

Parents of Preschool Children Newly Diagnosed with Autism Spectrum Disorder:  
The Effectiveness of a Self-Directed On-line Parent Training and Support Program on  
Parent and Child Outcomes

by

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## Abstract

Parents of preschool children newly diagnosed with Autism Spectrum Disorder (ASD) often experience high levels of anxiety, stress and depression. Given the seriousness of the child's diagnosis and the compromise in parenting and family functioning, families are typically referred to formalized treatment programs that provide support for both the child and parents. However, with rising prevalence rates there is often a long waitlist to access formalized treatment programs. The purpose of this study was to develop and evaluate a self-directed on-line training and support program, that was designed to support parents immediately after their child's diagnosis. A prospective consecutive sample of family participants were recruited through a Child Development Clinic directly after diagnosis ( $n = 21$ ). The mean age of parent participants was 36 years and the majority were female (81%), married (86%), employed (71%), and had a university degree (67%). The mean age of child participants was 40 months, with the majority being Caucasian (62%) and male (76%). An experimental study with a randomized, masked, waitlist control design was used to compare the treatment group that received access to the on-line training and support program ( $n = 9$ ), to a waitlist control group ( $n = 12$ ). On average the Parent Treatment group completed 71% of the training, with four of the nine parents completing 100% of the training. Parents in the treatment group had significantly lower post-test scores in Stress compared to parents in the Control Group  $F(1,18) = 4.46, p = .05$ , and significantly higher post-test scores in Family Support  $F(1,18) = 4.83, p = .04$ , and Knowledge of ASD and ASD Treatment  $F(1,18) = 4.28, p = .05$ . No differences between groups were found for parents use of Intervention Skills  $F(1,18) = .03, p = .86$ , or for child engagement  $F(1,18) = 1.03, p = .32$ , or child expressive communication  $F(1,18) = .06, p = .81$ . The results support the use of the self-directed online training program as a resource for parents of children newly diagnosed with ASD.

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**In memory of  
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### List of Acronyms

AAC	Augmentative and Alternative Communication
ABA	Applied Behaviour Analysis
CAC	Computer Mediated Communication
CARD	Center for Autism and Related Disorders
DIR	Developmental, Individual Difference, Relationship
ESDM	Early Start Denver Model
FIQ	Family Impact Questionnaire
FSS	Family Support Scale
HREB	University of Manitoba Health Research Ethics Board
IBI	Intensive Behavioural Intervention
IDI	Intensive Developmental Intervention
NDBI	Naturalistic Developmental Behavioural Intervention
NPDC	National Professional Developmental Center
PECS	Picture Exchange Communication System
PKQ	Parent Knowledge of ASD and ASD Intervention Questionnaire
POMEIT	Parent Observation Measure of Early Intervention Techniques
PRT	Pivotal Response Training
PSI-SF	Parenting Stress Index Short Form
PSOC	Parent Sense of Competence Scale
RIT	Reciprocal Imitation Training
STAR	Strategies for Teaching based on Autism Research
TEACCH	Treatment & Education of Autistic & Communication Handicapped Children

## Chapter 1: Introduction

### Background

Autism Spectrum Disorder (ASD) is a neurological disorder that causes complex developmental difficulties within the first three years of life. Preschool children diagnosed with ASD typically have pervasive deficits in social interaction and communication, and the occurrence of repetitive and restrictive behaviours (American Psychiatric Association, 2013). Parenting a preschool child with these characteristics, coupled with the impact of receiving a diagnosis of ASD, creates high levels of parental anxiety, stress, depression, and general mental health difficulties (Sansosti, Lavik, & Sansosti, 2012; Wong, Yu, Keyes, & McGrew, 2017). Given the seriousness of the child's diagnosis and the compromise in parenting and family functioning, families are typically referred to formalized treatment programs that provide support for both the child and parents.

In 2016, it was reported that Autism Spectrum Disorder (ASD) was diagnosed in approximately 1.5% of the children in the United States (Centres for Disease Control and Prevention, 2016). This is more than double the number of children diagnosed sixteen years earlier (Centres for Disease Control and Prevention, 2000). Given these rising prevalence rates and the resulting waitlists for public services, there is often a significant time delay between a child's diagnosis and the start of a formalized intervention program. In fact, some studies report that there can be a two-year delay between the parents reporting of their first concerns to their pediatrician, and the start of a formalized treatment program (Sansosti et al., 2012). Given that early ASD intervention has been shown to be an important factor in a child's immediate and later development (Corsello, 2005; Fenske, Zalenski, Krantz, & McClannahan, 1985; Rogers & Vismara, 2008), this delay in formalized service has critically important consequences for the

child, the family, and society.

### **Statement of the Problem**

One possible way to address this delay in formalized service is to recognize the potential of the parent in facilitating their child's development. Parents could participate in cost efficient, easily accessible, and effective training shortly after diagnosis, which would help them facilitate their child's development until formalized services begin. Given that there is consistent evidence to support the effectiveness of parent training and involvement once a child has entered a formalized treatment program (Gillette, & LeBlanc, 2007; Lang, Rispoli, Mandy, & Regeister, 2009), the potential effectiveness of parent training while waiting for a formalized treatment program should also be considered.

To address this need for accessible parent training, some service providers have recently developed on-line self-directed ASD treatment training modules. For example, Autism Internet Modules (<http://www.autisminternetmodules.org>), and the Provincial Outreach Program for Autism and Related Disorders e-Learning Modules (<http://www.autismoutreach.ca>). Although parents can easily access this training and facilitate their parenting knowledge and skills, research on the efficacy and effectiveness of self-directed on-line parent training programs is extremely limited (Hamad, Serna, Morrison, & Fleming, 2010; Ingersoll, Wainer, Berger, Pickard & Bonter, 2016; Nefdt, Koegel, Singer, & Gerber, 2010; Wainer & Ingersoll, 2015). Additionally, there is a lack of knowledge regarding the appropriate content, timing, and duration of a training program for parents of children newly diagnosed with ASD and conflicting evidence on the interactional effects between parent training and levels of parenting stress during this time period (Estes et al., 2014; Koegel, Bimbela & Schreibman, 1996; Minjarez, Mercier, Williams, & Hardan, 2013; Strauss, et al., 2012).

## **Purpose**

The primary purpose of the present study was to develop and evaluate the effectiveness of a self-directed on-line training and support program for parents of preschool children newly diagnosed with ASD. The secondary purpose was to assess the interactional effects, of a self-directed on-line ASD parent training and support program, and parent stress, on parent and child outcomes.

## **Rationale and Significance of the Study**

The present study is significant in that it addresses how parents can be afforded an efficient and effective learning opportunity to facilitate their involvement in the early intervention process with their child with ASD, as they wait for formalized services. First, this is important for the child as early parent intervention is critical to immediate and long-term outcomes (Ingersoll, & Dvortcsak, 2006). Second, it is important for the parent, as early parent training facilitates positive mental health and positive parent-child relationships (Mahoney & Wiggers, 2007; Patterson, Smith, & Miranda, 2012). Third, it is important for society as early parent training can be cost-effective, allowing resources to be spread more equitably among families in need (Solomon, Van Egeren, Mahoney, Huber, & Zimmerman, 2014). Fourth, it is important for researchers as there is a need for more data to determine the relationship between efficacy and efficiency of parent training, and the relationship between parent training and parent stress.

**1. Early intervention.** Early therapist-mediated ASD intervention has been shown to be an important factor in a child's immediate and later success (Corsello, 2005; Fenske et al., 1985; Rogers & Vismara, 2008). Additionally, parent-mediated early intervention for young children has also been shown to have a significant effect (Lang et al., 2009). Some believe there should be much more parent-mediated intervention and much less professionally driven intervention

(Mahoney & Wiggers, 2007), as parents are uniquely suited to realize a therapeutic relationship by identifying appropriate goals and objectives for their child, and by being able to closely monitor the child's progress within the natural family setting. Given the documented importance of early intervention and early parent involvement on child outcomes, there is a clear gap in practice if families must wait for up to a year for formalized intervention services to begin. It is clear that efforts to train parents to be involved in basic early intervention during this time frame is important and that research on how to efficiently and effectively train parents to facilitate early intervention is also important.

**2. Parent involvement.** Parenting a child with ASD involves challenges that often lead to stress, anxiety, and depression that in turn affect's the parent-child relationship and child outcomes (Sansosti et al., 2012). However, when parents become involved in intervention practices it leads to greater self-efficacy, reduced stress, and improvement in the parent-child relationship (Mahoney & Wiggers, 2007; Patterson et al., 2012). Additionally, when parents attend appropriate ASD parent training programs their stress can be reduced, they can become more optimistic, and the parent-child relationship may improve (Tonge et al., 2006). Given the documented importance of parent involvement and training to parent mental health and the parent-child relationship, there is a clear gap in practice if the parent is not trained for intervention and involvement as early as possible. Efforts to reduce parent mental health issues as early as possible are important and research that answers questions on how this can be accomplished, early in the process, is also important.

**3. The cost of intervention.** Formalized, comprehensive, behavioral ASD early intervention programs are typically labor intensive and costly (Chasson, Harris, & Neely, 2007; Peters-Scheffer, Didden, Korzilius, & Matson, 2011). Most comprehensive behavioural programs

provide between 25 to 35 hours a week in services and cost in the range of \$20,000.00 - \$60,000.00 USD per year, per child (Chasson et al., 2007). With the increase in prevalence rates, most publicly funded programs are not able to meet this demand in service and cost, and many families wait for months for service (Sansosti et al., 2012).

However, there are examples of alternative practical treatment methods that are evidence-based, but also cost effective. These programs take advantage of evidenced-based parent implemented and naturalistic interventions within the home environment. One approach that uses these evidence-based practices is the PLAY project (Solomon, Necheles, Ferch, & Bruckman, 2007; Solomon et al., 2014). The approach teaches parents an Intensive Developmental Intervention (IDI) based on a developmental-relational, social pragmatic approach, that uses a variety of naturalistic strategies supported by research (Casenhiser, Shanker, & Stieben, 2013; Greenspan et al, 2008; Ingersoll & Schreibman, 2006; Kasari, Gulsrud, Wong, Kwon, & Locke, 2010). Solomon reports that the method is cost effective (ranging from \$3000.00 to \$5000.00 USD per child, per year), practical, replicable, and easily disseminated (Solomon et al., 2014).

Solomon's research supports the rationale of parent training and naturalistic strategies in the home environment as an alternative to costly formalized behavioural service programs. However, the use of parent training and naturalistic strategies could also be used prior to, and complimentary to, formalized service programs, to reduce costs. For example, parents waiting for services who participated in cost-effective, self-directed, on-line training may require less costly individualized training when later enrolled in a formalized program. Additionally, early effective parent training is shown to reduce parent stress, increase parent self-efficacy, and improve the quality of parent-child relationships (Mahoney & Wiggers, 2007; Patterson et al.,

2012), which could also reduce the costs of later formalized social supports, such as counselling and respite services.

The present study is also important in that it adds needed data to the literature on the relationship between cost efficiency and effectiveness in early ASD intervention, by investigating the rationale for a continuum of services related to parent training. Presently, there are a significant number of parents who receive little or no training or support at all for a year or longer after diagnosis. Then, once their child does enter a formalized service, the parents receive individualized, labour intensive, costly, training. It would arguably be more cost-effective to have stages of parent training, starting with inexpensive self-directed on-line training shortly after diagnosis, leading to community-based group workshops later, and then finally to training within a formalized intervention service (Brookman-Frazee, Vismara, Drahota, Stahmer, & Openden, 2009; Coolican, Smith, & Bryson, 2010).

**4. Parent training: Efficacy, effectiveness and parent stress.** Although we know that there are a variety of ASD treatment methods and practices that have been found to be effective for preschool children, and that parent training has been found to be effective within certain formalized treatment programs, there is limited data on the synthesis of these two areas of research. Specifically, research does not indicate which methods or practices would be best for parent implementation for a preschool child not in a formal intervention program. Additionally, there is even less research on what treatment methods or practices would be best for parent implementation, learned through a cost-effective delivery system such as a self-directed on-line training program. Therefore, the present study is significant in that it furthers the research literature on how to combine evidence-based training content with a cost-effective delivery method for parents not yet in a formalized treatment program. In addition, there is limited

research addressing parenting stress after diagnosis and its interaction with training (Ingersoll et al., 2016). The present study examines the interaction effect between parent stress and on-line self-directed parent training in relation to parent and child outcomes.

### **Research Questions**

The purpose and rationale lead to three specific research questions. First, will parents who participate in a self-directed on-line parent training and support program develop significantly higher social support, knowledge and skill scores, and significantly lower stress scores after the training program, compared to a control group of parents who did not take the training? Second, will children of parents who took the parent training and support program have significantly higher scores in communication and social skills after the training program, compared to children of parents in the control group who did not take the training? Third, does the parents' beginning stress level, or change in stress level through the training program, affect the parents' knowledge and skill scores as well as the children's communication and social skills scores at the end of the training program in comparison to a control group?

## **Chapter II: Review of the Literature and Theoretical Framework**

A review of the literature was undertaken to determine what specific intervention strategies have evidence of effectiveness suitable for a parent-training program specific to parents of a child newly diagnosed with ASD. General ASD parent training paradigms are reviewed as well as specific paradigms related to ASD self-directed on-line parent training. On-line education design strategies are also reviewed as well as the influence of parent stress on parent training and child outcomes.

### **Review of ASD Interventions**

There is a continuum of ASD interventions that range from didactic, adult directed, behavioural approaches (McEachin, Smith, & Lovaas, 1993), to play based, child directed, developmental approaches (Solomon et al., 2007). Most research has examined behavioural approaches that utilize an applied behaviour analysis approach (National Autism Centre, 2009; Wong et al., 2015). These approaches have been found to be effective and range from highly structured programs utilizing discrete trial training in a one-to-one setting (Smith, Groen, & Wynn, 2000), to approaches that use applied behaviour analysis principles in more unstructured, naturalistic settings (Koegel, Koegel, Harrower, & Carter, 1999).

Developmental approaches are also well represented in the literature (Greenspan et al., 2008). These approaches range from unstructured, relationship based, child directed programs (Jocelyn, Casiro, Beattie, Bow, & Kneisz, 1998) to more structured interventions that utilize schedules and visual cueing within a development framework (Panerai, Ferrante, & Zingale, 2002). Recently, interventions representing the middle of the continuum that utilize both behavioural and developmental components have also been found to be effective (Dawson et al., 2010).

ASD interventions also range across a continuum of ages. Some interventions are designed for adults, some for adolescents and some for children. Additionally, because children have started to be diagnosed as toddlers or young preschool children, there is an emerging literature on interventions for toddlers and young preschool children under 4 years of age (Schertz, Reichow, Tan, Vaiouli, & Yildirim, 2012).

**Evidenced-based approaches to early autism intervention.** ASD interventions also have a continuum related to documented effectiveness. At one end of the continuum you have interventions that are considered “fringe” or “alternative” that are typically supported by anecdotal evidence (Smith, Oakes, & Selver, 2014), while interventions at the other end of the continuum are considered more mainstream and are supported by numerous scientific research studies (Odem, Boyd, Hall, & Hume, 2014). In recent years the term “evidence-based” has been used to identify the difference between interventions and their level of documented effectiveness or level of scientific support. For an ASD intervention to be considered evidence-based it needs to be evaluated using rigorous scientific method. However, there are different types of scientific method, with different levels of rigour. The three main types were originally defined by Nathan and Gorman (2002), and this set of criteria has become the standard for evaluating research in relation to interventions. The criteria were summarized by Rodgers and Vismara (2008) and presented as follows:

- Type 1 studies: Randomized, prospectively designed clinical trials using randomly assigned comparison groups, blind assessments, clear inclusion/exclusion criteria, state-of-the-art diagnosis, adequate sample sizes to power the analyses, and clearly described statistical methods. We also expected treatment fidelity measures (i.e., measurement of the degree to which the treatment as delivered adheres to the treatment model) to be included in Type 1 studies.
- Type 2 studies: Clinical trials using a comparison group to test an intervention. These have some significant flaws but not a critical design flaw that would prevent one from using the data to answer the study question. Type 2 studies provide useful information. We also included single-subject designs in this group.

Type 3 studies: May have significant methodological flaws. In this group we included uncontrolled studies using pre-post designs and studies using retrospective designs. (Rodgers & Vismara, 2008, p. 9)

For an intervention to be considered evidence-based it also needs to be replicated, and there are different levels of replication based on study type. The two main levels of replication requirements were originally defined by Chambless and Hollon (1998), and this set of criteria has become the standard. The criteria are summarized by Rodgers and Vismara (2008) and presented as follows:

1. “Well-established” requires treatment manuals, and clearly specified participant groups, and either of these characteristics:
  - a. Two independent well-designed group studies showing the treatment to be better than placebo or alternative treatment or equivalent to an established effective treatment.
  - b. Nine or more single-subject design studies using strong designs and comparison to an alternative treatment.
2. “Probably efficacious” requires clearly specified participant groups (treatment manual preferable but not required), and either of three characteristics:
  - a. Two studies showing better outcomes than a no-treatment control group.
  - b. Two strong group studies by the same investigator showing the treatment to be better than placebo or alternative treatment or equivalent to an established treatment;
  - c. Three or more single-subject design studies that have a strong design and compare the intervention to another intervention. (Rodgers & Vismara, 2008, p. 9)

When it comes to reviewing the evidence-base of studies related to autism intervention, these criteria have been updated in recent years. In 2009, and subsequently in 2015, the National Autism Centre released the National Standards Report, a review of current evidenced-based educational and behavioural approaches to autism intervention. They developed the Scientific Merit Rating Scale, based on Nathan and Goreman’s 2002 original criteria, to evaluate: appropriate research design, appropriate measures of dependent and independent variables, participant ascertainment and diagnostic assessment, and objectively demonstrated generalization and maintenance (National Autism Centre, 2015). Replication requirements included:

“Two group designs or 4 single-subject design studies with a minimum of 12 participants for which there are no conflicting results or at least 3 group design or 6 single-subject design studies with a minimum of 18 participants with no more than 10% of studies reporting conflicting results. Group and single-subject design methodologies may be combined.” (National Autism Centre, 2015, p. 35)

The National Professional Development Centre on Autism Spectrum Disorders (NPDC) also conducted an expansive review of the autism intervention literature (Wong et al., 2013). They also used criteria adapted from Chambless & Hollon (1998) and included the following replication criteria:

- (a) At least two high quality experimental or quasi-experimental group design studies
  - conducted by two different research groups.
- OR
- (b) At least five high quality single case design studies
  - conducted by at least three different research groups
  - Having a total of 20 participants across studies.
- OR
- (c) A combination of at least one high quality experimental/quasi- experimental group design study, and at least three high quality single case design studies.
  - conducted by at least two different research groups
  - (Wong et al., 2013. pp 15-16)

The National Standards Report (National Autism Center, 2015), found a variety of educational and behavioral treatment methods as “Established” (“Sufficient evidence is available to confidently determine that an intervention produces favorable outcomes for individuals on the autism spectrum. That is, these interventions are established as effective.”). The “Established” interventions were considered evidenced-based and included 14 different treatment ‘methods’ that were supported by available research, up to 2012.

The authors of the National Professional Development Center on Autism Spectrum Disorders report (Wong et al., 2013) found that a variety of behavioural, developmental and educational treatment practices were evidence-based (using their criteria listed above). In the report the authors examined the research literature up to 2011 and determined that there were 27 evidence-based ‘practices’ appropriate for autism intervention.

A difference between the two reviews is that the National Autism Center reviewers based their unit of focus on ‘methods’ of intervention that could be represented by broader interventions that included a combination of practices (e.g. comprehensive approaches looking at both efficacy and effectiveness) used to promote general social, language and behaviour goals. The NPDC review paper based their unit of focus solely on individual ‘practices’ used to promote specific skills or outcome objectives (e.g. a focused approach looking at efficacy). Although the number of ‘methods’ differs significantly from the number of ‘practices,’ almost all of the ‘practices’ outlined are found in combination within the ‘methods.’ This is encouraging as each review used well documented and similar criteria to establish if specific interventions were ‘evidence-based’ and each review found similar results, supporting each other’s findings. Given these findings, the 14 intervention ‘methods’ and 27 intervention ‘practices’ found in these two reviews will be considered evidence-based intervention practice that could be considered as appropriate for inclusion in a parent training program.

Although the two studies had similar results on the types of interventions considered effective, the difference between method and practice is also an important consideration in the development of a parent-training program. More specifically, it is both useful to understand what type of comprehensive intervention methods support the general core challenges of autism in typical real world environments (effectiveness), but equally important to understand how individual ‘focused intervention practices’ support specific challenges, in specific contexts (efficacy).

**Comprehensive intervention methods.** Comprehensive Intervention methods are a unified set of practices derived from a theoretical framework and generally packaged together as a program to address the overall core deficits of autism. Some comprehensive methods (programs)

have been around since the 1970's (e.g. Treatment and Education of Autistic and related Communication Handicapped Children; TEACCH) (Schopler & Reichler, 1971), and some are relatively new (e.g. Early Start Denver Model; ESDM) (Dawson et al., 2010). Comprehensive programs tend to have four features: 1) They usually have a theoretical background or framework that guides the program and ties the individual practices together, and this information has been vetted and published in a peer review journal; 2) There is a detailed description of the model of delivery (e.g. procedures, curriculum, manual); 3) The program must address multiple outcomes related to the three core features of autism; and 4) The program should be intensive (at least 25 hours a week), and extensive (duration of at least 10 months or more as required; Odem et al., 2014). There have been at least 32 different Comprehensive Intervention programs identified that provide services to preschool children within the United States and Canada (Odem, Boyd, Hall, & Hume, 2010; Odem et al., 2014). Of these, 20 have a behavioural framework (e.g. Applied Behaviour Analysis; ABA: Intensive Behavioural Treatments; IBI) and are typically delivered by professionals, nine have a developmental and relationship based approach (e.g. Developmental, Individual, Relationship based approach: DIR/Floortime; Hanen Model), which supports parent delivery methods, and three that use idiosyncratic or hybrid models (e.g. TEACCH) which support professional and parent delivery practices (Odem et al., 2010).

***Comprehensive behavioural treatments (ABA, IBI).*** The most well researched treatment paradigm is ABA and/or IBI which is based on the traditional theory of behaviourism and a behaviour modification framework. Examples of these programs include The Lovaas Institute, The Princeton Child Development Institute, The Center for Autism and Related Disorders (CARD), and the Strategies for Teaching based on Autism Research (STAR). In these programs

children are typically taught individually using *discrete trial training* where complex tasks are broken down into manageable teaching units (*task analysis*). Children are *prompted* and then *reinforced* for positive performance. The small manageable teaching units are then *chained* together to shape the more complex task, which is then *generalized* to additional environments where the *reinforcement* is *faded* to more natural consequences. A hallmark of these treatments is the intensity of delivery and the strict keeping of data to document progress. Although all of the Comprehensive Behavioural Treatments use the methods above, there are differences between these programs based on delivery, settings, client age, and what additional practices are included. For example, there is a large evidence base for these methods being effective for preschool children while being delivered individually in clinic, home, and classroom environments by professionals (Peters-Scheffer et al., 2011; Virués-Ortega, 2010). However, there is less supporting evidence for their implementation within inclusive preschool environments, with children under age three, or within naturalistic home environments when delivered by parents (Odem et al., 2014).

***Developmental relationship-based treatments.*** There are nine formal Developmental Relationship Based treatments considered as comprehensive intervention methods (e.g. DIR/Floortime, Early Start Denver Model, and Project ImPACT; Odem et al., 2010; Odem et al., 2014). These approaches are based on developmental theory (constructionist) which takes into consideration a child's individual preferences in learning and sensory processing, in the development of early social relationships. Treatment is based on the importance of developing engaging social relationships (typically with parents) within daily living routines within natural family and community settings (Greenspan & Wieder, 2006; Mahoney & Perales, 2003). Treatment methodologies can be both unstructured and child directed, and semi-structured with

caregiver direction. A few of these treatment programs meet the criteria of evidence-based practice for delivery in inclusive preschool programs and within naturalistic home environments when delivered by parents (e.g. Developmental, Individual, Relationship Based, DIR; Casenhiser et al., 2013; Kasari et al., 2010; Pajareya & Nopmaneejumruslers, 2011; Solomon et al., 2007); and the Early Start Denver Model, (ESDM; Dawson et al., 2010; Odem et al., 2010; Odem et al., 2014). However, although there is promising initial evidence for other developmental-relationship based approaches, more research is required to meet the criteria for evidence-based practice. These strategies are typically used for preschool children between 2 and 5 years of age.

***Idiosyncratic comprehensive treatment methods.*** Idiosyncratic (peculiar, individual) comprehensive treatment methods include 3 different treatment approaches (Odem et al., 2010; Odem et al., 2014) the Higashi School (Larkin & Gurry, 1998), the Miller Method (Miller & Miller, 1973), and Division TEACCH (Treatment and Education of Autistic and related Communication handicapped CHildren: Panerai et al., 2002). These methods are based on diverse theoretical frameworks. As an example, TEACCH is based on behavioural, developmental and educational frameworks. The intent of the program is to make individualized modifications to the environment to help children focus on specific developmental skills. Structured work systems are developed, visual schedules are used, and children develop independence as their progress is reinforced and carefully monitored. Parents are also an integral part of the program. Although TEACCH has been around for forty years and there is evidence-based research supporting components of the program (Visual schedules: Carson, Gast, & Ayres, 2008; Self management systems: Stahmer, & Schreibman, 1992), a preliminary meta-analysis that combined 13 studies with various ages found that there was limited support for the comprehensive program (Virues-Ortega, Julio, & Pastor-Barriuso, 2013). Given that there was

even less support when the under 5 population was broken out, there is not enough evidence for this Comprehensive program to be considered evidence-based for preschoolers at this time (Odem et al., 2010; Odem et al., 2014). Additionally, there is not enough evidence to support the Higashi School or the Miller Method.

