The Impact of Behavioral Activation on Maternal Well-Being in Mothers of Children with Autism Spectrum Disorder

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The Impact of Behavioral Activation on Maternal Well-Being in Mothers of Children with Autism Spectrum Disorder

Christine Horne McAllister

A thesis submitted to the faculty of Brigham Young University in partial fulfillment of the requirements for the degree of Educational Specialist

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ABSTRACT

The Impact of Behavioral Activation on Maternal Well-Being in Mothers of Children with Autism Spectrum Disorders

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Autism Spectrum Disorder (ASD) is a developmental disorder known for deficits in language and social skills. It is often associated with maladaptive behaviors. Studies have indicated that these behaviors in children lead to increased stress, anxiety, and depression in mothers. This study examines the effects of parent-implemented Positive Behavior Support (PBS) and behavioral activation (BA) on reducing problem behaviors and increasing maternal wellness. The single subject study was conducted with three mothers (between the ages of 30 and 45) and their three children (between the ages of 5 and 7) with autism spectrum disorder. The results of this study demonstrate that while PBS implementation does reduce problem behaviors, it does not significantly impact maternal well-being. Results indicated that two of the three mothers were able to implement PBS interventions and their children demonstrated significant behavioral improvements. These mothers also engaged in high levels of valued activities both at baseline and during intervention and showed few depression symptoms. The third mother was not able to implement the interventions and her child demonstrated little behavioral progress. This mother showed signs of depression and did not make gains in this area. Further research may want to examine the relationship between behavioral activation and respite care, as well as the role of socioeconomic status.

Keywords: autism, maternal depression, problem behaviors, behavioral activation, positive behavior support, respite care
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CHAPTER 1: INTRODUCTION

Childrearing is shown to lead to decreased well-being in parents (Evenson & Simon, 2005), but when combined with the challenges associated with parenting a child with Autism Spectrum Disorder (ASD), the impact on well-being is even greater (Allik, Larsson, & Smedje, 2006). ASD is a neurodevelopmental disorder that presents with deficits in language and social abilities. It is commonly associated with repetitive and problem behaviors. The Center for Disease Control estimates that 1 in 68 children in the United States have ASD (Baio, 2014).

ASD is often accompanied by challenging and maladaptive behaviors. These behaviors can include physical aggression, non-compliance and tantrums (Small, 2007). These behaviors create challenges for parents and families. Along with experiencing high levels of stress, it becomes difficult for parents to manage daily tasks and activities. Many parents begin to withdraw socially (Horner, Carr, Strain, Todd, & Reed, 2002). Parents of children with ASD not only experience higher levels of stress and decreased mental health, but also experience decreased physical health (Allik et al., 2006). This is particularly true of mothers of children with ASD (Benjak, 2011; Lucyshyn et al., 2007).

Mothers of children with ASD have been shown to have lower overall life satisfaction and more feelings of anxiety and depression when compared with both mothers of children with other disabilities and children without disabilities (Benjak, 2011; Lucyshyn et al., 2007). Mothers are the primary caregivers of children with ASD and spend more time exposed to challenging behaviors accompanying ASD (Rao & Beidel, 2009). These behaviors may be a contributor in maternal distress (Phetrasuwan & Miles, 2009; Rao & Beidel, 2009).

Positive Behavior Support (PBS) has been used as a means to reduce challenging behaviors in children with ASD (Dunlap & Fox, 2011). More specifically, parent-implemented
PBS has been effective in reducing problem behaviors in children with ASD; however, a review of the studies on PBS prior to 1996 revealed that less than 1% of studies using PBS included a quality of life measure (Carr et al., 1999). After this analysis, some additional research was focused on the effect of PBS on quality of life, but mainly quality of life for the child or family unit as a whole. Feldman, Condillac, Tough, Hunt, and Griffiths (2002) did find improvements in quality of life after PBS interventions, but these quality of life measures were inclusive of the whole family, not parent or parents specifically. The National Research Council suggests that a top priority for the nation should be finding interventions that not only help children, but also support the parents (National Research Council, 2001). A multifaceted intervention approach targeting mother and child may be useful in increasing quality of life and well-being for both.

Behavioral activation (BA) is a program that focuses on increasing value-oriented activities to reinforce positive feelings and has been successful in treating depression in different settings and populations (Cuijpers, van Straten, & Warmerdam, 2006). BA could be an effective treatment to reduce the stress in mothers of children with ASD; when coupled with parent-implemented PBS it could be a method that meets the needs identified by the National Research Council, for both mother and child.
CHAPTER 2: LITERATURE REVIEW

In the 1970 and 1980’s, several studies demonstrated that raising children leads to decreased psychological well-being in adult caregivers and parents. A study conducted by McLanahan and Adams (1989) is an illustration of these findings. They analyzed the data from the “Americans View Their Mental Health Surveys,” to find that parenting has a negative impact on adult well-being in several dimensions including anxiety, happiness and self-satisfaction. More recently Evenson and Simon (2005) examined the relationship between parenthood and depression and found results similar to the early body of research. They found that, in general, parents report significantly higher rates of depression than non-parents. This was true even when socio-demographic and status characteristics were held constant.

Parenting in general can be stressful, but when amplified by the challenges of ASD, higher rates of not only stress but also depression and anxiety are seen (Baker-Ericzen et al., 2005; Rao & Beidel, 2009). Primary caregivers of children with ASD consistently report higher levels of stress than parents of typically developing children (Baker-Ericzen et al., 2005; Rao & Beidel, 2009). Additionally, in a self-report survey of 108 mothers of children with autism, mothers who reported higher levels of stress also reported higher levels of depressive symptoms (Phetrasuwan & Miles, 2009).

**Autism Spectrum Disorder (ASD)**

ASD is a neurodevelopmental disorder characteristically known for deficits in communication and social abilities, along with repetitive behaviors. It is found worldwide and crosses all racial, ethnic, cultural, and social boundaries (Belfer, 2008). ASD is typically manifest in the first years of life. In the last 40 years the prevalence of autism has increased greatly. The US Centers for Disease Control and Prevention estimate that, as of 2014, 1 in 68
children have an Autism Spectrum Disorder (ASD). This amount is more than 10 times what was estimated 4 decades ago. While ASD is four times more common in males than females, both genders are affected (Baio, 2014).

