

**EXPLORING THE STAGES OF CHANGE AND PERCEIVED BARRIERS TO  
TREATMENT MODELS WITHIN THE CONTEXT OF PARENTAL  
ADHERENCE TO AN EARLY INTERVENTION PROGRAM**

by

© Dana M. Noseworthy

A Thesis submitted to the

School of Graduate Studies

in partial fulfillment of the requirements for the degree of

**Master of Science**

**Psychology Department**

Memorial University of Newfoundland

**May 2016**

St. John's

Newfoundland and Labrador

## **ABSTRACT**

Parent-mediated early intervention programs depend on the willingness and ability of parents to complete prescribed activities with their children. In other contexts, internal factors, such as stages of change, and external factors, such as barriers to treatment, have been shown to correlate with adherence to service. This researcher modified the Stages of Change Questionnaire as well as the Barriers to Treatment Participation Scale (BTPS) to use with this population. Despite initial interest, twenty-three parent participants were referred to the researcher over the course of three years, with only five parents taking part in the study. A population base ten times that of the current sample would be required recruit enough participants (fifty-one) to provide sufficient power. This feasibility study discusses the results of the five parent participants. Findings suggest that the modified Stages of Change Questionnaire may not be sensitive enough for use with the current sample, while the modified BTPS may yield useful information for service providers.

## **ACKNOWLEDGEMENTS**

Over the course of eight years, you accumulate quite a number of people to thank. Having finally come to the end of this journey, ‘thank you’ barely seems to cover the gratitude that I feel. To my supervisor, Dr. Christine Arlett, for staying with me through the long haul, even after your retirement – thank you. Dr. Arlett’s unwavering, gentle support helped encourage me to keep going, especially when the completion of this degree seemed so far out of reach. Thank you to those who served on my committee at various points of my journey, Dr. Stacey Wareham, Sharon Batstone, and Dr. Ian Neath. Many thanks to fellow researchers who answered my questions along the way, including Dr. Alan Kazdin, Dr. Lori Roggman, Dr. Matthew Nock, and Dr. Malcolm Grant. Also, I would like to say a special thank you to Brenda Crewe, who made the practical side of finishing this degree a little bit easier.

I have enormous appreciation for my husband, Adam; for continuing to push me to complete this endeavor, which also meant reading our daughter many bedtime stories without me.

Finally, I would like to dedicate this work to my daughter, Zoe. Thank you for always sending me off to ‘school’ with a hug, a kiss, and a smile. I hope that I have shown you to never give up on your goals; that learning is and should be a lifelong process; and to be proud of your accomplishments.

## Table of Contents

<b>Abstract.....</b>	<b>ii</b>
<b>Acknowledgements .....</b>	<b>iii</b>
<b>List of Tables .....</b>	<b>v</b>
<b>List of Figures.....</b>	<b>vi</b>
<b>List of Appendices.....</b>	<b>vii</b>
<b>Foreword.....</b>	<b>viii</b>
<b>Introduction.....</b>	<b>1</b>
<b>Method .....</b>	<b>35</b>
<b>Results .....</b>	<b>46</b>
<b>Discussion .....</b>	<b>84</b>
<b>References.....</b>	<b>109</b>
<b>Appendices.....</b>	<b>119</b>

## **List of Tables**

Table 1: Direct Home Services Program statistics for fiscal years 2009 - 2012 .....	35
Table 2: Demographics of Parent Participants.....	47
Table 3: Additional Services Availied of by Children in the Direct Home Services Program.....	51
Table 4: Barriers to Treatment Participation Scale - modified scores from Time 2 and Time 3 .....	71
Table 5: Parent Quality Ratings at Time 2 and Time 3 .....	74
Table 6: Staff Quality Ratings for each Parent Participant at Time 2 and Time 3 .....	75
Table 7: Average length of visits for each parent .....	78
Table 8: Comparison of Time 2, Time 3, and Overall Adherence Scores.....	79
Table 9: Correlation Matrix for all measures completed by participants .....	81

## List of Figures

<i>Figure 1.</i> Breakdown of recruitment of parent participants. ....	48
<i>Figure 2.</i> Comparison of scores of part 1 of the Barriers to Treatment Participant Scale – modified at Times 2 and 3. . ....	72
<i>Figure 3.</i> Comparison of scores of part 2 of the Barriers to Treatment Participant Scale – modified at Times 2 and 3. . ....	73
<i>Figure 4.</i> A comparison of home visit quality ratings given by both staff and parents at Time 2 and Time 3. ....	76
<i>Figure 5.</i> A comparison of relationship quality ratings given by both staff and parents at Time 2 and Time 3. ....	77
<i>Figure 6.</i> A comparison of adherence scores at Time 2 and Time 3 for parent participants. ....	80

## **List of Appendices**

Appendix A– Ethics Approval Letter .....	119
Appendix B - Demographic Questionnaire.....	122
Appendix C – Stages of Change - Modified Questionnaire (Readiness for Change) .....	125
Appendix D – Barriers to Treatment Participation Scale – modified .....	129
Appendix E – Weekly Visit Log .....	135
Appendix F – Quality of Home Visit – staff rating .....	137
Appendix G – Quality of Home Visit - parent rating .....	139
Appendix H – Information Letter for Staff .....	142
Appendix I – Recruitment Script .....	146
Appendix J – Information Letter for Families .....	148

## **Foreword**

The following thesis was based upon a research study designed in the fall of 2008 which sought to assess parental readiness for change and perceived barriers to treatment over the course of a family's first 6 months of involvement in an early intervention program targeting developmental stimulation. Based upon discussions with the program manager, the desired number of participants was deemed obtainable. The original method and ethics application were written with the view of obtaining at least 50 participants.

Initial ethical approval was obtained from the Human Investigation Committee (now known as the Human Research Ethics Authority) on April 2, 2009. Over the next year, recruitment numbers were much lower than expected. Subsequently, two research extensions were granted April 2, 2010 and April 2, 2011. Even with these extensions, recruitment remained low.

While writing the final draft of this thesis, a suggestion came from my committee that the work completed could be best presented within the framework of a feasibility study. From this perspective, the results are used to discuss difficulties related to methodological issues, such as participant recruitment and the development of suitable assessment measures, and provide information necessary to enable a larger scale study. The reader is asked to keep this shift in focus in mind while reading the thesis.



Early intervention programs for children strive to improve the development and skill level of these children, effecting immediate change and intending to improve later outcomes. Initial studies assessed the efficacy of early intervention programs by measuring the gains that children made during intervention and the extent to which the gains were sustained after intervention. More recently, however, investigators have become interested in the processes underlying successful early intervention. Questions such as “What defines quality intervention?” and “Why do some families choose not to participate in early intervention?” are now receiving attention.

Many early intervention programs use a parent-mediated approach to programming (Eiserman, Weber, & McCoun, 1995). That is, parents are trained in intervention strategies and are expected to complete these activities with the child in the absence of the practitioner<sup>1</sup>. However, all parents will not be equally able to change their behaviour and interaction style in order to serve as interventionists for their children (Marfo & Dinero, 1991; Miedel & Reynolds, 1999). It would be helpful to practitioners, then, if one were able to identify which parents will be capable of effectively carrying out programming with their children and which parents, for whatever reason, will not be able to do so. By identifying barriers to service recruitment and retention, early intervention programs may be able to modify delivery models to reach and retain more families (Korfmacher et al., 2008; McCurdy & Daro, 2001).

---

<sup>1</sup> Parent refers to the child’s caregiver who is involved with the intervention program; at times, this may be the child’s biological, foster, or adoptive parent or even the child’s grandparent. The terms practitioner, interventionist, and home visitor are used interchangeably throughout this thesis, and are used to reference the person delivering the early intervention program to the child and family.

Researchers studying addictions have used measures derived from change models, such as the Transtheoretical model, as a way to identify clients who are ready for change (e.g., Prochaska & DiClemente, 1982). While these measures address intrapersonal factors such as motivation, external factors also impact on the parent's ability to participate in treatment. For example, inability to take time off work may interfere with a parent's ability to keep appointments with professionals. Kazdin, Holland, Crowley, and Breton (1997) developed the Barriers to Treatment Participation Scales (BTPS) as a way to measure these external factors.

The present study was designed to investigate whether measures such as the Stages of Change questionnaire (McConaughy, Prochaska, & Velicer, 1983) and Barriers to Treatment Participation Scale (Kazdin et al., 1997) can assist practitioners in determining which families are likely to adhere to intervention, and those who may have more trouble doing so. As there were no existing measures designed for this population, it was necessary for the researcher to modify measures of readiness for change and of external barriers to treatment. This, together with difficulties in recruitment reported in similar research studies, led to the feasibility study described in this thesis.

### **What is early intervention?**

Before delving into a discussion on early intervention, it is necessary to have a clear understanding of what is being referred to as early intervention within this thesis. Early intervention is a term used to describe a wide variety of programs, experiences and services. Entering 'early intervention' into a literature search results in publications related to nursing, social work, psychology, occupational therapy, education and others.

Definitions include, “the facilitation, acceleration, or at least the maintenance of developmental progress among the participants” (Dunst & Rheingrover, 1981, p. 288); “to intervene with infants and toddlers below age three who are already handicapped or ‘at risk’ for developmental delay or disorders” (Greenberg & Calderon, 1984, p. 1); “intervention undertaken to influence the development and learning of young children (aged up to 5 years) with or at risk for developing disabilities. Early intervention includes systems, services, and supports designed to: enhance the development of young children; minimise the potential for developmental delay; minimise the need for special education services; enhance the capacity of families as caregivers” (Oser & Ayankoya, 2000, as quoted in Korfmacher, Green, Spellman, & Thornburg, 2007, p. 5). A review of these definitions raises specific issues with respect to the timing, nature and delivery of early intervention. Each of these will be discussed with reference to the early intervention program being studied here, the Direct Home Services Program.

First, while many researchers agree that early intervention occurs “early” in life, this is where the agreement ends. Some researchers consider early intervention to be that which occurs before the age of three, while others consider this to include any intervention that occurs prior to school entry. Still others include preschool or the beginning school years as early intervention. Programs can start at various times too – with some beginning when mothers are expecting their babies (or even before), others beginning at birth, and others at a later stage in life. There is no standard for the duration of early intervention, and this can vary widely. For the program that will be studied in the present research, “early” intervention occurs at any time from birth to school entry.

Involvement in the program can end when the child enters school, is no longer demonstrating developmental delays, or the parent decides to discontinue involvement in service.

Secondly, there is no single type of intervention that is considered to define early intervention. With respect to the goals of the intervention, there are a wide range of programs captured, including services that bolster overall family functioning, those that target the parent-child relationship, those that focus on child development and others that attempt to meet combinations of all three goals. Further, some researchers have indicated that early intervention may involve formal as well as informal supports (Dunst, 2000). That is, any support that is provided to a family may be considered an early intervention to enhance developmental outcomes. The program studied here focuses primarily on child outcomes across a variety of developmental domains such as academics and speech and gross motor skills, as well as helping parents to avail of and advocate for needed supports.

Third, early intervention may be delivered in a variety of settings. Intervention may take place within the home, or it may be school or clinic-based. Some programs have provided a combination of home and center-based intervention. The current program primarily uses the home as the place of intervention, though community sites such as child care centres or playgroups may be involved.

The diversity of early intervention programs presents a difficulty when researchers are looking either to evaluate early intervention as a whole or to make

comparisons concerning the effectiveness of different intervention programs. With this in mind, a review of the early intervention research will now be presented.

### **A review of early intervention research**

Ramey and Ramey (1999) describe the trajectory that led to the widespread development of early intervention programs in the United States. Based on observations that children who grew up in impoverished environments often exhibited lower developmental gains and/or increased behavioral difficulties, researchers began to advocate for early educational enrichment programs. The main goal was to ameliorate the effects that poverty was presumed to be having on child development. In the United States, governments began funding these enrichment programs during the 1960s as a way to respond to the concerns of researchers and voters alike.

Many reviews have looked at the early intervention programs that were implemented in the 1960s and 1970s. The Consortium for Longitudinal Studies was a collaboration between various intervention researchers formed in 1975 to pool data from a number of studies on experimental preschool programs for disadvantaged children (Darlington, Royce, Snipper, Murray, & Lazar, 1980; Royce, Lazar, & Darlington, 1983). It is important to note that the programs included in the review were diverse; some programs only had a preschool component, others concentrated on home visits that sought to teach mothers how to interact more effectively with their young children, and yet other programs consisted of a combination of these two approaches. To guard against pooling influencing the findings, experimental group children were only compared with controls from their own project. Two follow-ups were conducted on the children, the first

in 1976 and the second in 1980. Both project children and their controls participated in the follow-ups which included individually administered intelligence tests, information from school records, performance on school achievement tests, and interviews with participants and parents.

These researchers found a fading effect on IQ, whereby the programs had significant effects on IQ upon completion, but the differences tapered off after three to four years and were no longer significant thereafter (Darlington et al., 1980). Effects on school competence were longer lasting. It was observed that by grade seven, significantly fewer children who had taken part in an early intervention program had been placed in special education classrooms compared with peers who had not received the program (Royce et al., 1983). Further, they were less often held back a grade in school. Darlington et al. (1980) did not report any significant interactions of sex, ethnic background, or preprogram IQ with the results discussed.

Encouraged by this research, early intervention programs became quite popular and flourished, most often targeting those children who were at-risk for developmental concerns, specifically those children who were growing up in impoverished environments. While many early intervention programs, such as the well-known Head Start Programs, focus on raising the pre-academic skills of children experiencing poverty, there is another group of children who also benefit from early intervention, though they are less often studied. These are the children who are considered handicapped or organically impaired. These children may have diagnoses such as Cerebral Palsy, Down Syndrome, or even hearing loss. Bailey and Bricker (1984, 1985), Dunst and Rheingrover

(1981) and Greenberg and Calderon (1984) were interested in both the effectiveness of early intervention with this subgroup of children and the issues that surround research on this particular group of children.

In a review of thirteen early intervention programs for severely handicapped infants and young children, Bailey and Bricker (1984) found that all of the programs reviewed reported some form of positive outcome. That is, all programs measured some dimension of child development and found a positive change after a period of intervention. They also raised many questions that have overwhelmed efficacy research for this population, including the definition of the population (i.e., how is “handicapped” defined), issues with outcome measures, program variability, and study designs.

Karl White is known for attempting to bring together the vast anthology of early intervention studies conducted prior to 1985 and compiling their results (White, 1985; White & Casto, 1985). For a detailed description of White’s procedure for this meta-analysis, the reader is directed to the cited articles. White included studies that reported on children with a biological handicap as well as those who lived in disadvantaged neighbourhoods. White reported that the early intervention programs had substantial immediate effects but few of these effects stood up in long-term evaluations. White also reported that interventions that included parent involvement showed similar success to interventions that did not include parents – contrary to expectations, there was no evidence that interventions using parents were more effective than those that did not involve parents. As for the often stated “earlier is better,” White found few evaluations of this declaration and, in those that were found, there was little difference between the

scores of children who started early intervention programs earlier and those who started them later in childhood.

While White's attempt at pooling together the results of the multitude of studies is certainly useful, caution should also be taken in interpreting the results. Dunst and Snyder (1986) critiqued White's meta-analysis across a number of themes. In particular, they highlight that within the review, all home-based interventions were pooled together and all center-based interventions were pooled, though there were no doubt many differences between them. Also, children with organic impairments were pooled with children with environmental setbacks. Dunst and Snyder (1986) also assert that the studies that were being compared did not actually measure the same construct, such that their effect sizes would not be comparable. These themes are only a sample of the critiques offered by Dunst and Snyder, but illustrate the point that the meta-analysis may not have produced sound conclusions.

### **Measuring the Effectiveness of Early Intervention.**

Dunst and Rheingrover (1981) have highlighted methodological weaknesses that were apparent in many of the early efficacy studies. In particular, ethical considerations related to withholding intervention from a developing child hindered the use of experimental designs in this research area so most of the studies reported were deemed quasi-experimental (e.g., because they did not include a control group). A pitfall of not having truly experimental designs is that confounding variables cannot be ruled out as possible explanations for the results found in the studies. Ottenbacher and Peterson (1985) conducted a quantitative review of a large number of early efficacy studies and



found that studies with larger effect sizes were those found to have lower internal validity. That is, larger effect sizes were found to be associated with studies that did not control for competing variables, consistent with Dunst and Rheingrover's review (1981).

Dunst and Rheingrover (1981) also cited instrumentation as a concern. In the initial effectiveness literature, many researchers used a comparison of pre-intervention IQ and post-intervention IQ to measure the impact of early academic intervention on children. Zigler and Trickett (1978) highlighted the multitude of factors that could impact IQ scores in this population, including past experience, familiarity with the test materials and motivational factors. In their 1982 study, Zigler, Abelson, Trickett, and Seitz (1982) showed that even for children who received no intervention, there was a significant increase in IQ score on retesting, presumed to be related to the children's familiarity with the test and with the testing experience.

Some researchers questioned the value of standard IQ measures for children who have an organic impairment as they may not give a true measure of the capabilities of these children (Simeonsson & Wiegerink, 1975). For example, using a standard Weschler test with a child who has a speech difficulty or a motor impairment will result in a lower and non-meaningful IQ score. However, given that at that time there were no other standardized options to assess cognitive development, and no scales that referenced delayed children, Simeonsson and Wiegerink acknowledged that using this measure was a necessary evil of the time. Since then, more specialized assessment tools have come into existence and norms are available for more varied groups of children.

Greenberg and Calderon (1984) questioned whether IQ scores were an equally meaningful outcome measure for all early intervention programs. For example, the impact of a program that targets increasing a mother's responsiveness to her child may not be accurately measured by a change in the child's IQ score. Marfo and Kysela (1985) pointed out that many researchers have looked only at child outcomes as a measure of early intervention success, neglecting other targets such as parent and family functioning. With regards to effectiveness, Greenberg and Calderon (1984) question what one can consider the hallmark of effectiveness for early intervention programs with these children. While changes in IQ have often been used to measure effectiveness in other early intervention programs, these programs may actually target different goals than raising a child's IQ or preacademic skills. For example, Greenberg and Calderon question, "is a program effective if there are no long-term effects on the child's developmental level, but there are effects on parental attitudes toward the child or deafness, or lower levels of reported family stress? (p. 5)." In this respect, effectiveness should be defined by the goal of the program in question, and outcome measures should reflect these goals. Zigler and Trickett (1978) proposed that a measure of social competence would reflect broader developmental outcomes than standard IQ scores. Similarly, Darlington et al. (1980) considered later school competence as a way to measure the long-lasting effects of early intervention programs for low-income youth, rather than focusing solely on a measure of intelligence such as the Stanford-Binet.

Within the context of the above discussion, Dunst and Rheingrover (1981) analyzed the experimental designs and conclusions of forty-nine studies that used

organically handicapped children as participants. Many of the studies (18 of the 49) used a one-group pretest-posttest design to assess change in some measure between the start of intervention and the end. Others used a pretest-posttest design comparing the intervention group with a non-equivalent control group (11 of the 49). Only four of the forty-nine studies met criteria to be considered experimental designs, though these studies used matching to obtain their control group and as a result can only be considered truly experimental on a minimal standard. Based on the lack of experimental design and failure to control for confounding variables, these researchers assert that the results of the majority of the reported studies are actually uninterpretable and meaningless.

While researchers at the time may have been aware of the issues with using the pre- and post-test IQ score comparison, there was still some difficulty in coming up with an evaluation that all could agree on. The purpose of Bailey and Bricker's (1985) evaluation of an early intervention program was not so much to investigate the effectiveness of the particular program, but instead to demonstrate an alternative means of evaluation. They were most interested in documenting developmental change in the child, and did so by using a pre- post- test design. These researchers used both a norm-referenced test, which would allow them to compare the children's scores to other normative scores, and a criterion-referenced assessment of skills that the child was demonstrating at the time. Both measures assessed multiple areas of development, including gross motor, fine motor, language, cognitive and social-emotional development. These researchers found significant positive improvements in development on both the norm-referenced and criterion-referenced assessments.

Evaluation studies, especially the longer-term follow-up studies, have been criticized for failing to take into account the effects of life experiences that the children had outside of the early intervention (Ramey & Ramey, 1999). Dunst and Snyder (1986) question why we would expect early intervention to have a long-term effect on a measure such as IQ. They argue that improvement between pre-intervention and post-intervention is sufficient to demonstrate program efficacy. Changes between post-intervention and follow-up, according to Dunst and Snyder (1986), reflect the impact of the broader social system on the development of the child after the intervention ceases.

**Investigating the processes of early intervention.** In their review of early intervention research studies from 1975 – 1985, Marfo and Kysela (1985) highlight the lack of an evaluation of process variables. That is, most evaluations only reported whether intervention programs were deemed effective or ineffective, but did not provide information about the reasons why a particular program may have been more or less effective.

More current studies, however, have included process measures in addition to outcome measures (Korfmacher, et al., 2008). That is, researchers have become more interested in what makes an intervention work well, as opposed to how well particular “brand name” programs are working. One focus has been retention of participants. McCurdy and Daro (2001), for example, raised the question of why programs designed to help parents are not always taken advantage of or have high rates of drop out. They state, “If we know why and how individuals make decisions to use voluntary services, we can

begin to form new approaches to service delivery that increase retention rates and the effectiveness of parenting programs (p. 113).”

### **Child Development: More than just the child**

Many of the great child development theorists have acknowledged the importance of the child’s interaction with others and their environment with respect to the process of their development. John Bowlby highlighted the importance of responsive parenting in his attachment theory; Albert Bandura explained that children can learn by observing the actions of others and their consequences in his social learning theory, and Jean Piaget introduced the idea that children are active agents in their learning and must experience the world in order to progress in their development. While these theorists highlighted the fact that children learn and develop within an interactive context, a large proportion of researchers initially studied children in isolation, often ignoring the contribution of the environment and those within it (Bronfenbrenner, 2001). Bronfenbrenner (1974; 1979) called his peers to task on this oversight, and challenged them instead to start attending to all of the factors that influence children’s learning and development.

