stress (Serrata, 2012; Silva & Schalock, 2012) there is potential that parents are overwhelmed with daily life that it is unfathomable for these parents to respond to the invitation to participate in a graduate research study.

The intent of this study is twofold. The study's first objective is to investigate if there is a discrepancy in understanding early intervention services between parents regardless of ethnicity. In this study, parents of children diagnosed with ASD are considered a marginalized population as an extension of their child's disability. The second objective of this study is to provide insight to improve how information is delivered regarding early intervention services to parents by individuals who work with this population. Grounded in characteristics or specific methods of communication indicated by the participants, acuteness on how to mitigate communication breakdowns regarding accessing early intervention are explored through a co-cultural theoretical lens.

The practical impact of this research is a benefit to society as there is minimal research regarding how early intervention services are communicated to parents with children diagnosed with ASD. By researching this topic, both private and public sectors that provide early intervention services to children with ASD can assess how their institution is communicating what services are available. Agencies can utilize the information explored to develop effective programs to ensure social justice and equality regarding access to early intervention services.

### **Literature review**

This research study draws from and contributes to health communication (Camara & Orbe, 2010; Conti-Becker, 2009; Goggin, 2009; Pedlar & Hutchinson, 2000; William-Piehota et al., 2010), early intervention for ASD (American Psychiatric Association (APA), 2013; Corsello, 2005; Rogers, 1996), co-cultural communication theory (Camara & Orbe, 2010; Orbe, 1997) and disability rights (Ouellette-Kuntz et al., 2012; Parker, 2006; Woodgate, 2012).

### **Health Communication**

A common theme developed when reviewing health communication literature is that the vast majority of the research is in relationship to typically developed population rather than persons with disabilities. Williams-Piehota et al. (2010) state that health communication influences attitudes and beliefs as well as raise awareness of issues yet there is minimal communication directed to the disabled population. As minimal communication is directed to populations diagnosed with disabilities, there is limited ability to draw from previous literature; specifically as we examine parents of children diagnosed with ASD. Parents who receive information regarding their child's disability, have information presented to them by healthcare professionals that may not take into account language difficulties, stress levels, (Silva & Schalock, 2012) or the grieving process associated with learning your child has a disability

(Boushey, 2001). All of which impact how the parent receives the information as parents are required to make decisions regarding treatment and intervention options for their child diagnosed with ASD. Therefore, diagnostic information received by parents from healthcare professionals shapes the parent's attitudes and beliefs towards the diagnosis of their child along with intervention options.

Further, specialists in the medical field such as paediatricians and psychiatrists, who diagnose ASD, need to understand how healthcare professionals receive and communicate information. Conti-Becker (2009) argues that although the World Health Organization's International Classification of Functioning (ICF) is a framework accepted by a variety of healthcare related disciplines, this platform has limitations in transforming how healthcare professionals perceive disabilities. As early intervention services are most often comprised of a multidisciplinary team, it is essential to understand how each specialization of healthcare professionals conceptualize health communication and the framework that is used when assessing disabilities. Understanding this framework is important to determine how healthcare professionals are executing the delivery of diagnosis and treatment options not only between the parent and the professional but also between members of the multidisciplinary team.

Beyond communicating between healthcare professionals and parents of children diagnosed with ASD, there is a need to understand the shift in how disability is communicated by the human service field. Pedlar and Hutchinson (2000) discuss how the shift in the human service system in Canada has impacted individuals with disabilities. In this paper, Pedlar and Hutchinson (2000) examine the human service field in relation to adults with developmental disabilities. They discuss how due to a decrease of government funding, a monetary value is placed upon services that are necessary to meet the needs of individuals with disabilities. This

creates an environment where services for those with disabilities are based on financial ability of the individual rather than the need of the individual. Therefore, it is presumed that this shift in focus of a monetary value being associated with meeting the needs of individuals leads to a gap in service as needs are prioritized based on the cost of the service rather than the impact to society. Although the paper discusses this shift in relation to services for adults with developmental disabilities, a similar shift in perspective is assumed to have also taken place across all sectors of the human service field.

### **Early Intervention**

As early intervention has been empirically supported, (Corsello, 2005; Rogers, 1996) drawing from the information regarding success continues to affirm the necessity to equal access to intervention services. Both studies examined the efficacy of early intervention programs from previous studies. Although the early intervention programs examined differed, both Corsello (2005) and Rogers (1996) agreed that early intervention is critical in the development of individuals diagnosed with ASD. Rogers (1996) also concluded that overall gains were made for individuals that included increase in IQ, improved social behaviour, increased language skills and a decrease in symptoms associated with ASD.

Studies have been conducted regarding perceptions in accessing early intervention from the perspective of professionals in the USA (Pizur-Barnekow et al., 2012); however, similar studies conducted in Canada were unable to be located. No studies were found from the perspective of the parent accessing early intervention services for their child diagnosed with ASD. As well, studies regarding culture, ASD, and early intervention were not from a Canadian perspective (Ennis-Cole, Durodoye & Harris, 2013; Kang-Yi, Grinker & Mandell, 2013; Tincani, Travers & Boutot, 2009). However, these studies are valuable in framing the research as early

intervention is continuously concluded to be an effective option for individuals diagnosed with ASD regardless of the cultural background of the study. Although these studies were conducted mainly in the United States, information in these studies are relevant to this study as Canada is seeing a rise in prevalence rates of ASD similar to the increase in prevalence in the United States.

Canada's prevalence rate follows the increase seen in the United States, making it imperative to ensure early intervention services as one aspect of support during the life span of individuals diagnosed with ASD. The current prevalence rate of ASD in Canada is unknown as there is no monitoring body within the country that accurately surveys ASD diagnosis and the country is in the initial stages of developing a national surveillance system of ASD (Health Canada, 2012). However, Ouellette-Kuntz et al. (2013) provide a glimpse into the prevalence rate in Canada based on data collected in 2008 in Newfoundland and Labrador along with data from Prince Edward Island and Southeastern Ontario in 2010. Ouellette-Kuntz et al. (2013) report that from this information there has been an estimated annual increase in the prevalence of ASD from 9.7% to 14.6 %. Similarly, the Centres for Disease Control and Prevention in the United States have also seen a rise in prevalence of ASD. In 2000 the prevalence rate of children diagnosed with ASD was one in 150 and has risen to a rate of one in 88 in 2008 (Centres for Disease Control and Prevention, 2012, pp. 1-2). Therefore, as prevalence rates are on the rise, the access to early intervention supports becomes critical to ensure the best possible treatment is provided to children diagnosed with ASD.