Children with ASD often demonstrate maladaptive and challenging behaviors. These can include, but are not limited to, physical aggression, tantrums, noncompliance, property destruction, and other disruptive behaviors (Small, 2007). These behaviors create unique parenting challenges. They limit family functionality and community involvement in many cases. They have also been shown to stifle feelings of personal growth in parents. Along with experiencing high levels of stress, many parents aren't able to efficiently complete daily activities and begin to avoid social activities as well (Horner et al., 2002). In studies that focused directly on parents of children with autism, it was reported that the parents experienced a lower standard of living, decreased mental and physical health, and lower quality close relationships (Allik et al., 2006; Benjak, 2011). Benjak (2011) surveyed 346 parents using a Subjective Quality of Life (SQoL) measure called the Personal Well-being Index (PWI). This particular measure focuses on seven domains that, when combined, are representative of overall life satisfaction. Participants included 177 parents of children with ASD and 169 parents of children without disabilities (control participants). It was found that parents of children with ASD had a lower overall SQoL, when compared with parents of children without disabilities. Furthermore, the parents of children with ASD had lower scores than the control parents in all seven domains represented by the SQoL, including achievement in life, community connectedness and future security. These factors, as well as those discussed earlier, combine to increase stress in parents of children with ASD and reduce overall well-being.
In a study spanning 10 years, Lucyshun et al. (2007) found that child problem behavior led to parent feelings of anxiety and depression. Olsson and Hwang (2001) also looked at depression rates in parents of children with autism and parents of children with intellectual disability. Compared to parents of children without autism or intellectual disability (control group) who had a mean score of 5 on the Beck Depression Inventory (BDI), mothers of children with autism had a mean depression score of 11.8. Scores on the BDI range from 0 to 63, with scores over 10 indicating mild depression. The scores from the mothers represent minimal depression in control mothers versus mild depression in mothers of children with autism.

Another notable finding of the study was the discrepancy between the scores of mothers and fathers of children with autism. Fathers of children with ASD had a mean score of 6.2, which, although higher than control parents, still falls in the minimal depression range. (Olsson & Hwang, 2001). This finding illustrates that, while both parents of children with autism are at greater risk for depression, mothers are at greater risk than fathers. When looking at 89 parents of preschool age children with autism, it was found that mothers reported significantly higher rates of depression than fathers (Hastings et al., 2005). Dabrowska and Pisula (2010) studied parents of children with ASD, parents of children with Down syndrome, and parents of typically developing children. They found that parents of children with ASD reported higher levels of stress. The mothers’ levels were higher than the fathers’ levels. They used the Questionnaire of Resources and Stress and found that the higher the dependency of the child, the more limits there were on family opportunities. Allik et al. (2006) surveyed 61 parents of children with ASD and 59 parents of typically-developing children. Mothers of children with ASD reported lower physical health than the mothers of the control group and the fathers of both groups. A
relationship was also found between a child's behavioral characteristics and a mother’s well-being; increased behavioral difficulties lead to decreased maternal well-being.

Mothers are the primary caregivers of children with ASD; they spend more time with the children, and as a result, are exposed to challenging behavior more frequently. These behaviors may contribute to maternal stress more than the diagnosis itself. (Phetrasuwan & Miles, 2009; Rao & Beidel, 2009). A child with ASD may present with behaviors such as screaming, physically resisting tasks, running away and other disruptive actions. As a result of these behaviors, the family has to do almost everything for the child, such as taking care of daily necessities including personal hygiene care, eating and dressing. This can be a significant cause of stress (Lucyshyn et al., 2007). Hastings et al. (2005) found, when looking at 89 parents of children with autism, that maternal stress was significantly related to the behavior of the child. This was a replication of previous studies with similar results. Studies have looked at the impact of parent-implemented positive behavior support plans for children with ASD. In an analysis of parent-implemented behavior support plans, a relationship was found between the quality of life reported by parents and reductions in their children's challenging behaviors (Small, 2007).

**Positive Behavior Support (PBS)**

PBS is a tiered, assessment-driven approach to the prevention of problem behaviors (Powell, Dunlap, & Fox, 2006). It is a process that includes identifying problem behaviors, conducting a Functional Behavior Assessment (FBA) and then implementing a behavior support plan. FBA employs a group of procedures that seek to explain the function and purpose of a behavior. This type of assessment attempts to determine the antecedents and consequences of behavior to explain how the environment is reinforcing the behavior. There are three main
functions of behavior associated with FBA: attention or access to something desired, escape or avoidance of something undesired, or sensory stimulation (Martens & Lambert, 2014).

Finding practices that support parents' ability to manage the challenging behaviors of their children with ASD has been identified as an area of particular importance (Small, 2007). Research supports the efficacy of PBS as a method for reducing challenging behaviors in children (Dunlap & Fox, 2011). Current research focusing on parent-implemented PBS has also shown positive outcomes. One example of empirical support for the efficacy of this method is the work of Estes et al. (2012), which looked at 48 children with an ASD diagnosis ranging from 18 to 30 months old. The participants were randomly assigned to a community intervention group or the Early Start Denver Model (ESDM) group. The ESDM is a model that uses the principles of applied behavior analysis and focuses deeply on parent involvement in the intervention. After two years of intervention, the ESDM group was found to have greater brain and behavioral development, promoting positive long-term outcomes.

The National Research Council identified the inclusion of parents, as treatment providers, as an essential component of autism intervention (National Research Council, 2001). Further empirical support of this method is shown by Frea and Hepburn (1999). Parents of children with autism were taught how to conduct a functional assessment and intervene for their child’s extreme problem behaviors. Findings illustrated lower rates of problem behaviors following FBA training and parent-implemented interventions. Vaughn, Wilson, and Dunlap (2002) worked with a seven-year-old with autism. The child’s mother implemented a plan to reduce inappropriate behaviors in a fast food restaurant. The findings showed that the parent-implemented PBS not only reduced problem behaviors in the child, but also increased positive behaviors in the mother, such as smiling at the child during play, holding the child on her lap,
etc. Barton and Fettig (2013) analyzed 13 studies involving parent-implemented functional assessment interventions. They found that in all 13 studies, parent-implemented FA-based interventions were successful in reducing challenging child behavior.