Bronfenbrenner’s Ecological Systems Theory (1979) emphasizes the idea that children are active agents who influence the world around them and are in turn influenced by the world. He envisaged this interaction as occurring within nested systems. The immediate system (the microsystem) has a direct impact on the child (and the child on it); this system is contained within the broader mesosystem, which has an effect on the microsystem and vice versa. The child’s home and parents would be considered components of the microsystem, whereas other environments such as school or the

community at large would be seen as part of the mesosystem. Components of the microsystem, such as parents, are also a part of the exosystem, which is entirely exclusive of the child. As the exosystem has an effect on components within the microsystem, it can indirectly influence the child. For example, what happens in a parent's workplace (exosystem) may trickle down to impact the child indirectly. Following this line of reasoning, it starts to become apparent how events that may not happen directly to a child can play a role in that child's development.

As a child's family is part of the microsystem, the family is seen as being an important agent in the child's development. Bronfenbrenner saw the potential impact of the microsystem, and that by supporting this environment (and the components within it), then development could also be supported. Bronfenbrenner stresses that how effectively parents can perform parenting duties is a function of how supported they are (2005, p. 54). He also highlights the importance of parents being available when he says, "Children suffer when their parents neglect them, whether because of the distresses of unemployment or from long hours of rewarding work," (2005, p. 210).

Considering Bronfenbrenner's Ecological Systems Theory, the potential of an early intervention program to help support a family in promoting their child's development cannot be emphasized enough. This line of thinking has prompted interventionists to involve parents in their child's programming to a greater extent. This shift in practice, as well as its impact on service delivery will be examined next.

## **Evolving roles of parents in early intervention**

Historically, early intervention programs were child-centered (Landy & Menna, 2006). That is, interventionists considered the child in isolation, separate from the family unit, and worked exclusively with the child, most often in a clinical setting outside of the home. In this view, interventionists were seen as experts who would decide, independent of parents, the goals to be worked on with the child. As already discussed, in 1974 Bronfenbrenner criticized this child-centered view and asserted the importance of looking at the child in a holistic manner, within the natural ecological environment of the family home. According to Bronfenbrenner, successful intervention would involve the entire family unit, not just the child.

**Child-centered vs. family-centered programming.** Family-centered approaches to intervention have been evolving since Bronfenbrenner's influential statements. In the early 1990's, many early intervention programs in the U.S. were legislated to follow a family-centered approach (Bailey, Buysse, Edmondson, & Smith, 1992). At that time, many professionals found the shift from child-centered practice to family-centered practice to be difficult. Specific sticking points were the professional no longer being seen as an "expert," but instead as a co-manager of the program, as well as the varying ability of parents to participate in a family-centered approach (Bailey et al., 1992; Bjorck-Akesson & Granlund, 1995).

Harbin, McWilliam, and Gallagher (2000) describe the family-centered approach as having four main components: "(a) Responding to family priorities, (b) empowering family members, (c) employing a holistic (ecological) approach to the family, and (d)

demonstrating insight and sensitivity to families” (p. 397). We will now examine how these principles differ from the child-centered approach.

***Responding to family priorities.*** In a child-centered approach, professionals work exclusively with the child and emphasize their role as “experts” on children and child development (Bailey et al., 1992). Following this model, the professional would assess a child and choose goals to work on based on their own expertise. Within a family-centered approach, however, parents are key agents in choosing the goals that will be worked on within the family throughout intervention. That is, goals are chosen through agreement between the professional and the parent. When parental priorities and goals differ from those of the professional, the professional is expected to yield to the preferences of the parent (Bailey et al., 1992).

***Empowering Family Members.*** One strategy used in the family-centered approach to empower families is the involvement of the parent as an active participant in their child’s program. Parent involvement may include any of the following: parental partnering with professionals, parenting classes, or parents completing early intervention activities with their children (White, Taylor, & Moss, 1992). Further, as previously stated, in the family-centered model parental priorities are valued and professionals are expected to design programming that not only respects a parent’s priorities, but also works on the goals that parents deem important for their child.

Early intervention programs that are home-based and parent-mediated ask that the parent complete specified activities with the child on a set schedule. That is, parents are expected to be a co-therapist (Winton, Sloop, & Rodriguez, 1999). Not only does this



satisfy the requirement of empowering families, but it is also sensitive to the fact that parents are active in their child's life. Winton et al. (1999) point out that parents can often educate professionals, increasing the dynamic relationship between parent and professional.

***Employing a holistic (ecological) approach to the family.*** Home visiting is one strategy commonly linked with a family-centered approach to early intervention. Home visiting itself is not an intervention but merely describes where the intervention program is conducted (Korfmacher et al., 2008; Landy & Menna, 2006). Gomby, Larson, Lewit, and Behrman (1993) argue that home visiting allows the professional to view the child and parents within their natural environment. Certainly, by visiting the family at home there is a greater chance of meeting more family members, observing more natural interactions among family members and observing factors which might be having an impact on child development. Home visits allow for a more accurate assessment of factors such as housing conditions, quality of toys and play opportunities and availability of food. This increased knowledge can inform intervention efforts, which may include connecting the family with other community agencies and supports where appropriate.

***Demonstrating Insight and Sensitivity to families.*** By visiting families within their home, Gomby et al. (1993) argue that professionals are also better able to understand the family's values and to tailor service delivery to them. Practitioners are able to gain a better understanding of activities that are in agreement with parental values and level of functioning. By traveling to the family home, professionals demonstrate sensitivity to the fact that transportation may be difficult for families, or that a child may

find visiting the clinic setting stressful. Further, visits are typically scheduled by mutual agreement by both parent and professional, making it more likely that the visit will be at an optimal time for the child and family.

**Parent-mediated intervention.** A family-centered approach is not necessarily parent-mediated. In a parent-mediated approach, professionals train the child's parents in strategies and techniques, allowing the parent to work directly with the child on a more frequent basis than a professional would be able to (Eiserman et al., 1995; White et al., 1992). Practitioners may spend less time with each individual child, and thus are able to provide service to more children. Some researchers have implied that the parent-mediated approach is a direct result of budget constraints. Despite this potential criticism, Eiserman et al. (1995) have shown that parent-mediated intervention can be just as effective, and sometimes even more effective, than professional clinic-based intervention.

In the fall of 1987, Eiserman et al. (1995) designed a study to investigate how a clinic-based (low parent involvement) intervention strategy compared with a home-based parent-mediated approach (high parent involvement). In order to address the relative cost-effectiveness of the two strategies, they ensured that interventionists in both conditions were spending the same amount of time in client-related activities, meaning that in the clinic-based approach, interventionists saw children in dyads, rather than individually. The children involved in this study had moderate speech delays, and the interventionists of interest were Speech Language Pathologists. In the parent-mediated approach, parents were taught how to perform the intervention techniques, while in the clinic-based intervention parents did not receive any direct instruction. At one and two years post

initiation, Eiserman et al. found significant differences favouring the parent-mediated approach. At the final follow-up (42 months post initiation), there were no longer any significant differences between the two groups of children on any of the developmental measures. So, the parent-mediated approach may be both cost-effective and beneficial to the children receiving the intervention. Further, as this intervention approach requires less professional time for each child, it should result in more children having access to intervention.

### **Parent variables and their effect on early intervention**

While there is support for the effectiveness of parent involvement in early intervention, one cannot lose sight of the fact that parents vary in their willingness and ability to complete prescribed activities with their children in the absence of the professional. Miedel and Reynolds (1999) caution that professionals cannot assume that all parents will want to be, or are able to be, involved in their child's intervention. In fact, the majority of high-risk families, who arguably need intervention most, actually drop out of intervention within the first year (Landy & Menna, 2006).

Concern about the attrition rates of early intervention programs, or with low initial enrolment is nothing new (McCurdy & Daro, 2001). There has been some research into this issue, but the results are contradictory and only look at static characteristics of participants, such as age or marital status (McCurdy & Daro, 2001). McCurdy and Daro (2001) argue that process variables, such as intent at enrolment, may be better predictors of program adherence. They point out that a parent's readiness to change may be one predictor for program adherence. These researchers highlight the fact that there has been

little to no research that has followed parents from the start of intervention until termination in order to assess the mechanisms that may influence their behaviour.

LaForett and Mendez (2010) hypothesized that parental psychological disorder, in their study represented by parental depression, would be a barrier to parent participation in a Head Start early childhood education program. Parents were followed over one year of the intervention and completed a shortened version of the Center for Epidemiologic Studies – Depression scale at two time points during the study, the spring and the fall. For each respondent, the scores from assessments at both time points were summed to give a composite score and the parents were placed into three categories: never depressed, sometimes depressed, and chronically depressed. These researchers found that parents who were sometimes depressed showed significantly lower involvement scores than did those who were never depressed. Interestingly, parents who reported chronic depression did not differ significantly from parents who had never been depressed or those who were sometimes depressed in their levels of involvement. This suggests that the relationship between depressive symptoms and parent involvement is a complex one, and it cannot be assumed that depressed parents will be less involved with their child's intervention. Further, it highlights the fact that one cannot simply assume that a particular variable will have a linear effect on adherence with a service.

Just as Bronfenbrenner asserted that a child does not exist in isolation, one must remember that a parent exists within a family and community dynamic as well. It may be necessary to recognize that not all parents will be ready or willing to take part in a parent-mediated approach to early intervention. Mahoney et al. (1999) argue that parent-

mediated services should be considered only one option as some families may not be ready to take on this level of responsibility. A parent's degree of participation in treatment is affected both by internal motivation and external barriers. In order to have a holistic picture of the parent's ability to participate, it might be helpful to assess both of these factors.

**Internal parent variables.** One measure that has been used in other contexts to assess internal motivation for participation is the Stages of Change Questionnaire (McConaughy et al., 1983). This questionnaire finds its basis in the Transtheoretical Model (TTM). The TTM is a model that places individuals into stages of change based upon their current feelings and behaviour with regards to the behaviour to be changed (Prochaska & DiClemente, 1982). There are four main stages described within the Prochaska & DiClemente's original Transtheoretical Model. In the first stage, labelled "pre-contemplation", individuals do not perceive their behaviour to be a problem and are therefore not considering changing the behaviour. In the second stage, known as "contemplation", individuals acknowledge their behaviour is a problem and are considering changing their behaviour but have not yet attempted to make any changes. In the third stage, called the "action" stage, individuals are making active attempts at changing their behaviour. Finally, in the fourth stage, referred to as "maintenance", individuals have successfully changed their behaviour, but continue to work on maintaining this change. It should be noted that a more recent version of this model includes a fifth stage, labelled "preparation" which is positioned between contemplation and action stages (DiClemente et al., 1991).

One of the practical applications of the TTM is that individuals are thought to have different expectations of treatment depending on which stage of change they are currently experiencing. If practitioners are working within a different stage of change than the client, the mismatch of expectations and intervention strategies may contribute to premature termination of treatment (Prochaska & DiClemente, 1982).

Different areas of health research have employed the TTM. In 1991, DiClemente, et al. explored whether a five-step model of the TTM could predict smoking cessation behaviour. They categorized smokers as being in the pre-contemplation, contemplation or preparation stages based on their answers to a stages of change questionnaire. When the researchers followed up with the smokers one and six months later, those who were viewed to be in the preparation stage reported significantly more quit attempts than their counterparts in the pre-contemplation and contemplation stages. Further, a greater proportion of those in the preparation stage reported “not currently smoking” at follow-up as compared with their counterparts.

Medvene, Base, Patrick, and Wescott (2007) used a modified stages of change questionnaire to predict how responders would feel about advance directives in medical care. They found that those responders who were in the pre-contemplation and contemplation stages agreed with more negative statements about advance directives than positive statements. On the other hand, those responders who were seen as being in the action or maintenance stages agreed with more positive statements about advance directives than negative statements. These authors argue that knowing which stage a

responder is in could help with educating them about the benefits of advance health care directives.

With regards to a parent-mediated intervention, a practitioner may assume when they contact a family to start intervention that the parent is in the action stage. The practitioner may immediately begin to give the parent activities to complete with their child. However, if the parent is still in the pre-contemplation or contemplation stage of change, they may not yet be ready to engage in the “action” necessary to change their behaviour - that is, they may not be ready to complete the activities with their child. If practitioners instead determined the stage of change that parents were in prior to the commencement of intervention, they could work within that stage to help the parent (and child) progress through treatment more successfully. Presently, there is no research in this area to either support or refute the use of stages of change within the early intervention realm.

**External parent variables.** Life events can impact a parent’s ability to participate in their child’s intervention. Parents who see the value in a home-based program for their child may not be able to make time for these visits, for a variety of reasons (Pretis, 2011). Additionally, parents may have their own needs that interfere with their child’s treatment, such as depression (LaForett & Mendez, 2010). Kazdin et al. (1997) termed these factors “barriers to treatment.” These researchers propose four types of barriers: (1) stressors and obstacles that compete directly with completion of treatment; (2) treatment demands and issues; (3) perceived relevance of treatment; and (4) the relationship with the therapist. Kazdin et al. (1997) validated their measure, the Barriers to Treatment Participation Scale

(BTPS), using parents of children who were referred for outpatient treatment at a child psychiatry service. It was found that families who scored higher on the BTPS (i.e., perceived more barriers to treatment) attended treatment for significantly fewer weeks and had higher rates of both cancelled and missed appointments than those who reported lower levels of barriers. Kazdin and colleagues identify the BTPS as a way to screen families in situations where continued involvement in treatment is a priority.

Kazdin's BTPS has been primarily used for studies based in mental health clinics, and its application within community settings has been limited. Girio-Herrera, Owens, and Langberg (2013) used a modified version of the BTPS to assess help-seeking behaviour in parents of at-risk kindergarteners. The authors converted the scale to the future tense, asking the parents to imagine that they wanted to get mental health or counselling services for their children when they completed the scale. That is, this study assessed parents' perceived barriers to obtaining treatment rather than barriers experienced while receiving treatment. The authors reported that a majority of parents (61%) endorsed at least one barrier that would preclude their ability to obtain treatment for their child.

It stands to reason that parents involved with a home-based early intervention program would also encounter barriers that might impact on their ability to take part in the program. Presently, there is no research to indicate the level of barriers that parents experience with a home-based intervention program. One of the objectives of the current study was to explore whether the BTPS would be able to identify both the extent to which



parents are experiencing barriers to treatment and the barriers that are most commonly experienced by these parents.

### **Evaluating the quality of early intervention**

Researchers have found it difficult to determine and measure quality indicators of intervention (Aytch, Cryer, Bailey, & Selz, 1999; Bailey, Aytch, Odom, Symons, & Wolery, 1999; Roggman, Boyce, Cook, & Jump, 2001). Aytch et al. (1999) identified four major components of early intervention which would make it difficult to assess quality: “early intervention programs (1) represent a broad range of services, (2) are highly individualized, (3) seek to address multiple child and family goals, and, (4) many desired features of quality are highly subjective. (p. 12)” Each of these components will now be discussed in turn.

As has already been mentioned, early intervention does not describe a particular type of intervention, but instead may be taken to mean any intervention that is completed with a child, and/or his or her family, early in life. For instance, services may focus on developmental or medical needs; be based in the home, community or hospital; and may focus on either the child, family, parent, or all of the above (McCollum, 2002). Services have different goals and have different service delivery models. As such, assessing the quality across these different types of interventions would require tools that are sensitive to a variety of desirable features.

Early intervention services strive to be individualized to the family and the child. Indeed, by being family-based, early intervention strives to meet the family and child where they are rather than expecting them to conform to professional expectations.

Programming may, for example, be designed around activities or characters that a child prefers and the same intervention program may therefore look quite different in various family contexts. Individualization of programs and program practices make it hard to ensure that programs are delivered in the same way each time (Zigler & Trickett, 1978).

While initially early intervention may have had a primary goal of increasing a child's academic performance, current practice includes a variety of goals for both the child and the family at large (Bailey et al., 1992). Again, as intervention is family-based, goals identified as being important may vary from family to family. Bailey et al. (1992, p. 16) highlight that "early intervention programs should be dynamic in their response to immediate and ongoing family priorities and needs." This flexibility around goals adds to the complexity of assessing the quality of an intervention program.

Finally, many features considered desirable for quality intervention may be subjective in nature, such as having a good relationship between parent and professional; having visits proceed well; and having both children and parents engaged in the visit. It is recognized that a good parent-professional relationship is key to effective intervention, but assessing the quality of this relationship is complex (Korfamacher et al., 2007). A "good" relationship may look different depending on a family's values, the cultural context and the nature of the professional involved. Assessments of relationship quality are necessarily subjective and subject to bias. Parents tend to perceive and report their helping relationships with professionals in an overly positive way (Korfmacher et al., 2007).

In the context of the above difficulties, Aytch et al. (1999) used research on child care for typically developing children as a model, identifying both structural and process-based indicators of quality for early intervention with developmentally delayed and handicapped children. Structural indicators were variables such as the education of professionals involved, access to particular services, or program evaluation. Process-based indicators were variables such as the design of visits, the specific materials used and the relationship between the parent and the professional. Aytch et al. (1999) describe the development of two versions of a measure incorporating these indicators, one to be completed by the program and one to be completed by the parent. However, to date this measure has not been the basis of any published research and the current researcher was unsuccessful in receiving information from the lead investigator concerning the status of the tool.

Goetz, Gavin, and Lane (2000) reported satisfactory reliability and validity for a measure looking at the quality of relationship between the professional and the parent, and at the degree to which the intervention was family-centered, the Family Provider Interaction Analysis (FPIA). The FPIA was based on an earlier tool, the Verbal Interaction Analysis System (VIAS), developed by Johnson and Brady (as cited in Goetz et al., 2000) in which researchers rate videotaped verbal interactions between parent and professional as opposed to having parent and professional complete questionnaires. Johnson and Brady used different coding categories for family members and for service providers, whereas the FPIA was developed so that the same coding categories could be

used for both (Goetz et al., 2000). However, once again, no published research exists using the FPIA.

Finally, Roggman et al. (2001) used a collaborative approach to design an assessment of quality for an early intervention program. These researchers worked closely with program staff to determine which factors were indicators of quality for the program and then developed measures to assess quality from multiple perspectives. These measures included parent and professional ratings of quality and researcher ratings of a videotape of the parent-professional dyad. The rating scales looked at both the perceived quality of the home visit as well as the perceived quality of the parent-professional relationship. By working closely with program staff to develop measures that would be useful to the program at large, these researchers had a high participation rate among service providers, and subsequently parents. They found that parents who perceived their home visits to be positive also reported having a positive relationship with their home visitor. Also, parents who were seen as being more engaged during their home visits were seen as having higher quality home visits and better relationships with their home visitor. Interestingly, parents reported higher perceptions of quality of home visit than did the professionals or the researchers. The work of Roggman et al. (2001) stands out in the sparse research on the quality of home visits. Even since their pioneering study, little research has been done on this aspect of early intervention.

### **Early intervention up close: The Direct Home Services Program**

The Direct Home Services Program (DHSP) is an early intervention program offered by the Government of Newfoundland and Labrador via regional health

authorities. This program has been available to the children of Newfoundland and Labrador since 1975. Intervention workers, known as Child Management Specialists (CMSs), visit children and families in their homes to deliver programming. At its inception, the program was modeled after the Portage model (Shearer & Shearer, 1972). Chippett (1999) states that the early years of the program saw intervention driven mainly by the Child Management Specialists: these interventionists would assess the child in the home, select skills to work on from these assessments, and then instruct the family to carry out interventions as appropriate. However, a shift to a more family-centered practice was seen in 1996, in line with the developments of early intervention research previously discussed. Overall, Chippett reported the DHSP to be in line with the guidelines for early intervention at the time of review (1999).

The Direct Home Services Program is available to children from birth to school entry who are exhibiting a developmental delay or are considered at risk for developing a delay. That is, children who are growing up in impoverished environments, or have other medical conditions (such as hearing loss) which may place them at risk for developing a delay, would also be considered eligible for the program. Some children come to the program with diagnoses such as Cerebral Palsy or Down Syndrome, while other children may be exhibiting a delay in the absence of a diagnosis.

Referrals to this program may come from a variety of sources, including but not limited to a family doctor, public health nurse, social worker, or specialist at the hospital. Parents are also able to initiate a referral on their child's behalf for this program. Once a referral is received, a Child Management Specialist meets with the family in their home

to complete the screening process. The screening process includes completing a developmental screening tool and informing the family about the program in detail. To be eligible for service, the child must exhibit a significant delay in one or more of the five developmental areas tested: academic, social-emotional, physical, self-help and communication. Eligibility criteria vary based on child chronological age. As already stated, some children may also be considered “at risk” of developing a delay and be considered eligible on this basis. See the following table for a summary:

<b>Chronological Age</b>	<b>Eligibility Criteria</b>
Infant (0 -11 months)	A delay of 4 months in one area of development, or A delay of 2 months in two areas of development
Toddler (12 – 23 months)	A delay of 6 months in one area of development, or A delay of 3 months in two areas of development
Toddler (2 - 2.5 years)	A delay of 9 months in one area of development, or A delay of 4 months in two areas of development
Preschooler (2.5 – 6 years)	A delay of 12 months in one area of development, or A delay of 6 months in two areas of development

It is important to note that parents of children with a diagnosis of Autism (or Autism Spectrum Disorder) may choose to take part in a more intensive home therapy program. Thus, once a child is diagnosed with Autism, they typically move from the Direct Home Services Program to the Intensive Applied Behavioural Analysis program, also offered by the Government of Newfoundland and Labrador. The ABA program has been available to the children of Newfoundland and Labrador since 2001 and is available to children from the time of diagnosis until grade four entry.

The Direct Home Services Program has been the focus for early intervention research previously. Marfo et al. (1992) sought to examine how both program and non-program variables influenced early intervention outcomes. Two hundred families involved with the Direct Home Services Program completed and returned questionnaires on demographics and the Parent Evaluation Questionnaire, which included measures of satisfaction with the program, parent knowledge gain and worker competence. In addition to this, parents also completed the Child Expectations Scale, Family Resources Scale and Home Screening Questionnaire. Children's scores on the program's developmental assessment tool, the Alpern-Boll Developmental Profile, were also accessed to determine the developmental gain shown while the child was involved with the program.

The variables from these questionnaires were broken into three different classes: child variables (e.g., child chronological age, entry developmental age and post-intervention developmental age), program variables (e.g., time spent in intervention, worker competence), and family ecology variables (e.g., family resources, quality of child's home). Most research on early intervention up to this point had only addressed whether program variables could explain differences in program outcomes, but these researchers were interested in the contribution that family ecology variables (that is, non-program variables) could have on outcomes for children. They found that none of the purely demographic variables under family ecology, such as family income, correlated significantly with any of the child or program variables. However, children who were developmentally higher functioning (i.e., showed fewer and smaller developmental lags) tended to have parents who were more satisfied with the intervention; these children also

had parents who tended to have higher expectations for their children. Further, it was reported that a combination of variables (entry-level developmental age, quality of the home environment and parental satisfaction) explained 67.9% of the variance in post-developmental age. Entry level child variables and family ecology variables explained more of the variance of early intervention outcomes than did program specific variables. This highlights the need for future research to not only look at program variables when evaluating early intervention, but also to take into consideration child characteristics and family ecological variables.