*Alternative treatment approaches.* Alternative treatment approaches are either standalone treatments or ones that provide additional support to regular treatments. These can be related to additional health issues or to the co-morbid diagnoses that often accompany ASD. Although these types of treatments are not evidenced-based for the specific treatment of ASD, they can often provide support for accompanying issues that may provide moderating effects for how evidenced-based autism treatments are received. In fact, a recent study noted that over 50 % of families in the United States use alternative treatments as part of their daily or weekly treatment routine (Wong & Smith, 2006). Although a full review of these methods is beyond the scope of this paper, some common alternative approaches should be mentioned. These would include: Medications used for health, behaviour, sleeping; Gluten/Casein free diets, Vitamin or Nutritional supplements, Acupuncture, and Sensory Integration Therapy. There are numerous other Alternative methods used and for a complete review the reader is referred to Smith et al., (2014).

One extremely common alternate treatment approach is Sensory Integration Therapy. Sensory processing issues in children with autism have been described over the decades (Ayres, 2005), and have recently been added as one of the diagnostic criteria under ‘Restricted, Repetitive Patterns of Behavior, Interests, or Activities’ in the new DSM-5 (American Psychiatric Association, 2013). Until recently sensory-integration therapy to deal with sensory processing issues has been seen as a ‘fringe’ or alternative therapy. However, there is some evidence showing the utility of sensory integration therapy (Schaaf, 2011), and one specific RCT

study with significant results using a manual, fidelity measures, and standardized outcome measures (Schaaf, et al, 2013). However, continued research is needed to see if sensory integration therapy is in fact an evidence-based practice. Given that recent studies suggest that between 45 and 96 % of children with autism demonstrate sensory processing issues (Ben-Sasson et al. 2009; Lane, Young, Baker, & Angley, 2010), and that parents often request support for these issues (Goin-Kochel, Mackintosh, & Myers, 2009; Green et al., 2006), some training to help parents understand and deal with these issues should be considered.

**Focused intervention practices.** Focused intervention practices are individual ASD interventions used to promote specific skills or outcome objectives. The authors of the National Professional Development Center review paper on ASD evidence-based intervention practices found that 24 focused intervention practices have proven efficacy for behavioural, social and communication outcomes, for preschool children (Wong et al., 2013). A summary of these practices will be provided in the following section, with important practices related to parent implementation highlighted. The focused intervention practices will be examined under three broad theoretical constructs, Behavioural Practices, Developmental Practices and Educational Practices.

***Focused behavioural intervention practices.*** Twelve of the 24 intervention practices are individual behavioural practices that meet the current criteria for evidenced-based intervention practice as reviewed by the National Professional Development Center review paper on ASD: *Antecedent-based interventions; Differential reinforcement of alternative, incompatible, or other behavior; Discrete trial teaching; Extinction; Functional behavior assessment; Picture Exchange Communication System; Pivotal Response Training; Prompting procedures; Reinforcement; Response interruption/redirection; Task analysis; and Time delay.* These

behavioural practices are typically not used individually and most need to be used in unison with the others (e.g. a *Task analysis* leads to *Discrete trial training* that uses *Antecedents*, *Prompting procedures*, *Time delay*, *Reinforcement*, and *Extinction*). This collective grouping of practices, amount to a comprehensive program typically known as Applied Behaviour Analysis (ABA), or Intensive Behavioural Interventions (IBI), which was discussed earlier in the section on Comprehensive Intervention Methods. With these specific methods it should be noted that *Discrete trial training* and *Task analysis* only have evidence to support their use with children 36 months and older (Wong et al., 2013).

Although we would not expect a parent of a newly diagnosed child with ASD to undertake the extensive training required to implement a formalized ABA or IBI program, it is important for parents to understand some simple and typical evidence supported behavioural practices such as prompting and reinforcement, that could be used within everyday routines and natural environments to promote general development. Additionally, parents could be introduced to the use of objects and visuals for communication purposes (e.g. *Picture Exchange Communication System*; Bondy & Frost, 1994).

In addition, some behaviour practices noted for their usefulness in reducing challenging behaviour could also be simplified for parent use in the home environment. For example, understanding how inappropriate behaviours can be triggered and/or reinforced, (*Functional Behaviour Assessment*; Kodak, Fisher, Clements, Paden, & Dickes, 2011), how a child's attention can be diverted away from an inappropriate behaviour, to start a new appropriate behaviour (*Response interruption/redirection*; Ahrens, Lerman, Kodak, Worsdell, & Keegan, 2011); and how we can reduce an inappropriate behaviour by reinforcing a different behaviour

(*Differential reinforcement of alternative, incompatible, or other behavior*; Rozenblat, Brown, Brown, Reeve, & Reeve, 2009).

***Focused educational intervention practices.*** Eight individual Educational Intervention practices meet the current criteria used by the NPDC for evidenced-based practice: *Functional communication training; Modelling; Peer-mediated instruction and intervention; Scripting; Self-Management, Social narratives; Social skills training; and Technology-aided instruction and intervention.* These Educational practices are not dependent on each other, like most Behavioural practices, but may be used together, and together with Developmental or Behavioural practices. Except for *Modelling* all Educational practices previously listed only have evidence to support their use in children 36 months and older (Wong et al., 2013).

In general, Educational Intervention practices typically involve a type of direct or indirect teaching, modelling or instruction. This can come from teachers within classroom setting (e.g. *Functional communication training, Scripting, Self-management*), from peers within structured and unstructured settings (e.g. *Peer groups, Social skills training*), or from parents in the home environment (e.g. *Modelling, Social narratives, Technology-aided instruction and intervention*). Most Educational Intervention practices rely on the child imitating an adult or peer based on behaviour that has been modeled, or scripted. These treatments aim to train children with autism to imitate others, a skill used by typical children to learn a variety of interactive, play and communication skills (Ingersoll & Gergans, 2007). Reciprocal Imitation Training where the adult first imitates the child, leading to the child imitating the adult, can be used to initiate the process (Ingersoll & Schreibman, 2006). *Modelling* interventions themselves rely on caregivers providing a demonstration of a task to a child with the intention that the child will imitate the task either immediately or at a deferred time (National Autism Center, 2009). This procedure can

be taught in structured settings (Murzynski & Bourret, 2007), or in unstructured naturalistic settings (Carr & Darcy, 1990), for simple basic tasks (Buffington, Krantz, McClannahan, & Poulson, 1998), or for more complex behaviours (Nikopoulos & Keenan, 2007). *Modelling* procedures can be done in person, with live models (Gena, Couloura, & Kymissis, 2005), or through video modelling (Hine, & Wolery, 2006). Another method is *Scripting* where the child is given a verbal description of a behaviour or skill as a model to practice frequently, before attempting the behaviour or skills in the actual environment (Murdock & Hobbs, 2011). *Social narratives* or story-based interventions are similar. A detailed but short narrative (story) is written to model or describe appropriate social behaviour, to identify relevant social cues, or to teach specific social skills. Children are read the story often to help them to learn the appropriate social behaviour (Barry & Burlew, 2004). *Social skills training* is also similar in that children receive individual or group-based instruction on social skills using *Social narratives* or *Modeling* and then imitate or practice the skills (Kroeger, Schultz, & Newsom, 2007). Additionally, although many of these methods are modelled by adult's they can additionally be modelled through *Peer-mediated instruction* where typically developing peers are taught to model for the child with autism within cooperative learning activities (Trembath, Balandin, Togher, & Stancliffe, 2009). Finally, a variety of the above methods can be modelled through *Technology-aided instruction and intervention* where a child is learning or participating in a modelled skill or behaviour through the predominant use of technology such as a smart phone, tablet, computer, or speech generating device (Mineo, Ziegler, Gill, & Salkin, 2009).

Parents of a child newly diagnosed with ASD should certainly be introduced to the educational practice of *modeling* to help promote the child's imitation skills. *Reciprocal Imitation Training* where the adult first imitates the child, leading to the child imitating the adult,

is an easily trained and evidence supported modelling practice that can be used to initiate this process (Ingersoll & Schreibman, 2006). Parents could also be easily introduced to other modelling practices using *Technology-aided instruction and intervention* through a review of ASD education apps for computer, tablets and phones (Mineo et al., 2009).

***Focused developmental intervention practices.*** Four individual Developmental Practices meet the criteria used by the NPDC for evidenced-based practice: *Parent-implemented intervention; Naturalistic intervention; Visual supports; and Exercise* (Wong et al., 2015). These developmental practices can be used separately or together, and together with educational practices (e.g. *Peer mediated instruction, Modelling, Social narratives*). Developmental practices would also work together with some behavioural practices (e.g. *Reinforcement and Extinction*).

The main developmental practices are *Naturalistic intervention* and *Parent implemented interventions*. *Naturalistic interventions* are typically child-directed with the professional or parent following the child's lead to encourage functional skills within natural or typical settings such as the family's home or the child's day care or nursery school (Kashinath, 2006). These treatments often target joint attention, engagement, reciprocal interactions, and social communication, and through caregiver responsiveness facilitate the child's motivation for play and social initiations (Wong, Kasari, Freeman, & Paparella, 2007). This collection of strategies may also be known as Incidental Teaching (Charlop-Christy & Carpenter, 2000), Enhanced Milieu Teaching (Hancock & Kaiser, 2002), or Embedded Teaching (Grisham-Brown, Schuster, Hemmeter, & Collins, 2000). These strategies are appropriate for use with children under five years of age (Wong et al., 2013), but can also be used with older children.

In *Parent-implemented* interventions professionals teach, and/or model and/or coach parents (individually or in groups) to implement social, communication and behavioural practices with

their children within natural settings and daily living routines. Parenting training has been used since the 1970's (Schopler & Reichler, 1971) and is used extensively today (Patterson et al., 2012). In fact, *Parent-implemented* interventions are used in most evidence-based comprehensive early autism interventions (Reichow & Barton, 2014), and some believe there should be much more parent-mediated intervention and much less professionally driven intervention specifically for toddlers and preschoolers (Mahoney & Wiggers, 2007).

*Visual supports* are typically a series of visuals used to assist children with ASD in participating in the activities, routines and transitions of their day, or the specific individual steps involved in a more complex task (Bryan & Gast, 2000). Schedules can be presented through environmental arrangements, or visually as objects, photographs, line drawings, words, numbers, or symbols, and they are typically used to target skill development, independence, self-management, and self-regulation (Morrison, Sainato, Benchaaban, & Endo, 2002). These strategies are typically used for children 2 years of age and older (Wong et al., 2015).

*Exercise* is an approach where the child is given scheduled periodic times of physical exercise including aerobic, strength, and stretching activities appropriate to the child's developmental age or need for self-regulation. Developmentally, young children need opportunities to alternate sedentary learning activities and active unstructured activities. The younger the age of the preschool child, the less time they should spend in structured sedentary learning activities (Oriel, George, Peckus, & Semon, 2011). Additionally, specific types of *Exercise* may help with under-developed movement related sensory systems (e.g. tactile, vestibular, and proprioceptive) that may facilitate attention, engagement, and self-regulation (Schaaf, 2011).

Naturally, a training program for parents of newly diagnosed children with ASD would include a large component of *Naturalistic intervention* and *Parent implemented intervention* practices as the foundation to promote their child's early skills in joint attention, engagement, reciprocal interactions, and social communication. Teaching parents the use of visual supports to facilitate independence is also quite feasible, as is the use of a schedule for exercise and other sensory-based experiences.

### **Summary of intervention methods and practices**

First, although the above practices have been divided by theoretical underpinnings into Behavioural, Educational and Developmental approaches, there is in fact significant overlap between the three. For example, practices may be developmental in theory, educational in practice, and behavioural in delivery (e.g. the *Picture exchange communication system*). Additionally, Behavioural, Educational and Developmental practices often work together in complimentary ways and may be best used when a specific practice is chosen to address a specific objective or goal. Most of the practices listed are operationally defined in narrow parameters to address specific outcomes. These narrow definitions can be useful for parents wanting to target a specific issue, skill, or outcome. In fact, if parents received adequate training they could develop an individualized plan for their child by picking specific individual practices to address specific goals and outcomes in what is now termed a 'technical eclectic' approach (Odem, Hume, Boyd, & Stabel, 2012).

Second, this review identified a variety of evidence-based methods and practices that could be implemented by parents in the home environment. However, much more research is required to determine the amount and type of training required to teach parents how to implement these strategies effectively.

Third, some of the comprehensive intervention methods and individual practices listed are best suited to older pre-school children or school-aged children. In fact, some do not have an evidence base to support their use with children under 36 months of age (e.g. Discrete Trial Training, Task Analysis, Peer-mediated instruction and intervention, social skills training; Wong et al., 2013). Given that the Center for Disease Control and Prevention (2016) estimates that 43% of children are diagnosed before age three, and that parents of children newly diagnosed with ASD would want intervention strategies appropriate for this demographic, research on ASD interventions specific to toddlers will also be reviewed.

### **ASD interventions for toddlers**

Given that there has been a significant increase in the number of overall children being diagnosed with ASD (one child in 150 in the year 2000 vs one child in 68 in 2016; Centres for Disease Control and Prevention, 2000, 2016), it is likely that there has also been a significant increase in the number of toddlers being diagnosed with ASD. Over the last decade there has been an emphasis on toddler ASD screening, and toddler ASD diagnostic assessment, (Luyster, et al., 2009; Robins, Fein, Barton, & Green, 2001) which has led to an increase in research on ASD interventions appropriate for toddlers.

Although research on toddler focused ASD interventions is relatively new, twenty studies were found and reviewed by Schertz et al. (2012). The authors found that through examining the purpose of the reviewed studies and the outcome measures used, that there were six areas of intervention focus: joint attention, communication, imitation, general development, play and family well-being. The authors additionally noted that joint attention was a prominent area of focus (Schertz et al., 2012) likely because it is a foundation skill for later social and communication skills. Subsequent reviews (Bradshaw, Steiner, Gengoux & Koegel, 2015;

French & Kennedy, 2017; Rogers & Vismara, 2014) confirmed that joint attention and family well-being were a focus of interventions and noted augmented and alternative communication as an additional area of intervention.

Schertz et al. (2012) also reviewed the methods of intervention used across the studies and identified 39 different intervention strategies, while French & Kennedy (2017) noted 32 different models of intervention. In review of the 39 strategies documented by Schertz, and the 32 models documented by French & Kennedy, it was found that different terminology was used in the literature to describe similar evidenced-based intervention strategies. To summarize, most of these interventions fall within one of six methodological categories: (1) Child Directed; (2) Imitation; (3) Prompting/Modeling; (4) Augmentative / Alternative Communication; (5) Behavioural; and (6) Structured Teaching.

The first category is a Child Directed methodology that could be considered synonymous with the term or concept of “follow the child’s lead” (Greenspan & Weider, 2006; Ingersoll, Dvortcsak, Whalen, & Sikora, 2005; Schertz & Odem, 2007; Vismara & Lyons, 2007; Weatherby & Woods, 2006) and “caregiver responsiveness” (Dawson et al., 2010, Mahoney & Perales, 2005) as well as an appreciation for the child’s unique learning style and individual sensory profile (Greenspan & Wieder, 2006; Schaaf, et al, 2013). These intervention strategies were mostly used to facilitate joint attention, joint engagement, or social synchrony (pointing, showing, coordinating looks between objects and people, and coordinating engagement between people), as the beginning foundations for social communication (Dawson et al., 2010, Kasari et al., 2010; Whalen & Schreibman, 2003).

The second is an Imitation methodology which would be synonymous with any treatment that facilitates any type of imitation of others either physically or verbally, including Reciprocal

Imitation Training (Cardon & Wilcox, 2011; Ingersoll & Gergans, 2007). The above intervention strategies were used primarily to facilitate imitation, joint attention and social communication.

The third is a Prompting/Modeling methodology which would be synonymous with any treatment that provides a series of structured physical prompts like hand-over-hand, or gestural prompts (Jones, Carr, & Feely, 2006; Vismara & Rodgers, 2008) or more naturalistic or play based environmental prompts like “Communication Temptations,” or verbal prompts (Rocha, Schreibman, & Stahmer, 2007; VanDerHeyden, Snyder, DiCarlo, Stricklin, & Vigianos, 2002). Any modelling done in person, or through video modelling would also be synonymous with this methodology (Carter et al., 2011; Gena et al., 2005; Hine & Wolery, 2006; Murzynski & Bourret, 2007). These intervention strategies were used to facilitate joint attention, play, general development, and communication.

The fourth is an Augmentative /Alternative Communication methodology which would be synonymous with using any low or high technology devices used to supplement the comprehension or production of communication. Examples include: The Picture Exchange Communication System (PECS), the use of electronic switch devices, or the use of computers, tablets or smart phones (Bondy & Frost, 1994; Dyches, 1998; Park, Alber-Morgan, & Cannella-Malone, 2010; Son, Sigafos, O’Reilly, & Lancioni, 2006). These intervention strategies are primarily used to facilitate communication, joint attention and engagement.

The fifth is a Behavioural methodology which would be synonymous with more structured programs like Discrete Trial Training, Antecedents treatments, and Intensive Behaviour treatments (Esch, Carr, & Grow, 2009; Jones et al., 2006; Landa, Holman, O’Neill, & Stuart, 2011; Vismara & Rodgers, 2008) as well as other treatments that use behaviour principles in more naturalistic ways such as Pivotal Response Training (Koegel, Carter, & Koegel, 2003;

Reichow & Wolery, 2009, Rocha et al., 2007; Vismara & Lyons, 2007; ) and positive behavioural supports (Wetherby & Woods, 2006). These intervention strategies are most often used to facilitate imitation, communication, and joint attention.

The sixth is a Structured Teaching methodology which would be synonymous with the TEACCH approach (Mesibov, Shea, & Schopler, 2004). It would also include any treatment techniques that structure learning environments, routines, and the physical or sensory environment (Dawson, et al., 2010, Landa et al., 2011; Schertz & Odom, 2007), or that make use of object or visual schedules (Morrison et al., 2002). The intervention strategies were used to facilitate joint attention, imitation, play, general development and communication.

These early methods of intervention for toddlers and early preschool children are critical to review and operationalize because they are important in determining what outcome measures are used to measure effectiveness, what settings are used, and what agents are used for early intervention. Schertz et al., (2012) concluded that the methods used individually or in combination have evidence of a small to large magnitude of effect dependent on the focus of the intervention. Larger effects were found for interventions focusing on parent joint attention/social synchrony, with smaller but significant effects for communication, imitation, engagement, play, general development, and family well-being. The setting for the interventions was noted as the home environment for ten out of the twenty studies reviewed, and the agent was noted as the parent or caregiver in either a full or partial role in thirteen of the twenty studies (Schertz et al., 2012). In summary, this evidence strongly supports the role of the parent and the family home in the early intervention of toddlers and preschool children. The evidence further suggests that early intervention should be focused on joint attention and social synchrony to a greater degree, and communication, play, imitation, and family well-being to a lesser degree (Schertz et al., 2012).

Effective intervention strategies used by professionals and parents typically fall within one of six categories; Child Directed, Behavioural, Imitation, Prompting/Modelling, Augmentative or Alternative Communication and Structured Teaching. Finally, of the intervention strategies implemented exclusively by parents, Child Directed and Behavioural strategies have the most research support, followed by Augmentative or Alternative Communication, Structured Teaching, and Prompting / Modelling (Schertz et al., 2012). Collectively, this research highlights the fact that toddlers with ASD, and their parents, need unique clinical support.

Recently, clinical practice guidelines have been developed specifically for toddlers with ASD (Zwaigenbaum et al., 2015). These guidelines clearly recommend the involvement of parents in treatment (Summary Statement 2, Zwaigenbaum et al., 2015) and the importance of parent support and well-being (Summary Statement 4, Zwaigenbaum et al., 2015). Further, they note current best practice should include both a developmental and behavioural approach to treatment (Summary Statement 1, Zwaigenbaum et al., 2015) and include treatments that target social communication, emotional/behavioural regulation and adaptive behaviours (Summary Statement 3, Zwaigenbaum et al., 2015).

### **Parent Training Intervention Approaches**

The Parent Training intervention approaches examined in this review fall into three categories: Social Learning (Bandura, 1971; Skinner, 1953); Momentary Process (Holden, 2014); and Social Cognition (Holden, 2014). A majority of parent training research studies use a social learning approach to train parents how to use antecedents and consequences to change child behaviour (Lafasakis & Sturme, 2007). This approach highlights that parents can directly influence child behaviour and the effectiveness of the parent training is measured in child outcomes. Other parent training research studies use a momentary process approach to examine

transactional influences between the parents and the child. Parents are taught a variety of ways to react to the child's changing behaviour and need to react with different techniques to keep responsive dyadic synchrony within any given momentary interaction (Kasari et al., 2010). The effectiveness of this type of parent training is measured in both child and parent outcomes. The third type of research study uses a social cognition approach. Parents' beliefs, expectations, attitudes, perceptions, attributions, etc. are measured before the parent training and then after the parent training. Positive changes in the parents' "cognitions" are assumed to then have an influence on the child (Steiner, 2011). The effectiveness of this type of parent training can be measured in parent outcomes alone, or in both parent and child outcomes. Additionally, some of the research studies reviewed use a combination of these research approaches (Siller, Hutman, & Sigman, 2013; Tonge et al., 2006).

### **ASD Parent Training Programs.**

Parent training is defined as, "An educational effort that attempts to enhance or facilitate parent behaviours that will influence positive developmental outcomes in their children" (Steiner, Koegel, Koegel, & Ence, 2012, p. 1219). Parent training (e.g. teaching parents intervention skills) can be distinguished from psycho-education (e.g. teaching parents knowledge about autism); however, most ASD parent training programs start with some psycho-educational components as an introduction.

**Content of ASD parent training programs.** The content of parent training programs for children with ASD vary in focus and in the use of intervention methods and practices. The majority of parent training programs focus on improving beginning social interactions such as joint attention and engagement (Kasari et al., 2010; Siller et al., 2013), increasing parent responsiveness (Siller et al., 2013), and improving communication (Lang et al., 2009). Other

programs focus on reducing problem behaviours (Koegel, Koegel, & Surratt, 1992), increasing self-help skills (Kroger & Sorensen, 2010), and improving social skills (Sofronoff, Leslie, & Brown, 2004). Additionally, there are some parent training programs with a strong psycho-educational focus on increasing parent knowledge and skill level (Lerman, Swiezy, Perkins-Parks, & Roane, 2000), and decreasing parent stress (Blackledge & Hayes, 2006; Tonge et al., 2006).

**Individualized parent training programs.** Parent education is typically delivered in an individualized manner where a therapist works one-to-one with parents and their child within clinical or community settings. Individualized parent training is also used in a variety of autism treatment programs ranging from programs with a developmental focus, to programs with a behavioural focus (Greenspan & Wieder, 2006; Ingersoll & Dvortcsak, 2009; Lafasakis & Sturme, 2007). A typical approach in individualized parent training starts with direct teaching within didactic conversations and through the provision of written materials. Sequentially, or in combination, therapists will also demonstrate or model specific techniques, and then facilitate parent involvement with their children while providing direct instruction, coaching and reinforcement (Gillette, & LeBlanc, 2007). Additionally, some parent training programs video-tape parent-child interactions, and then provide didactic feedback to parents while reviewing the video (Solomon et al., 2007). Individualized parent training has been shown to be effective in developing parenting skills (McConachie & Diggle, 2007), and in the subsequent development of their children's skills (Oono, Honey, & McConachie, 2013). However, even though this type of parent education is considered "best practice" it is time consuming, costly, and is only accessible to parents when they have started formalized services for their child.

**Group parent training programs.** In the research literature, ASD group parent training programs have usually been part of larger training intervention programs that also included individualized parent training (Carter et al., 2011; Whittingham, Sofronoff, Sheffield, & Sanders, 2009). Although the immediate advantage of group training is that it is a more efficient way to manage therapist time and reduce costs, there are also secondary effects. Research from other types of Group Parent Education Programs (parent training not specific to autism) has shown that parents who participate with similar parents tend to develop a sense of solidarity which leads to the normalization of certain feelings, which can ultimately lead to a reduction in the parents' stress. Furthermore, parents can build on these classroom relationships and develop social support networks that may further facilitate stress reduction (Kerr & McIntosh, 2000).

There may also be some disadvantages to group parent training. First, the training will be more generic and less individualized to the specific child and family. Secondly, although the secondary effects of group training may be advantageous to some parents, other parents may feel intimidated by group experiences, or may simply not yet be ready to participate or share within group settings (Kerr & McIntosh, 2000).

