A FAMILY-CENTERED, POSITIVE BEHAVIOR SUPPORT APPROACH FOR A 
CHILD WITH AUTISM AND AN ANXIETY DISORDER 

by 
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A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF 
THE REQUIREMENTS FOR THE DEGREE OF 

MASTER OF ARTS 

in 

THE FACULTY OF GRADUATE STUDIES 

(Special Education) 

THE UNIVERSITY OF BRITISH COLUMBIA 

(Vancouver) 

April 2010 

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Abstract

A large proportion of children diagnosed with autism spectrum disorders (ASD) also experience anxiety-related problem behavior. This study evaluated an approach to behavioral family intervention that synthesized evidence-based practices in Positive Behavior Support (PBS) and the treatment of anxiety disorders in children. The study empirically investigated the effectiveness and acceptability of the integrated approach for ameliorating the anxiety-related problem behavior of a child with autism and an anxiety disorder in a community-based swimming routine. A 4-year-old child with the dual diagnosis of autism and an anxiety disorder, and her mother, who also had an anxiety disorder, participated in the study. The study employed an experimental, single-subject, changing criterion design and a case study time-series design, using a multiple-probe strategy. Results were constrained by the parent’s conditional withdrawal from the study during the intervention phase. A functional relationship was not documented but the approach was correlated with improvement in child participation in the swimming routine along the anxiety hierarchy. The intervention also was associated with a decrease in percentage of intervals of problem behavior but no improvements were observed in latency in minutes to termination or successful completion of the routine or in steps completed in the routine. Parent treatment fidelity data indicated that the parent implemented the PBS support plan with a high degree of accuracy. The parent also rated the plan as being socially valid and contextually appropriate. Results are discussed with reference to previous research, contributions to the literature, future directions, and implications for practitioners and researchers who are involved in interventions for children with ASD and anxiety-related problem behavior.
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ACKNOWLEDGEMENTS

I thank the research family for allowing me to be involved in your lives for five months. Thank you for your willingness to work together and to learn from each other. You have blessed me with an experience that enriches my understanding of autism and anxiety. I also thank Jo DiTomasso for introducing me to this family, thank you for your optimism and support throughout the process.

I also thank my thesis advisor, Dr. Joseph Lucyshyn for guiding me through my journey of learning how to be a researcher. Thank you for mentoring me and sharing your insight and wisdom in positive behavioral support with families of children with autism. Your genuine enthusiasm in helping families is inspiring. Thank you also for helping me see past the scope of the study and helping me learn the life lesson of being patient.

I also am grateful for the mentorship of the other members on my research committee, Dr. Pat Mirenda and Dr. Lynn Miller. Pat, thank you for your help with the literature review and also for your insight into the design of the PBS plan. Lynn, thank you for sharing your expertise in anxiety with me. I appreciated your help with the Parent Interview Schedule of the ADIS for DSM-IV:C, the design of the anxiety hierarchy and directing me to towards key articles about conducting exposure with children.

I also am grateful for my fellow colleague and friend, Rachel Zylka. Thank you for volunteering your time to code files for interobserver agreement and also for your encouragement and optimism throughout this process.

I also thank my husband, Simon, and my family and friends for their support and during the research process. Thank you for your prayers and reminding me to trust that God is always in control.
DEDICATION

To my parents
CHAPTER 1

Introduction

ASD and Anxiety

A large proportion of children diagnosed with autism spectrum disorders (ASD) also experience anxiety-related problem behavior (Gillott, Furniss, & Walter, 2001; Kim, Szatmari, Bryson, Streiner, & Wilson, 2000; Muris, Steerneman, Merckelbach, Holdrinet, & Meester, 1998). Prevalence rates of anxiety disorders among individuals with an ASD are reported to be as high as 70-84% (Muris et al.; Simonoff, Pickles, Charman, Chandler, Loucas, & Baird, 2008). Kanner (1943) suggested that some of the peculiar behaviors in children with ASD such as insistence on sameness, rigid routines, and odd fixations may be anxiety-driven. Some unusual behaviors such as hand-flapping, hand-biting, lining objects up, and echolalia (i.e., repeating a word and/or phrase) may be coping mechanisms to manage seemingly constant levels of high anxiety (Gillot et al., 2001). Thus, unless such anxiety-related problem behaviors are ameliorated, children with ASD and their families are likely to have great difficulty participating together in valued family routines in the home and community. There are many studies describing interventions for childhood anxiety disorders for the typical population of children. There also are several studies that describe interventions for children with ASD who engage in problem behaviors (Binnendyk & Lucyshyn, 2009; Boettcher, Koegel & McNerney, 2003; Buschbacher, Fox, & Clarke, 2004; Clarke, Dunlap, & Vaughn, 1999; Lucyshyn et al., 2007). However, few studies specifically have focused on effective interventions for children with ASD who engage in anxiety-related problem behavior in natural family settings. To date, no study has combined
evidence-based components of treatment for children with anxiety disorders (Bouchard et al., 2004) with the best practice features of positive behavior support (PBS) in family settings for children with ASD (Lucyshyn, Horner, Dunlap, Albin, & Ben, 2002). Doing so may strengthen the effectiveness and efficiency of interventions for children with ASD who engage in anxiety-related problem behavior in the home and community with family members. Doing so also may enhance the acceptability and feasibility of treatment from the perspective of family members implementing anxiety interventions in family settings. The following sections of Chapter 1 provide an overview of ASD and anxiety disorders, followed by a review of the extant literature on the treatment of anxiety disorders in typical children and in children with ASD. Based on the extant literature three recommendations for improving intervention for children with ASD and anxiety-related problem behavior are offered. The chapter concludes with a description of the PBS approach and the study’s research questions.

**Autism Spectrum Disorders**

The Pervasive Developmental Disorders (PDD), more commonly known as Autism Spectrum Disorders (ASD) encompasses 5 sub-categories: Autistic Disorder (i.e., autism), Asperger Syndrome, Rett’s Disorder, Childhood Disintegrative Disorder (CDD), and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). Children with ASD are characterized by pervasive impairments in three main areas of development: reciprocal social interaction; communication skills; and the presence of repetitive or stereotyped behaviors, interests, and activities (APA, 2000). Autism is referred as a spectrum disorder because its symptoms, range of abilities and characteristics are expressed in different combinations and range in severity for each
individual (Mash & Wolfe, 2002). No two children diagnosed with ASD will display exactly the same autistic traits and the nature of impairments many change over time. Although the DSM-IV-TR does not separate autism from high-functioning autism, some researchers categorize children with autism who have less pervasive cognitive and communication impairments as having high-functioning autism (HFA) (APA, 2000).

To account for the range of abilities within the autism spectrum, the diagnostic criteria for autistic disorder as described in the DSM-IV-TR allows for some variation but must include these key features:

1. Qualitative impairments in social interaction (expressed by at least two of the following: marked impairment in eye-gaze and facial expressions, failure to foster developmentally appropriate friendships, lack of spontaneous seeking to share enjoyment, interests and/or lack of social or emotional reciprocity)

2. Qualitative impairments in communication (expressed by at least one of the following: delay or lack of spoken language, inability to initiate or sustain conversation, stereotyped use of language and/or lack of developmentally appropriate spontaneous make-believe play or social imitative play)

3. Restricted, repetitive and stereotyped patterns of behavior, interests, and activities (expressed by at least one of the following: preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal in intensity and focus, inflexibility adherence to specific, nonfunctional routines or rituals, repetitive motor movements like hand flapping or whole-body movements like rocking, and or persistent preoccupation with parts of objects)
Developmental abnormalities are usually suspected by 12 months of age and by
definition, the onset of ASD is prior to 3 years of age. ASD occurs more frequently in
males than females, with approximately four to five males diagnosed for every one
female (APA, 2000). The prevalence of ASD is increasing; ASD is now recognized as
the most common neurological disorder affecting children and one of the most common
developmental disabilities. Epidemiological studies are still trying to capture an accurate
estimate. The most recent data from the Center for Disease Control and Prevention
indicate that on average 1 in 110 children in the United States have ASD (Rice, 2009).
Prevalence rates for each sub-type of ASD are displayed in Table 1.1 in order of greatest
prevalence (Fombonne, 2003).

Table 1.1: Prevalence of Autistic Spectrum Disorders

<table>
<thead>
<tr>
<th>Sub-type of ASD</th>
<th>Prevalence rates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td>~ 20 in 10,000 = ~ 73,000 Canadians</td>
</tr>
<tr>
<td>Asperger</td>
<td>~ 5 in 10,000 = ~ 15,000 Canadians</td>
</tr>
<tr>
<td>PDD NOS</td>
<td>~ 15 in 10,000 = ~ 47,000 Canadians</td>
</tr>
<tr>
<td>Rett’s Disorder</td>
<td>~ 1 in 10,000 = ~ 3,150 Canadians</td>
</tr>
<tr>
<td>Childhood Disintegrative Disorder</td>
<td>~ 0.2 in 10,000 = ~ 500 Canadians</td>
</tr>
</tbody>
</table>

Normative Anxiety

Anxiety is a normal part of development and is expected at various times
throughout the lifespan. Between 7 months to 1 year of age, separation anxiety/ stranger
anxiety is commonly observed in most infants (Berk, 2008). The first day of school is
also an event that causes anxiety for many children and their parents. During the school
years, anxiety related to tests, public speaking and making friends are expected. For adolescents and young adults, it is normal to feel anxious about personal relationships, personal appearance, school and the future (Biedel & Turner, 2005). Stressful life events and major transitions such as pregnancy, divorce, re-marriage and moving to a new location are other normative causes for anxiety (Berk, 2008).

Anxiety is accompanied by somatic (i.e., physical), behavioral and cognitive changes within the individual. Physical changes in the body with symptoms such as restlessness, stomach aches, blushing, palpitations, muscle tension, perspiration on the hands and feet, trembling, shaking, increased blood pressure and bodily coldness (Ginsburg, Riddle, & Davies, 2006; Simpson, 1990). Behaviorally, the individual may avoid or delay the situation (e.g., taking an inordinate amount of time to get ready for an event), engage in repetitive behaviors (e.g., tapping a pen, pacing) and anxiety-coping mechanisms such as nail-biting, hair-twirling or smoking. Children may express anxiety by clinging to a parent, having a tantrum, being disobedient (i.e., “acting out”), pretending to be sick, or refusing to speak (Beidel, 2005). Cognitively, a person’s thoughts may become fixated on negative and undesirable outcomes, and there is a feeling of dread, trepidation and worry (Wagner, 2005).

Anxiety Disorders

Some level of anxiety is normal and adaptive; thus the determining factor of whether or not anxiety is normal can be determined by its impact on daily functioning. There are eight important questions to consider in determining if intervention is necessary (Miller, Barrett, & Hampe, 1974; Marks, 1969):
1. Is the fear out of proportion to the demands of the situation?

2. Can it be explained or reasoned away?

3. Is the fear beyond voluntary control?

4. Does the fearful reaction persist unchanged for an extended period of time?

5. Does the fear lead to avoidance of the situation?

6. Is the fear un-adaptive?

7. Is the fear connected with a particular age or stage? (i.e., is it developmentally appropriate?)

8. Does the fear interfere with social, emotional, or academic functioning?

The indicators of problem anxiety is summarized in Table 1.2 (Wagner, 2005)

**Table 1.2: Indicators of Problem Anxiety**

<table>
<thead>
<tr>
<th>Normal Anxiety</th>
<th>Problem Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reasonable</td>
<td>Excessive</td>
</tr>
<tr>
<td>Productive</td>
<td>Detrimental</td>
</tr>
<tr>
<td>Manageable</td>
<td>Uncontrollable</td>
</tr>
<tr>
<td>Mobilizing</td>
<td>Paralyzing</td>
</tr>
<tr>
<td>Specific</td>
<td>Pervasive</td>
</tr>
<tr>
<td>Time-limited</td>
<td>Chronic</td>
</tr>
<tr>
<td>Age-matched</td>
<td>Age-mismatched</td>
</tr>
</tbody>
</table>

Individuals who experience excessive and debilitating anxiety that interferes with daily living are said to have an anxiety disorder (Mash & Wolfe, 2002). Normal anxiety (e.g., separation anxiety) that is experienced beyond the appropriate developmental age is also considered to be problematic. As Miller (2002) explained, “anxiety disorders in children refer to developmentally inappropriate fears or appropriate fear that leads to excessive distress or dysfunction” (p. 4). Of the many disorders afflicting individuals today, anxiety disorders are the most common type of mental disorder diagnosed in children, adolescents, and adults (Beidel & Turner, 2005). However, it is important to remember
that “not all anxiety becomes a problem, and not all problem anxiety becomes a disorder. Children can display a wide variety or a high number of anxiety symptoms without ever developing a disorder” (Wagner, 2005, p. 33). Table 1.3 provides an overview of the six types of childhood anxiety disorders, as categorized by the Diagnostic and Statistical Manual 4th edition-Text Revision (DSM-IV-TR), and rates of prevalence in the general and autistic populations (Leyfer et al., 2006; Mash & Wolfe, 2002; Muris et al., 1996; Simonoff et al., 2008).
Table 1.3: Overview of Childhood Anxiety Disorders

<table>
<thead>
<tr>
<th>Type of anxiety disorder</th>
<th>Description</th>
<th>Age of onset</th>
<th>Prevalence in general population</th>
<th>Prevalence among individuals with ASD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Separation Anxiety Disorder (SAD)</td>
<td>Children with SAD show excessive distress involving leaving home and worry excessively about attachment figures (i.e., parents) leaving them or something harming them. May occur along with school reluctance or refusal.</td>
<td>7-8 years</td>
<td>10%</td>
<td>0.5%&lt;sup&gt;2&lt;/sup&gt; 11.9%&lt;sup&gt;4&lt;/sup&gt; 74%&lt;sup&gt;2&lt;/sup&gt;</td>
</tr>
<tr>
<td>Generalized anxiety disorder (GAD)</td>
<td>Children with GAD seem to be perpetually and excessively worried about everything. GAD is global impairment and interferes with all the activities and events in the child’s life.</td>
<td>10-14 years</td>
<td>3-6%</td>
<td>2.4%&lt;sup&gt;4&lt;/sup&gt; 13.4%&lt;sup&gt;2&lt;/sup&gt;</td>
</tr>
<tr>
<td>Specific phobia</td>
<td>Children with specific phobia display fear that is age inappropriate, irrational or exaggerated. They may show avoidance of a specific item (i.e., spiders, needles) or situation (i.e., being on an airplane) that poses no or little threat to others and continue to exhibit anxiety despite evidence that the object or event is not harmful. Also known as simple phobia.</td>
<td>7-9 years (peak at 10-years)</td>
<td>2-4%</td>
<td>8.5%&lt;sup&gt;2&lt;/sup&gt; 44%&lt;sup&gt;4&lt;/sup&gt; 63.6%&lt;sup&gt;3&lt;/sup&gt;</td>
</tr>
<tr>
<td>Social Phobia</td>
<td>Children with social phobia show a persistent fear of social environments that could lead to social evaluations and judgments. Children with social phobia excessive worry about mundane social events: walking in a classroom, going to the mall, ordering a meal at a restaurant. They have a intense desire to be liked by other people but constantly fear social rejection so much that the child may avoid social events altogether. May occur with selective mutism (i.e., individuals who do not talk in specific social situations but will speak at home or other settings).</td>
<td>13-16 years (during adolescence)</td>
<td>1-3%</td>
<td>7.5%&lt;sup&gt;4&lt;/sup&gt; 20.5%&lt;sup&gt;3&lt;/sup&gt; 29.2%&lt;sup&gt;2&lt;/sup&gt;</td>
</tr>
<tr>
<td>Disorder</td>
<td>Description</td>
<td>Age</td>
<td>Prevalence</td>
<td>Notes</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-------------</td>
<td>------------</td>
<td>------------------------------</td>
</tr>
<tr>
<td>Obsessive-compulsive disorder</td>
<td>Obsessions are persistent and intrusive thoughts, ideas, impulses or images, which are usually irrational or highly unlikely to occur in real life. Compulsions are repetitive and intentional behaviors or mental acts that are performed in response to an obsession. For example, a child may be obsessed about contamination and how this may lead to sickness and death. These exaggerated and irrational thoughts lead the child to engage in persistent hand-washing.</td>
<td>9-12 years</td>
<td>2-3%</td>
<td>8.2%² 37%⁴</td>
</tr>
<tr>
<td>Panic Disorder</td>
<td>Panic disorder usually occurs in late adolescence but can occur in childhood as well. Children and teens with Panic Disorder experience unexpected and repeated panic attacks. This is typically followed by at least one month of concern about having additional attacks and/or a fear of something bad happening because of the panic attack (such as going crazy, losing control, or dying). May occur with agoraphobia, where the individual is so paralyzed with fear about when the next panic attack will occur that he/she refused to leave the house and avoid public places.</td>
<td>15-19 years</td>
<td>1-5%</td>
<td>0%⁴ 10.1%²</td>
</tr>
<tr>
<td>PTSD</td>
<td>PTSD occurs after the child experiences a traumatic and stressful life event (i.e., natural disaster, kidnapping, violence, accident). The core features of PTSD are re-experiencing the traumatic event, avoidance of associated stimuli and numbing of general responsiveness and symptoms of extreme arousal that last for over a month after stressful event.</td>
<td>Any time</td>
<td>Depends on the sample</td>
<td>No research found</td>
</tr>
</tbody>
</table>

¹Mash and Wolfe, 2002
²Simonoff et al., 2008
³Muris, 1998
⁴Leyfer et al., 2006
Anxiety disorders can occur in isolation but research also has documented considerable comorbidity with other mental and physical disorders. Many children and adolescents with an anxiety disorder suffer from more than one type. Depending on the study, comorbidity rates ranges from 31%-49.7% (Beidel & Turner, 2005). Comorbidity between anxiety disorders and autism spectrum disorders are increasingly being recognized (Muris et al., 1998).

**Prevalence of Anxiety in Individuals with ASD**

Several studies have explored the prevalence of anxiety disorders among children with ASD. Muris et al. (1998) found that, in a sample of 44 children with autism or PDD-NOS, 84.1% of the children met the full DSM-III-R criteria (APA, 1987) for at least one anxiety disorder. A recent study by Simonoff et al. (2008) examined psychiatric disorders in 112 children ages 10-12 using an epidemiological, population-derived sample and a standardized interview to determine rates of DSM-IV disorders in children with ASD. The researchers interviewed the children’s parents using the Child and Adolescent Psychiatric Assessment Parent Version (CAPA) to determine if these children had other comorbid DSM-IV psychiatric disorders. Simonoff and colleagues found that 70% of children with ASD in their study had at least one comorbid disorder and 41% had two or more. Collectively, over half the group had a DSM-IV diagnosis of ASD and an anxiety disorder. These studies suggest that the prevalence of an anxiety disorder among children with ASD is high. Other researchers have compared the prevalence of anxiety disorders in children with other demographic groups of children. These studies are described below.
Children with ASD vs. Typically Developing Children

Prevalence of anxiety disorders among children on the autism spectrum have been compared to typically developing children. For example, Kim, Szatmari, Bryson, Streiner, and Wilson (2000) compared 21 children with Asperger syndrome and 47 children with high functioning autism (HFA) to a random sample of 1,751 children in the community. In this study, HFA was defined as having a mental age score higher than at least half of one’s chronological age (i.e., if the child was 6 years old, he/she would have to have a mental age score of at least 3 to be included in the study). The researchers found that the children with Aspergers syndrome and HFA demonstrated a higher rate of anxiety and depression problems than the community sample. There were no differences in anxiety levels between those with Aspergers syndrome and those with HFA. Both groups showed higher than normal levels of anxiety when compared to age and gender-matched norms.

The column on the right side of Table 1.3 displays the prevalence rates of anxiety in typically developing children versus children with ASD in a number of other studies as well. At a glance, it is clear that anxiety disorders are more prevalent in children with ASD than typically developing children. Depending on the study and the measure(s) used to assess anxiety, there is much variability among prevalence rates. Leyfer et al. (2006) noted that there is much discrepancy between different studies because comorbid psychiatric disorders in children and adults with ASD can be hard to diagnose. Challenges such as difficulties with expressive language and impairments in perspective taking, complex information processing, central coherence, and executive functioning make it very challenging for individuals with ASD to describe their mental states and
emotional experiences. Thus, the level of functioning of the sample group and the type of instrument used to assess an anxiety disorder may help explain the discrepancies between different studies.

**Children with ASD vs. Children with Conduct Disorder**

Green, Gilchrist, Burton, and Cox (2000) compared 20 male adolescents with Aspergers syndrome (AS) to a group of 20 adolescent males with conduct disorder (CD) on various measures of psychosocial functioning and psychiatric morbidity. The adolescents were interviewed using the modified Isle of Wight Semistructured Informant and Child Interviews (Rutter, 1989). Parents filled out the Isle of Wight Semistructured Informant Interview. Results showed that adolescents with AS showed greater totals of anxiety-related symptoms such as worrying, hypochondrias, nonsituational anxiety or panic and specific fears than the group with CD. Furthermore, 55% of the group with AS had two or more anxiety symptoms whereas only 10% of the group with CD had two or more anxiety symptoms. Results from the parent-report assessment also indicated that the group with AS had more problems with worrying, fears, and obsessions and compulsions.

**Children with ASD vs. Children with Specific Language Impairment**

Gillot, Furniss, and Walter (2001) compared children with ASD with a matched group of children with Specific Language Impairment (SLI) and typically developing children. Children in all three groups had intelligence and reading abilities within the normal range and attended mainstream schools. Results indicated that children with ASD experienced more social anxiety than the SLI group or the typically developing group.
Results revealed that 47% of the children with ASD had clinically significant levels of anxiety, based on the self-report Spence Social Worries Questionnaire (Spence, 1995).

**Children with ASD vs. Children with Down Syndrome**

Evans, Canavera, Kleinpeter, Maccubbin, and Taga (2005) compared four groups of children: children with ASD, children with Down syndrome, typical children matched for mental age, and typical children matched for chronological age. Parents filled out an anxiety survey that contained 69 anxiety-eliciting situations/stimuli on a 5-point Likert scale. According to parent reports, children with ASD were rated as more anxious than all comparison groups. The researchers found that individuals with ASD had significantly more anxious symptoms than the children with Down syndrome regarding social anxieties and anxiety specific to animals. Children with Down syndrome displayed the least anxious symptoms of the group.