In a 1993 thesis, McLennon extended Marfo's research by investigating how family ecology could impact on the efficacy of the program. One hundred thirty-two families involved in the Direct Home Services Program completed questionnaires asking about family demographics and parent satisfaction with the program. Similar to the previous research, McLennon also used program assessments to assess the children's developmental gains over time. She found that children from "better" home circumstances (e.g., higher parental education, and higher income) showed more developmental gains over time. She also found that higher parental expectations for how the program would help their child were associated with greater developmental gains by the children. Finally, children who had access to a higher variety of play opportunities (e.g., more toys, more play experiences) were found to show greater gains. Based on these results, McLennon argued that early intervention should not only focus on the daily intervention with the child, but also on helping to support the parent with education and financial support, where needed.



The Direct Home Services Program will be the program of focus and provide participants for the current research. It should be noted that while the Direct Home Services Program is a province-wide intervention program, it is delivered by the various health authorities and as such is broken down into regions. At the time of writing, the Direct Home Services Program employs 71 CMS's province-wide. The present study accessed individuals involved with the Direct Home Services Program under the Eastern Urban region of Eastern Health. This encompassed individuals living in St. John's, NL and the surrounding areas. This region employs 30 CMS's and provides service to approximately one hundred children per month.

### **The present study**

The focus of this research was to evaluate whether measures completed prior to starting an early intervention program could predict parental adherence with the early intervention program. As there has been little exploration in the area of parental factors and early intervention, this research had the goal of answering the questions:

1. Can practitioners use modified versions of the Stages of Change Questionnaire and the Barriers to Treatment Participation Scale to predict the degree of adherence parents will demonstrate with a parent-mediated early intervention program?
2. Do parents in the 'action' stage adhere more with intervention than those in the 'pre-contemplation' and 'contemplation' stages?

3. Do scores on the Stages of Change Questionnaire and Barriers to Treatment Participation Scale correlate with quality of home visits, as indicated by a composite of parent and staff reported quality?

Power analysis for a moderate effect size of 0.20 ( $\alpha = 0.05$ ) required a sample size of 51 participants. Such a sample size was deemed obtainable from the Direct Home Services in discussion with the program manager. Table 1 shows program statistics for the DHSP across fiscal years 2009-2012. While numbers were unavailable for how many children started active intervention each month, it can be seen that yearly referrals to the DHSP ranged from 84 – 105, with average active cases ranging from 50 – 100 per month. While these numbers seem adequate to satisfy the power requirements, low recruitment and attrition rates can be high in health research (McDonald et al., 2006). It was not common practice to explicitly report difficulties with recruitment in research in the 1980's and 1990's. McConaughy, et al. (1983) did not report such difficulties, but did use four separate recruitment sites in order to obtain their final number of 155 subjects. Roggman, et al. (2001) had a potential sample of 103 participants from a multi-site evaluation of a publicly funded intervention program, but were only able to obtain full data, including observations and video recordings, for 49 participants. As such, there was uncertainty around realistically recruiting sufficient participants from this population. In the design of this study, it also became necessary for the researcher to modify existing measures in order to meet the needs of the study population. The National Institute for Health Research (NIHR) states that a feasibility study can be used to “estimate important parameters that are needed to design the main study” (NIHR Evaluation, Trials, and

Studies, 2012, “Feasibility studies”). As a result, it was decided that the present research would be a feasibility study to inform whether these measures and this population could support a larger scale research study.

Table 1

*Direct Home Services Program statistics for fiscal years 2009 – 2012*

	2009 – 2010	2010 – 2011	2011 – 2012
Total number DHSP staff	15	20	25
Total DHSP referrals	84	89	105
Average Active DHSP cases (per month)	50	50	100
Total ABA referrals	46	43	77

*Note.* ABA referrals refers to the number of children diagnosed and referred to the Autism Early Intervention program – a program served by the same DHSP staff who provide service to the DHSP children who are referred without a diagnosis of autism. Source of information was a personal communication with the Program Manager for Direct Home Services Program in St. John’s, NL on April 10, 2014.

DHSP Staff (Child Management Specialists) were asked to recruit parents to complete questionnaires prior to and throughout the first six months of intervention, while interventionists completed alternate questionnaires throughout the same six months. The relationships between these questionnaires as well as the actual adherence to the home visit schedule were explored. Further, issues around recruitment and the meaningfulness of the measures were highlighted.

## **Method**

### **Design**

A non-experimental repeated measures correlational design was used. That is, participants were not divided into a control group and experimental group, but were

instead all parents receiving intervention. Further, the same measures were administered over time, and any changes were noted.

### **Ethical Approval**

Ethical approval was provided by the Human Investigation Committee on April 2, 2009. (Appendix A). Extensions of this approval were granted on April 2, 2010 and April 2, 2011.

### **Sample**

Participants were recruited from the Direct Home Services Program in St. John's, NL. All families who started active intervention between the period of April 23, 2009 and August 31, 2011 were potential participants. Based on the design of this study, only those starting intervention during this time were approached; families who were already in receipt of services were not considered for participation. While there was no target number of participants for the feasibility study, the researcher was interested in obtaining as many participants as was possible in the given time to assess the potential of a larger scale study.

### **DHSP Staff.**

All DHSP staff (twenty-five) were informed about this study and provided the opportunity to participate. Five staff members volunteered their time for this project and one of these potential participants was not carrying the appropriate caseload at the time. In the end, four Child Management Specialists took part in this study.

## **Measures**

### **Demographic questionnaire.**

A demographic questionnaire was developed for this study (Appendix B). This questionnaire gathered participant-specific information, including age, marital status, occupation, number and ages of children, amount of familial support, amount of external support, and education level.

### **Stages of Change Questionnaire – Modified (Readiness for Change).**

The current study used a modified version of the Stages of Change questionnaire originally developed by McConaughy et al. (1983). A full version of the questionnaire can be found in McConaughy, DiClemente, Prochaska and Velicer (1989). This questionnaire is based on the four-stage transtheoretical model (Prochaska & DiClemente, 1982). As already noted, newer versions of the transtheoretical model include five stages (DiClemente et al., 1991). However, as the Stages of Change questionnaire had been adapted to other areas of health research, it was decided that the four-stage model of TTM would suffice for this study. McConaughy et al. (1983) developed a 32-item questionnaire, which asks individuals to rate their agreement with each statement on a 5-point Likert scale (1=strongly agree; 5=strongly disagree). There are four subscales for this measure, each reflecting a stage of change (pre-contemplation, contemplation, action and maintenance.) Each subscale contains 8 items. Examples of items under each subscale include: “As far as I’m concerned, I don’t have any problems that need changing” (pre-contemplation), “I have a problem and I really think I should work on it” (contemplation), “I am really working hard to change” (action), and “I have

been successful in working on my problem but I'm not sure I can keep up the effort on my own" (maintenance). Items are summed for each subscale; the subscale with the highest score, reflecting the highest level of agreement with the items, indicates the stage of change in which the respondent is considered to be. McConaughy et al. (1983) found that 58% of the variance of the stages of change questionnaire was explained by the four stages, or subscales. Coefficient alphas for each scale were as follows: Pre-contemplation, .88; Contemplation, .88; Action, .89; Maintenance, .88.

The questionnaire developed by McConaughy et al. was primarily utilized for subjects availing of mental health and addictions supports. Other researchers have adapted this questionnaire to their own areas of research, such as adolescent delinquency (McLeod, 2007). In keeping with this practice, the questionnaire used in the current study is based on McConaughy et al.'s questionnaire, with the wording changed to reflect the current population (Appendix C). For example, "As far as I'm concerned, I don't have any problems that need changing" becomes "As far as I'm concerned, my child does not have any difficulties." All statements were modified to reflect the parent's stage of change in relation to their child's development. Prior to data collection, a parent involved with the Direct Home Services Program read over this questionnaire to ensure clarity.

#### **Barriers to treatment participation scale (BTPS) – Modified.**

The BTPS is a two-part instrument, used to highlight barriers that parents may encounter when participating in their child's outpatient treatment (Kazdin et al., 1997). This measure was used to explore the impact that external factors have on a parent's ability and motivation to participate in an early intervention program. Part One of the

instrument contains 44-items that assess barriers as perceived by parents, rated on a 5-point Likert scale (1= “never a problem”, 5= “very often a problem”). Four subscales sort barriers into the following categories: stressors and obstacles that compete with treatment (e.g., scheduling of appointment times), treatment demands and issues (e.g., treatment not being what was expected), perceived relevance of treatment (e.g., treatment not seeming to be working), and relationship with the therapist (e.g., not liking the therapist). All 44-items can be summed to yield a total barrier score. Part Two of the instrument is a critical events scale that contains 14 items. Parents indicate whether each event happened within the specified time by answering yes or no. Examples of critical events include: moving to another house or apartment, loss of job and death within the family.

This scale, developed and evaluated by Kazdin et al. (1997), was based on a group participating in clinic-based behavioural intervention for children. The internal consistency of the first part of the scale was found to be .86 for both coefficient alpha and the Spearman-Brown coefficient, suggesting high levels of internal consistency for the total barriers score of the scale. A factor analysis revealed that the majority of variance (66%) was explained by the first factor, comprised of items 15 (“I lost interest in coming to sessions”) and 11 (“Treatment was not what I expected.”) In light of this, the authors felt it was more useful to report the total barriers score as opposed to separate subscales. The critical life events scale, or second part of the BTPS, was not significantly related to the perceived barriers score ( $r = .11$ , not significant).

Currently, there is no instrument that exists to measure barriers to treatment in an early intervention population. As a result, this study modified Kazdin et al.’s BTPS to

better reflect the barriers associated with a home-based early intervention program (Appendix D). A focus group was conducted with DHSP staff (Child Management Specialists) to evaluate items that would and would not relate to this population. In this way, the instrument was modified to reflect the needs of the population. Fifteen statements were left unchanged, such as “Treatment lasted too long (too many weeks).” For twenty-two statements, changing wording to reflect home visits was all that was necessary. For example, “My child refused to come to the sessions” was changed to “My child refused to take part in sessions.” Seven statements which had no equivalent in a home visiting context were deleted, such as “Finding a place to park at the clinic.” Further, some issues specific to home visiting were added, such as “My home was not clean on a day that a home visit was scheduled.” The critical life events scale was not modified in any way.

Prior to data collection, a parent involved in the Direct Home Services Program read through this questionnaire to ensure clarity. Again, as with the Stages of Change – Modified questionnaire, these changes can be viewed as a limitation in terms of psychometric information concerning the questionnaire, but were necessary in order to reflect the nature of the current service.

### **Adherence.**

It was necessary to have some measure of adherence with home visits. Staff completed a weekly log (Appendix E) as a way to monitor how many visits were scheduled and how many actually occurred with each family. The ratio of number of visits completed to number of visits expected was taken as the family’s adherence score.



Any visits cancelled for reasons outside of a family's control (e.g., staff on leave), were removed from the ratio.

Staff also indicated on their log whether families continued to be interested in service or whether they had stopped receiving service. If service terminated, staff were asked to indicate whether this was due to family withdrawal, family move, or family being consistently unavailable for home visits.

### **Quality of home visits.**

Two measures of home visit quality were used: a measure completed by staff and a measure completed by the parent.

Staff completed a modified version of the Quality of Home Visit Survey for each family after three months and six months of active intervention (Appendix F). This survey was developed by Roggman et al. (2001) and has also been used in research by Necoechea (2007). The full survey asks staff to rate the quality of home visit instruction, the quality of the relationship between staff and parent, current family functioning and family improvement since enrolment. Given that this study was only interested in the quality of home visits, it was decided to omit ratings for current family functioning and family improvement. For the quality of the home visit relationship, the ratings range from 1 (tense, difficult, a sense of uneasiness) to 5 (outstanding, effective relationship), with all points in between having a description. The scale for the quality of home visits ranges from 1 (distractions, crisis oriented) to 5 (outstanding, what every home visit should be), with all points in between having a description. Psychometric qualities were not reported by Roggman et al. (2001).

Parents also completed the Quality of Home Visit Questionnaire, developed by Roggman and colleagues (2001; Appendix G). Like staff, parents completed this questionnaire after three months and six months of active intervention. The parent version of the questionnaire has two parts. The first part of the questionnaire assesses the relationship between the parent and the home visitor. Fifteen items are rated on a 5-point Likert scale (1= “strongly disagree”, 2= “somewhat disagree”, 3= “neither disagree/agree”, 4= “somewhat agree”, and 5= “strongly agree”). Some sample items include, “My home visitor is supportive of me”, and “My home visitor has a generally positive relationship with me.” The second part of the questionnaire evaluates the quality of home visits from the parent’s perspective. Fourteen items are rated on a 5-point Likert scale (1= “strongly disagree”, 5= “strongly agree”). Some sample items include, “My home visits are a positive experience,” and “My home visits involve both me and my home visitor working together.”

Further, staff recorded and reported the length of the home visit on their weekly logs (Appendix D) so that the relationship between length of home visit and home visit quality could be explored.

## **Procedure**

### **Contact with DHSP staff.**

Staff with the Direct Home Services Program were treated as participants and were recruited on a voluntary basis. To recruit practitioners, the researcher gave two brief information sessions about this project to Direct Home Services staff during regularly scheduled staff meetings. These information sessions invited practitioners to participate

in the study and explained what would be expected of them. Staff were informed that the main purpose of the study was to investigate whether certain pre-intervention measures can predict parental adherence with the intervention program. No hypotheses were shared with staff. The researcher stressed that the data from this study would not be shared with the employer, and would not be used as an evaluation of the home visitor. Those interested in participating were asked to schedule a time with the researcher to review the project procedure and measures that the staff were expected to complete. At this time, staff were provided with an information letter outlining their expected involvement and consent forms were signed (Appendix H).

Staff were not required by the employer to participate, but could choose to do so on a voluntary nature. Further, staff did not receive any compensation for taking part in the project. Neither the direct managers of staff, nor their employer, were made aware which staff members participated in the research. Staff were not required to write their names on any measures, but used a code assigned to them by the researcher. Only the researcher had access to this code.

The researcher maintained contact with DHSP staff who chose to participate for the duration of the study. Information shared consisted of

- 1) contact information for interested families
- 2) weekly logs for those families who chose to participate
- 3) completion of the Quality of Home Visit measures after three months and six months of intervention.

**Contact with families.**

DHSP staff members who chose to participate in the research informed families of this research project during their first contact with the family. The researcher provided staff members with a script to read to family members to ensure that all potential participants received the same information (Appendix I). Families who expressed interest gave verbal consent for the staff to provide the researcher with their contact information.

The researcher then contacted the family by telephone, briefly described the research project and answered any questions the family had. At most, the researcher made three phone calls to a family. If after making three phone calls and/or leaving three telephone messages, the family did not return contact with the researcher, the family was deemed not interested in this study. Families who continued to be interested in participating were given the option to either come to the Psychology Department Clinic or be visited in their home. All families chose to be visited in their home by the researcher. During the initial meeting, the researcher reviewed consent forms in person and received written consent prior to administering the measures (Appendix J).

During the initial meeting, the researcher administered the Stages of Change - Modified Questionnaire to the parent (or caregiver) of the child involved with the early intervention program. If there were two parents present in the home, measures were completed by the parent who would typically be taking part in Direct Home Services visits. Demographic information was also collected during the initial meeting. The researcher gave parents the questionnaires to complete on their own, but remained available to answer any questions.

Following the initial meeting, DHSP staff continued active intervention with the family as per usual protocols. The researcher followed up with families and administered measures to parents after three months and six months of active intervention. Measures administered at the follow-ups included the modified Readiness for Change Questionnaire, the modified Barriers to Treatment Participation Scale, and the parent ratings of quality of home visits. The presentation of these measures was counterbalanced across individuals as much as possible, by placing them in an envelope in a counterbalanced order. Following the final collection, families were debriefed and thanked for their time.

	<b>Questionnaires</b>		
	<b>Pre-Intervention</b>	<b>At 3 months</b>	<b>At 6 months</b>
<b>Parents</b>	Demographic Questionnaire	Barriers to Participation Scale – Modified	Barriers to Participation Scale - Modified
	Stages of Change - Modified	Stages of Change - Modified	Stages of Change - Modified
		Quality of Home Visit measure	Quality of Home Visit measure
<b>Program Staff</b>	Weekly home visit log (ongoing)	Quality of Home Visit measure	Quality of Home Visit measure

#### **Follow up with staff who participated.**

Once data collection had concluded, staff members who had taken part in the study were invited to complete follow-up interviews. Due to availability, only two of the four CMSs who took part were able to be interviewed. The purpose of the interview was to assess the staff participants' experience throughout the study process, as well as to identify potential reasons why others, staff members and families might not have chosen

to participate. Interviews were completed by the researcher with each staff member separately and in-person.

## **Results**

### **Sample**

It is estimated that half of the twenty-five Child Management Specialists (CMSs) carried DHSP cases over the course of the three years of investigation, so approximately twelve staff were eligible to take part in this study. Five CMSs volunteered to take part but one of these staff members was not starting new DHSP clients at the time of data collection. Therefore, four CMSs both agreed to participate and had the appropriate caseload.

In total, twenty-three potential parent participants were informed of the study. Of this number, thirteen parents declined to participate upon initial contact by the CMS. Ten parents were contacted by the researcher. Four parents did not return contact with the researcher. One parent initially indicated that they were interested in the study and completed consents but did not return questionnaires or engage in any further contact with the researcher. Five parents ultimately completed this study (See Figure 1).

### **Follow-up with Staff who participated**

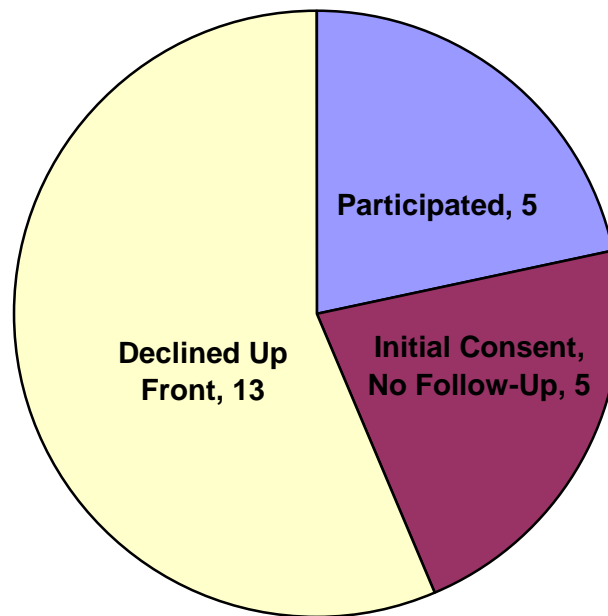
During follow-up, only two CMSs were available to meet with the researcher. Both CMSs indicated that using the script to dialog about the study with potential participants worked well. One staff participant indicated that the families seemed eager to participate, while the other found families seemed sometimes to agree to participate even though they might not be processing what was being said to them. Both staff participants

Table 2

*Demographics of Parent Participants*

Participant	Age	Marital Status	Education Level	Work Status	Total Children	Age of Involved Child	Total Services
1	21-30	Common Law Marriage	College or University Degree	Part-time	2	4	6
2	31-40	Single, Never Married	High School Diploma	Full-time	2	2	6
3	31-40	Married	Some College or University	Full-time	3	3	10
4	41-50	Married	College or University Degree	Currently On leave	3	3	4
5	31-40	Single, Never Married	High School Diploma	Unemployed	3	3	6

*Note.* All respondents were mothers of children involved with the Direct Home Services Program.



*Figure 1.* Breakdown of recruitment of parent participants.

felt that the time required to complete the weekly log forms and follow-up questionnaires were minimal. As one staff participant said, “The form was in the file, I’d just tick, tick, tick.” The other staff participant indicated that she would complete the form in between home visits, which worked well for her.

With regards to reasons why families might have chosen not to participate, three themes emerged from the interviews. Firstly, parents might have a number of other things



going on in their lives and involvement in the study would have been “somebody else coming into the house.” Secondly, some families may find it difficult to engage in any service or activity. One staff participant described this struggle with respect to “any participation in anything, not just in yours, but in anything that requires them to do [something]...” Finally, many families that have complex issues are difficult to get in touch with. Service providers find it difficult to contact these families, and indeed the researcher also found making contact difficult. As described by one staff participant, “Because you would get them interested but then there would be cancelled visits, and they wouldn’t return calls to you, there was some of that that went on as well. I would assume that that impacted.”

When asked why other staff members might have chosen not to take part, some interesting themes were also brought to the surface. First, the voluntary nature of the study, such that staff may have felt that if they did not need to participate then they would choose not to. One CMS felt that other staff members may not have understood the potential that this research had to inform the provision of service. As one CMS said, “Some people could care less?” indicating that for some staff members it might have just been another demand in a busy schedule. Further, it was identified that some staff members might have felt that the research was a critique of their work. Finally, one CMS said, “sometimes I think staff are reluctant to ask parents to do anything outside of the program.”

While it cannot be confirmed that these reasons are the underlying cause for individuals choosing not to take part in this study, these themes certainly inform us of

possible explanations why individuals may opt not to participate in a study such as this one.

## **Demographics**

Demographic information of parent participants can be seen in Table 2. All participants were mothers of children involved with the Direct Home Services Program, with a range in age categories from 21 – 50 years. Three mothers were married or in a common-law relationship, while two mothers identified as being single. All mothers reported attaining at least a high school diploma, with three of them having completed some college or university. Two of the parent participants were currently not working, with one mother reporting being unemployed while the other was currently on leave from work. Three parents reported working in some capacity – whether part-time or full-time. There is currently no information available on the general demographics of all participants in the Direct Home Services Program (J. Young-Guerra, personal communication, April 1, 2016). As such, it is unclear if this parent sample is representative of the Direct Home Services Program at large.