**Telehealth and telepractice training.** To reduce costs and improve equity of access to services, parent training has been provided through telehealth and telepractice (Hall, Culler, & Frank-Webb, 2016; Ingersoll, Shannon, Berger, Pickard, & Holtz, 2017; Neely, Rispoli, Gerow, Hong, & Hagan-Burke, 2017; Vismara, McCormick, Young, Nadhan, & Monlux, 2013). Similar to Individualized and Group parent training, telehealth and telepractice parent training interventions are varied and include behavioural approaches (e.g. ABA parent training; Heitzman-Powell, Buzhardt, Rusinko, & Miller, 2014), developmental approaches (e.g. Early Start Denver Model; Vismara, McCormick, Young, Nadham, & Monlux, 2013) and naturalistic

approaches (e.g. Incidental teaching; Kobak et al., 2011). In telehealth, clinicians provide individualized teaching, coaching, and counselling in real time through telephone conference calls or through internet-based video conferencing applications. In telepractice, parents receive individualized video-conferencing as well as access to internet based educational opportunities (e.g. lectures, written materials, visuals, videos, multi-media learning modules, quizzes, etc.; Neely et al., 2017). These internet based educational opportunities can be presented in a didactic linear fashion by the clinician (e.g. a set of defined lesson plans guided by the clinician in a specific order at specific times) or in a self-guided or self-directed fashion (e.g. parents can engage in a set of on-line learning modules, independently, at any time, in any order).

A systematic review of telepractice for parents of children with ASD indicates that parents can make significant improvements in ASD treatment knowledge and intervention implementation, which can subsequently lead to improvements in children's communication and social engagement (Parsons, Cordier, Vaz & Lee, 2017). However, the authors noted that there were some mixed results and that because of a small number of studies ( $n = 7$ ), generalization should be limited. In another systematic review Neely et al. (2017), concluded that parents can increase their fidelity of intervention implementation using telepractice, that parents were highly satisfied with telepractice training (strong social validity), and that there is enough converging literature to indicate that telepractice delivery is cost efficient, time efficient, and resource efficient (Neely et al., 2017).

Researchers have also strived to understand the "active ingredients" within telepractice training and there is some evidence to support that the clinician providing 'performance feedback' to the parent through videoconferencing, is an important component in improving the fidelity of parent intervention implementation (Ingersoll & Berger, 2015; Neely et al., 2017).

However, researchers are also beginning to examine the effectiveness and efficacy of ‘self directed’ educational approaches for parents, to broaden access to services without the use of a dedicated clinician (Ferdig et al., 2010; Ingersoll et al., 2016).

**Self-Directed parent training programs.** In general, there are a variety of Self-Directed parent training opportunities that exist. Parents can simply read books, articles, or even research papers or formal training manuals (Ingersoll & Dvortcsak, 2009). In today’s world most self-directed ASD parent education and training comes from the internet (Hall et al., 2016). There are a variety of videos on You Tube at (<https://www.youtube.com>), or the Autism Speaks web site at (<https://www.autismspeaks.org>), that exemplify different ASD treatment methods, as well as more formalized internet-based learning models such as the Autism Internet Modules at (<http://www.autisminternetmodules.org>), or the Provincial Outreach Program for Autism and Related Disorders e-learning modules in British Columbia at (<https://www.autismoutreach.ca/elearning>).

There are distinct advantages to on-line self-directed parent education. Some parents for example may be self-conscious about their lack of knowledge and would enjoy the anonymity of on-line learning, as well as the ability to learn at their own pace without being judged (Hamad, et al., 2010). They would also be able to retake the lessons at any time, to help in the original learning of materials, or as reviews to help with maintenance of learning over time. On-line training is also easily accessible and available at any time, from any location. This eliminates transportation issues, scheduling issues, and remoteness issues (Parsons et al., 2017). From the clinician’s point of view, self-directed on-line learning saves time, and is cost and resource efficient (Hamad et al., 2010). Additionally, the exact same material is often delivered in the exact same manner which can create reliability or training fidelity (Wainer & Ingersoll, 2013).

The disadvantages of self-directed on-line parent education are similar to group training in that the training is generic and not individualized to the specific child and family. Additionally, in on-line training, parents would also not reap the secondary benefits of group training such as vicarious learning, or the personalized building of social networks within the class (Kerr & McIntosh, 2000).

**Self-directed on-line parent training research.** Measuring the effectiveness and efficacy of self-directed on-line ASD parent intervention training is just beginning to be explored through empirical studies. Self-directed on-line ASD parent intervention training specifically, has been examined in seven studies to date. Changes in parent knowledge of intervention implementation has been examined in three studies (Hamad et al., 2010; Jang et al., 2012; Kobak et al., 2011), while changes in parent knowledge and observed intervention skills and subsequent changes in the child's observed skills has been examined in four studies (Ingersoll et al., 2016; Nefdt et al., 2010; Wainer & Ingersoll, 2013; and Wainer & Ingersoll, 2015).

In 2010, Hamad et al. examined an on-line parent-training program to teach parents (and other novice service professionals) behavioural intervention knowledge. After going to an online web site, parents did a knowledge pre-test, then completed three multimedia learning modules on positive reinforcement, relationship building, and prompting, and then took a post-test. The multimedia training modules included lectures, practical exercises, video demonstrations, study questions, and frequent on-line quizzes. The entire training time varied by participant from four to eight hours. The study included 51 participants of which 14 were parents (the study's methodology allowed for the specific tracking of parent results). The results for parents indicated that there was a statistically significant difference between the mean pre-test score and the post-test score [ $M (SD) p = .0001$ ; Pre-test 68.8 (15.6); post-test 82.9 (4.9)], indicating that parents

can effectively acquire behavioural ASD treatment knowledge from a self-directed on-line parent training program. Additionally, participants responded that they found the on-line modules easy to navigate, appreciated the self-directed component and found the information appropriate and applicable. The study did have some limitations, in that the study had a small sample size of parents ( $n = 14$ ), and there was a lack of a randomized control group.

In 2011, Kobak et al. investigated an on-line parent training tutorial (Enhancing Interactions) designed to teach parents knowledge on how to promote social communication skills and manage challenging behaviours in their children with ASD. Parents first completed a 24-question knowledge pre-test specific to strategies in Enhancing Interactions, then completed three on-line multi-media training modules, then completed the same 24 questions as a knowledge post-test. The multi-media training modules included text, graphics, and video that described the core characteristics of ASD and their effect on communication and behaviour, a review of teaching strategies (reinforcement, modelling and prompting), and specific strategies to enhance communication. The study included 23 parent participants. The results indicated a statistically significant difference between the mean pre-test and post-test score [ $M (SD) p = .001$ ; Pre-test 12.6 (4.2); post-test 20.4 (2.4)], indicating that parents effectively acquired ASD treatment knowledge from a self-directed on-line parent training program. Parents on average also rated user-friendliness as excellent, and found the tutorial well organized, and clearly presented. Criticisms included wanting bigger graphics, longer video's and more girls included in examples. Although this study provides further evidence that parent ASD intervention knowledge can be learned via a self-directed on-line program, the study has the same methodological limitations as Nefdt et al. (2010); i.e. no randomized control group.

In 2012, Jang et al. conducted a study to explore the effectiveness of an eLearning program

for training parents of children with ASD in the content of applied behaviour analysis (ABA). The program was a self-directed on-line training system requiring 30-40 hours to complete. The program utilized visual notes, vocal instruction, video clips, and multiple-choice quizzes; and contained 9 modules covering 15 topics (Introduction to ASD, Introduction to ABA, Introduction to Discreet Trial Training, The Antecedent, The Response, The Consequence, The Inter-Trial Interval, Prompting and Fading, Shaping, Chaining, Discrimination Training, Defining Behaviour, Functions of Behaviour, Antecedent-Based Interventions, and Consequence-Based Interventions). A 20-question multiple choice exam (randomly chosen from a pool of 109 questions during each administration) was administered pre- and post-training as a dependent measure, to a treatment group ( $n = 14$ ), and a waitlist control group ( $n = 14$ ). The results indicate that the treatment group had significantly higher change scores between pre- and post-tests compared to the waitlist control group ( $t(26) = 3.138, p = .004$ ), indicating that the self-directed on-line program was effective in increasing parent knowledge of ABA principles and procedures. Qualitatively, the authors noted that of the 17 participants that responded, all had positive feedback about the eLearning program while two participants complained about the length of the program. With the inclusion of a randomized waitlist control group this study was more rigorous than previous studies by Hamad et al., (2010) and Kobak et al., (2011), strengthening the evidence that self-directed on-line training can be effective in teaching parents ASD treatment knowledge.

In 2010, Nefdt et al. used a randomized clinical trial to study the effectiveness of a self-directed Multimedia DVD/Manual based distance education program to teach Pivotal Response Training (PRT). The study included 27 parents with no previous training in PRT, and a child diagnosed with ASD who was less than five years old. Parents first completed a demographic

questionnaire and the Parenting Stress Index (PSI: Abiden, 1995). Baseline results indicated that there were no significant differences on any of the demographic variables or the initial stress levels between the two groups (treatment and waitlist control). However, both group's mean score on the PSI indicated clinically significant levels of stress (above the 90<sup>th</sup> percentile). Before starting the training program and after the training program parents were video recorded playing with their child for a 10-minute period. Pre- and post-measures included, parent implementation of skills, parent language opportunities, parent confidence, and child communication improvement.

The parent training program included 14 training modules accessed via a self-directed Multimedia DVD with an accompanying parent manual. The content of the modules was specific to PRT and was designed to train parents how to motivate their child to engage in social communication. After completion of the 14 modules, caregivers were given the additional opportunity of viewing videos of other caregivers implementing PRT and critiquing their implementation of PRT skills through a multiple-choice format. Immediate feedback to these questions was provided by the program.

Results indicated a significant difference between the control group (CG) and treatment group (TG) at post-test on the effective implementation of PRT techniques [M (SD),  $p = .000$ ; (CG) - 5.71(7.18); (TG) - 75.35(26.61)], implementation confidence [M (SD),  $p = .001$ ; (CG) - 2.21(1.42); (TG) - 3.85(1.14)], and increased use of language opportunities [M (SD),  $p = .000$ ; (CG) - 27.86(5.40); (TG) - 75(21.31)]. Additionally, at post-test children's use of functional utterances in the treatment group were also significantly better in comparison to the control group [M (SD),  $p = .001$ ; (CG) - 16.14(6.77); (TG) - 39.12(31.45)].

Results also indicated a significant difference within the treatment group from pre-test to post-test on the effective implementation of PRT techniques ( $F = 107.02$ ,  $p = .000$ ,  $d = 4.12$ ; Pre-test mean 16.53, post-test mean 75.35), implementation confidence ( $F = 16.37$ ,  $p = .001$ ,  $d = 1.28$ ; Pre-test mean 2.6, post-test mean 3.9), and increased use of language opportunities ( $F = 91.58$ ,  $p = .000$ ,  $d = 2.23$ ; Pre-test mean 30.00, post-test mean 75.00). Additionally, children's use of functional utterances in the treatment group also significantly improved ( $F = 16.23$ ,  $p = .001$ ,  $d = 1.28$ ; pre-test mean 11.96, post-test mean 39.12).

Parents were also questioned about the ecological validity of the training program using a questionnaire answered with a 0-5-point Likert scale. Parents reported that the DVD was useful and informative [ $M(SD) = 4.62(0.50)$ ]; easy to understand [ $M(SD) = 4.77(0.43)$ ], changed the way they interacted with their child [ $M(SD) = 4.46(0.52)$ ], that they would recommend the training to other parents [ $M(SD) = 4.54(0.52)$ ], and that their child was communicating more [ $M(SD) = 3.85(0.99)$ ]. This was the first randomized controlled study to show using parent and child observation measures that parents and their children with ASD can significantly increase their skills using a self-directed Multimedia DVD/Manual based parent training program.

Wainer and Ingersoll (2013) used a single subject multiple-baseline study design to assess the effectiveness of an on-line self-directed distance learning program to teach service providers and parents Reciprocal Imitation Training (RIT). The parent sample consisted of three mothers and their children who were diagnosed with ASD. Before and after the training program parents were video recorded playing with their child for a 10-minute period. Pre and post measures included, parent knowledge of RIT, parent implementation of RIT, and child imitation skills.

The program consisted of 5 learning modules that included audio lectures, power point presentations, videos, and quizzes after each section. The first four modules were completed by

parents within 12 minutes respectively, while the fifth module took approximately 40 minutes. The entire set of modules was completed by parents over a forty-five-day period.

Results indicate that participants scored significantly better on the RIT knowledge test, pre-test [M(SD) = 68.89%(12.44%)]; post-test [M(SD) 89.44%(7.26%)]. The three parents all improved their use of RIT techniques, two to fidelity of implementation. Consequently, two children made substantial gains in imitation while one child showed a small gain. Parents were also asked open-ended questions about the ecological validity of the training program and responded that the training was helpful and easy to use, but that more video examples would have been helpful.

As this was a single subject design with a small sample size the findings need replication in a larger randomized controlled study. Additionally, the study was quite short, with no follow-up measures. This puts into question the maintenance and fidelity of treatment over time. However, the study did show through parent and child observation measures, that parents can significantly improve their knowledge and skill of intervention implementation, and that these improvements had a significant positive effect on their child.

Wainer and Ingersoll (2015) conducted a follow-up single subject multiple baseline study ( $n = 5$ ), that again measured parents use of RIT techniques after a self-directed internet-based tutorial. In addition, they also did a second measure after parents received a second session of coaching via video-conferencing. Results were similar to their 2013 study in that parents were able to increase their knowledge and skill scores after the self-directed program, however parents scored even better after the coaching sessions. Similarly, a majority of the children's skills increased after the self-directed program but increased even more after the coaching sessions.

There is also an important difference between Wainer and Ingersoll's 2013 and 2015 studies. In the 2013 study, all three parent participants were mandated to complete the self-directed on-line tutorial before post measurements. In the 2015 study, the five parents were not mandated to complete the tutorial before post measurement, and the range of completion varied from 30% to 100%. The authors noted that parents who completed 90% or more of the self-directed tutorial achieved fidelity of implementation in the post measure, while parents who completed less than 90%, achieved gains, but not fidelity of implementation. These findings provide further evidence that when self-directed on-line tutorials are utilized appropriately, they are effective. However, factors that influence the parents' use of the tutorial (e.g. stress, time, motivation) need further study.

Finally, Ingersoll et al. (2016), did a direct comparison between a self-directed on-line training program and the same self-directed on-line training program with concurrent videoconference coaching from a therapist. The on-line tutorial targeted social communication development and was adapted from Project ImPACT (Ingersoll and Dvortcsak, 2009), a Naturalistic, Developmental, Behavioural Intervention (NDBI) designed for parent mediated interventions. Parents were given pre-measures, post-measures at six months, and follow-up measures at nine months. Parent outcome measures included Parent Intervention Fidelity (observed over a 10- minute play period and a child snack), the Parent Sense of Competence Scale (PSOC) and the Family Impact Questionnaire (FIQ). Child outcome measures included Language (measured through direct observation of the parent-child interaction), and through parent questionnaire (MacArthur-Bates Communication Development Inventory). Child communication and socialization were also measured by parent interview using the Vineland Adaptive Behaviour Scales, Second Edition (VABS-II).

The on-line multimedia program included narrated slideshows with embedded video clips, quizzes, and video observation exercises with answers. The parents were also able to access a video library, to engage in an on-line forum with other participants, to access other written resources and links to relevant web-sites and received an e-mail tip-of-the-week. The program contained 12 self-directed modules each taking approximately 75 minutes to complete.

Results indicated that post-intervention parents in both treatment groups significantly increased their intervention skills, with parents in the therapist assisted group making significantly better gains than the self-directed group at post measures (self-directed pre-test [M(SD) = 1.77(.67)]; post-test [M(SD) 2.52(.78),  $p = .01$ ]; (therapy assisted pre-test [M(SD) = 1.62(.37)]; post-test [M(SD) 3.39(.76),  $p = .01$ ]. At follow-up parents in both groups maintained their increase in intervention skills, however, gains by the parents in the therapist assisted group were no longer significantly better than the self-directed group. This again suggests that self-directed on-line learning alone is effective in increasing parent intervention skills and further suggests that the long-term benefits of self-directed learning may be just as robust as therapist assisted self-directed learning. Additionally, parents improved at similar rates on self-efficacy and stress measures regardless of group assignment, providing evidence that self-directed on-line learning may be sufficient in increasing parent well-being.

Child measures of language similarly reflected the parents results in that children in both groups made significant gains at post measures, however children in the therapist assisted group did not make significantly better gains than children in the self-directed group. At follow-up children maintained their significant language gains in both groups and again the therapist assisted group did not have significantly better results than the self-directed group.

The documented advantage of therapy-assisted programming in this study was also confounded by the fact that all parents in the therapy-assisted group completed 100% of the self-directed on-line learning modules, while parents in the self-directed group on average completed only 69%. These results suggest that parent completion of the self-directed on-line training modules may be the active ingredient, instead of therapist assisted programming, in better parent and child gains in the therapy assisted group at post-measures.

In summary, these initial seven studies are limited yet promising. First, they collectively report strong efficacy and ecological validity. Parents find the self-directed on-line medium appealing (Hamad et al., 2010), easy to use (Kobak et al., 2011; Wainer & Ingersoll, 2013), and useful (Nefdt et al., 2010; Wainer & Ingersoll, 2013) highlighting the fact that parents enjoy the ease of accessibility as a major strength of the on-line medium. Constructively, parents also reported that they wanted more video examples (Kobak et al., 2011; Wainer & Ingersoll, 2013), more examples including girls (Kobak et al., 2011) and a manageable amount of content (two parents found 30-40 hours of content too much in Jang et al., 2012).

Second, the studies also provided evidence that the self-directed on-line medium can be effective in increasing parent knowledge of ASD interventions (Hamad et al., 2010; Jang et al., 2012; Kobak et al., 2011). Given these findings, we should also be able to provide parents with a variety of psycho-educational knowledge related to understanding ASD, the ASD diagnostic procedure, treatment options, community services, and stress management, as a way to not only increase relevant parent knowledge, but as a way to decrease parent stress and increase family well-being, which could also contribute to an increase in positive child outcomes. Further research is required to determine what types of parent knowledge best support family well-being.

Third, this set of studies also provides evidence that the self-directed on-line medium can be effective in increasing parents ASD intervention skills (Ingersoll et al., 2016; Nefdt et al., 2010; Wainer & Ingersoll, 2013; and Wainer & Ingersoll, 2015). The studies document that the medium can be effective in increasing parent intervention skills for singular practices such as Imitation Training (Wainer & Ingersoll, 2013), and for more comprehensive methods such as Pivotal Response Training (Nefdt et al., 2010) and Project ImPACT (Ingersoll et al., 2016). Although only these three practices have been reviewed, there is promise that self-directed on-line teaching of other practices appropriate to early parent implementation could also be effective (e.g. Prompting, Modelling, AAC, Structured Teaching, Incidental Teaching). However, further research is required in exploring the effectiveness of other evidence-based practices and methods.

Fourth, although therapist assisted self-directed on-line training has been shown to be advantageous compared to self-directed on-line training alone in parent and child skills at immediate post measures, the advantage may not be consistent in follow-up measures (Ingersoll et al., 2016). Additionally, there may not be an advantage to therapist assisted self-directed on-line training compared to self-directed on-line training alone, in increasing parent well-being (Ingersoll et al., 2016). Given that research in this area is extremely limited, more research is needed to understand where therapy assisted training is supportive, and where self-directed training alone is sufficient.

Fifth, the research reviewed highlights the potential of the on-line computer medium as a means to increase children's skills via parent education. Although only social communication and imitation skill outcomes have been reviewed, it is promising that other children's skills could also be significantly increased (e.g. joint attention, joint engagement, regulation, behaviour). Further research in additional child outcome measures is required.

Sixth, because it has been found that dosage can be a factor in parent and child outcomes (e.g. percentage of training completed by parents; Wainer & Ingersoll, 2015; Ingersoll et al., 2016), further research is required to examine the factors that influence parent completion of self-directed on-line training (e.g. demographics, levels of stress, length of training).

### **On-line Education Design Strategies**

Research indicates that there are a variety of design strategies that should be used in the development of an effective self-directed on-line course. These design strategies are related to constructionist learning theory, and to pedagogical, psychological, social and technological learning perspectives (Ghafri, 2013; Liu, Liao, & Pratt, 2009). Self-directed learning should be developed with consideration of strategies from both the cognitive and social components of constructionist theory (Ghafri, 2013; Liu et al., 2009). Pedagogical perspectives focus on the content of the course and the teaching strategies used. Psychological perspectives focus on the individual's learning disposition, perspective and needs, while social perspectives focus on the importance of social support and collaboration in the learning process. Technological perspectives focus on the technological tools used and the interface between the technology and the user. Additionally, both learning theory and learning perspectives, should be integrated in a pragmatic manner to produce an effective self-directed on-line course (Ghafri, 2013; Liu et al., 2009).

Most self-directed learning takes a constructionist view that knowledge is actively gleaned, obtained, built or constructed by a learner, rather than being passively received from a teacher (Jonassen, 1991). The construction of knowledge can occur through internal cognitive means or through a social context of interactions with others. Both are important in self-directed learning (Jonassen, 1991).

Cognitive constructionists believe we build knowledge through past experiences and through new information where we constantly internalize and reconstruct our understandings in individual and unique ways (Piaget, 1955). This means that we should scaffold self-directed learning experiences when appropriate, present individual flexibility in learning when we can, and present a variety of learning activities and strategies reflective of human learning styles (e.g. auditory, visual, kinesthetic; Ghafri, 2013; Jonassen, 1991; Liu et al., 2009).

Social constructionists believe that although there is an internal cognitive process, we facilitate this process through social discourse, and that we learn through social collaboration, discussions, negotiations, and information sharing (Palincsar, 1998). This means that self-directed learning should not be an isolated experience. Learning needs to include a social component where parents can feel safe and secure interacting with others, checking in on their learning with others, asking questions, participating in discussions, sharing information, etc. (Palincsar, 1998).

The pedagogical perspective of on-line or eLearning highlights the importance of content and teaching strategies related to self-directed learning (Liu et al., 2009). For parents of newly diagnosed children with ASD, the content should be clear and concise and divided into small units that can be accomplished within a short period of time (e.g. 30 minutes). The content should be structured to scaffold learning within lessons or units but should also be self-directed and flexible in that the parent can easily navigate the course and choose what content to address at what time (Ghafri, 2013; Liu et al., 2009; Wang, Peng, Huang, Hou, & Wang, 2008). The content and teaching strategies should also support and satisfy parents with different learning intentions and needs (e.g. content relevant for beginning and advanced learners, presented in ways to accommodate different learning styles; Ghafri, 2013; Liu et al., 2009; Wang et al., 2008).

The content should provide a variety of static definitions, explanations and demonstrations that are highlighted to enhance memory and understanding, as well as provide dynamic opportunities to explore and expand learning through additional resources outside of the course content (Ghafri, 2013; Liu et al., 2009). The learning strategies should also be dynamic in that the learner does not just passively receive information but is actively engaged with the program by having to type, or by clicking, highlighting, or dragging icons (Ghafri, 2013). The strategies for learning should also provide support for practice; and learning progress should be monitored often, through quizzes or tests (Ghafri, 2013).

The psychological perspective gives insight into how to design a course that reflects the parents' disposition, perspective, and needs. In this case, the course design should take into consideration that the parents, shortly after their child has been diagnosed with ASD, may be emotionally vulnerable, stressed, depressed, angry, or have a low frustration tolerance (Wang et al., 2008). The course should be designed so that parents can take the course from anywhere, at any time of day, from their platform of choice (e.g. computer, tablet, phone, android, Apple), and at their own pace (e.g. being able to stop and then start again later where they left off; (Liu et al., 2009, Wang et al., 2008). The course should also be “user-friendly” with a simple intuitive stress-free and aesthetic interface that presents positive learning supports through “error free” quizzes and tests (Liu et al., 2009). Finally, the course and the learning interface should provide the parent with a sense of on-line security and privacy Wang et al., 2008).

The social perspective for eLearning addresses the importance of parents constructing knowledge through an interactive process with others (Palincsar, 1998). The eLearning platform should provide easily accessible computer-mediated communication (CMC) opportunities (Liu et al., 2009) to connect with others through a variety of communication tools (e.g. email, chat

rooms, discussion forums, skype forums, blogs). The learning platform should offer easily accessible links to community support groups and on-line support groups that provide support and understanding for new parents (Ghafri, 2013; Liu et al., 2009). Additionally, learning can also be facilitated by encouraging parents to socially interact electronically with others through information sharing, collaboration, and the sharing of ideas, opinions, attitudes etc. (Palincsar, 1998). Easily accessible links should be provided for local and national web sites (Ghafri, 2013).

The technological perspective addresses the functionality of the computer platform and the interface between the computer and the parent. First, the course or modules should be fully downloadable or able to be streamed from a server to a computer without interruption (Ghafri, 2013; Liu et al., 2009). Second, the learning modules should integrate the use of text, graphics, animation, audio and video in the presentation of content when appropriate (Ghafri, 2013; Liu et al., 2009). Third, the interface should include standardized screens throughout each module and between modules to increase ease of use (Ghafri, 2013; Liu et al., 2009). Fourth, there should also be specific “guiding tools” that allows the user to navigate between screens, as well as “maps” that identify where you are in the course or module (Ghafri, 2013; Liu et al., 2009). Finally, the interface should be aesthetically pleasing, intuitive and easy to use, and have an introduction explaining how to use the interface as well as an easily accessible help menu (Liu et al., 2009).