### **Co-cultural Communication Theory**

The means to understanding and accessing early intervention supports is explored through a co-cultural theoretical lens. Orbe's (1998) co-cultural theory examines the power

relationships and approach to communication presented between marginalized groups and the dominant society. Orbe's (1998) co-cultural theory is used as the theoretical framework for studies associated with disabilities (Camara & Orbe, 2010; Cohen & Avanzino, 2010). This theory is utilized in previous studies regarding persons with disabilities; substantiating the use of Orbe's (1998) co-cultural communication theory as the lens when examining parents of children diagnosed with ASD.

### **Disability Rights**

Through Orbe's (1998) co-cultural theory lens and the knowledge that supports the positive impact of early intervention, this study's intent is in support of the rights of persons with disabilities (Office of the High Commissioner United Nations Human Rights, 2010; Ouellette-Kuntz et al., 2012; Parker, 2006; Woodgate, 2012) in relation to ASD. The literature reviewed consistently agrees that social justice, regardless of disability, is a human rights issue. Regardless of socio-cultural status of families, children diagnosed with ASD are entitled to equal access to early intervention.

Early intervention supports the guiding principles of the United Nations' Convention on the Rights of Persons with Disabilities (2006) that states, "in all actions concerning children with disabilities, the best interests of the child shall be a primary consideration" and that persons with disabilities should be offered "full and effective participation and inclusion in society". Therefore, the study's intent is to provide insight into how early intervention options for the child is effectively communicated giving the child the opportunity for inclusion in society to the best of their ability.

Through the literature review, gaps become apparent in the areas of health communication in relation to ASD, understanding of early intervention services from a Canadian

parent's perspective, and ASD examined from a co-cultural theoretical perspective. Building upon Orbe's (1998) co-cultural communication theory and the rights of persons with disabilities, the study is embarked upon to grow the body of literature regarding health communication, ASD, and early intervention.

## **Methods**

### **Theoretical Framework**

As this study's focus was on a marginalized population, caregivers who are marginalized based on their child's diagnosis with ASD, the study was designed utilizing Orbe's (1998) co-cultural communication theory. Although the parent's ability or disability is not assessed within this particular study, it is acknowledged that parents of children with ASD have differing challenges and stressors within their life compared to parents with typical children (Silva & Schalock, 2012). Reid-Cunningham (2009) described the importance of examining this issue as "the lens of culture may be applied to disability in a variety of ways: Disability may be considered a culture, culture may be considered a disability, and cultural norms and values influence conceptions of disability". From this lens, this study recognizes that parents of children with ASD are a cultural group within themselves; a cultural group often marginalized due to their child's disability.

Co-cultural communication theory (Orbe, 1998) examines the power relationships and approach to communication presented between marginalized groups and the dominant society. Although this theory examines communication from the perspective of marginalized groups such as first nations, women, persons with disabilities, and groups that represent sexual orientation, it is not limited to just interaction with the dominant society. It can also encompass interactions with doctors, lawyers and other professionals that have created a power dynamic with another

individual. As this study examines how parents of children with a disability understanding early intervention supports provided by the medical, educational, and government systems, perceived notions of power dynamics between the noted systems and the parents potentially exist.

Co-cultural communication theory proposes two premises (Orbe, 1998) that influence the means by which participants were recruited for the study, the study design, and the data analysis. This theoretical perspective acknowledges both ethnicity and disability as cultures. Orbe (1998) proposed, “co-cultural group members are marginalized in the dominant societal structures” (Gundykunst & Mody, 2002) as the first premise. This initial premise dictated who would use the strategies that were proposed. As individuals who are disabled, and extended to those caring for individuals diagnosed with a disability such as ASD “...may be impeded by intentional and unintentional barriers” (Cohen & Avanzino, 2010) creating a division between the marginalized population and dominate society that impacts communication style. For this particular research paper, ethnic minority and the autism community fall within this premise confirming that this is the correct theory in which to examine this particular population and issue.

The second premise, “co-cultural group members use certain communication styles to achieve success” (Gundykunst & Mody, 2002, p. 190) is used to guide the data analysis. As Orbe (1998) states that co-cultural group members use multiple communication outcomes (assimilation, accommodation, and separation), the data was analyzed through the lens of each outcome. As there has been research which “identifies a link between interpersonal communication processes and outcomes related to health” (Duggan, Bradshaw & Altman, 2010 p. 335), understanding the importance of communication styles was essential when assessing how to increase access to health care supports. Although Orbe’s (1998) outcomes examined each strategy as being a beneficial means of interaction, when examining access to early intervention

services the outcome of separation is instinctually incompatible to access early intervention supports. This incompatibility impacts the study as individuals who meet the criteria to participate chose to not engage with the survey. By separating themselves from participation in the survey, information regarding how these parents understand early intervention services is unable to be documented in the research. This means of communication provides further challenge to the study, as these individuals were not represented in the data.

In order to reach successful outcomes of communication, Orbe (1998) proposed nine means that persons with disabilities, or other marginalized groups, would use in order to negotiate communication success. These means are non-assertive assimilation, assertive assimilation, aggressive assimilation, non-assertive accommodation, assertive accommodation, aggressive accommodation, non-assertive separation, assertive separation, and aggressive separation (Orbe 1998). It is within these means that the effectiveness in obtaining early intervention supports by parents with children diagnosed with ASD was examined. It should be addressed that “co-cultural group members will adopt one or more communication orientations depending on a number of interrelated components” (Lapinski & Orbe, 2007, p. 139), confirming that individuals do not solely use one style and switch between styles dependent on the desired outcome of the situation.

As individuals do not use a singular style of communication, consideration to the design and analysis of the research study was done with this in mind. The study allowed for individuals to participate through an online survey, contact the research to obtain a paper copy of the survey, and individuals were given the opportunity to speak to the researcher directly. Further, each outcome is used to examine the data collected to ensure each method of communication from the co-cultural theoretical perspective is addressed.