In summary, the current literature reveals that many individuals with ASD experience higher levels of anxiety symptoms than typically developing children, as well as children with Conduct Disorder, Specific Language Impairment, and Down syndrome. It should be noted that it is difficult to determine if the high rates of anxiety are “due to effects of the core features of autism, life experiences, or a comorbid psychiatric disorder superimposed on the autism and the life experiences of the child” (Leyfer et al., 2006, p. 850). Nevertheless, the high rates of anxiety in individuals with ASD cannot be overlooked.
Development of Anxiety

From a behavioral perspective, there are three main theories that explain the acquisition of anxiety: direct conditioning, observational learning, and verbal information transfer. These theories are discussed below.

Direct Conditioning

Early behaviorists like Watson and Rayner (1920) demonstrated direct fear conditioning in an interesting (although now widely regarded as unethical) experiment. A young boy, Albert, initially showed no anxiety around animals but was anxious in the presence of loud noises. In this classic experiment, Watson and Rayner paired a neutral stimulus (e.g., rat, rabbit, dog, etc.) with loud noises and conditioned little Albert to develop a specific phobia of those animals. In behavioral terms, Albert’s anxiety was acquired through a condition of negative reinforcement. Once something is conditioned either purposefully (as in this experiment) or naturally (e.g., getting a bee sting), there is an automatic feeling of relief whenever the feared stimulus is avoided (i.e., negative reinforcement) (Mash & Wolfe, 2002).

Observational Learning Theory

Muris, Steerneman, Mercklebach, and Meesters, (1996) examined the role of parental anxiety and modeling and its contribution to the development of anxiety in children. The children filled out the Spielberger State-Trait Anxiety Inventory (Spielberger, 1973) for children and a revised version of the Fear Survey for Children (Gullone & King, 1992). The parents completed adult versions of these two self-report assessments. Parents also were asked to rate the extent to which they generally expressed fears in the presence of their children on a Likert-type scale. Results indicated a positive
relationship between anxiousness of mothers and their children, suggesting that parental modeling contributed to the development of anxiety in the children. That is, “children of mothers who often expressed fears exhibited the highest fear levels, children of mothers who never expressed fears had the lowest levels, while children who sometimes expressed fears fell in between” (Muris et al., 1996, p. 267). The researchers speculated that social referencing and observational learning accounted for the development of childhood anxiety.

**Verbal Information Transfer**

This theory suggests that children can develop anxiety by being told that a certain stimulus/situation is frightening. Whaley, Pinto and Sigman (1999) compared 18 clinically anxious mothers and their children to a control group of mothers. They found that anxious mothers were more critical and pessimistic. They were less positive, less affectionate, less warm and smiled less than parents of children without an anxiety disorder. Whaley and colleagues also found that the characteristic interactions between mothers and children were a reliable and salient predictor of child anxiety. That is, anxious mothers acted or spoke to their child in such a way that potentially contributed to elevated levels of anxiety in their child.

Another study found that parent’s behavior could influence a child to be anxious in an ambiguous situation. Barrett, Rapee, Dadds, and Ryan (1996) asked children with anxiety disorders what they would do in a number of ambiguous situations that could be interpreted as either threatening or non-threatening. Half of these ambiguous situations referred to physical threats (e.g., “On the way to school you get a funny feeling in your tummy; what do you do?”) or social threats (e.g., “You see a group of kids playing a
great game and when you come closer, they are laughing; what do you do?). Two of these situations were selected to be discussed afterwards with their parents. Barrett and colleagues found that children who initially interpreted a situation as non-threatening were highly influenced by anxiety-provoking thoughts during discussions with their parents. Upon hearing negative comments from their parents, children were much more likely to change their answers and interpret the situation as threatening. These findings suggested that “children might be learning to interpret and respond to certain situations within their family contexts [and] for anxious children, avoidance increased greatly after family discussions” (Barrett et al., 1996, p. 201). This study seems to indicate that parental comments may shape and perhaps maintain anxiety responses.

Researchers have hypothesized that ASD may lead to increased susceptibility for experiencing anxiety. There are four potential explanations for the high prevalence of anxiety in ASD includes: (a) impairments in social skills; (b) differences in information processing; (c) problems with behavioral inhibition; and (d) abnormal processing in the amygdala. These explanations are provided below.

**Impairment of Social Skills**

It has been hypothesized that the lack of social skills in children with ASD leads to increased teasing from peers, which in turn exacerbates pre-existing social anxiety. Bellini (2004) found that “adolescents with autism spectrum disorders exhibit anxiety levels that are significantly higher than those of the general population” (p. 78). Furthermore, Bellini (2004) found a correlation among social skill deficits, negative interactions, and anxiety. Social anxiety in youth with autism spectrum disorders: assertion skills and level of empathy. As assertion skills decreased, social anxiety
increased. The correlation between social anxiety and empathy was more complicated and was represented in this study as a curvilinear relationship. Individuals with little empathy experienced minimal social anxiety, perhaps because they were oblivious to many social situations that could be anxiety-provoking. As empathy increased; social anxiety also increased - these individuals were aware and fearful of such situations. However, as empathy scores rose higher, social anxiety decreased. Bellini (2004) hypothesized that these individuals probably had the awareness and the social skills to handle these situations.

**Differences in Information Processing**

Another theory is that children with ASD may experience increased anxiety because of the way in which they process information. Many believe that typical children develop anxiety disorders because they are overselective in their information processing style; that is, anxious children misinterpret ambiguous situations because they fail to consider the global context (Chalfant, Rapee, & Carol, 2007). If over-selectivity is a factor in anxiety, it may help explain why children with ASD are vulnerable to increased anxiety, since a common characteristic of ASD is a tendency to be overselective to specific stimuli in their environment (Lovaas, Koegel, & Schreibman, 1979).

**Behavioral Inhibition**

Evans et al. (2005) hypothesized that fears and anxieties are related to the deficits that characterize ASD. He found that fears were related to behavioral inhibition and “that fear correlated with conduct problems, impulsivity, and hyperactivity in children with ASD is consistent with behavioral, emotional and self-organization that characterize ASD” (p. 23).
Abnormal Processing in the Amygdala

The amygdala has been identified as an important factor in the etiology of anxiety disorders. The amygdala is involved in emotions such as fear and aggression, and has been linked to abnormal anxiety, fears, and phobias in people with ASD (Markram, Rinaldi, La Mendola, Sandi, & Markham, 2007). These authors suggested that “it is possible that abnormal processing in the amygdala might be central to the generation of excessive fears” (p. 901). In their study, female rats were treated with valproic acid (VPA) and produced offspring that displayed autistic-like symptoms such as decreased social interaction, increased repetitive behavior, and decreased sensitivity to pain. Both the autistic-like rats and untreated rats were then exposed to a standard fear conditioning apparatus (i.e., a cage with a floor with steel rods that delivered scrambled shock). The researchers found that VPA-treated rats had longer-lasting fear memories that were overgeneralized and hard to extinguish. Furthermore, their amygdalas were hyperactive to electrical stimulation, indicating that excessive fear could be caused by the hyper-reactivity and hyper-plasticity found in the lateral amygdala which may be due to a deficit in the inhibitory system. The authors concluded that, “enhanced fear processing and memories could perhaps underlie what has been considered core symptoms of autism” (Markam et al., 2007, p. 908). However, this study is based on an animal model, so conclusions must be regarded with caution.

Exposure-based Interventions

Cognitive behavioral therapy (CBT) is increasingly described as the psychotherapeutic treatment choice for children and adolescents struggling with an anxiety disorder (Bouchard, Mendlowitz, Coles & Franklin, 2004; Dadds, Spence,
Holland, Barrett, & Laurens, 1997; Kendall, 1994; Kendall et al., 1997; Manassis et al., 2002; Shortt, Barrett, Dadds & Fox, 2001; Silverman et al., 1999). CBT is believed to be “the only non-pharmacological treatment that has received strong empirical support for the treatment of anxiety disorders” (Bouchard et al., 2004, p. 57). March and Mulle (1998) defined CBT as an intervention approach that “provides cognitive and behavioral corrective information that targets specific symptoms in a way that logically connects theory, interventions, and outcome” (p. 33). Cognitive behaviorists believe that maladaptive thinking leads to maladaptive behavior; thus, intervention requires alteration of perceptions, thoughts, images, and beliefs (King & Ollendick, 1997).

An integral part of correcting cognitive deficiencies and distorted thinking patterns can involve a behavioral procedure known as exposure. Exposure is defined as “any procedure that confronts the person with a stimulus which typically elicits an undesirable behavior and an unwanted emotional response” (Marshall, 1985, p.121). The most common form is gradual or graded exposure, where a person is confronted with the feared circumstance gradually over time, progressing from least-to-most anxiety provoking (Bouchard et al., 2004). For instance, for dog phobia, a child would be exposed to low-level threat of dogs (pictures of dogs in cartoons, books, etc.) and progressively be exposed to interactions with dogs until the child could tolerate petting a dog. The rate of exposure (i.e., frequency of exposure spaced over time) and the duration of each exposure session (i.e., brief vs. prolonged) can vary. “Exposure works by providing corrective information that is incompatible with the dysfunctional associations stored in memory or the formation of new and more functional associations” (Bouchard, 2004, p.58). The concept of habituation is also important to the process of exposure. As
defined by March and Mulle (1998), habituation is “a neurobehavioral response in which symptoms decrease across successive exposure trials” (p. 34). When the individual first comes into contact with the anxiety-provoking stimulus, the “fight or flight” instinct is triggered and the sympathetic nervous system is activated. The sympathetic nervous system arouses the individual for defensive action. When the stimulus ceases to be a threat, the parasympathetic nervous system reverses the effects of the sympathetic nervous system and works to calm the individual (Myers, 1998). Individuals with anxiety-related problem behavior are often trapped in a cycle of negative reinforcement. The individual flees from the anxiety-provoking stimulus before habituation and realization of non-occurrence of negative consequences can occur. Thus, exposure seeks to break the individual’s pattern of escape-avoidance (i.e., escaping from the anxiety-provoking stimulus before habituation has a chance to occur). The belief is that, although confrontation with the anxiety-provoking stimulus is initially uncomfortable, anxiety will eventually diminish and erroneous thinking patterns will be disconfirmed when the individual is repeatedly exposed to the anxiety-provoking stimulus in the absence of the feared negative consequence (Bouchard et al., 2004).

**Anxiety Hierarchy**

It is important that exposure to the anxiety-eliciting stimulus is done gradually. Gradual exposure is especially important when working with children with anxiety disorders. Gradual exposure gives the child explicit control over selection of exposure targets. As described by March and Mulle (1998), gradual exposure is recommended when working with children because “it helps to make the treatment predictable, controllable, and most importantly, successful” (p. 37). Using an anxiety hierarchy, or a
stepped plan that details the gradual exposure “experiments”, to expose gradually a child to increasingly anxiety-provoking stimulus is important, because if initial exposure exercises are too difficult, the child may refuse to engage in subsequent exposure sessions (Bouchard et al., 2004).

The construction of the anxiety hierarchy is usually based on a conversation with the individual. The clinician works with the child to come up with a list of anxiety provoking situations. Younger children may need more assistance with generating these scenarios. A clinician may use a rating scale from 0-10 (0 = no anxiety; 10 = a lot of anxiety) to help the child rate each scenario. Based on the child’s ratings of each scenario, the clinician arranges the list in order of least to most anxiety provoking for exposure sessions (Anxiety BC, 2007-2010). When conducting exposure with children, it is crucial that initial exposure exercises are successful or the child may refuse to participate in future exposure exercises (Bouchard et al., 2004). Also, beginning with an exposure task in which the child will likely be successful may help increase the child’s perceived self-efficacy. Furthermore, previous success may provide momentum for the child and help him/her overcome the next exposure task on the anxiety hierarchy (March & Mulle, 1998).

**Considerations in Using Exposure with Children**

As previously discussed, when working with children, it is especially important that exposure is gradual, as children tend to tolerate anxiety less well than adults (March & Mulle, 2008). Bouchard et al. (2004) noted that young children generally require a stronger behaviorally based component to intervention than older children, with extensive parental involvement. Furthermore, incorporating a child’s “superheroes” or imaginary
characters may help the child manage his or her anxiety and confront the anxiety-provoking stimulus or situation. In Table 1.4, special considerations in the use of exposure with children are summarized (Bouchard et al., 2004, p. 59).

**Table 1.4: Fundamental Principles when using Exposure with Children**

- Adapt the treatment to developmental levels and challenges.
- The treatment plan should be based on a solid case conceptualization.
- A strong therapeutic alliance is essential.
- A psycho-educational component (i.e., explanation of how exposure works) is essential prior to initiating exposure.
- Exposures should be progressive with respect to a hierarchy of feared situations.
- Eliminate distractions.
- Encourage the use of coping strategies to facilitate *remaining* in the feared situation.
- Many repetitions of the exposure are needed.
- Parental involvement is crucial.
- Homework outside the treatment session is fundamental for success.
- Always reward effort, not just success. Every effort to confront a feared situation is an achievement.

**Exposure Procedures for Children**

Depending on the clinician and the needs of the child, the number of sessions, the type of exposure (i.e., with or without response prevention; *in vivo* or imaginal or role play), and the level of involvement of parents may vary in exposure treatment for children with an anxiety disorder. Table 1.5 (Bouchard et al., 2004, p. 60) outlines the basic procedure of designing and implementing exposure treatment for children.

Bouchard et al. (2004) recommend that exposure tasks should be practiced until they no longer cause anxiety in the child. Practicing an exposure task repetitively until it is boring is important for these reasons: (a) practice allows the child to build up his/her sense of self-efficacy and negate negative predictions; (b) multiple practice makes it more difficult to discount past successful experiences; and (c) rehearsal of an exposure task in a variety of settings increases generalizability.
Table 1.5: Exposure Procedures with Children

1. Explain the exposure procedure, including why and how.
2. Create a hierarchy of fears.
3. Educate the child to use an anxiety rating scale consistent with his/her developmental level to aid in monitoring his/her anxiety during exposure.
4. Assign a numerical value to each fear (e.g., 0 = no anxiety to 10 = extreme anxiety).
5. Determine any sub-hierarchies and assign a rating to these.
6. Remember to include confrontation with atypical feared situations.
7. Begin with something low on the hierarchy and create an exposure plan in consultation with the child.
8. Therapist models exposure procedure.
9. Practice imaginal exposure if necessary, then, in vivo exposure (continuously monitor anxiety ratings and remain in the situation, until task perceived as tedious, i.e., anxiety lowers)
10. Reward effort!
11. Homework- practice exposures outside the treatment session often.
12. Use parents as co-therapists for treatment compliance and practice.
13. Move up the hierarchy.

Review of Interventions Utilizing Exposure for the Typical Population

There are several studies that indicate the effectiveness of exposure intervention for children with anxiety disorders. Macdonald (1975) conducted a multiple treatment behavior therapy package for an 11-year-old boy who had severe dog phobia. Due to past experiences at a young age with dogs, the boy refused to go outdoors, which negatively affected his social relationships. In this study, the treatment package consisted of: (a) imaginal exposure (i.e., imaging oneself encountering the anxiety-provoking stimulus) on an anxiety hierarchy; (b) relaxation training; (c) dog interaction and skill training; (d) modeling of positive interactions with a dog, and (e) assignments that required the boy to go outside (e.g., walking home from school, watching a baseball game outdoors). The child progressed from imagining positive interactions with a dog, to looking at photographs of a dog, to listening to a recording of a dog barking, to observing a trainer interact with a dog, and finally interacting with the dog himself. The exposure tasks were guided by an anxiety hierarchy. The child did not advance to the next exposure task until
he was able to remain calm and relaxed in the current exposure task. The child’s parents were not directly involved in the intervention but were prompted to reinforce the child when he remained calm in the presence of dogs. This was very important because Macdonald found that the parents were reinforcing the child’s anxiety-related problem behavior more than calm, appropriate behavior around dogs. This multi-component treatment was very successful. By the sixth session, the child could go outdoors without worrying about dogs. At the two year follow-up, the child continued to feel comfortable outdoors in the presence of dogs and developed a positive social network.

Leitenberg and Callahan (1973) conducted a study in which individuals with four different types of specific phobias were treated. Participants had fears of heights, snakes, electric shock, or darkness. Participants all participated in a gradual exposure intervention. They were repeatedly exposed to increasingly more intense presentations of the anxiety-eliciting situation/stimulus (e.g., for acrophobia, participants had to climb higher and higher on a ladder as they made progress). Participants were given feedback and reinforced for gains in performance. Leitenberg and Callahan found that “regardless of different etiologies, regardless of whether or not fears are rational or irrational, and regardless of whether or not fears are transitory or long lasting, the same treatment can be equally effective in reducing escape-avoidance behaviors” (p. 19). Thus, repeated exposure to the feared stimulus coupled with feedback and reinforcement is commonly used when the goal is mainly behavioral (i.e., getting on a plane, being close to a dog).

Pomerantz, Peterson, Marholin and Stern (1977) trained a mother to implement a gradual exposure treatment plan for her son who was afraid of the water (i.e., aquaphobia). Whenever water was running in the bathroom, the boy would run away
screaming and hide, which caused the mother to resort to bathing him forcefully once every 10 days. The parent participated in the construction of an anxiety hierarchy for the bathing routine and learned how to conduct *in vivo* water desensitization. Sessions were conducted 5 days a week for 30 minutes each time. The first two sessions were modeled by the therapist while the mother observed. The procedure began with telling the boy that if he came into the room, he could have a glass of Pepsi (i.e., the chosen reinforcer). Upon entering the room, the boy received the Pepsi and lots of social reinforcement (e.g., praise, hugs, and kisses). When this step of the anxiety hierarchy was completed, the next step was conducted in the same manner. Laughter or saying the word “water” was used as indicators to move to the next level on the anxiety hierarchy. If the boy indicated signs of anxiety (e.g., whimpering, crying), he was removed from the bathroom. The next day, the exposure task was lowered to the situation that was previously mastered. The practitioner modeled the first and second session and the boy’s mother conducted session three and all sessions afterwards. The therapist was close by and provided verbal cues and prompts (e.g., when to reinforce her son, when to take him out of the bathroom), but prompts decreased as the mother gained confidence and skill in implementing the desensitization protocol. On the eighth day of intervention, the boy was able to take a bath without crying or complaining and this behavior was maintained at the six-month follow-up. Pepsi was no longer required as a reinforcer.

Ost, Svensson, Hellström, and Lindwall (2001) conducted a one-session gradual exposure intervention for children and youth with specific phobia. In this randomized clinical trial, 60 children (ages 7-17) who were diagnosed with various specific phobias were randomly assigned to one of three conditions: (a) child-only (b) child and parent; or
(c) wait-list control group. Treatment consisted of a three hour ERP session in which the child was gradually exposed to the anxiety-provoking stimulus *in vivo*. There was no formal cognitive component to the treatment but clinicians encouraged participants to draw realistic conclusions regarding their beliefs toward the anxiety-provoking stimulus after the exposure task was completed. Results found that one session of exposure intervention for both the child-only and the child and parent groups resulted in a decrease in phobic severity ratings as reported by an independent assessor as well as improvements in the children’s self-ratings of anxiety. There were no significant differences between the child-only and the parent and child treatment groups at post-treatment or at 1-year follow-up. Participants in the wait-list control group made little or no improvements (Ost et al., 2001).

**Review of Interventions Utilizing Exposure with Individuals with ASD**

Similar to intervention for typically developing children, the literature on interventions for children with ASD and an anxiety disorder is largely influenced by the behavioral and cognitive-behavioral paradigms. However, there is a concern that children with ASD may not have the cognitive requirements to participate in and benefit from the cognitive components of intervention (White, 2004). Thus, many of the interventions that include a cognitive component are geared toward individuals with Aspergers syndrome or individuals who function at a higher cognitive level such as those with HFA.

Interventions utilizing *in vivo*, exposure-based interventions are reviewed.

**In Vivo Exposure-Based Interventions**

A study by Ricciardi, Luiselli, and Camare (2006) used an exposure technique known as “contact desensitization” to help an 8-year-old boy with autism overcome a
specific fear of animatronic objects (e.g., electronic animated figures such as dancing Elmo and blinking Halloween decorations). The child was exposed to the anxiety-inducing stimulus and positively reinforced contingent on completion of steps in the exposure hierarchy (Ricciardi et al., 2006). Similarly, Luiselli (1978) helped a 7-year-old boy with autism overcome anxiety associated with riding the bus with gradual exposure. The boy began by sitting on a non-moving bus with his mother and his therapist. Then he sat on the non-moving bus only with his therapist, and finally, he sat on the bus alone. After completing these steps, he went through these steps again while the bus was moving and each step was reinforced with preferred edibles. Within only 9 treatment days, the child was riding the bus to and from school independently.

Exposure techniques also have been shown to be successful with individuals with ASD and cognitive deficits. Shabani and Fisher (2006) helped an 18-year-old boy diagnosed with autism, severe mental retardation, and Type 2 diabetes overcome needle phobia. Given his medical condition, checking his glucose levels was imperative for his health. They gradually decreased the distance between the needle and his arm, reinforced him for keeping his arm still, and ignored problem behavior. By session 30, the researchers were able to draw blood without any problem behavior. These results were generalized to other settings (e.g., a nurse’s office) and needle phobia was no longer a problem at the 2-month follow-up.

Rapp, Vollmer, and Hovanetz (2005) also utilized gradual exposure to help a 14-year-old girl with autism and severe mental retardation overcome her anxiety of swimming pools. The researchers gradually exposed her to various depths of water while contingently reinforcing each step with edibles and praise. By session 12, the girl enjoyed
swimming in different swimming pools and reinforcement with edibles was no longer necessary.

**Strengths of Extant Literature**

The studies discussed above provide empirical evidence for the effectiveness of exposure-based interventions in the amelioration of childhood anxiety disorders. Collectively, these studies show several strengths, both in regard to intervention design and research methodology. These strengths include: (a) gradual exposure to anxiety-eliciting stimulus (e.g., Luiselli, 1978; Macdonald, 1975; Pomerantz et al., 1977; Ricciardi et al., 2006; Shabani et al., 2006); (b) individualized intervention (e.g., Pomerantz et al., 1977); (c) parental involvement (e.g., Luiselli, 1978; Pomerantz, 1977); (d) use of experimental research designs (e.g., Leitenberg & Callahan, 1973; Ricciardi, 2006; Shabani & Fisher, 2006); and (e) long term follow-up (e.g., Macdonald, 1975; Ost et al., 2001). These strengths are briefly discussed below.

