

**PARENT OUTCOMES IN GROUP INTERVENTION FOR CHILDREN WITH
AUTISM SPECTRUM DISORDER**

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Abstract

It has been shown that having a child with autism spectrum disorder (ASD) impacts parents in many ways. However, there is limited research examining changes of these impacts over time, especially in the context of children's intervention. This study examined changes in personal wellbeing, family quality of life, mental health issues, and parenting stress in 178 parents of children with ASD receiving a group behavioural intervention. The groups had varying levels of parent involvement, which was also considered, along with differences between mothers and fathers. Data were collected via questionnaires administered at the beginning, end, and at a 9- to 11-week follow-up of the group intervention. Overall, there were significant improvements in mental health issues and parenting stress from the beginning to the end of the group. While there were no differences between mothers and fathers with regard to changes over time, some relevant differences were noted in their baseline scores. The group with higher parent involvement showed significantly better improvements in personal wellbeing, family quality of life, and parenting stress than the lower involvement group. Possible mechanisms of change in the outcome variables were also examined. At follow-up, all gains in the outcome variables were maintained. The findings suggest that group behavioural interventions for children with ASD can have a positive impact on parents, and that groups with greater parent involvement offer even more benefit. Importantly, these changes are maintained beyond the end of the group. The mechanisms by which improvements are seen suggest aspects that could be incorporated by children's service providers.

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Parent Outcomes in Group Behavioural Intervention for Children with Autism Spectrum Disorder

Children with autism spectrum disorder (ASD) are characterized as having impairments in social interaction and communication, along with stereotypic and repetitive behaviour (American Psychiatric Association [APA], 2013). These children vary greatly in their abilities and disabilities, with some functioning at a typical level and others requiring assistance for most of their daily activities (Kanne et al., 2011; Pugliese et al., 2015). Prevalence estimates for ASD are estimated to be from approximately 1 in 100 (Anagnostou et al., 2014) to as high as 1 in 59 (Baio et al., 2018). It has generally been reported that ASD is more common in boys than girls, with a ratio of approximately 4 to 1 (Fombonne, 2009), although some research suggests that girls and women may be underdiagnosed for a number of reasons, and that the ratio is likely closer to 3 to 1 (Loomes et al., 2017; Ratto et al., 2018). Raising a child with ASD can impact parents in a number of ways, as will be detailed below.

The following sections include a brief review of current literature as it pertains to ASD symptomatology and related behaviours. The impact on parents of children with ASD will then be considered, as guided by a theoretical model. Evidence-based interventions for ASD will be discussed, including those incorporating parent involvement, followed by a description of the current study's purpose.

ASD Symptomatology and Other Notable Behaviours

According to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; APA, 2013), the criteria for ASD include: 1) deficits in social-emotional reciprocity, nonverbal communication, and maintaining and/or developing relationships; and 2) at least two types of restricted and repetitive patterns of behaviour (i.e., stereotyped or repetitive behaviour,

inflexibility or ritualized behaviours, restricted and fixated interests, and/or abnormal sensory interests). The symptoms have to be present in the early developmental period, cause significant impairment in functioning, and should not be better explained by an intellectual disability (although it does not exclude this as a co-occurring diagnosis).

In addition to the core symptomatology, children with ASD often present with associated difficulties encompassing most life domains, including social skills, communication, cognitive ability, daily living skills, and behaviour. Consistent with one of the central characteristics of ASD, these children have significant social skills deficits, including difficulty with social interaction, non-verbal social cues, and appropriate social behaviour (Cervantes et al., 2013). Significant difficulties with communication, namely in the form of receptive and expressive language, as well as nuanced uses of language, are also common (Boucher, 2012). Nearly one third of children with ASD have a co-occurring diagnosis of an intellectual disability (Baio et al., 2018). Many children and adolescents rely on caregivers to support them in daily living activities such as dressing, eating, and toileting past a developmentally appropriate period (Smith et al., 2010).

Maladaptive behaviours (e.g., self-injurious behaviour, tantrums, and aggressive behaviour) occur at a higher rate in children with autism than typically developing children (Hill et al., 2014; Konst et al., 2013; Richards et al., 2012). Furthermore, children with autism are more likely to display these behaviours than children with other developmental disabilities such as Down syndrome or general intellectual disabilities (Griffith et al., 2010). Children with ASD also have more difficulty with emotion regulation than typically developing children (Samson et al., 2015). Intervention programs typically focus on decreasing maladaptive behaviours and encouraging the development of adaptive skills such as the ones highlighted above.

Impact on Parents

Since children with ASD present with such unique and often challenging characteristics, research examining impact on parents is imperative. Raising a child with ASD often carries with it demands significantly beyond those associated with raising a typically developing child (Smith et al., 2010). Perry (2004) developed a conceptualization of stress in parents of children with developmental disabilities, including ASD (see Figure 1). The Perry Model of Stress (Perry, 2004) provides a framework for how different child, family, and environmental factors lead to parental outcomes. Specifically, child characteristics and other life stressors are mediated and/or moderated by individual and family resources, along with formal and informal supports, leading to both positive and negative outcomes, which are conceptualized as being relatively independent of one another. The model was designed for clinical settings and applied research. Although it was developed as a static model, with factors examined at a single point in time (Perry, 2004), it is possible to adapt this conceptualization for use in a more fluid manner, whereby positive and negative outcomes result in changes to personal and family resources that may then lead to different outcomes over time.

The following sections will summarize the literature across a range of factors related to impact on parents who have a child with ASD. In particular, personal wellbeing, family quality of life, mental health issues, and parenting stress will first be addressed as they function as outcomes in the present study. Then, a variety of other constructs within the Perry Model of Stress (2004) will be highlighted.

Personal Wellbeing

Parents' personal wellbeing (also described in the literature as "quality of life") can be impacted by having a child with ASD. Parents of children with ASD report lower levels of

wellbeing than parents with typically developing children (Costa et al., 2017). Furthermore, parents of children with ASD have lower wellbeing compared to parents of children with other disabilities (Eisenhower et al., 2005; Griffith et al., 2010). A study of French-Canadian families found an association between parents' quality of life and children's adaptive skills, whereby parents of children with ASD who were more dependent reported a lower quality of life (Cappe et al., 2018). Since personal wellbeing can be impacted by child characteristics, it would be useful to examine this element in the context of changes to child characteristics, such as those that occur through treatment programs.

Family Quality of Life

Family quality of life (FQOL) is a construct that emerged within the field of developmental disabilities and encompasses many aspects of family functioning, recognizing that the family serves as an important resource for its members and society at large (Samuel et al., 2012). Family quality of life is associated with child characteristics such as daily living skills and behaviour problems (Gardiner & Iarocci, 2015). Hsiao and colleagues (2017) found an inverse association between family quality of life and parent stress. Family quality of life has also been found to be strongly mediated by the mental health and marital satisfaction of the reporting parent (O. Weiss, 2013). These findings illustrate the relationship between individual members' experience and the greater family system. Therefore, there is indication to consider this construct even when studying individual parents.

Mental Health Issues

Parents of children with ASD are at a high risk of having mental health issues. For example, a study by Bitskia and Sharpley (2004) found that, in their sample of parents, two-thirds had clinically significant levels of depression and half had clinically significant levels of

anxiety, although their sample was nearly entirely composed of mothers. Hastings, Kovshoff, Ward, and colleagues (2005) had a more balanced sample of mothers and fathers and found that mothers reported more depression than fathers. Furthermore, Teague et al. (2018) found that parents of children with ASD experience more mental health issues than parents of children with other developmental disabilities. It has been well established that mental health issues are very common in this parent population. However, there is limited research examining factors that may lead to changes in parents' mental health, and particularly those that may lead to improvement.

Parenting Stress

Raising a child with ASD comes with additional sources of stress related to parenting. Parents of children with ASD experience higher stress compared to parents of typically developing children (Hayes & Watson, 2013; Rao & Beidel, 2009; Siu et al., 2019). Children's externalizing behaviours have been shown to predict parenting stress more than other child characteristics, such as age, gender, and ASD severity (Lecavalier et al., 2006; McStay, Dissanayake, et al., 2014, Siu et al., 2019). Costa and colleagues (2017) found that parents' perception of their child's difficulties predicted parenting stress more than the child's objective difficulties. Other individual factors have also been found to impact parenting stress, as will be highlighted below, and it is important to continue to explore this complex construct in parents of children with ASD.

Coping

Parents employ different types of coping strategies, and there is a body of research examining the coping strategies of parents of children with ASD. Several different theories and conceptualizations of coping are present in the literature. Traditional coping literature in the general population (e.g., Folkman & Lazarus, 1980) classifies coping into problem-focused

(preoccupation with managing the source of stress) versus emotion-focused (preoccupation with emotional aspects of stress). A study by Hastings, Kovshoff, Brown, et al. (2005) included a factor analysis that resulted in four categories of coping strategies used by parents of children with ASD: active avoidance, problem-focused, positive, and religious/denial coping. Research has found that parents of children with ASD use avoidance strategies more often than parents of typically developing children (Pisula & Kossakowska, 2010). Benson (2010) found that avoidant coping was related to depression, while more positive coping strategies were associated with higher levels of well-being. Similar findings were reported by Pozo et al. (2014), whereby positive and problem-focused coping strategies were associated with higher levels of wellbeing in mothers. Active coping strategies have also been found to be associated with lower levels of parenting stress (Zaidman-Zait et al., 2017). Coping styles are an important consideration but there is little research examining changes in coping over time in relation to parent outcomes.

Parents' Relationship

Having a child with ASD can impact the parents' relationship, and marital difficulties are more common in parents of children with ASD (Hartley et al., 2017; Sim et al., 2016). Some research suggests that marital quality may serve as a mediating factor for other maternal outcomes, such as wellbeing and parenting efficacy (Benson & Kersh, 2011; Carter et al., 2009), as well as stress and depression (Weitlauf et al., 2014). A longitudinal study by Hartley and colleagues (2012) found that children's problem behaviour predicted changes in mothers' reported marital satisfaction, with more severe behaviours associated with lower marital satisfaction. Therefore, marital/relationship satisfaction is a relevant construct to take into consideration when studying parent outcomes.

Family Hardiness

Family hardiness refers to the way the family, as a unit, appraises and handles life events and changes (McCubbin et al., 1986). Having a child with ASD introduces more potential life events and changes, making this a relevant construct when studying these families. J. Weiss et al. (2013) found that family hardiness mediated the association between stressors and family distress. Overall, there is very limited research examining this construct within the ASD literature. In thinking of the family system, family hardiness is a meaningful aspect to include.

Parenting Self-Efficacy

Parenting a child with ASD often requires better developed parenting skills, as well as different skills altogether, than parenting a typically developing child. For example, parents of children with ASD often need to advocate for various supports, manage challenging behaviours, and navigate complex service systems. According to Bandura (1982), self-efficacy consists of "...judgements of how well one can execute courses of action required to deal with prospective situations" (p. 122). Unsurprisingly, parents of children with ASD report lower parenting self-efficacy than parents of children with other disabilities (Smart, 2016). In mothers of children with ASD, poor self-efficacy is associated with stress, depression, and feelings of guilt, but interestingly it is not associated with actual knowledge of ASD (Kuhn & Carter, 2006). Therefore, increasing self-efficacy is more complicated than simply increasing one's ASD knowledge base. Additionally, self-efficacy may act as a mediating factor between child problem behaviours and maternal mental health (Hastings & Brown, 2002). Parenting self-efficacy has been demonstrated to be a key variable when studying parents of children with ASD, especially in the context of opportunities to improve this perception (e.g., through involvement in child's treatment).

Social Support

Having available social supports can be essential for functioning and wellbeing of parents of children with ASD, as has been highlighted by research. For example, social support has been found to be related to maternal wellbeing and life satisfaction (Ekas et al., 2010). Social support may also mediate some of the stressors of having a child with ASD, leading to more positive outcomes (J. Weiss et al., 2013; Zablotsky et al., 2013). The type of support is also important, with some research demonstrating that informal support, such as that received from friends and relatives, has an even bigger impact on stress reduction and wellbeing than formal supports, such as respite services and teachers (Shepherd et al., 2020). Still, formal supports, and especially ASD-specific supports, are endorsed as being very important by parents of children with ASD (Pepperell et al., 2018). Therefore, even when evaluating formal programs and supports, it is also important to measure informal sources of support.

Other Stressors

There are many other stressors and considerations that impact parent outcomes, and some are especially relevant for parents of children with ASD. Stressors may include major life events, such as job loss, death of a family member or close friend, changes in living circumstances, and changes in children's service providers. Lower socioeconomic status (SES) has been associated with more parenting stress and mental health issues in mothers of children with ASD (Phetrasuwan & Miles, 2009; Zablotsky et al., 2013). Since publicly funded services usually have long wait lists, many parents resort to paying for private services, resulting in financial burden (Jarbrink et al., 2003). Stressful family events have been found to be associated with changes in maternal mental health issues (Benson, 2018). When evaluating outcomes of parents, other life stressors should be taken into consideration alongside main study variables.

Positive Impact

While much research has focused on the negative aspects of raising a child with ASD, there is also research that examines the positive aspects of raising a child with a developmental disability (Hastings, Beck, et al., 2005). For example, parents of children with ASD may experience increased patience and greater tolerance for differences in others (Patterson, 2007). A qualitative study with a sample of Israeli parents of children with ASD found themes of empowerment and growth, spiritual-emotional experience, interpersonal relationships, and new possibilities (Waizbard-Bartov et al., 2019). These positive outcomes are not mutually exclusive with negative ones, meaning that a family can experience both simultaneously (Perry, 2004; Trute et al., 2007). This research highlights the value of including both negative and positive measures of parenting a child with ASD to obtain a broader understanding. Furthermore, positive factors may mediate the effects of negative factors for parent outcomes, but there is a gap in this research area.

Differences between Mothers and Fathers

Much of the research in this field has included predominantly mothers, with literature on fathers being extremely limited. The literature that does exist has shown some differences between mothers and fathers of children with ASD. For example, mothers and fathers experience different challenges related to different child characteristics, with mothers more negatively affected by children's externalizing behaviour (McStay, Trembath, et al., 2014). Similarly, a study by Allen et al. (2013) found that mothers' and fathers' levels of stress are impacted by different child characteristics, whereby maternal stress is predicted by the child's sociability while paternal stress is predicted by the child's sensory and cognitive awareness. In regard to coping, a study examining a Spanish population found that mothers have been found to utilize

more positive and problem-focused strategies than fathers (Pozo et al., 2014). Examining relationships between mothers' and fathers' wellbeing and quality of life and changes in child characteristics is something worthwhile to understand the needs of these parents as a unit and as individuals. Additionally, a number of research studies have reported that mothers are more likely to be unemployed or employed only part-time compared to fathers (e.g., Baker & Drapela, 2004; McCall & Starr, 2018; Pozo et al., 2014). Overall, the literature highlights some differences between mothers and fathers. In light of these findings, it is important to continue to explore and better understand differences between mothers and fathers, and efforts should be made to include fathers in research when possible.

Behavioural Interventions for ASD in Ontario

Several treatment options are available for children with ASD, but the most empirically supported are those using behavioural techniques (National Autism Center, 2015; Steinbrenner et al., 2020; The Ontario Association for Behaviour Analysis, 2017; Vismara & Rogers, 2010). One especially well-researched treatment for children with ASD is intensive behavioural intervention (IBI), which involves the implementation of techniques based on principles of applied behaviour analysis (ABA) in an intensive (20 or more hours per week) manner addressing a large range of skill domains. IBI has been shown to be efficacious in changing children's IQ, adaptive skills, and autism severity (Eldevik et al., 2009; Peters-Scheffer et al., 2011; Virués-Ortega, 2010; Vismara & Rogers, 2010).

Since child characteristics have an impact on parents, it would make sense that improvements of these child characteristics through ABA and IBI would also be associated with improvement in parent factors. Indeed, parents have reported a greater decrease in stress attributed to IBI, as compared to other interventions such as speech-language therapy and

occupational therapy (Shepherd et al., 2018). However, there is a large gap in the literature examining parent outcomes in the context of IBI and ABA interventions more generally.

In Ontario, IBI was provincially funded for children with ASD between 2000 and 2018. IBI entails the investment of considerable resources due to the high number of hours required each week on an individual basis by properly trained and supervised therapists, resulting in long wait lists. Notably, IBI has been shown most effective when implemented at a young age (Perry et al., 2013; Perry et al., 2011).

In 2011, the Ontario Ministry of Children and Youth Services began an initiative to provide children and youth with ASD with less intensive ABA services (which require less resources). These services involve the implementation of behavioural techniques that address one or more of four skill domains: communication, daily living, behaviour/emotional regulation, and social skills. Depending on the specific geographical region, these are often offered by way of short-term intervention groups (usually 2-hour weekly or twice weekly sessions over 9 to 11 weeks) that target one of the four skill domains above. In these instances, children are placed into small groups suited to their abilities and needs. In addition to group intervention for the children, groups have varying components of parent involvement. In 2018, a new Ontario Autism Program was implemented. Under this new program, all children are given an annual monetary cap for services funded by the provincial government, with a maximum lifetime cap. A new needs-based program is set to be implemented in April 2021, but the details of this program have not yet been released. Due to the amount of funding provided under the current plan, many families cannot afford to pay for IBI and instead opt for cheaper (i.e., much less intensive) interventions. As a result, the demand for aforementioned group ABA is speculated to have increased substantially.

Although these interventions are evidence-based as far as child outcomes, there is limited to no research evaluating these groups with regard to their possible impact on parent outcomes.

ABA Group Instruction and Parent Involvement

Studies examining the outcomes of treatments using principles of ABA have demonstrated that individuals can learn a wide range of skills, such as daily living, social, and communication skills, depending on individual goals (Matson, et al., 2012; Matson et al., 2007; National Autism Center, 2015; Smith & Iadarola, 2015; Steinbrenner et al., 2020; The Ontario Association for Behaviour Analysis, 2017). Group instruction using ABA techniques (e.g., in classrooms) is an efficient and useful method that has demonstrated some success (Leaf et al., 2017; Smith & Iadarola, 2015). Group interventions use a variety of approaches informed by evidence-based practices. Some are packaged, manualized interventions, such as the Program for the Education and Enrichment Relational Skills (PEERS; Laugeson & Frankel, 2010) and Improving Parents as Communication Teachers (Project ImPACT; Ingersoll & Dvortcsak, 2019). Others develop curriculums utilizing ABA practices that have been well-documented to be effective (e.g., behavioural skills training, video modeling, task analysis; National Autism Center, 2015; The Ontario Association for Behaviour Analysis, 2017) to develop their curriculum.

Parent training within ABA, which entails teaching intervention techniques to parents who then administer the intervention to their child (i.e., acting as their child's therapist), has been well-documented to be effective for children's skill development (e.g., McConachie & Diggle, 2007; Suppo & Floyd, 2012). Some more naturalistic approaches focus more on coaching parents how to interact with their child while still maintaining a goal-oriented approach (e.g., Brian et al., 2017) There is evidence that more intensive parent training may lead to better child

outcomes (Bearss et al., 2015). Of course, taking on more intensive roles can be quite time-consuming and present as a source of additional stress, with some research highlighting that mothers report a greater sense of strain as demands for their involvement increase (Schwichtenberg & Poehlmann, 2007). Therefore, rather than relying on parents to be responsible for all aspects of an intervention, it is sensible to have them be involved to the extent feasible as part of an intervention administered primarily by professionals, especially in cases where these interventions are publicly funded.

Some intervention programs for children include a parent involvement component, whereby parents develop complementary skills for teaching or supporting their children who are participating in an intervention. Parent involvement in intervention can have great benefits, including both child and parent improvements (Suppo & Floyd, 2012; Tonge et al., 2006). For example, parent involvement in intervention is associated with significant child gains, maintenance, and generalization of target skills (Beaumont & Sofronoff, 2008; Mandelberg, Frankel, et al., 2014; Mandelberg, Laugeson, et al., 2014; Tonge et al., 2014).

Research examining parent outcomes in interventions that include their involvement is relatively limited, although findings thus far have been hopeful. Karst (2014) evaluated outcomes in a 14-week social skills manualized program for adolescents with ASD, in which their parents attend concurrent didactic sessions. Compared to a wait-list control group, the experimental group showed a trend of improvement in parenting stress and self-efficacy, but there was a lack of significant findings, possibly due to a small sample size of 50 participants between both groups. Another study by Tonge et al. (2006) found that parents of young children with ASD who took part in a 20-week parent training program (with or without a behaviour management skills training program) experienced improvements to their wellbeing and mental health, as

compared with a control group. Notably, the parent training programs in this study also included components targeted specifically at parents, such as managing parental stress, mental health issues, and grief. Another study by Stadnick and colleagues (2015) examined a 12-week parent-mediated intervention and found that in addition to greater gains in child communication skills, parent stress was reduced. Within the IBI field, Solish and Perry (2008) found an association between parent involvement and self-efficacy. However, this has not really been explored within less intensive ABA services such as the group ABA programs with a parent component. Overall, there also remains a gap in the literature with regard to the degree and mechanisms of change in parent outcomes and it is, therefore, not clear which factors are contributing to changes when they do take place.

A review of the literature revealed that, within the already limited research examining parent outcomes, follow-up data is rarely collected, though available studies with follow-ups reveal promising results. For example, a study by Feldman and Werner (2002) followed up with parents of children with developmental disabilities (including ASD) up to five years after a parent behavioural training program and found that parent stress, family quality of life, and self-efficacy were better than in parents with children on a wait list. However, the sample size was only 36 across both groups and was also made up of parents of children with broader developmental disabilities rather than ASD-specific. Tonge and colleagues (2006) collected follow-up data 6 months after their parent training program within an ASD sample. Mental health and personal wellbeing improvements made by parents who received parent training were found to be further improved at the follow-up, as compared to a control group. Given the limited knowledge available with regard to parent outcomes after parent training or involvement is over,

it is important for follow-up data to be collected when possible to better understand the lasting effects in the context of other factors.

Intensity of parent involvement can vary greatly, from parent education using handouts to instructional sessions to hands-on parent-child training. As highlighted by Wainer and colleagues (2017), there is a large gap in the research in regard to parent outcomes within interventions that incorporate their involvement. It is important to explore the way in which outcomes range in relation to varying levels of parent involvement. There are some studies examining different intensities of parent training in which they are steered to be the main therapists or coached on how to interact with their child. However, different intensities of parent involvement within a professional therapist-led framework (i.e., parent involvement is supplemental) is not well-researched.

Purpose

The purpose of my dissertation was to investigate four key parent outcomes: parents' personal wellbeing, family quality of life, mental health issues, and parenting stress. More specifically, I aimed to examine whether these variables changed as a child with ASD participated in an ABA group (with variable levels of parent involvement) in a community service agency. This investigation was theoretically guided by the Perry Model of Stress (Perry, 2004) and the literature reviewed above. Therefore, the outcome variables (personal wellbeing, family quality of life, mental health issues, and parenting stress) were examined in the context of child characteristics (age, gender, adaptive abilities), other life stressors (SES, life events), individual parents' personal resources (coping, positive gain, parenting self-efficacy), family system resources (marital satisfaction, impact of having a child with a disability, family hardiness), informal social supports, and formal supports.

The research questions I addressed regarding these four parent outcomes were: 1) Do parents report a change in personal wellbeing, family quality of life, mental health issues, and/or parenting stress after their child with ASD has received a block of ABA services? 2) Do mothers and fathers display different scores or patterns of change over the time that the child has received ABA services? 3) Do parents participating in specific types of ABA groups with a more intensive parent involvement component demonstrate better outcomes? 4) What are the mechanisms for changes from the beginning of the group to the end? 5) Are changes maintained at a 9- to 11-week follow-up?

Method

This project received approval from ethics boards at both York University and Surrey Place (previously known as “Surrey Place Centre” before rebranding of the organization). Recruitment began in April 2016 and data collection concluded in September 2017. This study employed a longitudinal, correlational (i.e., non-experimental) design.

Participants

Participants were parents of children with ASD who were receiving group ABA intervention at Surrey Place (excluding programs that were primarily parent-administered). The final sample consisted of 178 primary caregivers (40 males, 134 females, 4 unknown; see below for recruitment procedures). Within this sample, there were a total of 11 couples (i.e., both of a child’s parents) who participated. See Table 1 for participant demographic information. The participants came from a diverse cultural and socioeconomic background (see Tables 1 and 2). The children (143 males, 35 females) ranged in age from 3 to 18 years ($M = 9.17$, $SD = 3.62$).

Recruitment and Data Collection Procedures

At the time of data collection, four blocks of groups were running at Surrey Place each year (January to March, April to June, July to August, and September to December). Recruitment took place in April 2016, September 2016, January 2017, and April 2017. Due to the condensed programming during the summer block (July to August), participants were not recruited during this timeframe. A total of 718 children received services from eligible groups, resulting in at least 718 potential participants (if a child had more than one primary caregiver, they would also be eligible for participation).

Caregivers took part in an orientation during the first session of each ABA group at Surrey Place. At the end of this orientation, clinicians provided all parents with an information letter describing this project (see Appendix A) and read aloud a brief script outlining the study (see Appendix B). A researcher (myself or a fellow graduate student from the same research laboratory) was introduced to the group and the clinician left the room to eliminate any perception of pressure to participate. The researcher provided potential participants with a summary of the study and an informed consent form to review (see Appendix C). The researcher answered any questions that potential participants had. Caregivers who were interested in participating were asked to carefully read the informed consent form and sign if they agreed. As a small token, a voucher for a drink from the in-house café was given to those who agreed to participate during this period following the orientation. Parents who could not immediately decide if they would like to participate were given the option to fill out a form with their contact information for the researcher to follow up at a later time (see Appendix D). On the rare occasion that a researcher was not able to attend a group, the clinicians read the appropriate section of the

script and provided interested parents with the contact information form, which was passed along to me.

Upon agreement to participate, participants were assigned a unique Participant ID and given the option of completing the Time 1 Questionnaire (see Appendix E, as well as description below) in pen-and-paper format or online. Participants were asked to complete the questionnaire within two weeks of the start date, although this was not always accomplished. I conducted reminder phone calls and emails up to two weeks from the ideal date. At the end of the child's ABA program (9 to 11 weeks), parents were contacted again to complete the Time 2 Questionnaire (see Appendix F, as well as description below) within two weeks of the group end date. Nine to 11 weeks later, depending on the length of the group, parents were contacted a final time to complete the Time 3 Questionnaire (see Appendix G, as well as description below). The same reminder procedures were utilized to ensure participants complete the questionnaires as close to the target dates as possible and to attempt to minimize attrition.

A total of 265 parents of the 718 (36.9%), from 19 types of groups (see Appendix H), agreed to participate (i.e., signed the consent form and were assigned a Participant ID). Of those, 178 (67.2%) followed through by completing at least one questionnaire. Of the 178, 88 (49.4%) completed all three questionnaires, 41 (23.0%) completed two questionnaires, and 49 (27.5%) completed one questionnaire. See Appendix I for a flowchart of participants.

Measures

The variables collected for this study were chosen in reference to the Perry Model of Stress (Perry, 2004). Questionnaires were compiled to collect data that operationalized the different domains of the model (see Appendix J). Due to the longitudinal nature of this study, and the expectation of change in certain variables due to the intervention, some of the constructs

(in addition to the outcome variables) were collected at all time points, as will be illustrated below.

Time 1 Questionnaire

The Time 1 Questionnaire (see Appendix E) encompassed several areas, as described below. The sections are described in accordance with their fit in constructs within the Perry Model of Stress (Perry, 2004).

Child Characteristics. Children's date of birth and gender were collected (see items A1 and A2 in Appendix E). The GO4KIDDS Brief Adaptive Scale (see items A4 and A5 in Appendix E; Perry et al., 2015), an 8-item brief adaptive measure with good validity and reliability ($\alpha = .87$), assesses children's communication, social, and self-help skills. Participants endorse the statement most closely resembling the level of functioning of their child in each of the skill areas. Some recent, unpublished use of this measure within our research team has suggested that the summary first item can be omitted without negative consequence for psychometric properties. Therefore, this method was employed for the current study with the goal of minimizing questionnaire completion time. The internal consistency of this 7-item scale in the current study was good ($\alpha = .88$). The mean score of the seven items was calculated, with higher scores associated with better adaptive abilities.

Other Life Stressors. Stressful life events were captured by a list of 23 items related to stressful events for the family and 10 items related to stressful events for the child (see section E in Appendix E; Abidin, 2012 as adapted by Perry & Weiss, 2008). The total number of stressful life events was calculated for each participant.

Demographic information (summarized in Tables 1 and 2) was collected, including marital status, caregiver age, sex, relationship to the child, country of birth, first language, level

of education, occupation, and employment status (see section F in Appendix E; Perry & Weiss, 2008). SES was calculated using an adapted version of the Barratt Simplified Measure of Social Status (BSMSS; Barratt, 2006). Using the BSMSS, the respondent's and, when applicable, spouse's education level was assigned a score between 3 and 21 and their occupation was assigned a score between 5 and 45 (based on occupation categories). Since the occupation list in the BSMSS is not exhaustive, some of the occupations provided by the respondents were not listed. In these cases, I consulted with a fellow senior graduate student, who had previously demonstrated inter-rater reliability with this measure, to reach agreement of the proper designation. Education and occupation scores of the respondent and their spouse were added and divided by two (or left as is in single-parent households), resulting in a total score between 8 and 66. When a single parent was not working, their occupation score was based on the category that most closely matched their education level. When one parent in a two-parent household was not working, the education level score of both parents was divided by 2 but the occupation score was included in whole. The author of this measure was consulted regarding this adapted scoring and approved its use (W. Barratt, personal communication, February 1, 2019).