Although parent-implemented PBS has been shown to reduce problem behaviors in children, little research has considered the impact of parent-implemented PBS on maternal well-being. Estes et al. (2009) suggest that if we are to improve outcomes for parents, as well as children with developmental disabilities, psychological distress is relevant. A trend is beginning to emerge in intervention research to work with parents and caregivers of children with ASD, instead of just the children themselves (Jones, Hasting, Totsika, Keane, & Rhule, 2014). In a study looking at the mothers of 215 preschool-aged children, they fell into one of five groups: mothers of typically developing children, mothers of children with ASD, mothers of children with undifferentiated developmental delays, mothers of children with Down syndrome, and mothers of children with cerebral palsy. The children with cerebral palsy and ASD were both reported to have the highest levels of behavior problems. Overall, the levels of stress paralleled the levels of behavior, but mothers of children with ASD reported the highest levels of stress. It appeared that there were other characteristics contributing to the stress of mothers of children with ASD, outside of behavior problems, that have not yet been identified (Eisenhower, Baker, & Blancher, 2005). Due to these outside characteristics, changing the behavior of children with ASD alone may not fully reduce the stress, or improve the well-being, of the mothers.

The National Research Council (2001) identifies developing interventions that are not only appropriate for children, but that support the needs of parents, as a strong national priority. In an article by Phetrasuwan and Miles (2009), the top four sources of stress for parents of children with autism were listed. Two of the four had to do with parent needs. The parents
reported they struggled to find time for their own activities and interests, and struggled to give themselves permission to engage in activities of their choice. A multifaceted approach, including parent-implemented PBS and Behavioral activation (an intervention that focuses on parents engaging in chosen activities) may be useful in addressing both child and parent quality of life and wellness.

**Behavioral Activation**

Behavioral activation (BA) is a behavior treatment for depression based on research that found a correlation between an individual's mood and the number of activities they engage in that they consider pleasant and important (or valued). It was found that individuals participating in more pleasant activities experienced better moods (Lewinsohn & Graf, 1973). BA examines how an individual responds to their environment after they become depressed. It posits that if people engage in pleasant activities that they value, they will gain reinforcement from those activities and continue engaging in them, which will reduce depression (Jacobson, Martell, & Dimidjian, 2001). It further suggests that as the environment is manipulated and the individual begins to regain positive reinforcement from the environment, an internal change will follow (Ekers, 2011). The treatment was first introduced in 1990 (Hollon & Garber, 1990). It became a commonly adopted term in 2010 (Dimidjian, et al., 2010) and is also known as activity scheduling. BA is considered a brief psychotherapeutic approach with three main objectives: increase activities that are associated with a sense of individual value, reduce activities that lead to isolation from that sense of individual value, and change behavior (solve problems) that limit the individual’s sense of value (Ekers, 2011). The process of BA allows individuals to monitor their activities and moods and then create a schedule to engage in more pleasant and desired activities. It is often used in correlation with cognitive therapies to treat depression. A
comprehensive meta-analysis conducted by Cuijpers, van Straten, and Warmerdan (2006) illustrated that BA was effective. It also suggested that activity scheduling is appealing for depression treatment because it is time efficient, uncomplicated, and doesn’t require a high level of skill from either therapist or patient.

Behavioral activation has been used in different settings to treat depression. For example, it was used at a mental health facility with 25 patients who suffered from depression. The patients were divided and half of the group was treated using a brief form of behavioral activation. While the other half was a control group that had contact with a counselor but did not receive any specific treatment. The group that was treated with the brief form of behavioral activation showed significant reduction in depression symptomology (reported using the Beck Depression Inventory) as compared with the control group (Hopko, Lejuez, LePage, Hopko, & McNeil, 2003). Dimidjian et al. (2006) did a randomized trial using 241 participants that met the criteria for major depression according to the DSM-IV. The participants were randomly assigned to one of four groups for treatment: a behavioral activation group, a cognitive therapy group, an anti-depression medication (ADM) group, and a placebo pill group. Researchers evaluated the effectiveness of these four treatments in lowering depression, measured using clinical interviews and self-report. The findings indicate that BA is as effective as ADM and more effective than CT in reducing depression. As a follow up study, the participants were contacted again and asked to participate in a study by Dobson et al. (2008). They considered the prevention of relapse and recurrence of major depression as previously treated by BA, ADM and CT. BA was found to be as effective as medication in preventing the relapse and recurrence of major depression. It was also found that BA might be similar to cognitive behavior therapies in its ability to have an enduring effect on depression.
Rationale for the Study

Parent-implemented PBS is effective in reducing problem behaviors of children with ASD, but the impact of this treatment on maternal well-being needs more research attention. The behaviors associated with ASD are thought to contribute to stress in mothers, but other factors such as social withdrawal, lack of time to engage in desired activities and guilt over giving themselves permission to engage in desired activities also impact maternal well-being.

Behavioral activation is a treatment for depression that is founded on a correlation between engaging in pleasant or desired activities and an individual’s mood. It is based on the behavioral concept of reinforcement. If an individual engages in pleasant activities, they will gain reinforcement from doing so; this reinforcement will reduce depression. The present study looks at coupling parent-implemented PBS with BA to increase well-being and quality of life for children and parents living with ASD.

Research Questions

The study will seek to answer the following research questions:

1. What is the impact of parent-implemented PBS on outcomes for children with ASD?
2. What is the impact of behavioral activation on maternal well-being?
3. What is the impact of maternal well-being on treatment adherence?
4. What is the relationship between implementation, well-being and behavioral activation with our study sample?
CHAPTER 3: METHODS

Hypotheses

Based upon the literature, we made the following hypotheses:

1. Parent-implemented PBS will result in improvements in child behavior.
2. Behavioral activation will be an effective method of reducing depression in mothers of children with autism.
3. Greater maternal well-being will lead to increased treatment adherence.
4. Parents who experience greater activation will experience greater well-being and will be able to implement PBS interventions for their children with greater ease and fidelity.

Parent Participants

The participants were three mothers of children with autism spectrum disorder. The first participant, “Linda,” was Caucasian and in her early 40s. She had four other children living at home; one of the other children was diagnosed with autism spectrum disorder. She did not work outside of the home, but she did volunteer and service work for the local school and church. Based on household income, her family fell in lower middle class range. The second participant, “Elizabeth,” was Pacific Islander and in her early 40s. She had four other children living at home, none with a diagnosed disability. She did part-time work for a family business, outside of the home. She also did volunteer work for her local school. Based on household income, her family fell in the upper middle class range. Lastly, the third participant, “Amy,” was Caucasian and in her early 30s. She had one other child living at home, who had no diagnosed disabilities. She worked part time outside of the home, in addition to volunteer work. Based household
income, her family fell in the upper middle class range. All of the participants’ children who participated in the study, were the second to last child in the family. The participants were recruited through social media and parent organizations (e.g. Facebook support groups for parents of children with ASD). They were also recruited through referrals from other participants.