**Gradual Exposure to Anxiety-Eliciting Stimulus**

All the studies included gradual exposure to the feared stimulus/situation. Many of these studies had participants arrange a list of anxiety-eliciting situations in order of least to most distressing. By first exposing the child to the least threatening situation, he or she learns to apply and practice coping techniques while facing a situation that is within his/her repertoire. Furthermore, exposing the individual to the least threatening situation first also increases his or her ability to overcome the situation successfully and feel empowered and confident that he/she also can overcome a slightly more distressing situation on the hierarchy. By confronting the anxiety-provoking situation and using
adaptive, coping strategies to overcome it, the individual is reinforced for facing the anxiety-provoking stimulus rather than fleeing from it (Wagner, 2005).

**Parent Involvement**

The importance of parent involvement in helping children with anxiety cannot be overstated. When parents learn to encourage and promote non-anxious, coping behaviors, children fare better in overcoming anxiety (Wagner, 2005). Of the studies reviewed, three studies included parents in the intervention process (Macdonald, 1976; Ost et al., 2001; Pomerantz et al., 1977). In one study, researchers trained the parent to act as the primary interventionist (Pomerantz et al., 1977). One of the advantages of training the parent is that treatment gains are likely to be maintained after the clinician is no longer involved because the parent has learned the skills to sustain the behavior change. As noted by Lucyshyn et al. (2002), parental involvement is a key element in intervention success because “if families can solve problems of child behavior and learning in family contexts, then they can begin to overcome the myriad of caregiving challenges. In so doing, they build a life with their child that is characterized by less stress and more happiness and success” (Lucyshyn et al., 2002, p. 4).

**Use of Experimental Research Design**

An experimental design requires a sequence of conditions that enable causal conclusions regarding the effects of an independent variable (Cooper, Heron, & Heward, 2007). Experimental research designs are the most rigorous because they allow meaningful comparison of the effects of the presence and absence (or different values) of the independent variable (Cooper et al., 2007). All but three of the studies reviewed employed an experimental research design. Some studies randomly assigned subjects to
either a treatment group or a wait-list control group (e.g., Leitenberg & Callahan, 1973; Ost et al., 2001). For example, Leitenberg and Callahan (1973) randomly assigned participants into either treatment or no-treatment conditions. After post-treatment results between the experimental and control groups were compared, participants in the control group also received the treatment. In this way, positive behavior change in participants could be attributed to the independent variable (i.e., treatment for anxiety) and all participants recruited for the study could benefit from the treatment.

All of the studies for children with ASD an anxiety disorder were single-subject studies (Luiselli, 1978; Rapp et al., 2005; Ricciardi et al., 2006; Shabani & Fisher, 2006). Thus, these studies lacked larger subject pools with which to conduct group designs with randomized trials. Studies with a single subject or small group of subjects demonstrated experimental control by employing single subject research methodology (Kennedy, 2005). Single-subject experimental designs that were employed included: (a) ABAB reversal designs (e.g., Shabani & Fisher, 2006; Rapp et al., 2005) and (b) changing criterion designs (e.g., Riccardi et al., 2006). As with experimental group designs, the use of a single-subject experimental research designs is advantageous over traditional case study descriptions or studies that consist of only a baseline and intervention condition because such designs “provide experimental documentation of unequivocal relationships between manipulation of independent variables and change in dependent variables” (Horner, 2005, p. 169).

**Long Term Follow-Up**

It is important the improvements achieved during intervention are durable and sustainable over time. Almost all of the studies reviewed conducted follow-up assessment
2 to 6 weeks after treatment was over. A few notable studies (e.g., Macdonald, 1975; Ost et al., 2001; Rapp et al., 2005) conducted long term follow-up assessment 10 months to 2 years after treatment. Pomerantz et al. (1977) contacted the parent biweekly for 2 months following the intervention and confirmed that the child was no longer afraid of water and took baths regularly without problem, even after the family moved to another state. Shabani and Fisher (2006) conducted a 2-month follow-up and confirmed that the child was no longer afraid of needles and allowed his mother to draw blood and measure his glucose levels without problem behavior on a daily basis. He also was able to remain calm when blood was drawn in new settings, such as the nurse’s office. Long term follow-up and generalization beyond the intervention setting are important elements to treatment success as consumers are seeking long term change and practical intervention that make meaningful differences in their lives (Carr et. al, 1999).

**Potential Treatment Effectiveness Components**

Collectively, the extant literature provides a solid foundation of evidence-based treatment for decreasing anxiety-related problem behavior in children. However, there are a few additional components that were not mentioned in the extant literature that may enhance the effectiveness of intervention for children with ASD that are engaged in anxiety-related problem behaviors. These components are: (a) use of functional assessment; (b) enhanced use of antecedent-based interventions; and (c) consideration of contextual fit with family ecology (O’Neill, Horner, Albin, Sprague, Storey & Newton, 1997; Lucyshyn et al., 2002). These components may further contribute to a successful intervention in which anxiety-related problem behavior are rendered irrelevant and ineffective at achieving their purpose, improvements in child behavior are durable over
time, and support strategies are sustainable within the complexities of family life (Albin, Lucyshyn, Horner, & Flannery, 1996; O’Neill et al., 1997). In the following subsections, I discuss each of these components and their potential contribution to anxiety interventions for children with ASD.

Use of a Functional Assessment

A functional assessment is a systematic method of assessing the individual’s behavior in relation to the environment. Unlike a medical diagnosis, functional assessment does not lead to a simple, prescriptive match for problem behavior. Instead, functional assessment leads to an intervention process in which environments are individualized or redesigned and new skills are taught to replace problem behavior (O’Neill et al., 1997). As noted by O’Neill et al. (1997), functional assessment is “a process for gathering information that can be used to maximize the effectiveness and efficiency of behavioral support” (p. 3). There is substantial evidence for the effectiveness of functional assessment in guiding successful intervention design for children with developmental disabilities (Galensky, Miltenberger, Stricker & Garlinghouse, 2001; Horner, 1994; Magnito-McLaughlin, Mullen-James, Anderson-Ryan, & Carr., 2002; Schwartz et al., 2001). The use of functional assessment is typically not used in the design of anxiety interventions for the typical population. However, for the population of individuals with developmental disabilities, a functional assessment may help identify the setting events, antecedent stimuli and specific consequences that maintain anxiety-related problem behavior. In a meta-analysis of 109 behavioral intervention studies that used an antecedent and/or teaching strategies, Carr et al. (1999) showed that treatment success rates with interventions for atypical populations nearly
doubled when interventions were based on a prior functional assessment. Thus, conducting a functional assessment may offer a more complete picture of the variables that set the stage for, occasion, and maintain anxiety-related problem behavior in children with autism.

**Emphasis on Antecedent-Based Intervention**

Antecedent-based interventions include setting event and antecedent strategies. Setting events are events that change the momentary value of reinforcers. Setting events increase the likelihood that problem behavior will occur but do not directly occasion problem behavior (Horner, Vaughn, Day & Ard, 1996). For example, the characteristics of an anxiety disorder affect the valence of a stimulus and the value of different forms of reinforcement in its presence. The stimulus takes on an aversive valence and the value of escaping the stimulus increases. Support strategies that are designed to minimize or neutralize the setting event increase the likelihood that the anxiety provoking stimulus does not occasion problem behavior, and thus may contribute to the effectiveness of anxiety interventions for children with ASD.

Antecedent strategies modify the antecedent triggers that occasion problem behavior. These strategies are used before a problem behavior occurs in an effort to prevent the problem behavior and occasion desired behavior or alternative replacement behavior (Kern & Clarke, 2005; Miltenberger, 2006). For example, increasing predictability, providing choices, and using visually presented positive contingencies may prevent anxiety-related problem behavior and occasion appropriate behavior in children with ASD who engage in anxiety-related problem behavior (Ahearn, Clark, Macdonald, 2006; Dyer, Dunlap & Horner, 1990; Flannery & Horner, 1994; Miltenberger, 2006).
All of the studies reviewed included the use of gradual exposure, a core antecedent strategy that reduces the aversiveness of the anxiety-provoking stimulus and thus promotes desired child behavior in the presence of the stimulus. However, the studies reviewed did not describe any additional setting event or antecedent strategies that integrated “ecological, preventative, teaching, and consequence strategies into a well-balanced whole that addressed [the] function of problem behavior and the setting events and triggers for problem behavior” (Lucyshyn et al., 2002, p. 21). The importance of designing behavioral interventions based on a thorough understanding of the relationship between setting events, antecedent events and problem behavior is increasingly gaining support in the field of behavioral psychology (Horner et al., 1996; Luiselli, 2006). Doing so when designing interventions for children with ASD and anxiety-related problem behavior may enhance the effectiveness and efficiency of interventions.

**Consideration of contextual fit**

The construct of contextual fit has recently gained currency as an important consideration when designing behavior support plans (Albin et al., 1996; Carr, 1997; Allen & Warzak, 2000). It has been suggested that in addition to building a technically sound behavior support plan, it is equally important to ensure that the plan possesses a good contextual fit with the persons who will be implementing the plan (e.g., parents, teachers) and with the environments in which the plan is to be implemented (e.g. homes, schools). Doing so may increase the likelihood that behavior support plans are acceptable and feasible to consumers, implemented with fidelity by typical agents of change, and sustainable over time in natural environments.
Two studies to date have examined the contributions of contextual fit to the outcomes of behavior support in family settings. Moes and Frea (2000) compared parent implementation of two different interventions for a child with autism in the home; one intervention was prescriptive, based on a functional assessment and evidence-based practices described in the literature. The other intervention was contextualized, based on a functional assessment and collaborative decision making with the family in regard to parent preferences, goals and values, and resources. Results showed that the contextualized approach was associated with higher levels of implementation fidelity, maintenance of behavioral improvement, generalization to a non-trained routine, and high parental ratings of goodness-of-fit.

In a second study by Moes and Frea (2002), the researchers taught three families to implement functional communication training (FCT) with their child with autism within important family routines. Families were first introduced to prescriptive FCT and then to contextualized FCT that was informed by information about each families’ context. Results indicated that the contextualized intervention was associated with improvements in parent perceptions of treatment acceptability and may have contributed to the stability and durability of reductions in problem behavior.

Of the anxiety treatment studies reviewed, none described the gathering of information about family ecology for the purpose of developing a contextually appropriate intervention. Albin and colleagues (1996) described a family ecology assessment that, when administered in tandem with a functional assessment, is designed to enhance the contextual appropriateness of behavior interventions implemented by families. In this assessment, family members in collaboration with the interventionist
identify and define valued family routines in which child problem behavior occurs and that they would like to improve. This is followed by a broader family ecology assessment that identifies family strengths, resources and social supports, stressors, and family goals (Albin et al., 1996). This information is then used to design behavior interventions that build on family strengths, utilize family resources and social supports, aim to diminish family stressors, and address family goals. Use of this assessment tool in collaboration with families of children with ASD and other developmental disabilities has been associated with the design and implementation of behavior support plans that evidenced meaningful and durable improvements in child behavior and participation in family routines (Binnendyk & Lucyshyn, 2009a; Binnendyk & Lucyshyn, 2009b; Cheremshynski & Lucyshyn, 2008; Lucyshyn, Albin, & Nixon, 1997; Lucyshyn et al., 2007). The adoption of such a family ecology assessment within the development of interventions for children with ASD and anxiety-related problem behavior may enhance the contextual appropriateness of the intervention for the family. This in turn may improve treatment outcomes. When an intervention for anxiety-related problem behavior in children with ASD reflects family goals, builds on family strengths, utilizes family resources and social supports, and addresses family stressors, families may be more likely to view the intervention as acceptable and feasible, implement the intervention with fidelity, and sustain the use of the intervention over time.
Positive Behavior Support

Interventions for children with ASD and anxiety-related problem behaviors may be enhanced by including the three additional components described above. Research that integrates evidenced-based components for the treatment of anxiety disorders (i.e., exposure-based treatment, parent involvement, and long-term follow-up) with best practice features of behavior interventions for children with developmental disabilities (i.e., intervention guided by functional assessment, consideration of setting event and antecedent strategies, and attention to contextual fit) may enhance the acceptability, effectiveness, and sustainability of interventions for children with the dual diagnosis of ASD and an anxiety disorder in the natural contexts of family life.

Positive behavior support (PBS) is an emerging evidence-based approach for addressing problem behavior in children that is compatible with evidence-based practice in the treatment of childhood anxiety disorders (Carr et al., 2002; Lucyshyn et al., 2002). PBS is defined as “a collaborative, assessment-based approach to developing individualized interventions for people with problem behavior. Behavior support plans emphasize the use of proactive, educative and reinforcement based strategies to achieve meaningful and durable behavior and lifestyle outcome” (Lucyshyn et al., 2002, p. 9). When applied to children in family contexts, the main focus of PBS is to empower family members to achieve meaningful and durable improvements in child behavior and family quality of life as a whole. Intervention research in PBS has advanced to the point where it is increasingly being recognized as an acceptable and effective approach for addressing the problem behavior of persons with developmental disabilities (Carr et al., 2002; Lucyshyn et al., 2002).
The effectiveness of a PBS approach has been empirically investigated in home and community settings. PBS has been implemented in these settings to: (a) increase adaptive behavior such as functional communication, food acceptance, and participation in valued family routines; and (b) decrease externalizing problem behavior such as aggression, self-injury, and food refusal (Binnendyk and Lucyshyn, 2009; Boettcher, Koegel, McNerney, & Koegel, 2003; Buschbacher, Fox, Clarke, 2004; Clarke, Dunlap & Vaughn, 1999; Galensky et al., 2001; Lucyshyn et al., 1997; Magnito-McLaughlin, Mullen-James, Anderson-Ryan, & Carr, 2002; Moes & Frea, 2000; Vaughn, Dunlap, Fox, Clarke & Bucy, 1997; Vaughn, White, Johnston, & Dunlap, 2005).

There also is emerging evidence of the durability of intervention outcomes when a PBS approach is used. Several studies have shown that treatment gains were maintained 9 months to 2 years post-intervention (Binnendyk & Lucyshyn, 2009; Buschbacher et al., 2004; Carr et al., 1999; Feldman, Condillac, Tough, Hunt, & Griffiths, 2002; Lucyshyn et al., 1997; Lucyshyn et al., 2007). For example, Lucyshyn et al. (2007) conducted a study with a family of a young child with autism across a 10-year period, beginning when the child was 5-years old. The PBS approach was associated with a 93% reduction in problem behavior and improvements maintained up to 7-years post-intervention.

Collectively, research on PBS offers empirical support for the following suppositions: (a) parents are capable of implementing an intervention plan with support from an interventionist; (b) a functional assessment is an important procedure to pinpoint variables related to problem behavior and to inform the design of a multicomponent intervention that addresses the identified variables; (c) a contextualized approach based on collaboration with the child’s parents may lead to a more effective, acceptable, and
durable intervention; and (d) multiple outcome measures beyond decreases in problem behavior (i.e., social validity, goodness-of-fit, quality of life) portrays a more holistic picture of treatment success.

**Table 1.6: Key Features of Positive Behavior Support with Families**

1. **Collaborative partnerships.** Practitioners work with family members in a reciprocal relationship that is respectful, trusting, and caring. Family members are considered to be experts regarding their child and their family culture and ecology.

2. **Family-centered principles and practices.** Practitioners consider the family’s ecology and culture and aim to build on family strengths and capabilities in the behavior support plan. Practitioners strive to empower family members with the knowledge and skills to solve problems on their own.

3. **Meaningful lifestyle outcomes.** Valued outcomes include factors that not only ameliorate the child’s behavior but improve quality of life for the child and family as well.

4. **Functional assessment.** A functional assessment includes a clear description of the problem behavior, antecedents that reliably predict when the problem behavior will and will not occur, identifies the consequences that maintain the problem behavior and is based on direct observations (O’Neill et al., 1997).

5. **Problem behavior as problems of learning.** Problem behavior are viewed as functional for the person engaging in it, thus, intervention consists of re-teaching the child more appropriate ways of meeting one’s need and teaching family members to reinforce these new behaviors.

6. **Communication as the foundation of positive behavior.** Much of problem behavior is due to the individual’s inability to effectively communicate his/her wants and needs. Practitioners work with family members to teach the child to communicate in more appropriate and effective ways (i.e., verbal speech or alternative augmentative devices)

7. **Multicomponent support plans.** A multicomponent support plan addresses each feature of the problem behavior as identified by the functional assessment and includes (a) ecological interventions; (b) preventative strategies; (c) strategies to teach new behaviors/skills; (d) effective consequences; and (e) emergency procedures. PBS emphasizes antecedent strategies such as increasing predictability, choice and enriching environments.

8. **Contextual fit with family life.** Family members are the key implementors of PBS and intervention occurs in the natural context (e.g., the family’s home). Therefore, the support plan must possess a good contextual fit with the child, with family members, and with the family settings in which support strategies will be implemented.

9. **Implementation Support.** Practitioners work closely with family members and train them to deliver the intervention with fidelity. An implementation plan is developed that describes the training and support activities that will be used to empower the family members to successfully implement the PBS plan with the child and improve child behavior.

10. **Continuous evaluation of multiple measures of treatment outcome.** During a process of PBS multiple outcome measures are gathered, including levels of problem behavior and adaptive behavior, parent ratings of social validity and contextual fit, and measures of child and/or family quality of life.
Although there is growing evidence that PBS is an effective approach for children with ASD engaged in problem behavior, a PBS approach has not yet been investigated for children with ASD and anxiety-related problem behavior. The anxiety-related studies reviewed in this chapter described key components of an effective intervention for a child with an anxiety disorder, but no research to date has synthesized these components with the key features of PBS. Lucyshyn et al. (2002) suggested that when the key features of PBS inform the design of an intervention plan, families are more likely to view the plan as acceptable and feasible and are more likely to implement plan components with fidelity. Given this, a family-centered PBS approach may contribute to the existing literature on family-based intervention for children with ASD and an anxiety disorder. Thus, the purpose of the study was to investigate the effectiveness and acceptability of a family-centered PBS approach for decreasing the anxiety-related problem behavior of a child with the dual diagnosis of ASD and an anxiety disorder.

**Research Questions**

The study aims to address the following questions:

- Is there a functional relationship between a family-centered positive behavior support approach and an increase in child participation in a community-based, anxiety-provoking routine?
- Is there a correlation between a family-centered, positive behavior support approach and a decrease in anxiety-related problem behavior for a child with ASD in a community-based, anxiety-provoking routine?
- Is there a correlation between a family-centered, positive behavior support approach and an increase in steps completed in a community-based, anxiety-provoking routine?
• Is there a correlation between a family-centered, positive behavior support approach and the maintenance of improvements in child behavior and routine participation six weeks following termination of implementation support?

• Is the behavior support plan socially valid from the parent’s point of view?

• Does the behavior support plan possess a goodness of fit with the family’s ecology from the parent’s point of view?
CHAPTER 2

Methods

Participant Recruitment

After initial proposal of the study was approved by my research committee, I waited to obtain approval from the Behavioral Research Ethics Board (BREB). After providing additional provisions regarding the study, approval from BREB was obtained (see Appendix A). To recruit a family with a child with ASD and an anxiety disorder, I contacted agency representatives at local agencies that supported children with ASD and provided them with information about the study and the criteria for participant selection. Agency representatives gave a letter of initial contact (Appendix B) to families whom they believed met the criteria for the study.

The criteria for participant selection were (a) a child with ASD between the ages of 4 to 7 years old; (b) auditory comprehension and expressive language ability equivalent to a typical 3-year-old; (c) anxiety-related problem behavior in at least one home-based or community based routine; (d) residence in the Lower Mainland for at least the next 8 months; (e) the child’s parents willing to participate in a process of comprehensive assessment, behavior support plan design and plan implementation in one valued family routine; (f) the family willing to be periodically videotaped in the targeted routine; and (g) the family not experiencing other major stressors in their life.

If a family was interested participating in the study, my contact information was provided so the family could contact me to set up an initial screening interview (see Appendix C). When families contacted me, I explained the purpose of the study and criteria for participation and conducted a brief questionnaire that gathered preliminary
information about problem behavior and the settings in which problem behavior occurred. At the end of the interview, if it appeared that the family met the study’s criteria, I requested the family’s consent to participate in more in-depth screening activities (see Appendix D). These activities included: (a) review and/or administration of the Preschool Language Scale-4; (b) administration of anxiety assessments (Spence Preschool Anxiety Scale-Parent Version and the Parent Interview Schedule of the ADIS for DSM-IV:C); and (c) completion of a family routine assessment with the parents. The preliminary screening recruitment procedures are described below.

**Preschool language scale-4**

Part of the study criteria was to ensure the child had auditory comprehension and expressive language abilities equivalent to a typical 3-year-old. The Preschool Language scale-4 is a standardized assessment that can be used to determine whether or not a child has a language disorder. The PLS-4 can be used to test receptive and expressive language skills with children from 2 weeks through 6 years of age (PLS-4; Zimmerman, Steiner, & Pond, 1979).

**The Spence Preschool Anxiety Scale**

The Spence Preschool Anxiety Scale is an assessment that can be administered by researchers or practitioners. The scale consists of 28 scored anxiety items completed by the parent. Each item is rated on a 5-point Likert-type scale from 0 'not at all' to 5 'very often true' (see Appendix E). It provides an indication of whether a child shows elevated levels of anxiety. It is to be used in combination with a clinical diagnostic interview if a diagnosis is required. It provides a preliminary assessment of anxiety in preschool age
children and can be conducted by practitioners and researchers (Spence, Rapee, McDonald, & Ingram, 2001).