Individual's Personal Resources. Positive gain of raising a child with ASD was examined using the Positive Gain Scale (see section B3 in Appendix E; Pit-ten Cate, 2003). This 7-item measure uses a 5-point scale (1 = *Strongly Disagree* to 5 = *Strongly Agree*) to capture the positive aspects of having a child with a disability (e.g., "Since having this child, I feel I have grown as a person"). Previous studies with samples similar to the current one found alphas of .80 and .87 (MacDonald et al., 2010; MacMullin et al., 2011). The internal consistency of this scale in the current study was good ($\alpha = .83$). The mean score was calculated for this scale, with higher scores indicating greater positive gain of having a child with ASD.

Parents' coping strategies were measured with the Brief COPE (see section B4 in Appendix E; Carver, 1997). The scale is made up of 28 statements on a 4-point scale, with items such as "I've been taking action to try to make the situation better" and "I've been making jokes about it." The author of this measure suggests scoring the items into 14 subscales (e.g., denial, positive reframing, humor) each with two items. However, with a goal of conserving degrees of freedom, it was decided that the least number of variables would be optimal to represent coping strategies. Therefore, a series of factor analyses were performed. First, an exploratory factor analysis resulted in eight factors, which did not fulfill the goal of conserving degrees of freedom. Based on a study with a similar sample (Luthra, 2018), a confirmatory factor analysis was conducted using her factors with minor adjustments (i.e., removing one item). The final best fitting model, although not a great fit, was two-factor model ($CFI = .789$, $TLI = .767$, $RMSEA = .071$, $SRMR = .126$, $\chi^2 = 440.881$, $df = 251$, $p < .001$). Confirmatory factor analyses of models with more factors did not have sufficiently improved fit to justify using more degrees of freedom and were not as conceptually sensible. Thus, the final scoring was done using two subscales- positive (e.g., "I've been getting emotional support from others") and negative (e.g., "I've been giving up the attempt to cope"). The positive subscale had good internal consistency ($\alpha = .86$) and the negative subscale had acceptable internal consistency ($\alpha = .76$). The mean scores of each of the items on each of the two subscales were calculated, with higher scores on the positive subscale and lower scores on the negative subscale indicating "better" coping.

Parenting self-efficacy was measured using the Family Subscale of the Family Empowerment Scale (see section B1 in Appendix E; Koren et al., 1992). This subscale measures perception of parenting abilities using 12 items (e.g., "When problems arise with my child, I handle them very well", "I am able to get information to help me better understand my child") on

a 5-point scale, with a good internal consistency ($\alpha = .87$). In the current study, this scale had very good internal consistency ($\alpha = .89$). The mean score of this scale was used, with higher scores indicating a greater sense of parenting self-efficacy.

Family System Resources. Participants who identified as being married or in a long-term relationship were asked to answer two questions examining happiness with the relationship and the amount of support they receive from their partner for their child with ASD (see section B6 in Appendix E; Perry & Weiss, 2014). With only two items on a 5-point scale, this measure had rather low internal consistency ($\alpha = .67$) but has been shown to be useful in other studies in our research group (e.g., Patterson et al., 2018; O. Weiss, 2013). The sum of these items was used to represent marital satisfaction in the context of having a child with ASD.

The impact of having a child with ASD was assessed using the Family Impact of Childhood Disability Scale (Trute et al., 2002), including additional items that were later added by the original authors of the measure (see section C1 in Appendix E; Trute, et al., 2007). This 20-item measure uses a 4-point scale to assess the positive (e.g., “The experience has made us come to terms with what should be valued in life”) and negative (e.g., “Because of the situation, we have hesitated to phone friends and acquaintances”) outcomes of having a child with a developmental disability. Trute and colleagues (2007) reported that the overall scale is valid when compared to other measures of similar constructs and has good internal consistency ($\alpha = .81$ for the Positive Family Impact subscale and $\alpha = .89$ for the Negative Family Impact subscale). In the current study, both subscales had good internal consistency ($\alpha = .82$ for the Positive Family Impact subscale and $\alpha = .88$ for the Negative Family Impact subscale). The mean scores were calculated for the Positive and Negative Family Impact subscales for use in further analyses.

Family hardiness, a family's sense of control over their lives, was measured using the Adaptive Appraisal subscale from the Inventory of Family Protective Factors (see section C2 in Appendix E; Gardner et al., 2008), which is a 4-item subscale (e.g., "Our family has coped well with one or more major stressors in our lives") with good internal consistency ($\alpha = .83$). This scale also had good internal consistency in the current study ($\alpha = .82$). The mean score of this subscale was calculated, with higher scores associated with greater family hardiness.

Informal Social Support. Social Support was measured using 13 items on a 6-point scale (including an option for *Not Available*), rating a range of people and groups (e.g., relatives, co-workers) about how helpful they are to the family (see section C4 in Appendix E; adapted from Dunst et al., 1984). With regard to the helpfulness rating in the current study, internal consistency was good ($\alpha = .82$). The total number of available supports was calculated, as well as the mean helpfulness score of all available sources.

Formal Supports and Services. Participants were asked to indicate the services they have accessed for their child over the past year from a checklist of 18 professionals (e.g., family doctor, dentist, behaviour therapist; see section D1 in Appendix E, Perry & Weiss, 2008). The sum of services accessed was calculated. Additional items were developed for the current study of overall satisfaction ratings for these services (see section D2 in Appendix E) and how services fit with their child's and family's needs (see section D3 in Appendix E), along with a section for any open-ended comments (see section D4 in Appendix E). The internal consistency of the four ratings was good ($\alpha = .88$). The mean of these items was calculated.

Positive and Negative Parent Outcomes. Parenting stress was evaluated using the Questionnaire on Resources and Stress – Friedrich Short Form (see section B2 of Appendix E; Friedrich et al., 1983), made up of 20 true-false statements evaluating this area (e.g., "The

constant demands for care for ____ limit growth and development of someone else in our family”, “It is easy for me to relax”). Some items on the scale are worded positively (e.g., “I can go visit with friends whenever I want”), while some are worded negatively (e.g., “I have given up things I have really wanted to do in order to care for ____”). Items were reverse coded when necessary in such a way that “0” represented lower stress and “1” represented higher stress. Internal consistency was good for the negatively worded items ($\alpha = .87$), acceptable for the positively worded items ($\alpha = .72$), and excellent for all items combined after reverse recoding ($\alpha = .90$). The mean of items (after recoding) was calculated, resulting in a number between 0 and 1, with scores closer to 1 meaning a higher parenting stress score.

The Kessler-10 (see section B5 in Appendix E; Kessler et al., 2003) is a brief screening tool for mental health issues (anxiety and depressive symptoms), which consists of 10 items, each rated on a 5-point scale, that is valid and has been shown to have excellent internal consistency ($\alpha = .93$). The internal consistency for this scale in the current study was identical ($\alpha = .93$). The mean score of all items on this scale was calculated. Higher scores indicated higher instances of mental health issues.

The Personal Wellbeing Index 5th Edition (see section B7 in Appendix E; International Wellbeing Group, 2013) measures individual quality of life using nine items rated on an 11-point scale, encompassing satisfaction across most life domains (e.g., health, sense of achievement, part of community). International research has found acceptable to good internal consistency ($\alpha = .70$ to $\alpha = .85$; International Wellbeing Group, 2013). In the current study, this scale had excellent internal consistency ($\alpha = .92$). The mean score was calculated, with higher scores indicating higher personal wellbeing.

Family quality of life was measured using the Beach Center Family Quality of Life Scale (see section C3 of Appendix E; Hoffman et al., 2006). This 25-item measure uses a 5-point scale to examine satisfaction with a broad range of family variables (e.g., “My family has the support we need to relieve stress”, “My family member with a disability has support to make friends”) and has good reported validity and internal consistency ($\alpha = .88$). In the current study, this scale had excellent internal consistency ($\alpha = .95$). The mean score of all items was calculated, with higher scores indicating higher family quality of life.

Time 2 and Time 3 Questionnaires

The Time 2 and Time 3 Questionnaires (see Appendices F and G) are identical to each other and made up of portions of the Time 1 Questionnaire. The variables from the Time 1 Questionnaire were assessed with regard to whether or not they were expected to change over the course of the study, which determined their inclusion in Time 2 and 3 Questionnaires. See Appendix K for a summary of all questionnaire constructs, including whether they were included either at Time 1 only or in all three time points. Some of the scale instructions in Time 1 Questionnaire asked respondents to consider the past 12 months when answering. In these cases, instructions were adapted to consider the past 30 days for the Time 2 and 3 Questionnaires.

Parent Involvement

Each ABA group curriculum (see Appendix H) was evaluated to determine the intensity of parent involvement. The expected level of caregiver involvement greatly ranged, with tasks as simple as helping with homework to more committed tasks of attending weekly caregiver sessions. Involvement was dependent upon the nature of the specific ABA group (e.g., some groups were based on manualized programs that set out specific requirements for caregiver participation). I used clinical judgement in determining the involvement level. After

experimenting with a number of different classification systems, a dichotomous variable was deemed to be the most appropriate and parsimonious. Groups that were expected to include less than a total of 5 hours of caregiver involvement over the 9 to 11 week period of the group were considered to be *low parent involvement* (sometimes shortened to *low involvement*), while groups that were expected to include more than 5 hours of involvement were considered *high parent involvement* (sometimes shortened to *high involvement*). Unfortunately, objective, real-time measurement of individual parents' actual attendance and involvement was not available.

Results

Preliminary and Descriptive Analyses

Prior to the main analyses, the data were screened for distribution and missing data. These are described below, along with other considerations. See Table 3 for descriptive data for all study variables across timepoints.

Missing Data

For every measure within each questionnaire, the threshold for calculating the score (as outlined in the Measures section) was that at least 75% of the items needed to have been completed (e.g., on an 8-item scale, mean item scores were calculated if at least 6 items were completed). Cases were not systematically deleted based on missing data, but rather excluded only from analyses for which their data were missing.

Time

Ideally, questionnaires should have been completed on the first day of the ABA group, the last day of the ABA group, and on a specific follow-up date equivalent to the length of the ABA group. However, due to the reality of collecting data in a community service provider setting, these ideals were not attainable. Since the Time 1 Questionnaire provided a baseline

score, which was quite important, cases for analyses using Time 1 data were only included if completed within two weeks (14 days) of the first day of the group.

Change Scores

For repeated measure variables, a change score was calculated to demonstrate the increase or decrease from one timepoint to the next. These were used for several of the key analyses. See Table 4 for descriptive data for change scores, along with a reminder of relevant scale information.

Multiple Parents Per Child

There were only 11 couples in total, and not all had complete data, which influenced the types of statistical analyses that would be most appropriate. For some statistical tests, having more than one parent report on a child would violate the assumption of independence. Therefore, such cases were identified and, when one case needed to be used over another, the more complete case was chosen. If both cases had equally completed data, the father was picked due to the lower number of fathers in the sample.

Completers versus Non-Completers

Independent-samples t tests were carried out on all the study variables to compare participants who completed Time 1 only versus participants who completed two or more timepoints. Of 21 comparisons, there was only one significant difference between the groups, with participants who completed two or more timepoints having a moderately higher SES score ($M = 49.13$, $SD = 10.19$, $n = 123$) than those who completed only one timepoint ($M = 44.66$, $SD = 11.81$, $n = 41$), $t(162) = -2.34$, $p = .02$, $d = .41$.

Mental Health Issues

Given previous literature on the proportion of mental health issues in parents of children with ASD, along with the availability of suggested cut-offs for the Kessler-10 screening tool (Kessler, 2003) used in the current study, this variable was given some additional attention, in terms of describing the nature of this clinical sample. At Time 1, 80 participants (50.6% of 158 participants who completed the measure at this time point) met the cut-off for mental health issues. Of those 80 participants, 29 (36.2%) were in the *mild* range, 23 (28.8%) were in the *moderate* range, and 28 (35%) were in the *severe* range. At Time 2, 46 participants (40.4% of the 114 participants who completed the measure at this time point) met the cut-off for mental health issues. Of those, 21 (45.7%) were in the *mild* range, 13 (28.3%) were in the *moderate* range, and 12 (26.1%) were in the *severe* range. Finally, at Time 3, 44 (43.6% of the 101 participants who completed the measure at this time point) met the cut-off mental health issues. Of those, 15 (34.1%) were in the *mild* range, 14 (31.8%) were in the *moderate* range, and 15 (34.1%) were in the *severe* range.

Correlations among study variables and outcome variables at Time 1

Scores of the independent variables from Time 1 were correlated with the Time 1 scores of the four outcome variables- personal wellbeing, family quality of life, mental health issues, and parenting stress. The results are organized according to the domains within the Perry Model of Stress (Perry, 2004). See Table 5 for a summary of the results, which are highlighted below. Due to the number of correlations, only those with a significance of $p < .01$ will be underscored below, with suitable magnitude descriptors of “small” when the correlation is between .10 and .49, “medium” between .50 and .79, and “large” when the correlation coefficient is above .80 (Cohen, 1988).

Child Characteristics. Child's age at the start of the group and gender were not significantly related to any of the outcome variables. Child's adaptive behaviour was negatively correlated with parenting stress to a small degree.

Other Life Stressors. SES was not significantly correlated with any of the outcome variables. Total number of life events was moderately negatively correlated with personal wellbeing and family quality of life, and positively related to mental health issues to a small degree and parenting stress to a moderate degree.

Individual's Personal Resources. Positive gain was positively correlated with personal wellbeing to a moderate degree and family quality of life to a large degree, while it was moderately negatively correlated with mental health issues and parenting stress. Negative coping was largely negatively correlated with personal wellbeing and family quality of life, and highly positively correlated with mental health issues and parenting stress. Positive coping was not significantly correlated with any of the outcome variables. Parenting efficacy was highly positively correlated with personal wellbeing and family quality of life, and highly negatively correlated with mental health issues and parenting stress.

Family System Resources. Family hardiness was strongly positively correlated with personal wellbeing and family quality of life, and negatively correlated with mental health issues to a moderate degree and parenting stress to a large degree. Marital satisfaction was moderately positively related to personal wellbeing and family quality of life, while it was moderately negatively correlated with mental health issues and parenting stress. The positive subscale of the impact on family (of having a child with ASD) was moderately positively related to personal wellbeing and family quality of life, while it was correlated negatively to a small degree with mental health issues. The negative scale of the same measure was negatively correlated with

personal wellbeing to a high degree and family quality of life to a moderate degree, while it was positively correlated with mental health issues to a moderate degree and parenting stress to a high degree.

Informal Social Support. The total number of informal social support sources available was positively related to personal wellbeing to a moderate degree and family quality of life to a large degree, while it was negatively correlated with mental health issues to a small degree and parenting stress to a moderate degree. Satisfaction with informal social support was positively correlated to a moderate degree with personal wellbeing and to a high degree with family quality of life, as well as negatively correlated with mental health issues to a small degree and parenting stress to a moderate degree.

Formal Supports and Services. The total number of formal services received was positively correlated with parenting stress to a small degree, but not with any other outcome variables. Satisfaction with services was moderately positively correlated with personal wellbeing and family quality of life, while it was negatively related to mental health issues to a small degree and moderately to parenting stress.

Correlations Among Time 1 Variables and Change Scores of Outcome Variables

Scores from Time 1 were also correlated with the change scores (Time 2 minus Time 1) of the four outcome variables. As above, the results are organized according to the domains within the Perry Model of Stress (Perry, 2004). See Table 6 for a summary of these results, as well as below for highlights. Once again, only p -values of $< .01$ will be considered noteworthy.

Child Characteristics. Child's age at the start of the group, gender, and adaptive skills were not related to any of the change scores of the outcome variables.

Other Life Stressors. SES was not significantly related to any of the change scores of outcome variable. Total number of life events at Time 1 was not significantly related to any of the change scores of outcome variables.

Individual's Personal Resources. Positive gain was not significantly correlated with changes in any of the outcome variables. Negative coping at Time 1 was moderately negatively correlated with changes in parenting stress and mental health issues. Positive coping at Time 1 was not significantly related to the outcome variables, nor was parenting efficacy at Time 1.

Family System Resources. Family hardiness at Time 1 was negatively correlated with change in personal wellbeing to a small degree and change in family quality of life to a moderate degree. Marital satisfaction was negatively related to change in family quality of life to a moderate degree, while it was positively correlated to a small degree with change in mental health issues. Positive and negative impacts on family (of having a child with ASD) were not significantly correlated with any changes in the outcome variables.

Informal Social Support. The total number of informal social support available and satisfaction with informal support at Time 1 were not significantly related to changes any of the outcome variables.

Formal Supports and Services. The total number of formal services received and satisfaction with services at Time 1 were not significantly correlated with changes in any of the outcome variables.

Research Question 1: Do Parents Report a Change in Personal Wellbeing, Family Quality of Life, Mental Health Issues, and/or Parenting Stress after their Child with ASD has Received a Block of ABA Services?

In order to assess for changes in each of the outcome variables, a paired samples t test was used. In addition to statistical significance, a great focus was also placed on effect sizes using Cohen's d , as described above (Cohen, 1988). It is of note that only one parent per child was used for these analyses (selected as described above).

Personal wellbeing and family quality of life both remained about the same, with no significant differences from Time 1 to Time 2. Parenting stress significantly decreased from Time 1 to Time 2, but the magnitude of this change is very small. Mental health issues also significantly decreased to a small degree from Time 1 to Time 2. See Table 7 for a summary of the results. See Figures 2, 3, 4, and 5 for the participant-level growth plots of each of the outcome variables over time, and Figures 6, 7, 8, and 9 for the overall means of each outcome variable over time.

Research Question 2: Do Mothers and Fathers Display Different Scores or Patterns of Change over the Time that the Child has Received ABA Services?

Outcome variable Time 1 scores of mothers and fathers (i.e., men and women in the sample, not couples) were compared using independent samples t tests. Levene's test for equality of variances was found to be violated for personal wellbeing ($F = 5.13, p = .02$) and mental health issues ($F = 4.06, p = .046$), so a Welch's t test was used for these two outcome variables. There were no significant differences between mothers and fathers on personal wellbeing, $t(69) = 1.15, p = .26, d = .04$, parenting stress, $t(153) = -.95, p = .34, d = .19$, or family quality of life $t(153) = 1.70, p = .09, d = .20$. Regarding mental health issues, there was a significant difference,

to a small degree, in Time 1 scores, with mothers having more severe mental health issues than fathers $t(72) = -2.21, p = .03, d = .39$.

In addition, other Time 1 variables were also examined (see Table 8). On independent samples t tests, compared with fathers, mothers had moderately higher scores for positive coping ($p = .009, d = .53$) and, at the same time, slightly higher negative coping ($p = .07, d = .37$). Mothers also reported, to a small degree, both lower marital satisfaction ($p = .07, d = .38$) and satisfaction with formal services ($p = .07, d = .37$) compared to fathers. A chi-square test of independence was performed to examine whether employment status differed between mothers and fathers. Fathers were moderately more likely to work full-time than mothers, $\chi^2(2, N = 143) = 12.92, p = .002, V = .30$. No other Time 1 variables differed significantly.

Complete data for outcome variables was only available for 23 fathers, which posed some limitations with regard to the analyses that could be carried out. Therefore, in order to examine whether mothers and fathers might have changed over time in the study differently, an independent samples t test was conducted using the change scores of each outcome variable, with caregiver gender as the grouping variable (see Table 9 for a summary of the results). Mothers and fathers did not significantly differ on change scores of any of the outcome variables. However, it is interesting to note that there were small effect sizes for family quality of life and mental health issues, indicative of possible differences between mothers and fathers on these variables. Mothers' mental health issues improved more than fathers' mental health issues. Furthermore, mothers' family quality of life slightly increased, while there was a very small decrease for fathers. See Figures 10, 11, 12, and 13 for mothers' and fathers' means of each outcome variable over time.

Research Question 3: Do Groups with a More Intensive Parent Involvement Component Demonstrate Better Outcomes?

Time 1 scores of participants in the low and high parent involvement groups were compared using independent samples *t* tests. As can be seen in Table 10, the high involvement group had significantly younger children ($p < .001$, $d = .75$) and accompanying lower adaptive scores that would be expected given the younger age group ($p = .007$, $d = .52$). It should be noted that these variables were not highly correlated with any of the outcome variables at Time 1 or in terms of change scores (see Tables 5 and 6). Importantly, there were no significant differences between the groups on any of the Time 1 outcome variables (see Table 11), suggesting the groups, though not randomly assigned, were comparable with regard to the outcome variables at baseline.

My main interest was whether groups with higher parent involvement would show better changes than lower parent involvement. This would be well addressed by comparing the change scores of these two groups. Therefore, independent samples *t* tests evaluating the change scores of each outcome variable between low and high parent involvement groups were carried out (see Table 12 for a summary of these results). In terms of personal wellbeing, the low involvement group had a decline in their scores, while the higher group had an increase in their scores, with a significant difference between their change scores approaching a medium effect size ($p = .02$, $d = .47$). The parenting stress of the high involvement group also decreased more significantly than that of the low involvement group ($p = .04$, $d = .42$). While there were no significant differences in regard to family quality of life ($p = .09$, $d = .34$), the low involvement group had a decrease in their scores, while the high involvement group increased, and there was a small effect size. There were no significant differences in the two involvement groups with respect to mental health

issues. See Figures 14, 15, 16, and 17 for means of low and high involvement groups on each outcome variable over time.

Research Question 4: What are the Mechanisms for Changes from the Beginning of the Group to the End?

To assess possible mechanisms of change in the outcome variables (personal wellbeing, family quality of life, mental health issues, and parenting stress), a series of hierarchical regressions were performed. The variables were arranged into “Controls”, “Level of Involvement”, “Mechanisms”, and “Dependent/Outcome Variables”. Within these categories, variable groupings were arranged based on the Perry Model of Stress (Perry, 2004), while incorporating variables representing changes over time as well as the parent involvement variable. Once the variable arrangement was finalized, the configuration of the blocks and the order in which they were entered was determined. See Figure 18 for a visualization of the variable arrangement.

Four hierarchical regressions were produced, one for each of the four dependent variables (outcome variables). Block 1 included: Time 1 “Stressors”, including Child Characteristics (age, gender, adaptive score) and Other Stressors (life events, SES). The second block consisted of Time 1 “Resources”, including Individual’s Personal Resources (positive gain) and Family System Resources (positive impact on family, negative impact on family, family hardiness, and marital satisfaction). The third block consisted of Time 1 “Supports”, including Informal Social Support (helpfulness of social support) and Formal Supports and Services (total number of formal services). In the fourth block, the single variable representing the parent involvement level was entered. In the fifth block, change scores of the following variables were entered: Individual Personal Resources (changes in parenting efficacy, negative coping, and positive

coping) and Formal Supports and Services (changes in satisfaction with services). Finally, due to prior research findings that self-efficacy is associated with parent involvement (Brian et al., 2017; Solish & Perry, 2008) and self-efficacy may mediate parent outcomes such as mental health issues (Hastings & Brown, 2002), I was interested in exploring whether self-efficacy might relate differently to the dependent variables in parents with high versus low levels of involvement. Therefore, an interaction term between changes in parenting efficacy and parent involvement was entered in the final block. However, in order to conserve power, only interaction terms that were significantly contributing to the model were retained for the final model variables.

Personal Wellbeing

Regression results for personal wellbeing are presented in Table 13. The first regression model, made up of Child Characteristics and Other Life Events, predicted 3% of the variance in personal wellbeing change scores, $F(5, 83) = .54, p = .75$. When Family System Resources were added, as well as positive gain, this accounted for 14.5% of the variance ($p = .02$) for a total of 17.6%, $F(10, 78) = 1.67, p = .10$. With the addition of satisfaction with social support and formal services, the variance accounted for increased by 3.8% ($p = .17$) to 21.4%, $F(12, 76) = 1.72, p = .08$. In the fourth model, the parent involvement variable was added, and this contributed an additional 3.2% of the variance ($p = .08$) for a total of 24.6%, $F(13, 75) = 1.88, p = .046$. The interaction of changes in parenting self-efficacy and parent involvement was not significant and therefore removed from the final model. The final regression model added change scores of parenting efficacy, negative coping, positive coping, and satisfaction with formal services, which predicted an additional 22.4% of the variance ($p < .001$), bringing the total variance of personal wellbeing change scores predicted by the model to 47%, $F(17, 71) = 3.70$,

$p < .001$. In particular, personal wellbeing change scores were significantly predicted by Time 1 positive gain ($\beta = .32, t = 2.45, p = .017, sr^2 = .08$), Time 1 family hardiness ($\beta = -.26, t = -2.25, p = .028, sr^2 = .07$), changes in negative coping ($\beta = -.49, t = -4.47, p < .001, sr^2 = .22$), and changes in positive coping ($\beta = .27, t = 2.86, p = .005, sr^2 = .10$).

Family Quality of Life

As shown in Table 14, the first regression model to predict family quality of life, with Child Characteristics and Other Life Stressors as predictors, showed that these variables accounted for 2.5% of the variance of changes in family quality of life, $F(5, 83) = .42, p = .83$. The second model, in which Family System Resources and positive gain were added, accounted for an additional 16.9% of the variance ($p = .01$), for a total of 19.4%, $F(10, 78) = 1.88, p = .06$. Next, the addition of satisfaction with informal social support and total number of formal services received accounted for an additional 3.4% of the variance ($p = .19$), for a total of 22.8%, $F(12, 76) = 1.87, p = .05$. In the fourth regression model, parent involvement accounted for just 1% of the variance ($p = .31$), and the overall model was now predicting 23.9% of the variance, $F(13, 75) = 1.81, p = .06$. The interaction of parenting self-efficacy and parent involvement was not significant and removed from the model. The final regression model, which added change scores of parenting efficacy, negative coping, positive coping, and satisfaction with formal services, predicted another 10.9% of the variance ($p = .025$), for a total 34.8% of the variance in family quality of life change scores, $F(17, 71) = 2.23, p = .01$. In this final model, changes in family quality of life were significantly predicted by Time 1 marital satisfaction ($\beta = -.29, t = -2.50, p = .015, sr^2 = .08$) and changes to negative coping ($\beta = -.26, t = -2.16, p = .034, sr^2 = .06$).

Mental Health Issues

The regression for mental health issues is presented in Table 15. In the first model, Child Characteristics and Other Life Stressors predicted 7.5% of the variance of mental health issues change scores, $F(5, 83) = 1.35, p = .25$. With Family System Resources and positive gain added, the new model predicted an additional 11.1% of the variance ($p = .07$), for a total of 18.6% of variability predicted, $F(10, 78) = 1.78, p = .08$. In the third model, satisfaction with informal social support and total number of formal services did not explain any additional variance, $F(12, 76) = 1.45, p = .16$. Similarly, the addition of parent involvement intensity in the following block also did not account for any additional variance, $F(13, 75) = 1.33, p = .21$. The fifth model added change scores of parenting efficacy, negative coping, positive coping, and satisfaction with formal services, and these predicted 21.9% of the variability ($p < .001$), bringing the total to 40.6% of the variability of changes in mental health issues, $F(17, 71) = 2.86, p = .001$. In this case, there was a significant interaction effect between changes in parenting efficacy and the intensity of parent involvement, which was added to the final model and accounted for a unique 4.3% of the variance ($p = .02$). The final regression model for changes in mental health issues showed that the variables entered accounted for 44.9% of the variance, $F(18, 70) = 3.17, p < .001$. None of the Time 1 variables were significant in the final model. Changes were significantly predicted by changes in negative coping ($\beta = .50, t = 4.40, p < .001, sr^2 = .22$) and the interaction term of changes in parenting efficacy and parent involvement ($\beta = -.29, t = -2.34, p = .02, sr^2 = .07$). More specifically, as can be seen in Figure 19, there was a significant interaction effect between parenting efficacy and the intensity of parent involvement, with the high parent involvement showing increases in parenting efficacy associated with higher improvement in mental health issues and decreases in parenting efficacy associated with worse

mental health issues, whereas within the low involvement group it did not matter whether parenting efficacy changed with regard to changes in mental health issues.

Parenting Stress

As can be seen in Table 16, with regard to changes in parenting stress, the first regression model included Child Characteristics and Other Life Stressors, which accounted for 6.9% of the variability in scores, $F(5, 83) = 1.23, p = .30$. The addition of Family System Resources and positive gain resulted in prediction of a unique 5.9% of the variance ($p = .39$), with the model accounting for 12.8% of the variability of parenting stress change scores, $F(10, 78) = 1.15, p = .34$. Adding satisfaction with informal social support and total number of formal services only accounted for an additional 2.3% ($p = .36$), with the total variance accounted for at 15.1%, $F(12, 76) = 1.13, p = .35$. The addition of parent involvement only accounted for 1.2% of the variability ($p = .30$) and this fourth model was predicting 16.4% of the variability of changes in parenting stress $F(13, 75) = 1.13, p = .35$. In the final model, change scores for parenting efficacy, negative coping, positive coping, and satisfaction with formal services predicted an additional 26.5% of the variability ($p < .001$), for a total of 42.9% of the variance of parenting stress change scores accounted for by the variables, $F(17, 71) = 3.14, p < .001$. In this final model, none of the Time 1 variables were significant but parenting stress changes were significantly predicted by changes in parenting efficacy ($\beta = -.26, t = -2.47, p = .016, sr^2 = .08$) and changes in negative coping ($\beta = .44, t = 3.82, p < .001, sr^2 = .17$).