For each parent participant, information was also gathered on the children living in the home. The total number of children living in the home environment varied from 2 to 3 children. The age of the child involved with the Direct Home Services Program ranged from 2 - 4 years old, with the majority (3) being 3 years old. For each child involved with the DHSP, parents reported the number and type of additional services they were accessing for their child. The number of additional services ranged from 4 to 10, and the specific services can be seen in Table 3.

Table 3

*Additional Services Aailed of by Children involved in the Direct Home Services Program*

	<u>Participant</u>				
	1	2	3	4	5
Daycare	X		X		X
Public Health Nurse	X	X		X	
Family Doctor	X	X	X	X	X
Paediatrician		X	X		
Speech Language Pathologist	X	X*	X	X	X*
Occupational Therapist			X		
Ophthalmologist		X*	X		
Ear, Nose, and Throat Specialist	X		X		X
Cardiologist		X	X		
Plastic Surgeon			X		
Endocrinologist			X		
Psychologist					X*
Social Worker	X			X	X

*Note.* All those denoted with \* indicates a service that the child was waitlisted for at the time of response, i.e., the child was not receiving active intervention from this service, but had been identified as a child who required the service.

As can be seen, the level of involvement varies across the children. While some services listed, such as daycare, are supportive in that they provide parents with time to engage in other activities away from their children, the majority of services require parental time to attend appointments and participate in treatment with their child. Total number of services can be an indication of the commitment level required by families to support their child. The type of service can also indicate the amount of time and degree of involvement that is expected of the parent. The higher number of medical specialties that the child is followed by, then the higher the number of specialist appointments that would be scheduled for this child. Also, some of these specialties may be connected to other

treatments such as surgery (e.g., Plastic Surgeon) or schedules of therapy time (e.g., Speech Language Pathologist).

This table highlights the demands that are placed on a family of a child with increased needs. For children who are involved with a large number of services, parents experience a demand on their time in order to facilitate services. That is, even though a parent may realize the importance of service, at times they may find it difficult to balance other demands (e.g., work, other children, their own health) in order to avail of services. This will be further explored when we look at the information obtained from the Barriers to Treatment measure.

### **Data Analysis**

This researcher investigated expected relationships with Pearson correlations and used qualitative research methods to take an in-depth look into the responses of each parent participant. It must be noted that since the study was not initially designed with a qualitative approach in mind, the information is limited by what was available from the questionnaires used. Individual scores will be presented to highlight patterns that appear in the data. First, this study looks at whether the data of the five parent participants can answer the research questions and second, the results will advise whether a larger scale quantitative study is possible with the current population.

### **Qualitative Analysis**

Pseudonyms have been added to the case studies to help the reader follow along with each participant. All pseudonyms are random and are not associated with

participant's real names in any way. After these case studies are presented, a summary of the trends apparent from these cases will be provided.

**Anna (parent participant 1).**

***Demographics.***

At the time of the study, Anna was aged 21 – 30 years old and was living in a common-law relationship. She had completed postsecondary education and was engaged in part-time work. Anna had 2 children, both of whom lived with her at home. The child involved with the Direct Home Services Program was 4 years old. Anna reported that she received no direct outside support (e.g., no one outside of the home helped her around the house or with the children). Her child was involved in a number of outside services, including daycare, public health nurse, family doctor, speech language pathologist, ear, nose and throat specialist, and social worker.

***Stages of change.***

Initially, Anna presented in the action stage and remained in this stage at both the three-month and six-month follow-ups.

***Barriers to treatment.***

At the three-month assessment of perceived barriers to treatment, Anna showed a perceived barriers score of 51 (range of possible scores 47 – 235). For this participant, the barrier rated highest was “My child refused to take part in sessions,” which was rated at 3 on the 5-point scale (1 “never a problem,” up to 5 “always a problem”). At the six-month assessment, Anna's score rose slightly to 54. After six months of intervention, Anna's

highest rated barrier, also given a rating of 3, was “Information in the visit and handouts seemed confusing.”

On Part 2 of the BTPS-modified, Anna did list some major life events, or stressors, that occurred within the time of intervention. At the first follow up (three months), she indicated that her health status had changed in the last 3 months and also that a close friend or relative had gotten very sick or passed away. At the 6-month follow up, Anna noted that there had been an alcohol or drug problem within the extended family, and again that a close friend or relative had gotten very sick or passed away.

***Adherence.***

Anna showed 100% adherence with program visits. That is, she did not cancel any visits with the home visitor and completed all scheduled visits as expected.

***Quality.***

Anna rated the quality of home visits using the highest possible scores for all items on the questionnaires at Time 2 and Time 3. She did not return the questionnaire for relationship quality at Time 2, but rated it as 5 (the highest score) at Time 3. The perceived quality was not reported as high by the home visitor. The quality of the home visits at both Time 2 and Time 3 was rated as 1 (“Distractions, crisis oriented”). At both Time 2 and Time 3, the quality of the relationship was rated as 2 (“adequate for working, but some difficulty”). Average length of visit for Anna was 90 minutes, with a range of 60 minutes to 120 minutes. This was the highest of all the participants. It is unclear, however, if this was due to the need of the family, the comfort of the family with the

home visitor or if this home visitor's visits are typically run longer than her colleagues' visits do.

***Possible implications.***

Anna showed complete adherence with program visits, the ideal in a home visiting program. One could look at this participant for potential indicators of such superior adherence. Anna was found to be in the action stage of change upon entry into intervention, and also did not perceive any of the listed barriers as significant obstacles to service delivery throughout follow-up. It would seem, then, that this parent was ready for intervention and did not experience any barriers to the treatment offered. Interestingly, the presence of stressors such as change in health status of the parent did not affect adherence with home visits. Anna viewed the quality of these visits to be very high, indeed the highest score possible. She also rated her relationship with the home visitor very highly. From the home visitor's perspective, however, home visits often had distractions or were crisis oriented, and the relationship was only perceived as "sufficient" for getting work done. This indicates that, according to staff, perfect adherence with home visits may not necessarily correspond with other desired aspects of intervention.

**Beth (parent participant 2).**

***Demographics.***

Upon initial assessment, Beth was a single mother in the 31-40-year-old range. She had completed high school and was working on a full-time basis. Beth had 2 children, both of whom lived with her at home. The child involved with the Direct Home

Services Program was 2 years old. Beth reported that she received no outside support to help with her household or children. Outside services that Beth's child was involved with were public health nurse, family doctor, paediatrician, and heart specialist. This child was also on a waitlist for services from speech language pathology and an ophthalmologist.

### ***Stages of change.***

Initially, Beth presented in the action stage of change and remained in this stage at both the three-month and six-month follow-ups.

### ***Barriers to Treatment.***

At the first assessment of perceived barriers to treatment at three months, Beth showed a barriers score of 48 (range 47 – 235). The highest rated barrier for this participant was “My child was sick on the day when a visit was scheduled,” which was rated as a 2 (“rarely a problem”).

At the six-month follow-up, Beth's score increased slightly to 53. The highest rated barriers, given a score of 3, were “My child was sick on the day when a visit was scheduled”, “Crises at home made it hard for me to be available for a visit” and “I felt I had to give too much personal information to the home visitor.” Next to these barriers on the questionnaire, was the added handwritten comment of “Due to open heart surgery but never a problem after to return to sessions.”

Beth did not report any major life events or stressors throughout the duration of intervention, as listed on part 2 of the BTPS. However, as has already been noted, there was mention of “open heart surgery” written on one of the questionnaires. Possible issues with reporting the occurrence of events will be addressed in the discussion.



### ***Adherence.***

Overall, Beth showed an adherence score of 0.88 (14 completed / 16 expected). At the first follow-up at three months, adherence with visits in the previous three months had been 0.89 (8 completed / 9 expected) and at the final follow-up, the adherence score with visits was 0.86 (6 completed / 7 expected). It is important to note that while it may appear that there was a slight decrease over time; Beth only cancelled one visit during each time span. Essentially, she remained at a constant high level of adherence with expected home visits.

### ***Quality.***

At the first report, following three months of intervention, Beth scored the quality of the home visits as 4.29 and the quality of the working relationship between parent and professional as 4.87. At Time 2, she rated the visits as 4.79 and the relationship as 4.93. Once again, the home visitor did not view the visits as being of quite the same level of quality. In the first report, the visitor rated the quality of visits as 2, or “adequate for information and some activities”, and the relationship as 2, or “adequate for working, but some difficulty.” At the six-month follow-up, the staff rating of home visit quality remained the same, while the rating of relationship quality rose to 3, or “typical, comfortable, at ease.” Again, there was a disagreement between the parent and staff ratings of quality aspects, with the staff rating being lower than the parent’s. The average length of a home visit for Beth was 59.64 minutes, or one hour, with a range of 55 to 70 minutes.

### ***Possible implications.***

While the changes were small, Beth showed a slight increase in reported barriers to treatment from the three-month follow-up to the six-month follow-up, with a self-report of a member of the family receiving a surgery during the second follow-up. In addition to this, she showed a slight decrease in adherence with home visits from the first follow-up to the second. It would be understandable that a family member receiving surgery during the time of intervention would impact on the ability to maintain regular (generally weekly) home visits. Quality of the home visit and relationship with the home visitor was rated very high by this participant; however, the home visitor did not rate these factors quite as highly. On the initial report, both the quality of home visits and the working relationship were rated as adequate. However, on the second report, the home visitor did report that the quality of the relationship had improved to be at a “comfortable” working level.

### **Carol (parent participant 3).**

#### ***Demographics.***

When she first met with the researcher, Carol was a mother in the 31 - 40-year-old range, in a married relationship. She completed some postsecondary education, and worked on a full-time basis. Carol had 3 children, all of whom lived at home. The child involved with the Direct Home Services Program was 3-years-old. Carol reported no support with her children or household outside of her home. This child was involved in quite a number of services, including daycare, family doctor, paediatrician, speech

language pathologist, ear, nose and throat specialist, ophthalmologist, occupational therapist, cardiologist, plastic surgeon, and endocrinologist.

***Stages of change.***

Initially, Carol's scores were in the action stage of change and remained there for the three-month follow-up. No follow-up was completed with Carol after six months as she had discontinued service by that time.

***Barriers to treatment.***

At the first assessment of barriers to treatment at the third month of intervention, Carol showed a high score for perceived barriers at 115. The highest rated barriers for Carol, rated at a 5, or always a problem, were "Treatment did not seem to be working," and "Getting time off so I could be available for home visits." Many other barriers were rated as a 4, or often a problem, including "Scheduling of appointment times for visits," "Visits conflicted with another of my activities (classes, job, friends)," "I lost interest in home visits," "My child was sick on the day when a visit was scheduled," "Treatment added another stressor to my life," "My child's skill level seems to have improved, therefore treatment no longer seems necessary," "The home visitor wasn't available often enough," "I had a disagreement with my partner about whether we should continue with treatment," and "Treatment took time away from spending time with my children." No major life events were reported to have occurred during the first three months of intervention.

There is no second assessment of perceived barriers to treatment as Carol terminated service with the Direct Home Services Program prior to six months of

involvement. Carol posted the highest barriers to treatment score of all the participants, at essentially half the highest possible score, and double that of the other participants.

### ***Adherence.***

Overall, Carol showed an adherence score of 0.71 (10 completed / 14 expected) with visits. However, when this is broken down, we see that during the first three months of intervention, adherence with scheduled home visits was 0.89 (8 completed / 9 expected). During the latter three months of service, adherence with scheduled home visit was 0.40 (2 completed / 5 expected) and Carol ultimately withdrew from service early. By breaking the adherence score into these segments, we see a sharp decrease in adherence after the first three months of intervention. Of note, is the fact that the adherence score for the second time span was only calculated based on time within service (i.e., 5 visits into the second time span), as opposed to including all the visits that would have been scheduled had this participant continued in service.

### ***Quality.***

Carol scored the quality of home visits and the relationship with the home visitor the lowest of all participants in this study. On the initial report she gave the quality of the home visit 2.57, and the working relationship a rating of 3.27. As this family terminated service prior to the six-month follow-up, we do not have second reports for quality of visits. Additionally, the home visitor associated with this family failed to return a completed questionnaire for quality so we are unable to determine whether the home visitor agreed about the poor quality of visits and relationship with this client. With

regards to the length of visits, the average length was 61 minutes, or one hour, with a range of 55 minutes to 70 minutes.

***Possible implications.***

Carol started intervention in the action stage of change and remained there throughout the time she took part in the study. However, there was a drastic change in Carol's adherence score from the first half of the study to the second half. Of particular interest is Carol's Barriers to Treatment score, which was not only the highest of all participants, but was approximately double that of the other participants' scores. It is quite possible that Carol's high level of barriers to treatment were the underlying reason for low adherence with home visits and ultimately early termination of services. Given the number of other services that this child was involved in, participating in the Direct Home Services program would have been another appointment which required Carol to take time off work. Further, Carol scored the quality of home visits and the relationship with the home visitor the lowest of all participants in this study. One interpretation of these ratings is that this intervention did not meet the needs of this child, and accordingly the quality of visits was perceived very low. Another interpretation could be that with low visit adherence, service would be inconsistent at best and so the quality of the relationship with the home visitor and the quality of the home visits themselves would suffer. Indeed, it seems logical that high levels of barriers and low levels of adherence would be associated with a low quality of working relationship and home visit quality.

**Danielle (parent participant 4).**

***Demographics.***

At the time of the study, Danielle was a mother in the 41 – 50-year-old range, in a married relationship. She held a postsecondary diploma or degree and was currently on leave from work. Danielle had 3 children, all living at home. The child involved with the Direct Home Services Program was 3 years old. Danielle reported receiving no outside support with her children or household. Compared to the other participants, this child was involved in relatively few outside services including public health nurse; family doctor; speech language pathologist; and social worker.

***Stages of change.***

Initially, Danielle presented in the action stage of change and continued to do so at the three and six month follow-ups. Danielle left a number of handwritten comments on her stages of change questionnaires. For example, next to item 4, “It might be good for me to start spending more time challenging my child,” Danielle wrote “We already do.” For item 23, “I might be part of my child’s difficulty, but I really don’t think I am,” she wrote “Child had difficulty before we adopted him but he is now doing really well. He has come such a long way, we are very proud of him.” In general, Danielle wrote comments indicating the positive work that the parents were already doing for statements that elicited sentiments of not working hard enough, or of not thinking the child needed extra help.

### ***Barriers to treatment.***

At both assessments of perceived barriers to treatment, Danielle showed a score of 47. Thus, this participant's perception of barriers did not change throughout intervention. Danielle rated all barriers as a 1, or never a problem, indicating that she did not view any of the listed barriers as being a hindrance to receiving service.

### ***Adherence.***

The overall adherence score for Danielle was 0.91 (20 completed / 22 expected), a high level of adherence. Broken down, we see that Danielle's adherence during the first three months of intervention was 0.82 (9 completed / 11 expected), and this increased to 1.00 (11 completed / 11 expected) in the latter 3 months of intervention; Danielle showed an increase in adherence with visits over time.

### ***Quality.***

Danielle scored the quality of home visits as 4.29 initially, and this level fell to 3.57 on the second report. She scored the quality of relationship consistently high at 5 on both the initial report and the second report. The home visitor, however, reported an opposite effect. The home visits were scored as 2 or, "adequate for information and some activities" initially, and the working relationship was scored as 3/5 or, "typical, comfortable, at ease". At the follow-up, though, the home visitor had perceived quality to have improved. The home visits were scored as 5, or "Outstanding, what every home visit should be," and the quality of the working relationship was now scored as 4, or, "Better than most, feeling of partnership." Again, we see the parent and staff rating disagreeing when it comes to visit quality. With regards to length of home visits, the

average length of a home visit for this family was 60.25 minutes, or one hour, with a range of 55 minutes to 75 minutes.

***Possible implications.***

Danielle showed an increase in adherence to 100% by the second half of the intervention. However, she remained in the same stage of change throughout intervention and showed the same Barriers to Treatment Participation score throughout intervention. Again, being in the action stage of change and having low levels of barriers were both related to high adherence scores. With regards to quality, Danielle rated the working relationship consistently high across intervention but rated the quality of home visits as declining slightly from the first report to the second. The home visitor, on the other hand, saw an increase in the quality of home visits as well as in the working relationship. For this participant, it appears that being in the readiness stage of change, having low levels of barriers, and perceiving the intervention as being high quality were all associated with high adherence scores. The Direct Home Services Program seemed to be a good match for this child and family.

**Ellen (parent participant 5).**

***Demographics.***

Upon initial assessment, Ellen was a single mother in the 31 – 40-year-old range who reported to have never been married. She held a high school diploma and was currently unemployed. Ellen had 2 children of her own, but had 3 children living in her household. The child involved with the Direct Home Services Program was Ellen's biological child, and was 3 years old. Ellen reported that she had someone who came by



to help her with the children, 2 – 6x per week. A number of outside services were utilized by this child, including daycare; family doctor; ear, nose and throat specialist; and social worker. This child was also on the waitlist for service from speech language pathologist and psychologist.

***Stages of change.***

Initially, Ellen presented in the contemplation stage of change. At the three-month follow-up, her scores were in the action stage of change and remained there for the six month follow up. Therefore, between the start of intervention and the three-month follow-up, Ellen moved from the contemplation stage of change to the action stage.

***Barriers to treatment.***

At the first assessment of perceived barriers to treatment at the third month of intervention, Ellen exhibited a barriers score of 56. The highest rated barrier for this participant, rated at a 4, was “My child refused to take part in sessions.” Major life events listed for Ellen during this time span were “My child changed daycares during treatment” and “My home visitor changed during treatment.”

At the six-month follow-up, Ellen’s perception of barriers to treatment decreased slightly to a score of 52. The highest rated barrier, rated at a 3, was “I felt I had to give too much personal information to the home visitor.” Major life events listed during this stage of intervention were “I moved to another house or apartment during the time my child was being visited.”

### ***Adherence.***

Ellen showed a consistent level of 0.75 adherence with expected home visits (12 completed / 16 expected). That is, this participant's level of adherence was 0.75 at the three-month follow-up (6 completed / 8 expected) and again at the six-month follow up (6 completed / 8 expected). Essentially, 25% of visits were cancelled by Ellen.

### ***Quality.***

Ellen scored the quality of home visits as 4.57 on the initial rating, but this declined to 4.21 on the second rating. The quality of the relationship with the home visitor saw a similar decline, from 4.93 down to 4.27. The home visitor, however, reported the home visits to increase in quality, from 1, or "Distractions, crisis oriented," to 2 or "adequate for information and some activities." The home visitor rated the working relationship fairly low at 2, or "adequate for working together, but some difficulty." This remained consistent across both reports. Once again, parent and staff disagreed on the quality ratings. The average length of visits for Ellen was 81.25 minutes, with a range from 60 minutes to 120 minutes. The reported length of visits was on the higher end when compared with other participants in this study.

### ***Possible implications.***

Ellen was the only participant to start intervention in a stage other than action. At the start of intervention, Ellen presented in the contemplation stage of change and progressed to the action stage by the three-month follow-up and remained there for the six-month follow-up. Over time, Ellen showed a slight decrease in perceived barriers to treatment. This transformation in stages of change and barriers to treatment had no effect

on adherence with intervention for Ellen. It is possible that starting intervention at a stage other than action played a role in never increasing adherence with home visits. The home visitor saw an increase in the quality of home visits from the initial report to the second report. It is possible that this was associated with Ellen's movement from the contemplation stage of change to the action stage. That is, she would have been more willing and able to make changes in her own behaviour when it came to interacting with her child. Interestingly, though, Ellen saw a decrease in the quality of home visits during this time. It is unclear whether this perceived decrease in quality was associated with the level of adherence.

### **Overall implications.**

While one must be cautious about the interpretations they make about the data presented, there are a few trends that seem rather apparent in this small data set. First, of the parents that took part, all were in the action stage of change by the end of the 3-month follow-up. Interestingly, only one parent was found to be in the contemplation stage at the initial contact while all others were already in the action stage. So, for the parents who chose to take part in this study, readiness was not an issue for their involvement in the program. That is, the parents presented here were all ready to take part in the intervention within the first three months of service.

Second, even when parents show they are ready for the intervention, barriers to treatment may impede the parent from availing fully of the program. Beth (Participant 2) showed a slight increase in reported barriers in the second phase of intervention, and a slight decrease in visit adherence was observed. For Carol (Participant 3), very high

scores of barriers were observed along with a sharp decrease in adherence with visits and ultimately, early withdrawal from the program.

Finally, perceptions of home visit quality seem to vary depending on whether you are the parent involved in intervention or whether you are the home visitor providing intervention. For all participants where comparison scores existed, it seemed that parents rated the quality of working relationship and quality of home visits much higher than the professionals. Further, in some cases parents reported a decline in the quality of home visits over time, whereas the home visitors saw an increase in the quality of these visits. It seems clear, then, that factors which determine the perceived quality of home visits vary in some way for parents and professionals.

### **Quantitative Analysis**

Caution must be taken when interpreting Pearson correlations within this data set. With low numbers of participants, a data point that varies from the rest may greatly influence the correlation reported. Too few data points make it hard to clearly outline the possible relationship between variables. However, relationships that prove significant in this data set may indicate future directions for research. Similarly, pattern analysis of individual scores can serve to highlight trends and suggest future directions. Ultimately, a larger scale analysis would more adequately answer the research questions posed.

### **Stages of Change.**

Four of the five parents were in the action stage of change at the start of intervention and remained there for the duration of intervention. The other parent was found to be in the contemplation stage at the start of intervention but was found to be in

the action stage of change at the three-month mark. Based on this low level of variance, no analyses were performed. This data set is unable to answer the question of whether parents in the action stage of change adhere more with intervention than those in other stages. However, looking at Table 9, it can be seen that the adherence score of the parent who initially presented in the contemplation stage of change (Ellen), was 0.75 at Time 2, which was the lowest of all adherence scores at that time. Interestingly, even though this participant was found to be in the action stage of change at Time 2, their adherence score remained constant at 0.75 for the duration of intervention.

### **Barriers to Treatment.**

The Barriers to Treatment Participation Scale (BTPS) is broken into two parts; Part One measures barriers that may be associated with the program while Part Two concerns major life events that may have happened in the recent past of the respondent. Individual participant scores as well as means and standard deviations for these measures can be seen in Table 4. It is important to remember that the Likert scale for Part One of the measure goes from 1 – 5 for each statement. A participant who answered “never” experiencing each barrier, or 1, to each statement would receive a score of 47. Thus, participants with scores close to 47 should be viewed as rarely experiencing barriers, while those with higher scores would indicate more frequent experiences of barriers. In view of this, it can be seen that most participants are reporting relatively few barriers to participation at Time 2 with the exception of Participant 3 (see Figure 2). Her score of 115 is double that of the other four (range 47 – 56). Participant 3 did not complete a questionnaire at Time 3 as she had withdrawn from the service by that time. With regards

to the second part of the BTPS, parental report of the frequency of major life events within the last 3 months ranged from 0 to 2. Families that reported more life events at Time 2 also reported more life events at Time 3, as can be seen in Figure 3. It is unclear if the events reported were distinct events or if parents reported the same event at two time points.