The Parent Interview Schedule of the Anxiety Disorder Interview Schedule

The Parent Interview Schedule of the Anxiety Disorder Interview Schedule for DSM-IV: Child Version (ADIS for DSM-IV:C) was used to determine whether or not the child had a diagnosed anxiety disorder (Silverman & Albano, 1996). It is a semi-structured symptom oriented diagnostic interview targeting children between the ages of six and 18 years old and takes approximately one hour to complete. The ADIS for DSM-IV: C obtains quantifiable data on symptoms and assesses the course and severity of pathology. In addition to assessing for seven types of anxiety disorders, it also includes an assessment of affective disorders and externalizing disorders (Silverman & Albano, 1996). Both the Parent and the Child Interview Schedules of the ADIS for DSM-IV:C have been shown to be “highly reliable for deriving diagnoses with either child or parent information” (Silverman, Saavedera, & Pina, 2001, p.942). Typically, the Child Interview Schedule of the ADIS for DSM-IV:C is conducted with the child, and the self-reported results from the child and parents are compared. It was anticipated that the child recruited for the study would not meet the cognitive requirements necessary to complete the ADIS for DSM-IV:C. Thus, only the Parent Interview Schedule of the ADIS for DSM-IV:C were conducted.

Family Routine Assessment.

I conducted a two-part interview to gather more information regarding anxiety-eliciting routines (see Appendix F). The first part of the interview gathered information related to: (a) valued home and community activities in which the child participates in or
used to participate in; (b) routines or activities that are unsuccessfully due to anxiety-related problem behavior; and (c) which routines are a priority for intervention. The second part of the interview guided the parent to define a successful routine in term of the six elements of family activity settings as described by Gallimore et al. (1993). Information was gathered in regard to the time and place of the routine, the people who were involved, the resources needed to make the routine successful, the steps and sequence of the routine, and the goals and values that was reflected in the routine.

**Pilot Observations**

The final preliminary screening procedure consisted of two pilot observations conducted in the settings identified by the parents during the family routine assessment. If anxiety-related problem behaviors were confirmed in at least one of the settings, the family was given the formal consent form to participate in the study (Appendix G).

**Participant**

One child with Autism Spectrum Disorder and her mother participated in the study. She was 4 years and 6 months old when the study began. The child, Claire (a pseudonym), was diagnosed with autism at the age of 2 years and 2 months. Her parents describe her as being a sweet, affectionate, and social little girl. She liked to play with Barbie dolls, read books, and watch Disney movies. Claire was verbal and spoke in full sentences. Seven months prior to the study, a speech and language pathologist assessed Claries’ language abilities using the Preschool Language scale-4 (PLS-4; Zimmerman, Steiner, & Pond, 1979). Claire’s auditory comprehension was rated at the age equivalent of 3 years 3 months and her expressive communication was rated at 3 years and eight months. I administered the Spence Preschool Anxiety Scale at the family’s home. Results
indicated that Claire’s overall anxiety levels were about three times higher than typically developing 4-year-old children (Spence, Rapee, McDonald, & Ingram, 2001). The Parent Interview Schedule of the Anxiety Disorders Interview Schedule for DSM-IV:C (Silverman & Albano, 1996) was administered by a graduate student at the University of British Columbia over the phone. The assessment was recorded for the purpose of supervision and an integrity check to be conducted afterwards. A registered psychologist completed the integrity check by listening to the recorded phone conversation and looking for discrepancies in data collection. The assessment indicated that Claire’s anxiety met clinically significant levels, warranting a diagnosis for separation anxiety, specific phobia, and social phobia.

Claire was the only child in a Canadian family. She lived at home with her mother and father. Claire’s father, Ben (a pseudonym), was an accountant and worked long hours at the office. Claire’s mother, Dana (a pseudonym), was a stay-at-home mother and the primary parent participant throughout the research and family support process. For several years prior to the study, Dana had struggled with mental health issues. Specifically, she was diagnosed with generalized anxiety disorder (GAD). Dana was on medication and regularly visited a psychologist to keep her anxiety and general well-being at a stable and manageable level.

From the time of Claire’s autism diagnosis, Claire received support from a behavioral consultant. At the time of the study, Claire received approximately 8 hours/week of ABA-based intervention at home. Claire also attended a full-day preschool 5 days a week and received support from a speech and language pathologist and an occupational therapist monthly.
Setting and Materials

One setting, in the form of a family swimming routine in the community, was collaboratively defined with the parent. Dana chose the swimming routine because: (a) it was a priority routine for her and Claire’s father; (b) she believed that she would enjoy taking Claire to the pool; (c) the activity was not weather-dependent; (d) Claire used to enjoy playing in the pool in the past; and (e) the family was planning a trip to Disneyland and she wanted Claire to play in the hotel pool.

After the swimming routine was selected, Dana collaborated with me to define the content and structure of the swimming routine in terms of the concept of an activity setting and its six elements (Gallimore, Goldenberg, & Weisner, 1993; O’Donnell, Tharp & Wilson, 1990). Specifically, Dana described: (a) the time and place of the routine; (b) the people present; (c) the material resources used; (d) the tasks and how they were organized; (e) the family’s goals, values, and beliefs that informed the routine; and (f) the common patterns of interaction that would occur during the routine. I encouraged Dana to generate a vision of the routine that was (a) consistent with Claire’s characteristics, (b) congruent with the family’s goals and values, and (c) sustainable over time.

The envisioned routine that emerged from the interview was summarized into a one-page operation definition (see Table 2.1). Dana subsequently used this definition to structure implementation of the routine during baseline and intervention.
Table 2.1: Operational Definition of Swimming Routine

<table>
<thead>
<tr>
<th>Time and Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Routine occurs either before or after preschool (9:00-10:00 a.m./ 1:30-2:30 p.m.) or on the weekends in the afternoon.</td>
</tr>
<tr>
<td>2. Routine will occur at community pool.</td>
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</table>

<table>
<thead>
<tr>
<th>People Present</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Mother</td>
</tr>
<tr>
<td>2. Child (i.e., 4-year old daughter)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Material Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. bathing suit</td>
</tr>
<tr>
<td>2. towel</td>
</tr>
<tr>
<td>3. change of clothes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mother’s tasks</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Enter pool building with daughter.</td>
</tr>
<tr>
<td>2. Change into bathing suit and help daughter get changed into bathing suit.</td>
</tr>
<tr>
<td>3. Walk out of changing room.</td>
</tr>
<tr>
<td>4. Say “Let’s go swimming”.</td>
</tr>
<tr>
<td>5. Walk with child on pool deck.</td>
</tr>
<tr>
<td>6. Walk with child down pool steps.</td>
</tr>
<tr>
<td>7. Talk and play with child in water for at least 15 minutes.</td>
</tr>
<tr>
<td>8. Walk with child and get out of pool (i.e., get up pool steps).</td>
</tr>
<tr>
<td>9. Walk with child to changing rooms.</td>
</tr>
<tr>
<td>10. Change and help daughter get changed into dry clothes.</td>
</tr>
<tr>
<td>11. Exit pool building.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Child’s tasks</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Enter pool building with mother.</td>
</tr>
<tr>
<td>2. Change into bathing suit.</td>
</tr>
<tr>
<td>3. Walk with parent onto pool deck.</td>
</tr>
<tr>
<td>4. Walk with parent down pool steps.</td>
</tr>
<tr>
<td>5. Talk and play with parent in water at least 15 minutes.</td>
</tr>
<tr>
<td>6. Walk with parent and get out of pool (i.e., climb up pool steps).</td>
</tr>
<tr>
<td>7. Walk with parent to changing rooms.</td>
</tr>
<tr>
<td>8. Change into dry clothes.</td>
</tr>
<tr>
<td>9. Exit pool building with mother.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Child and Family Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Child will overcome anxiety and swim in the community pool.</td>
</tr>
<tr>
<td>2. Child will play with parent in pool for at least 15 minutes.</td>
</tr>
<tr>
<td>3. Family will have a normalized activity they can enjoy together year-round.</td>
</tr>
<tr>
<td>4. Family will not experience stress due to child’s anxiety-related problem behavior.</td>
</tr>
<tr>
<td>5. Family will learn to support the child in a community-based activity.</td>
</tr>
</tbody>
</table>
Assessment activities occurred at the family’s home. The preliminary pilot observation and two baseline probes occurred at the local community pool. However after the second baseline probe, the parent noted that although she had envisioned the swimming routine occurring at the local community pool, the pool did not have a shallow end and had very limited public swim hours (i.e., 9:00-10:00 am on weekdays; 3:00-5:00 pm on weekends). Dana suggested switching to a nearby university pool since Claire attended preschool on the University’s campus. The University pool was very child-friendly and had greater flexibility in public swim hours (i.e., from 9:00 am – 2:30 pm on weekdays; 1:00-5:00 pm on weekends). I spoke with the manager of the University pool and he was receptive to having us conduct the study there. Thus, the third baseline probe and initial training phase sessions occurred at the University pool.

**Measurement**

The study used a multiple probe measurement procedure (Horner & Baer, 1978) to monitor the dependent variables and to document implementation of the independent variable. Observations were conducted intermittently throughout the study. Observation probes were used to provide the basis for determining whether behavior change occurred during each phase of the study. These were referred to as observation probe sessions. Horner and Baer (1978) suggested that the use of a multiple probe technique is appropriate when prolonged baselines are impractical or could have a negative effect on participants. Given the anxiety-eliciting nature of the routine for the child and the parent’s own anxiety issues, a multiple probe measurement procedure was deemed most appropriate. A multiple probe procedure has been shown to be feasible and acceptable to families in PBS research in which parents serve as implementors of positive behavior
interventions in family contexts (Buschbacher et al., 2004; Clarke et al., 1999; Lucyshyn et al., 2007; Vaughn et al., 1997). The basic measurement procedure is described below.

**Equipment and Materials**

Observations during the swimming routine were videotaped using a digital video camera. Afterwards, I converted the digital video tape into .wmv files and observed the downloaded digital observation files in Dr. Joseph Lucyshyn’s lab in the Faculty of Education at the University of British Columbia. The digital observation files were played on Windows Media Player. Windows Media Player automatically displays time passing in seconds as the digital video plays. The second coder and I used this “stopwatch” feature to record data on child and parent behavior. A data sheet and a pencil were used to record target behavior and to calculate interobserver agreement.

**Training Sessions and Observation Sessions**

Two types of sessions occurred during the swimming routine: (a) training sessions; and (b) observation probe sessions. These are briefly described below.

**Training sessions.** Training sessions occurred at the University pool during the intervention phase. The parent, child and I participated in training sessions. During each training session, I implemented the PBS plan with the child and gradually transferred stimulus control to the parent. At the end of every training session, the parent and I filled out an implementation checklist and collected data on the following: (a) the extent to which each support strategy was implemented; (b) steps completed in the routine; (c) steps completed in the anxiety hierarchy; (d) mother’s ratings of the child’s anxiety during the last trial of the targeted step on the anxiety hierarchy; (e) problem behavior
that occurred; and (f) a 3-item social validity check (i.e., whether the goals were appropriate, strategies were effective, and routine was successful).

**Observation probe sessions.** Observation probe sessions were conducted at the University pool. Probe sessions were scheduled on days that were convenient for the parent and at times she had envisioned for the swimming routine (i.e., before or after preschool). On days that an observation probe session was scheduled, support activities did not occur. Before an observation session, the parent and I completed several preparation tasks. I reviewed the operational definition of the envisioned routine with the parent and ensured that the general structure of the routine and necessary materials were present (e.g., bathing suit, towel etc.). I attached a wide-angle lens and a special microphone that captures sounds at a distance on the video camera. During observation probe sessions, I videotaped the child and parent carrying out the swimming routine. I maintained a position approximately 3 feet away from Claire and her mother. I attempted to keep both Claire and her mother in the field of vision, but if Claire stepped outside of the video camera’s field of view, I kept the camera focused on Claire.

To minimize physical, psychological, and sociological risks to the child and family, a criterion level of problem behavior that would terminate an observation session was developed in collaboration with the parent (Carr & Carlson, 1993; Lucyshyn et al., 2007). Prior to the initiation of observation probe sessions, Dana and I agreed on tolerable and intolerable problem behavior that would terminate the routine. If an instance of intolerable problem behavior was observed (i.e., pinching), the routine immediately would be terminated. When five instances of tolerable problem behavior
were observed (i.e., low intensity behavior such as verbal protests) the routine would be terminated.

**Dependent Variables**

The study had eight dependent variables: (a) child steps completed within an anxiety hierarchy for entering the swimming pool; (b) latency in minutes to termination or successful completion of the swimming routine; (c) percentage of steps completed in the swimming routine; (d) percentage of intervals of problem behavior; (e) parent-rated levels of child anxiety; (f) parent implementation fidelity of the PBS plan; (g) parent average rating of the social validity of PBS approach; and (h) parent index of the support plan’s goodness of fit with family ecology. The first dependent measure, child steps completed in the anxiety hierarchy, served as the sole experimental dependent measure; that is, the measure that was evaluated for change within a single subject experimental research design. Latency in minutes, percentage of steps completed, percentage of intervals of problem behavior, and parent average rating of child anxiety were evaluated for change within a case study, time series design. Parent implementation fidelity, parent average rating of social validity, and parent index of goodness of fit served as additional descriptive data.

**Child Steps Completed within an Anxiety Hierarchy**

An anxiety hierarchy is a list of anxiety-evoking stimulus conditions that are sequenced according to the degree of anxiety each stimulus condition is presumed to elicit, from least threatening to most threatening. The anxiety hierarchy is typically developed in collaboration with the child (Bouchard et al., 2004). However, due to the child’s cognitive ability, I was not able to develop the hierarchy with Claire’s
involvement. Instead, the parent and I developed an anxiety hierarchy for Claire that originally included 14 steps. Later, it was evident that going from the edge of the second step of the pool to tapping one foot on the bottom of the pool was too big of a step for Claire. Accordingly, two additional steps were added to ensure that the hierarchy continued to represent a gradual exposure to the anxiety-provoking stimulus throughout the anxiety hierarchy. The revised 16 steps of the anxiety hierarchy are presented in Table 2.2. A registered psychologist at the University of British Columbia approved of the steps in the hierarchy before the intervention was initiated.

At the end of each training session, I recorded each step in the hierarchy that was completed and the number of trials completed at each step. As noted above, the targeted routine was terminated when Claire exhibited: (a) the first instance of intolerable problem behavior or (b) the fifth instance of tolerable behavior. A successful step in the hierarchy was scored as completed when Claire demonstrated the behavioral requirements of the step and the criterion for problem behavior was not reached during the particular step. The percentage of steps in the hierarchy completed in the target routine was calculated by dividing the number of steps in the hierarchy completed by the total number of steps in the hierarchy, then multiplying by 100.
Table 2.2: Anxiety Hierarchy Developed for the Swimming Routine

1. Put toes in and out of the water
2. Sit on edge of pool, put feet in the water
3. Go on first step and get back out of pool
4. Go on first step and put toes on edge of step (i.e., on black line)
5. Go on second step and back up to first step
6. Go on second step and put toes on edge of step (i.e., on black line)
7. One foot tap clipboard 3 inches from bottom of the pool
8. One foot tap clipboard 1 inch from bottom of the pool
9. One toe tap clipboard placed on the bottom of the pool
10. One foot flat on clipboard placed on bottom of the pool
11. Both feet on bottom of pool
12. Stand in pool and splash the water
13. Walk 3 steps to parent in shallow end (i.e., within arm’s reach)
14. Walk 5 steps to parent in shallow end
15. Walk 10 steps to parent in shallow end
16. Splash and play in the water for 15 minutes.

Latency in Minutes to Termination or Successful Completion of Routine

Claire’s problem behaviors were distressing to her mother and possibly for other people at the pool. For this reason, an observation and data recording strategy similar to one developed by Carr and Carlson (1993) was used. A criterion level of problem behavior for terminating the observation of the swimming routine was collaboratively defined with Dana. The criterion balanced the parent’s goal of having Claire participate in a community-based outing with the ethical need to ensure physical safety and minimize psychological risk. The criterion level of problem behavior for terminating the routine is described in Table 2.3.
Table 2.3 Criterion Level of Problem Behavior for Termination of Routine

<table>
<thead>
<tr>
<th>Tolerable behaviors</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Four instances of fearful talk: vocalizations/statements/questions that Claire made indicating that she will get hurt or that she is hurt (although she was not). For example, saying “Ow!” (vocalization), “I’m going to cry!” (statement), or “Are you ok?” (question).</td>
</tr>
<tr>
<td>2. Four instances of verbal protest: vocalizations made such as “No!” or other forms of defiant statements (For example, “No touching!” “No grabbing!” “I don’t want to”).</td>
</tr>
<tr>
<td>3. Physical problem behavior:</td>
</tr>
<tr>
<td>(a) Four instances of screaming.</td>
</tr>
<tr>
<td>(b) Four instances of physical resistance: resisting adult assistance to complete the task (i.e., getting in the pool). Examples include leaning away from the adult or swatting adult’s hand away when adult reaches to hold her hand.</td>
</tr>
<tr>
<td>(d) Four instances of leaving assigned area: assigned area for the pool is defined as moving away from the path way towards the pool entrance when entering the pool and moving away from the pathway towards the changing room when leaving the pool.</td>
</tr>
<tr>
<td>(e) 1 minute of a tantrum: flopping to the floor accompanied by screaming, crying or verbal protest</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Intolerable behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The first instance of physical aggression: defined as negative physical contact toward another person that causes distress, pain or injury. Examples include hitting or pinching.</td>
</tr>
</tbody>
</table>

Latency to termination of the swimming routine due to anxiety-related problem behavior was defined as the number of minutes that elapsed between the initiation of the routine and: (a) the first instance of intolerable problem behavior; or (b) the fifth instance of tolerable problem behavior. Latency to successful completion of the routine was defined as the time to completion of all critical tasks in the routine without the criterion level of problem behavior occurring at any step of the routine.

Either Claire’s mother or I made the decision to terminate an observation because of problem behavior. When the frequency of problem behavior met the criteria for termination, I prompted Dana to stop the routine. After the swimming routine was terminated, Dana guided Claire back into the change room. When I was not sure if the criteria for terminating a session was met (e.g., how many times Claire resisted holding
her mother’s hand) I continued to videotape until I was certain that the criteria was met. In this event, I determined the latency in minutes to the criterion level of problem behavior by observing the videotape and evaluating the frequency of problem behavior exhibited by Claire during the routine.

If the criterion for termination due to problem behavior did not occur, the observation session continued until the routine was completed. If the swimming routine was completed successfully, I used the observation data file’s time to record the total time of the routine.

**Percentage of Steps Successfully Completed in Target Routine**

The parent and I identified nine steps in the swimming routine. These steps were defined as follows: (1) walk on the pool deck towards the pool entrance; (2) walk to the shallow end of the pool and stand at the edge of the pool at the entrance of the pool steps; (3) go down the first step (4) go down the second step; (5) take the last step and stand in the pool; (6) walk into the pool; (7) splash and play in the water (e.g., kicking/splashing the water for 15 minutes); (8) climb up the pool step(s) and out of pool and (9) walk back to the change room.

A “successful step” was marked as completed when Claire executed all of the behavioral requirements of the step and the criterion for termination due to problem behavior was not reached during that particular step. If all of the steps were successfully completed, I recorded each step as it was completed in the routine up to the last step. In contrast, if during any step, the criteria termination due to problem behavior was reached, the step was considered unsuccessful and observation of the routine was terminated. When this occurred, I recorded the number of steps successfully competed before
termination of the routine. The percentage of steps successfully completed in target routines was calculated by dividing the number of steps completed by the total number of steps, then multiplying by 100.

**Percentage of Intervals of Problem Behavior**

Anxiety-related problem behavior was divided into three categories: (a) anxious talk; (b) verbal protest; and (c) physical problem behavior. Anxious talk was defined as vocalizations/statements/questions that Claire made indicating that she will get hurt or that she was hurt (although she was not). These included for example, saying “Ow!” (vocalization), “I’m going to cry!” (statement), or “Are you OK?” (question). Verbal protests were defined as vocalizations such as “No!” or other forms of defiant statements (e.g., “I don’t want to!” “You can’t make me,” “No grabbing me”). Physical problem behaviors included: (a) screaming; (b) crying; (c) physical resistance (i.e., pulling hand away when parent tried to hold her hand; turning body away from parent when parent tried to physically guide the child); (d) physical aggression (e.g., hitting or pinching); (e) leaving the assigned area (i.e., moving away from the pathway towards the pool steps); and (f) tantrum (i.e., flopping to the floor accompanied by screaming, crying or verbal protest).

A partial-interval recording system using 10 second intervals was used to measure the percentage of intervals of the occurrence of problem behavior (see Appendix H). If problem behavior was observed at any time during the 10 second interval, the interval was scored as an “occurrence.” If problem behavior was not observed during the 10 second interval, the interval was scored as a “non-occurrence.” The percentage of intervals of problem behavior was calculated by dividing the number of intervals in
which Claire engaged in problem behavior during the swimming routine by the total
number of intervals, and then multiplying by 100.

**Parent-Rated Levels of Child Anxiety**

At the end of each observation session, Dana indicated how anxious she perceived Claire to be on a 5 point Likert-type scale (see Appendix I).

**Parent Implementation Fidelity of PBS Plan**

The degree to which an independent variable is implemented as intended is known as treatment integrity (Peterson, Homer, Wunderlich, 1982). Treatment integrity “is necessary, but not sufficient, for the demonstration of a functional relationship between experimenter-manipulated independent variables and dependent variables” (Gresham, 1993, p. 257). The independent variable in this study was a positive behavior support plan designed to improve child behavior and participation in a community-based routine. Parent implementation fidelity of the PBS plan was determined by measuring the extent to which the parent implemented PBS strategies accurately within the targeted routine.

Parent implementation fidelity of the PBS plan was defined as accurate implementation of the following ten positive behavior support strategies (see Table 2.4): (a) gradual exposure; (b) visual schedules; (c) positive contingency statement(s); (d) safety signal(s); (e) pro-active pre-corrective statement(s); (f) choices; (g) contingency map; (h) brave talk; (i) contingent praise/tangible reinforcement; and (j) redirection when problem behavior occur. These strategies constituted the core components of the multicomponent behavior support plan that Claire’s mother implemented in the swimming routine. I scored both intervention observation probe sessions for parent
accurate implementation of intervention components. A partial-interval recording system was used to score parent implementation of strategies (see Appendix J). Parent behavior was scored as the percentage of 30-second intervals of accurate implementation. During each 30 second interval, the parent’s accurate implementation of one or more strategies was scored as an “occurrence.” If the parent engaged in an error in the implementation of one or more strategies during an interval, the interval was scored as an “occurrence-error” interval. If use of one or more strategies did not occur during an interval, the interval was marked as a “non-occurrence.” The percentage of intervals of implementation fidelity was calculated by dividing the number of intervals the parent exhibited accurate use of the support strategies by the total number of intervals and then multiplying by 100.