Research Question 5: Are Changes Maintained at a 9- to 11-week Follow-up?

In order to address whether changes that occurred between Time 1 and Time 2 were maintained (or whether there was further improvement) from Time 2 to Time 3, non-inferiority testing was utilized. In this context, the non-inferiority testing involved setting a cut-off score

that represented a meaningful amount of a “loss” with regards to the change scores from the Time 2 (end of group) scores to the Time 3 (9- to 11-week follow-up) scores. These cut-off scores were contrasted against the confidence interval upper or lower limits (depending on the variable) to establish that no significant loss occurred (i.e., that the participants’ scores were, at least, not worse over time).

Cut-off scores for the maintenance criteria were calculated using the change scores from Time 1 and Time 2 outcome variables. One standard deviation was either added to, or subtracted from, the mean, depending on which direction would indicate a loss (i.e., mental health issues and parenting stress would be worse if score increased, personal wellbeing and family quality of life would be worse if scores decreased). One-sample *t* tests were executed on the Time 2 to Time 3 change scores. Two one-sided tests were performed to obtain upper and lower confidence interval values. Using the cut-off criteria described above, each outcome variable was examined. None of the bounds of the confidence intervals exceeded respective cut-off values, meaning changes were maintained (and scores actually continued to travel in the direction of improvement). See Table 17 for a summary of these results.

Discussion

The purpose of my dissertation was to contribute to the understanding of parents of children with ASD. More specifically, I sought to examine parents’ personal wellbeing, family quality of life, mental health issues, and parenting stress in the context of their child’s ABA group intervention. Although there is growing literature looking at parent outcomes within intervention programs for children with ASD, this research area is in its early stages of development. Since parents are such a pivotal source of support for these children, this topic ought to be a central consideration for service providers and researchers.

The first research question examined whether parents reported a change in personal wellbeing, family quality of life, mental health issues, and/or parenting stress after their child with ASD received a block of ABA services. While there were no changes in personal wellbeing or family quality of life, there were improvements in mental health issues and parenting stress, although these were small changes. Karst (2014) found that there was a trend for improvement in parenting stress, but non-significant results possibly due to the intervention group only having a sample size of 23. The sample size in the current study was larger and did find that parenting stress was significantly reduced. Tonge and colleagues (2006) found that in their intervention groups, there was an improvement of both mental health and wellbeing. While mental health issues improved to a small degree in the current study, there was no significant gains with regard to wellbeing. In the study by Tonge et al. (2006), their parent intervention component also included a component targeting parent and family functioning. Therefore, it would make sense that this would have an impact beyond that of a predominantly child-focused involvement. In the current study, even though the changes were not large in magnitude, they are noteworthy because the groups were focused on child skill development and not targeting parents' outcomes specifically like the study by Tonge et al. (2006). Therefore, improvements in mental health issues and parenting stress over the course of group participation are promising results. It is interesting that the two “positive” constructs (i.e., personal wellbeing and family quality of life) did not change, but the two “negative” constructs (i.e., parenting stress and mental health issues) did. It is important to consider the mechanisms of these changes, as there may be additional supports or activities that could be easily implemented through treatment programs to address the needs of parents as well as children. This will be elaborated upon in the discussion of the fourth research question.

In my second research question, I examined whether mothers and fathers had different scores initially or different patterns of change through the ABA group. In terms of Time 1 (baseline) scores, there were few differences. Mothers had higher positive coping scores than fathers, which is consistent with previous research findings (e.g., Pozo et al., 2014). Fathers were much more likely to work full-time than mothers, while mothers were more likely to be unemployed or work part-time, which is again similar to other studies (e.g., McCall & Starr, 2018). Previous research has also shown that, in a sample of mostly mothers of children with developmental disabilities (including ASD), giving up career or education significantly was associated with lower family quality of life (O. Weiss et al., 2014). In the current study, mothers were also found to have more significant mental health issues at baseline, as has been highlighted in previous research (e.g., Hastings, Kovshoff, Ward, et al., 2005).

Upon examination of changes in the outcome variables between mothers and fathers from the beginning to the end of the group, no significant findings emerged. However, there was a trend for greater decline in mental health issues in mothers (possibly due to a regression to the mean, since mothers had higher baseline scores than fathers). Additionally, the trend with regard to family quality of life scores showed a slight increase in mothers, while there was a decrease in fathers. Since no significant results were found, and effect sizes were small, this should be interpreted with caution but may be worthy of future research. Overall, the differences between mothers and fathers were minimal. Similar to other studies, the proportion of mothers who participated in my study was higher than fathers, which likely impacted the analyses. For example, due to the smaller number of fathers, it is possible that significant differences were not identified due to low power. If future researchers are able to recruit a higher number of fathers, this would allow for exploration of these variables in a more representative manner.

The third research question investigated whether groups with a higher expected parent involvement component had better outcomes than those with lower parent involvement. In fact, higher parent involvement was associated with significantly greater improvement in personal wellbeing than the low parent involvement group, to a moderate degree. Notably, personal wellbeing actually decreased over time in the low parent involvement group. Some potential ways to explain this may be that parents in the higher parent involvement groups gain a greater sense of control or self-efficacy, are able to see changes in the child related to the intervention or involvement, and/or have a better understanding of the child through greater participation. Regarding family quality of life, although no significant results emerged, there was a similar trend (with small effect size) for family quality of life to increase in the high parent involvement group and slightly decrease in the low parent involvement group. In addition, parenting stress decreased significantly more in the high parent involvement group, though to a small degree. Possible thoughts around this are that parents may have had an increase in their parenting self-efficacy (discussed in the next research question) or that there was a greater improvement in child behaviour (these data were, unfortunately, not collected). Changes in mental health issues did not significantly differ between the two groups, suggesting that parent involvement in the ABA group did not affect mental health issues. Overall, then, it seems clear that the higher parent involvement was associated with a number of benefits for parents over and above the lower involvement. This has clear implications for service providers designing these kinds of intervention programs, as will be discussed in the clinical implications section below.

The fourth research question asked which possible mechanisms were associated with potential changes in personal wellbeing, family quality of life, mental health issues, and parenting stress from the beginning of the group until the end of the group. This was heavily

informed by the Perry Model of Stress (Perry, 2004) with regard to which variables were included and stage of entry into analyses. Most of the outcome variables were well-predicted by the models, with 47%, 35%, 45%, and 43% of the variance explained for changes in personal wellbeing, family quality of life, mental health issues, and parenting stress, respectively. Although there is a large amount of variance (53-65%) not explained by the models, this is not surprising given the virtually infinite number of additional factors that could be considered (e.g., engagement in self-care activities, changes in child characteristics, job satisfaction, etc.).

Personal wellbeing was particularly predicted by Time 1 positive gain and family hardiness, and by changes in positive coping and negative coping. Individuals who identified more positive gain from having a child with a disability (in this case ASD) had greater improvements in personal wellbeing after the ABA group. Furthermore, parents whose coping improved (i.e., positive coping increased, and negative coping decreased) also saw improvement in personal wellbeing. This is consistent with the findings of Benson (2010) and Pozo and colleagues (2014), who found that greater positive coping was associated with higher well-being, although they did not examine these over time. Interestingly, parents who indicated lower family hardiness at baseline saw greater gains in personal wellbeing over the time of the group, which will be discussed further below. Personal wellbeing was the best predicted outcome variable, indicative of the appropriate application of the current model.

The variables that most meaningfully predicted family quality of life change scores were Time 1 marital satisfaction and change in negative coping. Again, a paradoxical result emerged whereby parents with lower marital satisfaction saw greater gains in family quality of life, also addressed below. Decreases in negative coping strategies were associated with greater gains in family quality of life over the course of the group. Overall, changes in family quality of life were

the least accounted for of the outcome variables. Given this finding, a regression was run using the Time 1 (baseline) scores to evaluate the appropriateness of the variables in the model in predicting family quality of life. With this model, family quality of life is very well-predicted by the variables (accounting for 68.4% of the variance). Therefore, when examining changes in family quality of life, the current model could be missing other factors within this mechanism of changes, such as those more specifically focused on the family system or a longer time frame of measurement.

Mental health issues change scores were predicted by change in negative coping and the interaction effect of change in parent involvement with parenting efficacy. Most notably, a decrease in negative coping was the best predictor for decreases in mental health issues, whereas changes in positive coping did not have a significant association. Benson (2010) found an association between avoidant (negative) coping and depression, which is consistent with the current findings. Additionally, the interaction of parenting self-efficacy and the intensity of parent involvement was a significant predictor. Specifically, within the high parent involvement group, mental health issues improved with increases in parenting efficacy and worsened when parenting efficacy decreased. However, in the low parent involvement group, it did not matter whether parenting efficacy increased or decreased, as far as effects on mental health issues. Previous research by Hastings and Brown (2002) showed that self-efficacy was a mediator for maternal mental health issues in the context of child behaviour problems. This, along with greater parent involvement associated with higher self-efficacy (Solish & Perry, 2008), serves as a potential explanation for these results, since the high involvement group may have had more opportunities for changes in self-efficacy.

Finally, changes in parenting stress were particularly predicted by changes in both parenting efficacy and negative coping. An increase in parenting efficacy and decrease in negative coping was associated with greater improvements in parenting stress. Changes in parenting stress were not very well-predicted by the other variables (e.g., child characteristics, other life stressors, family factors). Notably, when examining baseline scores of parenting stress using all other variable baseline scores, to ensure that the constructs were appropriate for this outcome variable, these were very well predicted by the other model variables.

As described above, the direction of the relationship with family hardiness and marital satisfaction were not as would be expected (e.g., negative correlation with changes in personal wellbeing and family quality of life). In the preliminary analyses, this was also noted as an unexpected direction for the correlation. In an attempt to investigate, a post-hoc analysis looked at the upper and lower quartiles of the outcome variables with each of the predictor variables and showed that the upper quartile (i.e., greatest increase in personal wellbeing and family quality of life) had a negative correlation with family hardiness, while the lower quartile (i.e., the greatest decrease in personal wellbeing and family quality of life) had no to a slightly positive correlation with family hardiness and marital satisfaction, although these were not significant. This suggests that the parents who benefited the most were those that had lower family hardiness at Time 1. One interpretation of this is that parents that came from families that were less cohesive had more to gain than those who already had strong family support. Another explanation could be regression to the mean within the more extreme baseline scores of the outcome variables. Another important consideration is the comparison of the static score (in this case family hardiness or marital satisfaction) to the change scores. Change scores have received some criticism in the past, but there is also support for using these in regression models (Allison,

1990). In this case, examining the upper and lower quartiles provided an explanation for the way in which the Time 1 independent variables and change score were associated, and it was not a problem with the change scores per se.

The Perry Model of Stress (Perry, 2004) has been previously adapted for examining the couple relationship in the context of having a child with ASD (Bluth et al., 2013). However, as far as I am aware, the current study was the first time that the Perry Model of Stress (Perry, 2004) has been adapted for use in examining changes over time, illustrating its usefulness in this novel manner. The original variable organization was mostly preserved, but with some adjustments with regard to variable placement that were measured over time. This application was exploratory, and decisions were informed by empirical data as well as clinical experience. Future researchers wishing to examine changes over time may wish to utilize a similar adaptation. However, this is an area for further development, as additional predictors variables could be added to better account for changes in outcome variables.

The final research question examined whether changes were maintained at a follow-up period equivalent to the group length (i.e., 9 to 11 weeks after the end of the group). Across personal wellbeing, family quality of life, mental health issues, and parenting stress, parents did not experience a significant loss of any gains. Notably, the direction of the change scores of Time 2 to Time 3 were all indicative of a continued trend of improvement (e.g., personal wellbeing continued to increase, mental health issues continued to decrease). Longer follow-up periods (e.g., 6 months or 12 months) would provide further information about this potential continued growth. In one of the very few studies that have followed up years after parent training (Feldman & Werner, 2002), there was maintenance of gains, demonstrating that parent gains resulting from parent involvement can continue (or at least be retained) past the program or

intervention. However, prior research has focused on more intense parent involvement, and this is one of the only studies looking at parent involvement within a therapist-led intervention. If involvement in these kinds of interventions results in continued benefits, it provides an even stronger support for service providers to extend such opportunities to parents. Likewise, funding bodies should recognize the value of supporting the investments associated with adding these components to child-focused treatments.

Clinical Implications

Further notable findings emerged and are important to underline as clinical implications. Consistent with much of the literature examining mental health issues in parents of children with ASD (e.g., Bitskia & Sharpley, 2004; Teague et al., 2018), the current sample had high levels of mental health issues (symptoms of anxiety and/or depression). At Time 1, 50.6% of the participants met the recommended cut-off for the Kessler-10 screening tool (Kessler, 2003), as compared with 13% of the general population (Kessler et al., 2003). Even more concerning, 32.3% were in at least the *moderate* range and 17.7% were in the *severe* range of the measure. By Time 2, the proportion of those that met the cut-off reduced to 40.3%, but this is still three times the general population estimate. This highlights that these parents are greatly at risk of experiencing clinically significant anxious or depressive symptoms, adding to the well-established literature.

Parents play a key role in their children's lives, therefore their personal wellbeing, family quality of life, mental health issues, and parenting stress are relevant in the context of children's interventions. Since mental health issues and parenting stress did show a decrease over the duration of the ABA groups, additional improvements to these as well as the other outcome variables may be possible. With this in mind, service providers should consider ways of

incorporating supplemental materials or sessions to enhance these parent outcomes. A number of recommendations are offered below.

Given that improvement in parenting self-efficacy was one of the mechanisms associated with a reduction in parenting stress, it would be helpful for service providers to ensure that this is an area targeted when possible. For example, skill-building opportunities for parents can be more regularly offered within child interventions (e.g., opportunities during the last 15-30 minutes of an ABA group session). Another mechanism identified was that of coping, and in particular negative coping. Decreases in negative coping were associated with improvements in all four outcome variables. This makes a strong case for finding ways to incorporate activities that may enhance this. There is some literature that may offer insight into potential ways of enhancing parent outcomes. Mindfulness and acceptance have been found to mediate the effects of children's behaviour problems on parents' stress and mental health issues (Jones et al., 2014). Self-compassion has also been found to be a stronger predictor of personal wellbeing, stress, and mental health issues than child symptom severity (Neff & Faso, 2015). It has also been suggested that parents be taught cognitive reappraisal or reframing, which has been associated with improvement in well-being and stress (Costa et al., 2017). Parent-specific programs targeting acceptance, mindfulness, self-compassion, and cognitive reappraisal/reframing could be offered by service providers, who may consider offering these to coincide with the timing of the child's ABA group (or other intervention) in order to increase ease of access for families. Children's service providers could also develop a network of professionals who can provide this support to parents. In situations where resources are limited, self-help materials could be offered (although this may be more beneficial for some parents than others).

With regard to parent involvement in children's interventions, results indicated that there were some benefits to higher parent involvement. Given the benefit for children (e.g., Tonge et al., 2014) and parents, significant parent involvement should be a routine part of intervention programs whenever possible. A study by Blackman and colleagues (2020) explored the efficacy of online ABA parent training and found it to be comparable to in-vivo training. Another study by Ingersoll and colleagues (2016) found that an online therapist-assisted training program resulted in improvements in self-efficacy, stress, and positive perceptions of the child, in addition to improvements in child's social skills and language. Such online options could be appealing and more feasible for families who have limited time or difficulty traveling to treatment centres. However, it is important to balance parent involvement that leads to better outcomes while avoiding overburdening parents and increasing risk of burn-out. Further investigation of different levels of parent involvement may find the optimal amount required for positive child and parent outcomes.

It is important to note the transactional relationship between parent and child variables, as was proposed by Sameroff (1975), whereby children's behaviour can influence their parents, who then behave in a way that influences the child, and so on. Indeed, a study by Jellett et al. (2015) explored the relationship between children with ASD and their parents using a path analysis. Results of that path analysis illustrated that children's behaviour problems are associated with depressive symptoms in parents, which then impacts family functioning. Therefore, with the current findings of improvement to some parent factors, it is possible that this would "feed" back into the family system and have a positive impact on the child with ASD.

Limitations and Future Research

This study had a number of limitations, many of which were associated with the reality of conducting research in a community setting, which greatly reduces control over a number of factors. Limitations of this study will be discussed below, with direction for future research incorporated throughout.

The sample size of this study was modest, limiting the ability to accurately detect significant findings. In particular, the number of fathers, although higher than many other studies in this field, limited the conclusions that could be drawn due to a lack of statistical power. Furthermore, analyses comparing the two parent involvement groups were also limited by the current sample size. Also, most of the children were boys, as is often the case for research within the ASD field, and a reality of the higher ratio of boys diagnosed over girls.

Efforts were made to minimize attrition by following up with reminders, but most participants did not complete all three timepoints. Questionnaire completion time also greatly varied, which meant that some data was not used to preserve confidence in results. Since participants with higher SES were more likely to complete multiple time points, this may have had an impact on the results. However, importantly, SES was not significantly correlated with any of the outcome variables at Time 1.

The research design of the current study did not include a control group, and participants were not randomly assigned to parent involvement groups (although the two groups were comparable on all outcome variables), meaning that conclusions are limited, and the effect of the parent involvement level cannot be confirmed as the reason for differences between groups. Future studies utilizing a controlled experimental design with random assignment would yield the most powerful results but are very difficult to conduct in clinical settings for ethical and

pragmatic reasons. It would be more feasible to expand on this study by collecting the same data using a wait list control group and combining it with the current data, to examine if changes in the variables occur independently of children's treatment program or parent involvement.

Several limitations exist with respect to the measures used in this study. Most significant is that all of the data aside from parent involvement was collected via questionnaires, meaning it relied on self-report. However, nearly all of the measures had good to excellent internal consistency, which is promising. The coping measure was split into two subscales, whereas some researchers have used more subscales (e.g., Benson, 2010; Hastings, Kovshoff, Brown et al., 2005). However, the results of the current study using the two-factor coping was in line with previous findings. Future studies with larger sample sizes may wish to utilize more subscales to further explore coping in relation to personal wellbeing, family quality of life, mental health, and parenting stress. Marital satisfaction was measured only two items, which is not a comprehensive understanding of this construct, which may be important to explore in future research.

Another limitation was that standardized child data were not available. Collection of this information was considered but, in consultation with the service agency, the logistical factors eliminated this option (clinicians were not able to dedicate time to provide this and including extensive child information in the parent questionnaires would have made these too lengthy). Therefore, any potential changes in child characteristics (e.g., problem behaviour, communication skills) were not included in any of the analyses, which may have provided additional information regarding possible reciprocal mechanisms of changes in parent outcomes. Future studies that have the option of collecting child data in conjunction with parent outcome data would offer a better understanding of these mechanisms.

In addition, the parent involvement categories were established in a rather crude fashion. Similar to the limitations related to child data, it was not possible to have the clinicians assess each parent's actual involvement, so categories were assessed based on the program descriptions rather than actual measurement of hours or participation. This was another consequence of collecting data within a community setting. In future studies, measures of parent knowledge and skill, as well as amount of time spent in sessions, should be collected if possible.

Finally, it is important to note the limitations of the representativeness of this sample, similar to struggles shared by most research studies. Specifically, although over 700 families received an invitation to participate, only 36.8% agreed to participate and of those, 67.2% followed through with participation. However, the sample was very demographically diverse, and measures had reasonable distributions, which does reduce the likelihood of being an overly biased sample. As well, the participants were recruited in person through a public and central service agency which makes them likely less biased than is the case in many studies.

Conclusion

Despite its limitations, this study adds to the scarce knowledge of parent outcomes in the context of intervention for children with ASD. This information has important clinical implications, some of which can be relatively easy to implement with reasonable time, cost, and/or other resources. Therefore, these results can be used along with other pieces of evidence to advocate for services geared at increasing the overall wellbeing of these parents. Given the finite amount of funding available for programs, it is in the best interest of service providers and funding bodies to work together to provide the most efficient and effective services to both children and parents. In cases where children's treatment could incorporate aspects that also contribute to positive parent outcomes, the benefit of this should be clear. Improving the lives of

children with ASD and their families has implications beyond the child and family unit. Children who receive appropriate intervention are more likely to gain skills that may lead to relying on less future funding. Furthermore, parents who have higher wellbeing and family quality of life, with less mental health issues and parenting stress, are more likely to be able to contribute positively to society (e.g., remain employed, be active members of their communities). Importantly, investing in this population sends the message that they matter and are rightfully deserving of such an investment.

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Table 1*Participant Demographics*

	<i>N</i> (%) or <i>M</i> (<i>SD</i>)	Range
Respondent ^a		
Biological parent	154 (94.5)	-
Adoptive parent	5 (3.1)	-
Grandparent	1 (.6)	-
Foster parent	3 (1.8)	-
Marital Status ^a		-
Married or common-law	140 (85.4)	-
Separated, divorced, single, or widowed	23 (14.0)	-
Respondent age (years) ^b	43.65 (6.64)	24-61
Region of birth country ^c		
North America	97 (59.9)	-
East Asia	26 (16.0)	-
European Union	11 (6.8)	-
South Asia	10 (6.2)	-
Africa	5 (3.1)	-
Middle East	4 (2.5)	-
South America	3 (1.9)	-
Eastern Europe	3 (1.9)	-
The Caribbean	3 (1.9)	-
Years in Canada ^a		
Born in Canada	94 (57.3)	-
<5	6 (3.7)	-
5-9	13 (7.9)	-
10-20	22 (13.4)	-
>20	29 (17.7)	-

^a*n* = 163. ^b*n* = 159. ^c*n* = 162.

Table 2*Participant Socioeconomic Status Descriptive Data*

	<i>n (%) or M (SD)</i>	Range
Education level ^a		
College/university	90 (54.9)	-
Graduate degree	42 (25.6)	-
Partial college/university	13 (7.9)	-
High school	11 (6.7)	-
Partial high school	5 (3.0)	-
Junior high school	3 (1.8)	-
Employment Status ^b		
Full-time	75 (46.0)	-
Part-time	32 (19.6)	-
Unemployed	56 (34.4)	-
Barratt score (SES) ^a	48.02 (10.76)	16-66

^a*n* = 164. ^b*n* = 163.

Table 3*Descriptive Information of Variables Across All Time Points*

Variable	Time 1 (Start of Group)		Time 2 (End of Group)		Time 3 (Follow-up)	
	<i>M (SD)</i>	Range	<i>M (SD)</i>	Range	<i>M (SD)</i>	Range
Children's adaptive score	3.88 (.84) ^a	1.43-5.00	-	-	-	-
Life events	2.67 (2.05) ^b	0-11	1.46 (1.65) ^c	0-9	1.77 (2.14) ^d	0-5
Positive gain	4.13 (.59) ^e	2.43-5.00	-	-	-	-
Negative coping	1.81 (.48) ^f	1.00-3.20	1.68 (.42) ^c	1.00-3.30	1.75 (.50) ^g	1.00-3.50
Positive coping	2.69 (.57) ^b	1.00-4.00	2.65 (.53) ^c	1.08-4.00	2.61 (.58) ^g	1.07-4.00
Parenting self-efficacy	3.85 (.57) ^a	2.17-5.00	3.80 (.56) ^h	2.25-5.00	3.77 (.59) ⁱ	2.17-5.00
Mental health issues	2.14 (.90) ^b	1.00-5.00	1.94 (.79) ^c	1.00-4.90	2.00 (.86) ^g	1.00-5.00
Personal wellbeing	6.40 (1.94) ^j	1.22-9.89	6.47 (1.71) ^c	2.00-9.67	6.52 (1.90) ^d	.11-10.00
Marital satisfaction	7.48 (1.91) ^k	2.00-10.00	7.60 (1.85) ^d	2.00-10.00	7.69 (1.78) ^l	2.00-10.00
Positive impact on family	2.75 (.57) ^m	1.33-3.90	-	-	-	-
Negative impact on family	2.48 (.75) ^m	1.00-4.00	-	-	-	-
Parenting stress	.44 (.27) ^c	0-.95	.40 (.26) ^r	0-1	.39 (.26) ^s	0-.95
Family hardiness	3.60 (.75) ^b	1.50-5.00	-	-	-	-
Family quality of life	3.70 (.68) ^b	1.76-5.00	3.72 (.70) ^c	1.60-.00	3.72 (.72) ^d	1.80-5.00
Informal social support (satisfaction)	2.90 (.80) ^b	1.33-5.00	-	-	-	-
Formal supports (total number)	4.68 (2.32) ⁿ	0-11	3.29 (1.80) ^c	0-8	3.21 (2.00) ^g	0-9
Formal supports (satisfaction)	3.22 (.97) ^o	1.00-5.00	3.65 (.78) ^p	1.00-5.00	3.49 (.99) ^q	1.00-5.00

^a*n*=168. ^b*n*=165. ^c*n*=116. ^d*n*=103. ^e*n*=167. ^f*n*=159. ^g*n*=104. ^h*n*=118. ⁱ*n*=107. ^j*n*=166. ^k*n*=148. ^l*n*=90. ^m*n*=164. ⁿ*n*=163. ^o*n*=160. ^p*n*=115.

^q*n*=100. ^r*n*=117. ^s*n*=106.

Table 4*Change Score Descriptive Information*

Measure	Time 1 to Time 2 <i>M</i> (<i>SD</i>)	Time 2 to Time 3 <i>M</i> (<i>SD</i>)	Measure Scale for Reference
Other life stressors			
Life events	-1.16 (1.64) ^a	.18 (1.90) ^b	Total Number (0-33)
Individual personal resources			
Negative coping	-.14 (.37) ^c	.04 (.38) ^d	Mean Score (1-4)
Positive coping	-.07 (.45) ^e	-.09 (.47) ^d	Mean Score (1-4)
Parenting self-efficacy	-.02 (.36) ^f	-.06 (.40) ^g	Mean Score (1-5)
Family system resources			
Marital satisfaction	.06 (1.17) ^b	.03 (1.17) ^h	Total Score (2-10)
Formal supports and services			
Total number	-1.16 (1.82) ^c	-.24 (1.62) ^d	Total Score (0-18)
Services fit and satisfaction	.41 (.95) ^c	-.17 (.79) ⁱ	Mean Score (1-5)
Outcome variables			
Personal wellbeing	.05 (1.31) ^e	.06 (1.13) ^b	Mean Score (0-10)
Family quality of life	.05 (.57) ^a	.01 (.44) ^b	Mean Score (1-5)
Mental health issues	-.19 (.62) ^e	.00 (.47) ^d	Mean Score (1-5)
Parenting stress	-.04 (.15) ^j	-.02 (.12) ^g	Mean Score (0-1)

^a*n*=104. ^b*n*=88. ^c*n*=101. ^d*n*=89. ^e*n*=103. ^f*n*=106. ^g*n*=92. ^h*n*=77. ⁱ*n*=86. ^j*n*=105.

Table 5*Correlations Among Independent Variables at Time 1 and Outcome Variables at Time 1*

	Personal Wellbeing	Family Quality of Life	Mental Health Issues	Parenting Stress
Child Characteristics				
Child's age	-.09 ^a	-.15 ^b	.00 ^b	.11 ^c
Child's gender	-.03 ^a	.15 ^b	.02 ^b	.10 ^c
Child's brief adaptive	.12 ^b	.05 ^b	-.10 ^d	-.20 ^{**c}
Other Life Stressors				
Barratt score (SES)	.07 ^e	.03 ^e	-.05 ^f	-.02 ^e
Total life events	-.32 ^{***d}	-.37 ^{***d}	.28 ^{***e}	.35 ^{***d}
Individual's Personal Resources				
Positive gain	.40 ^{***b}	.54 ^{***c}	-.31 ^{***d}	-.35 ^{***a}
Negative coping	-.52 ^{***g}	-.51 ^{***h}	.70 ^{***g}	.61 ^{***i}
Positive coping	.11 ^b	.04 ^e	.00 ^d	.10 ^d
Parenting efficacy	.59 ^{***b}	.60 ^{***d}	-.51 ^{***d}	-.65 ^{***c}
Family System Resources				
Family hardiness ^d	.60 ^{***}	.62 ^{***}	-.45 ^{***}	-.52 ^{***}
Marital satisfaction	.48 ^{***j}	.48 ^{***k}	-.30 ^{***l}	-.33 ^{***j}
Positive impact on family ^e	.33 ^{***}	.41 ^{***}	-.20 ^{**}	-.17
Negative impact on family ^e	-.51 ^{***}	-.47 ^{***}	.40 ^{***}	.75 ^{***}
Informal and Formal Supports				
Informal support available	.44 ^{***d}	.57 ^{***d}	-.26 ^{**e}	-.44 ^{***d}
Informal support satisfaction	.48 ^{***d}	.53 ^{***d}	-.27 ^{***e}	.42 ^{***d}
Formal services received	.03 ^f	-.03 ^f	-.03 ^m	.22 ^{**f}
Formal services satisfaction ^g	.43 ^{***}	.38 ^{***}	-.28 ^{***}	-.35 ^{***}

^an= 166. ^bn= 165. ^cn= 167. ^dn= 164. ^en= 163. ^fn= 162. ^gn=159. ^hn= 157. ⁱn= 158. ^jn= 148. ^kn= 146. ^ln= 147. ^mn= 161.