### **Quality Measures.**

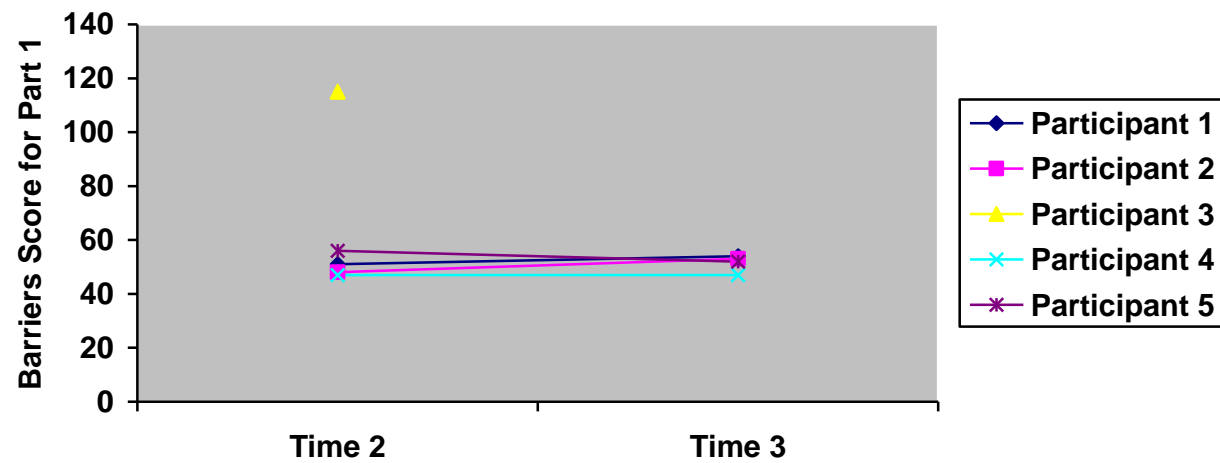
Both parents and home visitors completed measures of home visit quality. The individual scores as well as the means and standard deviations for these measures can be seen in Tables 5 and 6. For both parent and staff responses, a score of 1 indicate a low quality rating, while 5 is the highest quality rating. It is interesting to note that staff and parent reports of quality of visits are quite different (see Figures 4 and 5). In several instances, parents rated the visits and working relationship as having high quality, while staff rated them as low to mediocre.

Length of visit seemed to vary across parent participant, as can be seen in Table 8. While the overall average visit time was 70.43 minutes, three of the five parents had visit times close to one hour, while the other two participants had visits closer to one and a half hours. The length of visit did not correlate with other aspects of quality.

Table 4

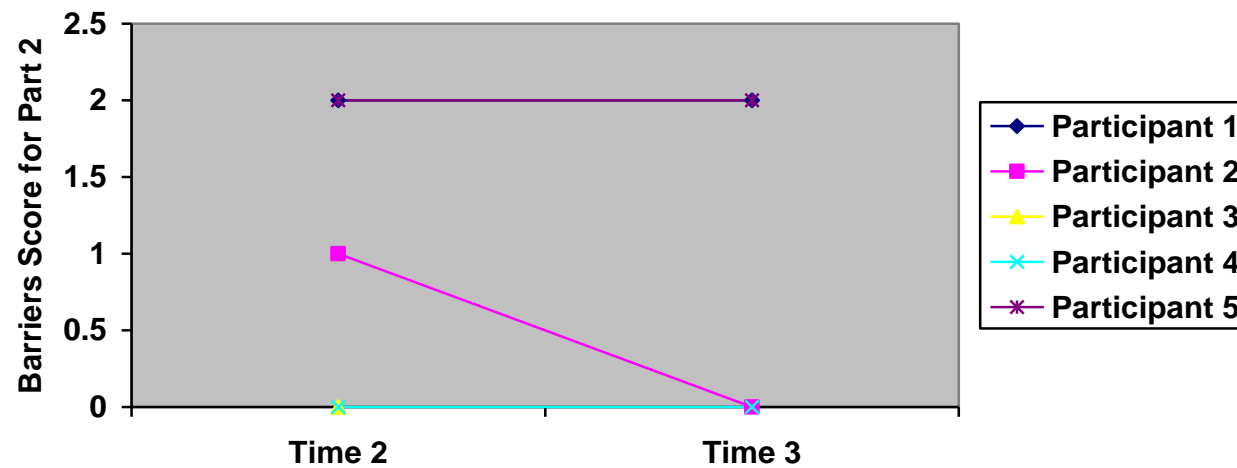
*Barriers to Treatment Participation Scale - modified scores at Time 2 and Time 3*

	<u>Time 2</u>						<u>Time 3</u>					
	BTPS Part 1			BTPS Part 2			BTPS Part 1			BTPS Part 2		
Parent Participant												
1 (Anna)	51			2			54			2		
2 (Beth)	48			1			53			0		
3 (Carol)	115			0			-			-		
4 (Danielle)	47			0			47			0		
5 (Ellen)	56			2			52			2		
Overall Score	<u>N</u>	<u>M</u>	<u>SD</u>	<u>N</u>	<u>M</u>	<u>SD</u>	<u>N</u>	<u>M</u>	<u>SD</u>	<u>N</u>	<u>M</u>	<u>SD</u>
	5	63.40	29.06	5	1.00	1.00	4	51.50	3.11	4	1.00	1.15



*Figure 2.* Comparison of scores of part 1 of the Barriers to Treatment Participant Scale – modified at Times 2 and 3. No comparison score is available for participant 3 as they terminated service prior to Time 3 and did not complete follow-up questionnaires.





*Figure 3.* Comparison of scores of part 2 of the Barriers to Treatment Participant Scale – modified at Times 2 and 3. This scale measures how many significant life events were present in the participant’s life in the previous 3 months. No comparison score is available for participant 3 as they terminated service prior to Time 3 and did not complete follow-up questionnaires.

Table 5

*Parent Quality Ratings at Time 2 and Time 3*

	<u>Visit Quality</u>						<u>Relationship Quality</u>					
	Time 2			Time 3			Time 2			Time 3		
Parent Participant												
1 (Anna)		5.00			5.00		-				5.00	
2 (Beth)		4.29			4.79		4.87				4.93	
3 (Carol)		2.57			-		3.27				-	
4 (Danielle)		4.29			3.57		5.00				5.00	
5 (Ellen)		4.57			4.21		4.93				4.27	
Overall Score	<u>N</u>	<u>M</u>	<u>SD</u>	<u>N</u>	<u>M</u>	<u>SD</u>	<u>N</u>	<u>M</u>	<u>SD</u>	<u>N</u>	<u>M</u>	<u>SD</u>
	5	4.14	0.93	4	4.39	0.64	4	4.52	0.83	4	4.80	0.35

Table 6

*Staff Quality Ratings for each Parent Participant at Time 2 and Time 3*

	<u>Visit Quality</u>						<u>Relationship Quality</u>					
	Time 2			Time 3			Time 2			Time 3		
Parent Participant												
1 (Anna)		1			1			2			2	
2 (Beth)		3			2			2			3	
3 (Carol)		-			-			-			-	
4 (Danielle)		2			5			3			4	
5 (Ellen)		1			2			2			2	
Overall Score	<u>N</u>	<u>M</u>	<u>SD</u>	<u>N</u>	<u>M</u>	<u>SD</u>	<u>N</u>	<u>M</u>	<u>SD</u>	<u>N</u>	<u>M</u>	<u>SD</u>
	4	1.75	0.96	4	2.50	1.73	4	2.25	0.50	4	2.75	0.96

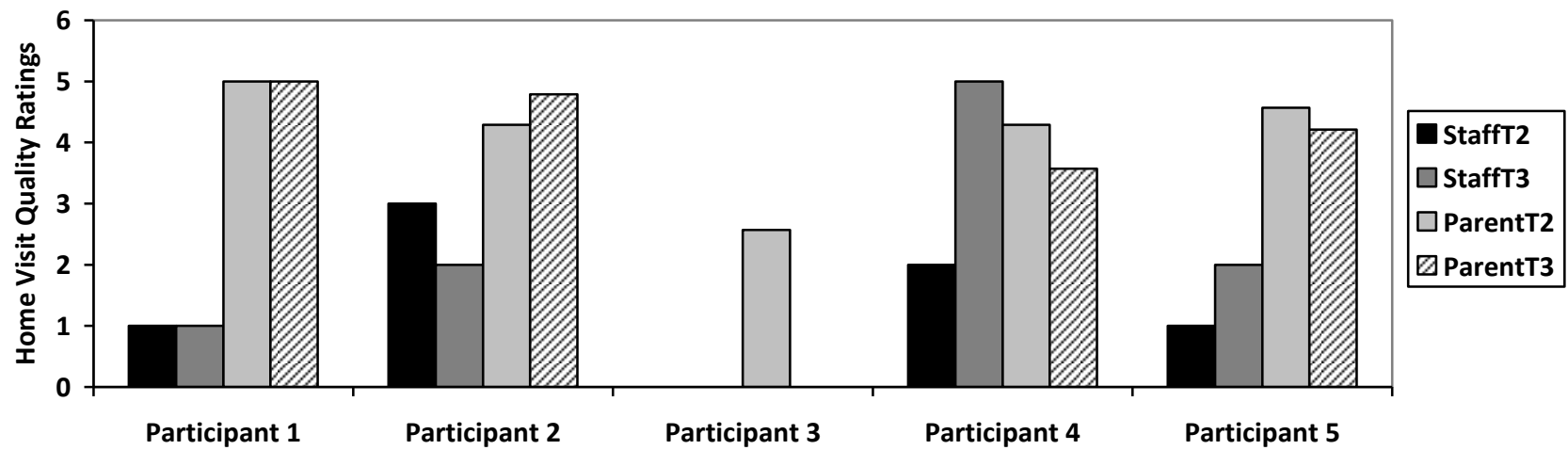
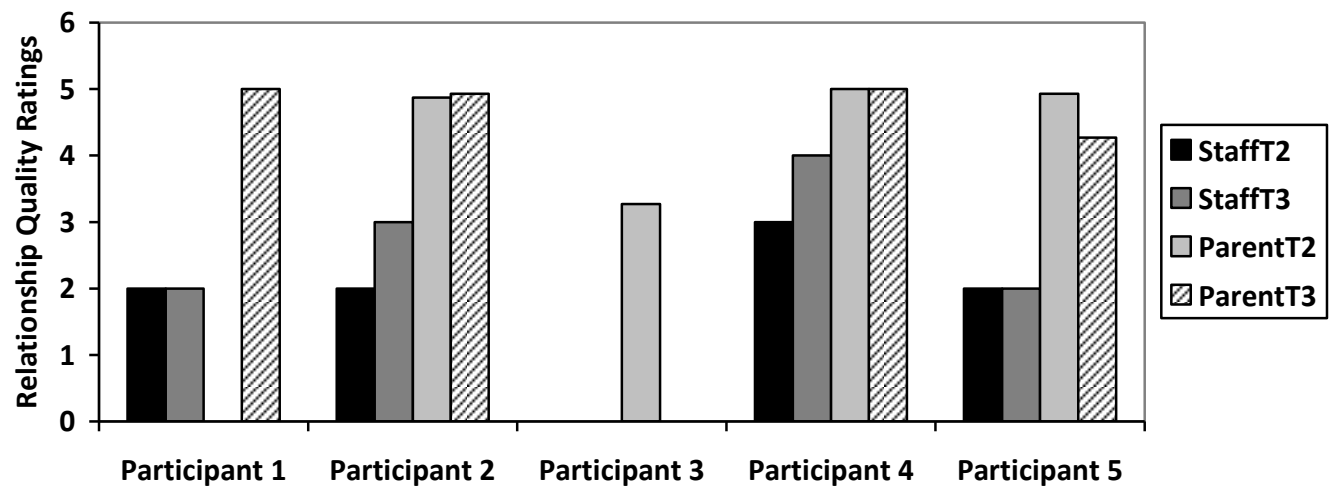


Figure 4. A comparison of home visit quality ratings given by both staff and parents at Time 2 and Time 3.



*Figure 5.* A comparison of relationship quality ratings given by both staff and parents at Time 2 and Time 3.

Table 7

*Average length of visits for each parent*

<u>Parent Participant</u>	<u>Time (minutes)</u>
1 (Anna)	90.00
2 (Beth)	59.64
3 (Carol)	61.00
4 (Danielle)	60.24
5 (Ellen)	81.25
Overall	70.43

**Adherence.**

Table 8 shows the individual scores as well as means and standard deviations for adherence scores. Adherence was operationally defined as number of completed visits divided by number of expected visits. As visits are expected to be weekly during the first six months of intervention, it would be expected that twenty-six home visits would be completed in this time. However, a number of factors may impact on the actual number of visits scheduled, such as a typical visit time falling on a holiday, or the home visitor being off. These “missed visits” were removed from the ratio because they were not under the control of the parent. For our adherence ratio, then, the number of completed visits was divided by the number of scheduled expected visits.

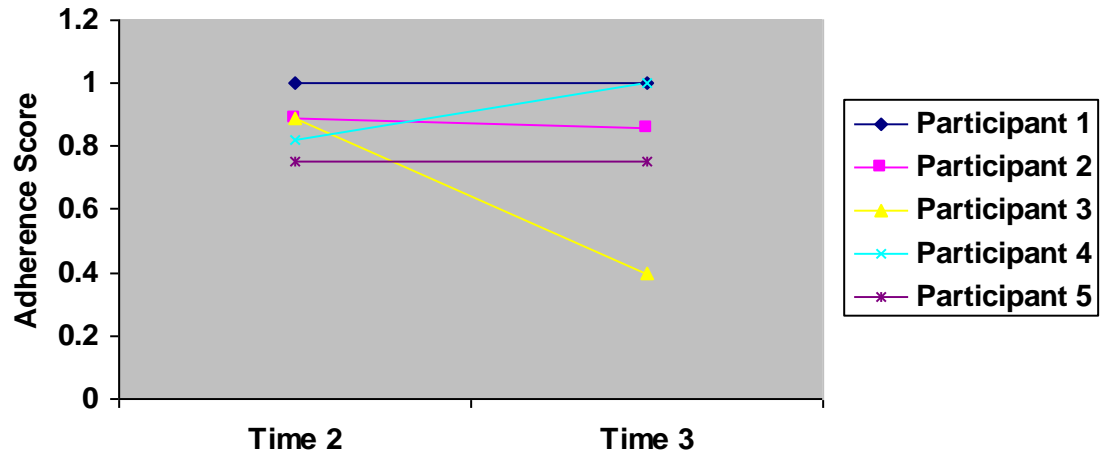
Table 8

*Comparison of Time 2, Time 3 and Overall Adherence Scores*

	Time 2		Time 3		Overall	
Parent Participant						
1 (Anna)	1.00		1.00		1.00	
2 (Beth)	0.89		0.86		0.88	
3 (Carol)	0.89		0.40		0.71	
4 (Danielle)	0.82		1.00		0.91	
5 (Ellen)	0.75		0.75		0.75	
Collapsed	<u>M</u> 0.87	<u>SD</u> 0.09	<u>M</u> 0.80	<u>SD</u> 0.25	<u>M</u> 0.85	<u>SD</u> 0.12

In Table 8, the adherence of participant 3 stands out, as their score dropped from 0.89 in the first three months of intervention to 0.40 in the second half of the study.

Figure 6 depicts the difference in adherence for this participant in relation to the others. It is important to note that this participant withdrew from service prior to 6 months of intervention. Secondly, participant 4 was the only parent to show an increase in adherence with home visits, moving from 0.82 during the first three months of intervention, to 1.00 (i.e., completing all expected visits) in the second half of the study.



*Figure 6.* A comparison of adherence scores at Time 2 and Time 3 for parent participants.

### **Correlation Matrix and Relationships.**

This researcher was interested in whether barriers would predict a parent's ability to adhere with the expected schedule of home visits. See Table 9 for the correlation matrix for all measures. Part One of the BTPS-modified at Time 2 (three months of intervention) was found to be negatively correlated with adherence with home visits at



Table 9

*Correlation matrix for all measures completed by participants*

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. BTPSP1T2	-														
2. BTPSP2T2	-.47	-													
3. BTPSP1T3	0.42	0.84	-												
4. BTPSP2T3	0.86	0.91	0.56	-											
5. Adhereover	-.70	0.27	0.10	-.10	-										
6. AdhereT2	0.08	0.12	0.53	0.12	0.60	-									
7. AdhereT3	-.93*	0.35	-.30	-.25	0.88*	0.16	-								
8.QAvgLength	-.28	0.90*	0.57	0.99*	0.25	0.15	0.28	-							
9. QStaffVT2	-.73	-.64	-.17	-.91	0.03	0.01	0.03	-.91	-						
10.QStaffRT2	-.58	-.87	-.97*	-.58	0.16	-.29	0.54	-.56	0.17	-					
11.QStaffVT3	-.52	-.91	-.99*	-.67	-.07	-.50	0.31	-.68	0.30	-.96*	-				
12.QStaffRT3	-.82	-1.0*	-.84	-.91	0.14	-.22	0.44	-.89	0.64	0.87	0.91	-			
13.QParentVT2	-.93*	0.73	0.62	0.86	0.72	0.07	0.89*	0.62	-.77	-.49	-.69	-.77	-		
14.QParentST2	-.99*	0.49	-.95	-.04	0.70	-.55	0.93	0.29	-.46	0.89	0.89	0.54	0.99*	-	
15.QParentVT3	0.15	0.68	0.96*	0.38	0.36	0.74	-.05	0.42	-.02	-.85	-.92	-.68	0.59	-1.0*	-
16.QParentST3	-.89	-.52	-.14	-.54	0.89	0.72	0.88	-.44	0.45	0.38	0.28	0.52	-.02	0.13	0.15

\*p&lt; 0.05

Time 3 (six month of intervention),  $r = -0.93$ ,  $p = 0.02$ . That is, higher reported levels of barriers at Time 2, were associated with lower adherence with home visits in the subsequent half of intervention. Barriers at Time 2 did not correlate significantly with adherence at Time 2, ( $r = 0.08$ ,  $p = 0.90$ ), or with adherence overall, ( $r = -0.70$ ,  $p = 0.34$ ). These values indicate that a measurement of barriers associated with the program may be able to predict parents' subsequent adherence with home visits. However, it should also be noted that this relationship seems heavily influenced by participant 3. Figure 2 shows that this participant had much higher barriers at Time 2, and Figure 4 shows that this participant had a drastic decrease in visit adherence at Time 3, while all other participants remained stable.

Further, Barriers from Part One reported at Time 2 (three months of intervention) were found to be significantly negatively associated with quality ratings provided by the parents at Time 2. For the parent quality rating of the home visit, this correlation was  $r = -0.924$ ,  $p = 0.025$ ; for the parent quality rating of the home visitor, this correlation was  $r = -0.991$ ,  $p = 0.009$ . This suggests that an increased number of barriers results in parents reporting a lower quality in home visits. However, this relationship was not found in these same measurements at Time 3. Looking at Figure 2, it can be seen that Participant 3 reported markedly higher barriers on Part One of the measure than did other participants at Time 2. It appears, then, that the scores from Participant 3 influenced this relationship at Time 2.

As well, Table 6 shows that this participant reported lower ratings of home visit and relationship quality. It must be pointed out that this parent was no longer receiving

active intervention at Time 3, and thus did not provide measures at this time. This suggests that the relationship between barriers and quality ratings was particularly salient for that participant.

Part Two of the BTPS-modified, concerning major life events, was not found to show any association with adherence with home visits. However, this second part of the BTPS-modified did show a positive relationship with some measurements of quality. Measured at Time 2, the second part of the BTPS-modified showed a significant positive correlation with visit length,  $r = 0.895$ ,  $p = 0.04$ . That is, as more life events were reported, average home visit length also increased. The positive relationship with average home visit length continued after six months of intervention,  $r = 0.994$ ,  $p = 0.006$ . This indicates that an increased number of life events is associated with longer average home visits.

The second part of the BTPS-modified showed a significant negative correlation with the staff rating of home visit quality,  $r = -0.966$ ,  $p = 0.034$ . That is, as more life events were reported by the parent, the home visitor reported a lower quality of home visit. Interestingly, this relationship was not observed between the parent rating of visit quality and level of life events. This suggests that only home visitors see the visits as diminishing in quality when parents are experiencing more barriers in the way of life events. That is, home visitors feel that the quality of home visits goes down when families are experiencing more stress.

It was thought that higher ratings of quality by the parent would also be associated with higher levels of adherence with home visits. Refer to Table 5 for the correlation

matrix for these measures. This relationship was only found between the parent measurement of home visit quality at time 2 (QParentVT2) with the adherence score for months 4-6 of intervention (CompT3),  $r = 0.89$ ,  $p = 0.04$ . It is interesting that this quality rating was not associated with the adherence score from months 1-3 of intervention, but instead showed a predictive relationship. So, parents who viewed quality as high at Time 2 were more likely to adhere with visits at Time 3. Again, this relationship seems to be heavily influenced by Participant 3.

While it may be tempting to dismiss Participant 3 as an outlier, it stands to reason that other service recipients may have a similar experience to this participant. With such low numbers of respondents, it is not possible to determine if this participant's scores are truly outliers. Accordingly, this researcher has chosen to explore the possibility that these scores reveal a relationship between high barriers, low ratings of quality and low visit adherence.

## **Discussion**

### **Recruitment**

It proved difficult to recruit high numbers of participants from the population of interest. Simply put, to recruit the desired 51 parent participants, it may be necessary to have a sample size ten times what was available in the present population.