Table 2.4: Operational Definitions of Positive Behavior Support Plan Procedures

1. **Gradual exposure:** The parent uses the anxiety hierarchy to gradually and systematically expose Claire to the anxiety-provoking situation. The parent does not verbally request or physically prompt the child to go beyond the step she is currently working on. The parent does not move up the anxiety hierarchy until Claire is showing no anxiety at the current step. The use of gradual exposure is scored if the parent does not verbally ask or physically prompt the child to go beyond the targeted step.
   a. Example: “Today let’s go to the second step of the pool”
   b. Non-example: picking up the child and putting her in the pool

2. **Visual schedule:** The parent visually shows Claire the exact order of events that will occur using either: (a) each step arranged on a velcro strip with Boardmaker PCS; or (b) the written list of “Today’s swim schedule.” The use of visual schedule is scored if: (a) the parent reads out the entire schedule before initiating the routine and/or (b) parent refers back to the visual schedule or written schedule at each step of the routine.

3. **Positive contingency statements:** A contingency statement involves the parent telling the child what to do and what the child will get after doing the requested behavior (i.e., “After you [do behavior], you can have [reinforcer]”). The reinforcer can be a preferred item (e.g., mermaid doll) or a preferred activity (e.g., singing together). A positive contingency statement is scored when the contingency statement is made before a significant problem behavior occurs.
   a. Example: “go down to the 2nd step and then you can have a chocolate chip!”
   b. Non example: “go and swim, it’s so much fun!”
Table 2.4 Operational Definitions of PBS Plan Procedures continued

4. Safety signals
A safety signal is a verbal cue that communicates to the child when a mildly aversive event is terminated (e.g., going in the swimming pool). A safety signal statement is scored when the statement is made before problem behaviour occurs.
   a. Example: “Just one more step and then you’re all done!”
   b. Non example: “Just go one step and you can have a treat!” (positive contingency statement)

5. Pre-corrective statements: defined as a proactive reminder given to the child of what appropriate behavior is expected. Use of verbal pre-correct is scored when the statement is made before a problem behavior occurs.
   a. Example: “Remember, if you need a break, you can say to mommy ‘I need a break’ or ‘wait one minute’ and Mommy will give you a break”
   b. Non example: “You can’t scream, I want you to use nice words” (statement given after problem behavior occurred)

6. Choices: A choice is when the parent allows Claire to make a decision during the swimming routine. For example, the parent may give Claire a choice of: (a) where she wants to enter in the pool (e.g., three different rails in the shallow end) and/or (b) a reinforcer (e.g., mermaid doll, chocolate chips). A choice does not necessarily require Claire to choose between two options (i.e., “Do you want [X] or [Y]”), if Claire understands the choices, the parent can use a more general question (i.e., “What do you want to do?)
   a. Example: “Today we’re learning to go to the 2nd step. After you try that, do you want the mermaid doll or a chocolate chip?
   b. Non example: “Here’s a chocolate chip.”

7. Contingency map: A contingency map shows Claire the pathways of appropriate and inappropriate behavior and the consequences that will follow for appropriate and inappropriate behavior. This step is scored if the parent reviews the contingency map with Claire before initiating the pool routine (e.g., on the pool deck) and/or if the parent reviews it before the third instance of tolerable problem behavior (i.e., anxious talk).

8. Brave talk: Brave talk occurs in three different situations. In the first situation, brave talk is defined when the parent encourages Claire to continue working on the targeted step in the anxiety hierarchy. The parent does not validate vocalizations, statements, or questions that Claire makes about being hurt or that she will get hurt (when she is not hurt). The parent ignores the anxious talk and redirects and models brave talk.
   a. Example: “That didn’t hurt, let’s go down to the 2nd step!
   b. Non example: “Oh no, are you OK?”
Table 2.4 Operational Definitions of PBS Plan Procedures continued

In the second situation, the parent models positive statements about swimming and re-assures Claire that the pool is a safe place and she will get a break.
   a. Example: “Being in the water is so nice!” “We’re safe in the pool!”
   b. Non example: “The water is too cold” “Be careful!”

In the third situation, in the highly unlikely event that Claire does get hurt while at the pool, the parent models calm talk and re-assures Claire that she will be OK
   a. example: “It’s OK, take a deep breath, you’re going to be just fine.”
   b. non example: “Oh no! Are you OK?”

9. Contingent praise/ tangible reinforcement: The parent delivers praise contingent on desirable behavior (within 3 seconds). Praise may be comprised of an evaluative comment and/or a descriptive comment.
   a. Examples: “Good job going down to the 2nd step!” “You are so brave standing in the pool!”
   b. Non example: “You can do it, you are such a brave girl!” (brave talk)

10. Redirecting when minor problem behavior occurs: If Claire engages in minor problem behavior (e.g., verbal protest, leaving assigned area) less than 3 times, the parent redirects Claire to the contingency map and reminds Claire of what she will receive if she completes the task.
   a. Examples: “Remember, if you scream at the pool, you don’t get M&Ms but if you listen to mommy and go on the 2nd step, you can have an M&M.”
   b. Non examples: “No screaming at the pool.”

Parent Average Rating of the Social Validity of the PBS approach

Claire’s mother also evaluated the social validity of the intervention approach.

Two social validity questionnaires were developed - a formal social validity questionnaire designed by Lucyshyn, Albin and Nixon (1997) and a 3-item brief social validity measure (Appendix K). I was unable to administer the formal social validity questionnaire before the parent’s conditional withdrawal from the study. I administered the brief 3-item social validity measure after each training and observation probe session. I read aloud each item on the questionnaire and the parent rated her agreement with three statements related to social validity. The statements were: (a) the goals of the plan are appropriate for my child; (b) the strategies/procedures are effective in improving my
child’s behavior and (c) the swimming routine was a success. The parent indicated her agreement with the statements using a 5 point Likert-type scale (1 = disagree; 5 = agree).

**Goodness-of-Fit of the PBS approach**

Contextual fit refers “to the congruence or compatibility that exists between specific features and components of a behavioral plan and a variety of relevant variables relating to individuals and environments” (Albin et al., 1996, p. 82). A goodness-of-fit assessment indicates the degree of suitability between the intervention support and the unique characteristics of the child and family (Bailey et al., 1990). A condensed, adapted version of the goodness-of-fit survey created by Albin et al. (1996) was used. The adapted version consisted of 12 items that sample across five parameters related to goodness-of-fit: (a) goals and expectations; (b) support roles; (c) congruence to lifestyle; (d) implementation effort and; (e) sustainability. The goodness of fit questionnaire was administered during the initial training phase. I gave the parent the questionnaire at the end of a training session and asked her to complete it at home and return it to me. The parent rated each item using a 5-point Likert scale (e.g., 1 = not at all, 5 = very well). The goodness of fit measure is present in Appendix L.

**Interobserver Agreement**

**Observer Training**

I was the primary observer conducting observations at the pool, downloading digital files onto the computer in the lab and coding the data. I trained another graduate student in the Faculty of Education at the University of British Columbia to serve as an interobserver agreement coder. The second coder coded 40% of all observation sessions balanced across baseline and intervention phase. Dependent measures that were coded
from the digital observation files were: (a) percentage of steps in the anxiety hierarchy completed; (b) latency to termination or successful completion of routine; (c) percentage of steps successfully completed in the target routine; (d) percentage of intervals of problem behavior; and (e) percentage of intervals of parent accuracy in the use of PBS plan strategies. Training materials provided to the second coder included: (a) instructions for observing video files on the computer; (b) data sheets; (c) operational definitions of dependent measures; and (d) examples and non examples of child problem behavior and parent accuracy of use of strategies. I trained the second coder to: (a) use the computer in the University lab to code data using Microsoft Windows Media Player; and (b) score dependent measures using designated data sheets. Training continued until we obtained 85% interobserver agreement across two consecutive observation sessions of the targeted routine. Samples of observation probe sessions from the baseline phase were used to practice coding percentage of intervals of problem behavior and percentage of steps successfully complete.

Once the PBS plan was designed and detailed operational definitions were developed for coding parent implementation fidelity, observer training for coding parent implementation fidelity of the PBS plan began. Due to the parent’s conditional withdrawal from the study, only two intervention phase observation probe sessions were collected. One of these was for training purposes. The second intervention phase observation probe session was coded independently for parent treatment integrity interobserver agreement.
Interobserver Agreement Procedure

To measure interobserver agreement, the second coder and I independently observed the same digital video files of an observation probe session and measured each of the following variables for agreement: (a) percentage of steps in the anxiety hierarchy completed (b) latency to termination or successful completion of routine; (c) percentage of steps in target routine completed; (d) percentage of intervals of problem behavior; and (e) percentage of parent accurate use of PBS plan strategies. IOA for each of the variables was calculated by dividing the number of agreements by the total number of agreements plus disagreements, and multiplying by 100 (i.e., A/(A+D) x 100, where “A” equals total agreements and “D” equals total disagreements). IOA checks were completed on at least 33% of the observation probe sessions, balanced across baseline and intervention phases.

Specific interobserver agreement procedures for each dependent variable are described below.

IOA for steps-in-anxiety-hierarchy-completed. The second coder and I independently observed the same digital video file of an observation probe session. We each had a checklist of all the steps in the anxiety hierarchy. Then we observed the digital video file and scored whether the targeted step was successfully completed during the swimming routine (either an occurrence or non-occurrence). An agreement is defined when the second coder and I both recorded either an occurrence or a non-occurrence during the swimming routine. The average agreement for intervals of problem behavior across all probe sessions was 100%.

IOA for latency to termination or successful completion of routine.

Interobserver agreement for latency to termination or successful completion of the
swimming routine was measured using a checklist that described the criterion level of intolerable behavior and tolerable behavior that required termination of the probe session. Interobserver agreement for the latency to termination or successful completion of a routine was measured using a checklist that listed the steps of the routine and reserved a space to note the time that the last step of the routine was completed. The second coder and I, separated by 1 meter and a visual barrier, simultaneously observed the digital video file of the observation probe session. If a criterion behavior occurred, the behavior was noted on the checklist. When the criterion level of problem behavior occurred (e.g., the first intolerable behavior, or the fifth instance of tolerable behavior), the behavior and time of termination was noted on the checklist. If the criterion level of problem behavior did not occur, the observers noted the time the routine was completed successfully. A margin of +/- 5 seconds was used to assess the agreement between times noted by each observer. Occurrence agreement for the termination of the session due to problem behavior was calculated by dividing the number of agreements of behavior(s)/time(s) to terminate a session by the number of occurrence agreements plus disagreements and multiplying by 100%.

Interobserver agreement for latency to successful completion of the swimming routine was calculated in two ways. Non-occurrence agreement for the criterion level of problem behavior (i.e., two observers independently agreed that the criterion level of problem behavior did not occur) was calculated by dividing non-occurrence agreement by non-occurrence agreement plus disagreement and multiplying by 100%. Occurrence agreement on latency to successful completion of the swimming routine (i.e., all the critical steps in the operationally defined routine were completed) was calculated by
dividing agreement (i.e., the time all of the steps in the routine were completed by agreement plus disagreement and multiplying by 100%).

Interobserver agreement for latency to termination or successful completion of the routine was completed with the second coder on 40% of observation probe sessions. Agreement checks were balanced across baseline and intervention. The average occurrence agreement across all latency to termination due to problem behavior was 100%. The average occurrence agreement across latency to successful completion of routine was 100%.

**IOA for percentage of steps successfully completed in targeted routine.** The second coder and I independently observed the same digital video file of a observation probe session. Using a checklist that described each step in the routine, we scored the number of: (a) steps successfully completed during the target routine (an occurrence); (b) steps not successfully completed (a non-occurrence); and (c) steps for which an opportunity was not presented, although required (a missed opportunity non-occurrence). An agreement was defined as both the second coder and I recording an occurrence, a non-occurrence or a missed opportunity non-occurrence during the same step of the routine. The average agreement for steps completed across all probe sessions was 100%.

**IOA for percentage of intervals of problem behavior.** The second coder and I independently observed the same video recordings of observation probe sessions and scored the number of 10 second intervals in which: (a) problem behavior was observed during the swimming routine (an occurrence); and (b) problem behavior was not observed during the swimming routine (a non-occurrence). The second coder and I coded each 10 second interval using the same operational definitions of problem behavior. An
agreement was defined as the second coder and I independently recording an “occurrence” or a “non-occurrence” of problem behavior during the same 10 second interval. The average agreement for intervals of problem behavior across all probe sessions was 94% (range, 93 to 95%).

**IOA for parent implementation of PBS plan strategies.** The second coder and I independently observed the same digital file of an observation probe session and scored the number of 30 second intervals in which: (a) the parent displayed accurate use of strategies in the family’s PBS plan (an occurrence); (b) the parent displayed inaccurate use of strategies in the family’s PBS plan (an erroneous occurrence); or (c) the parent was not observed using any of the strategies in the family’s PBS plan (a non-occurrence). An agreement was scored when both the second coder and I recorded an occurrence, an erroneous occurrence, or a non-occurrence of a strategy during the same 30 second interval. IOA for parent implementation fidelity was completed on 50% of probe sessions (i.e., 1 of 2). The average agreement across all support strategies was 91%.

**Research Design**

The study employed an experimental, single-subject, changing criterion design and a case study time-series design, using a multiple-probe strategy (Kennedy, 2005). The design had three phases: (a) baseline; (b) intervention (consisting of initial training and support and maintenance support); and (c) follow-up. Three baseline observation probe sessions were conducted to establish stable levels of problem behavior in the swimming routine. After baseline measurement, the intervention was implemented across a series of intervention sub-phases (i.e., gradual progression using the anxiety hierarchy). Each intervention sub-phase was represented by an *a priori* stepwise change
in the criterion level for target behavior along the anxiety hierarchy. Each sub-phase thus provided the equivalence of a baseline for the next sub-phase. Within a changing criterion design, experimental control is demonstrated when the level of behavior (i.e., Claire’s level of participation in the anxiety hierarchy for entering and playing in the pool) changes with each stepwise change in the present criteria on the anxiety hierarchy. Experimental control is demonstrated if it can be shown within the design that levels of responding do not change until the criterion is changed, regardless of the varied lengths of the sub-phases (Hartman & Hall, 1976).

A changing criterion design was employed to document progress along the anxiety hierarchy because it met the criteria as described by Horner et al. (2007) for use of the design. The design was appropriate because: (a) the target behavior was a behavior in the child’s repertoire that could be changed gradually; (b) the terminal goal was best approached gradually (i.e., gradual exposure to the next step on the anxiety hierarchy vs. forcing the child to go into the pool); (c) the problem behavior associated with the swimming routine was not so dangerous that behavior needed to be changed rapidly; (d) the independent variable included contingent use of reinforcement; and (e) withdrawal/reversal was impractical.

A case-study time series design was used to investigate the association between the PBS intervention and latency in minutes to termination or successful completion of the routine; percentage of steps completed in the routine; percentage of intervals of problem behavior; and parent ratings of the child’s level of anxiety. This design does not control for all threats to internal validity and as a result is unable to verify, unequivocally, a functional relationship between independent and dependent variables. Thus, a
functional relationship is based solely on steps completed in the anxiety hierarchy in the experimental, changing criterion design as described above. Nevertheless, Kazdin (1992) argued that, although case-study designs are not a substitute for experimental designs, case-study designs are strong designs that can contribute greatly to the development of scientifically useful information.

The multiple-probe technique was used because it avoided repeatedly exposing Claire and the parent to observation probes of the swimming routine prior to and during intervention. Given the parent’s own anxiety, it was crucial to minimize psychological risk and refrain from exposing the parent to the swimming routine before intervention anymore than necessary to establish a stable baseline (i.e., three baseline observation probe sessions). Also, observation probe sessions caused the parent some anxiety so it was beneficial during the intervention phase to use the multiple-probe technique during the intervention phase to reduce the number of video-taped intervention probe sessions. Thus, considering the anxiety-provoking nature of the routine for both Claire and her mother, continuous measurement during baseline and intervention phase may have been harmful to the child and parent. Horner and Baer (1978) indicate that in such situations, a multiple-probe technique should be employed. The multiple-probe design has been shown to be a rigorous, practical and time-efficient alternative to a traditional multiple baseline design (Murphy & Bryan, 2001).

**Collaborative Model**

A collaborative research model that integrated features of a Participatory Action Research (PAR) approach was employed for this study. A PAR approach refers to a process whereby “researchers and stakeholders (those who potentially benefit from
research results) collaborate in the design and conduct of all phases of the research process” (Turnbull, Friesen, & Ramirez, 1998, p.178). Turnbull and colleagues describe six levels of family participation that illustrate the extent of family involvement in decision making throughout the research process. In level 1, families have no involvement in influencing the purpose, content or direction of research. In level 6, families serve as co-researchers and are involved in every aspect of the study such as developing a research question, operationally defining dependent variables and selecting the research design (Turnbull et al., 1998).

In this study, the parent’s involvement was at level 4. The parent was not involved in selecting the research design, defining the research question, or analyzing and interpreting the results. Decisions regarding those aspects of the research were made in collaboration with my thesis advisor. However, the parent and I both were active decision-makers in other aspects of the study. In this collaborative research model, the parent: (a) participated in the comprehensive assessment (i.e., family ecology assessment, functional assessment, reinforcer assessment); (b) selected and defined the target routine; (c) helped define the primary dependent variables (e.g., steps in the anxiety hierarchy, problem behavior, steps completed); (d) participated in the selection of strategies for the PBS plan; (e) collected data (i.e., filled out the implementation checklist, completed the social validity and goodness of fit measures); (f) participated in solving problems that occurred during the study (e.g., adding additional steps in the hierarchy when Claire was not making progress) and (g) participated in working out procedural details. These included setting criteria for terminating an observation probe sessions, scheduling training sessions and data collection sessions, and determining the length of sessions.
A collaborative research model was appropriate for several reasons. First, given the parent’s history of anxiety, I needed to have the parent involved so I could adapt each step of the study to her needs. It was important that the parent did not feel overwhelmed by any feature of the study. It was also important to demonstrate that a parent with an anxiety disorder could collaborate and help implement a positive behavior support plan with her child with autism and an anxiety disorder. Second, collaboration allows for the collection of more types of data in a variety of settings and across longer periods of time (Albin et al., 1996). Involving the parent allowed me to collect multiple measures of intervention success (i.e., parent-rated levels of child anxiety, parent implementation fidelity of PBS plan, goodness of fit with family ecology). Third, collaboration helped facilitate “buy-in” with the intervention and helped promote interest and willingness on the part of the parent to stay involved in the intervention process. When a parent is treated as a valued partner in the research, the parent may feel more invested in the study. Social and ecological validity also are enhanced which could contribute to the sustainability and durability of intervention outcomes. Finally, a collaborative model was chosen because I wanted to empower the parent. I wanted the parent to gain a functional perspective of problem behavior. Moreover, I wanted the parent to be competent in generalizing the skills she learned to: (a) novel swimming pools with other people (e.g., the hotel pool at Disneyland, community pool with dad); and (b) across new and non-trained contexts (i.e., other anxiety-eliciting routines).

**Independent Variable**

The independent variable was a PBS approach to ameliorating anxiety-related problem behavior and consisted of four key components: (a) comprehensive assessment;
(b) PBS plan development; (c) implementation support plan development; and (d) implementation support.

**Comprehensive Assessment**

Prior to development of the positive behavior support plan, the following activities were completed: (a) family ecology assessment (b) functional assessment; (c) assessment of steps in target routine; (d) construction of the anxiety hierarchy; and (e) reinforcer assessment.

**Family ecology assessment.** The goal of the semi-structured interview was to gather information about the family’s ecology that would help me understand the family’s strengths, stressors, supports and resources, and goals (Lucyshyn, Kayser, Irvin, & Blumberg, 2002). As presented in Appendix M, the parent was asked six open-ended questions that helped me understand the family’s life. The information helped me design an intervention that possessed a good contextual fit with the family’s ecology. The assessment took about an hour to complete. The results of the interview are summarized below.

Dana described her over-arching goals as wanting Claire to be happy, healthy, and to do well in school. She described her desire for Claire to be more independent and try new things. Specific to the swimming routine, Dana wanted Claire to overcome her anxiety and enjoy going to the pool so they could have an activity that they could do together in the community. Dana shared her own anxiety about feeling judged negatively by other people. Her own personal goal was to refrain from allowing other people’s opinions or perceived opinions of Claire to affect her own well-being as a parent of a child with autism. Dana also described a family goal. She wanted her family to be able to
go on a vacation together and enjoy each other’s company. The family had booked a trip to Disneyland, and she wanted Claire to enjoy playing in the hotel pool.

To these goals, the family brought many strengths and resources. Dana reported that the encompassing strength of her family was their close-knit nature and Dana’s unconditional love for Claire. She reported that she and her husband had a strong marriage and made spending time together a family priority. The family also had an extensive system of social support. Claire’s grandmother (Dana’s mother) was a huge source of social support in the family. Dana spent time with her own mother almost every day. Other sources of support included the mother’s psychologist, Claire’s behavioral consultant, the team of behavioral interventionists that worked with Claire, and relatives and friends who lived close to the family. In addition, Dana reported that the family had recently returned to going to church and that she felt warmly supported by a caring community of Christian believers. Moreover, Dana stated that she was relieved that, although the autism funding they received was not enough to pay for all of Claire’s educational and behavioral support services, her husband provided a good income and they had enough money to pay for the services that Claire was receiving.

Despite the family’s many strengths and resources, the parent also described several significant stressors. One recurrent stressor was Dana’s mental health. She discussed how her anxiety disorder (i.e., GAD) caused her to frequently worry about Claire. Dana however informed me that although she often worried about Claire, it had been years since she was mentally unstable. She informed me that she was taking medication regularly and was regularly receiving counseling from a psychologist. She said that it was sometimes difficult to “keep it all together” and she worked hard to keep
her anxiety from interfering with being a loving, responsive, and patient parent to Claire. One specific area that Dana worried about was other people’s perception of Claire and how she was perceived as a parent. Dana’s anxieties were often focused on what other people thought about Claire. This caused Dana to avoid some social situations in which Claire might act inappropriately. Dana also mentioned that due to her anxieties about how Claire might behave, the family was very selective about the people they visited or had over to their house. Since Claire’s diagnosis, she regretted that they had lost many friends and did not entertain or go out as often as they used to. Another stressor was Claire’s sleep habits; Claire went to bed at a consistent time but talked out loud for hours before falling asleep and frequently woke up during the night. This caused Claire’s mother to get very little sleep at night.