* $p < .05$. ** $p < .01$. *** $p < .001$.

Table 6*Correlations Among Time 1 Independent Variables and Change Scores (Time 1 to Time 2) of Outcome Variables*

	Change in Personal Wellbeing	Change in Family Quality of Life	Change in Mental Health Issues	Change in Parenting Stress
Child characteristics				
Child's age	.00 ^a	-.06 ^a	.05 ^a	.09 ^b
Child's gender	.07 ^a	.10 ^a	.00 ^a	-.11 ^b
Child's brief adaptive	-.03 ^a	-.02 ^a	.06 ^a	.11 ^b
Other life stressors				
Barratt score (SES)	-.11 ^a	.03 ^a	.21 ^{*a}	.14 ^b
Total life events	.00 ^a	.10 ^a	.04 ^a	-.04 ^b
Individual's personal resources				
Positive gain	.00 ^c	-.07 ^c	.11 ^c	.02 ^d
Negative coping	.23 ^{*e}	.12 ^f	-.32 ^{**e}	-.27 ^{**c}
Positive coping	-.05 ^a	.03 ^a	-.09 ^d	-.23 ^{*c}
Parenting efficacy	-.14 ^a	-.11 ^a	.14 ^a	.17 ^b
Family system resources				
Family hardiness	-.28 ^{**a}	-.30 ^{**a}	.21 ^{*a}	.15 ^b
Marital satisfaction	-.24 ^{*g}	-.37 ^{***h}	.28 ^{**g}	.23 ^{*i}
Positive impact on family	-.06 ^a	-.11 ^a	.07 ^a	-.04 ^b
Negative impact on family	.17 ^a	.01 ^a	.07 ^a	.11 ^b
Informal and formal supports				
Informal support available	-.11 ^a	-.17 ^a	-.02 ^a	-.05 ^b
Informal support satisfaction	-.17 ^a	-.11 ^a	.06 ^a	.08 ^b
Formal services received	-.19 ^c	.17 ^c	.00 ^c	-.13 ^d
Formal services satisfaction	-.16 ^e	-.03 ^e	.13 ^e	.07 ^a

^a*n* = 108. ^b*n* = 110. ^c*n* = 107. ^d*n* = 109. ^e*n* = 106. ^f*n* = 105. ^g*n* = 99. ^h*n* = 98. ⁱ*n* = 100.**p* < .05. ***p* < .01. ****p* < .001.

Table 7

Comparing Outcome Variable Change Scores from Time 1 (Start of Group) to Time 2 (End of Group)

	Time 1 <i>M (SD)</i>	Time 2 <i>M (SD)</i>	Mean Difference	<i>t</i>	<i>df</i>	<i>p</i>	Cohen's <i>d</i>
Personal wellbeing ^a	6.45 (1.96)	6.47 (1.73)	.02	.14	99	.89	.01
Family quality of life ^b	3.67 (.69)	3.71 (.67)	.05	.80	100	.43	.07
Mental health issues ^a	2.13 (.87)	1.95 (.82)	-.18	-2.93	99	.004	.21
Parenting stress ^b	.42 (.26)	.38 (.25)	-.04	-2.56	100	.012	.15

^a*n*=100. ^b*n*=101.

Table 8*Comparing Time 1 Scores of Mothers and Fathers*

	Mothers' Time 1 Scores <i>M (SD)</i>	Fathers' Time 1 Scores <i>M (SD)</i>	Mean Difference	<i>t</i>	<i>df</i>	<i>p</i>	Cohen's <i>d</i>
Child's age	9.0 (3.50) ^a	9.85 (4.21) ^b	.85	1.17	145	.25	.23
Child's brief adaptive	3.88 (.83) ^c	4.00 (.80) ^b	.12	.74	144	.46	.15
Barratt score (SES)	47.99 (10.64) ^d	47.89 (10.28) ^b	-.10	-.05	142	.96	.01
Total life events	2.73 (2.08) ^e	2.37 (1.77) ^b	-.36	-.89	143	.37	.18
Positive gain	4.12 (.59) ^c	4.13 (.67) ^b	.01	.04	144	.97	.01
Negative coping	1.85 (.46) ^f	1.68(.51) ^g	-.17	-1.81	137	.07	.37
Positive coping	2.75 (.56) ^e	2.45 (.57) ^g	-.30	-2.63	142	.009	.53
Parenting efficacy	3.85 (.60) ^c	3.86 (.48) ^b	.01	.07	144	.94	.01
Family hardiness	3.58 (.74) ^c	3.69 (.77) ^b	.10	.70	144	.49	.14
Marital satisfaction	7.16 (1.97) ^h	7.90 (1.82) ⁱ	.74	1.82	125	.07	.38
Positive impact on family	2.77 (.58) ^e	2.70 (.52) ^b	-.08	-.67	143	.51	.13
Negative impact on family	2.48 (.75) ^e	2.47 (.73) ^b	-.01	-.06	143	.95	.01
Informal support available	8.23 (3.14) ^a	8.97 (3.25) ^b	.74	1.17	145	.24	.23
Informal support satisfaction	2.89 (.82) ^e	3.00 (.75) ^b	.12	.74	143	.46	.15
Formal services received	5.48 (2.51) ^a	6.03 (2.75) ^b	.55	1.08	145	.28	.22
Formal services satisfaction	3.16 (.97) ^j	3.52 (.95) ^g	.36	1.85	140	.07	.37

^a*n*=115. ^b*n*=32. ^c*n*=114. ^d*n*=112. ^e*n*=113. ^f*n*=108. ^g*n*=31. ^h*n*=97. ⁱ*n*=30. ^j*n*=111.

Table 9*Comparing Outcome Variable Change Scores of Mothers and Fathers*

	Mothers' Change Scores <i>M (SD)</i>	Fathers' Change Scores <i>M (SD)</i>	Mean Difference	<i>t</i>	<i>df</i>	<i>p</i>	Cohen's <i>d</i>
Personal wellbeing	.05 (1.41) ^a	.01 (.88) ^b	.04	-.13	101	.89	.04
Family quality of life	.07 (.61) ^a	-.03 (.45) ^c	.11	-.79	102	.43	.20
Mental health issues	-.23 (.65) ^a	-.07 (.47) ^b	-.16	1.11	101	.27	.28
Parenting stress	-.04 (.12) ^c	-.02 (.12) ^c	-.03	.76	103	.45	.19

^a*n*=80. ^b*n*=23. ^c*n*=24. ^d*n*=81.

Table 10*Comparing Time 1 Scores of Low Parent Involvement and High Parent Involvement*

	Low Involvement Time 1 Scores <i>M (SD)</i>	High Involvement Time 1 Scores <i>M (SD)</i>	Mean Difference	<i>t</i>	<i>df</i>	<i>p</i>	Cohen's <i>d</i>
Child's age	10.20 (3.67) ^a	7.62 (3.10) ^b	2.58	4.42	145	.00	.75
Child's brief adaptive	4.07 (.60) ^c	3.65 (1.03) ^b	.42	2.78	82	.00 7	.52
Barratt score (SES)	47.84 (9.90) ^c	48.17 (11.54) ^d	-.33	-.19	142	.85	.03
Total life events	2.69 (2.00) ^a	2.61 (2.05) ^d	.08	.23	143	.82	.04
Positive gain	4.07 (.61) ^c	4.21 (.60) ^b	-.14	⁻ 1.40	144	.16	.24
Negative coping	1.83 (.48) ^e	1.80 (.46) ^f	.03	.37	137	.71	.06
Positive coping	2.64 (.57) ^a	.27 (.58) ^g	-.11	⁻ 1.08	142	.28	.19
Parenting efficacy	3.83 (.52) ^c	3.88 (.65) ^b	-.05	-.46	104	.65	.08
Family hardiness	3.65 (.73) ^a	3.53 (.77) ^h	.12	.92	144	.36	.16
Marital satisfaction	7.46 (1.86) ⁱ	7.15 (2.10) ^j	.31	.87	125	.39	.16
Positive impact on family	2.70 (.57) ^a	2.84 (.55) ^d	.14	⁻ 1.43	143	.15	.24
Negative impact on family	2.45 (.74) ^a	2.53 (.75) ^d	.08	-.60	143	.55	.10
Informal support available	8.80 (2.92) ^a	7.76 (3.44) ^b	1.04	1.96	145	.05	.33
Informal support satisfaction	2.88 (.77) ^a	2.96 (3.45) ^d	-.07	-.53	143	.59	.09
Formal services received	5.36 (2.32) ^a	5.97 (2.89) ^b	-.61	⁻ 1.40	145	.16	.24
Formal services satisfaction	3.24 (.98) ^k	3.23 (.97) ^g	.01	.03	140	.96	.01

Note. Levene's test for equality of variance was violated for child's brief adaptive and parenting efficacy, Welch's *t* values are reported.

^a*n*=89. ^b*n*=58. ^c*n*=88. ^d*n*=56. ^e*n*=86. ^f*n*=53. ^g*n*=55. ^h*n*=57. ⁱ*n*=79. ^j*n*=48. ^k*n*=87.

Table 11

Comparing Time 1 Outcome Variable Scores of Low Parent Involvement and High Parent Involvement

	Low Involvement Time 1 Scores M (SD)	High Involvement Time 1 Scores M (SD)	Mean Difference	<i>t</i>	<i>df</i>	<i>p</i>	Cohen's <i>d</i>
Personal wellbeing	6.41 (1.75) ^a	6.35 (2.22) ^b	.06	.19	97	.85	.03
Family quality of life	3.68 (.66) ^a	3.71 (.70) ^c	-.03	-.24	144	.81	.04
Mental health issues	2.16 (.87) ^a	2.13 (.95) ^b	.03	.17	143	.86	.03
Parenting stress	.42 (.26) ^d	.45 (.28) ^e	-.02	-.47	144	.64	.08

Note. Levene's test for equality of variance was violated for personal wellbeing, Welch's *t* values are reported.

^a*n*=89. ^b*n*=56. ^c*n*=57. ^d*n*=88. ^e*n*=58.

Table 12

Comparing Outcome Variable Change Scores of Low Parent Involvement and High Parent Involvement

	Low Involvement Change Scores M (SD)	High Involvement Change Scores M (SD)	Mean Difference	<i>t</i>	<i>df</i>	<i>p</i>	Cohen's <i>d</i>
Personal wellbeing	-.23 (1.03) ^a	.40 (1.60) ^b	-.63	-2.40	98	.02	.47
Family quality of life	-.03 (.49) ^a	.17 (.68) ^b	-.20	-1.71	99	.09	.34
Mental health issues	-.18 (.54) ^a	-.17 (.71) ^b	.01	-.06	98	.95	.01
Parenting stress	-.01 (.15) ^a	-.07 (.13) ^c	.06	2.03	99	.04	.42

^a*n*=61. ^b*n*=39. ^c*n*=40.

Table 13*Summary of Hierarchical Regression Analysis for Changes in Personal Wellbeing*

Variable	Model 1			Model 2			Model 3			Model 4			Model 5		
	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β
Child gender	.27	.35	.08	.02	.35	.01	.00	.34	.00	.00	.34	.00	-.33	.31	-.10
Child age	-.01	.04	-.03	-.01	.04	-.02	-.02	.04	-.05	.00	.04	.01	.04	.04	.11
Child's adaptive skills	-.13	.19	-.08	-.11	.19	-.07	-.19	.19	-.12	-.14	.19	-.09	-.27	.17	-.17
Life events	-.01	.07	-.01	-.04	.07	-.07	-.03	.07	-.05	-.02	.07	-.04	-.04	.06	-.05
SES	-.01	.01	-.12	-.01	.01	-.09	-.01	.01	-.09	-.01	.01	-.11	-.00	.01	-.01
Positive gain				.44	.32	.20	.52	.32	.24	.51	.32	.24	.69	.28	.32*
Positive impact on family				-.21	.34	-.09	-.13	.35	-.05	-.17	.34	-.07	-.40	.31	-.17
Negative impact on family				.13	.22	.07	.10	.24	.05	.09	.24	.05	.03	.21	.01
Family hardiness				-.48	.23	-.27*	-.49	.23	-.28*	-.46	.23	-.26	-.46	.20	-.26*
Marital satisfaction				-.12	.08	-.18	-.10	.08	-.15	-.09	.08	-.14	-.05	.07	-.08
Social support							-.28	.20	-.17	-.27	.20	-.17	-.21	.19	-.13
Formal support							-.08	.07	-.14	-.08	.06	-.15	-.07	.06	-.13
Parent involvement										.53	.30	.20	.30	.26	.11
Δ Parenting efficacy													-.16	.36	-.05
Δ Negative coping													-1.77	.40	-.49***
Δ Positive coping													.78	.27	.27**
Δ Services satisfaction													.23	.15	.17
R^2		.03			.18			.21			.25			.47	
F for change in R^2		.54			2.79*			1.82			3.19			7.50***	

* $p < .05$. ** $p < .01$. *** $p < .001$.

Table 14*Summary of Hierarchical Regression Analysis for Changes in Family Quality of Life*

Variable	Model 1			Model 2			Model 3			Model 4			Model 5		
	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β
Child gender	.16	.16	.11	.08	.15	.06	.09	.15	.06	.09	.15	.06	-.01	.15	-.01
Child age	-.01	.02	-.08	-.01	.02	-.03	.00	.02	.01	.01	.02	.04	.01	.02	.09
Child's adaptive skills	.00	.08	.00	-.02	.08	-.03	-.01	.08	-.01	.01	.08	.01	-.01	.08	-.01
Life events	.02	.03	.08	.02	.03	.06	.00	.03	.01	.01	.03	.02	.00	.03	.01
SES	.00	.01	.04	.00	.01	.08	.00	.01	.07	.00	.01	.06	.01	.01	.10
Positive gain				.06	.14	.07	.03	.14	.03	.03	.14	.03	.06	.14	.07
Positive impact on family				.01	.15	.01	.06	.15	.06	.05	.15	.05	.00	.15	.00
Negative impact on family				-.09	.10	-.12	-.16	.11	-.21	-.17	.11	-.21	-.19	.10	-.24
Family hardiness				-.17	.10	-.22	-.18	.10	-.23	-.17	.10	-.21	-.15	.10	-.19
Marital satisfaction				-.10	.03	-.32**	-.10	.03	-.34**	-.10	.03	-.33**	-.09	.04	-.29*
Social support							-.05	.09	-.07	-.05	.09	-.06	-.03	.09	-.04
Formal support							.05	.03	.21	.05	.03	.20	.05	.03	.22
Parent involvement										.13	.13	.11	.06	.13	.05
Δ Parenting efficacy													.22	.18	.14
Δ Negative coping													-.42	.19	-.26*
Δ Positive coping													.16	.13	.12
Δ Services satisfaction													.06	.07	.10
R^2		.02			.19			.23			.24			.35	
F for change in R^2		.42			3.28**			1.67			1.03			2.98*	

* $p < .05$. ** $p < .01$.

Table 15*Summary of Hierarchical Regression Analysis for Changes in Mental Health Issues*

Variable	Model 1			Model 2			Model 3			Model 4			Model 5			Model 6		
	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β
Child gender	-.07	.16	-.05	.00	.16	.00	.00	.16	.00	.00	.16	.00	.16	.15	.10	.15	.15	.10
Child age	.02	.02	.09	.02	.02	.11	.02	.02	.11	.02	.02	.12	.00	.02	.03	.01	.02	.04
Child's adaptive skills	-.11	.09	-.15	-.11	.09	-.15	-.11	.09	-.15	-.11	.09	-.15	-.05	.08	-.07	-.06	.08	-.08
Life events	.01	.03	.04	.03	.03	.09	.03	.03	.09	.03	.03	.09	.03	.03	.11	.04	.03	.13
SES	.01	.01	.26*	.01	.01	.23*	.01	.01	.23*	.01	.01	.23*	.01	.01	.14	.01	.01	.13
Positive gain				.14	.15	.13	.14	.15	.14	.14	.15	.14	.04	.14	.04	.03	.13	.03
Positive impact on family				-.14	.16	-.13	-.13	.17	-.12	-.14	.17	-.13	-.02	.15	-.02	.01	.15	.01
Negative impact on family				.01	.10	.01	.01	.11	.01	.00	.11	.01	.03	.10	.03	.05	.10	.05
Family hardiness				.11	.11	.13	.11	.11	.13	.11	.11	.14	.06	.10	.07	.07	.10	.08
Marital satisfaction				.08	.04	.24*	.08	.04	.25*	.08	.04	.25*	.06	.04	.19	.06	.03	.19
Social support							-.01	.09	-.01	-.01	.09	-.01	-.02	.09	-.02	-.02	.09	-.02
Formal support							.00	.03	-.01	.00	.03	-.01	.00	.03	.00	.00	.03	-.01
Parent involvement										.05	.14	.04	.14	.13	.11	.16	.12	.13
Δ Parenting efficacy													-.09	.18	-.05	.25	.23	.15
Δ Negative coping													.82	.19	.49***	.83	.19	.50***
Δ Positive coping													-.06	.13	-.05	-.14	.13	-.10
Δ Services satisfaction													-.11	.07	-.17	-.11	.07	-.17
Δ Efficacy*involvement																-.85	.36	-.29*
R^2	.08			.19			.19			.19			.41			.45		
F for change in R^2	1.35			2.12			.01			.12			6.53***			5.45*		

Note. Efficacy*involvement: parenting efficacy by parent involvement interaction term (both were centred).

* $p < .05$. ** $p < .01$. *** $p < .001$.

Table 16*Summary of Hierarchical Regression Analysis for Changes in Parenting Stress*

Variable	Model 1			Model 2			Model 3			Model 4			Model 5		
	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β	<i>B</i>	<i>SE B</i>	β
Child gender	-.05	.04	-.13	-.03	.04	-.09	-.04	.04	-.10	-.04	.04	-.10	.02	.04	.05
Child age	.00	.00	.10	.00	.00	.09	.00	.00	.07	.00	.01	.03	.00	.00	-.04
Child's adaptive skills	.02	.02	.11	.02	.02	.10	.02	.02	.10	.01	.02	.07	.02	.02	.12
Life events	.00	.01	-.04	.00	.01	-.01	.00	.01	.03	.00	.01	.02	.00	.01	.05
SES	.00	.00	.14	.00	.00	.12	.00	.00	.13	.00	.00	.14	.00	.00	.03
Positive gain				-.00	.04	-.01	.00	.04	.01	.00	.04	.01	-.01	.03	-.03
Positive impact on family				-.02	.04	-.07	-.03	.04	-.12	-.03	.04	-.11	-.02	.04	-.08
Negative impact on family				-.01	.03	-.05	.01	.03	.04	.01	.03	.04	.02	.02	.12
Family hardiness				.01	.03	.06	.01	.03	.07	.01	.03	.06	-.01	.02	-.04
Marital satisfaction				.02	.01	.22	.02	.01	.22	.02	.01	.21	.02	.01	.21
Social support							.02	.02	.13	.02	.02	.13	.04	.02	.20
Formal support							-.01	.01	-.13	-.01	.01	-.13	-.01	.01	-.13
Parent involvement										-.04	.04	-.12	-.02	.03	-.06
Δ Parenting efficacy													-.10	.04	-.26*
Δ Negative coping													.18	.05	.44***
Δ Positive coping													.00	.03	.00
Δ Services satisfaction													.00	.02	.02
R^2	.07			.13			.15			.16			.43		
F for change in R^2	1.23			1.06			1.04			1.10			8.25***		

* $p < .05$. *** $p < .001$.

Table 17*Time 2 (End of Group) to Time 3 (Follow-Up) Change Score Cut-Off Criteria and Values*

	T1 to T2 Change Scores <i>M (SD)</i>	Cut-Off Criteria	T2 to T3 Change Scores <i>M (SD)</i>	Lower Confidence Interval	Upper Confidence Interval
Personal wellbeing	.02 (1.31) ^a	< -1.29	.08 ^b	-.17	.32
Family quality of life	.46 (.58) ^c	< -.53	.02 ^b	-.07	.12
Mental health issues	-.18 (.61) ^a	> .43	-.02 ^d	-.12	.07
Parenting stress	-.04 (.15) ^c	> .11	-.02 ^e	-.04	.00

^a*n* = 100. ^b*n* = 85. ^c*n* = 101. ^d*n* = 86. ^e*n* = 89.

Figure 1

Perry Model of Stress (Perry, 2004)

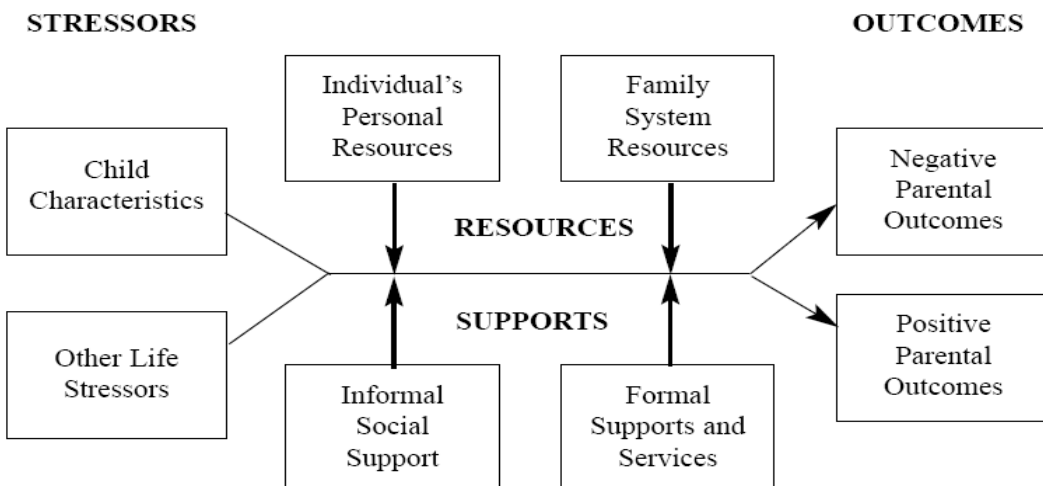
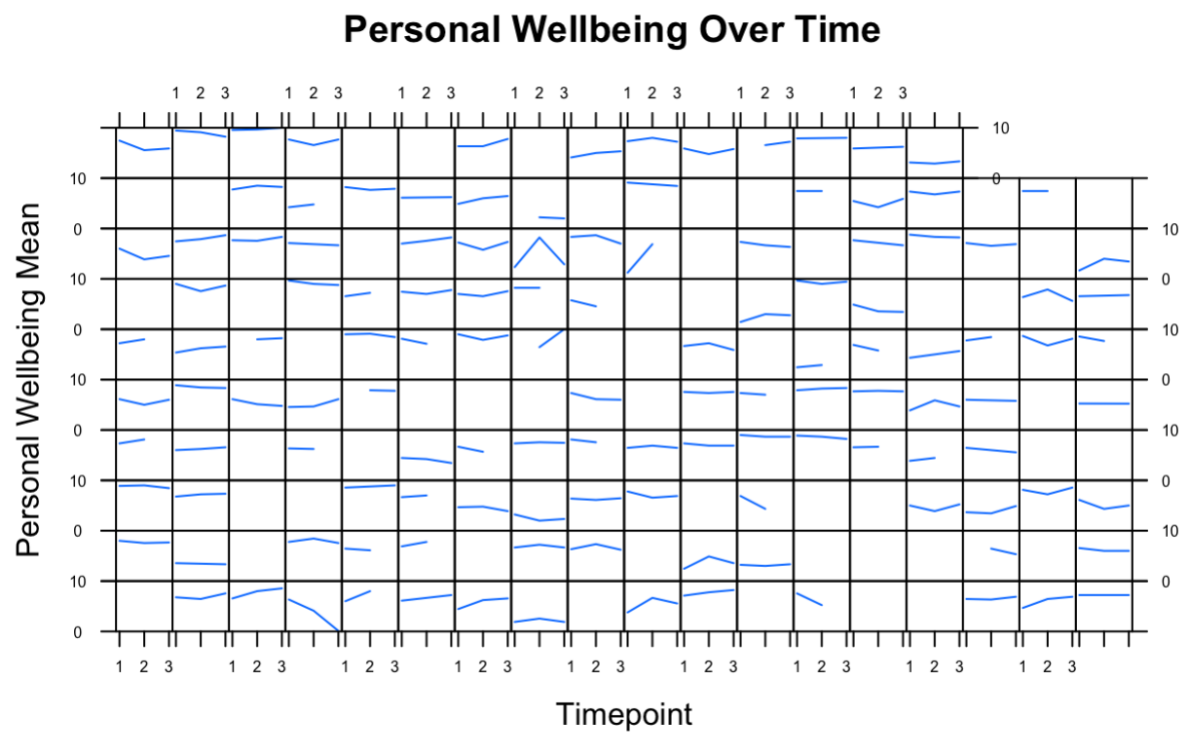