### **Parent Stress**

Qualitative research on parent perspectives, through the early ASD diagnostic process and before a formal treatment program begins, note that parents frequently have high levels of stress (Sansosti et al., 2012). Parents report delays in getting a diagnosis, difficulty fully understanding the diagnosis, difficulty understanding their role, long wait times for receiving formalized

services for their children, difficulty in receiving professional advice as to what supports are available, and difficulty understanding the “roadmap” to present and future services (Sansosti et al., 2012). Additionally, parents feel that they will now need to significantly change their social lives to accommodate special services for their child. They are also personally concerned about their child’s communication, behaviour, social, and self-help skills, concerned about other people’s opinions, stereotyping, lack of understanding, and the social stigma of their child’s diagnosis (Papageorgiou & Kalyva, 2010; Sansosti et al., 2012). Inevitably, this laundry list of concerns leads to high levels of anxiety, stress, depression, and general mental health difficulties.

This increase in parent stress becomes especially important when we examine child outcomes of early intervention and how these outcomes are mediated and moderated by parent stress. Specifically, research has shown that with an increase in parenting stress, there is a decrease in effectiveness of early intervention (Osborne, McHugh, Saunders, & Reed, 2008; Robbins, Dunlap, & Plienis, 1991). However, when an individualized early parent training program for children with ASD does include content related to: understanding the diagnosis, understanding treatment options, and helping parents feel self-efficacious, then parenting stress has been found to decrease (Diggle, McConchie, & Randle, 2002; McAleese, Lavery, & Dyer, 2013). Second, when a component of the training focuses on parents’ knowledge of services available, managing parental stress, and family and community responses to autism; parents’ mental health scores improve (McAleese et al., 2013; Tonge et al., 2006). Third, when a training program uses a strength-based approach and positive reframing strategies (reframing negative thoughts and highlighting the strengths of children with ASD; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Hastings & Johnson, 2001; Steiner, 2011) parents become more optimistic and less stressed. Fourth, many parents receive comfort and a reduction in stress from individual

relationships (Benson, 2006), and group relationships (Crnic & Low, 2002). Mackintosh, Myers, and Goin-Kochel (2006) report that the most frequent source of parent support is other parents of children with ASD. These relationships are typically forged within formal support groups (Mandell & Salzer, 2007), e-mail forums (Huws, Jones, & Ingledeu, 2001), and recently, on-line “chat rooms” (Lock, Bradley, Hendricks, & Brown, 2013).

Given these findings, it seems prudent that early self-directed on-line parent training interventions should strategically address ways to first alleviate parent stress as a way to increase the usefulness and effectiveness of parent training (Steiner et al., 2012). Specifically, programs should address parent stress by providing psycho-educational information on the ASD diagnostic process, and an overview to normalize the typical stages of grief that parents go through after a diagnosis (Benson, 2006). Parents should be introduced to specific coping and stress management strategies, a realistic but strength-based description of ASD characteristics, and a “road-map” to local supports and services (Benson, 2006). Early parent training should also address effective parent interventions presented in a strength-based format (Steiner, 2011). Additionally, early training programs should highlight to parents the importance of increasing their psycho-social support as a means to reduce stress (Benson, 2006), and provide on-line forums or chat rooms to encourage communication and support between parents.

### **Theoretical Framework**

A Bio-ecological Systems Theory (Bronfenbrenner & Ceci, 1994) was used as a guide in examining the interactions between parent training and support, parent stress, parent knowledge and skills and subsequent child outcomes. Bio-ecological systems theory highlights the importance of transactional influences between the child and caregivers and a series of

expanding environmental contexts or systems that can influence the caregiver's knowledge, skills, and level of stress (see Figure 1; Bronfenbrenner & Ceci, 1994).

**Figure 1. Bioecological Model of Parent Support and Training for Children with ASD.**

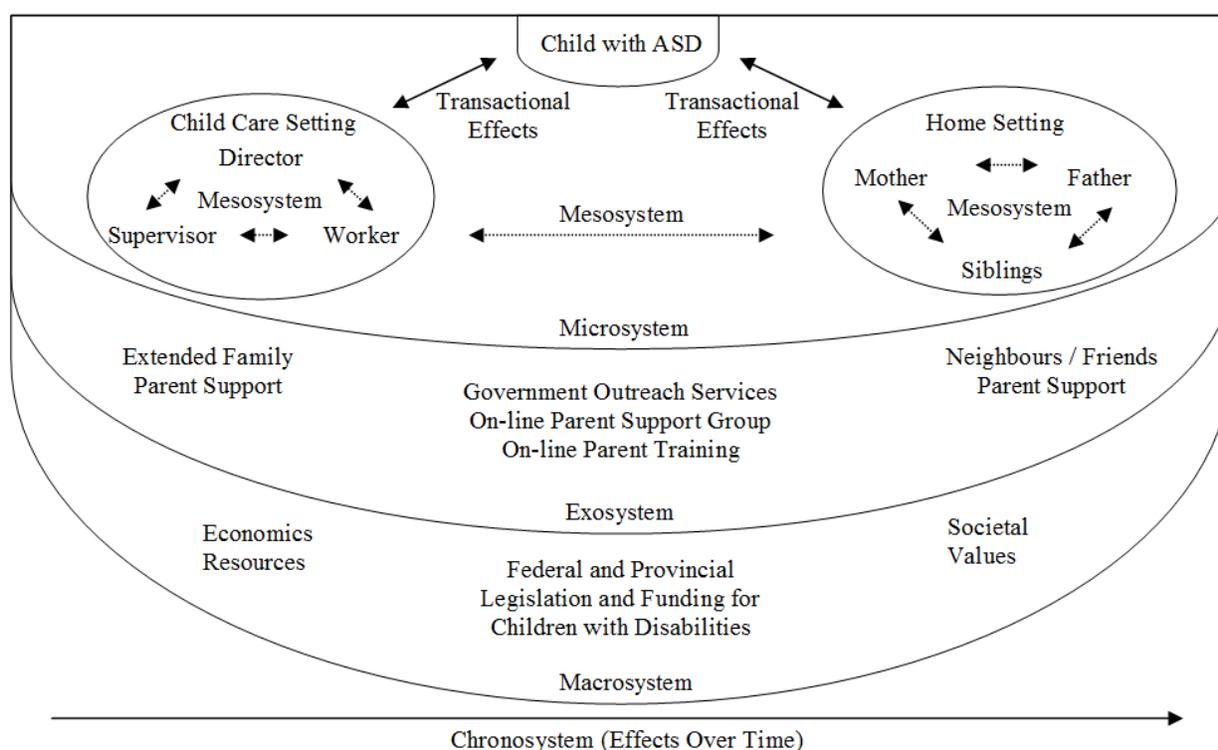


Figure 1. Inspired by "Nature-Nurture re-conceptualized in developmental perspective: A Bioecological Model" by U. Bronfenbrenner, and S. Ceci, 1994. *Psychological Review*, 101(4), 568-586.

Specifically, at the microsystem level (e.g. the family home and family members) the theory predicts the importance of naturalistic environments for young children and the transactional influence of the caregiver-child relationship (Bronfenbrenner & Ceci, 1994). In the context of the present study, if the members in the microsystem have easy access to appropriate psycho-educational and educational training so that they understand ASD, and ASD training methods, they may feel and act more understanding, confident, skilled, and less stressed, which will in turn have a positive effect on the child. At the mesosystem level (e.g. connections between micro-

systems) the theory predicts the importance of connections between family members (e.g. mother, father, and siblings working in synchrony), and other possible connections such as between childcare staff (e.g. director, supervisor, support worker) and the connections between family members and childcare staff (Bronfenbrenner & Ceci, 1994). In the context of this study, if all micro-system members receive the same ASD support and training and work in synchrony they could become less stressed, and better able to learn and implement training which could have a positive effect on the child at the mesosystem level. Additionally, at the exosystem level (a context not directly related to the child; e.g. on-line training from a social service agency, an on-line parenting support group, extended family and friends) parents receive support that can increase knowledge and skills and reduces stress, which could also have a positive effect on the child. At the macrosystem level (e.g. the cultural and political context of a society), the theory highlights how governments can value children with disabilities and fund programs (e.g. on-line parent training, on-line support groups) that support parents of children with ASD (Bronfenbrenner & Ceci, 1994). This in-turn can give parents a feeling of being valued which could reduce stress and have a positive effect on the child. At the chronosystem level (e.g. effects over time) the early timing of this training and support is crucial for developmental trajectories over the lifespan. Given this Bio-ecological systems theory perspective, preschool children with ASD should have significantly better outcomes when their caregivers utilize appropriate early training as well as receive social support and compassion from all levels of society (Bronfenbrenner & Ceci, 1994).

Finally, other theories were used as guides to contextualize the parent-training context, in a more functional way. Attachment theory guides us in considering the importance of helping parents learn specific techniques to establish and maintain affectionate bonds through sensitive

or responsive parenting (Ainsworth & Bell, 1970). Social learning theory prompts us to train parents in specific techniques like modeling (e.g. showing children what to do) and operant conditioning (e.g. rewarding children when appropriate; Bandura, 1971; Skinner, 1953) and Vygotsky's learning theory highlights the importance of learning within a social context and the use of techniques like scaffolding (e.g. creating manageable steps to learning; Vygotsky, 1978).

**Assumed determinants of parenting a child with ASD.** Belsky (1984) assumes that parenting behaviour is influenced or determined by three central variables; parent psychological resources, child characteristics, and contextual sources of stress and support. These determinants combine with each other to determine how a parent interacts with their child at any given time. Using Belsky's process model as a guide, a specific model of the determinants of parenting a child with ASD was created to frame assumptions on how parent training and social support effect parent stress, knowledge, and skills (see Figure 2).

**Figure 2. A Model of the Determinants of Parenting for a Child with ASD.**

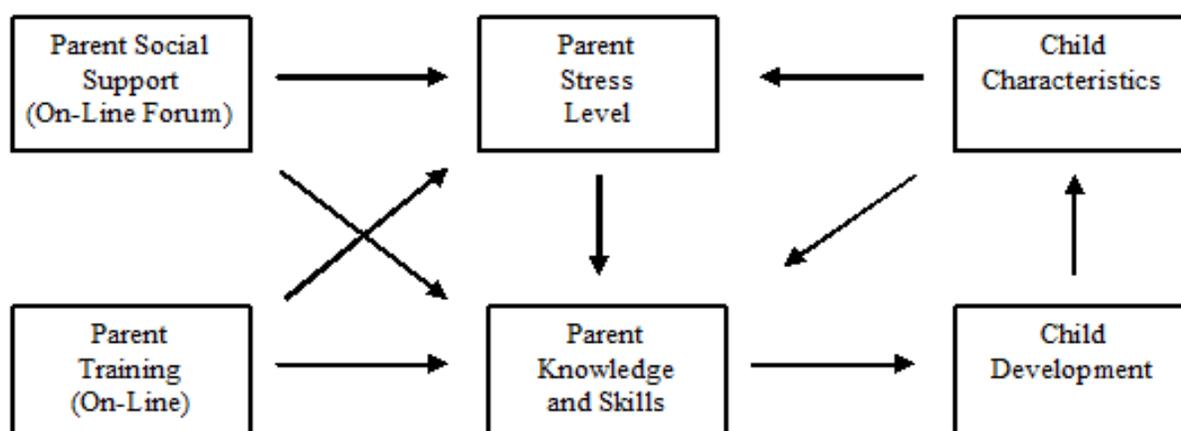


Figure 2. Inspired by "The determinants of parenting: A process model," by J. Belsky, 1984, *Child Development*, 83-96.

Within this ASD model of parenting (see Figure 2) contextual determinants play a prominent role, as parent social support and parent training is assumed to be compensatory by empowering parents and reducing child-related stressors (Belsky, 1984). Parent training is also assumed to be a powerful proximal influence in changing social cognitions so that: parental expectations are appropriate and realistic; mood is enhanced through increased parent self-efficacy; and parent empathy is facilitated by a better understanding of their child's behaviour (Belsky, 1984). Naturally, stable child characteristics and the context of situational determinants (the child's diagnosis of ASD) are also assumed to influence parenting behaviour moderated by the severity of the child's ASD characteristics. Collectively, it is also assumed that these determinants work together in an additive, moderating, and mediating way (Belsky, 1984). Parent training is assumed to: reduce the cumulative effects of stressors; to have a moderating effect on the parent child relationship; and to have a mediating effect by changing parental beliefs.

### **Literature Review Summary**

First, ASD self-directed on-line parent training programs for toddlers not enrolled in a formal program should have content focused on evidence-based interventions related to joint attention, engagement, imitation, communication, play, and family well-being, which have been shown to produce a medium to large effect on child outcomes (Schertz et al., 2012). Second, a very limited sample of studies have found that ASD on-line self-directed parent training is effective, as parents find the medium "appealing" and "useful," and results show that parent knowledge, parent skills, and child skills, can increase with training (Hamad et al., 2010; Ingersoll et al., 2016; Kobak et al., 2011; Neftd et al., 2010). Third, self-directed on-line training

design should follow a cognitive and social constructionist learning theory that addresses pedagogical, psychological, social, and technological perspectives (Ghafri, 2013; Liu et al., 2009). Fourth, bio-ecological system theory predicts the importance of early parent training and support programs; for reducing the cumulative effects of stressors on parents, supporting positive changes in parental beliefs, knowledge and skills, and in supporting positive changes in child development (Bronfenbrenner & Ceci, 1994). Fifth, more research is needed with families shortly after diagnosis to determine how self-directed on-line learning can be used to support parents in understanding ASD, family wellness, treatment, and community services, as a means to increase knowledge and reduce stress. Sixth, a high number of parents of toddlers with ASD have clinically significant levels of stress, and this possible factor needs further investigation in its relationship to parent self-directed on-line training usage and outcomes shortly after diagnosis.

The literature review reported was conducted to guide the development of an on-line self-directed training and support program designed for parents of preschool children newly diagnosed with ASD. The content and delivery design of the program was carefully developed to provide parents with a stress free, easily accessible opportunity to learn important basics about ASD, family well-being, community services, and ASD intervention strategies, within a parent supported environment. The training program consisted of six online multimedia modules that addressed ASD basics, parent stress and family support, community services, and parenting strategies related to joint attention, engagement, imitation, play, communication and behaviour. The support program was developed as a Google Group forum where parents could share information with other parent in the study.

The purpose of the present study was to develop an evidence-based self-directed on-line training program, and then evaluate its effectiveness for parents of preschool children newly

diagnosed with ASD. An additional purpose was to assess the interactional effects between the self-directed on-line ASD parent training and support program, and parent stress, on parent and child outcomes. It was predicted that parents participating in the training program would significantly increase their knowledge, intervention skills, and family support, while at the same time decreasing their levels of stress. It was further predicted that this change in parenting would lead to an increase in engagement and communication in their children. Finally, it is predicted that as the parents level of stress decreases, their knowledge and interventions skills will increase.

## **Chapter III: Method**

### **Introduction**

The following section first outlines ethics approval for the study, the participants in the study, the setting for the study, and the design and procedures of the study. Second, the independent variable is examined by reviewing the development and content of the self-directed on-line parent training and support program. Third, the parent and child dependent measures are discussed, and forth the data analysis and hypotheses are examined.

### **Ethics Approval**

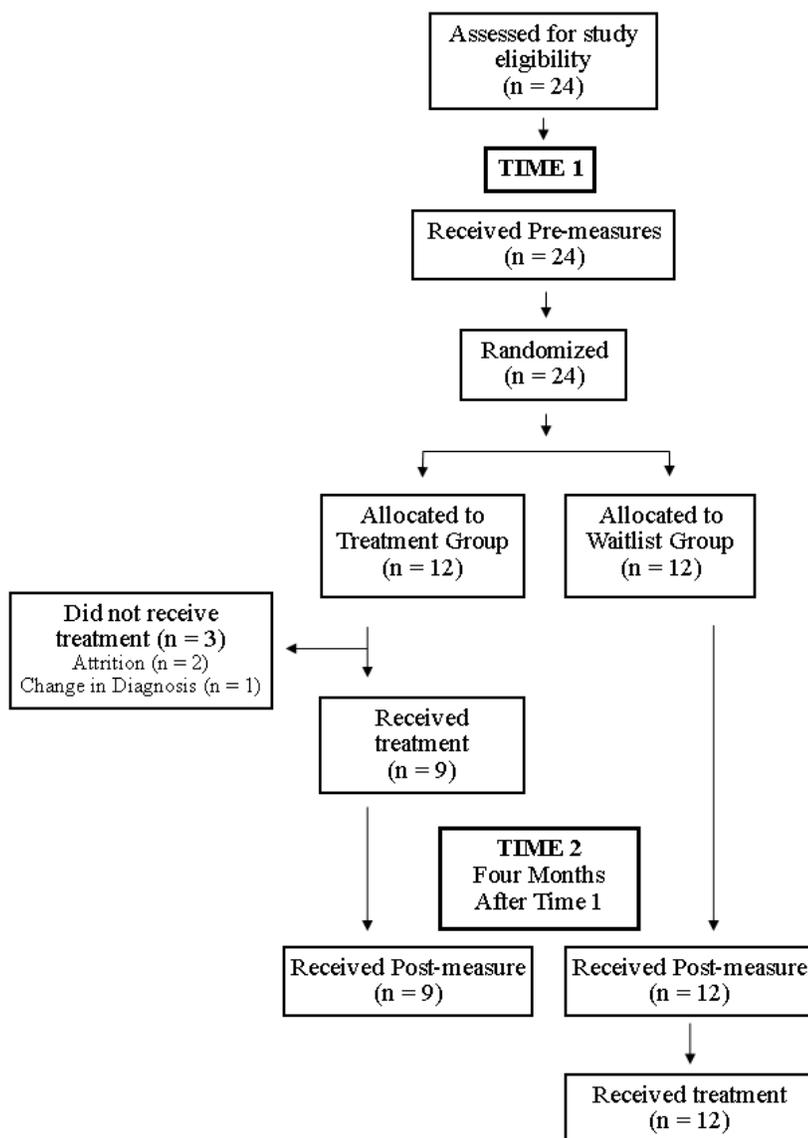
The study design and procedures were finalized and submitted to the University of Manitoba Health Research Ethics Board (HREB). The HREB granted the Certificate of Final Approval for the study in December of 2016, and reapproval in December 2017 (See Appendix A). Participant recruitment began March 2017 and continued until February 2018.

### **Participants**

Participants were recruited through the Winnipeg Child Development Clinic. The clinic provides public health care services for the multicultural urban population of greater Winnipeg, and the surrounding rural areas of Manitoba and Northern Ontario. Families were eligible for the study if their children were 60 months of age or less and had a formal diagnosis of ASD from a pediatrician at the Child Development Clinic. Additionally, on the demographic questionnaire (See Appendix B), parents needed to check “Yes” that they had access to the internet and “Yes” that they could read and write the English language. No other exclusion criteria were used as the sample was intended to be representative of the population that will eventually be offered the training program (e.g. all families who have a preschool child diagnosed with ASD, regardless of any other factors such as co-morbidity).

To estimate an appropriate sample size, previous similar randomized controlled studies were examined for sample size, and effect size (Carter et al., 2011; Dawson et al., 2010; Kasari et al., 2010; Schertz, Odem, Baggett, & Sideris, 2013). The average sample size was 42, with a range from 23 to 62 with effect size ranging from small to large. A power analysis was also used with data from a previous study (Minjarez et al., 2013). Means and standard deviations of scores on the Parenting Stress Index-Short Form for the treatment and control group were used in the ANCOVA Power Calculation PROC GLMPOWER in SAS v9.3 (Actual Power 0.804 and alpha = .05). The resulting sample size estimate required was 62 families. For this study a total of 24 families were originally recruited. One family excused themselves from the study because their child's diagnosis of ASD was removed after a second opinion, and two other families started the study but were unavailable to participate in treatment (did not access the training modules) or post-measures (See Figure 3), leaving a treatment group (n = 9) and a waitlist control group (n = 12).

Figure 3. Study Design Flow Chart



## Setting

The study was conducted at the Child Development Clinic in the Specialized Services for Children and Youth building. The clinic is Winnipeg's main diagnostic centre for preschool children, with approximately 300 children being diagnosed with ASD in 2017. The study was conducted within a nursery room setting within the Child Development Clinic. The nursery room is a typical early childhood education setting with small tables and chairs, a carpeted area for toy

play, a matted area with a small climber and slide, and shelves containing bins with a variety of toys, activities and crafts. Parents were asked to engage in play with their children in this room with a standardized set of toys for a ten-minute period, while being video recorded. Parents also filled out questionnaires in this room (see Appendix C). This setting was used twice for each parent and child, once for pre-measures and once for post-measures.

Additional settings would also include the location that parents accessed the internet to participate in the on-line training. Typically, this could be the parents home, but the training was also accessible from any setting or location where parents could access the internet. Lastly, any location that parents engaged with their children to implement the training could also be considered a setting. Specific information on additional settings was not gathered.

### **Design and Procedure**

The experimental study used a randomized, masked, waitlist control design that compared an intervention treatment group to a waitlist control group. After meeting criteria and consent requirements for participation in the study, families participated in pre-measures. Parents were measured on levels of stress, family support, ASD knowledge and ASD Intervention techniques. Children were measured on levels of social engagement and communication. Families were then randomized to either the treatment group or the waitlist control group. After pre-measures the treatment group parents received access to the on-line self-directed training and support programs for a four-month period. After four-months both groups were then re-assessed on the Parent and Child outcome measures and then the Control Group was given access to the on-line self-directed training and support programs (see Figure 3).

A prospective consecutive sample of participants was recruited through the Child Development Clinic from March 2017 to February 2018. Developmental Pediatricians at the

clinic distributed the study advertisement to parents of children newly diagnosed with ASD immediately after diagnosis. The advertisement included a brief explanation of the study and contact information for the principal investigator (see Appendix D). When contacted by participants, the principal investigator explained the study in full, the consent process, confidentiality, and answered any other questions the parents may have had. When the parents agreed to participate in the study and had signed the consent forms (see Appendix E), the principal investigator booked appointment times for the family at the Child Development Clinic Nursery Room for Pre-measures.

In the nursery room setting, one parent was asked to engage in free play with their child similar to how they would at home (using a standardized set of preschool toys). The parent was video recorded playing with their child for a ten-minute period, and then asked to answer four questionnaires: The *Demographic Questionnaire* (Appendix B), the *Parenting Stress Index-Short Form (PSI-SF)*, the *Family Support Scale (FSS)*, and the *Parent Knowledge of ASD and Early Home Intervention Questionnaire (PKQ)*, Appendix F). This procedure occurred at baseline (Time 1, within four months of diagnosis), and after the treatment period (Time 2, at least four months after the baseline measure, but within 8 months of diagnosis; see Figure 3). After baseline measures, families were randomly assigned to the treatment group, or the waitlist control group. A permuted block design of two was used consecutively as families finished the pre-measures. The second family of a given block was assigned to either the treatment group or the control group, the first family of the block assigned to the alternate group. To address selection bias a random numbers table and a pre-arranged opaque envelope system was used to randomly assign families (random assignment concealment). Twenty-four families were originally assessed for eligibility, received pre-measures and were randomized to a treatment group (n = 12) and a

waitlist control group (n = 12). Three Treatment Group families were consequently lost to attrition, leaving a treatment group (n = 9) and a waitlist control group (n = 12) for post-measures (see Figure 3).

Treatment group parents were then given access to participate in the self-directed on-line parent training and support intervention between Time 1 and Time 2, and the waitlist group parents were given access to the intervention after Time 2 (see Figure 3). Once parents were randomly assigned to the treatment group they received an email with a link to access the on-line training. No further prompting to access the modules was given. Parents were given unique codes to access the on-line resources to allow the principal investigator to track when and for how long parents accessed the on-line training and support. Treatment group parents were invited back to the nursery setting for Time 2 measurements after a four-month period. Additionally, after a four-month period the matched waitlist group parent and child were invited back to the original setting for Time 2 measurements, after which they were given access to the on-line training and support.

**Interobserver agreement of observational measures.** In order to address ascertainment bias the personnel hired to score the observational measures (University of Manitoba undergraduate students in Kinesiology), were masked as to the participant's group assignment and time of measure. The masking procedure involved each participant being assigned a code by the principal investigator. All data contained only the code with no specific participant identifiers. Inter-observer agreement between examiners was determined in the observational measures of each parent's intervention techniques and the child's measures of engagement and communication. For these observational measures, personnel were trained by the Principal Investigator. Inter-observer agreement (number of agreements divided by the number of

agreements plus disagreements multiplied by 100) was used in the training procedure until personnel exceeded 80% agreement, on each measure, for two consecutive observation trials. Additionally, after all observation data had been collected, reliability was calculated for a random sample of 20% of the observations, for each measure, using intra-class correlation.

**Self-directed on-line parent training and support program.** The independent variable was the self-directed on-line parent training and support program. The self-directed on-line modules were created in Microsoft power-point and then converted to an html on-line format using iSpring Suite, version 8.3.1, build 16521, by iSpring Solutions Inc. The html compliant modules were then uploaded to a secure password protected internet server on the iSpring Cloud. The quizzes in the modules were created using iSpring QuizMaker by iSpring Solutions Inc.