### **Method of Data Collection**

Mixed method research design is the framework for this research project. Although this method of research has a variety of definitions, at its core, mixed methodology is the collection and analysis of multiple modes of data, both qualitative and quantitative data, to develop an understanding of a particular question or phenomenon (Bergman, 2008; Evans, Coon & Ume, 2011; Greene, 2007). In conjunction with a co-cultural theoretical lens, mixed methods research also considers multiple perspectives to address the proposed research questions (Johnson, Onwuegbuzie & Turner, 2007). Specifically, the study provided two options an individual was able to participate: through the survey, either electronic or hardcopy, or through a semi structured interview. By providing options to how individuals were able to participate in the study, the individual chose from their perspective, how they preferred to interact with the researcher. Further, both the survey and interview method of data collection provides the researcher the ability to ask both quantitative and qualitative questions encouraging multiple perspectives to address the research question.

Along with utilizing mixed methodology, the research design was a cross-sectional study. A cross-sectional design is defined as “a study designed to capture on a measures of interests at one particular point in time from a selected sample” (Seale, 2012). As age of diagnosis of ASD can vary, gathering data at one specific point in time, rather than in relation to the onset of symptoms or diagnosis of ASD, supports the objectives of this study (Seale, 2012). Further, due to the limit of time that is allotted for this study to be conducted, a cross-sectional study provides results in the timeframe required for completion. Self-completed questionnaires and interviews were utilized to obtain data.

Self-report questionnaires were chosen as a data gathering method as participants are more likely to give more reliable answers to the questions compared to completing interviews when the questions asked were potentially embarrassing (Seale, 2012, p.182). For example, if discussing a parents' awareness of what early intervention supports were available or admitting their child is diagnosed with ASD were topics parents found embarrassing to speak of publically, parents may prefer to discuss these topics when they are anonymous to the researcher through a self-completion questionnaire. Self-completion questions (Appendix A) were available on-line to allow for the survey to be available to individuals across Canada. This also allowed individuals to access and complete the survey on their own schedule.

Face-to-face and phone interviews were also intended to provide multiple avenues that individuals could participate in the research. If an individual who had difficulty reading the English language or was unable to access the survey, online or in written form, individuals had an opportunity to participate through the interview process. Interviews were planned in order to ask more open-ended questions through a semi-structured interview, allowing for clarification of questions and equal access. . Questions were prepared for the semi-structured interview (Appendix B). The questions related to ethnicity, primary language, current early intervention services accessed for their child diagnosed with ASD, knowledge around what services are available for their child which they have chosen not to access, region of residence, and their perception of the effectiveness of how information regarding early intervention services was presented to them.

The survey was available electronically through "Fluid Survey". Fluid Survey was chosen as the electronic platform for the survey for two reasons. First, the information collected is only available to the individual who has created the survey. Each response and password is

encrypted and Fluid Survey does not use or sell any information gathered. Secondly, the information gathered is stored on servers that are located in Canada. This was important in choosing this platform as other survey platforms store the information gathered in the United States of America and is therefore subject to the guidelines of the U.S. Patriot Act. For those individuals wanting to participate who preferred not to complete a survey on line, paper copies along with self-addressed envelope and postage were available upon request. With both the electronic form and paper form of survey, participants were able to withdraw their participation at anytime.

If individuals wished to withdraw from participation in the electronic survey, they could exit the survey and the data would not be sent to the researcher or saved to any server. If a participant who submitted a paper copy of the survey wished to withdraw, the participant was informed they could contact the researcher directly to inform the researcher of their desire to withdraw from the study. All documentation regarding that participant immediately destroyed or removed from the data collection.

Survey questions included checklist, multiple choice and open-ended questions. Checklist questions are utilized in gathering information that can easily be forgotten (Fink, 2006). Specifically, these questions were utilized when examining which early intervention services have been accessed and whether or not they are publicly or privately funded. Multiple-choice questions were utilized to ensure uniform data collection and efficiently in gathering precise information (Fink, 2006). Specifically, information regarding demographics of the population responding to determine if the individual meets the criteria of the study utilized multiple-choice questions. As Orbe's (1998) co-cultural communication theory indicates how marginalized groups communicate with dominant society, participants were asked to self declare if they were a

minority in Canada. Allowing individuals to self declare as a minority in Canada eliminated the need for the researcher to assume if a participant perceived themselves to be a minority in Canada based on ethnicity. Open-ended questions were also added to gain insight into questions that are based on the participant's perceptions rather than fixed answers (Fink, 2006). These questions were in relation to the participant's perception of how early intervention services are communicated to them as well as if there are strategies that are effective in relaying this information.

### **Recruitment**

Based on Orbe's (1998) co-cultural theory, acknowledging that I, the researcher, may be perceived as part of the dominant society, individuals were introduced to the study in a variety of ways. The main strategy utilized volunteer sampling. Letter of invitations (see Appendix C) were distributed to autism support organizations, websites, social media forums, parenting support groups and posted throughout community and professional agencies both in print and electronically. Individuals were invited to complete a survey and were given the option to participate in the interview process within the letter of invitation. This allowed individuals to either speak to the researcher directly or anonymously complete a survey. Past and current clients of mine as well as any other people with perceivable or predictable conflict of interest were excluded from invitations to participate.

Criteria for this study consisted of three main points. First, it was requested that the primary caregiver of the child with ASD was the individual engaging in the survey. Since the primary caregiver is assumed to be dedicated to the organization of all aspects of the child's life, this was determined to be a necessary criteria as non-primary caregivers may not be responsible

in the family unit in determining and accessing early intervention supports or privy to information required for the study.

Secondly, the age of the child receiving early intervention supports was limited to six years of age or younger. The purpose of setting criteria to this age limit is in response to provincial funding for early intervention supports in British Columbia, Saskatchewan, Ontario, New Brunswick, Nova Scotia, Newfoundland and Labrador. In these provinces, early intervention is financially supported by government funds during the pre-school years (Madore & Pare, 2006). Thereafter, funding is reduced or no longer provided for early intervention services. Thirdly, the primary caregiver and child were required to reside in Canada.

Although the perception of ethnic minority parents is initially one aspect of this study, it is also a comparison between all parents of children with ASD. For this reason, the criteria included both majority and minority ethnicities. As there is no clear definition of minority, for clarity in this study, information from the Office of the United Nations High Commissioner for Human Rights (2010) was utilized to determine a definition of minority. For this research study minority was defined as non-dominant in ethnicity to the majority population in Canada and will self identify as an ethnic minority.