Figure 2

Individual Scores of Personal Wellbeing over Time



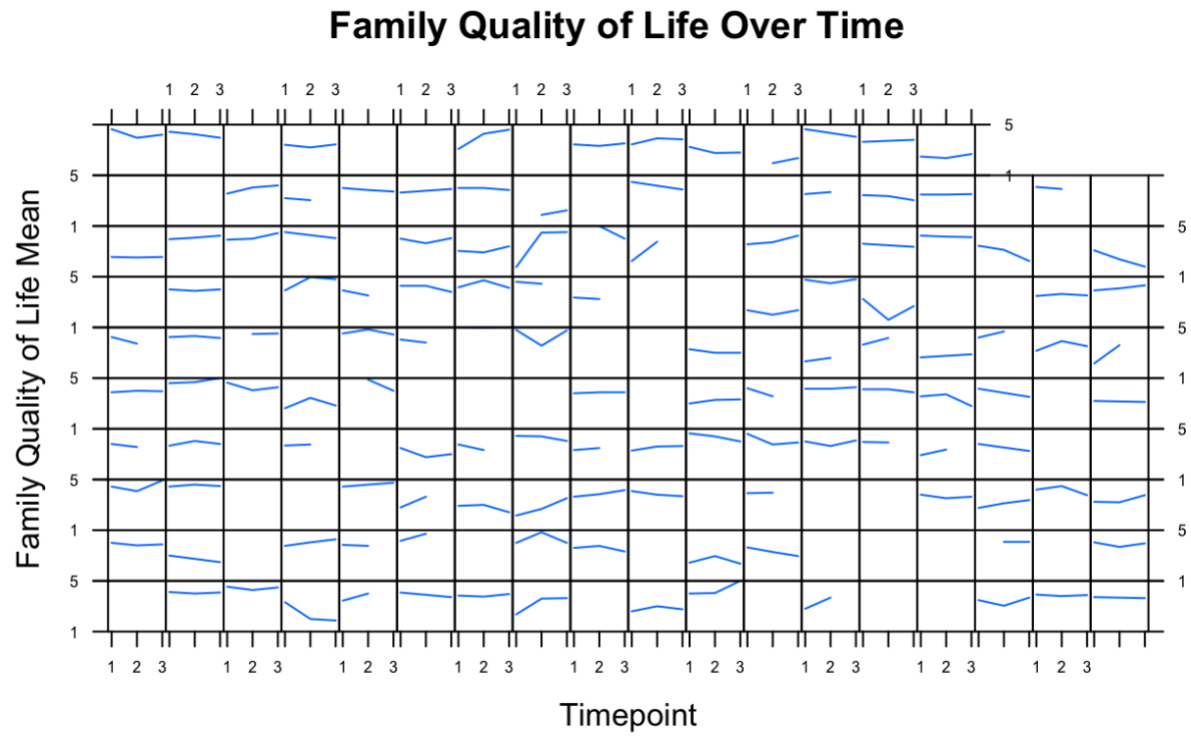


Figure 4

Individual Scores of Mental Health over Time

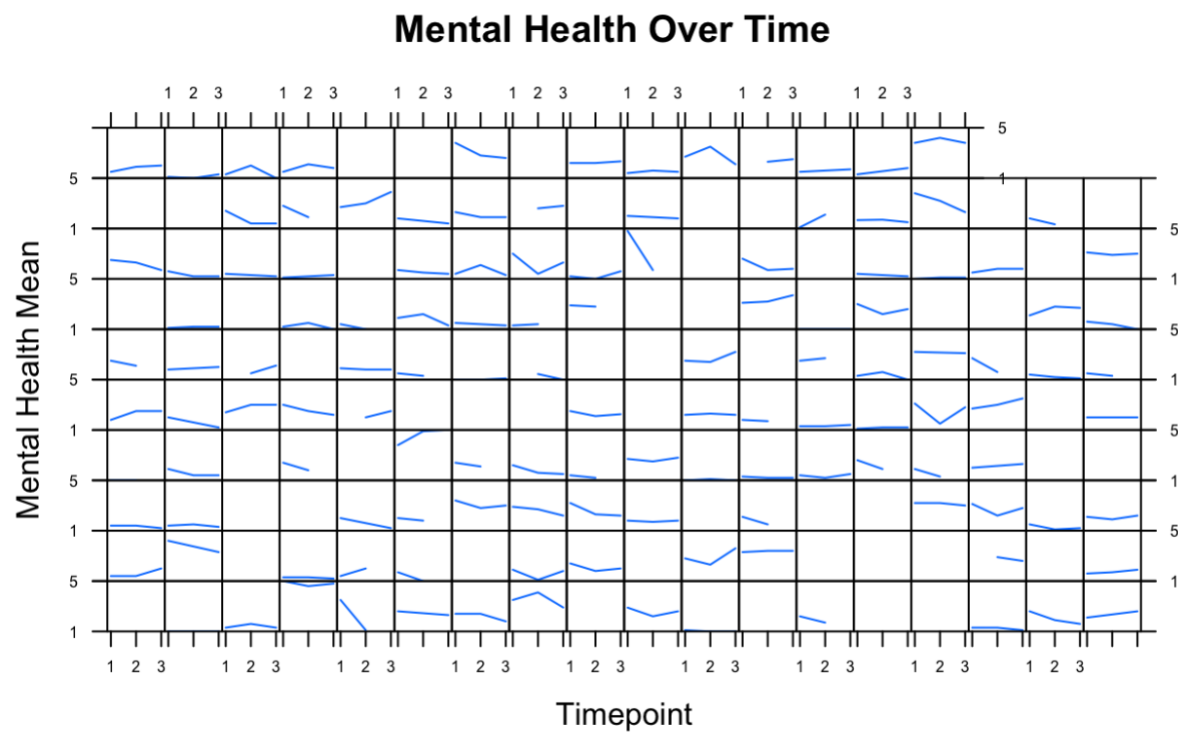


Figure 5

Individual Scores of Parenting Stress over Time

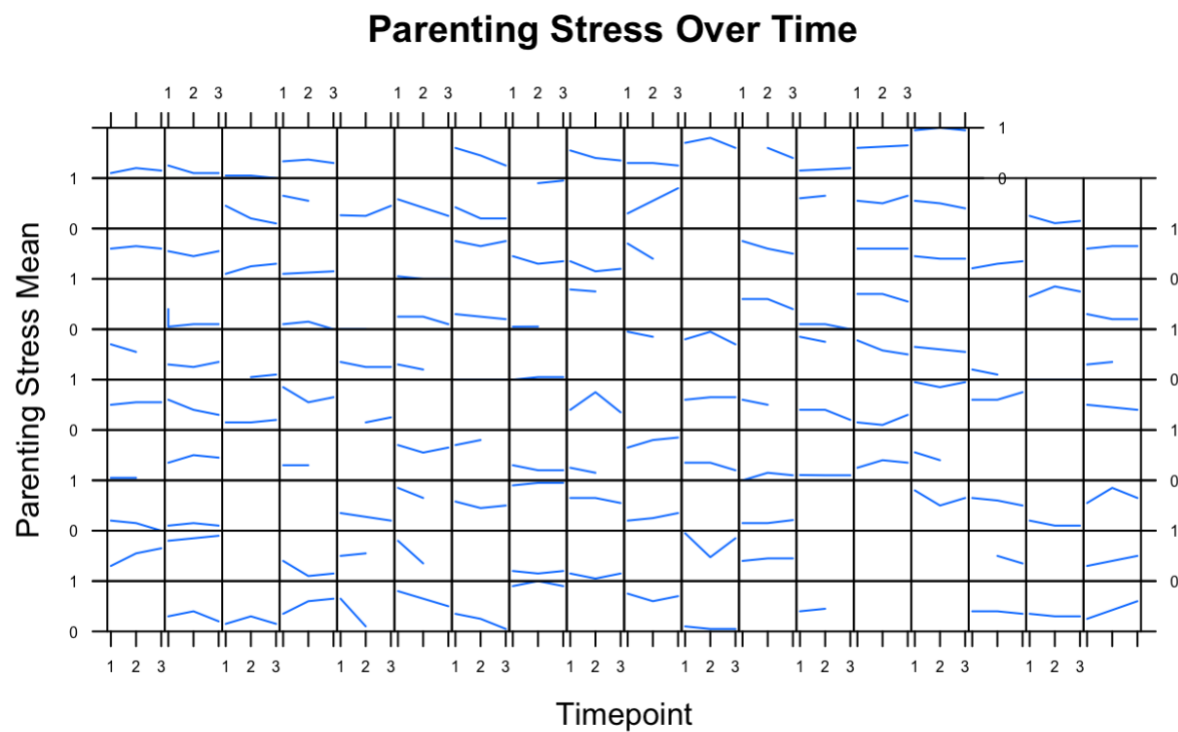


Figure 6

Personal Wellbeing Means over Time

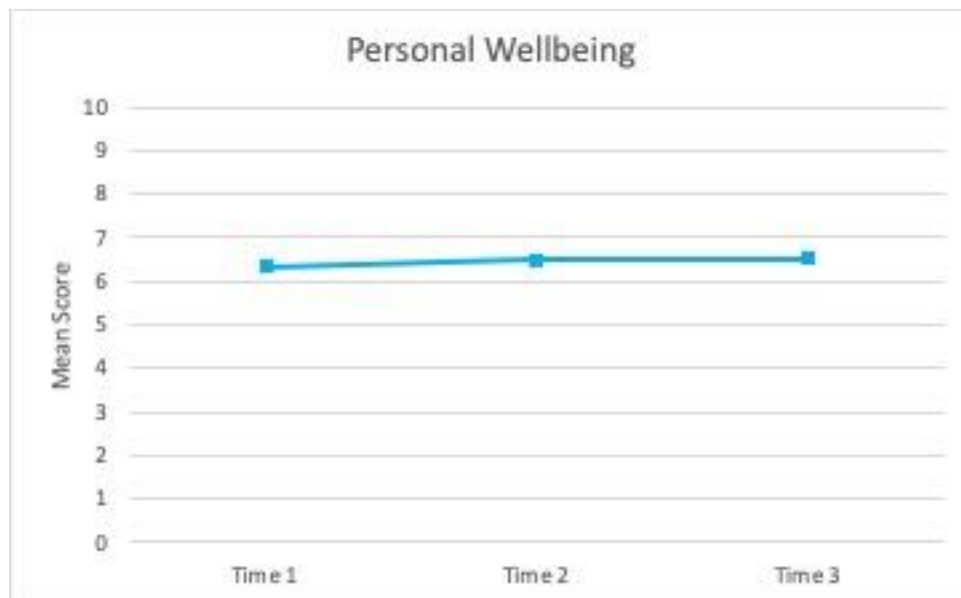


Figure 7

Family Quality of Life Means over Time

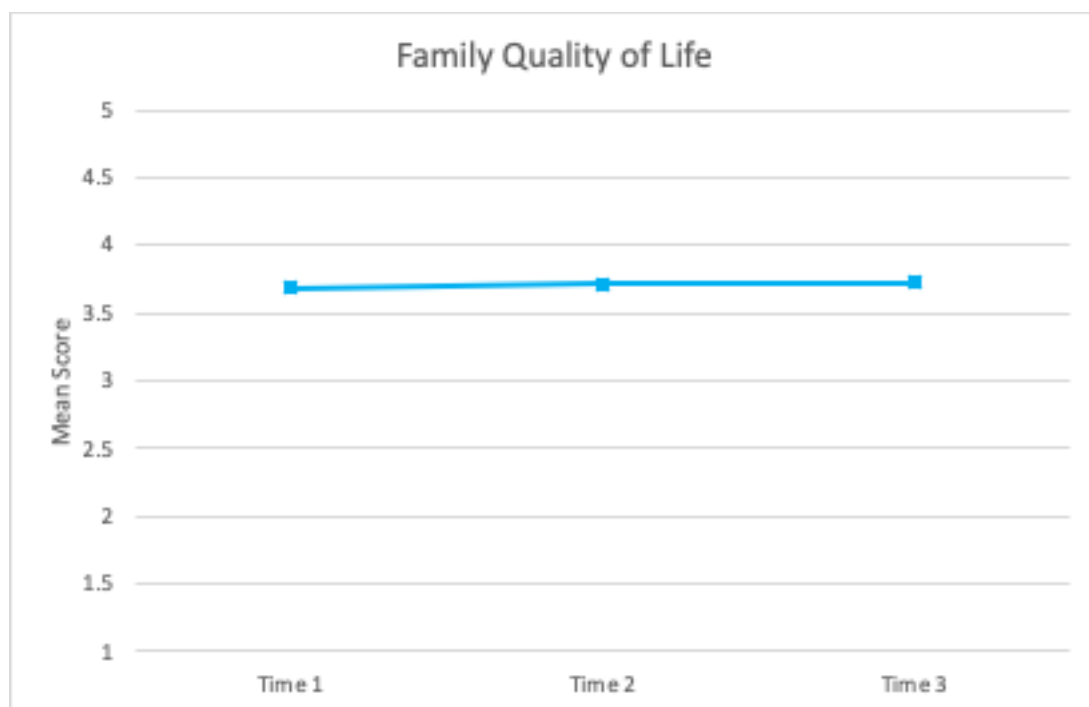


Figure 8

Mental Health Means over Time

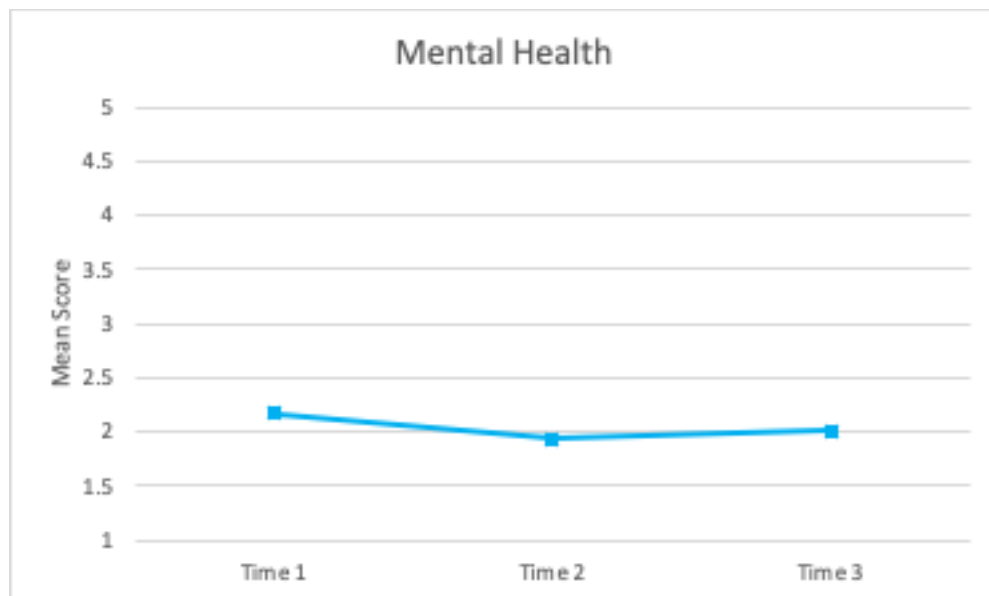


Figure 9

Parenting Stress Means over Time

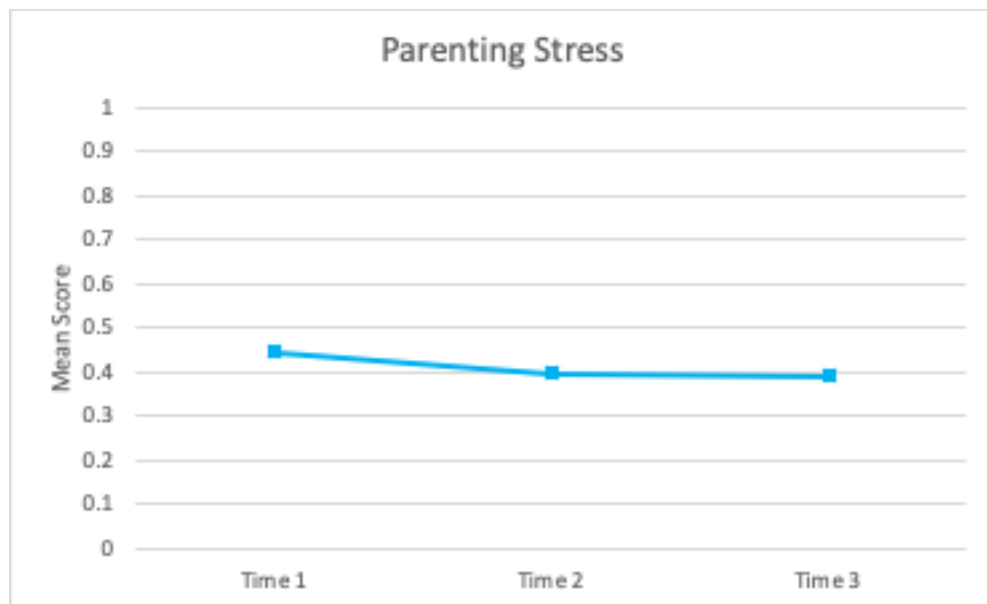


Figure 10

Mothers' and Fathers' Personal Wellbeing over Time



Figure 11

Mothers' and Fathers' Family Quality of Life over Time



Figure 12

Mothers' and Fathers' Mental Health Issues over Time



Figure 13

Mothers' and Fathers' Parenting Stress over Time

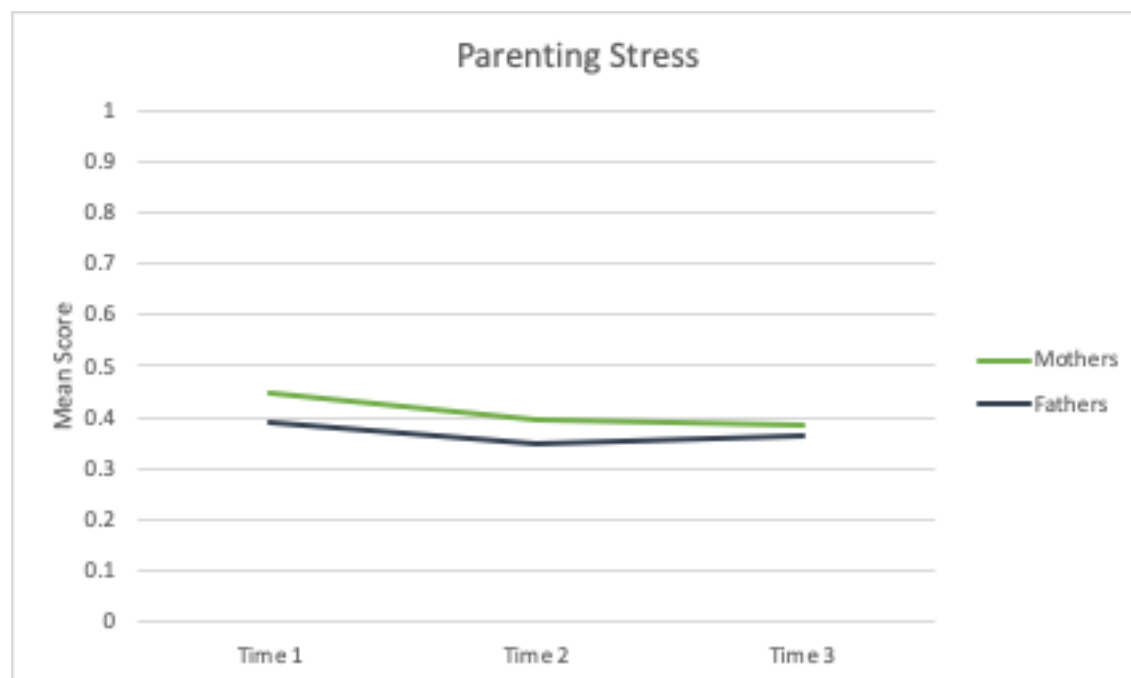


Figure 14

Personal Wellbeing over Time by Parent Involvement

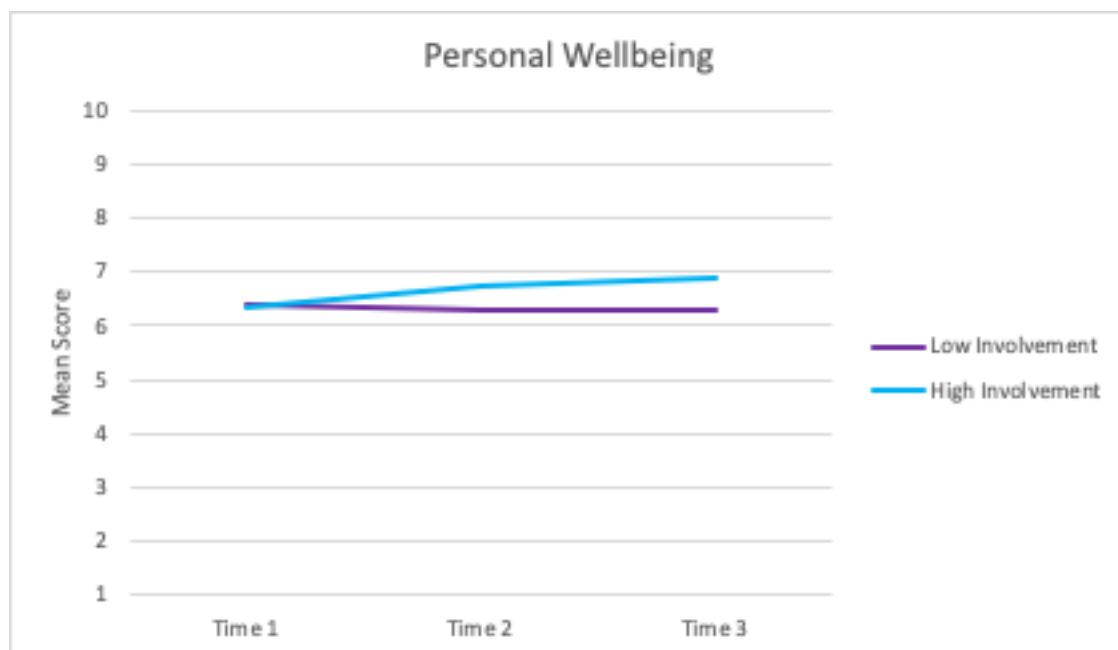


Figure 15

Family Quality of Life over Time by Parent Involvement

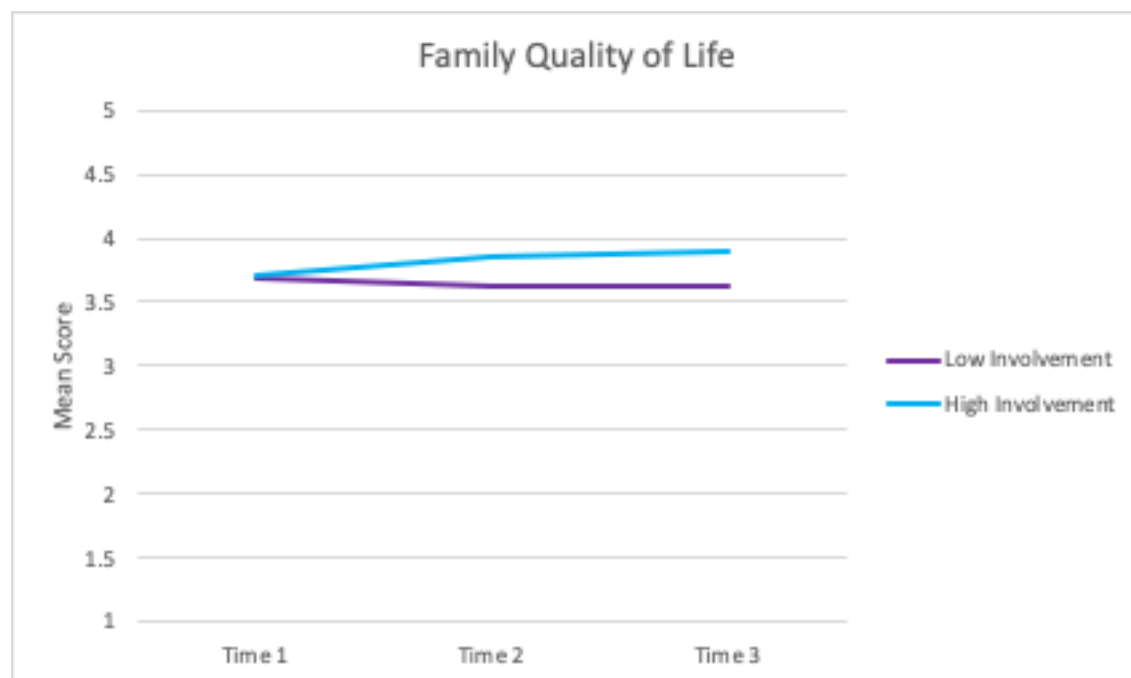


Figure 16

Mental Health Issues over Time by Parent Involvement

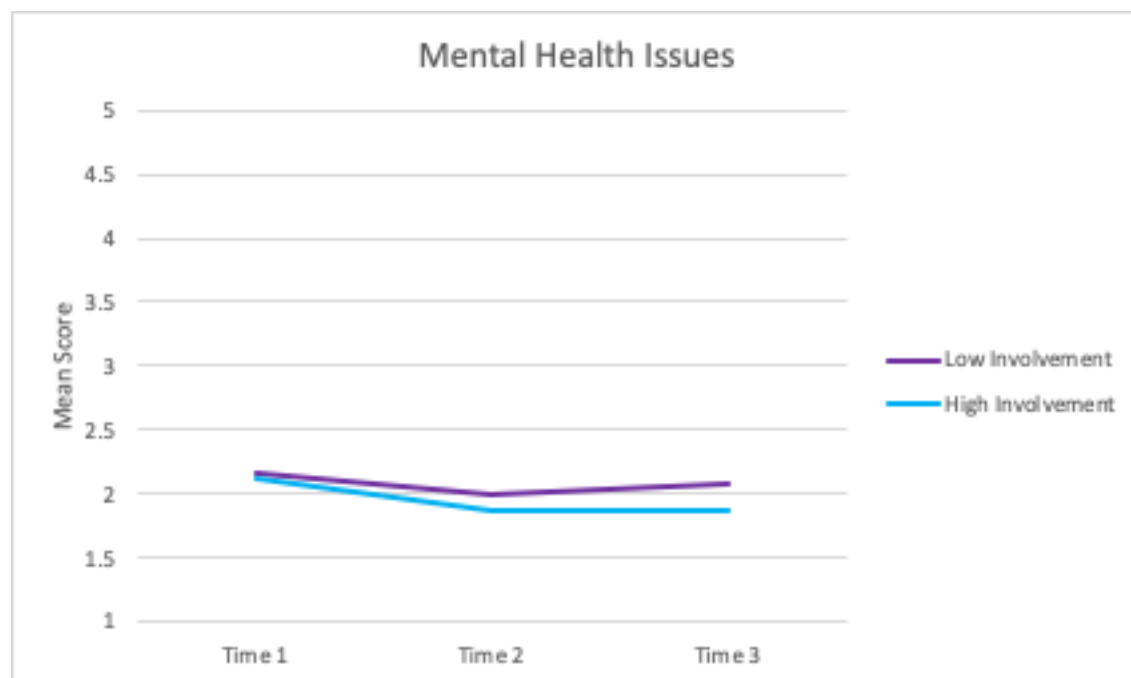


Figure 17

Parenting Stress over Time by Parent Involvement

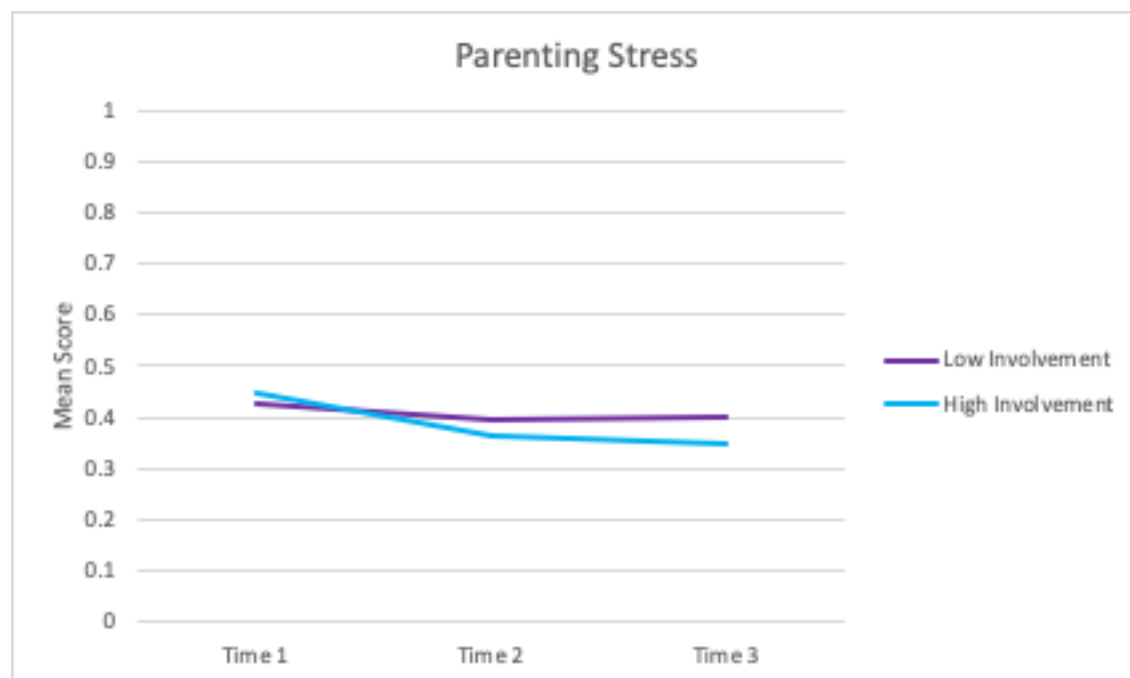


Figure 18

Perry Model of Stress (2004) Adaptation for Changes over Time

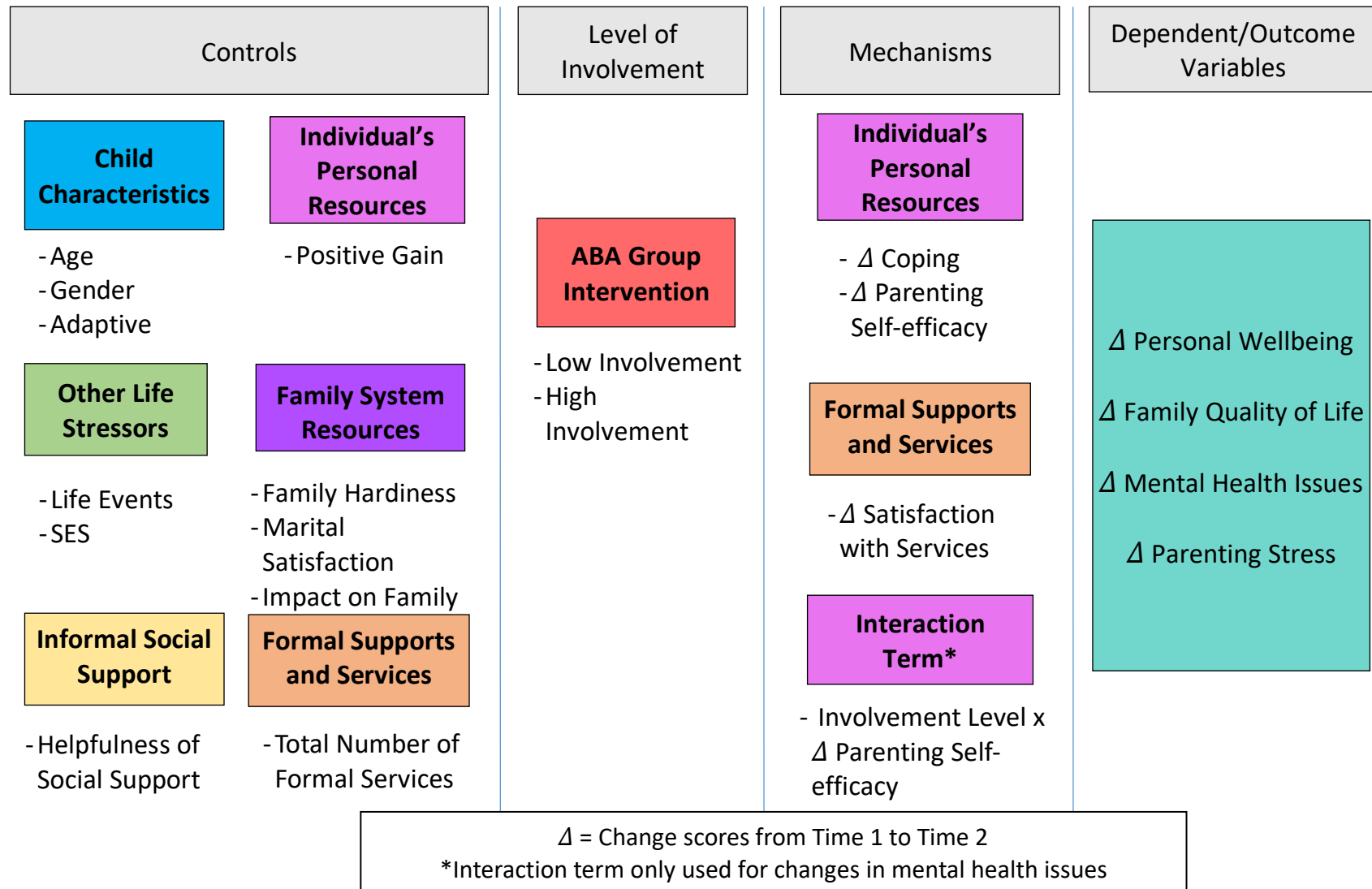
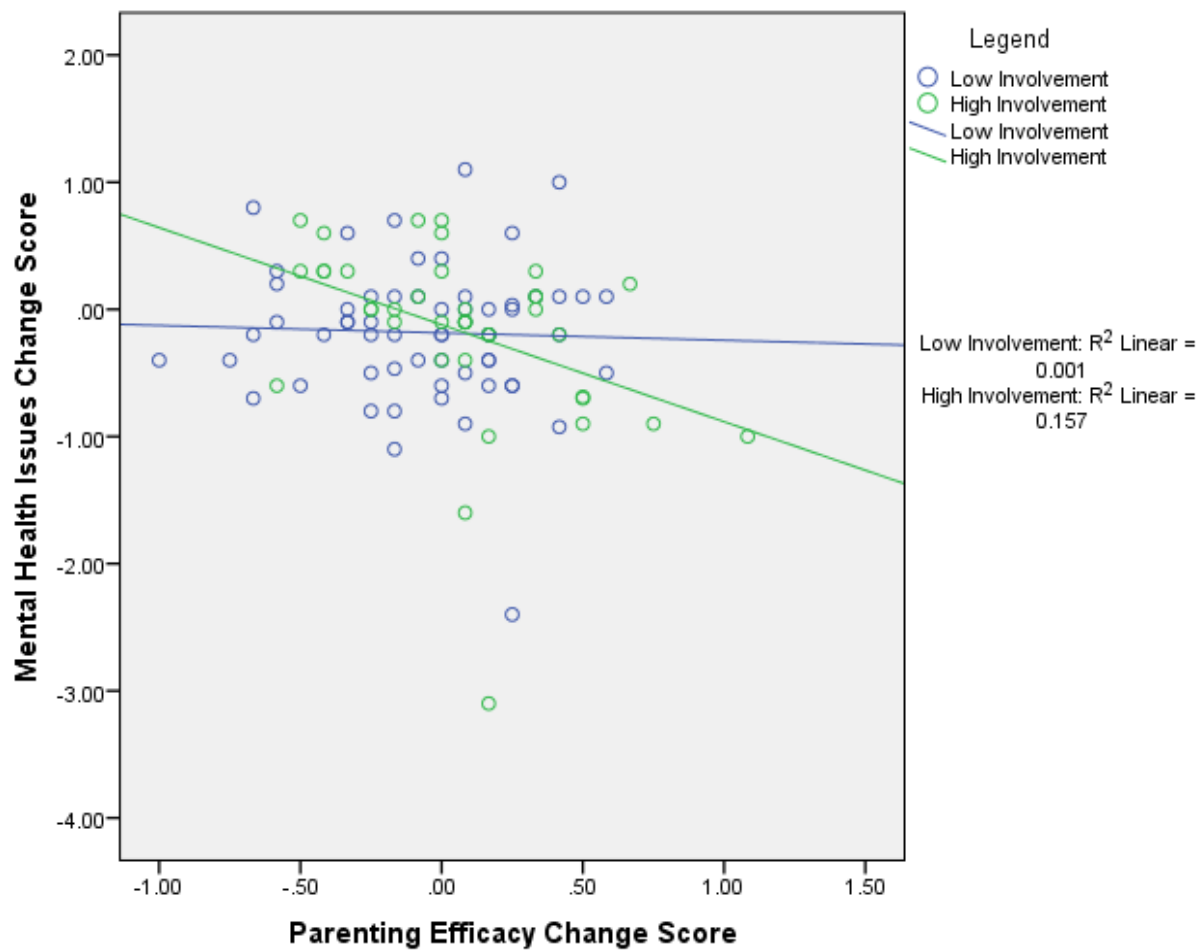