The modules were designed to reflect constructionist learning theory and pedagogical, psychological, social and technological learning perspectives. The secure on-line program consisted of six self-directed on-line training modules that could be accessed 24 hours a day using a computer, tablet or smart phone, running PC, Apple or Android software. Parents were also given an accompanying workbook with six sections corresponding to the six on-line modules. The modules were designed to accommodate different learning styles. Each on-line module contained multi-media presentations (e.g. text, graphics, animations, video presentations, navigation maps, and quizzes) and utilized an interface with standardized screens to increase ease of use. Parents could access sections or chapters in any order they preferred (e.g. the learning content was non-linear) and were able to interact with other parents taking the training through the on-line parent support forum Google Group. The content presented was clear and concise and divided into small sections that could be accomplished in a 20-30-minute period. Additionally, content was presented to facilitate basic learning (e.g. definitions, diagrams,

explanations, demonstrations, quizzes) within the program, as well as providing opportunities to expand learning through additional links to outside information on the internet. Written material was presented at a grade five reading level when possible, but sections did range from a Grade 5 to a Grade 16 level across the entire program as measured by the Flesch-Kincaid Grade Level statistic in Microsoft Word. The modules were also designed to be user-friendly and included a tutorial, help menu, standardized screens and navigations maps. For a screen shot example of the on-line self-directed training program see Figure 4.

Figure 4. Parent Autism Learning Modules Screen Shot.

MODULE 1	PARENT AUTISM LEARNING MODULES	
HOME	HELP	
TABLE OF CONTENTS	MODULE 1 UNDERSTANDING AUTISM SPECTRUM DISORDER	
WHAT IS AUTISM?	<h2>What Is Autism?</h2> <p><b>Autism or Autism Spectrum Disorder (ASD) is a complex neurobiological condition based in the brain.</b></p>	
HISTORY OF AUTISM		
DIAGNOSIS		
CAUSES OF AUTISM		
MODULE 1 QUIZ 1		
CO-OCCURRING DISORDERS		
HOW COMMON IS AUTISM		
AUTISM CHARACTERISTICS		
AUTISM MYTHS AND FACTS		
MODULE 1 QUIZ 2		
RETURN TO START	<p>Click the Tabs Below</p> <p>READ THE TEXT</p> <p>PLAY THE MOVIE</p> <p>VIEW THE NOTES</p> <p>RESOURCES</p>	
EXIT	PREVIOUS PAGE	NEXT PAGE

The content of the training program was developed based on the literature review of evidence-based practices appropriate for toddlers and preschoolers, and the literature review related to parent stress and parent intervention. Once developed the content was vetted by Early Autism Specialists from the Province of Manitoba. Re-organizations and revisions were made to

reflect content currently provided by Autism Specialists in the Pre-school Autism Service, Children's Disability Services, Department of Families, Province of Manitoba.

The program focused on six topics presented in 12 sections.

#### Module 1. Understanding Autism Spectrum Disorder

Section 1. What is Autism Spectrum Disorder; History of Autism; How is ASD Diagnosed; Causes of ASD.

Section 2. Co-Occurring Disorders; How Common is ASD; Characteristics of ASD; Autism Myths and Facts.

#### Module 2. Dealing with the Diagnosis

Section 1. Reactions to the Diagnosis; Grieving the Diagnosis; Dealing with Stress.

Section 2. Family Support; Telling Others; Moving Forward; Additional Resources.

#### Module 3. Understanding and Navigating Services

Section 1. Understanding Your Role as a Parent; Navigating Provincial Services.

Section 2. Types of Autism Treatment; Related Autism Treatments.

#### Module 4. Beginning Parent Intervention at Home

Section 1. Parent Intervention at Home; Your Child's Learning Profile – Temperament.

Section 2. Your Child's Learning Profile – Sensory; How Children Learn Through Interactions; Additional Resources.

#### Module 5. Parent Intervention – Setting the Stage for Engagement

Section 1. Creating Environments for Learning; Responsiveness Parent Teaching Strategies.

Section 2. Behavioural Parent Teaching Strategies; Parent Strategies for Promoting Engagement.

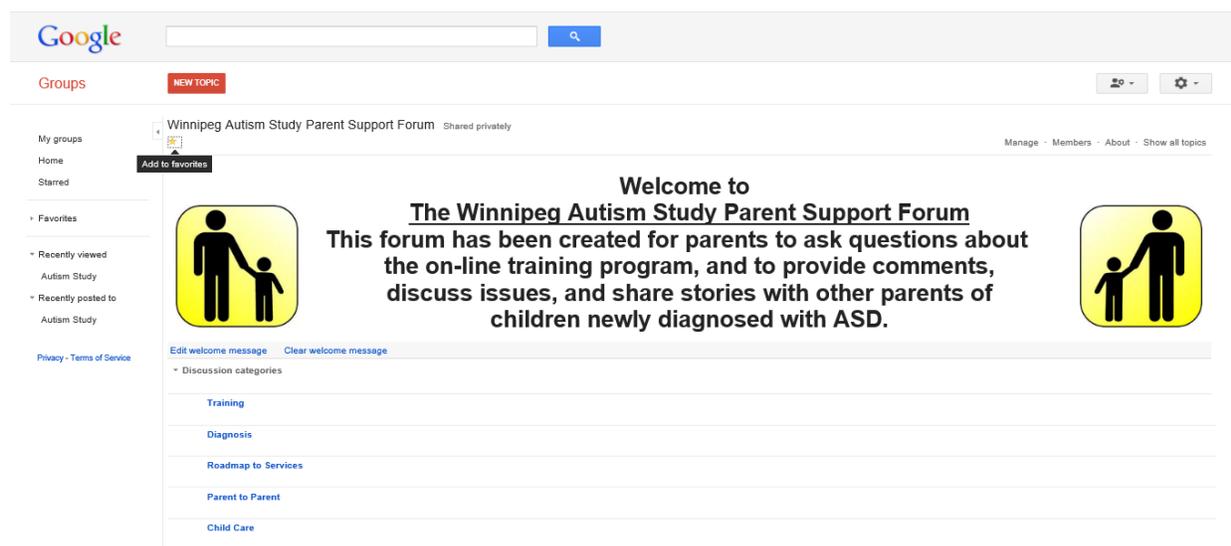
## Module 6. Parent Intervention – Imitation, Play and Communication

Section 1. Parent Strategies for Promoting Imitation; Parent Strategies for Promoting Play.

Section 2. Parent Strategies for promoting Non-Verbal Communication; Parent Strategies for Promoting Verbal Communication.

In addition to the on-line self-directed training, parents were also directed to an on-line parenting support and information sharing forum exclusive to the parents in the training program. This forum was provided as an internet approximation to group support that has been found to be an important component of the group training experience for parents of children with ASD (Mackintosh et al., 2006). Through the on-line forum parents were able to access other parents involved in the study, and were able to ask questions, answer questions, provide comments, and in general receive support and give support to others. The platform used for this forum was Google Groups. For a screen shot of the on-line parenting support and information sharing forum see Figure 5. Parents received individual access codes to the on-line resources allowing the investigator to track progress. Parents were also given a phone-line support number in case they experienced any technical difficulties.

Figure 5. Google Groups On-Line Parent Support Forum Screen Shot



**Dependent measures.** Outcome measures were collected to measure parents' level of stress (Parent Stress Index – Short Form, PSI-SF), family support level (Family Support Scale, FSS), parent knowledge of ASD and ASD Intervention (Parent Knowledge of ASD and Early Home Intervention Questionnaire, PKQ), parent intervention techniques (Parent Observation Measure of Early Intervention Techniques, POMEIT), and amount of parent training completed. The child outcome measures included observational assessments of child/parent engagement and child expressive communication.

**Parent outcome measures.** *Parenting Stress Index-Short Form* (PSI-SF; Abiden, 1995). The parents' level of stress was measured pre- and post-intervention using the PSI-SF. The PSI-SF was chosen because it has been found to be a valid and reliable instrument for measuring parent stress with a variety of parent groups including parents of children with autism (Zaidman-Zait, et al., 2011). Parents responded to 36 items (e.g. "I feel trapped by my responsibilities as a parent." "I feel alone and without friends.") using a five-point scale from 1 (strongly agree) to 5 (strongly disagree). All 36 items were then reverse scored with a final higher score indicating a higher level of stress. The overall score (range 36-180) of parent stress was produced, as well as three

subscale scores; Parental Distress (PD), Parent–Child Dysfunctional Interaction (P-CDI), and Difficult Child (DC). The short form is correlated to the full-length PSI at .94 and has an internal consistency coefficient alpha of .91 for the total scale, .87 for (PD), .80 for (P-CDI), and .85 for (DC); and a test-retest reliability coefficient of .84 for the total scale, .85 for (PD), .68 for (P-CDI), and .78 for (DC) (Abidin, 1995). Additionally, internal consistency was calculated for the data collected in this study for the PSI-SF using Cronbach’s alpha; total scale .90; (PD) .91; (P-CDI) .81; and (DC) .88.

*Family Support Scale* (FSS; Dunst, Jenkins, & Trivette, 1984). The FSS was chosen to identify and quantify the sources of the parents’ social support network pre- and post-intervention. This scale was selected because it has been found to be a valid and reliable measure of family support for parents in early intervention studies (Hanley, Tasse, Aman, & Pace, 1998). Parents responded to 18 items (e.g. My Friends, Co-workers, Day Care, Other parents, etc.) regarding a single question, “How helpful has each of the following been to you in terms of raising your child?” Parents’ respond by using a five-point scale from 0 (Not available) to 5 (Extremely helpful) to produce a total overall score (Range 0 – 90). The Scale has an internal coefficient alpha of .79, and a test-retest reliability coefficient of .91 (Dunst et al., 1984). Cronbach’s alpha for data in this study was (.75). For this study total overall score on the Family Support Scale was reported.

*Parent Knowledge of ASD and Early Home Intervention Questionnaire (PKQ)*. This questionnaire was developed specifically for this study to assess the parents’ perceptions of their knowledge of ASD and early home intervention techniques pre- and post-intervention. The content of the questionnaire reflects general knowledge and understanding of ASD and early intervention, and specific content taught in the self-directed on-line training program. The

questionnaire was initially developed and then reviewed and revised in consultation with preschool autism specialists with the Province of Manitoba. After revisions the number of questions was finalized at 30 and the readability was rated at a grade 7 level using the Flesch-Kincaid statistic in Microsoft Word.

Parents responded to 30 questions related to the diagnosis of ASD (e.g. *I understand how ASD is diagnosed.*); characteristics of children with ASD (e.g. *I understand why my child may have unusual sensory interests*); parental support (e.g. *I know the services available in the community to support my child and family*); and parent early intervention techniques (e.g. *I know ways to promote communication in my child*) using a 5 point scale from 1 (no understanding) to 5 (an excellent understanding) to produce an overall score (range 30 to 150). The *Parent Knowledge of ASD and Early Home Intervention Questionnaire* is found in Appendix F. Cronbach's alpha for data in this study was (.96). Because this is a new measure the test-retest reliability coefficient is not available.

*Parent Observation Measure of Early Intervention Techniques (POMEIT)*. This observation measure was used to assess the parents use of early intervention techniques during the pre and post 10-minute video recorded parent/child play sessions. The observation measure was developed specifically for this study to assess the parents use of the early intervention techniques specific to the training involved in this study. The operational definitions for the observation measure were initially developed and then reviewed and revised in consultation with preschool autism specialists with the Province of Manitoba and two University of Manitoba undergraduate students hired as personnel to score the observational measures. Using the observation measure, the personnel watched the 10-minute video across twenty, 30-second time sampled intervals and scored the parents within each interval on their usage of seven early

intervention techniques addressed in the on-line training; 1) Follows the Child's Lead/Engages Child, 2) Promotes Communication, 3) Reciprocity/Turn Taking, 4) Expanding/Modelling, 5) Imitation, 6) Promotes Regulation, and 7) Promotes Appropriate Behaviour. In the first three intervention techniques 1) Follows the Child's Lead/Engages Child, 2) Promotes Communication, and 3) Reciprocity/Turn Taking, parents were given a (+) if they engaged in the intervention technique 50% or more of the time during a specified 30-second interval, and a (-) if they engaged in the intervention technique less than 50% of the time. For the last four intervention techniques 4) Expanding/Modelling, 5) Imitation, 6) Promotes Regulation, and 7) Promotes Appropriate Behaviour, parents were given a (+) if the technique was used once within the 30 second interval, a (-) if the technique was not used when it could have been used, and NA if it was not appropriate or not required to be used within that time interval. The frequency count for each intervention technique across the 20 intervals was then totaled to provide the percentage of time that the parent used each technique within the 10-minute play session. The average across the seven intervention techniques was then calculated for a total percentage score. After all the observation data had been collected and scored a random sample of 20% of the observations were re-scored to check for reliability. The intra-class correlation was .87,  $p = .06$ . Cronbach's Alpha for the data in this study was (.74). The rating scale is provided in Appendix G; the intervention techniques operational definitions in Appendix H.

***Child outcome measures.*** The following dependent variables were related to the child's progress in response to parent training. Two developmental variables were monitored; changes in the child's engagement with the caregiver, and changes in the child's use of expressive communication.

*Joint Engagement Measure.* An observational measure was used to evaluate the child's level of joint engagement with the parent during the pre and post 10-minute video recorded parent/child play session. An evaluation of joint engagement was chosen as it is an important metric of parent child interactions, an important developmental precursor to communication, and a measurement that has been shown to be sensitive to treatment related changes for toddlers and early preschool children (Kasari, Freeman & Paparella, 2006; Kasari, Paparella, Freeman & Jahromi, 2008; Kasari et al., 2010; Schertz et al., 2013). The 10-minute parent/child video recorded play session from both pre and post intervention were observed continuously and coded in 5 second intervals for three levels of child engagement: Unengaged, Object Engagement, and Joint Engagement (see Appendix I for operational definitions). A data collection sheet for the time sampling procedure was used to record 120 five-second intervals, which totalled 10 minutes (see Appendix J). The frequency count for each exclusive category was then totaled to provide the percentage of time that the child spent in each level of engagement. Percentage of time in Joint Engagement was used for data analysis. After all the observation data had been collected and scored, a random sample of 20% of the observations were re-scored to check for reliability. The intra-class correlation was .89,  $p = .05$ .

*Expressive Communication Measure.* An observational measure was used to evaluate the child's expressive communication during the pre and post 10-minute video recorded parent/child play session. An expressive communication measure was chosen because it is a core deficit of ASD and a common outcome measure used to evaluate parent training interventions for toddlers and preschoolers with ASD (Beaudoin, Sebire, & Couture, 2014). The 10-minute parent/child video recorded play session from both pre and post intervention was observed continuously and coded in five second intervals for five levels of child expressive communications: Gestures,

Vocalizations, Word approximations, Words, and Multi-word utterances. Operational definitions from Harjusola-Webb and Robbins (2011), were used for the five levels of expressive communication and are listed in Appendix K. A data collection sheet was used to record a frequency count in each category over the 10-minute video recorded caregiver/child play session (see Appendix J). After all the observation data had been collected and scored a random sample of 20% of the observations were re-scored to check for reliability. The intra-class correlation was .99,  $p = .002$ .

*Data Integrity Measures.* Although the present study had participants randomly assigned to the treatment and control groups, the demographic composition of both groups was examined post hoc. Comparisons between the two groups were measured using a chi-square test for independence (with Yates continuity correction and  $p =$  Fisher Exact test) for categorical variables and t-tests (two-tailed) for continuous variables.

*Training Completion Measure.* Parents use of the on-line learning modules was tracked between Time 1 and Time 2, for the rate of completion of 12 sections over the six Modules. A parent was rated as completing a section when they completed the quiz at the end of the section. The number of quizzes completed out of 12 and the corresponding percentage of completion was calculated. The relationship between parent training completion percentages and change in parent and child outcomes from Time 1 to Time 2 was also calculated using a Pearson correlation coefficient. Parents' use of the on-line support forum was also tracked. Total number of comments was calculated.

## **Data Analysis**

All statistical analysis for the study was conducted in IBM SPSS Statistics, version 25. Statistical significance for all data analysis in the study was set at  $p \leq .05$ . Where applicable all

data analysis was done using two-tailed testing to explore relationships between variables. A modified intention-to-treat analysis was used to examine data (i.e. participants were only excluded if they did not participate in any of the treatment). The intention to exclude was determined before the post-measure data was analysed.

### **Hypotheses**

Four a priori hypotheses were tested for statistical significance. The first hypothesis was: Parents in the treatment group will have significantly different Family Support, Perceived Knowledge, Parent Intervention Techniques, and Stress scores at Time 2, compared to the control group. This hypothesis was tested individually for each measure using an Analysis of Covariance design (ANCOVA) to test for differences between groups while adjusting for any initial difference in individual scores. For example, the dependent variable was the post-test Parent Perceived Knowledge scores (ordinal, range 36-150), the independent variable was the Treatment Group versus the Control Group, and the covariate was the pre-test Parent Perceived Knowledge score. This was also done for the Parent Stress measure (ordinal, range 1-100), the Family Support measure (ordinal, range 0-90), and for the Parent Intervention Techniques measure (ordinal, range 0-100).

The second hypothesis was: Children of parents in the treatment group will have significantly different scores in Engagement and Communication at Time 2 compared to children of parents in the control group. This hypothesis was tested individually for each measure using an Analysis of Covariance design (ANCOVA) to test for differences between groups while adjusting for any initial difference in individual score. For example, the dependent variable was the post-test Engagement scores, the independent variable was the Treatment Group versus the Control Group, and the covariate was the pre-test Engagement scores. This was also done for the

Child Communication measure. Engagement differences were measured with the percentage of time in Joint Engagement (ordinal, range 0-100). Communication differences were measured through the combined frequency count of the five communication sub-scales (ordinal, range 0-120).

The third hypothesis was: Parents' perceived level of stress at Time 1 will influence the treatment effects on parent outcomes measures of Perceived Knowledge and Intervention Techniques at Time 2. Specifically, it was hypothesized that there will be a negative (inverse) correlation between parent perceived stress percentile scores at Time 1 and Parent Perceived Knowledge and Intervention Technique scores at time 2 (the lower the parents' stress score at Time 1, the higher the parents' Perceived Knowledge and Intervention Technique scores at Time 2). Additionally, it was hypothesized that there will be a negative (inverse) correlation between the parents' change in perceived stress percentile scores from Time 1 to Time 2 to parents' change in Perceived Knowledge and Intervention Technique scores from Time 1 to Time 2 (as parents perceived level of stress decreases from Time 1 to Time 2 parents' Perceived Knowledge and Intervention Technique scores will increase from Time 1 to Time 2). Correlations were conducted using Pearson's product-moment ( $r$ ) calculations.

The fourth hypothesis was: Parents' perceived level of stress at Time 1 will influence the treatment effects on child outcomes measures of Engagement and Communication at Time 2. Specifically, it was hypothesized that there will be a negative (inverse) correlation between perceived parent stress percentile scores at Time 1 and child Engagement and Communication scores at time 2 (the lower the parents' stress score at Time 1, the higher the child Engagement and Communication scores at Time 2). Additionally, it was hypothesized that there will be a negative (inverse) correlation between the parents' change in perceived stress percentile scores

from Time 1 to Time 2 to the children's change in Engagement and Communication scores from Time 1 to Time 2 (as parents perceived level of stress decreases from Time 1 to Time 2 the Child's Engagement and Communication scores will increase from Time 1 to Time 2).

Correlations were conducted using Pearson's product-moment ( $r$ ) calculations.

## Chapter IV: Results

### Participant Data

The mean age of parent participants was 36 years, with a range in age from 21 to 49 years. Most parent participants were female (81%), married (86%), employed (71%), and had a university degree (67%). The mean age of child participants was 40 months, with a range in age from 27 to 60 months. Most of the child participants were Caucasian (62%) and male (76%) and lived in a household with two children ( $m = 1.8$ , range 1-6) and two adults ( $m = 2$ , range 1-3). Detailed participant demographic information for both the treatment and control group is presented in Table 1.

Table 1  
Participant Demographic Information

	Group		
	Treatment (n = 9) n (%)	Control (n = 12) n (%)	Total (n = 21) n (%)
<b>Child Characteristics</b>			
Gender (female)	1 (11)	4 (33)	5 (24)
Age in months <i>M (SD)</i>	39 (10)	42 (7)	40 (8)
Age in months ( <i>min. - max.</i> )	(27 - 60)	(31 - 53)	(27 - 60)
<b>Parent Characteristics</b>			
Gender (female)	7 (78)	10 (83)	17 (81)
Married	8 (89)	10 (83)	18 (86)
Age in years <i>M (SD)</i>	36 (7)	37 (3)	36 (5)
Age in years ( <i>min. - max.</i> )	(25 - 49)	(32 - 42)	(25 - 49)
<b>Education</b>			
Some university	4 (44)	3 (25)	7 (33)
University degree	3 (33)	6 (50)	9 (43)
Graduate degree	2 (22)	3 (25)	5 (24)
<b>Employment</b>			
Employed	7 (78)	8 (67)	15 (71)
Homemaker	2 (22)	4 (33)	6 (29)
<b>Ethnicity (self-report)</b>			
Asian	1 (11)		1 (5)
Brazilian		1 (8)	1 (5)
Canadian	1 (11)	1 (8)	2 (10)
Caucasian	2 (22)	7 (58)	9 (43)
Filipino	2 (22)		2 (10)
Hispanic	1 (11)		1 (5)
Icelandic	1 (11)		1 (5)
Indian		1 (8)	1 (5)
Korean		1 (8)	1 (5)
White	1 (11)		1 (5)
Not reported		1 (8)	1 (5)
<b>Family Characteristics</b>			
Adults in home <i>M (SD)</i>	2.1 (0.60)	1.9 (0.29)	2.0 (0.45)
Children in home <i>M (SD)</i>	2.2 (1.48)	1.5 (0.67)	1.8 (1.12)

Note. *n* = number; *M (SD)* = Mean (Standard Deviation); *min. - max.* = Minimum age - Maximum age

## Data Integrity

The demographic composition of the treatment and control group was examined post hoc. Comparisons between the two groups were measured using a chi-square test for independence (with Yates continuity correction and  $p =$  Fisher Exact test), for the categorical variables, and t-tests (two-tailed) for the continuous variables. Testing revealed that the treatment and control groups were not significantly different on any demographic variables at the start of the study (see Table 2).

Table 2

### Group Demographic Comparisons

	Group		Test statistic	$p$ value
	Treatment n = 9	Control n = 12		
<b>Child Characteristics</b>				
Age in months $M$ ( $SD$ )	39 (10)	42 (7)	-.57 <sup>b</sup>	.58
Gender female n (%)	1 (11)	4 (33)	.44 <sup>a</sup>	.34
<b>Parent Characteristics</b>				
Age in years $M$ ( $SD$ )	36 (7)	37 (3)	-.57 <sup>b</sup>	.57
Gender female n (%)	7 (78)	10 (83)	.00 <sup>a</sup>	.99
Married n (%)	8 (89)	10 (83)	.00 <sup>a</sup>	.99
University degree n (%)	5 (55)	9 (75)	.22 <sup>a</sup>	.40
Employed n (%)	7 (78)	8 (67)	.01 <sup>a</sup>	.66
Ethnicity/Race (White/Caucasian) n (%)	6 (66)	8 (67)	.004 <sup>a</sup>	.67
<b>Family Characteristics</b>				
Adults in home $M$ ( $SD$ )	2.1 (.60)	1.9 (.29)	.99 <sup>b</sup>	.34
Children in home $M$ ( $SD$ )	2.2 (1.48)	1.5 (.67)	1.50 <sup>b</sup>	.15

Note.  $n$  = number;  $M$  ( $SD$ ) = Mean (Standard Deviation); <sup>a</sup> Chi-square test for independence (Yates correction;  $p =$  Fisher's Exact test); <sup>b</sup> t-test (two-tailed)

All data for the study was collected from the beginning of March 2017 to the end of February 2018. During this time 24 families started the study, three families were lost to attrition over the course of the study, which left a data set of  $n = 21$  for analysis. The data set was

checked for accuracy and was found to be complete (no missing data). Normality testing using the Kolmogorov-Smirnov statistic was conducted on the data sets for the four parent measures, and the two child measures. Data sets for the Parent Knowledge Questionnaire, Family Support Scale, Parent Observation Measure of Early Intervention Techniques, and Child Expressive Communication Measure were found to have a normal distribution ( $p > .05$ ). The Child Engagement Measure data was found to have a negative skewness  $-1.81$  ( $SE = .51$ ) and did not meet normality ( $p = .001$ ). However, given that parent participants were directed to “play” with their child, elevated levels of engagement were expected. A reflect and logarithm transformation was used to normalize the distribution. The Parenting Stress Index – Short Form data also had a negative skewness  $-1.15$  ( $SE = .50$ ) and did not meet normality ( $p = .005$ ). Again, this was expected as the literature clearly reports that parents of children newly diagnosed with ASD often have elevated levels of stress (Papageorgiou & Kalyva, 2010; Sansosti et al., 2012). Given that values for asymmetry between  $-2$  and  $+2$  are considered acceptable for normal univariate distribution (George & Mallery, 2010), a skewness of  $-1.15$  was considered appropriate for further parametric analysis. This data set was also found to have one outlier participant, but because the 5% trimmed mean and the actual mean were quite similar ( $TM = 85.47$ ,  $M = 83.90$ ) the participant was retained in the data set. Finally, because the data did not violate the assumption of homogeneity ( $F = 1.64$ ,  $p = .22$ ), it was considered appropriate for further parametric analysis.