Prior to engaging as a participant, each individual gave informed consent on the home page of the survey. Individuals were prompted to complete a form upon accessing the electronic survey and each print survey included an informed consent form attached to the survey to be completed by participants (see Appendix D). This process was modified in design for potential telephone interviews.

Individuals were invited to participate in the interview portion of the study on two occasions. The first occasion was on the letter of invitation where individuals were invited to

contact the researcher directly should they wish to participate in the interview portion. The second occasion occurred at the end of the survey where participants were invited to leave their preferred contact information should they wish to participate in the interview process.

Prior to the telephone interview, informed consent is gained by sending the informed consent out prior to telephone contact. The interview begins with the informed consent being read to the individual, questions would be answered and the individual would verbally agree to be a participant in the study. However, no individuals successfully participated in the interview portion of the study.

Participant recruitment began January 1, 2014 and continued until March 31, 2014. Invitations to participate were distributed across Canada and included a letter. The letter confirmed the ethical review board at Royal Roads University had reviewed the research project. Invitations to participate were initially distributed during the month of January both electronically and in paper format. Organizations that were sent invitations to participate were once again contacted during the last month of February to follow up if there were any questions regarding the research project.

### **Ethical Review**

As this study involved human subjects, an ethical review process was engaged in prior to beginning this research study. The formal review process was completed through the ethical review board at Royal Roads University and approval granted on August 27, 2013. Ethical review guidelines can be obtained through Royal Roads University in Victoria, British Columbia, Canada.

### **Findings**

From January 1, 2014 until March 31, 2014 individuals were able to participate in the survey. During this time period, 16 participants were recruited. Out of these 16 individuals, nine participants met recruitment criteria. Place of residency of participants include one in Alberta, four in British Columbia, one in Nova Scotia, and three in Ontario. Of these participants, seven described their ethnic background as Caucasian, one as Filipino and one as Latin American. Only one of these individuals self declared as a minority. When asked if they were aware of early intervention services available through government funding five answered yes, one responded no and three did not respond. The next question inquired into if the individuals were aware of what supports were available to ensure inclusion in the community; six responded yes, one responded no and two did not respond (see Table 1).

Table 1

*Demographics and Baseline of Services*

Question	Participants Responses
What province/territory do you reside in?	Alberta - 1 British Columbia – 4 Nova Scotia – 1 Ontario – 3
How do you describe your ethnic background?	Caucasian – 7 Filipino – 1 Latin American – 1
Do you identify yourself (your family) as a minority in Canada?	Yes – 1 No – 8
Are you aware of the early intervention services that are available through government funding?	Yes – 5 No – 1 No Response – 3
Are you aware of the community supports available for your child to ensure inclusion in community activities?	Yes – 6 No – 1 No Response - 2

The next two sections of the survey were in relation to current early intervention services and previous early intervention services. These questions were asked to prime parents into reflecting and thinking about early intervention services and their perception of acquiring these services. (see Table 2 & 3). Out of the responses in current and previous services, only one individual declared privately funding services. The no responses in this section were associated to participants who stated that their child was receiving the service however they did not declare how the service was being funded.

Table 2

*Current Early Intervention Services Accessed*

Current Early Intervention Service	Number receiving services	Funded Privately	Government Funded	No response
Behavioral Consultant	3		3	
Behavioral Intervention	4		4	
Community Aide	2		2	
Occupational Therapy	3		2	1
Physical Therapy				
Psychiatrist				
Psychologist				
Respite	2		1	1
Speech Language Therapy	4		4	
Other	2 – Not yet, long wait times; New	1-ABA therapy private paid	1	

Diagnosis and  
still interviewing  
places

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Table 3

*Previous Early Intervention Services Accessed*

Previous Early Intervention Service	Number receiving services	Funded Privately	Government Funded
Behavioral Consultant	2		2
Behavioral Intervention	1	1	
Community Aide			
Occupational Therapy	5		5
Physical Therapy	2		2
Psychiatrist			
Psychologist			
Respite	1		1
Speech Language Therapy	3		3
Other	1 – Still waiting for services and have yet to obtain services		

Further questions in the survey reflected the participant's perspective of early intervention services. From this portion of the survey it was revealed that four participants strongly agree that they are aware of what services are available for their child diagnosed with

ASD. Two agree and there was one respondent for each neutral and strongly disagree. One participant did not respond. This majority of agreement on understanding what services are available for their child shifts to neutral or strongly disagreeing when asked if the funding available for their child with ASD is communicated clearly. This point was interesting to conclude the majority of the participants did not perceive that they understood what funding was available for their child. This brings for the question if there is funding available for a child with ASD that has yet to be accessed for alternative or additional early intervention services available to the child within the funding (see Table 4).

Table 4

*Perception of Early Intervention Services Available*

Question	Strongly Agree	Agree	Neutral	Disagree	Strongly disagree	No Response
I feel I know what services are available for my child diagnosed with Autism Spectrum Disorder.	4	2	1	0	1	1
Funding, that is available for my child with Autism Spectrum Disorder, is communicated clearly to me by individuals associated with the funding programs.	2	1	4	0	1	1
I am aware of what early intervention programs are available for my child to access.	2	2	3	0	1	1

The participants were also given the chance to answer open-ended question and provide a qualitative reflection of how they gain understanding of services that are available. An overarching theme discovered when analyzing the data was that word of mouth was a primary aspect of how parents learned of what was available for their child. Comments varied from learning of early intervention supports through word of mouth from support groups, professionals previously involved with the child where relationships were already established, teachers, and other parents.

The second predominant theme that emerged from the participants was that they understood what was available through independent research. Participant 1 stated, “while a list of phone numbers and websites was given to me back then, I had to find out a lot of things on my own. Currently, a lot of information regarding events, workshops, and programs is either emailed to me or I find through social media” supporting that these parents are finding out information independently outside of the funding body after the initial list of agencies to contact was given. Although this list of agencies that provide services was given to Participant 2, there was a feeling of being lost in the attempt to find support and services for their child recently diagnosed with ASD. Participant 2 stated:

“My daughter is 22 months and was diagnosed at 19 months. I have no idea what assistance I am entitled to or anything. I live in a small town and have made several calls all with the same reply...’unfortunately there is a wait time and you will be added to the list’ ... Their letter said there was a wait time of 16-18 month wait. PATHETIC!”.

This demonstrated the challenges a parent faced when attempting to find early intervention supports. Although some parents who participated in the survey acknowledge now having a stronger understanding of what is available for early intervention, years after navigating the social system, Participant 2 demonstrates the frustration and challenges some parents face when

attempting to access early intervention supports. With these responses, the information was examined further through a co-cultural theoretical lens.