**Functional assessment.** A functional assessment is a method of assessing the purpose or function of problem behavior in relation to its context and gathering information about problem behavior that can be used to design an efficient and effective behavioral support plan (O’Neill et al., 1997). I conducted a functional assessment interview (FAI) and a functional assessment observation (FAO) with the participating family. The FAI took approximately 60 minutes to complete. After the FAI, the parent and I developed hypotheses about: (a) the function of anxiety-related problem behavior; (b) setting events that set the stage for anxiety-related problem behavior; (c) immediate antecedent stimuli that triggered problem behavior; and (d) events or situations that predicted positive behavior.

Following the formation of a hypothesis, I conducted a functional assessment observation (FAO) to confirm the hypothesis formulated by the FAI. The FAO involved
the direct observation of the swimming routine. Videotaped observation sessions during baseline were reviewed for the FAO. Using the FAO form, I observed the digital video files and documented the time problem behavior occurred, the antecedents and the consequences of problem behavior and my perception of the function of problem behavior during the event in which the behavior occurred. The functional assessment focused on all of the contexts in which problem behavior that occurred. However for the sake of brevity, functional assessment results related only to the swimming routine are summarized below.

The functional assessment indicated that Claire engaged in three categories of problem behavior specific to the swimming routine: (a) anxious talk; (b) verbal protest; and (c) physical problem behavior (which included screaming, crying, physical resistance, physical aggression, and tantrums). The functional assessment confirmed the perception that the anxiety-related problem behavior occurred at the swimming pool.

During the swimming routine, several ecological conditions appeared to contribute to Claire’s problem behavior. The main setting event was the parent’s own anxiety issues. Claire’s mother was anxious about taking Claire out in the community, especially doing new things (e.g., going to the swimming pool, going to the playground, going on play dates etc.) where it was likely that Claire might not behave appropriately. She also worried that if Claire engaged in problem behavior, bystanders would perceive her to be an incompetent parent. Due to her anxiety, the parent sometimes unknowingly modeled anxious behavior in the form of anxious talk. At times, when Claire engaged in anxious talk that was unsubstantiated (e.g., saying “You hurt me” when her mother reached for her hand), the parent apologized and stepped back. Another way that the
parent modeled anxiety was giving the child an opportunity to choose to go swimming or not. By allowing Claire to choose not to participate in novel activities (i.e., swimming), the mother reinforced both her own anxiety and Claire’s anxiety. As discussed by Muris et al. (1996) and by Whaley et al. (1999), observational learning theory and verbal information transfer offer an explanation as to how Dana may have influenced Claire’s anxiety disorder through modeling, shaping, and reinforcing anxious behavior.

The antecedent that provoked problem behavior was the parent’s request to the child to engage in the novel activity (i.e., get in the pool). If the parent tried to physically prompt Claire to get into the pool (i.e., hold her hand, gently tap her back towards the steps), problem behavior increased. Finally, the parent’s responses to problem behavior appeared to strengthen these behaviors. For example, when Claire screamed or verbally protested, the parent moved away and Claire did not have to go into the pool. The hypothesis derived from the functional assessment was that Claire engaged in problem behavior to escape the demand to engage in a novel task (i.e., get into pool).

**Construction of the anxiety hierarchy.** Bouchard et al. (2004) recommended that an anxiety hierarchy be constructed in collaboration with the child. However, due to the child’s cognitive level, this was not possible. Thus, the parent and I created an anxiety hierarchy. The parent and I discussed different scenarios related to the swimming routine and assigned a numerical value to each scenario. The scale ranged from 1 to 10 with 1 indicating minimal/no anxiety; 5 indicated moderate anxiety; and 10 indicated extreme anxiety. For example, “standing on pool deck watching people swim” was rated as 1 and “go on first step and get back up on the pool deck” was rated as 4. The items were sequenced according to the degree of anxiety the situation was perceived to elicit (King et
Construction of the anxiety hierarchy had two purposes: (a) to expose Claire to the least threatening item on the anxiety-hierarchy first (i.e., put toes in and out of the water) and gradually increase to more anxiety-provoking items (i.e., go down first step, second step etc.); and (b) to measure for the percentage of steps in the anxiety hierarchy completed. An anxiety hierarchy consisting of 16 steps was used to gradually expose Claire to the terminal goal of playing in the pool for up to 15 minutes with her mother.

Reinforcer assessment. I used a reinforcement assessment procedure known as the multiple stimuli without replacement procedure to determine and rank order Claire’s preferences. DeLeon and Iwata (1996) evaluated the multiple stimulus assessment procedure and found it to be simple to administer and effective at identify functional reinforcers. I discussed with the parent what toys and/or edibles the child liked and for which she might be motivated to work. The parent said that Claire liked anything to do with Disney princesses, Barbie dolls, My Little Ponies, and Disney music. Initially, the parent wanted to refrain from using edibles and so four toys were used during the assessment. They were a Barbie Fairytopia Magic Mermaid®, a princess Barbie, a pink My Little Pony® and a CD of Disney music. All four items were presented to the child and Claire was asked to choose one. After she chose an item, it was removed from the array and the child was asked to select another item from the remaining toys. The procedure was repeated until the child made a choice between the last two remaining items. The result from this assessment showed that, of the four toys presented to Claire, the Barbie Fairytopia Magic Mermaid® was most preferred, followed by the CD of Disney music. Claire was not very interested in the My Little Pony® and the princess Barbie.
During intervention, the Barbie Fairytopia Magic Mermaid® proved to be a functional reinforcer as it appeared to motivate Claire to move forward within the anxiety hierarchy. However the second identified reinforcer, Disney music, proved to be impractical. The parent and I did not want Claire to get the CD player wet or drop the CD player in the pool. Consequently, I discussed with the parent the use of edibles as a reinforcer. Dana was reluctant at first but agreed that chocolate would be a potent motivator and acceptable if given in small quantities. Following Dana’s consent to use edibles as a reinforcer, a second reinforcer sampling procedure was conducted. I conducted the reinforcer assessment using the same multiple stimuli without replacement procedure with three types of chocolates: chocolate chips, butterscotch chocolate chips, and M&M’s. Results from this assessment showed that Claire preferred chocolate chips and M&M’s but did not like butterscotch chocolate chips.

**PBS Plan Development**

Results from the functional assessment and the family ecology assessment were used to design, in collaboration with the parent, a technically sound and contextually appropriate PBS plan for the swimming routine. This process involved three steps: (a) building a summary statement and competing behavior pathways diagram; (b) identifying strategies to address anxiety-related problem behavior; and (c) selecting strategies that were likely to be both technically sound and contextually appropriate.

**Summary Statement and Competing Pathways Diagram**

Results from the functional assessment were used to develop a summary statement and competing behavior pathways diagram for the swimming routine. The diagram outlined the following four features of the problem behavior in the routine:
setting events, antecedent triggers, problem behavior, and maintaining consequences (i.e., function of problem behavior). The diagram also identified desired behaviors for the swimming routine and acceptable alternative replacement behaviors. The diagram guided the design of a technically sound plan that was aimed at rendering problem behavior irrelevant, ineffective and inefficient at achieving its purpose. See Figure 2.1. The logically linked support strategies are detailed in Figure 2.2.

Figure 2.1 Summary Statement/Competing Behavior Pathways Diagram.
<table>
<thead>
<tr>
<th>Setting Event Strategies</th>
<th>Preventative Strategies</th>
<th>Teaching Strategies</th>
<th>Consequence Strategies</th>
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</thead>
<tbody>
<tr>
<td>Use gradual exposure to systematically expose Claire to the most anxiety provoking situation. Use anxiety hierarchy to guide training sessions. Do not move to the next step on hierarchy until Claire is displaying minimal or no anxiety at the current step.</td>
<td>Use the visual schedule to promote desired behavior and ensure predictability. Show Claire the visual schedule and review each step of the swimming routine with her before initiating the routine. Also, refer back to the schedule as each step of the routine is complete.</td>
<td>Teach Claire to say, “I need a break” or “Wait one minute”. Teach Claire how to regulate her anxiety (i.e., deep breathing and modified progressive muscle relaxation). Read the modified social story about going swimming. Role-play targeted step before going to the pool.</td>
<td>If Claire goes into the pool, provide specific praise for going into the pool and give her the reinforcer she had chosen (i.e., mermaid doll, Barbie)</td>
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<td>Decrease parent anxiety by having graduate researcher, provide initial instruction and gradually ease parent into intervention role. Teach parent to: (a) model “brave” talk (i.e., by modelling and prompting parent to make statements that the pool is safe); (b) refrain from reinforcing responding to fearful talk that is has no real basis (i.e., parent ignores anxious talk and redirects to brave talk) (c) model “calm” talk for fearful talk that does have a real basis (i.e., parent ignores anxious talk and reassures child she will be OK)</td>
<td></td>
<td>If Claire asks for a break or for one minute, give Claire specific praise for using her words. Allow her to sit/stand by the pool. Do not ask her to try the targeted step for 1 minute. If Claire engages in fearful talk, actively ignore and redirect o brave talk.</td>
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<td>Use a safety signal to communicate to Claire how much more is expected before attaining the reinforcer (i.e., Just one more step and then you’re all done!)</td>
<td>If Claire starts to whine or protest (minor problem behavior), re-direct her to the contingency map and remind her of what she will receive if she completes the task. If Claire continues to whine or protest, redirect her to ask for a break. If Claire starts to tantrum or pinches (major problem behavior), implement crisis plan</td>
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<td>Setting Event Strategies</td>
<td>Preventative Strategies</td>
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<td>Use proactive pre-</td>
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<td>to do if she wants a</td>
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Identifying strategies to address anxiety-related problem behavior

The PBS plan included four types of strategies: (a) setting event strategies; (b) antecedent strategies; (c) teaching strategies; and (d) consequence strategies. These are described in detail below. When selecting strategies, emphasis was placed on those that had empirical support in the anxiety intervention literature and positive behavior support literature.

**Setting event strategies.** Setting events are events that change the momentary value of reinforcers and punishers. Setting events increase the likelihood that problem behavior will occur but do not directly occasion problem behavior (Horner, Vaughn, Day & Ard, 1996). Setting event strategies focused on: (a) minimizing the parent’s anxiety related to going swimming; and (b) teaching the parent to model brave talk and refrain from anxious talk that had no real basis. To minimize the parent’s anxiety, I provided the initial instruction to the child and gradually eased the parent into the intervention role. With each new step on the anxiety hierarchy, I modeled the step and provided the instruction. The parent observed and participated by delivering the reinforcer. After Claire had mastered a step on the anxiety hierarchy with me, the parent was eased into giving the instruction up to the mastered step (e.g., I gradually faded my proactive assistance to Claire and allowed the parent to give the initial instruction but stood near the parent and verbally prompted the parent, if needed). I also discussed with the parent the importance of modeling brave talk and avoiding acknowledging and reinforcing anxious talk. I identified several scenarios at home in which the mother might acknowledge the child’s anxious talk and thus inadvertently reinforce it. I brought up the example observed during a visit to the family’s home. Dana was putting a jacket on
Claire but she did not want to wear it. When Dana tried to put the jacket on, Claire engaged in anxious talk and said “Ow, you hurt me!” It was obvious that Claire was not hurt, but Dana apologized to Claire. The parent agreed on the significance of being aware of anxious behavior and understood the necessity of not modeling or reinforcing anxious talk. In instances during training sessions when Claire engaged in anxious talk, I modeled for Dana how to actively ignore Claire’s anxious comments and redirect and model brave talk (e.g., “That didn’t hurt, let’s go on the first step!”). I also modeled brave talk related to how the pool was a safe and fun place (e.g., “The water is so nice! The lifeguard keeps us safe at the pool!”).

**Antecedent strategies.** Antecedent interventions modify the antecedents that are functionally related to the problem behavior. They are strategies that are used before a problem behavior occurs in an effort to decrease the likelihood of problem behavior occurring and to increase the likelihood of desired behavior and alternative replacement behavior occurring (Kern & Clarke, 2005). Evidenced based antecedent strategies that were selected for Claries’ PBS plan included: (a) using the anxiety hierarchy to gradually expose Claire to the swimming routine (Bouchard et al., 2004); (b) using visual schedules to increase predictability of the sequence of steps involved in the swimming routine; (c) using positive contingency statements (e.g., “After you come down the first step, you can have a chocolate chip!”); (d) using proactive corrective statements to remind Claire what to do if she needs a break (e.g., “Remember, if you need a break, you just need to tell Mommy ‘I need a break’ and you can rest for 1 minute”); (e) embedding choices within the swimming routine (e.g., giving Claire a choice of: (i) where she wants to enter in the pool and (ii) reinforcer); and (f) modeling brave talk (e.g., “Oh you’re not hurt. Let’s go...
Teaching strategies. Five teaching strategies were included in the PBS plan. They included: (a) using the gradual exposure technique and working on the targeted step until Claire was no longer anxious; (b) teaching Claire to ask for a break instead of engaging in problem behavior; (c) teaching Claire deep breathing and a simplified progressive muscle relaxation procedure to regulate her anxiety (Cautela & Groden, 1978; Jacobson, 1929); (d) reading Claire a modified, dynamic Social Story™ (Gray, 1993); and (e) role-playing the targeted step before going to the pool (Cautela & Kearney, 1986). The Social Story™ was dynamic in nature in that the text in the story was specific to the current targeted step in the anxiety hierarchy throughout intervention. One of the pages in the story described the targeted step and this page changed as Claire progressed through the anxiety hierarchy. Thus, Claire was able to predict the extent to which she would be expected to enter the pool. When the intervention first began, this page reflected the first step on the anxiety hierarchy (i.e., “I am learning how to sit on the edge of the pool and put my feet in the water”). When Claire mastered this step, the page in Social Story™ was changed to the next step on the anxiety hierarchy (i.e., “I am get down on the first step and get back up”). Additionally, there was another page in the Social Story™ that was dynamic. As Claire mastered steps on the anxiety hierarchy, these mastered steps were added to a page that listed all the steps she had mastered. For
example, by the 11th training session, this page in Claire’s social story read “I am learning how to swim in the water, I already know how to put my toes in and out of the water, sit on the edge of the pool and put my feet in the water, go down the first step and go down the second step!”

Consequence strategies. The functional assessment revealed that Claire was engaging in problem behavior to avoid or escape the anxiety-provoking situation (i.e., avoiding going in the pool or escaping a request to enter the pool). Thus, it was important that the positive behavior support plan included consequences that made problem behavior ineffective and inefficient at producing the functional outcome of avoidance or escape and instead, reinforced alternative, appropriate behavior (Kern, 2005). It was equally important that the positive behavior support plan included consequence strategies that reinforced the desired behavior of entering and playing in the pool and the replacement behavior of asking for a break from entering and playing in the pool.

Furthermore, given the mother’s history of reinforcing Claire’s anxiety-related avoidance behavior, it was critically important to select consequence strategies in collaboration with the mother and ensure that she fully approved of the strategies in the plan and believed that the strategies were feasible. As discussed by Muris and colleagues (1996), observational learning theory contributes to our understanding of the development of anxiety disorders. Children may learn anxious behaviors from their parents. Therefore, a core consequence strategy was teaching the parent to ignore Claire’s anxious talk and redirect her to brave talk. Whaley and colleagues (1999) have found that parents that tend to catastrophize situations model, shape and reinforce anxious behavior in their children. Wagner (2005) indicated that parents that provide excessive reassurance,
support avoidance and/or participate in their child’s worries may strengthen the child’s anxiety. Thus, it was important for Dana to understand the consequences of these parent behaviors and refrain from engaging in them when Claire exhibited anxiety-related problem behavior.

Evidence-based consequence strategies in the PBS plan included: (a) the delivery of descriptive praise and a preferred item/activity contingent on calm, appropriate behavior (e.g., “Good job going on the second step, here’s a chocolate chip!”); (b) the delivery of a 1-minute break (up to three times) if Claire used alternative replacement behavior (i.e., asking for a break); (c) the parent actively ignoring Claire’s anxious talk and redirecting to brave talk (e.g., “That doesn’t hurt, let’s go down the next step. You’ll be so safe!”); (d) the parent redirecting Claire to the contingency map and/or verbally reminding Claire of what she would receive if she completed the task; (e) the parent prompting Claire to ask for a break if minor problem behavior continued (i.e., 3rd or 4th instance of verbal protest or whining); and (f) the parent calmly removing Claire from the pool and withholding the delivery of praise and a preferred item if major problem behavior occurred (e.g., pinching, tantruming).

Identifying Technically Sound and Contextually Appropriate Strategies

It was important that the support strategies identified in the PBS plan were not only technically sound (i.e., consistent with the laws of behavior) but were also contextually appropriate (Albin et al., 1996). After the initial PBS plan was drafted, I met with the parent in her home and discussed the strategies. The meeting lasted approximately one hour. Throughout the meeting, I acknowledged the contributions that Dana had made to the plan and encouraged her to suggest improvements to the proposed
intervention procedures. She agreed with most of the proposed setting event, antecedent, and skill-development procedures and was honest about which strategies were feasible and which strategies she was open to trying but needed coaching on how to implement. Specifically, she said that she was unsure about how to use the anxiety hierarchy to guide gradual exposure training sessions and how to manage the visual supports (i.e., visual schedule, contingency map). She commented that she was enthusiastic but also a bit nervous about starting the intervention process. She agreed that the plan was congruent with her goals, values, resources and skills and that the plan was feasible/ “do-able” within the setting (Albin et al., 1996). Dana informed me that the most important part of the plan was that I was going to give the initial instruction and that she would not feel the pressure of working through the steps in the anxiety hierarchy until that step was mastered with me. The finalized plan was typed and given to Claire’s mother. I gave Dana a week to read over the plan and also discuss the strategies with her husband before initiating training sessions at the pool. The finalized PBS plan is summarized in Table 2.5. In Appendix N, the full version of the finalized positive behavior support plan is presented. Additionally, a more parent-friendly, one page implementation checklist of support strategies was given to the parents. This checklist served as a prompt to use the strategies described in the support plan (see Appendix O).
Table 2.5: Summary of Positive Behavior Support Plan

Ecological Procedures
1. Build gradual exposure-based treatment utilizing an anxiety hierarchy.
2. Decrease parent anxiety by having graduate researcher (Vanessa), provide initial instruction and gradually ease parent into intervention role.
3. Teach parent to: (a) model brave talk; (b) refrain from responding to anxious talk that has no real basis; and (c) model “calm talk” for anxious talk that does have a real basis (i.e., Claire is hurt).

Antecedent Procedures
1. Show Claire the visual schedule and review each step of the swimming routine with her before initiating the routine. Also, refer back to the schedule as each step of the routine is complete.
2. Use positive contingency statement by telling Claire what to do and what she will get after doing the requested behavior (i.e., After you go down to the first step, you can have the mermaid doll).
3. Use a safety signal to communicate to Claire how much more is expected before attaining the reinforcer (i.e., Just one more step and then you’re all done!).
4. Use proactive pre-corrective statements to remind Claire what to do if she wants a break (e.g., “Remember if you need a break, you can say to mommy, “I need a break”).
5. Offer Claire choices of: (a) where she wants to enter in the pool (e.g., “do you want to go down the steps here or there?”) and (b) reinforcer (e.g., “do you want a chocolate chip or an M&M?”)
6. Use contingency map to teach Claire the positive consequences and negative consequences of following or not following through with the instruction.

Teaching New Behaviors
1. Teach Claire to get into the pool (using gradual exposure & anxiety hierarchy).
2. Teach Claire to ask for a break.
3. Teach Claire to regulate her anxiety through modified progressive muscle relaxation and deep breathing.

Consequence Strategies
1. Offer praise and a preferred toy if Claire completes the targeted step.
2. Give Claire a 1 minute break if she appropriately request for a break.
3. Actively ignore and redirect any unsubstantiated anxious talk by modeling brave talk (e.g., “We’re safe and having fun at the pool!”).
4. On the first or second instance of minor problem behavior, review the consequence map with Claire and remind her of the reinforcer that she will receive for completing the step.
5. On the third or fourth instance of minor problem behavior, redirect Claire to ask for a break.
6. De-escalate major problem behavior by: (a) in a firm but neutral tone saying “no”, (b) taking Claire into the changing room; (c) avoid talking to her or making eye contact while she is screaming or crying; (d) when she is calm, tell her matter-of-factly that she doesn’t get the reinforcer today but that she can try again next time.
During the initial intervention phase, additional strategies were added to the plan that addressed entering and exiting the pool. These strategies were added to the PBS plan as an addendum to the existing plan. Table 2.6 below describes the strategies for decreasing the likelihood of problem behavior occurring while walking from the changing room toward the pool entrance and walking from the pool back to the changing rooms.

**Table 2.6: Addendum of Strategies for the PBS Plan**

<table>
<thead>
<tr>
<th>Preventative strategies</th>
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<tbody>
<tr>
<td>1. Offer Claire a choice of holding your hand, your shirt or swim shorts (e.g., “Time to walk to the pool, do you want to hold on to mommy’s hand or my swim shorts?”)</td>
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<td>2. Use positive contingency statements by telling Claire what to do and what she will get after doing the requested behavior (e.g., After we get to the edge of the pool, you can have an M&amp;M; After you go to the changing room, you can listen to Disney music).</td>
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<table>
<thead>
<tr>
<th>Teaching strategies</th>
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<tr>
<td>1. Include holding mom’s shirt or swim shorts in the modified social story so it is clear to Claire that she is expected to hold on to either mom’s shirt or swim shorts while walking to the pool entrance.</td>
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<th>Consequence strategies</th>
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<tbody>
<tr>
<td>1. If Claire walks to the pool entrance holding either mom’s shirt or shorts and does not engage in problem behavior, praise her and give her a reinforcer (e.g., a M&amp;M)</td>
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<tr>
<td>2. If Claire engages in physical resistance, (minor problem behavior), re-direct her to ask to hold your swim shorts or shirt</td>
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<tr>
<td>3. If Claire starts to tantrum or pinches (major problem behavior), in a firm but neutral tone say “no”, take Claire out of the pool and walk with her or carry her to the change room. When she is calm, re-initiate the swimming routine.</td>
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</tbody>
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**Implementation Support Plan Development**

After the PBS plan was developed and finalized, I developed an implementation plan that defined: (a) training materials and support activities; (b) roles and responsibilities; and (c) a timeline for completing the support process.
Implementation Support

Implementation support was intended to be provided across two sub-phases: (a) initial training and support and (b) maintenance support. During the intervention phase, the parent conditionally withdrew from the study. For this reason, the planned maintenance support and follow-up phases were not completed. The initial training and support phase and the planned procedures for the maintenance support and follow-up phases are described below.