### **Parent Training Completion**

Of the 12 cases in the treatment group data set, a total of nine treatment participants accessed the self-directed on-line training modules (with attrition the Treatment Group went from 12 to nine). Parents use of the on-line training modules was tracked using three metrics: (1) the

number of logins to the website, (2) the number of hours and minutes logged into the website, and (3) the percentage of section quizzes completed at the end of each section. The average number of logins to the website, per participant, was 7.3 times, with a range of 1 through 19. The average number of hours and minutes logged into the website was 23 hours, 59 minutes (per family Time 1 to Time 2). However, this metric was not deemed useful as inspection of the data revealed extreme outliers (e.g. 92 hours) which could indicate that the participants' computer may have remained logged in after the participant had stopped engagement with the program. The average percentage of section quizzes completed was 71% with four of the nine parents completing 100% of the Modules (See Table 3). Completion percentages were also calculated for each section of the training, and for the first half of the training (modules related to family well-ness) and for the second half of the training (modules related to parent intervention at home; See Table 3).

Table 3

*On-line Training Participant Completion Percentages*

Module Sections	Completion %	
	Per Section	Per Half
1A. What is ASD	100%	
1B. ASD Characteristics	78%	
2A. Reactions to the Diagnosis	78%	85%
2B. Family Support	78%	
3A. Navigating Provincial Services	89%	
3B. Types of ASD Treatment	89%	
4A. Parent Intervention at Home	78%	
4B. How Children Learn	56%	
5A. Responsiveness Strategies	67%	57%
5B. Behavioural and Engagement Strategies	44%	
6A. Promoting Imitation and Play	56%	
6B. Promoting Communication	44%	

Treatment Participants	Completion % of all sections
1	33%
3	50%
1	58%
4	100%
9	71%

The parent training completion percentages were also examined regarding their association to changes in parent and child outcome measures from Time 1 to Time 2. A small positive correlation between parent training completion and parent perceived knowledge was found, but the correlation was not found to be statistically significant at  $p = .05$ , (see Table 4; Cohen, 1988). A moderate positive correlation between parent training completion and parent intervention skills was found, but the correlation was also not found to be statistically significant at  $p = .05$ , (see Table 4; Cohen, 1988). Additionally, Parent training completion had a moderate positive correlation to Child Engagement measures, that was not statistically significant at  $p = .05$ , and a moderate negative correlation to Child Communication, that was not statistically significant at  $p = .05$  (see Table 4; Cohen, 1988).

Table 4  
*Relationship Between Training Completion Percentage and  
Change in Parent and Child Outcomes from Time 1 to Time 2*

Measure	Training Completion Percentage
Parent	
PKQ	$r = .22^*$ , $p = .58$ , $R^2 = .05$
POMEIT	$r = .38^{**}$ , $p = .31$ , $R^2 = .14$
Child	
Engagement	$r = .31^{**}$ , $p = .41$ , $R^2 = .10$
Communication	$r = -.39^{**}$ , $p = .30$ , $R^2 = .15$

*Note.*  $n = 9$ ; PKQ = Parent Knowledge Questionnaire  
POMEIT = Parent Observation Measure of Early Intervention Techniques;  
 $r$  = Pearson correlation coefficient, \* = Small, \*\* Moderate (strength of relationship; Cohen, 1988);  
 $p$  = Statistical Significance;  $R^2$  = Coefficient of Determination

## Hypothesis 1

Parents in the Treatment Group demonstrated significantly lower post-test percentile stress scores compared to parents in the Control Group,  $F(1, 18) = 4.46$ ,  $p = .05$ ,  $\eta_p^2 = .20$ , as measured

by the Parenting Stress Index – Short Form. On average, parents in the Treatment Group reduced their stress scores on the Parenting Stress Index – Short Form 15% (81 to 66), while parents in the Control Group increased their overall level of stress 2% (85 to 87).

Parents in the Treatment Group were also found to have significantly higher post-test perceived knowledge scores compared to parents in the Control Group,  $F(1, 18) = 4.28, p = .05, \eta_p^2 = .19$ , as measured by the Parent Knowledge Questionnaire. On average, parents in the Treatment Group increased their scores on the Parent Knowledge Questionnaire 17% (101 to 127), while parents in the Control Group increased their knowledge scores 11% (92 to 108).

For the Family Support Scale, parents in the Treatment Group were found to have significantly higher post-test Family Support scores, compared to parents in the Control Group,  $F(1, 18) = 4.83, p = .04; \eta_p^2 = .21$ . On average, parents in the Treatment Group increased their scores on the Family Support scale 10% (34 to 43), while parents in the Control Group increased their Family Support scores 3% (32 to 35).

For the Parent Observation Measure of Early Intervention Techniques, parents in the Treatment Group did not show any significant differences in post-test scores compared to parents in the Control Group,  $F(1, 18) = .03, p = .86, \eta_p^2 = .002$ . On average, parents in the Treatment Group decreased their scores on the Parent Observation Measure of Early Intervention Techniques 1% (83 to 82), while parents in the Control Group decreased their Parent Observation Measure of Early Intervention Techniques 2% (82 to 80).

Table 5  
ANCOVA Results for Parent and Child Outcome Measures

Measure	Group				F	p	$\eta_p^2$
	Treatment n = 9		Control n = 12				
	Pre M (SD)	Post M (SD)	Pre M (SD)	Post M (SD)			
<b>Parent</b>							
PSI-SF	81.22 (20.90)	66.22 (31.10)	85.92 (15.24)	87.75 (12.26)	4.46	.05	.20
PKQ	101.56 (21.21)	127.44 (18.01)	92.67 (21.18)	108.83 (17.77)	4.28	.05	.19
FSS	34.56 (10.55)	43.33 (11.38)	32.17 (12.86)	35.17 (10.92)	4.83	.04	.21
POMEIT	83.22 (12.36)	82.62 (15.74)	82.14 (12.95)	80.86 (15.19)	0.03	.86	.002
<b>Child</b>							
Engagement	88.33 (8.28)	90.56 (9.55)	83.50 (17.12)	84.25 (11.79)	1.03	.32	.05
Communication	33.22 (26.42)	47.78 (32.28)	36.58 (24.41)	48.67 (30.18)	0.06	.81	.003

Note. M (SD) = Mean (Standard Deviation); PSI-SF = Parenting Stress Index-Short Form; PKQ = Parent Knowledge Questionnaire; FSS = Family Support Scale; POMEIT = Parent Observation Measure of Early Intervention Techniques. p = statistical significance;  $\eta_p^2$  = Partial eta squared

## Hypothesis 2

For the Child Engagement Measure, children in the Treatment Group were found to not have any significant difference in post-test scores compared to children in the Control Group  $F(1, 18) = 1.03, p = .32, \eta_p^2 = .05$ . On average, children in the Treatment Group increased their joint engagement scores by 2% (88 to 90), while parents in the Control Group increased their joint engagement scores by 1% (83 to 84).

For the Child Expressive Communication Measure, children in the Treatment Group were found to not have any significant difference in post-test scores compared to children in the Control Group  $F(1, 18) = .06, p = .81, \eta_p^2 = .003$ . On average, children in the Treatment Group increased their expressive communication scores by 12% (33 to 47), while children in the Control Group increased their expressive communication scores by 10% (36 to 48). See Table 5.

### Hypothesis 3

In the first step for Hypothesis 3, the relationship between parents perceived level of stress at pre-testing (PSI-SF), and parent perceived level of knowledge (PKQ) and parent use of early intervention techniques (POMEIT) at post-testing, was explored using the Pearson product-moment correlation coefficient. For parent perceived level of knowledge (PKQ) there was a small negative correlation ( $r = -.16$ ,  $n = 9$ ,  $p = .68$ ,  $R^2 = .03$ ) indicating that a lower score in parent stress at pre-testing had a small correlation to a higher score in the parents' level of knowledge at post-testing for this sample (Cohen, 1988). However, the result was not statistically significant. For parent use of early intervention techniques (POMEIT) there was a small positive correlation ( $r = .20$ ,  $n = 9$ ,  $p = .61$ ,  $R^2 = .04$ ) indicating that a higher score of parent perceived stress at pre-testing had a small correlation to a higher score in the parents' use of early intervention techniques at post-testing for this sample (Cohen, 1988). However, the result was not statistically significant.

For the second step, the relationship between the parents change in perceived level of stress from pre-testing to post-testing and change in parent perceived knowledge (PKQ) and parent use of early intervention techniques (POMEIT) from pre-testing to post-testing was explored using the Pearson product-moment correlation coefficient. For parent perceived knowledge (PKQ) there was a small negative correlation ( $r = -.27$ ,  $n = 9$ ,  $p = .48$ ,  $R^2 = .07$ ), indicating that a decrease in parent perceived stress from pre-testing to post-testing had a small correlation to an increase in the parents' level of perceived knowledge from pre-testing to post-testing for this sample (Cohen, 1988). However, the result was not statistically significant. For parent use of early intervention techniques (POMEIT) there was a moderate negative correlation ( $r = -.45$ ,  $n = 9$ ,  $p = .22$ ,  $R^2 = .20$ ), indicating that a decrease in parent perceived stress from pre-testing to post-

testing had a moderate correlation to an increase in the parent's use of early intervention techniques from pre-testing to post-testing for this sample (Cohen, 1988). However, the result was not statistically significant.

Table 6

Relationship Between Parent Stress at Time 1 to Parent and Child Outcomes at Time 2, and Relationship Between Parent Change in Stress Time 1 to Time 2 and Parent and Child Outcome Change Time 1 to Time 2.

Measure	Stress Time 1 to Outcomes Time 2	Change in Stress to Change in Outcomes
<b>Parent</b>		
PKQ	$r = -.16^*, p = .68, R^2 = .03$	$r = -.27^*, p = .48, R^2 = .07$
POMEIT	$r = .20^*, p = .61, R^2 = .04$	$r = -.45^{**}, p = .22, R^2 = .20$
<b>Child</b>		
Engagement	$r = .29^*, p = .45, R^2 = .08$	$r = -.57^{***}, p = .11, R^2 = .33$
Communication	$r = .19^*, p = .62, R^2 = .04$	$r = -.06, p = .88, R^2 = .004$

Note.  $n = 9$ ; Stress measurement - Parenting Stress Index-Short Form; PKQ = Parent Knowledge Questionnaire; POMEIT = Parent Observation Measure of Early Intervention Techniques;  $r$  = Pearson correlation coefficient \* = Small, \*\* = Moderate, \*\*\* = Large (strength of relationship; Cohen, 1988);  $p$  = Statistical Significance;  $R^2$  = Coefficient of Determination

#### Hypothesis 4

In the first step for Hypothesis 4, the relationship between the parents perceived level of stress at pre-testing (PSI-SF), and the Child Engagement and Child Expressive Communication measures at post-testing, was explored using the Pearson product-moment correlation coefficient. For Child Engagement there was a small positive correlation ( $r = .29, n = 9, p = .45, R^2 = .08$ ) indicating that a higher score in parent stress at pre-testing had a small correlation to a higher score in the child's level of Engagement at post-testing for this sample (Cohen, 1988). However, the result was not statistically significant. For the Child Expressive Measure there was also a small positive correlation ( $r = .19, n = 9, p = .62, R^2 = .04$ ) indicating that a higher score in

parent perceived stress from at pre-testing had a small correlation to higher scores in the child's level of expressive communication at post-testing for this sample (Cohen, 1988). However, the result was not statistically significant.

For the second step, the relationship between the parents change in perceived level of stress from pre-testing to post-testing, and the change in Child Engagement and Child Expressive Communication measures from pre-testing to post-testing, was explored using the Pearson product-moment correlation coefficient. For Child Engagement there was a large negative correlation ( $r = -.57$ ,  $n = 9$ ,  $p = .11$ ,  $R^2 = .33$ ) indicating that a decrease in parent perceived stress from pre-testing to post-testing had a large correlation to an increase in the child's level of Engagement from pre-testing to post-testing for this sample (Cohen, 1988). However, the result was not statistically significant. For the Child Expressive measure there was small negative correlation ( $r = -.06$ ,  $n = 9$ ,  $p = .88$ ,  $R^2 = .004$ ) indicating that a decrease in the level of parent stress from pre-testing to post-testing had a small correlation to an increase in the child's level of Expressive Communication from pre-testing to post-testing for this sample (See Table 5; Cohen, 1988). The result was not statistically significant.

## Chapter V: Discussion

Parents of preschool children newly diagnosed with ASD often experience high levels of stress and anxiety as they wait for formalized autism services for their child. The primary purpose of this study was to develop and evaluate a self-directed on-line training and support program designed to support parents after diagnosis. A review of the literature led to the development of a training program with content specific to supporting the needs of parents after diagnosis as well as content on evidence-based parent intervention strategies specific to children two to four years of age. It was hypothesized that parents who participated in the training program would decrease their level of stress and increase their perceived knowledge of ASD and ASD intervention skills, increase their level of family support, and increase their child's level of engagement and expressive communication. The secondary purpose of the study was to examine how parent stress interacted with the on-line training and support program to influence parent and child outcomes.

The results of the study show that on average the Treatment Group completed 71% of the training program over a four to six-month period with 44% of the Treatment Group completing 100% of the training program. Compared to the Control Group parents, the Treatment Group parents had statistically significantly higher post-test scores in perceived Knowledge of ASD and ASD intervention strategies, statistically significantly higher post-test scores in perceived levels of Family Support and statistically significantly lower post-test scores on perceived levels of stress. No differences between groups were found at post-measures for the parents use of intervention strategies, or for the child measures of engagement or expressive communication. Additionally, parent stress at the beginning of the study had only small, negative and positive, associations with parent and child outcomes (that were not statistically significant), but a

decrease in parent stress over the course of the study, lead to negative small, moderate and large correlations to changes in parent and child outcomes (that were not statistically significant).

Overall the results from the study support the use of the self-directed on-line program as a resource appropriate for parents of preschool children newly diagnosed with ASD.

### **Parent Measures**

In support of the first hypothesis, the results of the present study indicate that the use of the self-directed on-line training program may be an effective way for parents to significantly increase their perceived knowledge of ASD and evidence-based ASD intervention strategies. Because parent perceived knowledge was measured instead of actual knowledge it adds to the literature in that actual knowledge has only been examined in past similar studies (e.g. Hamad et al., 2010; Ingersoll et al., 2016; Jang et al., 2012; Kobak et al., 2011; Wainer & Ingersoll, 2013). It is important that parents not just increase their knowledge (which may be perceived or not), but actually feel like they have increased their knowledge. This increased self efficacy is likely to reduce parent stress, increase family well-being (Diggle et al., 2002; McAleese et al., 2013), and increase the parents' ability to provide effective early intervention for their child (Osborne et al., 2008; Robbins et al., 1991).

This latter result also supplements previous findings that parents can use a self-directed on-line medium to significantly increase their actual knowledge of ASD and behavioural ASD intervention strategies (Hamad et al., 2010; Kobak et al., 2011; Jang et al., 2012); as well as naturalistic and developmental interventions (Wainer & Ingersoll, 2013; Ingersoll et al., 2016). In addition to supplementing this emerging body of literature, the present study also adds specificity to the previous research in that parents in this study feel they were able to make significant gains in perceived knowledge immediately after diagnosis (specifically within four to

six-months), and that they were able to gain perceived knowledge in evidence-based parent mediated interventions strategies specific to two to four-year-old children. This is particularly helpful as it highlights the effectiveness of the training program as a method to provide initial intervention training to parents as they wait for later formalized intervention services. Also, in a larger context, the results also highlight the utility of the medium to support distance-learning for isolated or rural families.

The results of the present study also indicated that even though parents feel they gained knowledge of ASD and ASD Intervention strategies, they did not significantly increase their use of intervention strategies at post-measures. This finding is also reflected in the literature, as some researchers have found that for some parents', self-directed on-line training alone is not sufficient to increase parents use of intervention skills (Wainer and Ingersoll, 2013). However, other studies have found that self-directed on-line training alone has been sufficient to increase most parents use of intervention skills (Nefdt et al., 2010; Ingersoll et al., 2016). In these studies, the on-line training was quite extensive. For example, Nefdt et al., (2010), had 14 chapters of content in their training, while the training developed by Ingersoll and colleagues (2016), had 12 lessons requiring 15 hours of time to complete. Given that the on-line training content related to parent intervention in the present study contained only three modules that took approximately three to five hours to complete, it is probable that the training program was not extensive enough to significantly improve parent use of intervention strategies over the four-month period. Further, the findings suggest that a limited amount of content related to evidence-based parent intervention may be an adequate introduction to training to help parents gain knowledge, but more extensive training may be further required to increase parents use of early intervention strategies.

Another possible reason for the lack of a significant increase in parent use of intervention strategies may be related to the parents' lack of engagement with the training program. Only four of nine parents or 44%, completed the training program (see Table 3). Given that training completion has been shown to predict parents use of intervention strategies (Ingersoll & Berger, 2015), the parents low rate of engagement with the training program may also be contributing to the parents' low use of intervention strategies.

Finally, another reason for the lack of a significant increase in parent use of intervention strategies may be that the post-measures were taken too soon after the start of the training. Parents may not have been given enough time to turn their knowledge into practice. A follow-up study that measures parents' strategy use at intervals following a four-month post-measure could provide further explanation.

The results of the present study also suggest that parent use of the self-directed on-line training program is an effective method to significantly increase Family Support. Specifically, parents in the treatment group reported a significant increase in the level of helpfulness they received from others, and an increase in the number of people they found helpful. The above finding is important for a few reasons. First, families after diagnosis typically report significantly low levels of family well-being (Ekas, Whitman & Shivers, 2009), and an increase in social support has been shown to be a significant factor in increasing family well-being (Dunn et al., 2001; Ekas et al., 2008). Importantly, increases in family well-being are also associated with greater parent effectiveness in providing early intervention (Robbins et al., 1991). Second, it is important to note that the on-line training program in this study specifically directed parents to seek support from family and friends, emphasising specific information on how to tell others about the diagnosis, what types of supports to ask for, and information on local parent support

groups. Additionally, parents were provided with access to a specific parent support forum where parents could seek support from other parents in the training program. Given that Family Support increased significantly, these specific methods have initial support, but require further study. For example, support from family and friends has been shown to be more effective at reducing stress, when compared to support from formal community-based services (Boyd, 2002). Specifically, parents first seek support from their spouse, then from their extended family and friends, and then from other parents of children with ASD (Boyd, 2002). In the present study, parents accessed the on-line content related to Family Support at a high rate (i.e. 78%, See Table 3), but parents use of the on-line google group parent support forum was extremely low (e.g. two out of nine parents participated). This suggests that for the first four to six-months after diagnosis, parents may still be needing support from family and friends and may not yet have been ready to seek support from other parents of children with ASD. This brings into question the need for a parent support forum for an introductory training and support program for parents of children newly diagnosed with ASD. It may be more appropriate for parents to participate in on-line support groups at a later time, or to engage with other parents through different means. Further studies are required to investigate how parents receive support, and the utility of, and the timing of, on-line parent support forums.

The findings from the present study also indicate that parent use of the self-directed on-line training program significantly decreased parent stress. Specifically, parents in the treatment group decreased their overall level of stress by 15% while parents in the control group increased their overall level of stress by 2%. This finding is important as parents are reported to have significantly high levels of stress during and after the diagnosis (Sansosti et al., 2012), and decreases in stress are associated with better parent implemented early intervention (Osborn et al.,

2008). The above finding is also important as the on-line training was specifically designed to address parent stress by supporting their understanding of ASD, and their understanding of community-based ASD treatment services. Additionally, specific content addressed initial reactions to the diagnosis and provided content that normalized the grieving process. Parents were also introduced to specific methods to reduce physical symptoms of stress (e.g. progressive muscle relaxation), as well as the psychological symptoms of stress (e.g. Mindfulness). Additionally, on-line resources were also provided if parents wanted additional information about managing stress. Previous studies have also found that group classroom ASD parent training that addresses understanding ASD, treatment options, and stress, is effective in decreasing parent stress (Diggle et al., 2002; McAleese et al., 2013; Tonge et al., 2006). Thus, the findings from this study provide further support for including this type of content. However, more importantly, the findings from the current study indicate that this content can also be delivered effectively through a self-directed on-line training medium and provides further support for the effectiveness of self-directed on-line training programs as an effective method to provide support to parents immediately after diagnosis.

It is also important to note that previous studies have indicated that parents of children with ASD often have different stressors at different times (Papageorgiou & Kalyva, 2010; Sansosti et al., 2012). The results from the present study suggest that the training program addressed at least some of the right parent stressors at the right time (e.g. the four to six-month period after diagnosis). However, it is distinctly possible that parent stress could be reduced even further if different or additional content was addressed, or if different or additional content was addressed over a longer period or at different times. More research is required on the type and timing of content related to reducing parent stress delivered through the self-directed on-line medium.

## Child Measures

The second hypothesis was that children in the Treatment Group would have significantly higher engagement and expressive communication scores at Time 2 compared to children in the Control Group. The results from the present study show that children in the Treatment Group did not significantly increase their engagement and communication scores compared to children in the Control Group. Specifically, on average, children in the Treatment Group increased their joint engagement scores by 2% while children in the Control Group increased their joint engagement scores by 1%. For the communication measure, on average, children in the Treatment Group increased their expressive communication scores by 12%, while children in the Control Group increased their expressive communication scores by 10%. These findings differ to a similar study by Nefdt et al., (2010) who found that children in their Treatment Group did significantly increase their functional communication scores when compared to children in a Control Group. However, in the study by Nefdt and colleagues (2010), parents in the Treatment Group had also significantly increased their intervention skills compared to the Control Group, which differs to the present study. The lack of a significant increase in the child outcome measures in the present study may be directly linked to the lack of a significant increase in parent intervention skills. This finding is also supported in a similar study by Wainer and Ingersoll (2013), who found that parents who did not reach fidelity in intervention skills also had children with marginal gains. Another explanation for the children's lack of progress could be the short time period of the study. Children may not have had enough time to interact with their parents for them to learn new skills. A follow-up study that measures children's skills at intervals following post-measures could provide further explanation.

## Parent Stress and Training

The present study was also designed to provide information on how parent stress and parent self-directed on-line training interact to affect parent outcomes (Hypothesis 3). Parents' perceived levels of stress at the beginning of the study (pre-measures Time 1) were found to have small associations with parent outcomes at the end of the study (post-measures Time 2) with small effect sizes, that were not statistically significant (parent perceived knowledge,  $r = -.16$ ,  $p = .68$ ,  $R^2 = .03$ ; parent use of intervention skills,  $r = .20$ ,  $p = .61$ ,  $R^2 = .04$ ; Cohen, 1988). This finding does not support the hypotheses, as parents who started the study with low levels of stress were expected to do better than parents who were highly stressed. Comparisons to previous studies are not possible given that there is no previous ASD self-directed on-line parent training study that has looked at associations between initial parent stress and parent outcomes. A possible explanation for the unexpected outcome is that the parents' level of stress at pre-measures was uniformly high and this restricted range in scores lessened the chance to obtain significant associations (Goodwin & Leech, 2006). Additionally, the small  $n$  in the study also makes this difficult (Goodwin & Leech, 2006). Future studies with a larger  $n$  are required to explore this hypothesis further.

Similar to parent initial stress, a decrease in parent stress over the course of the study, was found to have a small negative correlation to an increase in parent knowledge of ASD and ASD intervention strategies, that was not statistically significant, and had a small effect size ( $r = -.27$ ,  $p = .48$ ,  $R^2 = .07$ ). Additionally, a decrease in parent stress over the course of the study, was found to have a moderate negative correlation ( $r = -.45$ ) to an increase in parent use of early intervention skills over the course of the study. However, although this correlation was also found to not be statistically significant ( $p = .22$ ), the effect size (coefficient of determination,  $R^2$

= .20) shows that change in parent stress helps to explain 20% of the variance in parent change in use of intervention skills. So, although this result is not statistically significant, the correlation coefficient and the coefficient of determination are promising, indicating that a reduction in parent stress may be associated with an increase in parent use of intervention skills, and that the lack of significance may be due to the low number of participants in the study. Future studies with a greater number of participants will be required to see if changes in parent stress are significantly associated with changes in parent perceived knowledge and intervention use.

If these results are supported in future studies it means that a reduction in parent stress supports an increase in parent knowledge and skills, or, that an increase in knowledge and skills supports a reduction in stress. In this case, it is logical to infer that a third factor (parent participation in the parent training program) may have been the causal agent for the correlation (i.e. parent participation in the training program simultaneously decreased parent stress while increasing parent knowledge and skills). This is important because the combination between the type of training content and the amount of the training, were appropriate to promote knowledge, while at the same time reducing stress. In previous research, the type and intensity of the training has been found to affect parents' levels of stress. Specifically, high intensity non-naturalistic strategies were found to increase parent stress, while low intensity training advocating naturalistic strategies tended to lower or maintain parent stress (Estes et al., 2014; Koegel et al., 1996; Minjarez et al., 2013). Given that the present study significantly reduced parent stress through a low intensity naturalistic training program, the results are consistent with previous research (Estes et al., 2014; Koegel et al., 1996; Minjarez et al., 2012). Also, since we know an increase in parent stress negatively affects outcomes (Osborne et al., 2008), we want to ensure that parents are afforded effective learning opportunities that don't increase stress. Given that

parents in the present study significantly increased their perceived knowledge and decreased their stress, and that there was a negative association between these two, suggests that the specific training was appropriate for parents of children newly diagnosed with ASD.