Through this lens, it is concluded that parents answered the research questions using differing means in accordance to Orbe's (1998) co-cultural theory. Parents conveyed their answers through a) separation, b) accommodation, and c) assimilation. As demonstrated in the responses from the participants, two conclusions were made. First, parents did not equally perceive availability of early intervention supports. Secondly, word of mouth was a predominant way for parents to become informed of early intervention services.

### **Discussion**

As the population being examined have a variety of uncertainties which include changes in diagnostic criteria for ASD, treatment options, socio-economic status, and parental stress levels to name a few, examination of the received responses from the data still yields a bountiful glimpse into the lack of available services, unclear understanding of funding and supports available for children diagnosed with ASD, and long wait times for services parents with children diagnosed with ASD encounter when interacting with the systems that provide early intervention services and supports.

When examining the information provided from the participants, to answer the first inquiry into this study (if there was a discrepancy between parents in understanding services) examination of the data shows inconsistencies in an understanding of early intervention across parents. As there was limited number of individuals whom self declared as an ethnic minority a clear picture could not be drawn whether ethnicity impacted the parent's perception of early intervention services. What was noted was a contrast between individuals who felt they

understood what funding and services were provided with individuals who felt they did not understand funding and service options.

The analysis proceeded to the second part of this question, why did the results and recruitment produce what they did and is there a method of communication for service providers and individuals representing government funding bodies that can support a more clear understanding of funds and services available?

The information as a whole was examined through the lens of co-cultural communication theory (Orbe, 1998). Each of Orbe's (1998) three means of communication is employed to gain insight into what way or manner parents obtain an understanding of early intervention services and communicated with the researcher through the survey. Further, by understanding the different strategies of communication that parents used during this survey, service providers and government funding bodies can employ this information when engaged in a conversation with parents with a child diagnosed with ASD when discussing early intervention services.

### **Separation**

Separation, in co-cultural communication theory, is when an individual's desired outcome is to separate from the dominant society, rejecting all, or most, interaction between them. This strategy is intuitively an unsuccessful strategy when assessing or accessing early intervention services. The individuals that viewed the survey and chose not to participate in the research can be explained as individuals utilizing the separation means of communication. Due to the mere fact I, as the researcher, am a graduate student conducting research created an unintentional power dynamic. This assumed power dynamic between researcher and participant potentially influenced the number of self-declaring ethnic minority as well as the number of participants in general. Within this strategy there are three different forms of separation: non-

assertive separation, aggressive separation, and assertive separation. From the results of the participants, and non-participants who fit the study's criteria, these three strategies can be utilized to examine and explain the results of the study.

The first strategy is non-assertive separation where an individual with a disability, or guardian of an individual with a disability, interacted by "maintaining a distance from the dominant group members" (Orbe, 1998). This notion can explain why a low number of individuals responded to the letter of invitation to participate. Parents with children diagnosed with ASD potentially avoided completing the survey, as they perceived the research and researcher as an extension of the dominant society. This particular strategy of avoiding participation in the survey creates a challenge when assessing how the dominant society can change their practice to support the parents and children affected by ASD. Without providing feedback, the parents have chosen not to provide information that potentially can contribute to a change in how information regarding early intervention services is communicated. Along with non-assertive separation, aggressive separation may explain the low number of participants.

Aggressive separation is a reactionary structure where parents may choose to communicate by "personal attacks on dominant group members' self-concepts" (Orbe, 1998). This particular aspect is not directly seen within this study. However, individuals who chose not to participate in the study may have opted to utilize this form of communication. Parents may have chosen to use aggressive separation in the form of criticizing the study or being skeptical of the intent of the research truly being able to affect change in the social system.

The third aspect of separation that is utilized to analyze the data is assertive separation. This method of communication is supported by participants who did not self declare as a minority although their cultural background is part of a minority group within Canada. The

individual in the study who did not declare as an ethnic minority yet described themselves from a cultural background that is a minority in Canada attempted to have the marginalized aspect, in this case their culture, be valued equally as those within the dominant society. Further, this strategy of communication may be seen through individuals who did not respond to the survey as choosing not to do so as their child being diagnosed with ASD is not perceived as a disability; rather the child's diagnosis is seen as one that does not require intervention to improve inclusion within society. These parents may wish to not access early intervention as they do not wish their child to become a part of the dominant society or change through integration supports.

Further, assertive separation can be utilized to explain why parents have chosen to look to other parents and the word of mouth method of gathering information to find out what early intervention supports are available. By using this method of communication, parents find comfort and support with other parents who have children diagnosed with ASD creating their own support network and may not feel the need to access supports through the government as they have created their own network outside of the ones presented by the dominant society.

### **Accommodation**

The next outcome to be used to examine the data is accommodation. Accommodation "rejects the arguments for a great melting pot" (Orbe, 1998). In regards to accessing early intervention supports, parents using this outcome may have requested that the early intervention services accept their child's disability and establish programs to meet their disability and special needs. Within accommodation there are three sub categories used to analyze the research data collected: non-assertive accommodation, aggressive accommodation, and assertive accommodation.

Non-assertive accommodation strategy can be utilized when examining the responses of majority of the individuals who participated in the research. As non-assertive accommodation, as presented by Orbe (1998), refers to individuals who use this method to communicate in an attempt to “invoke change through a seemingly constrained and non-confrontational manner”. Parents chose to participate in the study in an attempt to provoke change within the system in a perceived safe environment. Further, as the most consistent response when asked if the funding that is available is clearly communicated to them, there was a large portion of participants that answered that they felt neutral, a non constrained answer; it is neither an agree nor a disagree.

Aggressive accommodation is often described as individuals who attempt to be part of the dominant structure to create change and transformation. Within the confines of this study, and the questions asked, the adoption of this means of communication was unable to be demonstrated or interpreted.

Assertive accommodation orientation is demonstrated in the views of participants. Specifically, this is seen through the responses of Participant 1's response to being asked to describe how information regarding supports for your child with ASD is communicated with you. In this particular response the participant stated, “right now, I have a service coordinator. But, honestly, I don't really need one. I did not have one when my son was diagnosed 2 years ago” recognizing their needs but also acknowledging what was being provided to them by the social system. In this particular situation, although the participant did not aggressively state that they did not have a coordinator when they needed it at the beginning, it was implied perhaps in an attempt to transform when parents receive coordinators to support them in navigating early intervention supports.