**Children Participants**

The children who participated in this study were between the ages of 5 and 7 years old. Additionally, the participating children had all received an autism spectrum disorder diagnosis.  

**“Lilly.”** Linda’s daughter was 7 years old at the time of the study. She was of Caucasian descent and was diagnosed with intellectual disability and autism. Her primary means of communication was an iPad loaded with Proloquo. She had also been diagnosed with 2q13.2 Deletion Syndrome. She had four siblings, three older and one younger. She was receiving ABA services in her home when the study began, but was no longer receiving these services when the study concluded.  

**“Jonny.”** Elizabeth’s son was also 7 years old at the time of the study. He was of mixed Pacific Islander and Caucasian descent and had a diagnosis of autism spectrum disorder. His primary means of communication was an iPad loaded with Proloquo. He had four siblings, three older and one younger. He was receiving ABA services in his home at the time of the study.  

**“Brett.”** Amy’s son was 5 years old at the time of the study. He was of Caucasian descent. He had been diagnosed with autism spectrum disorder one year prior to the study and was fully verbal. He was receiving services under the education classification developmental delay previous to his diagnosis. He had not received ABA services prior to the study, but his
family began to have a behavior aide come to their home during the study. Brett had one younger sibling who did not have a diagnosed disability.

**Setting**

The study took place on the campus of Brigham Young University in Provo, Utah. It was conducted in a research lab and videotaped. Data were collected over a six-month period, with breaks for major holidays, family illness or emergencies. Parents reported on their home implementation of the positive behavior supports, but observational data were not collected in the home.

**Instruments**

The mothers completed several measures of well-being, including the *Acceptance and Action Questionnaire-II* (AAQ-II), the *Brief Family Distress Scale* (BFDS), the *Value Progress Questionnaire* (VPQ) and the *Depression Anxiety Stress Scale-21* (DASS-21). They also completed and returned the Daily Monitoring Form and the Life Area, Values and Assessment Inventory form, in correlation with the behavioral activation intervention. The child’s behavior was measured by checklist and direct observation, as is shown in Figure 1 below. Research assistants coded data both by live observation and by delayed video review.

**AAQ-II.** The mothers completed the AAQ-II each week. The AAQ is a widely used measure of experiential avoidance and psychological inflexibility; studies using this measure suggest it is a predictor of a wide range of quality-of-life outcomes including depression, anxiety and general mental health (Hayes, Luoma, Bond, Masuda, & Lillis, 2006). The AAQ-II consists of seven questions that employ a Likert-type scale ranging from never true to always true. Scores on the AAQ-II range from 7 to 49 with higher scores indicating higher psychological
inflexibility. The AAQ has a mean alpha coefficient of .84 and is considered to have a satisfactory structure and be reliable and valid (Bond et al., 2011).

**BFDS.** The Brief Family Distress Scale (BFDS) is a brief measure of crisis used by clinicians and researchers to quickly ascertain a family’s level of distress along a full continuum, from little distress to an experience of crisis. The scale ranges from a one indicating, “Everything is fine, my family and I are not in crisis at all,” to a 10 indicating “We are currently in crisis and it could not get any worse.” A study conducted in 2010 found this scale to be a valid measure of family distress (Weiss & Lunsky, 2010). The mothers also completed this on a weekly basis.

**DASS-21.** The Depression Anxiety Stress Scale-21 is a measure including three subscales: Depression, Anxiety, and Stress. It is designed to assess the emotional level of depression, anxiety and stress using a Likert-type scale. Each of the subscales has seven items relating to the three subscales (Allen & Wang, 2014). The Depression section includes things like, “I felt downhearted and blue,” the Anxiety section consists of things such as, “I felt I was close to panic,” and the Stress section has items such as, "I found myself getting agitated." The scale ranges from zero (Did not apply to me at all) to three (Applied to me very much, or most of the time). Cronbach's alpha, a measure of internal reliability, for the Depression and Anxiety subscale scores were .94 and .89, respectively (Crawford & Henry, 2003). The mothers completed this as a pre- and post-test for the behavioral activation intervention phase.

**VPQ.** The Value Progress Questionnaire is a clinical tool designed for parents implementing behavior change programs (Sandoz & Kellum, 2011). The VPQ contains questions about child outcomes that are aligned with parents’ values. In one section, the VPQ asks parent to rate their level of importance for a chosen value-based behavior and in another
section to rate level of action taken in service of those values. Acting in line with one’s values is thought to lead to a reduced stress response (Cresswell, et al., 2005). This tool was used weekly to assess parents’ value-oriented action for the previous week.

**Daily Monitoring Form.** The Daily Monitoring form tracks how an individual spends his or her time, hour by hour, each day. It further details if the time was spent doing something the individual finds enjoyable and important. This form was completed by the mothers several times weekly during the behavioral activation phase of the study and used to examine the level of activity taking place each week and the level of activity in enjoyable and important tasks each week.

**Life Areas, Values, and Activities Inventory.** The mothers completed this form during Session 2 of behavioral activation. It helped them identify their values in five different life areas: relationships; education/career; recreation/interest; mind, body & spirituality; and daily responsibility. The form then helped them translate their specific values in these domains into goal activities (Lejuez et al., 2011).

**Child Behaviors**

**Lilly’s behaviors.** Linda reported that Lilly frequently engaged in non-compliment behaviors, refusing to do non-preferred tasks, including schoolwork and activities of daily living. She also reported that Lilly often ruined expensive items, like her glasses or iPad, while engaging in non-compliant behavior. Non-compliance was one of the target behaviors for reduction. Non-compliance was defined as not following adult directions within a 10-second time limit. Linda also wanted Lilly to increase her vocalization. Lilly would use her Proloquo often, but would also use hand-over-hand guidance to direct others. Vocalization was defined as any vocal behavior.
**Jonny’s behaviors.** Elizabeth reported that Jonny would frequently chew on his clothes at school and home. This behavior was engaged in so often that it was frequently destroying clothing. Chewing on clothes was the indicated target behavior for reduction. Chewing was defined as placing his shirt in his mouth for more than one second. Functional communication was also targeted and was defined as vocal behaviors to solicit his mom’s attention.