The design of this study required two stages of recruitment: first, program staff (CMSs) were recruited to take part in the research. Once a CMS volunteered to take part in the study, then parent participants were recruited based on the CMS's caseload. Certainly, when the researcher conducted a meeting with the CMS's to determine level of

interest prior to initiating the research, there seemed to be great interest in the study. However, when it came time to volunteer to take part in the study, there was little actual uptake. When those CMSs who took part in the study were interviewed after the fact, a number of possible explanations were mentioned. CMSs already have a busy workday meeting with clients and completing in-office work; taking part in a research study would have been an extra demand on these CMSs, a demand that they might have been perceived as not fitting into their work day. Some CMSs might not have been comfortable approaching parents to take part in the research, an extra demand on top of the program being delivered. Finally, some CMSs may have been fearful that taking part in the study would have also been an evaluation of their work. These factors had been considered and minimized as far as possible: the paper work required from staff was kept to a minimal level, a script was provided for the CMSs to follow when approaching parents and they were given assurances concerning the confidentiality of the information collected. However, it is evident that these and perhaps other unknown factors were sufficient to deter staff from participating.

Once a CMS volunteered to take part in the study, they would then recruit parents who met the eligibility criteria for inclusion in the study (that is, a new family starting active intervention). In order to help with this procedure, staff were provided with a script to read to parents and those parents who identified that they would like to take part in the research were then contacted via phone by the researcher. Some parents decided up front that they did not want to take part in the research; but there were also others who informed the CMS that they would like to take part in the research but then did not return

calls from the researcher. It is possible that these parents did not want to disappoint or say “no” to the CMS, but then chose not to follow through on participating in the research.

Dunne et al. (1997) explored the possible differences in psychological and behavioural characteristics of responders and non-responders in a sexuality survey. In their study, participation was broken down as 27% initial refusal to take part; 19% initially agreeing but then failing to return completed questionnaires and 52% consenting to take part. Within the current sample of parent participants 56.5% initially refused to take part; 21.7% initially agreed but then either did not return contact with the researcher or did not return questionnaires; and 21.7 % consented and took part in the study.

Low recruitment and response rates plague health research. In clinical trials, some researchers have estimated that fewer than one third of trials reach their recruitment target and over half receive time extensions to meet appropriate sample sizes (McDonald et al., 2006). Other areas of health research, such as prenatal health, report response rates lower than 50 % (Gatny and Axinn, 2012). Brintnall-Karabelas et al., (2011) examined pre-existing data from screening interviews for studies by the National Institute of Mental Health (NIMH) in Maryland, USA. They were interested in identifying the reasons given for not participating in research by participants who were deemed eligible. Reasons given for choosing not to participate included protocol issues, such as the study not being what the participants wanted to take part in; lifestyle factors, such as not being able to get time off work; financial reasons, such as not being paid for the time involved to complete the study; taking part in other research and other reasons not specified.

One of the issues in attempting to determine factors contributing to whether people will or will not take part in research is getting them to participate in even telling the reasons behind their choice. Gatny and Axinn (2012) used a low involvement, high incentive approach to encourage pregnant women to tell researchers about the factors that might influence their decisions to take part in research. When women presented for their wellness checks, they were asked to participate in a short interview (15 minutes) and were provided a monetary incentive (\$20). The response rates were 89.4% in a public clinic setting and 94.7% for patients visiting a private clinic. Motivating factors that were rated as important were feeling that participation was an important contribution to science, that the results would be used to help others, and the opportunity to gain access to information.

Specific to the current research, Roggman et al. (2001) highlight the fact that home visits are often perceived as private, and shared only by the home visitor and family. For this reason, Roggman states, “home visitors and families may feel reluctant to have their visits observed and studied if they feel intruded upon” (p. 55). It is possible that both categories of participants (parents and staff) were reluctant to take part in the current research study because they felt they were being intruded on.

Brintnall-Karabelas et al. (2011) provide recommendations to increase recruitment rates in clinical research. Recommendations include meeting with researchers in non-clinical settings, making data-gathering as short and non-intrusive as possible, providing compensation, making times available outside of a typical work day schedule and providing access to cutting-edge medical treatment not generally available. These

authors highlight the need for researchers to be aware of these factors prior to research design. In the present research, the researcher was available to meet with parents outside of working hours, and was available to travel to their homes. It was highlighted that this research could help planning for future service, but would have no impact (benefit or otherwise) on the research participants. While each family was involved across a span of 6 months, amount of involvement at each time point consisted of completing 2 – 3 questionnaires (approximately 45 minutes). Compensation was not made available in this study but could be beneficial in the future to recruit larger numbers of participants, within ethical guidelines.

Researchers have also sought to identify demographic factors that might influence a person's decision to take part in health research and lead to non-representative samples. Typically, individuals with a higher level of education are more likely to choose to take part in research (Dunne et al., 1997). However, it is unclear whether this is because these individuals are more interested in participating or because they encounter fewer barriers with participating (e.g., no issues with reading or writing, having access to transportation, etc.). Indeed, in the current study, all those who chose to participate had at least completed high school and some also had post-secondary education. This level of education would not be representative of the population of parents who are involved with the DHSP, as there are also families involved with the program in which the parents have not completed high school.

Gatny and Axinn (2012) also reported differences in willingness to take part in survey research by race, with African American women being less willing to take part



than Caucasian women. While ethnicity was not a question on the demographic questionnaire, the researcher met with all parent participants at the start of the study; all mothers in this sample were Caucasian. Again, this small sample of Caucasian parents would not be representative of the parents involved with the DHSP, as families of other races are also involved in the program. The current sample possessed many of the traits similar to Dunne et al.'s (1997) responders suggesting that a difference may exist between the present study's participants and their peers who chose not to participate.

### **Predictors of adherence with home visits**

Adherence with an intervention has many components, from being available for the intervention, to taking part in the intervention and then following up with the intervention when the professional is no longer present. Analyzing whether a parent is taking part in a home visit and then following up on this after the fact is much harder to capture and analyze than simply being present. For this reason, the present researcher decided to use visits completed compared with visits expected as a measure of home visit adherence. However, there may be many reasons why a home visit is cancelled or rescheduled. With regards to the Child Management Specialist, they may be off on the day when a visit would normally occur, or for some reason the office might be closed. The current study excluded these numbers from the adherence ratio as the parent had no control over these variables. All other missed visits were included. While there are reasons for a parent to cancel or reschedule a visit that may be valid, such as child sickness or family vacation, deciding which reasons are valid and not valid is difficult, so it was decided it was best not to attempt this distinction. In addition, there are times when

a home visitor might arrive at a scheduled home visit and the family is not home. Parents may report that they forgot about the home visit or were running late at another appointment. Again, these visits were included as missed. While it may not be realistic to expect families to be available for home visits 100% of the time, many programs have their own criteria for an accepted number of cancelled appointments. For the Direct Home Services Program, a general guideline is that service will be re-evaluated after three consecutive cancelled visits, or three cancelled visits within six weeks.

Muzik et al. (2014) sought to identify predictors of treatment engagement in a sample of Caucasian and African American mothers. In their case, the intervention program consisted of 13 sessions; 3 of these sessions were individualized and 10 were in a group setting. Similar to the present study, engagement (i.e., attendance) was defined as the percentage of sessions attended. These researchers found maternal physical health and employment status to be the only significant predictors of program engagement, while others factors such as maternal age, race, household income, maternal mental health, and child health were not significant. Of most interest to the present study is the fact that mothers who held full-time employment showed significantly lower attendance rates than their unemployed and part-time employed peers. The current sample had two mothers who reported full-time employment (Beth and Carol). While Beth showed a consistently high rate of adherence, Carol showed a significant drop in adherence from 0.89 to 0.40 and ultimately early termination of service.

There was not enough variation in participant's stages of change scores to answer whether or not this measure could be a good predictor of home visit adherence. It is

possible that the subset of parents who chose both to take part in the Direct Home Services Program, and were motivated to take part in this study, were more likely to be in the action stage of change early on in the intervention process.

The Direct Home Services Program is a voluntary service. That is, parents have the option of availing of this service or not, and may choose to cease participating at any point. Referrals may come from a variety of sources, including doctors, public health nurses and parents themselves. It is possible that all parents who make the choice to take part in this intervention are already in the action stage of change, or at least close to it. However, it should not be forgotten that parents may feel pressured at times to avail of a service, particularly when this service is for their child and being recommended by a medical professional. It might be expected that parents who fall into this group would be in the pre-contemplation or contemplation stages of change with regards to intervention. A larger pool of participants would be necessary to determine whether all parents who choose to participate in the DHSP are already in or near the action stage of change, or whether this indicator could be used to predict adherence with program visits. With appropriate ethical approval, incorporating the stages of change measure as part of intervention rather than an additional task completed by a researcher, would make it more likely to obtain respondents at pre-contemplation or contemplation stages of change.

In a more recent review of the framework of the Transtheoretical Model, DiClemente (2005) talks about how the stages of change also indicate the processes of change that an individual needs to move through in order to move along the stages of change. For instance, an individual needs to become concerned about the present state of

things in order to initiate change in the pre-contemplation stage. In a practical sense, this could occur in the Direct Home Services Program when a CMS conducts the screening tool. For this program, Child Management Specialists first meet with a family to explain the Direct Home Services Program and to complete a developmental assessment. The findings of this assessment, as well as determination of if the child is eligible for this program (i.e., that the child is showing a developmental delay), are then communicated back to the parent. The consciousness-raising that would occur in an assessment where a CMS discusses strengths and deficits in development might spur some parents to move from the pre-contemplation stage to the contemplation stage. At this point, DiClemente (2005) describes an individual needing to complete a cost-benefit analysis where they must decide if taking on the new behaviour (in this instance, taking part in the intervention and adhering to it) will be beneficial to them. Following this possible movement path, it stands to reason that a majority of parents would already be in the action stage of change by the time their child is taken from the waitlist and starting active intervention. Considering this, future research may seek to assess initial stage of change at the point of first contact with the Direct Home Services Program; that is, at the eligibility assessment.

Increased barriers reported at three months of intervention were associated with decreased adherence at six months of intervention. This relationship between barriers and adherence was only observed in this one instance, but does indicate that increased barriers may be able to predict decreased adherence with home visits in the larger population.

As already stated, the current research modified the Barriers to Treatment Participation Scale to reflect a home-based intervention. Some barriers required re-wording to reflect a home-based early intervention program while others were not relevant to the present population. For example, “My child refused to come to the sessions” was changed to “My child refused to take part in sessions.” Financial cost was not a consideration for this program as it is offered free of charge to the family, so statements like “I felt that treatment cost too much” were removed from the current questionnaire. Should this modified questionnaire be used for future research, validation of the modified instrument on a larger sample of participants would be beneficial.

A number of barriers were identified in this study that may prevent parents from meeting with the home visitor on a consistent basis (i.e., adhere to the home visit schedule.) It is important to realize that the barriers presented here are not an exclusive list, and that any particular parent could be experiencing none, one or multiple barriers.

Weekly visits are demanding on time and may conflict with other life activities. Children with high medical needs are seen by a vast number of professionals, most often requiring both parent and child to travel to a centre to receive treatment. For these families, meeting with the home visitor may be just another appointment in a long list and parents may have to juggle priorities of medical appointments and appointments with the home visitor. For instance, one child was reported to be involved with ten other services in addition to the DHSP. Parents must find the time to commit to the visit, in the context of other priorities with their families and employer. Employer flexibility for time off to attend a child’s medical appointments is highly variable. Further, even those parents with

employers that are flexible regarding time off for a child's needs, may fear that extensive requests for time off will ultimately affect their perceived work performance. For working parents, then, time off to attend appointments with their child would certainly be a barrier to availing of a service. In support of this, Muzik et al. (2014) found that parents working full-time showed significantly lower adherence with attendance in an early intervention programs than their unemployed or part-time employed peers. Parents who participated in the present study, and were working, rated the barrier "Getting time off so I could be available for home visits," highly, suggesting that this time conflict was a struggle for them, too.

Further, other family commitments may interfere with a parent's ability to adhere to a schedule of visits. There may be additional children in the home, or other family demands such as caring for aging family members. These other family demands would also compete for a parent's available time, whether they are working or at home. For instance, a parent may have a visit scheduled with a home visitor for one child and then have a conflicting appointment for another child. This conflict in time will ultimately affect the parent's ability to comply with the expected visit.

A number of barriers related to child variables were also rated highly, such as the child refusing to take part in sessions, the child being sick on the day the visit was scheduled, and a child's skills improving from the start of intervention. It is certainly understandable that a child being sick would cause a visit to be cancelled; however, for some children with high medical needs, sickness may impact on service more often than for other children. In another instance where a child's skills have improved, parents may

not see a need for the same level of service as they received at the start of intervention. An understanding of what is occurring with the child would help staff to realize why adherence may be suffering.

Factors related to the program itself which were cited as barriers included the perception that treatment was not working and that the home visitor did not seem to be available often enough. Some children who are involved with the DHSP are also involved with a number of other professionals, such as Speech Language Pathologists, Physiotherapists and Developmental Pediatricians. Parents who are taking their children to these other specialists may not see an additional benefit to the support of an early interventionist. These parents may choose not to take part in the service, or to withdraw from service, if they do not feel that the early intervention program is offering any additional support to their child, or if they feel it is a duplication of service they are already receiving. It is also a possibility that this service model will not match the needs for all potential clients. A parent may feel that others services are better suited to their child's needs and choose to withdraw from service early, or not to avail of service at all. This possibility should be kept in mind as it is not realistic that a program will be able to meet the needs of all potential clients.

Finally, personal barriers may also factor into why a parent may not be available for consistent service. Those rated highly include the parent losing interest in home visits, perceiving home visits as another stressor in life, and having a disagreement with a partner about continuing intervention. These barriers point to a lack of connection between the parent and the program itself. For parents with higher education and access

to resources, being involved in an early intervention program may not be seen as crucial as it once was. In this age of the Internet, there is no shortage of information available on the appropriate developmental stages for toddlers, or for ideas on appropriate and creative ways to stimulate development. These parents may see themselves as experts on their children (indeed, they are), and do not feel they need to meet with an early interventionist. It appears that parents of children with special needs are reaching out to each other like never before – in person support groups, online support groups, and regular playdates assist these parents in connecting with others who are sharing the same experience. Through such a peer support system, these parents may feel connected in a way that they do not require the involvement of an early interventionist. While no research presently exists on this topic, it would be interesting to see if involvement in peer support groups affects involvement with an early intervention program. Clearly, if being involved with a program is being seen as a stressor in one's life, it might be easier to avoid the stressor and be less consistent with service.

The goal of research on perceived barriers to treatment is two-fold: to be able to identify those clients who are at increased risk of poor attendance or service withdrawal, and also for service providers to be better able to recognize and reduce perceived barriers (Kazdin et al., 1997). Accordingly, by identifying common perceived barriers across individuals, the Direct Home Services Program can attempt to reduce the perceived barriers. For instance, while home visits typically occur between regular working hours of 8:30 a.m. to 4:30 p.m., offering home visits at times outside of these hours may be beneficial for parents who are unable to get adequate time off work. Further, if program



staff are able to identify families that present with high levels of perceived barriers early on in intervention, they may be able to help address these barriers in order to help retain the family in intervention.

Parent report of home visit quality at three months of intervention showed a significant positive relationship with home visit adherence at six months. That is, increased quality ratings were associated with increased adherence at a later time, and lower quality ratings were associated with lower adherence. Other measures of quality were not related to home visit adherence.

Roggman et al. (2001) has stated the difficulty with attempting to assess home visit quality: quality depends not only on the purpose of the program in question, but also on the perception of the person defining quality. That is, parents and program staff may view home visit quality differently. Indeed, in the current study, parents and home visitors appeared to have different perceptions of home visit and relationship quality. Similar to Roggman's study, the majority of the parents in the current study rated the quality of their home visits as well as the quality of the relationship with their home visitor quite highly. Program staff, on the other hand, were much more cautious with their ratings. It is quite likely that this variation in quality rating was due to the fact that home visitors are able to compare visit quality across different families, whereas parents would be basing their quality rating on a sole interaction with one interventionist. It is also quite likely that parents and program staff have different definitions and expectations concerning home visit quality.

While Roggman (2001) reported positive correlational relationships between home visitor ratings of relationship quality and parent ratings of home visit quality, the present study did not find any significant correlations between parent and staff quality ratings. In fact, while the relationship was not significant, present results indicate a disagreement between parent reports of quality of intervention and the staff reports. Further, Roggman found that parent ratings of relationship quality and home visit quality were significantly positively related with each other, as were staff ratings of the same constructs. The same results were not found in the present study. While these measures were positively related at Time 2 between parental measures of quality, the same relationship was not observed for staff at Time 2, nor for either staff or parents at Time 3. It is possible that within the sample used, parents and staff had a different interpretation of intervention quality; as such, this mismatch in reported quality of intervention was seen.

Interestingly, at three months of intervention, an increased report of parent barriers to treatment was associated with lower reports of quality from the parents' perspective. That is, as more barriers were reported by parents, their reported levels of quality for both home visit and relationship with the home visitor decreased. This relationship was observed again for home visit quality, but not relationship quality, when the measure was repeated at six months. With regards to the second part of the barriers measure that looked at number of life events, reported life events at three months was significantly negatively correlated to staff reports of relationship quality at six months of intervention. That is, increased life events during the first three months of intervention

were associated with a lower ranking of working relationship quality by the home visitor. It is likely that when a parent is experiencing additional stressors, the ability to form a stable working relationship with the interventionist is affected. It must not be overlooked that lower satisfaction (i.e., lower perceived quality), may lead to an increase in perceived barriers. This relationship between perceived barriers to treatment and home visit quality underscores the importance of attempting to address barriers in order to improve the quality of home-based early intervention.

In addition to using parent questionnaires and staff questionnaires, Roggman et al. (2001) also completed observations by way of video recordings to evaluate the quality of home visitors. That strategy was not used in the present study, but could be an option in future studies, though it has the potential to further reduce participation as already discussed. One of the reasons Roggman used this methodology was to look at the fidelity of home visits (i.e., that all home visits contained what the program deemed to be necessary components). As the present study did not use this strategy, it is not possible to rule out the possibility that differences in home visit fidelity may underlie some of the variation in quality reported by both staff and parents. Indeed, it would be naïve to think that all four of the home visitors who took part in this study conduct their home visits in the same manner, or that all parents would report the same degree of quality with various home visitors and vice versa.

### **Possible issues with using self-report**

This study used measures that required parents and staff to self-report their beliefs and behaviours, as well as to report on the occurrence of past events. While this is one of

the most common methods used to gain information, there has been ample research highlighting its pitfalls.

Morsbach and Prinz (2006) highlight a number of issues with using a self-report measure. Initially, it is important that the respondent understand the question being asked and that this understanding is congruent with what the researcher intended. Next, it is required that a respondent recall relevant information from memory to answer the question. The respondent must compile this information and make inferences based on what the question is asking. For instance, if a question is asking about events that occurred within the last month, the respondent must find relevant memories and then estimate whether they did indeed happen in the last month. Finally, the respondent must edit the answer in order to fit the response format, whether it be an open-ended response, or fitting the response into a category. For example, they may need to determine whether an event that occurs 5 times in a month qualifies as “often” or “rarely.” In the present study, participants were asked to recall whether a certain barrier was a problem over the last three months, as well as whether certain life events happened within the last three months. It is quite possible that participants found it difficult to correctly recall whether these events happened within the specified time period.

Means and Loftus (1991) were interested in the validity of such self-reports, in particular for recurring and non-recurring events and also in the strategies used to recall these events. For the present research, any questions on home visits in particular would be deemed recurring events (e.g., on the first part of Barriers to Participation Scale – Modified, and on the Home Visit Quality questionnaire), whereas the questions on the

second part of the BTPS-modified would be deemed non-recurring events. Means and Loftus compared individuals' self-reports of health events against their use of a Health Maintenance Organization (HMO). They found that for non-recurring events, participants often reported remembering the specific incident in order to answer questions. However, for recurring events (e.g., regular visits to the dentist), participants often relied on generalist memories or scripts for what might have occurred within a specific visit. This may also be true for weekly visits by the home visitor in the Direct Home Services Program; parents may have a generalist memory of weekly visits and find it difficult to recall the specifics of certain visits. Further, Means and Loftus reported that recurring events may be harder for a respondent to place on a timeline than a non-recurring event; however, they did find that targeted interviewing could help the individual to place an event. In the current research parents were asked to report events within the last three months; it is possible that some parents may have had trouble placing these events on a timeline.

There are also other pitfalls that may be encountered when using a self-report measure for parents. First, any information that the respondent feels is sensitive in nature may fall victim to social desirability. Nichols (2014) reports on actual vs. reported handwashing in college students. They found that students reported very high rates of handwashing (99% of women and 93% of men), but when they observed actual behaviour, only 87% of women and 76% of men washed their hands,  $F(1, 221) = 4.69$ ,  $p = .03$ . Further, they found that of those that did wash their hands, only 73% of women and 58% of men washed their hands using soap. This study shows clearly the effect that

social desirability can have on self-reporting behaviour. The present study's measures of quality asked parents and staff to rate the quality of home visits as well as the quality of the working relationship. These evaluations may be sensitive in nature as parents and staff may feel pressured to rate quality highly. Indeed, most of the parent respondents rated their home visitor as highly as they could. This phenomenon also occurred in the data of Roggman et al. (2001).

Another possible explanation for the highly rated quality of both home visits and relationship with home visitor by parents is the cognitive strategy of satisficing in questionnaire research. Krosnick (1991) defines satisficing as expending little to no mental energy to answer a survey question. That is, initially a respondent may be motivated to comprehend the question, search their memory and retrieve an answer and then report this response to the researcher. After numerous questions, however, Krosnick describes the respondent as becoming fatigued, and perhaps expending less energy – not paying as much attention to the question, not searching their memory quite as thoroughly and not producing as high a quality answer as previously. As the survey continues, Krosnick believes that respondents become increasingly fatigued and may stop encoding and processing the question at all, and may instead simply analyze the question superficially and choose a response that they believe may be appropriate, rather than the answer that might be most accurate. Krosnick offers a variety of examples of satisficing, but perhaps the one that is most relevant in the present study is “endorsing the status quo.” Parents were asked to rate the quality of their home visits and relationship with their home visitor. It is possible that rather than think about each question thoughtfully,

that respondents instead endorsed answers that they believed would be associated with the status quo (i.e., that they should be happy with the home visits and home visitor and thus rate them highly.) This could perhaps explain why many of the respondents rated all quality items as a “5” or “strongly agree”. Lelkes et al. (2012) also warn that anonymous questionnaires may be more prone to satisficing as the respondent feels that they are not accountable for their responses and are not motivated to provide high-quality answers. Future research with parents could seek to diminish these possible satisficing effects by either shortening the length of the questionnaires, or by offering an incentive to increase motivation for completing the questionnaires.