### **Assimilation**

Assimilation “involves attempts to eliminate cultural differences including the loss of any distinctive characteristics, to fit in with dominant society” (Orbe, 1998) and at times was a beneficial means of communicating. When parents are attempting to access early intervention services their main goal is to attempt to provide services that will integrate their child into the dominant society.

Non-assertive assimilation is a means of communication that perhaps influenced the results of the study. As within this strategy, parents may have chosen not to disclose that their child has been diagnosed with ASD impacting the number of individuals that participated in this study. This strategy is ineffective as it leaves a gap in understanding effective means to communicate with parents seeking information for early intervention services.

Aggressive assimilation is yet another means of communication to be aware of. This particular strategy was not demonstrated within the context of this study. It is a method of communication that service providers and government funding bodies should acknowledge. This form of aggressive assimilation from a parent may be demonstrated as a parent denying early intervention supports for their child as an attempt to assimilate themselves and their child diagnosed with ASD with the dominant society. This potentially can be demonstrated in situations where parents are attempting to access any intervention possible in an attempt to “cure” their child of ASD to assimilate with the dominant society.

Assertive assimilation of communication style is demonstrated in the data as parents who stated that they actively engaged in word of mouth, support groups, and researching information independently. This strategy is successful if the parent has the skills and understanding as to where they can acquire information regarding early intervention support. A parent that engaged in this method of communication was demonstrated by Participant 3's comment that they have

found out what early intervention supports are available and effective through word of mouth, support groups, and research. By doing independent research, parents are then able to approach government funding bodies and service providers to negotiate and bargain for early intervention services having a clear understanding of what is already available for their child.

### **Summary**

Through the sample of participants in this study, it was determined that the participants' understanding of what early intervention services and funding was available for their child was not consistent across the sample. This inconsistency creates concern as services are funded through provincial government ministries, and Canadians across the provinces and territories are not receiving equal access to information regarding services required. Although an individual is Canadian, there is not an equal understanding of what funding and services are available.

This fosters uncertainty when examining how early intervention supports will impact social services, through assisted living, in the future for individuals diagnosed with ASD. As there are inconsistencies across provinces and territories, planning for the future social services becomes increasingly difficult if there is hesitation in what early interventions are consistently accessed and the efficacy rates of those programs. If individuals are not informed of what early intervention services are provided, or understand which of those programs are effective for their child, predicting how to develop and invest social supports is incomprehensible. This notion also continues to support a power dynamic between the disability community and the government system; as equality is not demonstrated through the perspective of parents of children diagnosed with ASD in relation to understanding services and funds available.

### **Limitations and Future Studies**

As the data was analyzed and the research process was reflected upon, limitations of the study became apparent. First, due to costs of translations and the limited funds available for this study, translations for the study to be available in a variety of languages was not possible. The fact the study was solely available in English can explain the lack of responses from ethnic minority groups. A second limitation of the study was the lack of successfully obtaining individuals to participate in the interview process. As triangulation utilizing self-completion surveys and interviews were part of the research design, supporting the self-completion surveys with the interviews was impossible. The explanation as to why I was unsuccessful in securing interview participants may reflect back to the stress levels of the parents and participating in the research interview was not a priority in their day-to-day life. One individual that responded to an invitation to participate in the interview process replied that due to trying to set up appointments and speak with service providers, she simply could not find time to dedicate to the interview process.

The third limitation is in relation to using a self-completion survey. As no participant self-declared as an ethnic minority, utilizing surveys as a method to gain understanding of this topic was arduous as, although it was attempted, specifically targeting ethnic minority groups to recruit participants was a consistent challenge and proved ineffective.

Having worked in the field with children, youth and families who are part of the disability community either directly or as a caregiver, there is a potential source for bias from the researcher. The research question was engaged upon based on experiential knowledge of the struggles and challenges parents may see while navigating the social system for early intervention services. As this study did not examine the perception of how information is communicated from the professionals within the organizations that provide early intervention

supports and funding, this study does not recognize all of the challenges that may be presented from this other perspective.

Further research is needed in understanding what methods are most effective communicating information with ethnic minority parents with children diagnosed with ASD. Focus groups, participant action research, and case studies regarding this topic are methodologies for future exploration. As concluded, regardless of ethnicity, there is a discrepancy between how effectively information about early intervention services is delivered to parents. Further investigation into how peer and word of mouth can be harnessed and utilized to ensure equal understanding and access to early intervention services is another area for future research.

### **Conclusion**

This study began with two specific intents. The study's first objective was to investigate the discrepancy between parents regardless of ethnicity. From the information collected, it was clear that there was a discrepancy across parents in accessing early intervention supports. As there was limited number of self-declared ethnic minority parents that participated in the research study, ethnicity was no longer a focus in the study as the parents of children diagnosed with ASD were considered a marginalized population as an extension of their child's disability.

The second intent of the study was to examine if there was a method that was effective in informing parents of early intervention supports that were available. Although there was a discrepancy of the effectiveness of how early intervention supports were communicated, a theme of finding information independently through word of mouth, outside of the government funding body appeared. Parents utilized independent research skills and talking to individuals that consisted of parents in support groups, teachers, and previous professionals as means of gaining information about what early intervention supports and funding was available. As a large portion

of the individuals who responded to the survey stated that they were neutral on understanding what funding is available for their child diagnosed with ASD, potential services are not being accessed based on not strongly understanding what funding is in place for those services.

As was determined by the responses of the participants regarding understanding early intervention services, there was no consistent feeling of understanding what services were available for their child. This inconsistency becomes problematic as services are funded through provincial government funds, as Canadians across the provinces and territories are not receiving equal access to information regarding services required. Upon completion of the research limitations became visible.

There is evidence to support that regardless of ethnicity, there is inconsistency between parents perception of what intervention services are available for their child. One dominant theme across participants is the use and access of word of mouth information. This opens the potential to investigate further into how funding agencies can utilize peer supports and word of mouth methods of communicating to ensure correct information is disseminated to the parents in a timely fashion regarding early intervention. Further, as demonstrated through the examination of the data through a co-cultural communication theory lens, recognizing that the population being examined engaged in multiple communication strategies allows for further understanding that there is not a sole method to communicate with this particular population. Information is required to be delivered in a variety of methods to ensure individuals using different methods to communicate have an opportunity to access information equally.