**Brett’s behaviors.** Amy reported that Brett would frequently talk off topic when speaking to adults and children. He would often interrupt the current topic to talk about preferred and repetitive subjects. Talking off topic was the identified target behavior for reduction and was defined as comments or responses to adult questions that differed from the correct or topic response.

**Procedures**

**Design and data analysis procedures.** A single-subject changing conditions design (ABC; Kazdin, 1982), embedded in multiple baselines was used. This type of design involved collecting baseline data, applying a positive behavior support treatment, and applying an additional treatment (to examine the impact on wellness). Data sets were analyzed with visual analysis methods by evaluating changes in level, trends, and variability within and between phases. To support visual analysis, Tau-U, a nonparametric effect size estimate was applied to each individual and combined for all individuals (Parker, Vannest, Davis, & Sauber, 2011). Tau-U provides an effect size and $p$-value for each individual’s change in slope and mean.

**Baseline.** During baseline, each mother completed the self-report measures for depression, family distress and overall quality of life. The mother also identified up to three problem behaviors her child was presenting with. For the first three weeks following these
intake items, child behaviors were observed by trained research assistants and self-report measures completed by the mother weekly to establish a baseline.

**Positive behavior support.** On the fourth week, a trained research assistant introduced parent-implemented positive behavior support as outlined below in Table 1. A trained behavior specialist conducted a functional assessment for the problem behavior identified by the mother in baseline, and a behavior support plan was developed. This plan was aligned with the function of the behavior and only used methods associated with positive behavior support, such as reinforcement and extinction. No aversive methods, such as punishment, were used. The mothers were trained in the PBS plan by a trained research assistant. The PBS plan was implemented in the lab setting and at home and continued for a number of weeks (differing depending on participant).

Table 1

*Positive Behavior Support Interventions*

<table>
<thead>
<tr>
<th>Child</th>
<th>Function</th>
<th>Intervention components</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lilly</td>
<td>Non-compliance/ Access to preferred activities</td>
<td>Teach functional communication skills, vocalization, to request preferred activities</td>
</tr>
<tr>
<td>Jonny</td>
<td>Self-stimulation</td>
<td>Teach vocalization as a competing response to having shirt in mouth</td>
</tr>
<tr>
<td>Brett</td>
<td>Escape of non-preferred conversation topics</td>
<td>Build functional communication skills to eventually teach on-topic communication</td>
</tr>
</tbody>
</table>

**Behavioral activation.** On week 8, 9 or 10 (depending on the participant) behavioral activation was introduced. A research assistant worked with the mother to implement the behavioral activation treatment as modified from the manual in Appendix A. During the first session of this phase, a discussion was held identifying risks accompanying a family of a child
with autism, including stress, anxiety and depression. The rationale for modifying behavior to avoid these risks was also discussed. The homework assignment for Session 1 of the behavioral activation intervention was completing the Daily Monitoring form for the week and ranking the importance and enjoyment associated with each activity. This is a modification of Session 1 from the manual in Appendix A. During Session 2, the mother was introduced to the Life Areas, Values and Activities Inventory. The goal of this session was to identify key values held by the mother in the various life areas and to align actions that could help the mother live according to her values. By the end of the session, the mother had the Activity Selection and Ranking sheet (in Appendix A) completed so she could begin taking value-oriented actions during the following week. The homework assignment to complete the Daily Monitoring form was ongoing through the process. In Sessions 3 and 4, the Daily Monitoring forms and activity planning were reviewed and revised for the coming week. Troubleshooting for activities that were planned but not accomplished was present during these sessions as well. In Session 5, a discussion of the skills associated with behavioral activation took place, but no further forms or homework were assigned after this point. The final session was modified from Session 10 (found in Appendix A). The use of contracts as detailed in the manual in Appendix A was not utilized, as the mothers involved in the study were not participating in this study as a treatment of clinical depression.

During the behavioral activation intervention the mothers continued to complete the self-report measures previously discussed, including the AAQ-II, BFDS and the VPQ (at times). At the end of the last session of the behavioral activation intervention, the PBS and the behavioral activation ceased. Self-report measures were gathered and behavior was observed for the next week as a follow up.
Table 2

*Behavioral Activation Goals*

<table>
<thead>
<tr>
<th>Mother</th>
<th>Example of goals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Linda</td>
<td>Sew</td>
</tr>
<tr>
<td></td>
<td>Play games with older kids</td>
</tr>
<tr>
<td>Elizabeth</td>
<td>Date night with husband</td>
</tr>
<tr>
<td></td>
<td>Go on a long run</td>
</tr>
<tr>
<td>Amy</td>
<td>Get a massage</td>
</tr>
<tr>
<td></td>
<td>Girl’s night out with friends</td>
</tr>
</tbody>
</table>
CHAPTER 4: RESULTS

Table 3 shows the overall results of the positive behavior support interventions. More specific data for each child is found in Figures 1 (Lilly), 2 (Jonny) and 3 (Brett).

Table 3

Positive Behavior Support Results

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Baseline Mean (SD)</th>
<th>Intervention Mean (SD)</th>
<th>TAU</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lilly Vocalization</td>
<td>15.67 (6.81)</td>
<td>15.67 (16.67)</td>
<td>0.11</td>
<td>ns</td>
</tr>
<tr>
<td>Lilly Compliance</td>
<td>37.00 (33.65)</td>
<td>33.00 (23.11)</td>
<td>0.11</td>
<td>ns</td>
</tr>
<tr>
<td>Jonny Functional communication</td>
<td>0.00 (0.00)</td>
<td>21.29 (0.15)</td>
<td>1.00</td>
<td>0.001</td>
</tr>
<tr>
<td>Jonny Chewing on shirt</td>
<td>40.32 (39.61)</td>
<td>7.86 (10.96)</td>
<td>0.76</td>
<td>0.01</td>
</tr>
<tr>
<td>Brett Appropriate communication</td>
<td>36.33 (11.44)</td>
<td>53.40 (11.39)</td>
<td>0.65</td>
<td>0.02</td>
</tr>
</tbody>
</table>

Lilly’s Behaviors

Lilly’s behaviors targeted during the positive behavior support intervention were increased compliance and vocalization. The data for both behaviors showed a flat overall trend and based on Table 3, the Tau U values were not significant for Lilly.