Initial Training and Support

The parent, the child and I participated in training sessions at the University pool. Prior to a training session, I completed several preparation tasks. I ensured all visual materials and reinforcers were present as well as the implementation checklist. The parent’s tasks included bringing Claire to the pool along with her bathing suit, a change of clothes, and the swimming Social Story™. After Claire was changed into her bathing suit, either the parent or I read a Social Story™ about swimming at the pool to the child and reviewed the visual schedule with her. I then carried the visuals and walked with the parent and child to the swimming pool entrance. At the pool, we worked on the target step on the anxiety hierarchy. Each time Claire completed the targeted step (e.g., put foot on the first step of the pool), she was offered a choice of a reinforcer (e.g., 1 minute with the mermaid doll or a chocolate chip). After completing 5-7 trials of the target step, Claire took a break, walked around the pool, and engaged in a preferred activity such as watching people swim or looking at posters in the pool. After the break, Claire completed 5-7 more trials of the target step. On days that Claire was tired, the swimming was terminated after the break. Training sessions lasted between 30-45 minutes.
During the initial training and support sub-phase, Dana was provided with the PBS plan that described each of the behavior support strategies to be used during the swimming routine. She also was provided with an implementation checklist (i.e., a succinct version of the written behavior support plan, composed of a list of each of strategies in the intervention). Dana used the checklist to self-monitor and self-manage the implementation of support strategies in the routine.

Training activities during the initial training and support phase included direct instruction, modeling, role play, and problem solving discussions. Given the parent’s history of anxiety, I designed the implementation support to allow for Dana to be present and observe while I gave the initial instruction during each new step on the anxiety hierarchy. For each step in the anxiety hierarchy, I provided direct instruction while Dana observed and encouraged Claire to follow my instructions and gave the reinforcer when she completed the targeted step. In the first step of initial training, I brought Claire’s desired behaviors at the swimming pool under my stimulus control. It was important that I gave the initial instruction during training sessions to instill confidence in Dana that Claire could go down the pool steps in the water. Modeling to the parent that Claire was capable and willing to complete the steps on the anxiety hierarchy helped decrease Dana’s anxieties regarding the swimming routine. The second step was to transfer stimulus control from me to the mother (Wolery & Gast, 1984). Specifically, this meant that Claire would follow directions that she had successfully completed with me with her mother as well. At first, I stood close by as Dana gave the instruction (e.g., “Go down to the second step”) and verbally prompted her to use the strategies outlined in the plan (e.g., positive contingency statements, visual supports, choices). As Dana’s mother
demonstrated mastery of the behavior support strategies, I faded my assistance and proximity. The process of transferring of stimulus control was made easier at the outset by having Dana involved in the delivery of reinforcement so that Claire positively associated her mother with the swimming routine.

**Maintenance Support**

Due to the parent’s conditional withdrawal from the study, the maintenance support phase was not initiated. If the parent rejoins the study, the maintenance support would be sequentially introduced when the swimming routine indicates clinically significant and stable improvements in child behavior across two to three consecutive observation sessions. Maintenance training and support activities would have three purposes: (a) to maintain the parent’s ability to support the child’s successful participation; (b) to strengthen the parent’s conceptual understanding of how to support the child’s emerging competence; and (c) to ensure that the family’s vision of a successful routine was being realized from the family’s point of view.

During the maintenance support subphase, the schedule of training and support sessions would decrease to one session every 1-2 weeks. The amount of implementation support also would decrease. I would briefly coach the parent just before the beginning of the routine, describing or modeling the skillful use of strategies that may be still weak in the parent’s repertoire. During the routine, I would only provide support if it appeared that the parent could not overcome the escalation of child problem behavior or self-correct a series of implementation errors. Dana would still use the implementation checklist during the maintenance support sub-phase, but would not be dependent on it. The implementation checklist would primarily serve as a reminder to implement the
support strategies just before the beginning of the routine. After the routine, I would provide brief feedback and emphasize the skillful use of support procedures.

**Follow-up**

Due to the mother’s conditional withdrawal from the study, the follow-up phase was not initiated. If the parent rejoins the study, the follow-up phase would begin after Claire maintained stable, appropriate behaviors in swimming routine and after Dana has demonstrated the ability to overcome at least one common obstacle to the maintenance of child success in the routine and demonstrated the ability to continue to implement the plan strategies with fidelity. Follow-up measurement would occur approximately one month after the final meeting in which maintenance support was discussed. After the follow-up session, additional training and support would be provided to the family if necessary.
CHAPTER 3

Results

Results presented are based on an incomplete study. Five months into the study, the parent’s symptoms of anxiety returned and the psychologist recommended that the parent take a break from the study. The study was in the initial training and support phase when the parent ceased her participation. The results presented are based on comparing baseline phase data (i.e., 3 observation probe sessions before intervention) with the existing intervention phase data (i.e., 2 observation probe sessions during intervention). In addition, training session data are presented on the child’s progress along the steps in the anxiety hierarchy.

Implementation of PBS Approach Results

Eight dependent variables were used to evaluate the impact of implementation of the family-centered PBS approach: (a) number of steps in the anxiety hierarchy completed; (b) latency in minutes to termination or successful completion of the swimming routine; (c) percentage of steps in the routine successfully completed (d) percentage of intervals of problem behavior; (e) parent-rated levels of child anxiety; (f) parent implementation fidelity of the PBS plan; (g) parent average rating of the social validity of the PBS approach; and (h) parent index of the support plan’s goodness of fit with family ecology. These eight variables are summarized below.

Steps in Anxiety Hierarchy Completed During Observation Sessions

The number of steps completed in the anxiety hierarchy during the swimming routine is shown in Figure 3.1. During baseline, Claire completed an average of 2.3 of the 16 steps in the anxiety hierarchy (i.e., range, 2-3). During intervention, Claire completed
Figure 3.1 Changing Criterion Design and Time-Series Design with Results across Multiple Dependent Measures
an average of 5 of the 16 steps on the anxiety hierarchy (i.e., range, 4 – 6). The first observation probe showed a step-wise increase to step 4 in the anxiety hierarchy. The second observation probe showed a step-wise increase to step 6 in the anxiety hierarchy.

**Steps in the Anxiety Hierarchy Completed During Training Sessions**

Figure 3.2 displays Claire’s progress during training sessions. It can be seen from the first training session to the last training session, Claire progressed from step 2 on the anxiety hierarchy to step 8. Claire’s anxiety at the last trial on the targeted step was determined by the parent and me at the end of the training session on a 3-point Likert-type scale (0 = no anxiety; 2 = some anxiety; 3 = very noticeable anxiety). When Claire appeared to show no anxiety at the targeted step, we moved one step up in the anxiety hierarchy. The first observation probe occurred after Claire completed step 4 in the anxiety hierarchy (i.e., going down to the first step) and had begun to work on step 5 (i.e., going down to the second step and coming back up to the first step). The sudden decline in progress in session 8 was due to an implementation error during session 7. In a manner inconsistent with the training protocol, Claire’s mother physically lifted Claire beyond the current step on the anxiety hierarchy. Claire immediately escalated into high intensity problem behavior (i.e., screaming loudly and crying) and the training session was immediately terminated. Consequently, Claire did not regain the progress she had made up to step 6 in the hierarchy (i.e., go the edge of the 2nd step) until session 9. The following visit to the pool was scheduled to be an observation probe session; however, the parent requested an additional training session. Thus, the second observation probe session occurred after session 10. Prior to the parent’s conditional withdrawal, Claire had completed step 8 in the anxiety hierarchy and was beginning to work on step 9.
Figure 3.2 Steps Completed in Anxiety Hierarchy During Training Sessions
Latency in Minutes

Figure 3.1 shows the latency in minutes to termination due to problem behavior or to successful completion of the swimming routine. During baseline, Claire spent an average of 3 minutes and 10 seconds in the swimming routine (range, 1:55 - 4:43) before the criteria for termination of the routine was met. All baseline observations required termination of the routine because five instances of tolerable problem behavior occurred (e.g., 5 instances of leaving the assigned area or 5 instances of anxious talk). During intervention, latency decreased to an average of 1 minute and 39 seconds (range, 0:33 - 2:45). During the first intervention observation probe, the routine was terminated at 2 minutes and 45 seconds due to a measurement error. The camera was turned off after the child completed the targeted step on the anxiety hierarchy and the rest of the routine was not videotaped. During this time, the child sat on the pool deck with her feet in the water, splashed her mermaid doll in the water, walked on the pool deck, watched other people swim, and walked back to the changing rooms. The latency of 2 minutes and 45 seconds was the time up to the child completing the targeted step in the anxiety hierarchy. However, the criterion for termination due to problem behavior was not reached when the videotaped observation was terminated. In the second intervention observation probe, latency decreased to 0:33 seconds because the criterion for termination of the routine due to problem behavior was reached. I had videotaped the entire swimming routine in which Claire walked into the pool, went down to the second step in the pool, sat on the edge of the pool with her legs in the water beside her mother, played by kicking her legs and splashing the water, splashed her mermaid doll in the water, and walked back to the changing room with her mother. The entire swimming routine was 13 minutes and 11
seconds long. However, when scoring the videotaped observation in the lab, I observed that the criterion for termination of the routine due to problem behavior was reached while the parent was walking with the child to enter the pool. The mother tried to hold Claire’s hand, but Claire physically resisted five times before reaching the entrance of the pool steps. Because Claries’ problem behavior was subtle (i.e., low intensity), I did not realize that the criteria was met until I coded the observation session in the lab.

**Steps Completed**

The number of steps completed during the swimming routine is shown in Figure 3.1. During baseline, Claire completed 2 of the 9 steps in the routine (i.e., 22% of the steps, no range). Following intervention, the average remained at 2 steps (i.e., 22% of the steps, range 11%-33%).

**Intervals of Problem Behavior**

Figure 3.1 shows the percentage of intervals of problem behavior. Overall, the data showed marked improvement in the swimming routine when comparing baseline to intervention phases. During baseline, the percentage of intervals of problem behavior averaged 56% across three observation probe sessions (range, 41% - 64%). These data indicated a steeply increasing trend. During intervention, problem behavior across two observation probes decreased to an average of 22% of intervals (range, 12%-33%).

**Parent Rated Levels of Child Anxiety**

Figure 3.1 displays Dana’s ratings of Claire’s anxiety during the baseline and intervention phases. During baseline, Claire’s mother perceived Claire’s anxiety to be on average 2.5 out of 5 (range, 2 - 3). On the rating scale, a rating of 2 meant “a little anxious” and a rating of 3 meant “somewhat anxious.” During intervention, Dana slightly
lowered her perception of Claire’s anxiety to an average rating of 1.5 (range, 1-2). A rating of 1 on the scale meant “not anxious”.

**Parent Use of Support Plan Procedures**

Figure 3.1 displays the parent’s use of support plan procedures. During intervention, the parent’s average percentage of intervals of accurate use of strategies was 83% (no range).

**Social Validity of PBS Approach**

Claire’s mother evaluated the social validity of the intervention approach. Due to the parent’s conditional withdrawal from the study, the formal social validity measure was not administered before the parent withdrew from the study. However, the brief 3-item social validity checklist was completed 13 times in total (i.e., across 11 training sessions and 2 intervention phase observation probe sessions). Across the 11 evaluations completed at the end of each training session and the 2 evaluations completed at the end of observation probe sessions, the parent consistently rated each of the items as “5,” indicating full agreement that: (a) the goals of the plan were appropriate for her daughter; (b) the strategies/procedures were effective in improving Claire’s behavior; and (c) the swimming routine was successful, given the parent of expectations for Claire’s participation at the time of each rating (i.e., entering the pool at the currently targeted step in the anxiety hierarchy).

**Goodness-of-Fit of PBS Approach**

The contextual fit of the behavior support plan was assessed using a condensed version of the goodness of fit survey created by Albin et al. (1996). It was intended that the parent complete the assessment during the beginning and middle of the intervention
phase. Due to the parent’s conditional withdrawal, the first goodness of fit measure was completed but the second measure was not. Across the 12 items, an average was computed and served as an index of goodness-of-fit. During these calculations, ratings for items 8 and 10 were converted to reflect the same interpretation as the other 10 items (e.g., 1 = poor fit; 5 = good fit). The average goodness-of-fit rating was 4.6.
CHAPTER 4

Discussion

Summary of Results

The purpose of the study was to investigate the effectiveness and acceptability of a family-centered PBS approach for decreasing anxiety-related problem behavior and increasing child participation in a community-based activity setting (routine) for a young child with a dual diagnosis of ASD and an anxiety disorder. The study also attempted to address the added challenge of supporting a mother, who herself had an anxiety disorder, to effectively implement a positive behavior support plan with her child in the targeted community setting in which anxiety-related problem behavior occurred – a local swimming pool. Results and consequently their interpretation are necessarily constrained by the participating mother’s conditional withdrawal from the study during the early part of the intervention phase due to a relapse in the symptoms of her anxiety disorder.

Within the changing criterion design, results showed two controlled, step-wise increases in steps completed in the anxiety hierarchy of steps by the child, from 3 of 16 steps in baseline to 6 of 16 steps during the second and last observation probe in the intervention phase. However, the rules of evidence for determining a functional relationship between the independent variable (i.e., the family centered PBS approach) and the dependent variable (i.e., steps in an anxiety hierarchy) required a minimum of three step-wise and stable increases across the steps of the anxiety hierarchy. Since only two step wise increases were observed and the stability of these changes was not established, the documentation of a functional relationship is not indicated by these data.
In regard to an association between implementation of the family-centered PBS approach and improvements in anxiety-related problem behavior and in routine participation, results are mixed and modest at best. Although there was a significant decrease in percentage of intervals of problem behavior from the baseline phase to the intervention phase, there was no improvement observed in latency in minutes to termination or completion of the swimming routine or in steps successfully completed in the routine.

Additional descriptive data indicated that the parent’s ratings of the child’s level of anxiety during the swimming routine improved slightly from baseline to intervention and that the parent implemented PBS strategies with a high level of fidelity during the swimming routine with her daughter. The slight decrease in parent rated levels of child anxiety may be understood in the light of specific procedures that were put in place (i.e., observation probe termination criteria) to prevent the child’s problem behavior from increasing beyond what the parent judged to be tolerable. During baseline, the swimming routine was terminated when Claire’s problem behavior met the criteria for termination. Thus, during baseline, parent rated levels of child anxiety may be low due to the termination of the swimming routine once the criteria was met.

Social validity ratings and the goodness of fit index indicated that the parent viewed the behavioral support approach as important and acceptable in regard to goals, procedures and outcomes, and that she viewed the behavior support plan as possessing a good contextual fit with the family’s goals, expectations, resources, and abilities.

Training data and anecdotal information suggest that the initial outcomes of the behavioral support effort prior to the mother’s conditional withdrawal were more robust.
than the observational data indicated and more consistent with the mother’s perception of the social validity of the approach.

A methodological error made during the first intervention observation probe and the need to adhere to a stringent criteria for termination of the routine due to problem behavior during the second intervention observation probe served to obscure the full extent to which tangible progress was made. During the first intervention observation probe, Claire was engaged in the routine for approximately 10 minutes. After Claire had completed the targeted step on the anxiety hierarchy (i.e., going down to the first step), Claire walked around the edge of the pool with her mother, sat at the edge of the pool with her mother while dangling her legs in the pool and playfully splashing the water, and finally, returned to the changing room with her mother. However, I stopped videotaping the routine immediately after the child completed the focused training on the targeted step in the anxiety hierarchy, forgetting that the observation probe needed to capture parent and child behavior across all of the steps in the routine and not only up to the targeted step in the anxiety hierarchy to which Claire was being gradually exposed.

In the second intervention probe, Claire engaged in a subtle problem behavior – physical resistance - while walking from the change room to the section of the pool that had steps for a more gradual entry into the pool. Physical resistance is one of the behaviors defined in the termination criteria for tolerated behavior. Within these criteria across baseline and intervention phases, if the child engages in 5 instances of physical resistance, the routine is terminated and latency in minutes as well as the other dependent measures are calculated up to that point in time. However, because of the subtle, low intensity nature of Claire’s physical resistance – gently pulling hand away from mother’s
hand – neither the mother nor I recognized that the criterion for termination had been reached. Consequently, and to be sure, consistent with observation probe protocol in this circumstance, the routine was videotaped from beginning to end and the criteria for termination or completion of the routine was determined by observing the videotaped session in the lab. When I coded the observation session, it became clear that the termination criterion was reached at a latency of 33 seconds into the routine. However, the entire routine was videotaped and lasted, from start to completion, for 13 minutes. Further observational analysis indicated that after the 5th event of physical resistance, additional instances of physical resistance did not occur until the mother asked the child to leave the pool area and return to the changing room. Only three instances of tolerable problem behavior occurred during the rest of the 13 minute routine. Claire said “ow” (another category of tolerate behavior) when Claire’s mother moved toward her in an attempt to get her down towards the second step. In the second instance, Claire said “no” (another category of tolerated behavior) when her mother told her it was time to go home, and when her mother attempted to take her daughter’s hand to walk to the change room, Claire gently pulled away a final time.

Due to the necessity of methodological consistency across baseline and intervention phases (i.e., maintaining the same criteria for termination), data for latency in minutes to termination or completion of the routine, for percentage of intervals of problem behavior, and for steps successfully completed did not show improvement when comparing baseline to intervention phases.

The study and its nominal results inform us of the risks and challenges of providing behavioral parent training and support to a parent with a diagnosed anxiety
disorder who is raising a child with a dual diagnosis of ASD and an anxiety disorder. After five months of participation in the study, the parent experienced a relapse in anxiety symptoms and was advised by her psychologist to take a break from the study. At that time, the parent and the behavioral consultant informed me that the parent’s symptoms occurred due to other factors in her personal life and were not a result of her participation in the study.

Although the results do not permit any firm conclusions about the efficacy of family-centered PBS for a child with ASD and an anxiety disorder, there is some anecdotal evidence during the intervention phase of positive changes in Claire’s behavior at the swimming pool that extend beyond the observational data. For example, when preparing to leave her home and drive with her mother to the pool, rather than express fear about going to the pool, which was observed and reported during baseline, Claire talked about going to the pool in a positive way (e.g., she expressed excitement when her mother told her it was a “swim day”). While at the pool, after the gradual exposure session at the steps leading down to the water, rather than wanting to leave and go home, which consistently occurred during baseline, she chose to stay at the pool and play around the edges of the pool. For example, she would sit with her mother at the edge of the pool with her feet dangling in the water and splash, which elicited squeals of delight. She also enjoyed dipping her mermaid doll into the water in a form of symbolic play in which the mermaid doll was swimming underwater, as mermaids tend to do. She enjoyed watching other people at the pool go down a slide and splash into the water, and later, as the training sessions and intervention observation probes progressed, she enjoyed sitting at the top of the slide and watching me take her mermaid doll and slide it down the slide.
and into the water. She also enjoyed walking around the pool with her mother and reading the posters on the wall or banners hanging from the ceiling. (e.g., reading “Canada” or “China”). Finally, when it was time to leave the pool, in clear contrast to baseline, she told her mother that she did not want to leave. Consequently, they often stayed 5 to 10 minutes longer (engaged in the above mentioned play).

Findings in relation to the extant literature, contributions to this literature, implication, limitations and cautions, and recommendations for future research are discussed below.

**Findings in Relation to the Literature**

A unique feature of the study was the way it combined components of evidence-based best practice in treating anxiety in children (Bouchard et al., 2004) with evidence-based practices from the positive behavior support literature (Horner, Carr, Strain, Todd & Read, 2002). The purpose of this synthesis was to design a PBS plan that was technically sound, contextually appropriate and socially valid for a child diagnosed with ASD and an anxiety disorder. Strategies derived from the anxiety literature included: (a) an anxiety hierarchy (King et al., 1999, Macdonald, 1975); (b) gradual and repeated exposure (Bouchard et al., 2004); (c) an interventionist modeling the exposure procedure (Bouchard et al., 2004); (d) role play practice (Bouchard et al., 2004); and (e) modified progressive relaxation training (Cautela & Groden, 1978). These strategies were combined with antecedent procedures derived from the PBS literature that helped to decrease likelihood of problem behavior (Horner et al., 1996, Kern & Clarke, 2005). These antecedent strategies, derived from the PBS literature, included: (a) visual supports (Dettmer, Simpson, Myles, & Ganz, 2000); (b) positive contingency statements
(Binnendyk & Lucyshyn, 2009); (c) safety signals (Binnendyk & Lucyshyn, 2009); (d) contingency mapping (Brown & Mirenda, 2006); (e) offering choices (Dyer, Dunlap & Winterling, 1990); and (f) a modified social story (Gray, 1993). In addition, specific consequence procedures were used to strength desired behaviors, replace problem behavior with functionally equivalent alternative behavior, and eliminate or minimize negative reinforcement. These strategies included: (a) using positive reinforcement (Kern, 2005) and (b) redirecting the child to use alternative replacement behaviors (i.e., asking for a break) rather than engaging in problem behavior (Halle, Bambara & Reichle, 2005).

Another feature derived from the PBS literature that informed the study was emphasis on contextual fit (Moes & Frea, 2000). Several features of the support plan process contributed to the PBS plan’s contextual appropriateness. First, intervention took place in a community setting that the mother preferred and that was close to her home. Second, the time of the routine matched the most convenient time for the family. Third, the steps and expectations of the routine were determined by the mother. Finally, the routine addressed an important superordinate goal of the parent, which was to be able to take Claire to Disneyland in the spring of 2010, and have her play happily in the pool at the hotel.