Equality in access to information can also be negotiated through individuals who work with service providers and represent funding bodies understand the variety of methods of communication that parents with children diagnosed with ASD may engage in. By understanding

how the parent is choosing to engage with the service provider or individual representing the funding body allows for a greater understanding in how to provide information and support regarding early intervention services for their child diagnosed with ASD.

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*Appendix A*

## Survey Questionnaire

**Question 1**

Do you have a child diagnosed with Autism Spectrum Disorder?

- Yes
- No

**Question 2**

Is your child 6 years old or younger?

- Yes
- No

**Question 3**

Would you define yourself as the primary caregiver of your child with Autism Spectrum Disorder?

- Yes
- No

**Question 4**

Do you reside in Canada?

- Yes
- No

**Question 5**

What province/territory do you reside in?

- Alberta
- British Columbia
- Manitoba
- New Brunswick
- Newfoundland and Labrador

- Northwest Territories
- Nova Scotia
- Nunavut
- Ontario
- Prince Edward Island
- Quebec
- Saskatchewan
- Yukon

### Question 6

How do you describe your ethnic background?

- Caucasian
- Chinese
- South Asian
- Black
- Filipino
- Latin American
- Southeast Asian
- Arab
- West Asian
- Japanese
- Korean
- Aboriginal
- Prefer not to answer
- Other : \_\_\_\_\_

### Question 7

Do you identify yourself (your family) as a minority in Canada?

- Yes
- No

**Question 8**

What early intervention services does your child currently receive? (check all that apply)

- Behavioral Consultant
- Behavioral Intervention
- Community Aide
- Occupational Therapy
- Physical Therapy
- Psychiatrist
- Psychologist
- Respite
- Speech Language Therapy
- Other: \_\_\_\_\_

**Question 9**

Of the current early intervention services, how are they funded?

	This service is paid by government program funds	This service is subsidized	I pay for this service	Not applicable
Behavioral Consultant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Behavioral Intervention	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community Aide	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Occupational Therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical Therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychiatrist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Speech Language Therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other services:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Question 10**

What early intervention services has your child received in the past? (check all that apply)

- Behavioral Consultant
- Behavioral Intervention
- Community Aide
- Occupational Therapy
- Physical Therapy
- Psychiatrist
- Psychologist
- Respite
- Speech Language Therapy
- Other: \_\_\_\_\_

**Question 11**

Of the past early intervention services, how were they funded?

	This service is paid by government program funds	This service is subsidized	I pay for this service	Not applicable
Behavioral Consultant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Behavioral Intervention	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community Aide	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Occupational Therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical Therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychiatrist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Speech Language Therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other services:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Question 12**

Are you aware of the early intervention services that are available through government funding?

- Yes
- No

**Question 13**

Are you aware of the community supports available for your child to ensure inclusion in community activities?

- Yes
- No

**Question 14**

Rate your perception to the following statements:

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I feel I know what services are available for my child diagnosed with Autism Spectrum Disorder.	<input type="checkbox"/>				
Funding, that is available for my child with Autism Spectrum Disorder, is communicated clearly to me by individuals associated with the funding programs.	<input type="checkbox"/>				
I am aware of what early intervention programs are available for my child to access.	<input type="checkbox"/>				

**Question 15**

Please describe how information regarding support for you child with Autism Spectrum Disorder is communicated with you.

**Question 16**

Are you interested in having a conversation with the researcher, Karlee-Anne Grant, to describe your experiences further?

- Yes
- No

**Question 17**

Please enter your first name, email and/or phone number if you would like to have the researcher contact you to discuss your experiences further.

*Appendix B*

## Semi Structured Interview Questions

- How would you describe your ethnic background?
- Is your child under the age of 6 years old?
- What province do you reside in?
- Who would you describe is the primary caregiver of your child diagnosed with Autism Spectrum Disorder?
- What early intervention services is your child currently receiving?
- How would you describe your understanding of what early intervention services are available for your child?
- How were you informed of early intervention services and funding?
- Describe how early intervention services and funding is/was communicated to you? (Who has communicated this to you? Was it effective? Have there been times where you struggled to get information regarding intervention services and funding?)

*Appendix C*

## Letter of Invitation

[Date]

Dear [Prospective Participant/organization],

I would like to invite you to be part of a research project that I am conducting. This project is part of the requirement for a Master's Degree in Intercultural and International Communication at Royal Roads University. My name is Karlee-Anne Grant and my credentials with Royal Roads University can be established by calling Jennifer Walinga, Director of the School of Communication and Culture, at (xxx) xxx-xxxx ext. xxxx or the thesis supervisor, Zhenyi Li at (xxx) xxx-xxxx ext. xxxx.

The objective of the research is to determine if there is a discrepancy between ethnic minority and ethnic majority Canadian parents of a child diagnosed with Autism in understanding and accessing early intervention supports provided by both private and public funds. In addition to submitting my final report to Royal Roads University in partial fulfillment for a Master of Arts in Intercultural and International Communication, I will also be sharing my research findings with academic journals and at academic conferences.

My research project will consist of either a survey or interview. The survey can be accessed online at <http://fluidsurveys.com/> and will consist of open-ended questions and fix choice questions. The survey is foreseen to last 15 minutes. The foreseen questions will be related to your identified ethnicity, early intervention services accessed for your child diagnosed with autism and perception of what early intervention services are available for your child.

The interview can be conducted in person or over the phone dependent upon location. Participation is voluntary. The foreseen questions will be related to your identified ethnicity, early intervention services access for you child diagnosed with autism and perception of what early intervention services are available for your child. An interpreter can be arranged if required.

Participation is voluntary. In order to participate in the interview portion of this study, please contact the researcher, Karlee-Anne Grant at xxxxxxxx@RoyalRoads.ca.

Survey information will be recorded on a survey database called Fluid Survey. Interviews will be digitally recorded and transcribed. The data collected is stored in Canada, where appropriate summarized, in anonymous format, in the body of the final report. At no time will any specific comments be attributed to any individual unless your specific agreement has been obtained beforehand. All documentation will be kept strictly confidential.

Upon summarized and documented as required in the final report, the raw data collected from both the survey and interview will be destroyed by June 30, 2014. A copy of the final report will be published and archived in the RRU Library.