Figure 1. Lilly’s PBS results.
**Jonny’s Behaviors**

Jonny’s behaviors were increased functional communication and decreased shirt in mouth. The data showed an increasing trend in functional communication across the study, but decreasing trend at follow up. The data for shirt in mouth decreased to a zero occurrence by the end of the intervention phase and remained at zero in follow up. The Tau U values, shown in Table 3, are significant for both of Jonny’s behaviors.

![Graph](image)

*Figure 2. Jonny’s PBS results.*

**Brett’s Behaviors**

Brett’s behavior was remaining on adult topic. The data showed an increasing trend across the study and remained high in the follow up phase. The Tau U Value for remaining on adult topic was significant, as shown in Table 3.
Scores from the AAQ-II

The parent participants completed the AAQ-II during each of their visits to the lab. Scores on the AAQ range from 7 to 49 with higher scores indicating higher psychological inflexibility.

**Linda’s scores.** Linda’s scores, as seen in Figure 4, varied moderately throughout the study, with an overall upward trend. The highest scores for this participant were seen during the final (behavioral activation) phase of the study. However, her final score, collected during follow up, was similar to her baseline score.

**Elizabeth’s scores.** Elizabeth’s scores, shown in Figure 5, did not show marked variability over the course of the study, with the exception of a large increase one week during the behavioral activation phase. The overall trend line was flat and her follow up score was lower than her baseline score.

**Amy’s scores.** Amy’s scores (refer to Figure 6) were moderately variable over the course
of the study, with a 9-point difference between the lowest and highest score reported. The highest scores were reported during follow up. The overall trend for Amy on this measure was an upward trend.

Figure 4. Linda’s AAQ results.

Figure 5. Elizabeth’s AAQ results.
The participants completed the BFDS on each of their visits to the lab. The scores ranged from 1 to 10, one being everything is going fine for the family and 10 being the family are in a state of crisis.

**Linda’s scores.** Linda’s BFDS scores are charted in figure 7. These scores indicate an overall increasing trend on the BFDS.

**Elizabeth’s scores.** Elizabeth had an overall increasing trend on the BFDS, as seen in Figure 8. She displayed the biggest difference in scores, going from “Everything is fine, but we sometimes have our difficulties,” to “Things are very stressful but we are getting by with a lot of effort.” This was a three point increase.

**Amy’s scores.** Amy had an overall increasing trend on the BFDS, as seen in Figure 9.

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Figure 6. Amy’s AAQ results.
Figure 7. Linda’s BFDS results.

Figure 8. Elizabeth’s BFDS results.
Scores from the DASS

The participants completed the DASS once before the behavioral activation phase began and once in follow up. The DASS has 21 questions, which are broken down in three different subscales: depression, anxiety and stress. Each subscale is summed and multiplied by two for the final score. The subscales have different cutoffs for severity rankings. On the depression subscale scores ranging from 0 to 13 indicate normal or mild symptoms, while scores over 21 indicate severe symptoms. On the anxiety scale scores ranging from 0 to 9 indicate normal or mild symptoms, while scores over 15 indicate severe symptoms. Finally, on the stress scale scores ranging from 0 to 18 indicate normal or mild symptoms, while scores over 26 indicate severe stress symptoms.

**Linda’s scores.** Linda was in the “moderate” range for depression symptoms at baseline and increased to the “extremely severe” range in follow up (refer to Figure 10). She was in the
mild range for anxiety at baseline and decreased to the normal range at follow up. She was also in the mild range for stress at baseline and remained there at follow up.

**Elizabeth’s scores.** Elizabeth was in the normal range for depression, anxiety and stress at baseline (refer to Figure 11). She remained there at follow up.

**Amy’s scores.** Amy was also in the normal range for depression, anxiety and stress at baseline (refer to Figure 12). She remained in the normal range in all three categories at follow up as well.

*Figure 10. Linda’s DASS results.*
Figure 11. Elizabeth’s DASS R results.

Figure 12. Amy’s DASS results.
Scores from the VPQ

The participants completed the VPQ on each of their visits to the lab during the baseline and positive behavior support phases. The VPQ had the parents rate, on a scale from 1 to 10, how important their child learning the new behavior through positive behavior support was to them. The parents then rated themselves on how much action they had taken that week in support of the behavior change and how satisfied they were with their action.

**Linda’s scores.** Linda identified the importance of and action taken for compliance in Figure 13, and vocalization in Figure 14. She showed an increasing trend in action taken toward both child behaviors. She also showed increased satisfaction with action.

**Elizabeth’s scores.** Elizabeth identified the importance of and action taken toward function communication in Figure 15 and refraining from having shirt in mouth in Figure 16. Her actions toward functional communication remained constant across the study, but the importance of the behavior and her action toward the behavior both had a slightly decreasing trend. Elizabeth’s action toward shirt in mouth and satisfaction with her action both had a constant trend across the study, but the importance of this behavior had a slightly increasing trend across the study.

**Amy’s scores.** Amy was not consistent in completing these forms on her visits to the lab. Her youngest child would accompany her and Brett to their lab appointments, making it more difficult for her to spend time completing all of the required paperwork.
Figure 13. Lilly’s compliance results.

Figure 14. Lilly’s vocalization results.
Figure 15. Jonny’s functional communication results.

Figure 16. Jonny’s shirt in mouth results.
CHAPTER 5: DISCUSSION

The purpose of this study was to identify how PBS influences outcomes for children with ASD and their mothers. The study also sought to determine if behavioral activation was an effective intervention to support the well-being of mothers of children with ASD. Based on the results PBS, when consistently implemented, is effective in reducing problem behaviors in children with ASD. Furthermore, engaging in activities that are enjoyable and important may correlate with lower depression symptoms in mothers of children with autism.

Research Questions Discussion

In regards to our first research question considering the impact of parent-implemented PBS on outcomes for children with ASD, it was found that the two mothers who were able to implement PBS consistently, saw a decrease in child problem behaviors. This indicates that, as shown in prior research, PBS was effective in creating positive behavior outcomes for children (Dunlap & Fox, 2011). PBS was not consistently implemented with the child that did not make behavioral progress or show positive outcomes. There may be several reasons why this mother was not able to implement the PBS as easily as the other mothers in the study. For example, this mother had another child at home who had been diagnosed with disabilities and may have required a high level of care. She also took on new responsibilities with her church that were time intensive. However, it is thought that if the mother had been able to consistently implement the positive behavior support that this child may have made progress like the others.