The present study was also designed to investigate the relationship between parent stress and parent training and how this affects child outcomes. The results of the present study indicate that a parent's higher level of stress at the beginning of the study had a small positive correlation with an increase in child outcome scores at the end of the study (post-measures Time 2). These correlations were also not statistically significant and had a very small effect size (Engagement –  $p = .45$ ,  $R^2 = .08$ ; Communication –  $p = .62$ ,  $R^2 = .04$ ). This finding did not support the hypothesis as it was expected that parents who started the study with lower levels of stress would have children with higher levels of engagement and expressive communication at the end of the study. Although there is no previous ASD self-directed on-line parent training study that has looked at associations between initial parent stress and child outcomes, there is one study that investigated the association of parent initial stress with child outcomes for an individualized therapist assisted ASD parent training program (Robbins et al., 1991). Robbins and colleagues (1991) found that a lower level of parent stress at the beginning of the study was associated with greater positive change in child outcomes a year later ( $r = -.82$ ,  $n = 12$ ,  $p = .01$ ). The finding from the present study does not corroborate this finding. However, in the present study parents uniformly presented with a significantly high level of stress ( $M = 81.22$  percentile, Range 40 - 99), while in the Robbins study, parents presented with lower and more varied levels of stress ( $M = 62.83$  percentile, Range 20 - 99). The larger variability in range of parent stress scores in the Robbins study may have supported the strong correlation coefficient (Goodwin & Leech, 2006).

Given these mixed results, future self-directed on-line ASD parent training studies should examine initial parent stress and its association to child outcomes.

Although initial parent stress was not significantly associated with child outcomes, a decrease in parent stress from pre- to post-measures was found to have a large negative correlation to an increase in child engagement scores from pre to post-measures ( $r = -.57$ ). Again, this result is not statistically significant ( $p = .11$ ), but the effect size (coefficient of determination,  $R^2 = .33$ ) shows that change in parent stress helps to explain 33% of the variance in child engagement scores. So, although this result is not statistically significant, the correlation coefficient and the coefficient of determination are promising, indicating that a reduction in parent stress may be associated with an increase in Child Engagement scores, and that the lack of significance may be due to the low number of participants in the study. Future studies with a greater number of participants will be required to see if changes in parent stress are significantly associated with changes in Child Engagement.

Finally, although parent change in stress was strongly associated with a change in child engagement, it had only a small association with a change in child expressive communication, with a small effect size, that was not significant ( $r = -.06$ ,  $p = .88$ ,  $R^2 = .004$ ). Given that an increase in expressive communication developmentally follows an increase in engagement, a significant increase may not yet have had a chance to develop within the study's short time frame. A follow-up study that measures children's expressive communication skills at intervals following post-measures could provide further insight into this relationship.

If the above results are supported in future studies with a larger  $n$  as proposed, then there is an argument that parent training leads to an increase in parent perceived knowledge, and that parent training that leads to an increase in parent perceived knowledge and a decrease in parent

stress, leads to an increase in parent skills and child engagement. Simply put, as parents' stress decreases and their perceived parenting knowledge and skills increase, they have an increased ability to positively influence their children's level of engagement. This interpretation provides support for the theoretical model of the determinants of parenting a child with ASD presented in the literature review (see Figure 2). Parent training is a proposed determinant of parent knowledge and skills and of parent levels of stress. Parent levels of stress is a proposed determinant of parent knowledge and skills, and parent knowledge and skill is a proposed determinant of child development (see Figure 2).

The results of this study may also provide support for the use of the Bio-ecological model as a guide in examining the interactions between society, parent training and support, parent stress, and subsequent child outcomes, over time. At the chronosystems level the results of the study support the early timing of the intervention as parents were able to gain knowledge, increase family support and reduce stress over the four to six-month period immediately after diagnosis. In addition, the results also suggest that the relationship between timing and training content is important as a majority of parents in the first four to six months after diagnosis accessed content related to understanding ASD, dealing with the diagnosis, and understanding community services, while a minority accessed content related to parent intervention at home. At the Macrosystem level, societal values and economic resources came together in the form of a MCNHR study grant which supported the development of on-line resources for parents. At the Exosystem level, these on-line resources were then shown to influence parent stress and perceived knowledge in the microsystem, as the model would predict. Additionally, although the results of this study show that the parent training was effective in reducing parent stress and increasing parent knowledge of ASD and ASD intervention strategies, parenting skills did not

significantly increase and subsequently parent influence on child outcomes was not observed, as the model also would have predicted (see Figure 1).

### **Parent Engagement with the Training Program**

Parent engagement with the training program in this study was measured by the number of training module quizzes completed, and by the parents' rate of use of the Google group parent support forum. Parent engagement rates with the on-line Google group parent support forum were extremely low. Only two parents posted to the website. The forum was developed to provide parents a means to communicate and develop relationships with other parents in the training program, as this had been shown to be an important element of the group training experience for parents of children with ASD (Mackintosh et al., 2006). The extremely low engagement rate may have occurred because of the low number of participants in the study. Also, parents were active in the training at different times across the span of 12 months, leaving only a few people to engage at any one time. The Google group platform may have also been unfamiliar to people which may have also deterred use. Use of a more popular platform such as Facebook may increase parent engagement rates in future studies. Alternatively, parent may not have been ready to engage with other parents of children with ASD as mentioned previously.

Parents engagement rates with the on-line training modules was significantly better. Parents in the Treatment Group on average completed 71% of the training, with four of the nine participants or 44%, completing 100% of the training program. This completion rate is significantly lower than what has been reported in other similar studies; 69% (Ingersoll et al., 2016), 79% (Nefdt et al., 2010) and 82% (Wainer & Ingersoll, 2015). However, in these studies, parents were given ongoing prompts by the researchers to complete the training. The present study was considered "open access" meaning parents were not continuously monitored for

engagement or given any on-going prompts by research staff to complete the on-line training. This was done to examine the effectiveness of the program as a stand-alone application not requiring therapist assistance. By comparison, Ingersoll and colleagues (2017) conducted a similar ASD on-line training study and compared a therapist assisted access group (parents prompted to complete the training) to an “open access” group (no prompting). With no prompting the completion rates dropped from 85% to 12% (Ingersoll et al., 2017). The 44% training completion rate obtained in this study is high compared to the Ingersoll study, as well as other studies using “open access” online training (Christensen, Griffiths, Korten, Brittliffe, & Groves, 2004; Wanner, Martin-Diener, Bauer, Braun-Fahrlauder, & Martin, 2010).

One factor that may have increased parent engagement rates in the present study is that the on-line modules could be accessed through a smart phone. Past studies have developed self-directed on-line programs that must run on a computer (Hamad et al., 2010; Ingersoll et al., 2016; Wainer & Ingersoll, 2013). However, in Canada, 76% of Canadians access the internet using their smart phones (Statistics Canada, 2017). In the present study the on-line program was made mobile compliant to both android and Apple smart phones, to support smart phone use. This factor may account for the open access completion rate being higher at 44%, compared to the 12% reported by Ingersoll and colleagues (2017). However, although parents in the present study could access the on-line content on their phone, they had to do it through an internet link provided in an email. This extra step could be simplified in the future if parents were provided with a specific phone app for immediate access to the on-line program.

Another factor that may have increased engagement rates, concerns parents’ perceptions of the length, complexity, and manageability of the training program (Dingfelder & Mandell, 2011; Wainer & Ingersoll, 2015). For example, Jang et al., (2012) reported that two of the participants

in their study reported that the 30-40-hour on-line ASD parent training program was too long. Additionally, Ingersoll et al. (2017), examined open access participant engagement rates for a self-directed online ASD parent training program that included 12 lessons that took 75 minutes each to complete. Each lesson included a slide show, written material, self-check questions, video-based exercises, homework plan and reflection questions. The authors found that most participants in the open access group discontinued the training after the second lesson. This may have been due to the participants' initial response of feeling overwhelmed at the length and complexity of the on-line training. In the present study the on-line training program was considerably shorter, and less complex. The training program contained six modules that took approximately six to eight hours to complete. Additionally, the training was presented in 12 manageable sections, that each took approximately 30 minutes to complete. This simplicity may have led parents to find the training manageable, which may have contributed to the higher completion rates found in this study. Future studies will need to consider this trade-off between content length and complexity, and parent engagement.

A third factor that may have influenced parent engagement rates in this study is the appropriateness of the content for the target audience. The content of the self-directed on-line training and support program was carefully developed to provide content that parents would recognize as appropriate for them to deliver to their toddlers and preschoolers. It is important to note that after a thorough review of ASD evidenced-based interventions strategies, it was found that only certain strategies had an evidence base for particular ages of children. Given that most children are diagnosed at age three (Centres for Disease Control and Prevention, 2016) and that the training and support program for this study was specifically designed to meet the needs of parents of children newly diagnosed with ASD, it was important to develop a training program

that focused on evidence-based strategies appropriate for children around three years of age. Further, some but not all available strategies had an evidence base for parent delivery, and as such, the final strategies included in the training program were those that had an evidence base for parent delivery, and for implementation with toddlers and preschoolers. Previous research examining self-directed on-line ASD parent training programs have been vague in reporting the evidence base for the original intervention strategies and the appropriateness of these strategies for the age group of their target population (Nefdt et al., 2010; Jang et al., 2012). Future research on the effectiveness of self-directed on-line parent training should clearly state the evidence base supporting the content of the original methods and practices and ensure that the training strategies have an evidence base for parent delivery as well as an evidence base for the targeted age group.

Beyond developing age and content specific subject matter for parent delivery, the content of the training program in this study was also informed by literature identifying the needs of parents after diagnosis (Papageorgiou & Kalyva, 2010; Sansosti et al., 2012). Given that parents after diagnosis are typically stressed about their understanding of ASD, ASD treatment, and community services (Papageorgiou & Kalyva, 2010; Sansosti et al., 2012), and that they are less effective at early intervention when they are stressed (Osborne et al., 2008), content was developed to first address the stressors, and then later address parenting intervention strategies. The first three modules in the current training program addressed these stressors. Module one supported parents in their understanding of ASD; Module two addressed grieving, stress and family support; and Module three addressed ASD treatment and community services. Support for the inclusion of this content was confirmed by the parent's rates of engagement with the different sections of the training program. For example, parents completed 85% of the three modules

related to family wellness and completed only 57% of the three modules related to parent intervention. Although this could be explained by the order of the content (family wellness modules came before parent intervention modules), parents knew they had the flexibility to be able to access any module in any order. Given this flexibility it seems possible that parents in this study were most interested in understanding ASD, learning to cope with the diagnosis, and accessing treatment services for their child, as a priority after diagnosis, before wanting to address parent intervention at home. It is important to note that most self-directed on-line ASD parent training studies to date, focus specifically on teaching parent intervention skills and have not focused on utilizing the medium as a means to increase family well-being (Hall et al., 2016).

The content in the self-directed on-line training program could also be further informed by feedback from other therapists that work directly with parents of children newly diagnosed with ASD (e.g. Child Development Counsellors, Family Service Workers). To this end the self-directed on-line training program and this research could be presented to the managers and therapists in Manitoba's Children's DisAbility Services, and feedback related to supporting parent well-being could be requested through a formal survey.

Given the promising results from this study, and the links between family well-being and outcomes (Osborn et al., 2008), more research is needed to confirm the utility of the medium as a means to promote family well-being immediately after diagnosis.

### **Limitations**

There are a few salient limitations to the present study. The foremost limitation to the study is the small sample size. The limited number of participants led to limited power for the ANCOVA analysis and likely contributed to a lack of statistical significance for all the correlation coefficient calculations. However, given there were some statistically significant

results for parent knowledge, family support and stress, future studies with a larger sample size are warranted. An additional limitation in the sample is that parents “self selected” to participate in the study and this sample of ‘go getters’ may not be representative of the general population. Additionally, 100% of the sample had some university education which is also not representative of the general population. The sample also only included people who could read and write English, and who had access to the internet, which is also not representative of the general population.

Another limitation to the study is its brevity (time term bias). Specifically, it is possible that if the parents had been tracked after the four-month period, parent completion rates for the parent intervention strategies may have increased. This in turn may have led to more robust parent intervention scores during post-measures as well as increases in child engagement and child expressive communication. A related limitation is the lack of a follow-up measure. Findings for this study are relevant to a four-month post measure, but these results could be significantly different at a later follow-up time. Future studies that take measurements a few times over the one-year period after diagnosis may be required to determine the effectiveness of the on-line program in supporting parents after diagnosis.

A further limitation is that although the study personnel that scored the data were masked to participant group and time of measurement, the participants were not masked as to their affiliation with either the treatment or control group. Control group parents who knew they had to wait four months to receive treatment may have become demoralized, stressed and less confident just by the act of not getting into the treatment group. Because of this they may have scored lower on post-measures. Although this study could be done in the future with control

group participants being masked to the treatment, researchers will have to weigh this against other possible biases that may develop because of the masking.

There are also limitations related to the outcome measures. First, the Parent Knowledge Questionnaire and the Parent Observation Measure of Early Intervention Techniques are new outcome measures specific to the training provided in this study. Because of this, direct outcome comparisons between this and other studies are difficult. Additionally, because both measures are new they have not been rigorously tested for reliability. Second, with a larger sample the subscales of the *Parenting Stress Index Short-Form* (Parental Distress, Parent-Child Dysfunctional Interaction and Difficult Child) could have been examined separately to determine if a specific sub-type of parent stress had a specific association to parent and child outcomes.

Furthermore, future work could include a qualitative component to the study. Parents could be asked specific questions about their use of coping strategies after diagnosis as this has been shown to affect a parent's level of stress (Lai & Oei, 2014). Parents could have also been asked to provide feedback through questionnaire or interview on the accessibility, usability, duration, and content of the training program, and how the training program could have been improved (Kobak et al., 2011; Hamad et al., 2010). Similarly, the modules could immediately be improved for accessibility. For example, alternative text or audio recordings could be put in place for any visuals provided in the modules, and text captions could be provided in the video clips. Additionally, the whole program should be translated and provided in French as French is an official language in Canada. As resources permit, translations to other languages are warranted. Lastly, parents could have been asked to provide feedback on their self-efficacy or level of confidence in using the parent strategies as this is also related to parent well-being and effective use of parent intervention strategies (Ingersoll et al., 2016).

Another limitation to the study is that the training program was not evaluated under ideal or controlled circumstances (e.g. the study focused on effectiveness and not efficacy). Future studies on the specific self-directed on-line training program used in this study could evaluate the program under more controlled environments. For example, in future trials, parents could be monitored closely and prompted to finish the entire training program in a specific time frame before post measures were taken.

### **Summary**

The results of this study provide further evidence supporting the effectiveness of self-directed on-line training programs to teach evidence-based parent-mediated ASD intervention strategies (Hamad et al., 2010; Ingersoll et al., 2016; Jang et al, 2012; Nefdt et al., 2010; Wainer & Ingersoll, 2015). The results also provide initial evidence supporting the effectiveness of a self-directed on-line training program to support family well-being immediately after diagnosis, by decreasing parent stress and by increasing family support. Findings from the present study indicate that parents demonstrate uniformly high levels of stress after receiving a diagnosis for their child and for some parents decreases in stress after diagnosis are associated with increases in parent use of early intervention strategies and increases in child engagement. The findings also provide additional information on how training content, timing and duration affect parent and child outcomes and suggest that training be provided in a tiered or sequenced approach as parents of preschool children newly diagnosed with ASD may be initially more interested in content related to family well-being and may later become more interested in parent intervention strategies. Future research should further investigate the balance between content, timing and duration so that self-directed on-line training programs can be developed that are effective in increasing both family well-being and parent knowledge and skills.

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## Appendix A

## Manitoba Health Research Ethics Board Certificate of Final Approval

		P126-770 Bannatyne Avenue Winnipeg, Manitoba Canada, R3E 0W3 Telephone : 204-789-3255 Fax: 204-789-3414	
UNIVERSITY OF MANITOBA		Bannatyne Campus Research Ethics Board	
<b>HEALTH RESEARCH ETHICS BOARD (HREB)</b> <b>CERTIFICATE OF FINAL APPROVAL FOR NEW STUDIES</b> Full Board Review			
<b>PRINCIPAL INVESTIGATOR:</b> Mr. Andrew Robson		<b>INSTITUTION/DEPARTMENT:</b> U of M/Graduate Studies/Applied Health Sciences	
<b>HREB MEETING DATE:</b> November 28, 2016		<b>APPROVAL DATE:</b> December 15, 2016	
<b>STUDENT PRINCIPAL INVESTIGATOR SUPERVISOR (if applicable):</b> Dr. Bev Temple		<b>ETHICS #:</b> [REDACTED]	
<b>EXPIRY DATE:</b> November 28, 2017			
<b>PROTOCOL NUMBER:</b> NA		<b>PROJECT OR PROTOCOL TITLE:</b> Parents of Newly Diagnosed Preschool Children with Autism Spectrum Disorder: The Effectiveness of a Self-Directed On-line Parent Training and Support Program on Parent and Child Outcomes	
<b>SPONSORING AGENCIES AND/OR COORDINATING GROUPS:</b> Manitoba Centre for Nursing and Health Research Grant			
<b>Submission Date(s) of Investigator Documents:</b> November 7 and December 12, 2016		<b>REB Receipt Date(s) of Documents:</b> November 7 and December 13, 2016	
<b>THE FOLLOWING ARE APPROVED FOR USE:</b>			
<b>Document Name</b>		<b>Version(if applicable)</b>	<b>Date</b>
<b>Protocol:</b> Protocol Clarification Letter dated December 12, 2016 Revised REB Submission Form submitted December 12, 2016			November 7, 2016
<b>Consent and Assent Form(s):</b> Research Participant Information and Consent Form Research Participant Information and Consent Form for Research Using Video			December 9, 2016 December 9, 2016
<b>Other:</b> Study Advertisement  Questionnaires/Scales/Instruments Appendix Demographic Form Data Collection Form Master List Form			submitted December 12, 2016 November 7, 2016 November 7, 2016 November 7, 2016 November 7, 2016
<b>CERTIFICATION</b> The University of Manitoba (UM) Health Research Board (HREB) has reviewed the research study/project named on this <i>Certificate of Final Approval</i> at the <i>full board meeting</i> date noted above and was found to be acceptable on ethical grounds for research involving human participants. The study/project and documents listed above was granted final approval by the Chair or Acting Chair, UM HREB.			
- 1 -			
umanitoba.ca/research			

## Appendix A (Cont.)

**HREB ATTESTATION**

The University of Manitoba (UM) Health Research Board (HREB) is organized and operates according to Health Canada/ICH Good Clinical Practices, Tri-Council Policy Statement 2, and the applicable laws and regulations of Manitoba. In respect to clinical trials, the HREB complies with the membership requirements for Research Ethics Boards defined in Division 5 of the Food and Drug Regulations of Canada and carries out its functions in a manner consistent with Good Clinical Practices.

**QUALITY ASSURANCE**

The University of Manitoba Research Quality Management Office may request to review research documentation from this research study/project to demonstrate compliance with this approved protocol and the University of Manitoba Policy on the Ethics of Research Involving Humans.

**CONDITIONS OF APPROVAL:**

1. The study is acceptable on scientific and ethical grounds for the ethics of human use only. *For logistics of performing the study, approval must be sought from the relevant institution(s).*
2. This research study/project is to be conducted by the local principal investigator listed on this certificate of approval.
3. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to the research study/project, and for ensuring that the authorized research is carried out according to governing law.
4. **This approval is valid until the expiry date noted on this certificate of approval. A Bannatyne Campus Annual Study Status Report** must be submitted to the REB within 15-30 days of this expiry date.
5. Any changes of the protocol (including recruitment procedures, etc.), informed consent form(s) or documents must be reported to the HREB for consideration in advance of implementation of such changes on the **Bannatyne Campus Research Amendment Form**.
6. Adverse events and unanticipated problems must be reported to the REB as per Bannatyne Campus Research Boards Standard Operating procedures.
7. The UM HREB must be notified regarding discontinuation or study/project closure on the **Bannatyne Campus Final Study Status Report**.

Sincerely,

John Arnett, PhD., C. Psych.  
Chair, Health Research Ethics Board  
Bannatyne Campus

## Appendix B Demographic Questionnaire

### Demographic Data

Protocol Title:

Parents of Preschool Children Newly Diagnosed with Autism Spectrum Disorder: The Effectiveness of a Self-Directed On-line Parent Training and Support Program on Parent and Child Outcomes

Child Date of Birth: Day \_\_\_\_\_ Month \_\_\_\_\_ Year \_\_\_\_\_

Gender: Male \_\_\_\_\_ Female \_\_\_\_\_

Parent Year of Birth: \_\_\_\_\_ Gender: Male \_\_\_\_\_ Female \_\_\_\_\_

Marital Status:

- Single never married
- Married or Domestic Partnership
- Widowed
- Divorced
- Separated

House Hold Size:

- Number of children in the home
- Number of adults in the home

What is your highest level of education?

- Some Schooling
- Some High School
- Completed High School
- Some University or College
- University or College Degree
- University or College Graduate Degree

Work Status:

- Employed
- Self Employed
- Unemployed
- Student
- Homemaker
- Retired
- Unable to work

Ethnicity: \_\_\_\_\_

Do you have access to the internet?  Yes  No Email: \_\_\_\_\_

Can you read and write the English language?  Yes  No

Version Nov. 7 2016 Date Collected: \_\_\_\_\_ Participant Code: \_\_\_\_\_

Data collected by: Print \_\_\_\_\_ Sign \_\_\_\_\_

Appendix C  
Playroom Setting



Appendix D  
Study Advertisement

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**Research Study for Parents of Children Newly  
Diagnosed with Autism Spectrum Disorder.**

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**UNIVERSITY OF MANITOBA** Faculty of Graduate Studies  
Department of Applied Health Sciences

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**Why participate in this study?**

Manitoba parents of preschool children newly diagnosed with Autism Spectrum Disorder wait for up to 12 months to receive government funded treatment services for their child and family. To support parents during this time an on-line parent training and support program has been developed. The on-line program provides information on Autism, how to deal with the diagnosis, community services, and parenting strategies, and can be accessed via the internet by computer, tablet or smart phone. The study is being done to evaluate how well this program supports parents and their children.

**Eligibility**

To be eligible for this study your child must have a recent diagnosis of Autism Spectrum Disorder and be under five years of age. Eligible participants will be entered into a draw to win a gift certificate to TOYS-R-US.

**Participation**

Participation in the study includes two, 1 hour appointments at the SSCY Centre, 1155 Notre Dame Ave. and participation in the on-line parent training and support program.

**Contact**

If you are interested in finding out more please contact:

Andrew Robson at \_\_\_\_\_ or rob \_\_\_\_\_ .ca

December 2016

Appendix E  
Consent Forms



UNIVERSITY  
OF MANITOBA

Faculty of Graduate Studies  
Department of  
Applied Health Sciences

202 Active Living Centre  
Winnipeg, MB. R3T 2N2  
t: 204.474.7806  
f: 204.474.7634  
[ahs\\_phd@umanitoba.ca](mailto:ahs_phd@umanitoba.ca)

## RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM

**Title of Study:** Parents of Newly Diagnosed Preschool Children with Autism Spectrum Disorder: The Effectiveness of a Self-Directed On-line Parent Training and Support Program on Parent and Child Outcomes

**Protocol number:**

**Principal Investigator:** Andrew Robson, SSCY Centre, 1155 Notre Dame Avenue. Winnipeg, MB. R3E 3G1, Phone:

**Co-Investigator:** Dr. Bev Temple, 89 Curry Place, University of Manitoba, Winnipeg, MB. R3T2N2, Phone:

**Sponsor:**

You are being asked to participate in a Clinical Trial (a human research study). Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this clinical trial and you may discuss it with your regular doctor, friends and family before you make your decision. This consent form may contain words that you do not understand. Please ask the principal investigator or study staff to explain any words or information that you do not clearly understand.

### Purpose of Study

Manitoba parents of children newly diagnosed with Autism, wait up to 12 months to receive government funded treatment services for their child. The primary purpose of this study is to address the training and support needs of parents during this time, by developing and testing an on-line Autism parent training and support program. The secondary purpose is to look at how the training program and parent stress, interact, to influence parent and child outcomes. You are being asked to take part in this study because you have recently had a preschool child diagnosed with Autism Spectrum Disorder. A total of sixty participants will be asked to participate in this study.

## Appendix E (Cont.)

**Study procedures**

In this study, you will be “randomized” into one of two study groups described below. “Randomized” means that you are put into a group by chance, like flipping a coin. In this case a random numbers table will be used to determine what group you will be assigned to. You will have an equal chance of being placed in either the “Treatment Group” or the “Waitlist Group.”

All families that have signed a consent form to participate in the study will be given an appointment time to attend the Child Development Clinic nursery play room at the Specialized Services for Children and Youth (SSCY) building for pre-measures. One parent will be asked to engage in free play with their child similar to how they would at home (using a standardized set of toys). The parent will be video recorded playing with their child for a ten-minute period, and then asked to fill out three questionnaires. The appointment will take approximately 45 minutes. The three questionnaires are: The *Parenting Stress Index-Short Form* (36 questions rated from 1- Strongly Agree to 5- Strongly Disagree); the *Family Support Scale* (18 items rated from 0- Not Available to 5- Extremely Helpful); and the *Parent’s Knowledge of ASD and Early Home Intervention Questionnaire* (30 items rated from 1- No Understanding to 5- An Excellent Understanding). After these pre-measures, families will be randomly assigned to either the “Treatment Group”, or the “Waitlist Group.”