While common belief is that anonymity increases the accuracy of self-report, especially when socially desirable responses are in question, Lelkes, Krosnick, Marx, Judd and Park (2012) actually found the opposite. By manipulating anonymity in student populations, the researchers were able to compare actual behaviour with reported behaviour for various tasks such as internet history and candy consumption. While their findings supported the notion that increasing anonymity increases the reporting of socially undesirable behaviour, they also found that increasing anonymity can decrease the accuracy of reporting these behaviours. They posited that this was because being anonymous made participants feel that they were unaccountable and may have decreased their motivation to answer the questions thoughtfully. These researchers, then, feel that being able to compare participants’ answers with some validity check would be an ideal way to ensure that anonymity is actually producing more accurate answers. It is unclear how much anonymity would have impacted the present study. While participants were

asked not to place any identifying information on the questionnaires and to then place them in sealed envelopes, each questionnaire did contain a code so that the researcher could match up completed questionnaires across time. Further, the researcher met with parent participants at three points across time and was also well known to the staff participants, making complete anonymity impossible.

### **Recommendations for Future Research**

Recruitment of the necessary participant numbers proved a challenge for this particular population. As such, it is recommended that a larger population be used in order to satisfactorily answer the research questions of interest. Obtaining a population base ten times as large as the present one will necessitate collaboration with similar programs in other provinces. There were instances in this research where not all questionnaires were returned. While this is bound to happen in all research, its effects were certainly felt in a study of this size. Conducting a larger scale study with the ability to routinely conduct follow-ups as opposed to relying on participants to return questionnaires would result in better response rates. Following Roggman et al.'s (2001) model, a more collaborative approach between both researcher and program staff may be required to help with "buy in" and to inform the researchers of methodological issues prior to data collection. It is apparent that attempting to get professionals to take part in a study on top of their busy work schedule on a voluntary basis proves to be difficult. That's not to say that individuals don't want the research to occur, but with a large team many members may feel that they do not have time to participate and other members of the team will step forward to do this. Providing some incentive for staff to participate



would be beneficial. For that matter, providing incentive to parent participants would also be of benefit. As was pointed out by staff members, many parents of children who would avail of the Direct Home Services Program have children who have a number of other appointments. Providing them with some payback for taking part in a study would likely encourage participation.

Secondly, a different design may increase uptake in the study. For instance, completing the initial demographics and stages of change-modified questionnaire as part of intake would increase the number of potential participants, and might increase participation rate by avoiding the necessity of scheduling a separate appointment. It could also provide initial information about future non-responders. Ethically, this approach would need to be designed in a way to respect the choice of parent participants to decline both this and further participation in the study. At the very least, a larger scale study may seek to keep track of non-identifying demographic factors for parents declining participation so as to garner more information about those families who choose not to take part in the study. Further, the current study only followed parent participants until the end of the 6-month follow-up, or until they withdrew from service. Future research could look to find a way to follow-up with parents who choose to terminate service early.

Thirdly, a larger scale study may seek to use or modify the measures used in the current study. At least for the present sample, little to no variation existed on the scores of the Stages of Change - Modified questionnaire. It is possible that this measure is not sensitive enough to reflect the changes, that the timing of when participants complete the

measure is not capturing the change (i.e., this measure needs to be completed at initial referral), or that there is some difference between participants that chose to take part and those that chose not to take part. The Barriers to Treatment Participation Scale – Modified did appear to show meaningful data with the present sample, and may be fine to use as is. The measures of quality captured the difference in perspective between parents and professionals, but future information about the fidelity of program delivery could be beneficial. And finally, the design of the adherence ratio score became subjective at times. Missed appointments could be due to the professional, parent, or child for reasons varying from sickness, vacation and conflicting appointment. A more stringent inclusion and exclusion criteria may need to be set for the visits included in this ratio.

### **Recommendations for Early Intervention Programs**

These recommendations are focused around the Direct Home Services Program, but may also be expanded to all early intervention programs. Further, these recommendations are based on the limited findings of this project.

First, when it comes to predicting adherence with home visits for this program, stages of change did not vary enough to be able to answer the question of whether this construct is associated with adherence or not. At this point it is unclear whether the lack of variability is true for all parents availing of the DHSP or just for the subgroup of parents who also chose to take part in this research. It does appear, however, that some assessment of barriers prior to entering service may be beneficial. It is important to note that the current client information questionnaire used by the DHSP may not capture all of the barriers that might impact on service, and instead a questionnaire that captures

variables from the categories already discussed (e.g., conflicts in time, child variables, and personal variables) might be more appropriate. Once a family is identified as having increased barriers to treatment, options to support the family prior to the start of intervention may need to be explored. Finally, while the quality of the program was rated highly across most participants, it may be valuable to conduct further research into the fidelity of program delivery to ensure that all clients are receiving a similar service. This would help ensure that low levels of adherence are not related to particular aspects of service delivery.

## **Conclusions**

Currently there is a need for research that addresses factors which interfere with the delivery of early intervention programs. It would not appear to be feasible to recruit sufficient participants within the Direct Home Services Program (Eastern Urban Region) to achieve the required degree of power in a reasonable period of time. However, using a larger population base and varying some aspects of study design may provide the required numbers to answer the research questions.

The current study did not find stages of change to vary across participants, and so could not evaluate whether this measure could predict which parents are more likely to comply with weekly home visits in this early intervention program. Perceived barriers to treatment, however, did seem to be related to low consistency in home visit attendance and ultimately in early termination of the program from one participant in this data set. Assessing barriers that may possibly be experienced by individuals prior to the start of intervention may help to identify those families that might require more assistance in

order to benefit most from the program. Further, while parents generally rated home visits and relationship quality high, higher barriers reported at Time 2 were associated with a lower quality rating of these variables by parents at Time 2. In addition, while parents may generally rate the quality of home visits and relationships as high, intervention staff sometimes disagree with these ratings. This suggests that an increased level of perceived barriers can reduce the level of intervention quality, and so by working to mediate barriers it may be possible to increase intervention quality. Indeed, the intent of any intervention is to support recipients in increasing adherence so that the intervention can have the full anticipated effect. This study suggests that by helping parents to overcome barriers, adherence rates may improve and increase the likelihood of positive intervention outcomes.

## References

- Aytch, L., Cryer, D., Bailey, D., & Selz, L. (1999). Defining and assessing quality in early intervention programs for infants and toddlers with disabilities and their families: Challenges and unresolved issues. *Early Education & Development, 10*, 7 – 23.
- Bailey, D., Aytch, L., Odom, S., Symons, F., & Wolery, M. (1999). Early Intervention as we know it. *Mental Retardation and Developmental Disabilities Research Reviews, 5*, 11 – 20.
- Bailey, D., Buysse, V., Edmondson, R., & Smith, T. (1992). Creating family centered services in early intervention: Perceptions of professionals in four states. *Exceptional Children, 58*, 298 – 309.
- Bailey, E., & Bricker, D. (1984). The efficacy of early intervention for severely handicapped infants and young children. *Topics in Early Childhood Special Education, 4*, 30 – 51.
- Bailey, E., & Bricker, D. (1985). Evaluation of a three-year early intervention demonstration project. *Topics in Early Childhood Special Education, 5*, 52 – 65.
- Bjorck-Akesson, L., & Granlund, M. (1995). Family involvement in assessment and intervention: Perceptions of professionals and parents in Sweden. *Exceptional Children, 61*, 520 – 535.

- Brintnall-Karabelas, J., Sung, S., Cadman, M., Squires, C., Whorton, K., & Pao, M. (2011). Improving recruitment in clinical trials: Why eligible participants decline. *Journal of Empirical Research on Human Research Ethics*, 6, 69 – 74.
- Bronfenbrenner, U. (1974). Is Early Intervention Effective? *Teachers College Record*, 76, 279 – 303.
- Bronfenbrenner, U. (1979). A Future Perspective. In Bronfenbrenner, U. (Ed.), *Making human beings human: Bioecological perspectives on human development* (pp. 50 – 59). Thousand Oaks, CA: Sage Publications Ltd.
- Bronfenbrenner, U. (2001). The bioecological theory of human development. In Bronfenbrenner, U. (Ed.), *Making human beings human: Bioecological perspectives on human development* (pp. 3 – 15). Thousand Oaks, CA: Sage Publications Ltd.
- Bronfenbrenner, U. (2005). *Making human beings human: Bioecological perspectives on human development*. Thousand Oaks, CA: Sage Publications Ltd.
- Chippett, D. (1999). *Early home based interventions with developmentally delayed young children*. (Unpublished master's thesis) Memorial University, Newfoundland and Labrador, Canada.
- Darlington, R., Royce, J., Snipper, A., Murray, H., & Lazar, I. (1980). Pre-school programs and later school competence of children from low-income families, *Science*, 208, 202 – 204.

- DiClemente, C. (2005). Conceptual models and applied research: The ongoing contribution of the Transtheoretical model. *Journal of Addictions Nursing, 16*, 5 – 12.
- DiClemente, C., Prochaska, J., Fairhurst, S., Velicer, W., Velasquez, M., & Rossi, J. (1991). The process of smoking cessation: An analysis of pre-contemplation, contemplation and preparation stages of change. *Journal of Consulting and Clinical Psychology, 59*, 295 – 304.
- Dunne, M., Martin, N., Bailey, J., Heath, A., Bucholz, K., Madden, P., & Statham., D. (1997). Participation bias in a sexuality survey: psychological and behavioural characteristics of responders and non-responders. *International Journal of Epidemiology, 26*, 844 – 854.
- Dunst, C. (2000). Revisiting ‘rethinking early intervention’. *Topics in Early Childhood Special Education, 20*, 95 – 104.
- Dunst, C. & Rheingrover, R. (1981). An analysis of the efficacy of infant intervention programs with organically handicapped infants. *Evaluation and Program Planning, 4*, 287 – 323.
- Dunst, C., & Snyder, S. (1986). A critique of the Utah State University early intervention meta-analysis research. *Exceptional Children, 53*, 269 – 276.

- Eiserman, W., Weber, C., & McCoun, M. (1995). Parent and professional roles in early intervention: A longitudinal comparison of the effects of two intervention configurations. *The Journal of Special Education, 29*, 20 – 44.
- Gatny, H., & Axinn, W. (2012). Willingness to participate in research during pregnancy: Race, experience, and motivation. *Field Methods, 24*, 135 – 154.
- Girio-Herrera, E., Owens, J., & Langberg, J. (2013). Perceived barriers to help-seeking among parents of at-risk kindergarteners in rural communities. *Journal of Clinical Child & Adolescent Psychology, 42*, 68 – 77.
- Goetz, A., Gavin, W., & Lane, S. (2000). Measuring parent / professional interaction in early intervention: Validity and reliability. *Occupational Therapy Journal of Research, 20*, 222 – 240.
- Gomby, D., Larson, C., Lewit, E., & Behrman, R. (1993). Home visiting: Analysis and recommendations. *The Future of Children, 3*, 6 – 22.
- Greenberg, M., & Calderon, R. (1984). Early Intervention: Outcomes and issues. *Topics in Early Childhood Special Education, 3*, 1 – 9.
- Harbin, G., McWilliam, R., & Gallagher, J. (2000). Services for young children with disabilities and their families. In Shonkoff, J., & Meisels, S. (Eds.), *Handbook of early childhood intervention (2nd ed.)* (pp. 387 – 415). New York, NY, US: Cambridge University Press.



- Kazdin, A., Holland, L., Crowley, M., & Breton, S. (1997). Barriers to Treatment Participation Scale: Evaluation and validation in the context of child outpatient treatment. *Journal of Child Psychology and Psychiatry*, 38, 1051 – 1062.
- Korfmacher, J., Green, B., Spellman, M., & Thornburg, K. (2007). The helping relationship and program participation in early childhood home visiting. *Infant Mental Health Journal*, 28, 459 – 480.
- Korfmacher, J., Green, B., Staerkel, F., Peterson, C., Cook, G., Roggman, L., Faldowski, R., & Schiffman, R. (2008). Parent involvement in early childhood home visiting. *Child Youth Care Forum*, 37, 171 – 196.
- Krosnick, J. (1991). Response strategies for coping with the cognitive demands of attitude measures in surveys. *Applied Cognitive Psychology*, 5, 213 – 236.
- LaForett, D., & Mendez, J. (2010). Parent involvement, parental depression, and program satisfaction among low-income parents participating in a two-generation early childhood education program. *Early Education and Development*, 21, 517 – 535.
- Landy, S., & Menna, R. (2006). *Early intervention with multi-risk families: an integrated approach*. Baltimore, Maryland: Paul H. Brookes Publishing Company.
- Lelkes, Y., Krosnick, J., Marx, D., Judd, C., & Park, B. (2012). Complete anonymity compromises the accuracy of self-reports. *Journal of Experimental Social Psychology*, 48, 1291 – 1299.

- Mahoney, G., Kaiser, A., Girolametto, L., MacDonald, J., Robinson, C., Safford, P., & Spiker, D. (1999). Parent education in early intervention: A call for a renewed focus. *Topics in Early Childhood Special Education, 19*, 131 – 140.
- Marfo, K., & Dinero, T. (1991). Assessing early intervention outcomes: Beyond program variables. *International Journal of Disability, Development and Education, 38*, 289 – 303.
- Marfo, K., Dinero, T., Browne, N., Gallant, D., Smyth, R., & Corbett, A. (1992). Child, program, and family ecological variables in early intervention. *Early Education and Development, 3*, 27 – 44.
- Marfo, K., & Kysela, G. (1985). Early intervention with mentally handicapped children: A critical appraisal of applied research. *Journal of Pediatric Psychology, 10*, 305 – 324.
- McCollum, J. (2002). Influencing the development of young children with disabilities: Current themes in early intervention. *Child and Adolescent Mental Health, 7*, 4 – 9.
- McConaughy, E., DiClemente, C., Prochaska, J., & Velicer, W. (1989). Stages of change in psychotherapy: A follow-up report. *Psychotherapy: Theory, Research, Practice, and Training, 26*, 494 – 503.

- McConaughy, E., Prochaska, J., & Velicer, W. (1983). Stages of change in psychotherapy: Measurement and sample profiles. *Psychotherapy: Theory, Research, and Practice*, 20, 368 – 375.
- McCurdy, K., & Daro, D. (2001). Parent involvement in family support programs: An integrated theory. *Family Relations*, 50, 113 – 121.
- McDonald, A., Knight, R., Campbell, M., Entwistle, V., Grant, A., Cook, J., Elbourne, D., Francis, D., Garcia, J., Roberts, I., & Snowdon, C. (2006). What influences recruitment to randomised controlled trials? A review of trials funded by two UK funding agencies. *Trials*, 7:9.
- McLennon, D. (1993). *Family ecology and the efficacy of early intervention*. (Unpublished master's thesis). Memorial University, Newfoundland and Labrador, Canada.
- McLeod, K. (2007). *Assessing stages of change among adolescent offenders: A new perspective*. (Doctoral dissertation). Retrieved from <http://www.collectionscanada.gc.ca/obj/thesescanada/vol2/002/NR29851.pdf>
- Means, B., & Loftus, E. (1991). When personal history repeats itself: Decomposing memories of recurring events. *Applied Cognitive Psychology*, 5, 297 – 318.
- Medvene, L., Base, M., Patrick, R., & Wescott, J. (2007). Advance directives: Assessing stage of change and decisional balance in a community-based educational program. *Journal of Applied Social Psychology*, 37, 2298 – 2318.

- Miedel, W., & Reynolds, A. (1999). Parent involvement in early intervention for disadvantaged children: Does it matter? *Journal of School Psychology, 37*, 379 – 402.
- Morsbach, S., & Prinz, R. (2006). Understanding and improving the validity of self-report of parenting. *Clinical Child and Family Psychology Review, 9*, 1 – 21.
- Muzik, M., Schmicker, M., Alfafara, E., Dayton, C., Schuster, M., & Rosenblum, K. (2014). Predictors of treatment engagement to the parenting intervention mom power among Caucasian and African-American mothers. *Journal of Social Service Research, 40*, 662 – 680.
- National Institute for Health Research (2012). *Feasibility studies*. Retrieved from [http://www.nets.nihr.ac.uk/glossary?result\\_1655\\_result\\_page=F](http://www.nets.nihr.ac.uk/glossary?result_1655_result_page=F)
- Necoechea, D. (2007). *Children at-risk for poor school readiness: The effect of an early intervention home visiting program on children and parents* (Doctoral dissertation). Available from ProQuest Dissertations and Theses database. (UMI No. 3270449)
- Nichols, A. (2014). Actual vs. reported behavior: Increasing handwashing in public washrooms. *Swiss Journal of Psychology, 73*, 41 – 46.
- Ottensbacher, K., & Petersen, P. (1985). The efficacy of early intervention programs for children with organic impairment: A quantitative review. *Evaluation and Program Planning, 8*, 135 – 146.

- Pretis, M. (2011). Meeting the needs of parents in early childhood intervention: The educational partnership with parents - good practice and challenges. *Journal of Policy and Practice in Intellectual Disabilities*, 8, 73 – 76.
- Prochaska, J., & DiClemente, C. (1982). Transtheoretical therapy: Toward a more integrative model of change. *Psychotherapy: Theory, Research and Practice*, 19, 276 – 288.
- Ramey, S., & Ramey, C. (1999). Early experience and early intervention for children “at risk” for developmental delay and mental retardation. *Mental Retardation and Developmental Disabilities Research Reviews*, 5, 1 – 10.
- Roggman, L., Boyce, L., Cook, G., & Jump, V. (2001). Inside home visits: A collaborative look at process and quality. *Early Childhood Research Quarterly*, 16, 53 – 71.
- Royce, J., Lazar, I., & Darlington, R. (1983). Minority families, early education, and later life changes. *American Journal of Orthopsychiatry*, 53, 706 – 720.
- Shearer, M., & Shearer, D. (1972). The Portage project: A model for early childhood education. *Exceptional Children*, 39, 210 – 217.
- Simeonsson, R., & Wiegerink, R. (1975). Accountability: A dilemma in infant intervention. *Exceptional Children*, 41, 474 – 481.
- White, K. (1985). Efficacy of early intervention. *The Journal of Special Education*, 19, 401 – 416.

White, K., & Casto, G. (1985). An integrative review of early intervention efficacy studies with at-risk children: implications for the handicapped. *Analysis and Intervention in Developmental Disabilities, 5*, 7 – 31.

White, K., Taylor, M., & Moss, V. (1992). Does research support claims about the benefits of involving parents in early intervention programs? *Review of Educational Research, 62*, 91 – 125.

Winton, P., Sloop, S., & Rodriguez, P. (1999). Parent education: A term whose time has passed. *Topics in Early Childhood Special Education, 19*, 157 – 161.

Zigler, E., Abelson, W., Trickett, P., & Seitz, V. (1982). Is an intervention program necessary in order to improve economically disadvantaged children's IQ scores? *Child Development, 53*, 340 – 348.

Zigler, E., & Trickett, K. (1978). IQ, social competence and evaluation of early childhood intervention programs. *American Psychologist, 33*, 789 – 798.

## Appendix A– Ethics Approval Letter



---

Faculty of Medicine

Human Investigation Committee  
2nd Floor, Eastern Trust Bldg.  
95 Bonaventure Avenue  
St. John's, NL Canada A1B 2X5  
Tel: 709 777 6974 Fax: 709 777 8776  
hic@mun.ca www.med.mun.ca/hic

April 22, 2009

**Reference #09.66**

Ms. Dana Noseworthy  
Department of Psychology  
Memorial University of Newfoundland

Dear Ms. Murray:

RE: "Can practitioners use parental stage of change and perceived barriers to treatment as predictors of compliance with an early intervention program?"

This will acknowledge receipt of your correspondence, dated April 20, 2009.

This correspondence has been reviewed by the Co-Chair under the direction of the Committee **full approval** of this research study is granted for one year effective **April 2, 2009**.

This approval will lapse on **April 2, 2010**. It is your responsibility to ensure that the Ethics Renewal form is forwarded to the HIC office prior to the renewal date. *The information provided in this form must be current to the time of submission and submitted to HIC not less than 30 nor more than 45 days of the anniversary of your approval date.* The Ethics Renewal form can be downloaded from the HIC website <http://www.med.mun.ca/hic/downloads/Annual%20Update%20Form.doc>

*The Human Investigation Committee advises THAT IF YOU DO NOT return the completed Ethics Renewal form prior to date of renewal:*

- Your ethics approval will lapse
- You will be required to stop research activity immediately
- You may not be permitted to restart the study until you reapply for and receive approval to undertake the study again

*Lapse in ethics approval may result in interruption or termination of funding*

For a hospital-based study, it is **your responsibility to seek the necessary approval from Eastern Health and/or other hospital boards as appropriate.**



Ms. D. Noseworthy  
Reference # 09.66  
April 22, 2009

Page 2

---

**Modifications of the protocol/consent are not permitted without prior approval from the Human Investigation Committee. Implementing changes in the protocol/consent without HIC approval may result in the approval of your research study being revoked, necessitating cessation of all related research activity. Request for modification to the protocol/consent must be outlined on an amendment form (available on the HIC website) and submitted to the HIC for review.**

This research ethics board (the HIC) has reviewed and approved the research protocol and documentation as noted above for the study which is to be conducted by you as the qualified investigator named above at the specified site. This approval and the views of this Research Ethics Board have been documented in writing. In addition, please be advised that the Human Investigation Committee currently operates according to *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* and applicable laws and regulations. The membership of this research ethics board is constituted in compliance with the membership requirements for research ethics boards as per these guidelines.

Notwithstanding the approval of the HIC, the primary responsibility for the ethical conduct of the investigation remains with you.

We wish you every success with your study.

Sincerely,



John D. Harnett, MD, FRCPC  
Co-Chair  
Human Investigation Committee

Fern Brunger, PhD  
Co-Chair  
Human Investigation Committee

C C Dr. R. Gosine, c/o Office of Research, MUN  
Mr. W. Miller, c/o Patient Research Centre, Eastern Health  
HIC meeting date: May 14, 2009

## Appendix B - Demographic Questionnaire

## Demographic Questionnaire

Code: \_\_\_\_\_

*About you:*

Are you:

- ☐ male
- ☐ female

How old are you?