Figure 19

Mental Health Issues and Parenting Efficacy by Parent Involvement Level



Appendix A: Information Letter

Information Letter

Dear Parent,

My name is Odette Weiss and I am a PhD student in the Clinical Developmental Psychology program at York University, under the supervision of Dr. Adrienne Perry. We are writing to invite you to participate in a research study that I am doing as part of my PhD dissertation. This study is about parents' wellbeing as their child with an Autism Spectrum Disorder participates in an Applied Behaviour Analysis (ABA) group. This letter will describe the study and let you know how you can participate if you choose to do so.

The project has been reviewed and approved by the Surrey Place Centre Research Ethics Board. It has also been reviewed by the Human Participants Review Sub-Committee for compliance with Senate ethics policy at York University. If you have any concerns about the ethics or consent process, you may contact [REDACTED]

What is this project about?

This study explores parent experiences as their child participates in an ABA group, with a special focus on the parents' wellbeing and quality of life. Past research has shown that having a child with ASD has a great impact on parents. For example, parents of children with ASD often experience high levels of stress associated with caring for their child. Some parents also report positive experiences, such as a better understanding of themselves or other people. It is possible that if a child with ASD participates in an ABA group, his/her parents may experience a change in wellbeing or quality of life. Therefore, one of the goals of this study is to see if this change is taking place or if other services are required to provide better supports for parents. Another goal is to see if parent participation leads to different outcomes in children's progress.

What will you be asked to do?

Over the course of approximately six months, you will be asked to complete three questionnaires. The first questionnaire will be completed close to the beginning of your child's start date for ABA services at Surrey Place Centre. The second questionnaire will be completed within the last week of your child's final ABA group session. The third and final questionnaire will be administered two to three months after your child has completed the ABA group session. With your consent, we will obtain information from Surrey Place Centre regarding your child's progress in the ABA group and questionnaires that are routinely administered by Surrey Place Centre as part of your child's service.

How long will it take?

The first questionnaire at the start of the ABA group will take approximately 30-45 minutes to complete. The second and third questionnaires will take about 15-20 minutes each. In total, your participation in this study is estimated to take about one hour.

How will your information be used?

- All information collected is private and kept confidential. No one will see the answers you give to questions except for members of the research team. You will be given an ID number.

Whenever information is put on a computer, only the ID number is used, with no names attached.

- We will not tell anyone at Surrey Place anything about your individual answers
- All information will be stored in a locked filing cabinet in a research laboratory in York University or secured on a password-protected computer. Any questionnaires completed electronically will be stored on a secure online server. Ten (10) years after the completion of the study, all paper records will be destroyed and electronic records deleted.
- Your name will not be in any reports or publications and no one will know your answers to our questions
- Your participation in this study is completely voluntary and you may withdraw at any time, without penalty.
- You do not have to answer all questions if you do not want to.
- If you decide not to answer some questions, or decide not to participate in the study at all, or decide not to complete the follow-up questionnaires, it will not affect the support you and/or your child receive from Surrey Place Centre in any way.

How can you become part of this study?

To participate in this study, please fill out the attached consent form. Please keep the second copy of the consent form, as well as this information letter, for yourself.

For more information about this project, please contact:



Thank you for reading this material and considering this request.

Sincerely,

Odette Weiss, M.A.
Ph.D. Candidate
Clinical Developmental Psychology
York University

Adrienne Perry, Ph.D., C. Psych, BCBA-D
Psychologist, Professor
Department of Psychology
York University

Appendix B: Clinician Script

Clinician Script

Dear Parents,

I have been asked to read this brief description of a study that may interest you. Researchers from York University are conducting research about the wellbeing of parents of children with Autism Spectrum Disorder. The study has been approved by Surrey Place Centre's ethics process.

You are free to be involved in the study or not, as you wish; it is not required. Your decision to either participate or not participate in the study will have absolutely no effect on the services that you are receiving here at Surrey Place Centre. The researchers will not share any detailed information with us about you.

Please read through the Information Letter to decide if you may be interested in participating.

[IF RESEARCHERS ARE ON SITE] A representative from the research study is here now and will be invited into the room to provide more information and see if you are interested in participating.

[IF RESEARCHERS ARE NOT ON SITE] Please notice the Parent/Caregiver Contact Information slip, which you are invited to complete in order for one of the researchers, Odette Weiss, to call you to inquire about whether or not you are interested in participating in this study. Completing this does not mean you agree to participate. Please return the completed Contact Information slip to me so that I may pass it on to Odette.

Thank you for your attention!

Appendix C: Consent Form

Parent Consent Form

I, _____, have read and understood the description provided to me about the research being conducted by Odette Weiss and Dr. Adrienne Perry. I understand that the research has been approved by the ethics approval processes of both Surrey Place Centre and York University. If you have any concerns about the ethics or consent process, you may contact _____.

I understand that my participation in the study is completely voluntary and I may choose to stop participating at any time. My decision not to volunteer will not influence the nature of my relationship with Surrey Place Centre or York University either now, or in the future. In the event that I withdraw from the study, all associated data collected will be immediately destroyed.

I understand that all information collected as part of this study will be kept confidential, except as required or allowed by law, and that specific information about myself and my child will only be seen by those directly involved in the research, under Dr. Perry's supervision. I also understand that when results are shared in papers or presentations, no names or any other information that could identify my family will be used. I understand that ten years after the study is complete, all of my paper and/or electronic data will be destroyed and/or deleted.

I have been provided with the proper information to contact someone if I have any questions about this study. I consent to the following (please check all that you agree to):

- ☐ I agree to participate in this study by completing three questionnaires over the next six months.
- ☐ I agree for information about my child's progress in the ABA group in which he/she is participating to be released to the researchers.
- ☐ I agree for questionnaires that I have completed as part of my child's ABA group to be released to the researchers.

Signature of Parent

Name (please print)

Date

- ☐ I would like to receive a summary of the results of the study
- ☐ I can be contacted in the future for other research projects (I could agree or decline at that time)

Email: _____

Phone number: _____

Appendix D: Contact Information Form

Groups for Kids & Parents- Parent/Caregiver Contact Information

ABA GROUP: _____

Dear Parent/Caregiver,

You have just received a letter explaining about this research project being done by Odette Weiss from York University, in partnership with Surrey Place Centre.

If you are interested in learning more about the study, kindly provide your name and phone number below. This indicates that you agree for Odette Weiss to phone you to discuss this study. Providing this information does **not** mean you are necessarily agreeing to participate in the study. You are just agreeing to be called.

We encourage you to review the letter you were given. When Odette Weiss calls you, she will explain the study further and answer any questions you may have. You will then be free to decide if you want to participate or not. You are free to say yes or no at that time.

NAME: _____ PHONE NUMBER: _____

PREFERRED TIME FOR CALLS: _____

Appendix E: Time 1 Questionnaire

GROUPS FOR KIDS & PARENTS: QUESTIONNAIRE AT START OF ABA GROUP

Thank you for agreeing to participate in our study. Please answer the questions in this survey as best as you can, making note of items that ask you to keep a certain period of time in mind. If you have any questions about the survey, please contact [REDACTED]

Today's Date: DD / MM / YYYY

Name of the ABA group in which your child is participating: _____

A. About Your Child (in the ABA Group)

A1. Child's Date of Birth: DD / MM / YYYY

A2. Child's gender: ☐ Male ☐ Female ☐ Other

A3. What is the birth order of the child you are reporting about (please circle)?

- | | |
|---|---|
| 1. Oldest or only child | 4. 4 th oldest child in family |
| 2. 2 nd oldest child in family | 5. 5 th oldest child or later |
| 3. 3 rd oldest child in family | |

A4. Child's Communication & Social Skills. Please circle the most accurate description of your child's skills in each of the following areas.

A4.A How much does your child understand spoken language?

1. Able to understand very little spoken language
2. Able to understand some basic language and simple instructions in familiar contexts (e.g. sit down)
3. Able to understand most basic instructions and questions
4. Able to understand most routine everyday language
5. Able to understand complex language about a wide range of topics

A4.B. How much does your child use spoken language to communicate?

1. Able to use very little meaningful speech
2. Able to communicate basic needs and wants
3. Able to communicate needs, wants, and some ideas
4. Able to communicate within a limited range of topics in a meaningful way
5. Able to communicate about a wide variety of topics in a meaningful way

A4.C. How much does your child engage in social interactions with familiar adults?

1. Shows little or no interest in social interactions with familiar adults
2. Shows limited social interest but will sometimes respond to familiar adults
3. Shows some social interest, responds to others, but does not initiate social interactions with familiar adults
4. Shows clear social interest, responds to others often and sometimes initiates social interactions with familiar adults
5. Engages a wide range of social interactions involving both responding and initiating social contact with familiar adults

A4.D. How much does your child engage in social interactions with other children?

1. Shows little or no interest in social interactions with other children
2. Shows limited social interest but will sometimes respond to other children
3. Shows some social interest, responds to others, but does not initiate social interactions with other children
4. Shows clear social interest, responds to others and sometimes initiates social interactions with other children
5. Engages in a wide range of social interactions involving both responding and initiating social contact with other children

A5. Child's Daily Living Skills. Please circle the most accurate description of your child's skills in each of the following areas.**A5.A. Eating**

1. Needs complete assistance with eating
2. Eats with fingers
3. Can use spoon but may be messy
4. Uses spoon and fork
5. Eats completely independently with proper use of all cutlery

A5.B. Toileting

1. Wears diapers day and night
2. Wears diaper but indicates when needs changing
3. Indicates or asks to use toilet, but does not go independently
4. Toilet trained in daytime (occasional accidents); wears diaper or pull up at night
5. Completely toilet trained day and night

A5.C. Dressing

1. Needs complete assistance dressing and undressing
2. Cooperates with dressing (e.g. raising arms, etc.)
3. Can remove or pull on/up clothes
4. Can dress self quite well but needs help with buttons, zippers, etc.
5. Can dress and undress self completely

B. About You. The following section asks about you as an individual.

B1. Parenting Efficacy. Below are a number of statements that describe how a parent or caregiver may feel about his or her situation. Please circle the response that best describes how the statement applies to you.

	<i>Not True At All</i>	<i>Mostly Not True</i>	<i>Somewhat True</i>	<i>Mostly True</i>	<i>Very True</i>
1. When problems arise with my child, I handle them very well.	1	2	3	4	5
2. I feel confident in my ability to help my child grow and develop.	1	2	3	4	5

	<i>Not True At All</i>	<i>Mostly Not True</i>	<i>Somewhat True</i>	<i>Mostly True</i>	<i>Very True</i>
3. I know what to do when problems arise with my child.	1	2	3	4	5
4. I feel my family life is under control.	1	2	3	4	5
5. I am able to get information to help me better understand my child.	1	2	3	4	5
6. I believe I can solve problems with my child when they happen.	1	2	3	4	5
7. When I need help with problems in my family, I am able to ask for help from others.	1	2	3	4	5
8. I make efforts to learn new ways to help my child grow and develop.	1	2	3	4	5
9. When dealing with my child, I focus on the good things as well as the problems.	1	2	3	4	5
10. When faced with a problem involving my child, I decide what to do and then do it.	1	2	3	4	5
11. I have a good understanding of my child's needs.	1	2	3	4	5
12. I feel I am a good parent.	1	2	3	4	5

B2. Parenting Stress. This part of the questionnaire deals with your feelings about your child. Imagine your child's name filled in on each blank. Give your honest feelings and opinions. Please answer all of the questions even if they do not seem to apply. If it is difficult to decide True (T) or False (F), answer in terms of what you or your family feel or do most of the time. Sometimes the questions refer to problems your family does not have. Nevertheless, they can be answered True or False even then.

	<i>True</i>	<i>False</i>
1. Other members of the family have to do without things because of ____.	<i>T</i>	<i>F</i>
2. Our family agrees on important matters.	<i>T</i>	<i>F</i>
3. The constant demands for care for ____ limit growth and development of someone else in our family.	<i>T</i>	<i>F</i>
4. I have given up things I have really wanted to do in order to care for ____.	<i>T</i>	<i>F</i>
5. ____ is able to fit into the social family group.	<i>T</i>	<i>F</i>
6. In the future, our family's social life will suffer because of increased responsibilities and financial stress.	<i>T</i>	<i>F</i>
7. I can go visit with friends whenever I want.	<i>T</i>	<i>F</i>
8. Taking ____ on vacation spoils the pleasure for the whole family.	<i>T</i>	<i>F</i>
9. The family does as many things together now as we ever did.	<i>T</i>	<i>F</i>

	<i>True</i>	<i>False</i>
10. I get upset with the way my life is going.	<i>T</i>	<i>F</i>
11. There are many places where we can enjoy ourselves as a family when _____ comes along.	<i>T</i>	<i>F</i>
12. It is easy for me to relax.	<i>T</i>	<i>F</i>
13. I get almost too tired to enjoy myself.	<i>T</i>	<i>F</i>
14. There is a lot of anger and resentment in our family.	<i>T</i>	<i>F</i>
15. The constant demands to care for _____ limit my growth and development.	<i>T</i>	<i>F</i>
16. I feel sad when I think of _____.	<i>T</i>	<i>F</i>
17. Caring for _____ puts a strain on me.	<i>T</i>	<i>F</i>
18. Members of our family get to do the same kinds of things other families do.	<i>T</i>	<i>F</i>
19. I rarely feel blue.	<i>T</i>	<i>F</i>
20. I am worried much of the time.	<i>T</i>	<i>F</i>

B3. Positive Gain. The following statements focus on your own and your family's experiences of having a child with ASD.

	<i>Strongly Disagree</i>	<i>Disagree</i>	<i>Not Sure</i>	<i>Agree</i>	<i>Strongly Agree</i>
1. Since having this child, I feel I have grown as a person.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
2. Having this child has helped me to learn new things/skills.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
3. Raising this child helps put life into perspective.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
4. Since having this child, my family has become closer to one another.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
5. Since having this child, my family has become more tolerant and accepting.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
6. Since having this child, I have become more determined to face up to challenges.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>
7. Since having this child, I have a greater understanding of other people.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>

B4. Coping. There are many ways to try to deal with problems. Different people deal with things in different ways, but we are interested in how you have tried to deal with your problems. Each item says something about a particular way of coping. Please indicate the extent to which you have been doing what the item says. Do not answer on the basis of whether it seems to be working or not- just whether or not you are doing it. Try to rate each item separately in your mind from the others.

	<i>Haven't Been Doing this at All</i>	<i>Been Doing this a Little Bit</i>	<i>Been Doing this a Medium Amount</i>	<i>Been Doing this a Lot</i>
1. I've been turning to work or other activities to take my mind off things.	1	2	3	4
2. I've been concentrating my efforts on doing something about the situation I'm in.	1	2	3	4
3. I've been saying to myself "this isn't real".	1	2	3	4
4. I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
5. I've been getting emotional support from others.	1	2	3	4
6. I've been giving up trying to deal with it.	1	2	3	4
7. I've been taking action to try to make the situation better.	1	2	3	4
8. I've been refusing to believe that it has happened.	1	2	3	4
9. I've been saying things to let my unpleasant feelings escape.	1	2	3	4
10. I've been getting help and advice from other people.	1	2	3	4
11. I've been using alcohol or other drugs to help me get through it.	1	2	3	4
12. I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
13. I've been criticizing myself.	1	2	3	4
14. I've been trying to come up with a strategy about what to do.	1	2	3	4
15. I've been getting comfort and understanding from someone.	1	2	3	4
16. I've been giving up the attempt to cope.	1	2	3	4
17. I've been looking for something good in what is happening.	1	2	3	4
18. I've been making jokes about it.	1	2	3	4

	<i>Haven't Been Doing this at All</i>	<i>Been Doing this a Little Bit</i>	<i>Been Doing this a Medium Amount</i>	<i>Been Doing this a Lot</i>
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4
20. I've been accepting the reality of the fact that it has happened.	1	2	3	4
21. I've been expressing my negative feelings.	1	2	3	4
22. I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
23. I've been trying to get advice or help from other people about what to do.	1	2	3	4
24. I've been learning to live with it.	1	2	3	4
25. I've been thinking hard about what steps to take.	1	2	3	4
26. I've been blaming myself for things that happened.	1	2	3	4
27. I've been praying or meditating.	1	2	3	4
28. I've been making fun of the situation.	1	2	3	4

B5. Feelings. Over the **past 30 days** how much of the time did **you** feel...

	<i>None of the Time</i>	<i>A Little of the Time</i>	<i>Some of the Time</i>	<i>Most of the Time</i>	<i>All of the Time</i>
1. Tired out for no good reason?	1	2	3	4	5
2. Nervous?	1	2	3	4	5
3. So nervous that nothing could calm you down?	1	2	3	4	5
4. Hopeless?	1	2	3	4	5
5. Restless or fidgety?	1	2	3	4	5
6. So restless that you could not sit still?	1	2	3	4	5
7. Depressed?	1	2	3	4	5
8. So depressed that nothing could cheer you up?	1	2	3	4	5
9. That everything was an effort?	1	2	3	4	5
10. Worthless?	1	2	3	4	5

B6. Marital Satisfaction. (if married or in long-term relationship)

Skip these 2 questions if you are single.

B6.A. How happy is your marriage/relationship?

1	2	3	4	5
Very unhappy	Unhappy	Mixed	Happy	Very Happy

B6.B. How much support do you feel you receive from your spouse/partner related to caring for your child with ASD?

1	2	3	4	5
Makes it More Difficult	Not Helpful	Somewhat or Sometimes Helpful	Very Helpful	Extremely Helpful, I depend on Them

B7. Personal Wellbeing. The following questions ask how satisfied you feel, on a scale from 0 to 10.

	<i>No Satisfaction at All</i>										<i>Completely Satisfied</i>
1. Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole?	0	1	2	3	4	5	6	7	8	9	10
2. How satisfied are you with your standard of living?	0	1	2	3	4	5	6	7	8	9	10
3. How satisfied are you with your health?	0	1	2	3	4	5	6	7	8	9	10
4. How satisfied are you with what you are achieving in your life?	0	1	2	3	4	5	6	7	8	9	10
5. How satisfied are you with your personal relationships?	0	1	2	3	4	5	6	7	8	9	10
6. How satisfied are you with how safe you feel?	0	1	2	3	4	5	6	7	8	9	10
7. How satisfied are you with feeling part of your community?	0	1	2	3	4	5	6	7	8	9	10
8. How satisfied are you with your future security?	0	1	2	3	4	5	6	7	8	9	10
9. How satisfied are you with your spirituality or religion?	0	1	2	3	4	5	6	7	8	9	10

C. About Your Family. The next section of the questionnaire asks about your family. This can include many people, including mother, father, partners, children, aunts, uncles, grandparents, etc. Please consider your “family” as people who think of themselves as part of your family (even though they may or may not be related by blood or marriage) and support and care for each other on a regular basis. Do not think about relatives who are only involved with your family every once in a while.

C1. Impact on Family. In your view, what have been the family consequences (positive and/or negative) of having a child with ASD in your family?

	<i>Not at All</i>	<i>To a Mild Degree</i>	<i>To a Moderate Degree</i>	<i>To a Substantial Degree</i>
1. We have experienced extraordinary time demands created in looking after the needs of this child.	1	2	3	4
2. We have had an unwelcome disruption to “normal” family routines.	1	2	3	4
3. The experience has brought us closer to God.	1	2	3	4
4. It has led to additional financial costs.	1	2	3	4
5. Family members do more for each other than they do for themselves.	1	2	3	4
6. Having a disabled child has led to an improved relationship with my spouse.	1	2	3	4
7. It has led to limitations in social contacts outside the home.	1	2	3	4
8. The experience has made us come to terms with what should be valued in life.	1	2	3	4
9. Chronic stress in the family has been a consequence.	1	2	3	4
10. This experience has helped me appreciate how every child has a unique personality and special talents.	1	2	3	4
11. We have had to postpone or cancel major holidays.	1	2	3	4
12. Family members have become more tolerant of differences in other people and generally more accepting of physical or mental differences between people.	1	2	3	4
13. It has led to a reduction in time we could spend with our friends.	1	2	3	4
14. The child’s disability has led to positive personal growth, or more strength as a person in mother and/or father.	1	2	3	4
15. Because of the situation, we have hesitated to phone friends and acquaintances.	1	2	3	4

	<i>Not at All</i>	<i>To a Mild Degree</i>	<i>To a Moderate Degree</i>	<i>To a Substantial Degree</i>
16. The experience has made family members more aware of other people's needs and struggles which are based on disability.	1	2	3	4
17. The situation has led to tension with my spouse.	1	2	3	4
18. The experience has taught me that there are many special pleasures from a child with disabilities.	1	2	3	4
19. Because of the circumstances of the child's disability, there has been a postponement of major purchases.	1	2	3	4
20. Raising a disabled child has made life more meaningful for family members.	1	2	3	4

C2. Family Hardiness. How true are the following statements for your family?

	<i>Not True At All</i>	<i>Mostly Not True</i>	<i>Somewhat True</i>	<i>Mostly True</i>	<i>Very True</i>
1. Our family has been able to resolve many (but not all) of our problems by ourselves.	1	2	3	4	5
2. Our family has control over many (but not all) events in our lives.	1	2	3	4	5
3. Our family has coped well with one or more major stressors in our lives.	1	2	3	4	5
4. Our family has been able to "make the best out of a bad situation" a number of times.	1	2	3	4	5

C3. Family Quality of Life. Please consider those people who think of themselves as part of your family and who support and care for each other **on a regular basis**. Please think about the past **12 months**.

How <u>satisfied</u> am I that...	<i>Very Dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither</i>	<i>Satisfied</i>	<i>Very Satisfied</i>
1. My family enjoys spending time together.	1	2	3	4	5
2. My family members help the children learn to be independent.	1	2	3	4	5
3. My family has the support we need to relieve stress.	1	2	3	4	5
4. My family members have friends or others who provide support.	1	2	3	4	5

	<i>Very Dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither</i>	<i>Satisfied</i>	<i>Very Satisfied</i>
5. My family members help the children with schoolwork and activities.	1	2	3	4	5
6. My family members have transportation to get to the places they need to be.	1	2	3	4	5
7. My family members talk openly with each other.	1	2	3	4	5
8. My family members teach the children how to get along with others.	1	2	3	4	5
9. My family members have some time to pursue our own interests.	1	2	3	4	5
10. Our family solves problems together.	1	2	3	4	5
11. My family members support each other to accomplish goals.	1	2	3	4	5
12. My family members show that they love and care for each other.	1	2	3	4	5
13. My family has outside help available to us to take care of special needs of all family members.	1	2	3	4	5
14. Adults in our family teach the children to make good decisions.	1	2	3	4	5
15. My family gets medical care when needed.	1	2	3	4	5
16. My family has a way to take care of our expenses.	1	2	3	4	5
17. Adults in my family know other people in the children's lives (friends, teachers, etc.).	1	2	3	4	5
18. My family is able to handle life's ups and downs.	1	2	3	4	5
19. Adults in my family have time to take care of the individual needs of every child.	1	2	3	4	5
20. My family gets dental care when needed.	1	2	3	4	5

	<i>Very Dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither</i>	<i>Satisfied</i>	<i>Very Satisfied</i>
21. My family feels safe at home, work, school, and in our neighborhood.	1	2	3	4	5
22. My family member with a disability has support to accomplish goals at school or at workplace.	1	2	3	4	5
23. My family member with a disability has support to accomplish goals at home.	1	2	3	4	5
24. My family member with a disability has support to make friends.	1	2	3	4	5
25. My family has good relationships with the service providers who provide services and support to our family member with a disability.	1	2	3	4	5

C4. Social Support. Listed below are people and groups that often times are helpful to members of a family raising a child. The following questions asks you to rate how helpful each source is to your family. Please circle the response that describes how helpful the sources have been to your family during the past **3 to 6 months**.