Please feel free to contact me at any time should you have additional questions regarding the project and its outcomes.

You are not compelled to participate in this research project. If you do choose to participate, you are free to withdraw at any time without prejudice. Similarly, if you choose not to participate in this research project, this information will also be maintained in confidence.

Please feel free to contact me at any time should you have additional questions regarding the project and its outcomes.

Name: Karlee-Anne Grant

Email: xxxxxxxx @RoyalRoads.ca

Telephone: (xxx) xxx-xxxx

Attached is a poster with information on how to participate. It would be of great appreciation if your organization were able to post this information to inform potential participants of this research opportunity.

Sincerely,

Karlee-Anne Grant



## An invitation to ALL parents with a child (6 years or younger) diagnosed with Autism Spectrum Disorder

Dear Parents,

I would like to invite you to be part of a research project that I am conducting. This project is part of the requirement for a Master's Degree in Intercultural and International Communication at Royal Roads University. My name is Karlee-Anne Grant and my credentials with Royal Roads University can be established by calling Jennifer Walinga, Director of the School of Communication and Culture, at (xxx)xxx-xxxx or the thesis supervisor, Zhenyi Li at (xxx)xxx-xxxx.

The objective of the research is to determine if there is a discrepancy between ethnic minority and ethnic majority Canadian parents of a child diagnosed with Autism Spectrum Disorder (ASD) in understanding and accessing early intervention supports provided by both private and public funds. In addition to submitting my final report to Royal Roads University in partial fulfillment for a Master of Arts in Intercultural and International Communication, I will also be sharing my research findings with academic journals and at academic conferences.

My research project will consist of either a survey or interview. The survey can be accessed online at <http://fluidsurveys.com> and will consist of open-ended questions, multiple choice and fix choice questions. The survey is anticipated to last 15 minutes. The foreseen questions will be related to your identified ethnicity, early intervention services accessed for your child diagnosed with ASD and perception of what early intervention services are available for your child.

The interview can be conducted in person or over the phone dependent upon location. Participation is voluntary. The foreseen questions will be related to your identified ethnicity, early intervention services access for your child diagnosed with ASD and perception of what early intervention services are available for your child.

Participation is voluntary. In order to participate in the interview portion of this study, please contact the researcher, Karlee-Anne Grant at [xxxxxxxxx@RoyalRoads.ca](mailto:xxxxxxxxx@RoyalRoads.ca) or by phone at (xxx)xxx-xxxx.

Survey information will be recorded on a survey database called Fluid Survey. Interviews will be digitally recorded and transcribed. The data collected is stored in Canada, and where appropriate, summarized in anonymous format in the body of the final report. At no time will any specific comments be attributed to any individual unless specific agreement has been obtained beforehand. All documentation will be kept strictly confidential.

Once analyzed and the thesis project is submitted to Royal Roads University, the raw data obtained will be destroyed after June 30, 2015 as per the BC Freedom of Information and Protection of Privacy Act (2013). A copy of the final report will be published and archived in the RRU Library.

You are not compelled to participate in this research project. If you do choose to participate, you are free to withdraw at any time without prejudice. Similarly, if you choose not to participate in this research project, this information will also be maintained in confidence.

Please feel free to contact me at any time should you have additional questions regarding the project and its outcomes.

Name: Karlee-Anne Grant  
Email: [xxxxxxxxx@RoyalRoads.ca](mailto:xxxxxxxxx@RoyalRoads.ca)  
Telephone: (xxx)xxx-xxxx

You are not compelled to participate in this research project. If you do choose to participate, you are free to withdraw at any time without prejudice. Similarly, if you choose not to participate in this research project, this information will also be maintained in confidence.

*Appendix D*

## Informed Consent

My name is Karlee-Anne Grant and I invite you to participate in a research project by completing a survey. This research project is part of the requirement for a Master of Arts in Intercultural and International Communication at Royal Roads University. My credentials with Royal Roads University can be established by calling Jennifer Walinga, Director of the School of Communication and Culture, at (xxx) xxx-xxxx ext. xxxx or the thesis supervisor, Zhenyi Li at (xxx) xxx-xxxx ext. xxxx.

This document constitutes an agreement to participate in my research project. The objective of the research is to determine if there is a discrepancy between ethnic minority and ethnic majority Canadian parents of a child diagnosed with Autism Spectrum Disorder (ASD) in understanding and accessing early intervention supports provided by both private and public funds.

In addition to submitting my final report to Royal Roads University in partial fulfillment for a Master of Arts in Intercultural and International Communication, the analysis of the information gathered is also intended for publication in journals and presentation at conferences.

Your participation in the research will consist of completing a survey that will be comprised of fixed choice, multiple choice and open ended questions and is foreseen to last 15 minutes. The questions in the survey will refer to your identified ethnicity, early intervention services accessed for your child diagnosed with ASD and perception of what early intervention services are available for your child.

Information will be recorded either online through Fluid Survey or by a hand-written survey and, where appropriate, summarized, in anonymous format, in the body of the final

report. At no time will any specific comments be attributed to any individual unless specific agreement has been obtained beforehand. All documentation will be kept strictly confidential. The hand written survey responses will be kept in a secure and locked location. The information submitted on Fluid Survey is stored in Canada and is only accessible by the researcher. Once analyzed and the thesis project is submitted to Royal Roads University, the raw data obtained will be destroyed after June 30, 2015 as per the BC Freedom of Information and Protection of Privacy Act (2013).

A copy of the final report will be published and archived in the RRU Library. Information from the thesis project will also be submitted to academic journals for publishing. If you, the participant, wishes to obtain a copy of the research, you may do so by contacting myself, Karlee-Anne Grant, at xxxxxxxx @RoyalRoads.ca. There is no intent for commercialization of the research findings.

I currently work in the field of disabilities as an Adult, Youth and/or Child Worker. As such, individuals whose child is/was a client associated with myself will not be solicited to participate in the survey. You are not compelled to participate in this research project. If you do choose to participate, you are free to withdraw at any time without prejudice. Participation in this survey will have no negative consequences of the services or funding, currently or in the future, related to early intervention services for your child diagnosed with ASD. If you choose not to participate in this research project, this information will also be maintained in confidence and anonymous. If you have questions at any point during the participation in this study, you can contact myself at xxxxxxxx @royalroads.ca.

**By checking 'yes' you consent to participating in the research project. Do you wish to participate in the research project?**

- Yes  No