Second, the impact of behavioral activation on maternal well-being was reviewed. Behavioral activation appeared to be a mediator for depression and to support maternal well-being. Elizabeth and Amy were not only able to make and keep activity goals over the course of the study, but they were both participating in important and enjoyable activities at baseline.
Their DASS scores were in the normal range both at baseline and follow up. Linda was not able to make and keep very many activity goals over the course of the study. She also wasn’t engaging in important and enjoyable activities at baseline. Her DASS scores, both at baseline and follow up, were elevated. This may suggest a possible positive relationship between behavioral activation and maternal well-being with our study participants. The mothers who were already engaging in behavioral activation, and were able to continue doing so, experienced greater maternal well-being, than the mother who was not able to engage behavioral activation. Elizabeth and Amy were also setting activity goals that were largely based outside of the home. They were able to do things that they enjoyed (for example, massages and date nights) while their kids were receiving appropriate care. Linda did not setting goals that would allow her to be away from the home, while her children were receiving appropriate care. Linda’s family had a lower household gross income, than the other two families participating in the study. This may have impacted her ability to set goals which required child care and an additional expenses. This indicates that socioeconomic status may also have been a factor in the mother’s ability to engage in enjoyable and important activities. Further, it may build upon the research favoring respite care as a mediator for stress for families of children with autism (Harper, Dyches, Harper, Roper, & South, 2013).

Third, we looked at the impact of maternal well-being on treatment adherence. Poor maternal well-being appeared to affect treatment adherence adversely. Elizabeth and Amy were both in the normal range in terms of well-being, specifically depression symptomology. Both of these mothers were able to consistently and effectively implement the positive behavior support routines leading to improvement in child behaviors. Linda was in the elevated range on well-being measures, indicating she was experiencing a higher than average number of symptoms that
decrease well-being. Specifically, she was showing a high number of depression symptoms. She struggled to keep her appointments at the lab, as well as implement the PBS routines at home. There may be other factors, outside of personal well-being, that may have contributed to ability to complete the given tasks and routines. These may include things such as the level of care her other children required at home, her own education level, her socioeconomic status and her personal characteristics including motivation. However, these results indicate that the mothers who experienced greater wellbeing also adhered to the both treatments, positive behavior support and behavioral activation, more consistently and thoroughly.

Last, the relationship between implementation, well-being and behavioral activation was considered within our study sample. The participants, who engaged in more activation, including activities that are both important and activities that are enjoyable, displayed higher well-being scores both in baseline and follow up. They were in the normal range on measures of depression, stress and anxiety. The same participants that were in the normal range were also able to implement interventions for themselves and their children with consistency. Within our sample, those participants who were able to engage in activities, often outside the home and without their children present, felt fewer symptoms of depression, anxiety and stress and were better able to implement measures to improve child outcomes. This may suggest that PBS and BA interventions were better suited to mothers who were not experiencing an elevated number of symptoms related to decreased well-being.

Limitations and Ideas for Further Research

The AAQ-II was used as a measure predicting overall quality of life outcomes including depression and anxiety. Linda and Amy had an upward trend on this measure, and Elizabeth had a neutral trend. Linda experienced more feelings of “emotions causing problems in her life,”
“worries getting in the way of her success,” and “most people are handling their lives better than I am” as the study progressed. Amy also increased in the feeling “most people are handling their lives better than I am.” These results indicate that parent-implemented PBS and behavioral activation interventions did not decrease self-reported behaviors consistent with psychological inflexibility. One reason for this may be that it has been suggested that the seven-question version of the AAQ-II may not work well as a process measure. Further research may want to consider looking at a better process measure, such as the full 22-question version, to see if both PBS and BA really do impact maternal psychological well-being. Another reason may be that outside factors influencing the family may have played a role in the mother’s psychological inflexibility. Many of the families experienced major life changes and stressors over the course of the study. These outside factors may have had a strong influence on how the mothers answered the questions on this particular version of this measure.

The BFDS assessed family distress. All three participants had an increasing trend on this measure. It is possible that participants’ perceptions of family distress were affected by outside circumstance. Thus, the effects of positive behavior support and behavioral activation were overshadowed by other circumstances affecting family distress. As with any study, it is difficult to control all outside factors influencing participants during the course of a study. This study was no exception; in talking with the participants during interview times at the beginning of each session, it was disclosed that things such as hospitalizations, school expulsion, moving, and changes in service providers were outside forces that may have affected the overall rating on the family distress scale for each week. These factors may also have played a role in the reporting of personal well-being measures, as well the ability to implement interventions. It is also possible that trying to adhere to PBS and BA treatments, especially simultaneously, may cause more
stress for mothers and families. Further research could consider this aspect of treatment implementation.

Linda was in the moderate range for depression at baseline and increased to the extreme range for depression by the end of the study. Linda was not engaging in valued activities at baseline. During the study, she struggled to keep appointments and follow through with goal activities that were set each visit. The few goal activities that were completed were home-based goals, meaning she was not getting out of the house and getting a break from caring for Lilly and her other children. The other two participants, Elizabeth and Amy, were not in the clinical range for depression, anxiety or stress at baseline. They were already engaging in some value-based activities at baseline. They also set and completed goals that took them outside of the home and gave them a break from the care of their child with a disability and their other children. It is thought, for this reason, that behavioral activation is mediator for quality of life, however it was likely a combination of behavioral activation, socioeconomic status and respite care that contributed to a higher quality of life.