How helpful has each of the following been to you in terms of raising your child?	<i>Not Available</i>	<i>Not at All Helpful</i>	<i>Sometimes Helpful</i>	<i>Generally Helpful</i>	<i>Very Helpful</i>	<i>Extremely Helpful</i>
1. My parents	N/A	1	2	3	4	5
2. My spouse/partner's parents	N/A	1	2	3	4	5
3. My relatives	N/A	1	2	3	4	5
4. My spouse/partner's relatives	N/A	1	2	3	4	5
5. Spouse or partner	N/A	1	2	3	4	5
6. My friends	N/A	1	2	3	4	5
7. My spouse/partner's friends	N/A	1	2	3	4	5
8. My own children	N/A	1	2	3	4	5
9. Other parents	N/A	1	2	3	4	5
10. Co-workers	N/A	1	2	3	4	5
11. Parent groups	N/A	1	2	3	4	5
12. Social groups/clubs	N/A	1	2	3	4	5
13. Church or religious community/spiritual leader	N/A	1	2	3	4	5

	<i>Not Available</i>	<i>Not at All Helpful</i>	<i>Sometimes Helpful</i>	<i>Generally Helpful</i>	<i>Very Helpful</i>	<i>Extremely Helpful</i>
14. My family or child's physician	N/A	1	2	3	4	5
15. Child's intervention program	N/A	1	2	3	4	5
16. School/day-care centre	N/A	1	2	3	4	5
17. Professional helpers (social workers, therapists, teachers, etc.)	N/A	1	2	3	4	5
18. Professional agencies (public health, social services, mental health, etc.)	N/A	1	2	3	4	5
19. Other: _____	N/A	1	2	3	4	5

D. Services. Please tell us about the services you have received for your child.

D1. Services Access. Please tell us about the services and supports your child has received **over the past year** (check all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Family doctor | <input type="checkbox"/> Behaviour therapist |
| <input type="checkbox"/> Pediatrician | <input type="checkbox"/> Case manager/service coordinator |
| <input type="checkbox"/> Emergency Room staff | <input type="checkbox"/> Social worker/counselor/family therapist |
| <input type="checkbox"/> Hospital admission | <input type="checkbox"/> Out-of-home respite care |
| <input type="checkbox"/> Psychiatrist | <input type="checkbox"/> In-home respite care |
| <input type="checkbox"/> Speech-language pathologist | <input type="checkbox"/> Specialized transportation services |
| <input type="checkbox"/> Occupational therapist | <input type="checkbox"/> Dentist |
| <input type="checkbox"/> Physical therapist | <input type="checkbox"/> Chiropractor |
| <input type="checkbox"/> Psychologist | <input type="checkbox"/> Alternative practitioners (e.g., naturopath, etc.) |

D2. Satisfaction with Services

In the last year...	<i>Very Dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither</i>	<i>Satisfied</i>	<i>Very Satisfied</i>
1. How satisfied have you been by services for your child with ASD?	1	2	3	4	5
2. How satisfied have you been by services for you and your family?	1	2	3	4	5

D3. Services Fit with Needs

In the last year...	<i>Not at all</i>	<i>A bit</i>	<i>Somewhat</i>	<i>Mostly</i>	<i>Completely</i>
1. Have the services you have received been a good match for your child's needs?	1	2	3	4	5
2. Have the services you have received been a good match for you and your family?	1	2	3	4	5

D3. Services- Comments. Do you have any comments about the quality or quantity of the services you have received and/or needed, at any time?

E. Life Events. Over the past **12 months**, have any of the following events occurred in your immediate family?

Has your family experienced (please check all that apply):

- ☐ Separation
- ☐ Divorce
- ☐ Marital reconciliation
- ☐ Marriage
- ☐ Pregnancy
- ☐ Other relative moved into household
- ☐ Moved to a new location
- ☐ Promotion at work
- ☐ Began new job
- ☐ Trouble with superiors at work
- ☐ Serious illness or injury
- ☐ Serious illness of close relative or friend
- ☐ Recent immigration
- ☐ Housing problems
- ☐ Legal problems
- ☐ Problems with police or other authority
- ☐ Death of immediate family member
- ☐ Death of close family friend
- ☐ Went deeply into debt
- ☐ Income increased substantially (20% or more)
- ☐ Income decreased substantially
- ☐ Alcohol or drug problem
- ☐ Serious mental health problems

Has your child with ASD (please check all that apply):

- ☐ Entered new school
- ☐ Been suspended or expelled from school
- ☐ Transitioned to middle school
- ☐ Transitioned to high school
- ☐ Transitioned out of high school
- ☐ Experienced another difficult transition. Please specify:

- ☐ Had difficulties with teacher. Please specify

- ☐ Lost a good Educational Assistant or Teacher
- ☐ Lost a good paid caregiver (e.g. a nanny, babysitter)
- ☐ Diagnosis of another child/family member with disability

F. Demographic Information

F1. How old are you? _____

F2. What is your marital status?

1. *Married or common-law*
2. *Separated, divorced, single, or widowed*
3. *Other*

F3. Please answer these questions about yourself, the person completing the survey:

F3.A. What is your gender?

☐ Male ☐ Female ☐ Other

F3.B. What is your relationship to the child?

1. *Biological parent*
2. *Adoptive parent*
3. *Step parent*
4. *Grandparent*
5. *Other (Please specify _____)*

F3.C1. Country of birth: _____

F3.C2. If born outside of Canada, how many years have you lived in Canada? _____

F3.D. What is your first language?

F3.E. What is the highest level of education completed?

1. *Less than 7th grade*
2. *Junior high / Middle school (9th grade)*
3. *Partial high school (10th or 11th grade)*
4. *High school graduate*
5. *Partial college (at least one year)*
6. *College / University graduate*
7. *Graduate degree (MBA, MA, PhD, etc.)*

F3.F. What is your occupation? Please be specific (e.g., legal secretary, bank executive, truck driver):

F3.G. Do you currently work outside the home?

1. *Not currently*
2. *Part-time*
3. *Full-time*

F4. If you have a partner, please answer these questions:

F4.A. What is his/her gender?

☐ Male ☐ Female ☐ Other

F4.B. What is his/her relationship to the child?

1. *Biological parent*
2. *Adoptive parent*
3. *Step parent*
4. *Grandparent*
5. *Other (Please specify _____)*

F4.C1. Country of birth: _____

F4.C2. If born outside of Canada, how many years has he/she lived in Canada? _____

F4.D. What is his/her first language?

F4.E. What is the highest level of education completed?

1. *Less than 7th grade*
2. *Junior high / Middle school (9th grade)*
3. *Partial high school (10th or 11th grade)*
4. *High school graduate*
5. *Partial college (at least one year)*
6. *College / University graduate*
7. *Graduate degree (MBA, MA, PhD, etc.)*

F4.F. What is his/her occupation? Please be specific: (e.g., legal secretary, bank executive, truck driver):

F4.G. Does he/she currently work outside the home?

1. *Not currently*
2. *Part-time*
3. *Full-time*

G. Additional Comments. Do you have any other comments about the impact of having a child with ASD?

END OF SURVEY

Thank you for taking time to complete this survey!

Appendix F: Time 2 Questionnaire

GROUPS FOR KIDS & PARENTS: QUESTIONNAIRE AT END OF ABA GROUP

Please complete the items below. You may remember some of the questions from the questionnaire that you completed when your child started the ABA group. Please make note of items that ask you to keep in mind a certain period of time. If you have any questions about the survey, please contact [REDACTED].

Today's Date: DD / MM / YYYY

A. About Your Child (in the ABA Group)					
A1. Child's Date of Birth: <u>DD / MM / YYYY</u>					
A2. Child's gender: <input type="checkbox"/> <i>Male</i> <input type="checkbox"/> <i>Female</i> <input type="checkbox"/> <i>Other</i>					
B. About You. The following section asks about <u>you</u> as an individual.					
B1. Parenting Efficacy. Below are a number of statements that describe how a parent or caregiver may feel about his or her situation. Please circle the response that best describes how the statement applies to <u>you</u> .					
	<i>Not True At All</i>	<i>Mostly Not True</i>	<i>Somewhat True</i>	<i>Mostly True</i>	<i>Very True</i>
1. When problems arise with my child, I handle them very well.	1	2	3	4	5
2. I feel confident in my ability to help my child grow and develop.	1	2	3	4	5
3. I know what to do when problems arise with my child.	1	2	3	4	5
4. I feel my family life is under control.	1	2	3	4	5
5. I am able to get information to help me better understand my child.	1	2	3	4	5
6. I believe I can solve problems with my child when they happen.	1	2	3	4	5
7. When I need help with problems in my family, I am able to ask for help from others.	1	2	3	4	5
8. I make efforts to learn new ways to help my child grow and develop.	1	2	3	4	5

	<i>Not True At All</i>	<i>Mostly Not True</i>	<i>Somewhat True</i>	<i>Mostly True</i>	<i>Very True</i>
9. When dealing with my child, I focus on the good things as well as the problems.	1	2	3	4	5
10. When faced with a problem involving my child, I decide what to do and then do it.	1	2	3	4	5
11. I have a good understanding of my child's needs.	1	2	3	4	5
12. I feel I am a good parent.	1	2	3	4	5

B2. Parenting Stress. This part of the questionnaire deals with your feelings about your child. Imagine your child's name filled in on each blank. Give your honest feelings and opinions. Please answer all of the questions even if they do not seem to apply. If it is difficult to decide True (T) or False (F), answer in terms of what you or your family feel or do most of the time. Sometimes the questions refer to problems your family does not have. Nevertheless, they can be answered True or False even then.

	<i>True</i>	<i>False</i>
1. Other members of the family have to do without things because of ____.	<i>T</i>	<i>F</i>
2. Our family agrees on important matters.	<i>T</i>	<i>F</i>
3. The constant demands for care for ____ limit growth and development of someone else in our family.	<i>T</i>	<i>F</i>
4. I have given up things I have really wanted to do in order to care for ____.	<i>T</i>	<i>F</i>
5. ____ is able to fit into the social family group.	<i>T</i>	<i>F</i>
6. In the future, our family's social life will suffer because of increased responsibilities and financial stress.	<i>T</i>	<i>F</i>
7. I can go visit with friends whenever I want.	<i>T</i>	<i>F</i>
8. Taking ____ on vacation spoils the pleasure for the whole family.	<i>T</i>	<i>F</i>
9. The family does as many things together now as we ever did.	<i>T</i>	<i>F</i>
10. I get upset with the way my life is going.	<i>T</i>	<i>F</i>
11. There are many places where we can enjoy ourselves as a family when ____ comes along.	<i>T</i>	<i>F</i>
12. It is easy for me to relax.	<i>T</i>	<i>F</i>
13. I get almost too tired to enjoy myself.	<i>T</i>	<i>F</i>
14. There is a lot of anger and resentment in our family.	<i>T</i>	<i>F</i>
15. The constant demands to care for ____ limit my growth and development.	<i>T</i>	<i>F</i>
16. I feel sad when I think of ____.	<i>T</i>	<i>F</i>

	<i>True</i>	<i>False</i>
17. Caring for _____ puts a strain on me.	<i>T</i>	<i>F</i>
18. Members of our family get to do the same kinds of things other families do.	<i>T</i>	<i>F</i>
19. I rarely feel blue.	<i>T</i>	<i>F</i>
20. I am worried much of the time.	<i>T</i>	<i>F</i>

B4. Coping. There are many ways to try to deal with problems. Different people deal with things in different ways, but we are interested in how you have tried to deal with your problems. Each item says something about a particular way of coping. Please indicate the extent to which you have been doing what the item says **over the past 3 months**. Do not answer on the basis of whether it seems to be working or not- just whether or not you are doing it. Try to rate each item separately in your mind from the others.

	<i>Haven't Been Doing this at All</i>	<i>Been Doing this a Little Bit</i>	<i>Been Doing this a Medium Amount</i>	<i>Been Doing this a Lot</i>
1. I've been turning to work or other activities to take my mind off things.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
2. I've been concentrating my efforts on doing something about the situation I'm in.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
3. I've been saying to myself "this isn't real".	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
4. I've been using alcohol or other drugs to make myself feel better.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
5. I've been getting emotional support from others.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
6. I've been giving up trying to deal with it.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
7. I've been taking action to try to make the situation better.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
8. I've been refusing to believe that it has happened.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
9. I've been saying things to let my unpleasant feelings escape.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
10. I've been getting help and advice from other people.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
11. I've been using alcohol or other drugs to help me get through it.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
12. I've been trying to see it in a different light, to make it seem more positive.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
13. I've been criticizing myself.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
14. I've been trying to come up with a strategy about what to do.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
15. I've been getting comfort and understanding from someone.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>

	<i>Haven't Been Doing this at All</i>	<i>Been Doing this a Little Bit</i>	<i>Been Doing this a Medium Amount</i>	<i>Been Doing this a Lot</i>
16. I've been giving up the attempt to cope.	1	2	3	4
17. I've been looking for something good in what is happening.	1	2	3	4
18. I've been making jokes about it.	1	2	3	4
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4
20. I've been accepting the reality of the fact that it has happened.	1	2	3	4
21. I've been expressing my negative feelings.	1	2	3	4
22. I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
23. I've been trying to get advice or help from other people about what to do.	1	2	3	4
24. I've been learning to live with it.	1	2	3	4
25. I've been thinking hard about what steps to take.	1	2	3	4
26. I've been blaming myself for things that happened.	1	2	3	4
27. I've been praying or meditating.	1	2	3	4
28. I've been making fun of the situation.	1	2	3	4

B5. Feelings. Over the **past 30 days** how much of the time did **you** feel...

	<i>None of the Time</i>	<i>A Little of the Time</i>	<i>Some of the Time</i>	<i>Most of the Time</i>	<i>All of the Time</i>
1. Tired out for no good reason?	1	2	3	4	5
2. Nervous?	1	2	3	4	5
3. So nervous that nothing could calm you down?	1	2	3	4	5
4. Hopeless?	1	2	3	4	5
5. Restless or fidgety?	1	2	3	4	5
6. So restless that you could not sit still?	1	2	3	4	5
7. Depressed?	1	2	3	4	5
8. So depressed that nothing could cheer you up?	1	2	3	4	5
9. That everything was an effort?	1	2	3	4	5
10. Worthless?	1	2	3	4	5

B6. Marital Satisfaction. (if married or in long-term relationship)*Skip these 2 questions if you are single.***B6.A. How happy is your marriage/relationship?**

1	2	3	4	5
Very	Unhappy	Mixed	Happy	Very Happy
unhappy				

B6.B. How much support do you feel you receive from your spouse/partner related to caring for your child with ASD?

1	2	3	4	5
Makes it	Not Helpful	Somewhat	Very Helpful	Extremely Helpful,
More Difficult		or Sometimes		I depend
		Helpful		on Them

B7. Personal Wellbeing. The following questions ask how satisfied you feel, on a scale from 0 to 10.

	<i>No Satisfaction at All</i>										<i>Completely Satisfied</i>
1. Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole?	0	1	2	3	4	5	6	7	8	9	10
2. How satisfied are you with your standard of living?	0	1	2	3	4	5	6	7	8	9	10
3. How satisfied are you with your health?	0	1	2	3	4	5	6	7	8	9	10
4. How satisfied are you with what you are achieving in your life?	0	1	2	3	4	5	6	7	8	9	10
5. How satisfied are you with your personal relationships?	0	1	2	3	4	5	6	7	8	9	10
6. How satisfied are you with how safe you feel?	0	1	2	3	4	5	6	7	8	9	10
7. How satisfied are you with feeling part of your community?	0	1	2	3	4	5	6	7	8	9	10
8. How satisfied are you with your future security?	0	1	2	3	4	5	6	7	8	9	10
9. How satisfied are you with your spirituality or religion?	0	1	2	3	4	5	6	7	8	9	10

C. About Your Family. The next section of the questionnaire asks about your family. This can include many people, including mother, father, partners, children, aunts, uncles, grandparents, etc. Please consider your “family” as people who think of themselves as part of your family (even though they may or may not be related by blood or marriage) and support and care for each other on a regular basis. Do not think about relatives who are only involved with your family every once in a while.

C3. Family Quality of Life. Please consider those people who think of themselves as part of your family and who support and care for each other **on a regular basis**. Please think about the past **3 months**.

How <u>satisfied</u> am I that...	<i>Very Dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither</i>	<i>Satisfied</i>	<i>Very Satisfied</i>
1. My family enjoys spending time together.	1	2	3	4	5
2. My family members help the children learn to be independent.	1	2	3	4	5
3. My family has the support we need to relieve stress.	1	2	3	4	5
4. My family members have friends or others who provide support.	1	2	3	4	5
5. My family members help the children with schoolwork and activities.	1	2	3	4	5
6. My family members have transportation to get to the places they need to be.	1	2	3	4	5
7. My family members talk openly with each other.	1	2	3	4	5
8. My family members teach the children how to get along with others.	1	2	3	4	5
9. My family members have some time to pursue our own interests.	1	2	3	4	5
10. Our family solves problems together.	1	2	3	4	5
11. My family members support each other to accomplish goals.	1	2	3	4	5
12. My family members show that they love and care for each other.	1	2	3	4	5
13. My family has outside help available to us to take care of special needs of all family members.	1	2	3	4	5

	<i>Very Dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither</i>	<i>Satisfied</i>	<i>Very Satisfied</i>
14. Adults in our family teach the children to make good decisions.	1	2	3	4	5
15. My family gets medical care when needed.	1	2	3	4	5
16. My family has a way to take care of our expenses.	1	2	3	4	5
17. Adults in my family know other people in the children's lives (friends, teachers, etc.).	1	2	3	4	5
18. My family is able to handle life's ups and downs.	1	2	3	4	5
19. Adults in my family have time to take care of the individual needs of every child.	1	2	3	4	5
20. My family gets dental care when needed.	1	2	3	4	5
21. My family feels safe at home, work, school, and in our neighborhood.	1	2	3	4	5
22. My family member with a disability has support to accomplish goals at school or at workplace.	1	2	3	4	5
23. My family member with a disability has support to accomplish goals at home.	1	2	3	4	5
24. My family member with a disability has support to make friends.	1	2	3	4	5
25. My family has good relationships with the service providers who provide services and support to our family member with a disability.	1	2	3	4	5

D. Services. Please tell us about the services you have received for your child.

D1. Services Access. Please tell us about the services and supports your child has received **over the past 3 months** (check all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Family doctor | <input type="checkbox"/> Behaviour therapist |
| <input type="checkbox"/> Pediatrician | <input type="checkbox"/> Case manager/service coordinator |
| <input type="checkbox"/> Emergency Room staff | <input type="checkbox"/> Social worker/counselor/family therapist |
| <input type="checkbox"/> Hospital admission | <input type="checkbox"/> Out-of-home respite care |
| <input type="checkbox"/> Psychiatrist | <input type="checkbox"/> In-home respite care |
| <input type="checkbox"/> Speech-language pathologist | <input type="checkbox"/> Specialized transportation services |
| <input type="checkbox"/> Occupational therapist | <input type="checkbox"/> Dentist |
| <input type="checkbox"/> Physical therapist | <input type="checkbox"/> Chiropractor |
| <input type="checkbox"/> Psychologist | <input type="checkbox"/> Alternative practitioners (e.g., naturopath, etc.) |

D2. Satisfaction with Services

In the last three months...	<i>Very Dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither</i>	<i>Satisfied</i>	<i>Very Satisfied</i>
1. How satisfied have you been by services for your child with ASD?	1	2	3	4	5
2. How satisfied have you been by services for you and your family?	1	2	3	4	5

D3. Services Fit with Needs

In the last three months...	<i>Not at all</i>	<i>A bit</i>	<i>Somewhat</i>	<i>Mostly</i>	<i>Completely</i>
1. Have the services you have received been a good match for your child's needs?	1	2	3	4	5
2. Have the services you have received been a good match for you and your family?	1	2	3	4	5

D4. Services- Comments. Do you have any comments about the quality or quantity of the services you have received and/or needed, at any time?

E. Life Events. Over the past **3 months**, have any of the following events occurred in your immediate family?

Has your family experienced (please check all that apply):

- ☐ Separation
- ☐ Divorce
- ☐ Marital reconciliation
- ☐ Marriage
- ☐ Pregnancy
- ☐ Other relative moved into household
- ☐ Moved to a new location
- ☐ Promotion at work
- ☐ Began new job
- ☐ Trouble with superiors at work
- ☐ Serious illness or injury
- ☐ Serious illness of close relative or friend
- ☐ Recent immigration
- ☐ Housing problems
- ☐ Legal problems
- ☐ Problems with police or other authority
- ☐ Death of immediate family member
- ☐ Death of close family friend
- ☐ Went deeply into debt
- ☐ Income increased substantially (20% or more)
- ☐ Income decreased substantially
- ☐ Alcohol or drug problem
- ☐ Serious mental health problems

Has your child with ASD (please check all that apply):

- ☐ Entered new school
- ☐ Been suspended or expelled from school
- ☐ Transitioned to middle school
- ☐ Transitioned to high school
- ☐ Transitioned out of high school
- ☐ Experienced another difficult transition. Please specify:

- ☐ Had difficulties with teacher. Please specify

- ☐ Lost a good Educational Assistant or Teacher
- ☐ Lost a good paid caregiver (e.g. a nanny, babysitter)
- ☐ Diagnosis of another child/family member with disability

G. Additional Comments. Do you have any other comments that you would like to make?

END OF SURVEY

Thank you for taking time to complete this survey!

Appendix G: Time 3 Questionnaire

GROUPS FOR KIDS & PARENTS: QUESTIONNAIRE AT FOLLOW-UP AFTER ABA GROUP

Please complete the items below. You may remember some of the questions from the questionnaire that you completed when your child finished the ABA group. Please make note of items that ask you to keep in mind a certain period of time. If you have any questions about the survey, please contact [REDACTED].

Today's Date: DD / MM / YYYY

A. About Your Child (in the ABA Group)					
A1. Child's Date of Birth: <u>DD / MM / YYYY</u>					
A2. Child's gender: <input type="checkbox"/> <i>Male</i> <input type="checkbox"/> <i>Female</i> <input type="checkbox"/> <i>Other</i>					
B. About You. The following section asks about <u>you</u> as an individual.					
B1. Parenting Efficacy. Below are a number of statements that describe how a parent or caregiver may feel about his or her situation. Please circle the response that best describes how the statement applies to <u>you</u> .					
	<i>Not True At All</i>	<i>Mostly Not True</i>	<i>Somewhat True</i>	<i>Mostly True</i>	<i>Very True</i>
1. When problems arise with my child, I handle them very well.	1	2	3	4	5
2. I feel confident in my ability to help my child grow and develop.	1	2	3	4	5
3. I know what to do when problems arise with my child.	1	2	3	4	5
4. I feel my family life is under control.	1	2	3	4	5
5. I am able to get information to help me better understand my child.	1	2	3	4	5
6. I believe I can solve problems with my child when they happen.	1	2	3	4	5
7. When I need help with problems in my family, I am able to ask for help from others.	1	2	3	4	5
8. I make efforts to learn new ways to help my child grow and develop.	1	2	3	4	5

	<i>Not True At All</i>	<i>Mostly Not True</i>	<i>Somewhat True</i>	<i>Mostly True</i>	<i>Very True</i>
9. When dealing with my child, I focus on the good things as well as the problems.	1	2	3	4	5
10. When faced with a problem involving my child, I decide what to do and then do it.	1	2	3	4	5
11. I have a good understanding of my child's needs.	1	2	3	4	5
12. I feel I am a good parent.	1	2	3	4	5

B2. Parenting Stress. This part of the questionnaire deals with your feelings about your child. Imagine your child's name filled in on each blank. Give your honest feelings and opinions. Please answer all of the questions even if they do not seem to apply. If it is difficult to decide True (T) or False (F), answer in terms of what you or your family feel or do most of the time. Sometimes the questions refer to problems your family does not have. Nevertheless, they can be answered True or False even then.

	<i>True</i>	<i>False</i>
1. Other members of the family have to do without things because of ____.	<i>T</i>	<i>F</i>
2. Our family agrees on important matters.	<i>T</i>	<i>F</i>
3. The constant demands for care for ____ limit growth and development of someone else in our family.	<i>T</i>	<i>F</i>
4. I have given up things I have really wanted to do in order to care for ____.	<i>T</i>	<i>F</i>
5. ____ is able to fit into the social family group.	<i>T</i>	<i>F</i>
6. In the future, our family's social life will suffer because of increased responsibilities and financial stress.	<i>T</i>	<i>F</i>
7. I can go visit with friends whenever I want.	<i>T</i>	<i>F</i>
8. Taking ____ on vacation spoils the pleasure for the whole family.	<i>T</i>	<i>F</i>
9. The family does as many things together now as we ever did.	<i>T</i>	<i>F</i>
10. I get upset with the way my life is going.	<i>T</i>	<i>F</i>
11. There are many places where we can enjoy ourselves as a family when ____ comes along.	<i>T</i>	<i>F</i>
12. It is easy for me to relax.	<i>T</i>	<i>F</i>
13. I get almost too tired to enjoy myself.	<i>T</i>	<i>F</i>
14. There is a lot of anger and resentment in our family.	<i>T</i>	<i>F</i>
15. The constant demands to care for ____ limit my growth and development.	<i>T</i>	<i>F</i>
16. I feel sad when I think of ____.	<i>T</i>	<i>F</i>

	<i>True</i>	<i>False</i>
17. Caring for _____ puts a strain on me.	<i>T</i>	<i>F</i>
18. Members of our family get to do the same kinds of things other families do.	<i>T</i>	<i>F</i>
19. I rarely feel blue.	<i>T</i>	<i>F</i>
20. I am worried much of the time.	<i>T</i>	<i>F</i>

B4. Coping. There are many ways to try to deal with problems. Different people deal with things in different ways, but we are interested in how you have tried to deal with your problems. Each item says something about a particular way of coping. Please indicate the extent to which you have been doing what the item says **over the past 3 months**. Do not answer on the basis of whether it seems to be working or not- just whether or not you are doing it. Try to rate each item separately in your mind from the others

	<i>Haven't Been Doing this at All</i>	<i>Been Doing this a Little Bit</i>	<i>Been Doing this a Medium Amount</i>	<i>Been Doing this a Lot</i>
1. I've been turning to work or other activities to take my mind off things.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
2. I've been concentrating my efforts on doing something about the situation I'm in.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
3. I've been saying to myself "this isn't real".	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
4. I've been using alcohol or other drugs to make myself feel better.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
5. I've been getting emotional support from others.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
6. I've been giving up trying to deal with it.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
7. I've been taking action to try to make the situation better.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
8. I've been refusing to believe that it has happened.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
9. I've been saying things to let my unpleasant feelings escape.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
10. I've been getting help and advice from other people.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
11. I've been using alcohol or other drugs to help me get through it.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
12. I've been trying to see it in a different light, to make it seem more positive.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
13. I've been criticizing myself.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
14. I've been trying to come up with a strategy about what to do.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>
15. I've been getting comfort and understanding from someone.	<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>

	<i>Haven't Been Doing this at All</i>	<i>Been Doing this a Little Bit</i>	<i>Been Doing this a Medium Amount</i>	<i>Been Doing this a Lot</i>
16. I've been giving up the attempt to cope.	1	2	3	4
17. I've been looking for something good in what is happening.	1	2	3	4
18. I've been making jokes about it.	1	2	3	4
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4
20. I've been accepting the reality of the fact that it has happened.	1	2	3	4
21. I've been expressing my negative feelings.	1	2	3	4
22. I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
23. I've been trying to get advice or help from other people about what to do.	1	2	3	4
24. I've been learning to live with it.	1	2	3	4
25. I've been thinking hard about what steps to take.	1	2	3	4
26. I've been blaming myself for things that happened.	1	2	3	4
27. I've been praying or meditating.	1	2	3	4
28. I've been making fun of the situation.	1	2	3	4

B5. Feelings. Over the **past 30 days** how much of the time did **you** feel...

	<i>None of the Time</i>	<i>A Little of the Time</i>	<i>Some of the Time</i>	<i>Most of the Time</i>	<i>All of the Time</i>
1. Tired out for no good reason?	1	2	3	4	5
2. Nervous?	1	2	3	4	5
3. So nervous that nothing could calm you down?	1	2	3	4	5
4. Hopeless?	1	2	3	4	5
5. Restless or fidgety?	1	2	3	4	5
6. So restless that you could not sit still?	1	2	3	4	5
7. Depressed?	1	2	3	4	5
8. So depressed that nothing could cheer you up?	1	2	3	4	5
9. That everything was an effort?	1	2	3	4	5
10. Worthless?	1	2	3	4	5

B6. Marital Satisfaction. (if married or in long-term relationship)

Skip these 2 questions if you are single.

B6.A. How happy is your marriage/relationship?

1	2	3	4	5
Very unhappy	Unhappy	Mixed	Happy	Very Happy

B6.B. How much support do you feel you receive from your spouse/partner related to caring for your child with ASD?

1	2	3	4	5
Makes it More Difficult	Not Helpful	Somewhat or Sometimes Helpful	Very Helpful	Extremely Helpful, I depend on Them

B7. Personal Wellbeing. The following questions ask how satisfied you feel, on a scale from 0 to 10.

	<i>No Satisfaction at All</i>										<i>Completely Satisfied</i>
1. Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole?	0	1	2	3	4	5	6	7	8	9	10
2. How satisfied are you with your standard of living?	0	1	2	3	4	5	6	7	8	9	10
3. How satisfied are you with your health?	0	1	2	3	4	5	6	7	8	9	10
4. How satisfied are you with what you are achieving in your life?	0	1	2	3	4	5	6	7	8	9	10
5. How satisfied are you with your personal relationships?	0	1	2	3	4	5	6	7	8	9	10
6. How satisfied are you with how safe you feel?	0	1	2	3	4	5	6	7	8	9	10
7. How satisfied are you with feeling part of your community?	0	1	2	3	4	5	6	7	8	9	10
8. How satisfied are you with your future security?	0	1	2	3	4	5	6	7	8	9	10
9. How satisfied are you with your spirituality or religion?	0	1	2	3	4	5	6	7	8	9	10

C. About Your Family. The next section of the questionnaire asks about your family. This can include many people, including mother, father, partners, children, aunts, uncles, grandparents, etc. Please consider your “family” as people who think of themselves as part of your family (even though they may or may not be related by blood or marriage) and support and care for each other on a regular basis. Do not think about relatives who are only involved with your family every once in a while.

C3. Family Quality of Life. Please consider those people who think of themselves as part of your family and who support and care for each other **on a regular basis**. Please think about the past **3 months**.