**Treatment Group**

Treatment Group parents will then be given access to participate in the on-line self-directed parent training and support program for a four- month period. Parents will be able to access the program anywhere with an internet connection using a computer, tablet, or smart phone. The parent training and support program consists of six on-line multi-media learning models that cover topics such as Understanding Autism Spectrum Disorder, Dealing with the Diagnosis, Understanding and Navigating Services, Beginning Parent Intervention at Home, and Parent Home Intervention Strategies. Parents will also be given access to an on-line parenting support and information sharing forum exclusive to parents in the training program. Through the on-line forum parents will be able to access a professional autism specialist and other parents involved in the study, and will be able to ask questions, answer questions, provide comments, discuss issues, share stories, and in general receive support and give support to others.

When Treatment Group parents have completed the on-line training (and after at least a four-month period has elapsed since the pre-measure), the parent and child will again be invited back to the nursery setting for post-measurements. The parent and child will again be video-recorded playing for a ten-minute period and asked to fill out the same questionnaires as they did in the pre-measure. The appointment will take approximately 45 minutes. Treatment Group parents will be expected to participate in the study for approximately 5 months.

## Appendix E (Cont.)

### Waitlist Group

After pre-measures, parents in the waitlist group will continue as normal for a four-month period. After four months, the parent and child will again be invited back to the nursery setting for post-measurements. The parent and child will again be video-recorded playing for a ten-minute period and asked to fill out the same questionnaires as they did in the pre-measure. The appointment will take approximately 45 minutes. After these post-measures, waitlist parents will be given access to the on-line training and support program for a four-month period. Waitlist Group parents will be expected to participate in the study for 5 months, but can fully participate in the on-line training and support for an additional 4 months.

The researcher may decide to take you off this study if your child is subsequently given an additional diagnosis. However, parents would still be given access to the training and support program.

You can stop participating in this study at any time. However, if you decide to stop participating in the study, we encourage you to talk to the principal investigator listed on the first page of this consent form.

### **Risks and Discomforts**

During this study you may experience anxiety, grief, anger, stress, or depression upon learning more about Autism, Autism treatment, public or community services, and how Autism and services may affect your child and family in the present, and in the future. It is possible that this treatment may involve risks to the participants which are currently unforeseeable.

### **Benefits**

By participating in this study, you will be exposed to valuable information that may help you to understand Autism, Autism treatment, public and community services, and parent intervention techniques. This increase in knowledge may lead to less stress and better parenting skills that may also benefit your child with Autism. By participating in this study you will also provide valuable information to the researcher on Autism parent training and support programs which could be used to benefit future parents of children newly diagnosed with Autism.

### **Costs and Compensation**

All clinic and professional fees which will be performed as part of this study are provided at no cost to you. You will be responsible for your own internet costs to access the on-

## Appendix E (Cont.)

line training and support program and for any costs incurred by you to attend two, one-hour long, appointments at the SSCY Centre. For completed participation in this study you be entered into a draw, with approximately 60 other participants, for a one-hundred-dollar gift certificate to TOY-R-US.

### **Alternatives**

You do not have to participate in this study to learn more about Autism, Autism treatments, Autism supports, community services, or parent intervention techniques. You are welcome to seek information on your own or to consult your doctor or therapist.

### **Confidentiality**

Information gathered in this research study may be published or presented in public forums, however your name and your child's name and any other identifying information will not be used or revealed. Each participant will be assigned a code by the primary investigator. All data will contain only the code with no specific participant identifiers. All digital video recordings, questionnaires, observations sheets, and participant code sheets will be kept in a locked cabinet in the office of the Principal investigator and on a password protected secured government computer server. Only the Principal Investigator co-investigator will have access to the locked cabinet. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law. The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes.

### **Voluntary Participation/Withdrawal From the Study**

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time by calling the principal investigator -

Your decision not to participate or to withdraw from the study will not affect you or your child's care at SSCY Centre. If the study staff feel that it is in your best interest to withdraw you from the study, they will remove you without your consent. We will tell you about any new information that may affect your health, welfare, or willingness to stay in this study.

### **Medical Care for Injury Related to the study**

You are not waiving any of your legal rights by signing this consent form nor releasing the investigator(s) or the sponsor(s) from their legal and professional responsibilities.

## Appendix E (Cont.)

**Questions**

You are free to ask any questions that you may have about your participation in this research study and your rights as a research participant. If any questions come up during or after the study or if you have a research-related injury, contact the principal investigator, Andrew Robson at \_\_\_\_\_ . For questions about your rights as a research participant, you may contact The University of Manitoba Biomedical Research Ethics Board at (204) 789-3389. Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

**Statement of Consent**

I have read this consent form. I have had the opportunity to discuss this research study with Andrew Robson and or his study staff. I have had my questions answered by them in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statement or implied statements. Any relationship (such as employee, student or family member) I may have with the study team has not affected my decision to participate. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this clinical trial is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

I understand that information regarding my personal identity will be kept confidential, but that confidentiality is not guaranteed. I authorize the inspection of any of my records that relate to this study by The University of Manitoba Research Ethics Board, for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

**I agree to being contacted in relation to this study. Yes  No**

**I agree to be contacted for future follow-up in relation to this study. Yes  No**

**Child's printed name:** \_\_\_\_\_

**Parent/legal guardian's printed name:** \_\_\_\_\_

**Parent/legal guardian's signature** \_\_\_\_\_ **Date** \_\_\_\_\_  
(day/month/year)

**Participant printed name** \_\_\_\_\_

**Participant signature** \_\_\_\_\_ **Date** \_\_\_\_\_  
(day/month/year)

## Appendix E (Cont.)



UNIVERSITY  
OF MANITOBA

Faculty of Graduate Studies  
Department of  
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## RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM FOR RESEARCH USING VIDEO

**Title of Study:** Parents of Newly Diagnosed Preschool Children with Autism Spectrum Disorder: The Effectiveness of a Self-Directed On-line Parent Training and Support Program on Parent and Child Outcomes

**Protocol number:**

**Principal Investigator:** Andrew Robson, SSCY Centre, 1155 Notre Dame Avenue.  
Winnipeg, MB. R3E 3G1, Phone:

**Co-Investigator:** Dr. Bev Temple, University of Manitoba, 89 Curry Place,  
Winnipeg, MB. R3T 2N2, Phone: !

**Sponsor:**

You are being asked to participate in a Research Study in which Video and or Pictures of you will be used. The information contained in Video and Pictures is considered personal Information as they present recorded information in which you may be identified. Please take your time to review and read this consent form carefully and any accompanying information. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask the study staff. Although the information captured in video and pictures is non-anonymous, confidentiality can be protected by restricting access to the video and to personal information such as the names of the participants or the institutions in which data will be captured.

### Purpose and Objectives of the Research

Manitoba parents of children newly diagnosed with Autism, wait for up to 12 months to receive government funded treatment services for their child. The primary purpose of this study is to address the training and support needs of parents during this time, by developing and testing an on-line Autism parent training and support program. The secondary purpose is to look at how the training program and parent stress, interact, to influence parent and child outcomes. You are being asked to take part in this study

## Appendix E (Cont.)

because you have recently had a preschool child diagnosed with Autism Spectrum Disorder. A total of sixty participants will be

asked to participate in this study. In order to determine if the training and support program is effective, a group of parents who take the training and support program, will be compared to a group of parents who have not yet taken the training and support program.

The "Treatment Group" of parents will be video recorded playing with their child for a ten-minute period prior to taking the on-line training and support program and then for a ten-minute period after taking the on-line training and support program for at least a four-month period. The "Waitlist Group" of parents will be video recorded playing with their child for a ten-minute period at the start of the study, wait four months, and then be video recorded playing with their child for a ten-minute period again, then given access to the on-line training and support program. The before and after videos from both groups will then be compared to see if the training program was effective in helping parents to use appropriate early intervention techniques in play with their child. The videos will also be compared to evaluate the child's progress.

Parents will be given an appointment time to attend to the Nursery Room of the Child Development Clinic at the SSCY Centre, 1155 Notre Dame Ave. The Nursery Room contains a carpeted area, a small table and chairs, and low shelves containing toys and activities. One parent and their child will be lead into the room, shown the toys and activities, and asked to engage in play with their child as they would at home. The parent and child will be allowed to settle in to play, and then the examiner will leave the room. Parents will then be video recorded playing with their child for a ten-minute period and then asked to sit at the small table and fill out three questionnaires. The total appointment time will be approximately 45 minutes. The video will be recorded using two digital video cameras situated within the room. The digital recordings will originally be stored on the Camera's SD memory cards which will then be collected by the examiner after the session. The video's will then be given a coded file name and then transferred to a password protected computer hard drive and a password protected secured Government computer server. The video on the SD memory card will then be deleted. The video recording stored on the password protected computer hard drive will be stored in a locked cabinet in the primary investigators office. The primary investigator and the co-investigator will be the only ones with access to the locked cabinet.

When all video has been collected, study personnel will view the video's on a secure computer in an office in the SSCY Centre. Parent's use of early intervention techniques, and the child's engagement and communication abilities will be assessed. Study personnel will not know whether the family is in the treatment or waitlist group or whether the video is a pre-or post measure. In addition, 20% of videos will then be reviewed by the principal investigator to ensure observer reliability. The video's will not

## Appendix E (Cont.)

be published, or presented to anyone else, or used in any way, for any other purpose. The video's will remain stored on a password protected hard drive, in a locked cabinet in the primary investigators office, and on the password protected secure government computer server for a 5-year period and then destroyed.

### **Benefits**

By participating in this study, you will be exposed to valuable information that may help you to understand Autism, Autism treatment, public and community services, and parent intervention techniques. This increase in knowledge may lead to less stress and better parenting skills that may also benefit your child with Autism. By participating in this study you will also provide valuable information to the researcher on Autism parent training and support programs which could be used to benefit future parents of children newly diagnosed with Autism.

### **Risks and Discomforts**

During this study you may experience anxiety, grief, anger, stress, or depression upon learning more about Autism, Autism treatment, public or community services, and how Autism and services may affect your child and family in the present, and in the future. It is possible that this treatment may involve risks to the participants which are currently unforeseeable.

### **Confidentiality**

Written Information gathered in this research study may be published or presented in public forums, however your name and your child's name and any other identifying information will not be used or revealed. Each participant will be assigned a code by the primary investigator. All data will contain only the code with no specific participant identifiers. All digital video recordings, questionnaires, observations sheets, and participant code sheets will be kept in a locked cabinet in the office of the main investigator and on a password protected secure government computer server. Only the principal investigator and co-investigator will have access to the locked cabinet. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law. The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes.

## Appendix E (Cont.)

### **Costs and Compensation**

All clinic and professional fees which will be performed as part of this study are provided at no cost to you. You will be responsible for your own internet costs to access the on-line training and support program and for any costs incurred by you to attend two, 45-minute-long, appointments at the SSCY Centre. For completed participation in this study you be entered into a draw, with approximately 60 other participants, for a one-hundred-dollar gift certificate to TOY-R-US.

### **Parent Viewing**

If you would like to view your videos notify the primary investigator and a viewing appointment will be scheduled.

### **Voluntary Participation/Withdrawal from the Study**

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time, by telling the examiner or by calling the Principal Investigator at [redacted]. Your decision not to participate or to withdraw from the study will not affect you or your child's care at SSCY Centre. If the study staff

feel that it is in your best interest to withdraw you from the study, they will remove you without your consent. We will tell you about any new information that may affect your health, welfare, or willingness to stay in this study.

In signing this document, I freely agree to participate in a research study in which video recordings containing my image will be viewed by study examiners for the purpose of this study only. I authorize the use of such data and recordings only for the scientific purposes specified above. I have been told that my name will not appear in any report or publication resulting from this study. I have been advised that while all feasible precautions are being taken to restrict the use of this video-data, it is not possible to fully guarantee these restrictions. I have read this consent form. I have had the opportunity to discuss this research study with the research staff. I have had all my questions answered by them in language I understand. The risks and benefits have been explained to me. I believe that I have not been unduly influenced by any study team member to participate in the research study by any statements or implied statements. Any relationship (such as employer, supervisor or family member) I may have with the study team has not affected my decision to participate and that I may choose to withdraw my consent and decline to be recorded and to participate in any activity related to this study at any time, without penalty, prejudice or consequence. I understand that I will be given a copy of this consent form after signing it. I authorize the inspection of any of my records that relate to this study by the University of Manitoba.

## Appendix E (Cont.)

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study and I have not released the researchers, sponsors, or involved institutions from their legal and professional responsibilities.

**Child's printed name:** \_\_\_\_\_

**Parent/legal guardian's printed name:** \_\_\_\_\_

**Parent/legal guardian's signature** \_\_\_\_\_ **Date** \_\_\_\_\_  
(day/month/year)

**Participant printed name** \_\_\_\_\_

**Participant signature** \_\_\_\_\_ **Date** \_\_\_\_\_  
(day/month/year)

**Researcher and/or Delegate's Signature** \_\_\_\_\_ **Date** \_\_\_\_\_

**Researcher and/or Delegate's printed name** \_\_\_\_\_

This research has been approved by the Health Research Ethics Board. If you have any concerns or complaints about this project, you may contact any of the above-named persons or the Human Ethics Coordinator at (204) 789-3389.

Appendix F  
Parent Knowledge of ASD and Early Home Intervention Questionnaire

**Parent Knowledge of ASD and Early Home Intervention Questionnaire**

**Please read each question and circle one number that best represents your understanding.**

**Level of Understanding**

<b>1 - None</b>	<b>2 - Little</b>	<b>3 - Moderate</b>	<b>4 - Good</b>	<b>5 – Excellent</b>
1. I understand how Autism Spectrum Disorder (ASD) is diagnosed.				1 2 3 4 5
2. I understand why Autism is called a spectrum disorder.				1 2 3 4 5
3. I understand why my child may have unusual sensory interests.				1 2 3 4 5
4. I understand why my child may have difficulties with eye-contact.				1 2 3 4 5
5. I understand why my child may like structure and routine.				1 2 3 4 5
6. I understand the stages a parent may go through after having a child diagnosed with ASD.				1 2 3 4 5
7. I understand the importance of accessing social support.				1 2 3 4 5
8. I understand the importance of engagement with my child.				1 2 3 4 5
9. I understand the importance of observing my child.				1 2 3 4 5
10. I understand the importance of playing with my child.				1 2 3 4 5
11. I understand the importance of following my child's lead in play.				1 2 3 4 5
12. I understand the importance of self-regulation in my child.				1 2 3 4 5
13. I understand the importance of emotion and affect in the development of communication.				1 2 3 4 5
14. I understand basic behavioural management principles.				1 2 3 4 5
15. I understand why my child misbehaves.				1 2 3 4 5

## Appendix F (Cont.)

**Parent Knowledge of ASD and Early Home Intervention Questionnaire Page 2.****Level of Knowledge**

<b>1 - None</b>	<b>2 - Little</b>	<b>3 - Moderate</b>	<b>4 - Good</b>	<b>5 – Excellent</b>
16. I know the three major areas of difficulty that children with ASD have.				1 2 3 4 5
17. I know of additional difficulties that a child with ASD may have.				1 2 3 4 5
18. I know the possible strengths a child with ASD may have.				1 2 3 4 5
19. I know why my child may have unusual interests.				1 2 3 4 5
20. I know why my child may have unusual behaviours.				1 2 3 4 5
21. I know specific ways to deal with mental stress.				1 2 3 4 5
22. I know specific ways to deal with physical stress.				1 2 3 4 5
23. I know the services available in the community to support my child and family.				1 2 3 4 5
24. I know early intervention methods for young children with ASD.				1 2 3 4 5
25. I know where to find reliable information on early intervention methods for ASD.				1 2 3 4 5
26. I know methods to help my child engage with me.				1 2 3 4 5
27. I know methods to help my child play with me.				1 2 3 4 5
28. I know ways to promote regulation in my child.				1 2 3 4 5
29. I know ways to promote communication in my child.				1 2 3 4 5
30. I know ways to effectively guide my child's behaviour.				1 2 3 4 5

### Appendix G Parent Observation Data Sheet

PALM Parent Observation Measure	ID# _____																				
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	
	0 - :30	:31 :60	1:01 1:30	1:31 2:00	2:01 2:30	2:31 3:00	3:01 3:30	3:31 4:00	4:01 4:30	4:31 5:00	5:01 5:30	5:31 6:00	6:01 6:30	6:31 7:00	7:01 7:30	7:31 8:00	8:01 8:30	8:31 9:00	9:01 9:30	9:31 10:00	%
<b>1. Follows Child's Lead Engages Child</b>																					
<b>2. Promotes Communication</b>																					
<b>3. Reciprocity / Turn Taking</b>																					
<b>4. Expanding / Modelling</b>																					
<b>5. Imitation / Mirroring</b>																					
<b>6. Promotes Regulation</b>																					
<b>7. Promotes Appropriate Behaviour</b>																					
<b>Note. 1 – 3 (+) = 50% of the time or more; (-) &lt; 50% of the time or 3 (-) examples</b>																					
<b>4 – 7 If a (-) is observed it is marked (-); If a (+) is observed with no (-) it is marked (+); or NA for not applicable</b>																					

## Appendix H

### Parent Intervention Fidelity Measure

#### Parent Intervention Fidelity Measure Operational Definitions (November, 2017)

1. Follows the Child's Lead / Engages Child (Positive) Parent observes their child and their intentional focus and then follows along with the child's intention in a way that promotes joint attention (child attends back and forth to the parent and the objects that the parent and child are playing with) or promotes joint engagement (The child and the parent are engaged in back and forth interactions within play with or without objects). It can be appropriate for the Parent to lead the play (e.g. make a suggestion) if the child is wandering or does not have any focus in play. Parents can follow physically and/or verbally. **(Negative)** The Parent is not observing or engaging with the child. The Parent is mostly (e.g. 50% of the 30 second interval) leading the play, changing the play, adding too much to the play, or adding unrelated play ideas. **(Marked as + or -)**
2. Promotes Communication (Positive) The parent adjusts their communication to facilitate understanding (e.g. uses gestures and words together, speaks slowly, stresses important words, repeats words, etc.). The parent follows the child's focus of attention and labels objects, or comments briefly on the child's play (e.g. "Blocks." "Oh, stacking blocks."). Parent interprets the child's facial expression, body language or gestures (non-verbal communication) and gives words to the expressions, body language or gestures (e.g. "More." "All done." "Blocks"). Parent repeats a child's attempt at communication (word approximation) with the correct pronunciation (e.g. Parent says "Yellow." after child says "Lellow."). Parent expands child's language (Child says, "Ball." Parent interprets and models, "I want ball."). The parent uses language appropriate to the child's level (e.g. The "one up" rule – If the child is using no words the parent uses single words. If the child is using single words, the parent uses two-word phrases. If the child is using two words phrases, the parent uses three-word phrases). If the child is talking in full sentences the parent responds with a natural flow of comments, questions and waiting. Parent asks open-ended questions (e.g. questions that do not have one fixed answer. - "What's next?" "What should we play now?" "Which one can I be?"). Parent at times waits for the child to initiate interactions. **(Negative)** Parent talks too much, or too fast for the child. Parent is talking about something not related to what the child is doing. Parent drills or overly question the child. Parent asks only closed ended question (e.g. "What colour is this?" "Where is the cow?" "What shape is this?") without any open-ended questions. Parent is silent, overly quiet, or misses opportunities to facilitate understanding or communication. **(Marked as + or -)**
3. Reciprocity / Turn Taking (Positive) Parent encourages back and forth interactions in communication and play. (e.g. Child is stacking blocks, parent takes a few blocks and hands them to the child one-by-one to stack; Child stacks a block, caregiver stacks a block, Parent and Child take turns back and forth in their play activities; Parent blows some bubbles and waits for child to request more bubbles, Child vocalizes something and the Parent vocalizes something back). The parent is actively trying to promote interactions back and forth between themselves and their child. **(Negative)** Parent is not trying to promote reciprocity or turn taking when it would have been appropriate. Talks too much, takes all the turns or none of the turns. Parent is too quick or misses the opportunity to wait to give the child a chance to have a turn. **(Marked as + or -)**
4. Expanding / Modelling (Positive) Parent imitates the child's play or engages with the child in play, and then when appropriate adds a small step, addition, idea, or expansion to the play (e.g. Child pushes car back and forth, caregiver pushes another car back and forth and then adds crashing the car). When appropriate, the Parent models an idea in play or provides a demonstration of a play task to the child, with the intention that the child will imitate the task and engage with the parent. **(Negative)** Parent misses an appropriate opportunity to imitate and then add a small step, addition, idea, or expansion to the play. Parent adds too many ideas at once, too big a step, or becomes overly directive in the play. **(NA)** Play is progressing nicely without need for expanding/modelling. **(Marked as + or - or NA)**
5. Imitation / Mirroring (Positive) Parent imitates the child's physical actions, actions with toys, or their gestures or vocalizations to promote joint attention or joint engagement. This is an appropriate strategy when a child is engaged in some play but is not attending to, or engaged with, the parent. **(Negative)** The Parent clearly misses an opportunity where imitation could have been appropriate. **(NA)** Play is progressing nicely without the need for imitation. **(Marked as + or - or NA)**
6. Promotes Regulation (Positive) The parent recognizes when the child is under-responsive, overly sedentary or over-focused in play and becomes more animated (e.g. more vocal, uses exaggerated expressions and gestures) and / or introduces a sensory or movement activity to promote responsiveness or engagement (e.g. a tickle game, chase game, patty cake). The parent recognizes when the child is over-aroused in play and becomes less arousing (e.g. quieter, slower, and softer) and / or directs child to a more structured activity or calming activity (e.g. looking at a book, hugging, rocking, cuddling). **(Negative)** Parent clearly misses an opportunity to help regulate the child. **(NA)** Child is well regulated and parent has no need to help regulate the child. **(Marked as + or - or NA)**
7. Promotes Appropriate Behaviour (Positive) The parent uses praise or positive reinforcement for the child's appropriate behaviour (e.g. "That's the way! Good girl! Well done!" "Great, here's another one"). Follows through with what the child wants or asks for, if appropriate. Parent helps the child in play when requested. The parent appropriately addresses the child's inappropriate behaviour (e.g. redirects the child's behaviour verbally or physically, model's appropriate behaviour, removes toys or objects, removes child from activity). Parent does not just tell child to stop an inappropriate behaviour, but tells them or guides them to what they should do instead. **(Negative)** Parent clearly misses an opportunity to address positive or negative behaviour appropriately. **(NA)** Parent does not have a need to address behaviour. **(Marked as + or - or NA)**

Appendix I  
Engagement Measure Operational Definitions

**Engagement Measure Operational Definitions**

**Unengaged**

The child is wandering or stationary and may be scanning the environment or have a fixed gaze but is uninvolved with someone or something.

**Object Engagement**

The child is actively engaged with any object alone, without any reference, reaction, or attention to a person.

**Joint Engagement**

The child references a person (e.g. looks at a person), or does not overtly look at the person but there is evidence that the child is aware of the other person (e.g. adults sits beside the child and child moves over slightly); engages with a person in the same activity or event (e.g. smiles or frowns at a person, sits in a person's lap, plays patty cake with a person, walks together holding hands), or is actively involved with a person with an object (e.g. stacking blocks together, exchanging items back and forth, imitating an adults actions on an object).

### Appendix J Parent Child Observation Data Sheet

Parent Child Observation Data Sheet										Observation Identification Number																						
Interval duration 5 seconds																																
Interval	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	Total	
Engagement	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U		
	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	
	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	
Communication	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G		
	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V		
	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A		
	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	
	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	
Interval	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60	Total	
Engagement	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U		
	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	
	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	
Communication	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G		
	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V		
	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A		
	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	
	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	
Interval	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75	76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	Total	
Engagement	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U		
	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	
	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	
Communication	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G		
	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V		
	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A		
	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	
	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	
Interval	91	92	93	94	95	96	97	98	99	100	101	102	103	104	105	106	107	108	109	110	111	112	113	114	115	116	117	118	119	120	Total	
Engagement	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U	U		
	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	O	
	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	J	
Communication	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G	G		
	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V	V		
	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A		
	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	W	
	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	M	
Engagement	U	Unengaged																				%	Sheet Total	/120								
	O	Object Engagement																				%	Sheet Total	/120								
	J	Joint engagement																				%	Sheet Total	/120								
Communication	G	Gestures																				Sheet Total										
	V	Vocalizations																				Sheet Total										
	A	Word Approximations																				Sheet Total										
	W	Words																				Sheet Total										
	M	Multiple Words																				Sheet Total										

Appendix K  
Child Expressive Communication Measure

Operational Definitions From:

Harjusola-Webb, S.A. & Robbins, S. H. (2012). The effects of teacher-implemented naturalistic intervention on the communication of preschoolers with autism. *Topics in Early Childhood Special Education, 32*, 99-110.

**Expressive Communication Measure**

**Gestures**

Physical movements made by the child in an attempt to communicate with the parent.

**Vocalizations**

A non-word verbal utterance voiced by the child in an attempt to communicate with the parent.

**Word Approximations**

Single-word approximations voiced by a child in an attempt to communicate with the parent.

**Words**

Single word utterances voiced by the child in an attempt to communicate with the parent.

**Multi-Word Utterances**

Multi-word utterances are a combination of two or more different words voiced by the child in an attempt to communicate with the parent.