- ☐ Under 20
- ☐ 21-30
- ☐ 31-40
- ☐ 41-50
- ☐ over 50

Check the box that indicates your current marital status:

- ☐ Married / Civil Union
- ☐ Living Common-Law (living together longer than 6 months)
- ☐ Widowed
- ☐ Separated
- ☐ Divorced
- ☐ Single, never married

Check the box for the highest level of school you have completed:

- ☐ Kindergarten – Grade 3
- ☐ Grade 4 – Grade 6
- ☐ Grade 7 – Grade 9
- ☐ Grade 10 – Grade 11
- ☐ High School Diploma
- ☐ Some College or University classes
- ☐ College diploma or University degree

Check the box for your current occupational status:

- ☐ Full-time work (30 or more hours per week)
- ☐ Part-time work (less than 30 hours per week)
- ☐ Currently on leave (maternity, sick leave, worker's compensation)
- ☐ Actively seeking employment
- ☐ Unemployed
- ☐ Student
- ☐ Retired

*About your family:*

How many children do you have? \_\_\_\_\_

How many children do you currently have living at home with you? \_\_\_\_\_

What are the ages of these children: \_\_\_\_\_

How old is the child involved with the Direct Home Services Program? \_\_\_\_\_

*About family support:*

Do you have anyone living outside your home who helps you take care of your child(ren)? ☐ Yes ☐ No

If you answered Yes, how often do you receive help?

- ☐ Everyday
- ☐ 2 - 6 times a week
- ☐ Once a week
- ☐ 2-3 times a month
- ☐ Once a month
- ☐ Less than once a month

Give examples of how you are helped:

---

---

Thinking of the child involved with Direct Home Services, Check the box for all of the services he/she uses:

<ul style="list-style-type: none"><li><input type="checkbox"/> Daycare</li><li><input type="checkbox"/> Public health nurse</li><li><input type="checkbox"/> Family doctor</li><li><input type="checkbox"/> Paediatrician</li><li><input type="checkbox"/> Speech-Language Pathologist</li><li><input type="checkbox"/> Ear, Nose and Throat Specialist (ENT)</li></ul>	<ul style="list-style-type: none"><li><input type="checkbox"/> Ophthalmologist</li><li><input type="checkbox"/> Occupational Therapist</li><li><input type="checkbox"/> Physiotherapist</li><li><input type="checkbox"/> Psychologist</li><li><input type="checkbox"/> Counsellor</li><li><input type="checkbox"/> Social Worker</li><li><input type="checkbox"/> Other _____</li></ul>
---	---

## Appendix C – Stages of Change - Modified Questionnaire (Readiness for Change)

### Readiness for Change Questionnaire

Each statement below describes how a person might feel when starting an intervention. Please indicate the extent to which you agree or disagree with each statement by circling the corresponding number. In each case, make your choice in terms of how you feel right now, not how you may have felt in the past or hope to feel in the future. Your responses will not affect your treatment in any way. Thank you.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1) As far as I'm concerned, my child does not have any difficulties.	1	2	3	4	5
2) I think it's time for me to start looking for ways to improve my child's development.	1	2	3	4	5
3) I am already doing things with my child to stimulate his/her development.	1	2	3	4	5
4) It might be good for me to start spending more time challenging my child.	1	2	3	4	5
5) My child is the one with the problem. I don't need to be involved in the program.	1	2	3	4	5
6) It worries me that my child may lose skills that we have already taught him/her.	1	2	3	4	5
7) I am finally working to improve my child's development.	1	2	3	4	5
8) I've been thinking that I might want to change the way I interact with my child.	1	2	3	4	5
9) I have already started to work on my child's development, but I think I need more help.	1	2	3	4	5
10) At times, I find challenging my child to be difficult, but I am working on it.	1	2	3	4	5
11) Being involved in treatment is a waste of my time because my child's difficulties are not my problem.	1	2	3	4	5

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
12) I'm hoping this service will help me to better understand my child's needs.	1	2	3	4	5
13) I guess I am not always the best parent, but I don't need to change.	1	2	3	4	5
14) I am really working hard to improve my child's development.	1	2	3	4	5
15) I know my child is behind and I really think should try to improve his/her development.	1	2	3	4	5
16) I'm not following through with what I should be doing to help my child, but I hope this service can help me do my part.	1	2	3	4	5
17) I might not always be successful in teaching skills to my child, but at least I am working on it.	1	2	3	4	5
18) I thought my child had already gotten better, but now I am struggling to keep working on his/her difficulties.	1	2	3	4	5
19) I wish I had more ideas of how to help my child.	1	2	3	4	5
20) I have started teaching my child skills, but I would like some help.	1	2	3	4	5
21) Maybe this service will be able to help my child and me.	1	2	3	4	5
22) I may need a boost to keep helping my child like I have already been doing.	1	2	3	4	5
23) I might be part of my child's difficulty, but I really don't think I am.	1	2	3	4	5
24) I hope my visitor will be able to tell me what I should do to help my child.	1	2	3	4	5
25) Anyone can talk about making changes, I am actually doing it.	1	2	3	4	5
26) All this talk about development is boring; why can't people just leave my child and me alone?	1	2	3	4	5

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
27) I have been doing really well with working on my child's skills, but I want my visitor to help me keep working.	1	2	3	4	5
28) It is frustrating because I thought my child had already 'caught up' to the children her age.	1	2	3	4	5
29) My child has difficulties, but so does every child; why do I need to spend time working on them?	1	2	3	4	5
30) I am actively working on helping my child.	1	2	3	4	5
31) I would rather accept my child's difficulties than try to work on them.	1	2	3	4	5
32) I have done a lot of work with my child to improve their skills and sometimes it is hard not to give up.	1	2	3	4	5



## Appendix D – Barriers to Treatment Participation Scale – modified

Part 1.

Please indicate on a scale of 1 – 5 (1 = Never a problem, 5= Very often a problem) how much each factor impacted your ability to take part in home visits.

Your responses will not affect the service you receive in any way. Thank you.

	Never a problem		Neutral		Very often a problem
1) My child refused to take part in the sessions	1	2	3	4	5
2) My home was not clean on the day a home visit was scheduled	1	2	3	4	5
3) My child was in other activities (sports, music lessons) that made it hard to be available for a visit	1	2	3	4	5
4) Scheduling of appointment times for visits	1	2	3	4	5
5) Treatment lasted too long (too many weeks)	1	2	3	4	5
6) Visits conflicted with another of my activities (classes, job, friends)	1	2	3	4	5
7) Treatment did not seem necessary	1	2	3	4	5
8) I did not like the home visitor	1	2	3	4	5
9) Home visits were too frequent	1	2	3	4	5
10) I felt program goals overlapped with those of other professionals we already see.	1	2	3	4	5
11) Treatment was not what I expected	1	2	3	4	5

	Never a problem		Neutral		Very often a problem
12) Information in the visit and handouts seemed confusing	1	2	3	4	5
13) My child had trouble understanding treatment	1	2	3	4	5
14) During the course of treatment I experienced a lot of stress in my life	1	2	3	4	5
15) I lost interest in home visits	1	2	3	4	5
16) I was sick on the day when a visit was scheduled	1	2	3	4	5
17) My child was sick on the day when a visit was scheduled	1	2	3	4	5
18) Crises at home made it hard for me to be available for a visit	1	2	3	4	5
19) I felt I had to give too much personal information to the home visitor	1	2	3	4	5
20) Treatment added another stressor to my life	1	2	3	4	5
21) I felt treatment did not seem as important as the visits continued	1	2	3	4	5
22) I felt this treatment was more work than expected	1	2	3	4	5
23) The program was too structured for my family.	1	2	3	4	5
24) I did not feel that I had enough to say about what goes on in treatment	1	2	3	4	5

	Never a problem		Neutral		Very often a problem
25) I feel treatment did not take my life and problems into account	1	2	3	4	5
26) The home visitor did not seem confident that treatment would work for my child	1	2	3	4	5
27) The home visitor did not seem confident in my ability to carry out programs	1	2	3	4	5
28) My child now has new or different problems	1	2	3	4	5
29) My child's skill level seems to have improved, therefore, treatment no longer seems necessary	1	2	3	4	5
30) Treatment did not seem to be working	1	2	3	4	5
31) I did not have money to buy necessary supplies for intervention (e.g. toys / crayons)	1	2	3	4	5
32) I do not feel the home visitor supported me or my efforts	1	2	3	4	5
33) The assigned work for me to do as part of this treatment was much too difficult	1	2	3	4	5
34) I did not have time for the assigned work	1	2	3	4	5
35) My child was never home to do the assigned homework	1	2	3	4	5
36) There was always someone sick in my home	1	2	3	4	5
37) The home visitor wasn't available often enough	1	2	3	4	5

	Never a problem		Neutral		Very often a problem
38) Getting time off so I could be available for the home visits	1	2	3	4	5
39) I was not comfortable being home alone with the home visitor	1	2	3	4	5
40) I had a disagreement with my partner about whether we should continue with treatment	1	2	3	4	5
41) I was too tired after work to be available for a visit	1	2	3	4	5
42) My job got in the way of being available for a visit	1	2	3	4	5
43) Treatment took time away from spending time with my children	1	2	3	4	5
44) I had trouble with other children at home which made it hard to participate in home visits	1	2	3	4	5
45) Program goals were not what I wanted to work on	1	2	3	4	5
46) The home visitor was not flexible with the visitation schedule	1	2	3	4	5
47) The home visitor did not follow up on what they said they would do	1	2	3	4	5

Part 2.

Please indicate whether the following events have happened to you in the last three months by circling yes if the event did happen, and circling no if the event did not happen:

1) I moved to another house or apartment during the time my child was being visited	Yes	No
2) My home visitor changed during treatment	Yes	No
3) My family changed in size (another baby or someone moved in or out of the home)	Yes	No
4) I lost my job or had a change in income	Yes	No
5) I got a job or changed jobs	Yes	No
6) There was an alcohol or drug problem in the family	Yes	No
7) There was physical or sexual abuse in the family	Yes	No
8) A close friend or relative got very sick or passed away during treatment	Yes	No
9) My child moved out of the home	Yes	No
10) A family member was put into an inpatient program or residential program	Yes	No
11) My child changed daycares during treatment	Yes	No
12) I had legal problems (arrest, driving violations, etc.)	Yes	No
13) I got separated or divorced	Yes	No
14) I got married	Yes	No
15) I started school	Yes	No
16) My health status changed	Yes	No

## Appendix E – Weekly Visit Log

## WEEKLY VISIT LOG

Staff code: \_\_\_\_\_

Family code: \_\_\_\_\_

To be completed for each scheduled home visit, within 24 hours of home visit when possible:

Date of Home Visit: \_\_\_\_\_

1. Did the home visit go ahead?

☐ Yes (Go to 2)

☐ No (Go to 3)

2. If yes, how long was the visit in minutes? \_\_\_\_\_ (Go to 4)

3. If no,

a) why not? \_\_\_\_\_

b) was the visit rescheduled?

☐ Yes, new visit day and time: \_\_\_\_\_

☐ No, sticking to weekly visitation schedule (will see client next week)

☐ No, other reason: \_\_\_\_\_

4. Will service continue to be offered to this family?

☐ Yes

☐ No, why not? \_\_\_\_\_



## Appendix F – Quality of Home Visit – staff rating

## STAFF RATINGS OF QUALITY OF HOME VISITS

Staff ID# \_\_\_\_\_

Family ID# \_\_\_\_\_

Date \_\_\_\_\_

Thinking of the last 3 home visits, please circle the number of the phrase that best completes the description of home visits that you had with this family.

1. **Quality** of relationship with primary parent is
  1. Tense, difficult, a sense of uneasiness
  2. Adequate for working together, but some difficulty
  3. Typical, comfortable, at ease
  4. Better than most, feeling of partnership
  5. Outstanding, effective relationship
  
2. **Quality** of home visits with this family
  1. Distractions, crisis oriented
  2. Adequate for information and some activities
  3. Typical, activities go well, parent cooperative
  4. Better than most, collaborate and learn together
  5. Outstanding, what every home visit should be

## Appendix G – Quality of Home Visit - parent rating

*Parent Satisfaction with the Home Visitor*

For each item, circle a number to indicate how much you disagree or agree with the statement about the practitioner who works with you.	Strongly Disagree	Somewhat Disagree	Neither Disagree/ Agree	Somewhat Agree	Strongly Agree
	1	2	3	4	5
<b>MY HOME VISITOR...</b>					
1. Has a generally positive relationship with me	1	2	3	4	5
2. Is easy to talk with	1	2	3	4	5
3. Is supportive of me	1	2	3	4	5
4. Seems to know a lot about children	1	2	3	4	5
5. Seems to know a lot about how to take care of children	1	2	3	4	5
6. Seems to know a lot about our community	1	2	3	4	5
7. Is well organized and prepared for our visits	1	2	3	4	5
8. Appreciates the ways my family is unique	1	2	3	4	5
9. Respects and supports my religion and my culture	1	2	3	4	5
10. Is responsive to my needs	1	2	3	4	5
11. Is responsive to my child's needs	1	2	3	4	5
12. Knows what my goals are	1	2	3	4	5
13. Plans things for our home visits that will help me reach my goals	1	2	3	4	5
14. Knows what my interests are	1	2	3	4	5
15. Plans things for our home visits that are interesting to me	1	2	3	4	5
Comments?					

Total Score =

The Total Score equals the sum of all circled numerals. Higher scores indicate higher parent satisfaction with the practitioner who works with them. Specific items may show areas of concern.

*Parent Satisfaction with Home Visits*

For each item, circle a number to indicate how much you disagree or agree with the statement about what happens on your home visits.	Strongly Disagree	Somewhat Disagree	Neither Disagree / Agree	Somewhat Agree	Strongly Agree
	1	2	3	4	5
<b>MY HOME VISITS...</b>					
1. Are a positive experience	1	2	3	4	5
2. Are enjoyable and fun	1	2	3	4	5
3. Give me a lot of information I need and want	1	2	3	4	5
4. Are planned in response to <i>my</i> family's needs and interests	1	2	3	4	5
5. Have changed as our needs have changed	1	2	3	4	5
6. Are planned well	1	2	3	4	5
7. Help me reach my goals	1	2	3	4	5
8. Are interesting to me	1	2	3	4	5
9. Involve both me and my home visitor working together	1	2	3	4	5
10. Help me solve my own problems	1	2	3	4	5
11. Help me make my own decisions	1	2	3	4	5
12. Get me playing with my child more	1	2	3	4	5
13. Help me take better care of my child	1	2	3	4	5
14. Help me make my child feel happy and secure	1	2	3	4	5
Comments?					

Total Score =

The Total Score equals the sum of all circled numerals. Higher scores indicate higher parent satisfaction with their home visits. Specific items may show areas of concern.

## Appendix H – Information Letter for Staff

## Information Letter - Staff

March 2009

Dear Participant,

I am a psychology student at Memorial University of Newfoundland currently working on my Master's thesis. My research project looks at the attitudes of clients involved with the Direct Home Services Program. At this time, I would like to invite you to participate in this research.

Participation in this project consists of the following:

1. Informing a family on initial contact of this research project and asking them whether they would like more information about the study.
2. Completing a form at the end of each home visit with families who choose to participate and forwarding it to the researcher.
3. Completing a questionnaire on the quality of home visits with families who choose to participate at 3 month and 6 month follow-ups.

Your choice to participate in this research is completely **voluntary**. Participation is in no way required by your employer. Neither your employer, nor your direct manager, will be informed about whether you chose to participate in this research.

You can be sure that all of your responses to the questionnaires are strictly confidential and anonymous. That is, families will not be aware of the information you provide to the researcher. You are not asked to write your name on the questionnaires so there is no way of knowing how you responded. Only people involved with the research (my supervisor and myself) will see the completed questionnaires, assuring that your responses are absolutely confidential. Questionnaires will be stored in a secure place when this project is completed.

The proposal for this research has been approved by the Human Investigations Committee (HIC). If you have any ethical concerns about the research that have not been dealt with, you may contact the Chairperson of HIC at [hic@mun.ca](mailto:hic@mun.ca) or at (709) 777-6974.

This research has the potential to influence the way in which early intervention programs are delivered to children and families. However, **it is not known whether this study will benefit you**. It is not expected that participating in this research will be harmful in any way. If you have any questions or concerns, feel free to contact me or my supervisor.

Thank you very much for your time.

Sincerely,

Dana Noseworthy, B.Sc., M.Sc. candidate  
Memorial University of Newfoundland  
[danam@mun.ca](mailto:danam@mun.ca)

Dr. Christine Arlett, Ph.D., R.Psych.  
Memorial University of Newfoundland  
[carlett@play.psych.mun.ca](mailto:carlett@play.psych.mun.ca)

## Consent Form – Signatures

**Study Title:** Can Practitioners use Parental Stage of Change and Perceived Barriers to Treatment as Predictors of Adherence with an Early Intervention Program?

**Investigators:** Dana Noseworthy, B.Sc.; M.Sc. candidate  
Christine Arlett, Ph.D., R.Psych.

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

### To be filled out and signed by the participant:

Please check as appropriate:

I have read the information letter	Yes { }	No { }
I have had the opportunity to ask questions and discuss this study.	Yes { }	No { }
I have received satisfactory answers to all of my questions.	Yes { }	No { }
I have received enough information about the study.	Yes { }	No { }
I have spoken to Dana Noseworthy and she has answered my questions	Yes { }	No { }
I understand that I am free to withdraw from the study		
• at any time		
• without having to give a reason		
	Yes { }	No { }
I understand that it is my choice to be in the study		
and that I may not benefit.	Yes { }	No { }

<b>I agree to take part in this study.</b>	<b>Yes { }</b>	<b>No { }</b>
--	----------------	---------------

\_\_\_\_\_  
Signature of participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of witness

\_\_\_\_\_  
Date



### **Researcher Signature**

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

\_\_\_\_\_  
Signature of investigator

\_\_\_\_\_  
Date

Telephone number: \_\_\_\_\_

## Appendix I – Recruitment Script

SCRIPT TO BE READ TO PARENT AT INITIAL CONTACT:

“As part of a research project with MEMORIAL UNIVERSITY, a master’s student is interested in looking at the attitudes of parents involved with the Direct Home Services Program. Involvement in this research is in no way connected to EASTERN HEALTH or with the intervention that I will provide. Participation in this research is COMPLETELY VOLUNTARY.

Are you interested in learning more about this study?” (YES or NO)

If NO:

Thank parent for their time, and proceed with your conversation.

If YES:

“In order for the researcher to tell you more, I will need to provide her with your first name and phone number. Do you give CONSENT for me to disclose this information to the researcher?” (YES or NO)

If NO:

Thank parent for their time, and proceed with your conversation.

If YES:

“Thank you. I will pass this information along to the researcher. You can expect to hear from her in the next day or two.” Followed by calling the researcher at 737 – 7698 and leaving a message with the name and telephone number of the interested parent.

## Appendix J – Information Letter for Families

## Information Letter - Parent

March 2009

Dear Participant,

I am a psychology student at Memorial University of Newfoundland currently working on my Master's thesis. My research project looks at the attitudes of clients involved with the Direct Home Services Program. At this time, I would like to invite you to participate in this research.

Participation in this project consists of the following:

4. 3 meetings with the researcher spaced over 6 months. These meetings can take place at the Memorial University Psychology Clinic or at your home if you choose. During each of these meetings you will be asked to complete questionnaires. This should take about 30 minutes of your time at each visit.
5. Access to information regarding the number of completed home visits with the home visitor and length of each home visit. No other details of the home visits will be provided to the researcher.

Your choice to participate in this research is completely **voluntary** and you may choose to drop out at any time. You are free to leave out any question(s) that you do not feel comfortable answering. When you are ready to return your questionnaires, just put them into the provided envelope and return them to me.

You can be sure that all of your responses to the questionnaires are strictly confidential and anonymous. You are not asked to write your name on the questionnaires so there is no way of knowing how you responded. Only people involved with the research (my supervisor and myself) will see the completed questionnaires, assuring that your responses are absolutely confidential. Questionnaires will be stored in a secure place when this project is completed.

Your choice to take part in this study will **not** affect your future service from the Direct Home Services Program. Your home visitor will not be told how you responded to the questionnaires. Your future service will not be affected by whether or not you choose to participate.

The proposal for this research has been approved by the Human Investigations Committee (HIC). If you have any ethical concerns about the research that have not been dealt with, you may contact the Chairperson of HIC at [hic@mun.ca](mailto:hic@mun.ca) or at (709) 777-6974.

This research has the potential to influence the way in which early intervention programs are delivered to children and families. However, **it is not known whether this study will benefit you**. It is not expected that participating in this research will be harmful in any way. But, if you find you begin to feel concerned or anxious you can contact the

Developmental and Behavioural Practitioner who visits you. If you have any other questions or concerns, feel free to contact me or my supervisor.

Thank you very much for your time.

Sincerely,

Dana Noseworthy, B.Sc., M.Sc. candidate  
Memorial University of Newfoundland  
[danam@mun.ca](mailto:danam@mun.ca)

Dr. Christine Arlett, Ph.D., R.Psych.  
Memorial University of Newfoundland  
[carlett@play.psych.mun.ca](mailto:carlett@play.psych.mun.ca)

## Consent Form – Signatures

Study Title: Can Practitioners use Parental Stage of Change and Perceived Barriers to Treatment as Predictors of Adherence with an Early Intervention Program?

**Investigators:** Dana Noseworthy, B.Sc.; M.Sc. candidate  
Christine Arlett, Ph.D., R.Psych.

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

### To be filled out and signed by the participant:

Please check as appropriate:

I have read the information letter	Yes { }	No { }
I have had the opportunity to ask questions and discuss this study.	Yes { }	No { }
I have received satisfactory answers to all of my questions.	Yes { }	No { }
I have received enough information about the study.	Yes { }	No { }
I have spoken to Dana Noseworthy and she has answered my questions	Yes { }	No { }
I understand that I am free to withdraw from the study		
• at any time		
• without having to give a reason		
• without affecting my future health care	Yes { }	No { }
I understand that it is my choice to be in the study		
and that I may not benefit.	Yes { }	No { }

<b>I agree to take part in this study.</b>	<b>Yes { }</b>	<b>No { }</b>
--	----------------	---------------

---

Signature of participant

---

Date

---

Signature of witness

---

Date

### **Researcher Signature**

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

\_\_\_\_\_  
Signature of investigator

\_\_\_\_\_  
Date

Telephone number: \_\_\_\_\_