How <u>satisfied</u> am I that...	<i>Very Dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither</i>	<i>Satisfied</i>	<i>Very Satisfied</i>
1. My family enjoys spending time together.	1	2	3	4	5
2. My family members help the children learn to be independent.	1	2	3	4	5
3. My family has the support we need to relieve stress.	1	2	3	4	5
4. My family members have friends or others who provide support.	1	2	3	4	5
5. My family members help the children with schoolwork and activities.	1	2	3	4	5
6. My family members have transportation to get to the places they need to be.	1	2	3	4	5
7. My family members talk openly with each other.	1	2	3	4	5
8. My family members teach the children how to get along with others.	1	2	3	4	5
9. My family members have some time to pursue our own interests.	1	2	3	4	5
10. Our family solves problems together.	1	2	3	4	5
11. My family members support each other to accomplish goals.	1	2	3	4	5
12. My family members show that they love and care for each other.	1	2	3	4	5
13. My family has outside help available to us to take care of special needs of all family members.	1	2	3	4	5

	<i>Very Dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither</i>	<i>Satisfied</i>	<i>Very Satisfied</i>
14. Adults in our family teach the children to make good decisions.	1	2	3	4	5
15. My family gets medical care when needed.	1	2	3	4	5
16. My family has a way to take care of our expenses.	1	2	3	4	5
17. Adults in my family know other people in the children's lives (friends, teachers, etc.).	1	2	3	4	5
18. My family is able to handle life's ups and downs.	1	2	3	4	5
19. Adults in my family have time to take care of the individual needs of every child.	1	2	3	4	5
20. My family gets dental care when needed.	1	2	3	4	5
21. My family feels safe at home, work, school, and in our neighborhood.	1	2	3	4	5
22. My family member with a disability has support to accomplish goals at school or at workplace.	1	2	3	4	5
23. My family member with a disability has support to accomplish goals at home.	1	2	3	4	5
24. My family member with a disability has support to make friends.	1	2	3	4	5
25. My family has good relationships with the service providers who provide services and support to our family member with a disability.	1	2	3	4	5

D. Services. Please tell us about the services you have received for your child.

D1. Services Access. Please tell us about the services and supports your child has received **over the past 3 months** (check all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Family doctor | <input type="checkbox"/> Behaviour therapist |
| <input type="checkbox"/> Pediatrician | <input type="checkbox"/> Case manager/service coordinator |
| <input type="checkbox"/> Emergency Room staff | <input type="checkbox"/> Social worker/counselor/family therapist |
| <input type="checkbox"/> Hospital admission | <input type="checkbox"/> Out-of-home respite care |
| <input type="checkbox"/> Psychiatrist | <input type="checkbox"/> In-home respite care |
| <input type="checkbox"/> Speech-language pathologist | <input type="checkbox"/> Specialized transportation services |
| <input type="checkbox"/> Occupational therapist | <input type="checkbox"/> Dentist |
| <input type="checkbox"/> Physical therapist | <input type="checkbox"/> Chiropractor |
| <input type="checkbox"/> Psychologist | <input type="checkbox"/> Alternative practitioners (e.g., naturopath, etc.) |

D2. Satisfaction with Services

In the last three months...	<i>Very Dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither</i>	<i>Satisfied</i>	<i>Very Satisfied</i>
1. How satisfied have you been by services for your child with ASD?	1	2	3	4	5
2. How satisfied have you been by services for you and your family?	1	2	3	4	5

D3. Services Fit with Needs

In the last three months...	<i>Not at all</i>	<i>A bit</i>	<i>Somewhat</i>	<i>Mostly</i>	<i>Completely</i>
1. Have the services you have received been a good match for your child's needs?	1	2	3	4	5
2. Have the services you have received been a good match for you and your family?	1	2	3	4	5

D4. Services- Comments. Do you have any comments about the quality or quantity of the services you have received and/or needed, at any time?

E. Life Events. Over the past **3 months**, have any of the following events occurred in your immediate family?

Has your family experienced (please check all that apply):

- ☐ Separation
- ☐ Divorce
- ☐ Marital reconciliation
- ☐ Marriage
- ☐ Pregnancy
- ☐ Other relative moved into household
- ☐ Moved to a new location
- ☐ Promotion at work
- ☐ Began new job
- ☐ Trouble with superiors at work
- ☐ Serious illness or injury
- ☐ Serious illness of close relative or friend
- ☐ Recent immigration
- ☐ Housing problems
- ☐ Legal problems
- ☐ Problems with police or other authority
- ☐ Death of immediate family member
- ☐ Death of close family friend
- ☐ Went deeply into debt
- ☐ Income increased substantially (20% or more)
- ☐ Income decreased substantially
- ☐ Alcohol or drug problem
- ☐ Serious mental health problems

Has your child with ASD (please check all that apply):

- ☐ Entered new school
- ☐ Been suspended or expelled from school
- ☐ Transitioned to middle school
- ☐ Transitioned to high school
- ☐ Transitioned out of high school
- ☐ Experienced another difficult transition. Please specify: _____
- ☐ Had difficulties with teacher. Please specify _____
- ☐ Lost a good Educational Assistant or Teacher
- ☐ Lost a good paid caregiver (e.g. a nanny, babysitter)
- ☐ Diagnosis of another child/family member with disability

G. Additional Comments. Do you have any other comments that you would like to make?

END OF SURVEY

Thank you for taking time to complete this survey!

Appendix H: Group Descriptions

Note: Group and caregiver involvement descriptions as per document provided by service agency, used by researcher to determine “Involvement Category”

Group Title	Group Description	Caregiver Involvement	Involvement Category
Picture Exchange Communication System	An introduction to communication through use of a picture exchange system. Participants will learn to use a picture exchange system to mand for desired items. Participants will work on increasing the number of items he/ she can request, increasing the frequency of requesting as well as generalization of pictures and items. Group focus includes: the physical exchange, increasing distance, developing persistence, picture discrimination, decreasing the need for external prompting to emit mands.	Parents/ Caregivers are required to attend each session with the participant as well as a 1-hour introduction to the group during session 1, and a 1-hour feedback and review on the final session. Parents/ caregivers provide reinforcers specific to their child. Parents/caregivers are expected to maintain and generalize this progression at home and in community settings relevant to the participant.	High
Basic Communication	An introduction to communication through use of the participants' vocal repertoire. Participants will learn to mand for desired items through verbal means. Participants will work on increasing the number of items he/ she can request, increasing the frequency of requesting as well as generalization of the items he/she can request. Group focus includes prompted vocal manding (with an echoic prompt), independent manding (without an echoic prompt), generalized vocal manding, frequency of vocal manding, developing persistence, decreasing the need for external prompting to emit vocal mands (echoics).	Parents/ Caregivers are required to attend each session with the participant as well as a 1-hour introduction to the group during session 1, and a 1-hour feedback and review on the final session. Parents/ caregivers provide reinforcers specific to their child. Parents/caregivers are expected to maintain and generalize this progression at home and in community settings relevant to the participant.	High
Language 1	Participants increase the complexity of his/ her manding as well as expand his/ her communication skills to include verbal behaviour beyond manding. Group focus includes increasing the participants manding repertoire; decreasing the need for external prompting to emit mands; increasing variety, frequency and generalization of manding repertoire; introducing and increasing the participants	Parents/ caregivers provide reinforcers specific to their child where appropriate. Parents/ caregivers receive information specific to their child's progression within the group and are expected to maintain and generalize this progression at home and in community settings relevant to the participant.	Low

Group Title	Group Description	Caregiver Involvement	Involvement Category
	tacting repertoire; basic listener responding (including responding to name, identifying objects and pictures and performing actions when instructed).		
Language 2	Participants increase the complexity of his/ her manding, tacting and listener responding behaviours as well as expand his/ her communication skills to include intraverbal responding. Group focus includes: increasing the participants' manding repertoire to include manding for actions and missing items; manding using 2 or more words (pour juice, open door); expanding the participants tacting repertoire to include an increase in the number of items he/she can label, generalized responding and verb-noun or noun-verb combinations; expanding listener responding to include an increase in the number of items he/ she can identify and actions he/ she can perform, generalized listener responding, and responding to verb-noun or noun-verb instructions; basic intraverbal responding such as fill-ins of songs, actions and animal sounds, responding to "What's your name", answering what, who, and where questions; beginning to identify items based on their function, feature or class through fill-ins and "Wh" questions.	Parents/ caregivers provide reinforcers specific to their child where appropriate. Parents/ caregivers receive information specific to their child's progression within the group and are expected to maintain and generalize this progression at home and in community settings relevant to the participant.	Low
Language 3	Participants increase the complexity of their existing manding, tacting, listener responding, intraverbal and feature, function, class repertoire. Participants also continue to improve his/ her linguistic structure. Group focus includes: manding using "Wh" questions; giving instructions/directions; manding for others to attend to him/her; advanced tacting including prepositions, pronouns and adjectives; listener responding including following directions with prepositions as well as following multiple step directions; expanding both tacting and	Parents/ caregivers provide reinforcers specific to their child where appropriate. Parents/ caregivers receive information specific to their child's progression within the group and are expected to maintain and generalize this progression at home and in community settings relevant to the participant.	Low

Group Title	Group Description	Caregiver Involvement	Involvement Category
	listener responding function, feature and class to include identifying items based on multi-components; answering questions regarding a story as well as describing various events, videos, stories etc.; improving syntax and language structure through use of correct plurals, possession, tense markers and noun and verb modifiers (where appropriate).		
ImPACT	Participants are taught social engagement, language, imitation and play skills through a mix of developmental and naturalistic intervention strategies. Group focus and topics of instruction include: set up your home for success; follow your child's lead; modeling and expanding language; communicative temptations; prompting and reinforcement; teaching your child expressive language; teaching your child receptive language; teaching your child social imitation; teaching your child to play.	Parents/caregivers are responsible for attending six, 2-hour group sessions without his/her child and six, 30-45 minute individual coaching sessions (group sessions and coaching sessions alternate each week). No children first session. Parents are also required to practice the skills learnt in the group and coaching sessions throughout the week at home or in community settings relevant to the child.	High
Social Skills 1	Participants are taught reciprocity, language, imitation and play skills as they relate to social engagement with his/her peers. Group focus includes: joint attention/ attending including looking at and orienting to others, following eye gaze, point or gestures, imitating simple motor actions of peers, gaining the attention of others and responding to bids for attention from a peer; greetings; social play including simple group games (Simon says, red light/green light), sharing and turn taking; expanding his/her manding repertoire to include manding from a peer, manding for attention of a peer and manding for information from a peer; listener responding including responding to his/her name, follow a simple motor action when instructed, and responding to instructions given to a group; basic intraverbal responses to a peer including answering basic social questions, answering yes/no questions and answering simple "Wh" questions; group skills including	Parents/ caregivers provide reinforcers specific to their child where appropriate. Parents/ caregivers receive information specific to their child's progression in the form of progress notes and parent handouts and are expected to maintain and generalize this progression at home and in community settings relevant to the participant.	Low

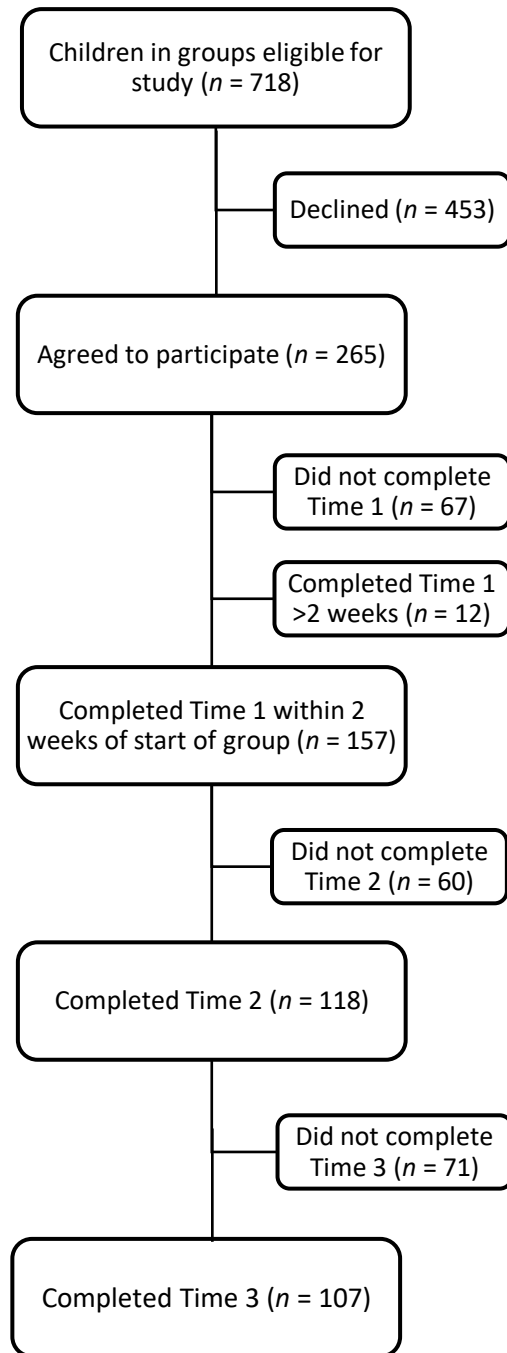
Group Title	Group Description	Caregiver Involvement	Involvement Category
	singing songs, show and tell, waiting, following group rules, responding to delayed reinforcement, following a schedule, preparing and eating snack.		
Social Skills 2	Participants learn conversation skills as they relate to greeting peers, initiating and maintaining play and participating in co-operative play including turn-taking and reciprocal imitation. Group topics of instruction include greetings & returning greetings; Introducing yourself; initiating a conversation; joining in play; ending play; relaxation techniques. Participants also practice group skills such as singing songs, participating in gross motor games and activities, waiting, transitioning between activities, turn taking, following group rules, responding to delayed reinforcement, following a schedule, and preparing and eating snack.	Parents/Caregivers are invited to attend 3 didactic sessions and 2 guided observation sessions: Week 2: Didactic 2hours; Week 3 or 4: guided observation 30 minutes; Week 5: Didactic 2 hours; Week 6 or 7: guided observation 30 minutes; Week 8: Didactic 2 hours.	High
Social Skills 3	Participants determine which of their existing social skills he/she would like to improve upon and which skills he/she can serve as a model/mentor to the other group members. This social skills group is comprised of didactic teaching, role play, discussion and practice of various advanced social skills. Group topics of instruction include greetings and returning greetings; introducing yourself; initiating and joining in conversations; responding to bids of conversation from others; appropriate vs inappropriate conversation topics; non-verbal conversations including reading body language; responding to non-verbal cues; recognizing emotions in yourself and others; relaxation techniques; friendship; hanging out. Participants also practice group skills such as participating in gross motor games and activities, waiting, transitioning between activities, turn taking in games and discussion, following group rules, problem solving as part of a group, responding	Participants complete activities and are given homework which may require parent/caregiver input and assistance, in turn providing the parent/caregiver with information regarding the areas the participant would benefit from support.	Low

Group Title	Group Description	Caregiver Involvement	Involvement Category
	to delayed reinforcement, following a schedule, and preparing and eating snack.		
Children's Friendship Training	Evidence-based parent-assisted social skills intervention for motivated children with emerging social skills who are interested in learning ways to help them make and keep friends. During each group session children are taught important social skills and are given the opportunity to practice these skills during real play activities (e.g. playing sports, board games, etc.). Group topics of instruction include being a good communicator; conversation skills; being turned down; slipping in; how to be a good sport through group games; how to set up play dates; how to resist teasing; respect towards adults; Bullying.	Parents are taught how to assist their children in making and keeping friends by providing feedback through coaching during weekly socialization homework assignments. Parents also participate in concurrent parent sessions to effectively coach and support their child (Parents must attend majority of the sessions)	High
PEERS Modified	The primary focus in this group is to address the development of complex and advanced social skills such as how to make and keep friends; using technology; having get togethers; learning the distinction between public information and private information; dealing with bullying and teasing.	Parents are invited to participate in a 15-minute reunification at the end of each group to discuss the lesson that was taught as well as the expectations for homework and practice during the week.	Low
Girls Group 2	Participants determine which of their existing health and hygiene skills she would like to improve upon and/or which new skills she needs the most practice. This ADL group is comprised of didactic teaching, role play, discussion and practice of various health and hygiene skills. Group topics of instruction include public vs. private, including behaviours, places and body parts; body changes through puberty; showering and washing hair; using deodorant; dental care; choosing the right clothes for the right place; wearing a bra; menstruation; touching rules; saying no.	Participants complete activities and are given homework which may require parent/ caregiver input and assistance, in turn providing the parent/caregiver with information regarding the areas the participant would benefit from support. Parents/caregivers are expected to maintain and generalize the skills taught as part of the group at home and in community settings relevant to the participant.	Low
Boys Group 2	Participants determine which of their existing health and hygiene skills he would like to improve upon and/or which new skills he needs the most practice. This ADL group is	Participants complete activities and are given homework which may require parent/caregiver input and assistance, in turn providing the	Low

Group Title	Group Description	Caregiver Involvement	Involvement Category
	comprised of didactic teaching, role play, discussion and practice of various health and hygiene skills. Group topics of instruction include public vs. private including behaviours, places and body parts; body changes through puberty; showering and washing hair; using deodorant; dental care; shaving; clothing including situation and weather appropriate clothing, caring for clothing and wearing clean clothing; erections and masturbation; illness and injury; touching rules; saying no and responding to no.	parent/caregiver with information regarding the areas the participant would benefit from support. Parents/caregivers are expected to maintain and generalize the skills taught as part of the group at home and in community settings relevant to the participant.	
Safety and Independence in the Kitchen 1	The primary focus of this early learners group will be to address the development of skills related to kitchen safety, food preparation and clean up skills. Group topics of instruction include hand washing; table manners; preparing simple snacks; clean up skills (e.g. sweeping, wiping, washing dishes, etc.); toaster safety; microwave safety.	Parents will be required to participate in a coaching component at the beginning and end of each two-hour session. Prior to the initial group parents will be required to attend a 2-hour session to familiarize themselves with strategies that will be used and the expectations of the homework outcomes and generalization strategies.	Low
Best Foot Forward - Working Together	The primary focus of this advanced group will be to address the development of skills related to participating in community settings, organization and pre-vocational skills. Group topics of discussion include: getting to know one another; identifying one's own strengths or interests; active listening skills; starting a conversation; conversation skills with different people; getting to know your conversational partner; perspective taking; respecting another's point of view; negotiation skill; getting along with others; working cooperatively in a group.	Participants complete activities and are given homework which may require parent/caregiver input and assistance, in turn providing the parent/caregiver with information regarding the areas the participant would benefit from support. Parents/caregivers are expected to maintain and generalize the skills taught as part of the group at home and in community settings relevant to the participant.	Low
Best Foot Forward - Employment	The primary focus of this advanced group will be to address the development of skills related to participating in community settings, organization and pre-vocational	Participants complete activities and are given homework which may require parent/caregiver input and assistance, in turn providing the	Low

Group Title	Group Description	Caregiver Involvement	Involvement Category
and Volunteerism	skills. Group topics of discussion include telephone etiquette; technology etiquette; organizational skills; working with your strengths; choosing a job/volunteer position; applying for a social insurance number; conducting a job search; networking; writing a resume; preparing for the interview; identifying positive work behaviours.	parent/caregiver with information regarding the areas the participant would benefit from support. Parents/caregivers are expected to maintain and generalize the skills taught as part of the group at home and in community settings relevant to the participant.	
Getting Ready for Group	Participants are taught basic group engagement skills, understanding basic contingencies, and caregiver separation through a mix of developmental and naturalistic intervention strategies. Group focus and topics of instruction include transition away from caregiver, understanding basic visual schedules, understanding contingencies (e.g., first/then), using a token system, following simple directions from group leader; teaching your child to be with other children and/or youth.	Parents/Caregivers are invited to attend 3 didactic sessions and 2 guided observation sessions: Week 2: Didactic 2 hours; Week 3 or 4: guided observation 30 minutes; Week 5: Didactic 2 hours; Week 6 or 7: coaching in session 30 minutes; Week 8: Didactic 2 hours"	High
Take a Deep Breath	Through various books about emotions/feelings, participants are taught to identify emotions both receptively and expressively. They are given strategies to assist them to understand when they are feeling upset, angry, excited happy or sad (i.e., stress-o-meter). They are also taught how to engage in activities such as deep breathing and mind/body awareness activities; identify emotions; label emotions; learn coping strategies to reduce reactions to stressful events (e.g., breathing exercises, relaxations exercises, redirection to calming activities); learn preventative strategies to reduce overall stress levels.	Parents/ Caregivers are responsible for participating in 3 workshops and 2 guided observations. The purpose of this is so the parent/caregiver can assist the child in practicing the strategies learned in the home environment.	High

Group Title	Group Description	Caregiver Involvement	Involvement Category
Secret Agent Society	Multi-component social skills intervention designed to improve emotional understanding and social skills. The program includes an animated computer game that teacher children emotion recognition, emotion regulation and social competence 9 weekly group sessions to apply the computer game content to everyday contexts. Parent training sessions (last 30 minutes of each group) to teach parents how to support their children in using these skills at home and in school. Weekly teacher tip sheet to help teachers encourage children's use of the skills taught in group to the classroom and playground. Target Skills: understanding that emotions exist on a continuum; identifying emotion from physical body clues; identifying simple and complex emotions from face, body and voice clues; coping with feelings of anxiety and anger; understanding what it means to be a good friends; talking and playing with others; coping with making mistakes, changes in routine and feelings of confusion or uncertainty; solving social problems; distinguishing accidents and friendly jokes from intentional and nasty ones; dealing with bullying and teasing	Parents/Caregivers must attend each session. Each group there will be work with parents and their children as well as parents separately. It is important that one consistent parent come each week as the material builds on itself, however, if more than one parent would like to attend that is fine. There will be homework.	High

Appendix I: Participant Flowchart

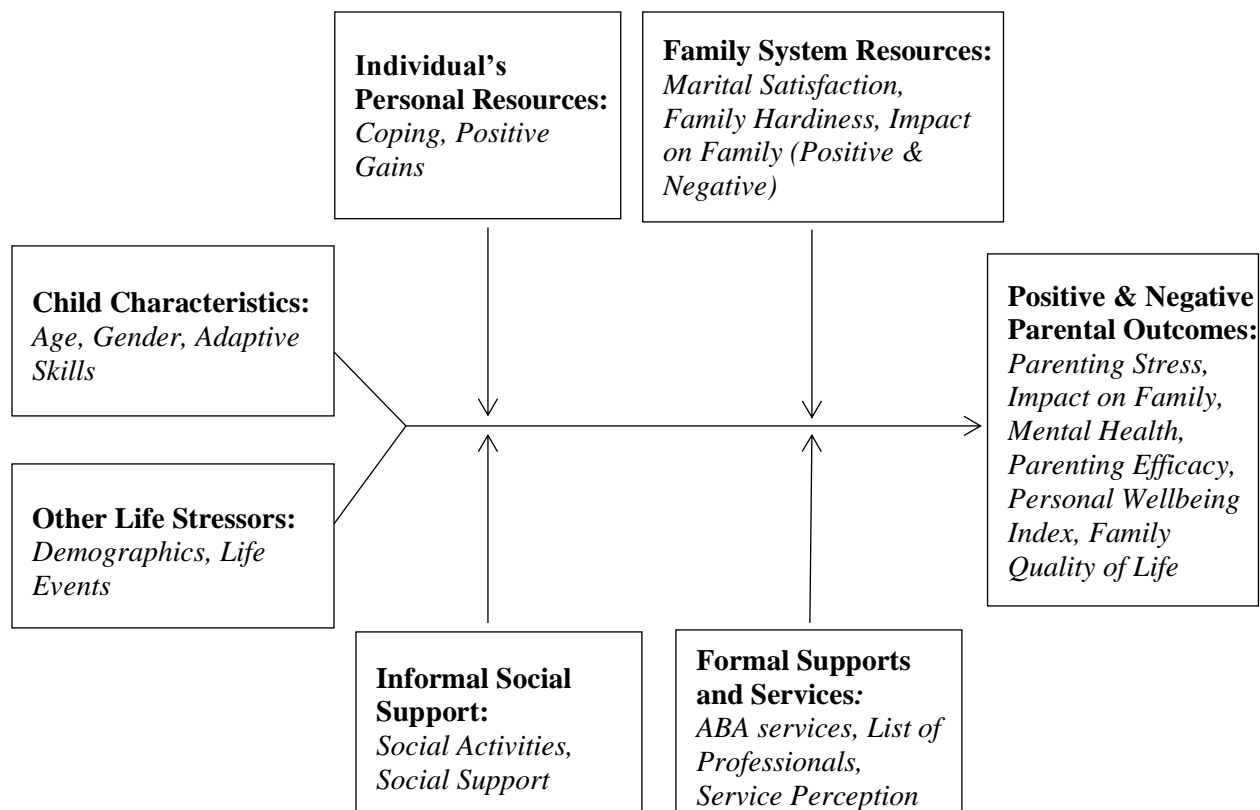
Note: 178 participants completed at least 1 questionnaire: 88 completed all three questionnaires, 41 completed two questionnaires, and 49 completed one questionnaire (of any timepoint)

Appendix J: Questionnaire Arrangement

Questionnaire Arrangement within Perry Model of Stress (2004)

STRESSORS

OUTCOMES



Appendix K: List of Measures

Model Construct	Section within Questionnaire	Measure Citation	Number of Items	Timepoints
Child Characteristics (child's age, gender, birth order, adaptive behaviour)	Child's Date of Birth (A1)	N/A	1	All Timepoints
	Child's gender (A2)	N/A	1	All Timepoints
	Child's birth order (A3)	N/A	1	Time 1
	Child's Communication & Social Skills (A4) & Child's Daily Living Skills (A5)	Perry, A., Taheri, A., Ting, A., & Weiss, J. (2015). The GO4KIDDS Brief Adaptive Scale. <i>Journal of Applied Research in Intellectual Disabilities</i> , 28, 594-597.	7	Time 1
Other Life Stressors (socioeconomic status, life events)	Life Events (E)	Perry, A. & Weiss, J. (unpublished questionnaire) GO4KIDDS Extended Survey.	33	All Timepoints
	About You and Your Family (F)	Perry, A. & Weiss, J. (unpublished questionnaire). GO4KIDDS Extended Survey.	18	Time 1
Individual's Personal Resources (coping, psychological factors)	Parenting Efficacy	Koren, P.E., DeChillo, N., & Friesen, B.J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. <i>Rehabilitation Psychology</i> , 37, 305-321.	12	All Timepoints
	Positive gain (B3)	Pit-ten Cate, I.M. (2003). Positive gain in mothers of children with physical disabilities. Unpublished doctoral dissertation. Southampton, UK: University of Southampton.	7	Time 1
	Coping (B4)	Carver, C.S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. <i>International Journal of Behavioural Medicine</i> , 4, 92-100.	28	All Timepoints
Family System Resources (marital satisfaction, family hardiness, family quality of life)	Family Hardiness (C2)	Gardner, D.I., Huber, C.H., Steiner, R., Vazquez, L.A., & Savage, T.A. (2008). The development and validation of the inventory of family protective factors: A brief assessment for family counselling.	4	Time 1
	Marital Satisfaction (B6)	Perry, A. & Weiss, J. (unpublished questionnaire). GO4KIDDS Extended Survey.	2	All Timepoints

Model Construct	Section within Questionnaire	Measure Citation	Number of Items	Timepoints
	Impact on Family (C1)	Trute, B. & Hiebert-Murphy, D. (2002). Family adjustment to childhood developmental disability: A measure of parent appraisal of family impacts. <i>Journal of Pediatric Psychology</i> , 27, 271-280.	20	Time 1
Informal Social Support	Social Support (C4)	Gleeson, J.P., Hsieh, C., Anderson, N., Seryak, C., Wesley, J., Choi, E.H.,...Robinson, J. (2008). Individual and social protective factors for children in informal kinship care. Retrieved from http://jacsw.uic.edu/kincare/research/FINALREPORT_2_-26-08.pdf (adapted Family Support Scale- Dunst, C.J., Trivette, C.M., & Deal. A.G. (1988). Enabling and empowering families: Principles and guidelines for practice. Cambridge, MA: Brookline Books)	19	Time 1
Formal Supports and Services	Service Access (D)	N/A- created for this study	2	All Timepoints
Positive & Negative Parent Outcomes	Parenting Stress (B2)	Friedrich, W.N., Greenberg, M.T., & Crnic, K. (1983). A short-form of the Questionnaire on Resources and Stress. <i>American Journal of Mental Deficiency</i> , 88, 41-48.	20	All Timepoints
	Feelings (B5)	Kessler, R.C., Barker, P.R., Colpe, L.J., Epstein, J.F., Gfroerer, J.C., Hiripi, E.,...Zaslavsky, A.M. (2003). Screening for serious mental illness in the general population. <i>Archives of General Psychiatry</i> , 60, 184-189.	10	All Timepoints
	Personal Wellbeing (B7)	International Wellbeing Group. (2013). Personal Wellbeing Index: 5 th Edition. Melbourne: Australian Centre on Quality of Life, Deakin University.	9	All Timepoints
	Family Quality of Life (C3)	Hoffman, L., Marquis, J., Poston, D., Summers, J.A., & Turnbull, A. (2006). Assessing family outcomes: psychometric evaluation of the Beach Centre Family Quality of Life Scale. <i>Journal of Marriage and Family</i> , 68, 1069-1083.	25	All Timepoints