The two participants who were (and continued throughout the study) participating in valued activities were not in the clinical range on quality of life measures, including depression, anxiety and stress. This research may support the research on respite care, showing that respite care is a mediator for depression (Dyches, Christensen, Harper, Mandleco, & Roper, 2016). Further research may want to more closely examine the relationship behavioral activation and respite care to see if behavioral activation is more effective for mothers of children with autism when the valued activities are those that allow the mother time away from home and the child with autism. This may include looking at the relationship between socioeconomic status and it’s role in behavioral activation.
References


APPENDIX A:

Brief Behavioral Activation Treatment for Depression -Revised Manual
(BATD-R; Lejuez et al., 2001)

List of Forms

Form 1. Daily Monitoring (with Activity Planning starting in Session 4)

Form 2. Life Areas, Values, and Activities Inventory

Form 3. Activity Selection and Ranking

Form 4. Contracts

Note. The manual should include multiple copies of Form 1 for each day throughout the course of treatment and of Form 4 for each person to be included in Contracts.
Form 1. Daily Monitoring

<table>
<thead>
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<th>Activity</th>
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<th>Importance (0-10)</th>
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<td>5-6 am</td>
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<td>2 → 5 am</td>
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Overall Mood for the day (0-10) ______
Form 2. Life Areas, Values, and Activities Inventory - Life Area (1/5): Relationships

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### Form 2. Life Areas, Values, and Activities Inventory- Life Area (2/5): Education/Career

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**Form 2. Life Areas, Values, and Activities Inventory- Life Area (3/5): Recreation/Interests**

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### Form 2. Life Areas, Values, and Activities Inventory-Life Area (4/5): Mind, Body, & Spirituality

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<th>Enjoyment (0-10)</th>
<th>Importance (0-10)</th>
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Form 2. Life Areas, Values, and Activities Inventory- Life Area (5/5): Daily Responsibilities

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</table>
Form 3. Activity Selection and Ranking

Instructions: List your desired 15 activities and rate the difficulty of each from 1 = least difficult to 15 = most difficult.

<table>
<thead>
<tr>
<th>ACTIVITY</th>
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</table>
Form 4. Contracts

What is an activity you could use help to complete? ______________________________________

Name one person who can help you with this activity: ______________________________

What are the ways this person can help you with this activity:

1. ______________________________________________________________________
2. ______________________________________________________________________
3. ______________________________________________________________________

Name one person who can help you with this activity: ______________________________

What are the ways this person can help you with this activity:

1. ______________________________________________________________________
2. ______________________________________________________________________
3. ______________________________________________________________________

Name one person who can help you with this activity: ______________________________

What are the ways this person can help you with this activity:

1. ______________________________________________________________________
2. ______________________________________________________________________
3. ______________________________________________________________________
Session One

**Session One Key Elements:**
1. Discussion of Depression
2. Introduction to Treatment Rationale
   - What about stressful life events and loss in your life?
3. Introduction to Daily Monitoring (Form 1)
   - Importance and Enjoyment Ratings
   - When should you complete the Daily Monitoring Form?
4. Important Points about the Structure of This Treatment

**Assignments:**
1. Complete Daily Monitoring Form

---

Session Two

**Session Two Key Elements:**
1. Daily Monitoring: Review Assignment (Form 1)
   - Troubleshooting
2. Treatment Rationale: Review
3. Complete Life Areas, Values, Activities Inventory (Form 2)

**Assignments:**
1. Complete Daily Monitoring (Form 1)
2. Review and Edit Life Areas, Values, and Activities Inventory (Form 2)
3. Review Appendix 1: Moving from Life Areas and Values to Activities

---

Session Three

**Session Three Key Elements:**
1. Daily Monitoring: Review Assignment (Form 1)
2. Life Areas, Values, and Activities Inventory: Review Assignment (Form 2)
3. Activity Selection and Ranking (Form 3)

**Assignments:**
1. Daily Monitoring (Form 1)
2. Continue to Review and Edit Life Areas, Values, and Activities Inventory (Form 2)
3. Review and Edit Activity Selection and Ranking

---

Session Four

**Session Four Key Elements:**
1. Daily Monitoring: Review Assignment (Form 1)
2. Daily Monitoring with Activity Planning (Form 1)

**Assignments:**
1. Daily Monitoring with Activity Planning for upcoming Week (Form 1)

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Session Five

**Session Five Key Elements:**
1. Daily Monitoring with Activity Planning: Review Assignment (Form 1)
2. Contracts (Form 4)
3. Daily Monitoring with Activity Planning for the Upcoming Week (Form 1)

**Assignments:**
1. Daily Monitoring with Activity Planning for the Upcoming Week (Form 1)
2. Continue Adding/Editing Contracts (Form 4)
Session Six

Session Six Key Elements:
1. Daily Monitoring with Activity Planning: Review Assignment (Form 1) _____
2. Contracts: Review Assignment (Form 4) _____
3. Daily Monitoring with Activity Planning for the Upcoming Week (Form 1) _____

Assignments:
1. Daily Monitoring with Activity Planning for the Upcoming Week (Form 1) _____
2. Continue Adding/Editing Contracts (Form 4) _____

Session Seven

Session Seven Key Elements:
1. Daily Monitoring with Activity Planning: Review Assignment (Form 1) _____
2. Life Areas, Values, and Activities Inventory: Concept Review and Edit (Form 2) _____
3. Daily Monitoring with Activity Planning for the Upcoming Week (Form 1) _____

Assignments:
1. Daily Monitoring with Activity Planning for the Upcoming Week (Form 1) _____
2. Continue Adding/Editing Contracts (Form 4) _____

Session Eight

Session Eight Key Elements:
1. Daily Monitoring with Activity Planning: Review Assignment (Form 1) _____
2. Activity Selection and Ranking: Concept Review and Edit (Form 3) _____
3. Daily Monitoring with Activity Planning for the Upcoming Week (Form 1) _____

Assignments:
1. Daily Monitoring with Activity Planning for the Upcoming Week (Form 1) _____
2. Continue Adding/Editing Contracts (Form 4) _____

Session Nine

Session Nine Key Elements:
1. Daily Monitoring with Activity Planning: Review Assignment (Form 1) _____
2. Contracts: Concept Review and Edit (Form 4) _____
3. Daily Monitoring with Activity Planning for the Upcoming Week (Form 1) _____

Assignments:
1. Daily Monitoring with Activity Planning for the Upcoming Week (Form 1) _____
2. Continue Adding/Editing Contracts (Form 4) _____

Sessions Ten and Beyond

Session Ten and Beyond Key Elements:
1. Daily Monitoring with Activity Planning: Review Assignment (Form 1) _____
2. Daily Monitoring with Activity Planning for the Upcoming Week (Form 1) _____
3. Preparing for the End of Treatment _____

Assignments:
1. Daily Monitoring with Activity Planning for the Upcoming Week (Form 1) _____
2. Continue Adding/Editing Contracts (Form 4) _____