The study closely followed principles in conducting exposure with children as discussed by Bouchard et al. (2004). One key principle is the development of a positive rapport between the child and the interventionist. It is a prerequisite to successful exposure and is developed by respecting the child, finding out what the child enjoys and incorporating these enjoyable things into the intervention process (Bouchard et al., 2004).
In this study, I built a strong positive rapport with Claire by intentionally associating myself with positive things the first few times I met with her. I spent time watching cartoons with her, reading her favourite books with her, playing dolls with her, and bringing toys with me whenever I visited the family’s home. Before initiating training sessions at the pool, I conducted a reinforcer assessment to determine powerful motivators to incorporate into the swimming routine. I found that Claire enjoyed singing so I began by using songs as a reinforcer whenever she put her toes in the water. I sang her favourite songs with her for 1-2 minutes (e.g., Slippery fish, Row row row your boat). Claire also liked a song called “Tap the icing.” This was a song she had learned in her ballet class. Her dance instructor used the analogy of tapping the icing on a cake with one’s toes to teach the children to tap the floor with their toes. Since Claire liked this song and it appeared to help her focus on tapping her toe forward, I printed out a picture of a birthday cake, laminated it and pasted it on a clipboard. I immersed the clipboard in the water to cue Claire to “tap the icing” on the cake. After Claire was successfully putting her toe on the clipboard when it was immersed in the water, I printed and laminated a picture of a footprint with a picture of Ariel (a Disney princess that Claire liked) and put this picture on the bottom of the pool to cue Claire to put her foot where the princess was. The positive rapport that I established with Claire played a large part in her successful progress up the steps on the hierarchy and consequently, down the steps into the pool. Claire came to trust me and enjoyed being at the pool with me.

Another factor that contributed to the progress of intervention was the emphasis of parent participation, a key principle of conducting exposure for children with anxiety disorders (Bouchard et al., 2004). The authors explained that parents often allow their
anxious child to avoid situations as a way of lessening their anxiety and thus, unknowingly reinforce the child’s avoidant behavior. Parents also may unwittingly model anxious behaviors. Bouchard et al. (2004) argued that it is important for parents to be involved in the intervention process so that they are educated and aware of how their own behavior influences their child’s behavior. Thus, a positive rapport between the researcher and the child is not enough; a collaborative partnership between the researcher and the parent must also be developed for treatment success.

The collaborative partnership between Dana and I was developed through the use of several strategies described by Webster-Stratton and Herbert (1993) that contribute to rapport, trust and collaborative problem solving during a process of behavior support. The first of the strategies was optimism. For example, I conveyed confidence in the strategies described in the PBS plan. When Dana expressed doubt in Claire’s ability to participate in the swimming routine, I emphasized the progress that Claire had made on the anxiety hierarchy and reassured her that Claire would complete all of the steps on the hierarchy. I also offered words of encouragement when the parent used a PBS skillfully and commended her for her effort during training sessions at the pool. Another strategy that I used to develop a collaborative partnership was self-disclosure. For example, I informed the mother of my own day-to-day struggles, which appeared to help the parent feel that she was not alone in dealing with the stresses and anxieties of life. I also disclosed that we shared the same Christian beliefs. Sharing a belief in the same religious source of hope, strength and comfort appeared to be beneficial in establishing rapport. I believe that the positive rapport and trust that I established with Dana served as a necessary foundation for the nascent, positive changes in Claire’s behavior at the
swimming pool. As Kazdin, Whitley and Marciano (2006) have stated: “the greater the quality of parent-therapist alliance during treatment, the greater the therapeutic changes in the child at the end of treatment” (p. 441). In this study, the strong collaborative partnership that I developed with Dana, I believe, helped her remain a committed partner in the behavior support and research process for 5 months.

Contributions

The study offers four unique contributions to the anxiety literature on behavioral intervention. These contributions are: (a) parent as research collaborator; (b) assessment of the natural family context; (c) anxiety hierarchy in a changing criterion design; and (d) multiple outcome measures. These contributions are described below.

Parent as Research Collaborator

The study demonstrated that it is possible for a parent diagnosed with an anxiety disorder to collaborate with a researcher in a natural setting in the community and actively participate in promoting improvements in anxiety-related problem behavior in a child with autism and an anxiety disorder. This study illustrated how a parent could become a partner in research and take an active role in several aspects of the clinical intervention and research process (Albin et al., 2002).

From a clinical perspective, Dana was an invaluable partner during the assessment and development of the PBS plan. Through a structured interview process (Lucyshyn, Kayser, Irvin, Blumberg, 2002), Dana collaborated with me to select a priority family activity setting and defined the routine in terms of the core elements of an activity setting: (a) place and time; (b) people present; (c) resources required; (d) tasks and their organization; and (e) goals and values (O’Donnell et al., 1990). During this dialogue, I
also gained important information about the family’s strengths and learned that the parent’s own anxiety would be a critical factor to consider throughout the study. When the parent revealed that she sometimes avoided novel activities in the community, I gently probed and asked her to elaborate. As she explained, I began to understand that Dana often worried about what people thought of Claire or herself as a parent. This gave me insight into planning an intervention that would take into consideration the parent’s specific anxieties. In this discussion, I asked the parent if she would prefer that I take Claire to the pool by myself so that she was not involved until Claire had mastered the targeted step in the anxiety hierarchy with me. However, the parent responded that if she were not at the pool, she would worry about how Claire was behaving with me. She said that she would rather be present at the pool and withstand possible stares from bystanders than be absent and worry about Claire. This discussion gave me great insight into Dana’s unconditional love for Claire and desire to protect Claire in all circumstances. An open dialogue also was essential during the development of the PBS plan. When we discussed the strategies in the proposed PBS plan, Dana was very honest about whether the strategies were feasible for her. For example, in the initial proposed plan, I proposed that we use video-modeling with a peer as a teaching strategy. However, after some consideration, Dana thought it would be too overwhelming to find a peer for the video and show Claire the video everyday. Consequently, this strategy removed from the finalized plan.

During the family ecology assessment, Dana selected the local community pool as the location for the swimming routine. After two baseline observations, Dana made an insightful observation. The community pool was not very child-friendly, as it lacked a
shallow end. Dana’s envision of the swimming routine was for Claire to be able to enter the pool and splash in the water but not necessarily swim in the water. Thus, Dana suggested switching locations to the university swimming pool. Claire attended preschool on the university campus, which made going to the pool convenient, and the pool had a large shallow end in which Claire could splash and play. Because the university pool was a better match with Dana’s envision of a successful swimming routine, I agreed with Dana’s suggestion and the university pool was selected as the setting for subsequent baseline measurement and intervention phase sessions. The parent also played an active role in deciding the number of swimming sessions during the week, the time of day of each session and the amount of time each swimming session lasted. I had suggested going to the pool three or four times a week to create momentum and build on success. The parent initially agreed with this but it became clear after two weeks that going to the pool three or four times a week was too intensive for the mother. When training sessions were scheduled for three or four times a week, the mother began to cancel about half the sessions.

After a discussion with my thesis advisor, I invited the parent to coffee to discuss the cancellations. In conformance with ethics guidelines related to frequent cancellations, I reminded the parent that her participation in the study was voluntary and that she was free to withdraw her participation at any time. I also assured her that doing so would not have any adverse effect on me as a graduate student. The parent replied that she did not wish to withdraw from the study and reiterated that swimming together with her daughter at the community pool was still a priority goal. However, the parent did share concerns with scheduling. She indicated that she could not commit to going to the pool more than
twice a week. I respected this and agreed with the mother. I emphasized to her the
importance of her voice in shared decision making. Subsequently, we did not schedule
more than two swimming sessions in a week. The time of day of intervention also was
controlled by the parent. Swimming sessions were initially scheduled in the morning
because Dana thought Claire would be more energetic in the morning. However, I
noticed that half of the swimming sessions were being cancelled in the morning, usually
an hour before we were scheduled to be at the pool. Again through an open discussion
with the parent, Dana revealed that mornings were not a good time to schedule
intervention since Claire’s sleep patterns were inconsistent. If Claire did not fall asleep at
her scheduled bedtime, Dana allowed her to sleep in rather than go swimming in the
morning. The parent also revealed that mornings are usually the hardest time of day for
managing her own anxiety. As a result, swimming training sessions and probe
observations were scheduled in the afternoon after Claire finished preschool. Dana also
contributed to determining the length of training sessions. At first, I had planned to be at
the pool for about an hour with two blocks of teaching trials (i.e., 5-7 trials of practicing
the targeted step, then a break walking around the pool and followed by another 5-7 trials
of practicing the targeted step). The parent was present at all sessions and found that two
blocks of teaching trials was too much. She worried that Claire would be too tired for her
home-based ABA intervention session that was scheduled in the afternoons after
swimming. In accordance with Dana’s suggestion, we planned only one block of teaching
trials during training sessions. Dana also had input in the timing of when to fill out the
implementation checklist. I had intended to fill out the implementation checklist with the
parent at the end of the swimming routine. I tried to do this a few times in the changing
room but it was clear that Dana was too preoccupied with getting Claire dressed and rushing home for Claire’s BI session. I asked Dana if she would prefer to call me later in the day when Claire was at home and settled into her BI session to complete the implementation checklist. Dana appreciated this suggestion and subsequently, we completed implementation checklists on the phone after swimming sessions.

From a research perspective, the parent participated in defining the independent variable by collaborating to create the anxiety hierarchy, to finalize strategies in the PBS plan, and define the activity setting of swimming in a community pool. Shared decision making with Dana during the intervention helped us design a PBS plan that was not only socially valid, but also contextually appropriate (Binnendyk & Lucyshyn, 2009; Albin et al, 2002). The parent also participated in gathering data on the dependent variables, completing ratings of child anxiety levels during observation probe sessions and evaluating the social validity and the goodness-of-fit of the behavioral support plan. Throughout each phase of the study, Dana controlled the pace of the study and helped to coordinate the scheduling of training sessions and observation probe sessions.

This level of collaboration with a parent with an anxiety disorder raising a child with a dual diagnosis of autism and an anxiety disorder is unprecedented in the literature on the treatment of anxiety disorders in children. In PBS research with families, there is growing evidence of the value of collaborative research procedures implemented within the context of single subject methodology (Binnendyk & Lucyshyn, 2009; Buschbacher et al., 2004; Lucyshyn, Albin, Nixon, 1997; Moes & Frea, 2002; Vaughn, Dunlap, Clarke, & Bucy, 1997). However, in all but one of these studies, the parents who implemented the intervention were psychologically healthy. Durand and Rost (2005)
have argued that within the emerging discipline of PBS, it is crucial to include families with different and perhaps challenging characteristics to further develop the viability of PBS for all families. This study offers preliminary, albeit incomplete, evidence that a parent diagnosed with an anxiety disorder can implement a positive behavior support plan with a child diagnosed with ASD and an anxiety disorder and attain some initial improvement in child behavior in a community setting.

**Assessment of the Family Context**

The study introduced to the anxiety literature assessment procedures that extend beyond functional assessment of problem behavior to also include assessment of the family context in which problem behavior occurred. Behavior support plans that are technically-sound but not contextually appropriate are less likely to succeed and if initially successfully, are less likely to maintain over time (Albin et al., 1996; Carr et al., 1999; Feldman et al., 2002). The study is the first in the childhood anxiety treatment literature to use a goodness of fit framework to guide the design of a multicomponent plan. It is consistent with a growing body of research in positive behavior support with families in which the construct of contextual fit is used as a guide for designing a plan that is not only technically sound from a functional perspective but also contextually appropriate from the perspective of the larger ecology of the family (Binnendyk & Lucyshyn, 2009; Clarke, Dunlap, & Vaughn, 1999; Lucyshyn et al., 1997; Moes & Frea, 2000).

**Anxiety Hierarchy in Changing Criterion Design**

A unique contribution of the study was the use of the anxiety hierarchy to inform stepwise changes in the changing criterion design. The measurement of steps in the
anxiety hierarchy lent itself to the use of a changing criterion single subject experimental research design. The changing criterion design allowed for the evaluation of a functional relationship between the independent variable and implementation of the core steps of the routine at the pool. Each step in the anxiety hierarchy represented a stepwise increase in the child’s expected participation in the swimming routine. Claire received a functional reinforcer contingent on achieving the next step in the anxiety hierarchy. Initial improvements in Claire’s behavior were associated with the two stepwise increases in the behavioral expectations of the swimming routine before the parent conditionally withdrew from the study. Using the anxiety hierarchy to inform controlled, stepwise improvements in child behavior in a changing criterion single subject research design appears to be a feasible and promising research strategy for examining functional relationships in small n research with children with ASD and anxiety disorders.

**Multiple Measures**

The multiple measures used in this study offer a model that can holistically portray a comprehensive picture of change in a family activity setting. Each dependent measure provided an important layer of information about the outcomes of the PBS approach. The anxiety hierarchy showed Claire’s gradual progress in participating in the core steps of swimming routine. The latency to termination or successful completion of the routine and percentage of steps completed revealed how long Claire and her mother stayed at the pool before the criterion level of problem behavior was reached or the routine was completed successfully. The percentage of intervals of problem behavior illustrated how often Claire engaged in problem behavior during the swimming routine. The parent rated levels of Claire’s anxiety offered insight into the parent’s perception of
the child’s perceived level of anxiety from baseline to intervention. Social validity and contextual fit measures provided an understanding of the family’s perspective on the acceptability of the goals, procedures, outcomes of the approach, and on the contextual appropriateness of the behavior support plan. Each of these measures fit together to form a comprehensive picture of the extent of change that occurred in the swimming routine following intervention (Kincaid, Knoster, Harrower, Shannon, & Bustamante, 2002).

**Unanticipated Problems**

**Time and Effort**

Experimental data and anecdotal evidence, taken together, indicated that Claire made meaningful progress along the anxiety hierarchy. When the intervention was terminated, she had reached step 8 out of the 16 steps in the anxiety hierarchy during the last training session. However, achieve this level of progress in collaboration with the parent was time-consuming and labour intensive. Helping Claire reach step 8 in the anxiety hierarchy took 11 training sessions across a period of 2 months. The amount of time and effort can be attributed to three major factors. First, Claire’s genuine anxiety of getting into the swimming pool required a gradual exposure based intervention, which by definition involves a slow and gradual approach. The second factor was Dana’s anxiety which influenced the amount of time she was able to invest in training activities at the pool on a weekly basis. Dana’s anxiety also was associated with cancellations of at least half of the sessions. The third factor was that the pool had a negative past association for both Claire and Dana. Their worry was substantiated as Claire had fallen while walking on the pool deck a year previously. This incident caused both Claire and Dana to be anxious about going to the pool. Accordingly, it was critical that the pace was slow and
gradual to help both the parent and child begin to associate a visit to the swimming pool with an enjoyable, successful and safe experience.

**Parent Implementation Error**

A key component of the behavior support approach was gradual exposure using the anxiety hierarchy. During one of the training sessions, the task on the hierarchy was for Claire to tap the bottom of the pool with her toe. She had been working on this step for the past three sessions with slow progress. Claire was capable of putting her toes over the edge of the second step but her foot was still at least five inches away from the bottom of the pool. Perhaps due to Dana’s desire to have Claire progress more quickly, during one of these trials, the parent went beyond the required step. She picked Claire up by her waist, walked down the required step with her, and held her waist deep in the water. Immediately, Claire started screaming and crying and the parent promptly took Claire out of the water. Claire continued to cry for about 10 minutes and was shaking from fear. The training session was ended and I helped the parent calm Claire down. Following this incident, it was decided that no physical prompting would be used and instead potent reinforcers (i.e., chocolate) would be introduced to motivate Claire to participate in the teaching trials. Furthermore, the parent felt regret for prompting her into the pool and expressed concern that Claire was traumatized by the incident and feared she would not go to the pool again.

Consequently, Dana cancelled the next two swimming sessions. After a discussion with my thesis advisor, I contacted the parent and proposed that I lead the next two training sessions with Claire while Dana observed while sitting on the bench at the pool. Dana enthusiastically agreed with this suggestion. As a result, the next two training
sessions occurred without Dana’s active participation. After being physically prompted in the water, Claire’s progress deteriorated slightly. Before that incident she was working on tapping her toe on the bottom of the pool, after the incident, she was hesitant to go down to the second step (i.e., a previously mastered step). It took two sessions before Claire was able to go down to the second step with minimal anxiety. This was an unanticipated incident in the intervention process that affected the pace and progress of the study.

Limitations

Parent Ceasing Participation

The parent made it clear at the initial prescreening meeting that she had an anxiety disorder but both the parent and the behavioral consultant indicated that the parent was mentally stable and would be a reliable, active and invested partner in the study. For 5 consecutive months, the parent proved to be a committed participant. However, in early January, the parent’s symptoms of anxiety returned and Dana’s psychologist recommended that she take a break from the study. At that time, the parent indicated her heightened anxiety levels were not due to participation in the study but other personal issues that had arisen. I spoke with the parent 8 weeks after she withdrew from the study; she confirmed that the relapse of her anxiety symptoms were partially due to other stressful factors in her life. However, she revealed that her participation in the study also contributed to her heightened anxiety. Specifically, she informed me that at the pool she tended to compare Claire to other children. She indicated that she felt anxious that Claire was not swimming and playing in the pool like other children her age. Furthermore, she indicated that she felt anxious when bystanders sometimes stared at us during our training sessions at the pool. I thanked the parent for her honesty. I emphasized that participation
in the study was voluntary and asked if she was still interested in continuing the swimming intervention. She confirmed her desire to have Claire play in the pool. However, she indicated that at that time, there were other problem behaviors occurring at home that required her focus (i.e., bath time, toilet-training). The parent’s conditional withdrawal from the study constrains the conclusions that can be drawn from the study in terms of the effectiveness of the family centered PBS approach.

**Research Design**

When using a changing criterion single-subject research design, it is recommended that the length of phases be varied (Kennedy, 2005). In this study, only one data point was collected at each change in the criteria to accommodate the mother’s anxiety over being videotaped. Internal validity would be increased if multiple data points were collected at each stepwise change in the criterion. If the family resumes the study, it is intended, given the parent’s anxiety disorder, to increase the rigor of the changing criterion design by randomly sequencing the number of videotaped observation sessions between one and three for each stepwise change in the criteria. This would balance the need to accommodate the mother’s sensitivity to being videotaped too often with the requirements of experimental control.

**External Validity**

Preliminary results, although promising, are based on one child and family within one routine. For this reason, the ability to draw conclusions about the potential effectiveness of the PBS intervention with other families is limited. Moreover, due to the parent’s conditional withdrawal from the study, the full results of the study are not yet known. Although there are other studies in which researchers successfully collaborated
with parents with added challenges (Lucyshyn et al., 2009; Lucyshyn, Albin, & Nixon, 1997) in home and community based routines, this is the first positive behavior support study in which both the parent and the child had diagnosed anxiety disorders. The characteristics of this family were unique, thus more research is needed to establish external validity.

Measurement Error

In the first observation, I made the error of turning off the camera after the child completed the targeted step (i.e., going to the first step) and did not film until the criteria for termination of the routine was met or when the routine was completed (i.e., parent walking back into the change room with the child). This error influenced the latency data in the results. If I had filmed the entire routine, the latency data would show an increase as compared to baseline.

Implications

Results of the study offer two implications for practitioners and researchers who are involved in behavioral interventions for children with ASD and anxiety-related problem behavior as well as important implications for working with a parent with mental health issues.

Enhanced Model of Support for Children with ASD and an Anxiety Disorder

The study is an example of the marriage between two different fields of social science: positive behavior support and clinical psychology. The study merged best practice features of positive behavioral support with key components of treatment for children with anxiety disorders. Key features of PBS that informed the assessment and intervention process included: (a) establishing a collaborative partnership with the parent;
(b) selecting a valued family activity setting as a unit of analysis; (c) adhering to family-centered principles and practices; (d) designing a multicomponent support plan that incorporated additional antecedent-based strategies; (e) conducting a functional assessment; (f) ensuring a good contextual fit; (g) providing implementation support; and (i) continuously evaluating outcomes using multiple measures. Key features of exposure-based intervention for children with anxiety disorders that were integrated into the support process included: (a) adapting treatment to suit the child’s developmental level; (b) developing a strong rapport with the child; (c) gradual exposure guided by a hierarchy of feared situations; (d) teaching coping strategies; and (e) parental involvement (Bouchard et al., 2004).

The integration of best practice features from PBS and clinical psychology offers the field an enhanced model of support. Although the results are constrained by the parent’s conditional withdrawal from the study, the preliminary results suggest a modest association between implementation of the approach and improvements in the child’s anxiety-related problem behavior at a community swimming pool. In addition, high levels of parent implementation fidelity, ratings of social validity and index of goodness-of-fit suggest that the approach holds some promise for being acceptable and feasible to parents of children with ASD and anxiety disorders.

The study also offers a model of parent-professional collaboration for families raising a child with ASD and an anxiety disorder in which one parent may also have a diagnosed anxiety disorder. During training sessions in the intervention phase, I provided the initial instruction while the parent watched, encouraged the child to participate, and delivered positive reinforcement. When Claire had mastered a step with me giving the
initial instruction, the parent carried out the step with me standing close by, coached and
provided help as necessary. As Dana’s ability to implement plan strategies improved and
she appeared comfortable and confident in supporting Claire, I faded my assistance and
proximity. This gradual stimulus fading approach to transferring stimulus control from
the interventionist to the parent may offer the field a strategic method for helping a parent
with an anxiety disorder become the primary support to her child with autism and an
anxiety disorder without overwhelming the parent with the responsibility of getting the
child through each step of an anxiety hierarchy (Wolery & Gast, 1984). For these
reasons, this study is unique in its contribution to the literature on positive behavior
support and the literature of anxiety disorders in children with ASD.

**Ongoing Accommodations to Ensure Integrity of Gradual Exposure**

During the process of intervention, several changes were made to the support
process to accommodate the child’s anxiety. One accommodation was adding additional
steps on the anxiety hierarchy to maintain the gradual nature of exposure sessions.
Another accommodation so that Claire could participate in the study involved making her
feel safe in the pool. After a month into training, Claire could go down to the second step
of the pool independently as long as she was holding the rail to get down the steps. One
problem with tapping her toe on the bottom of the pool was that she would have to let go
of the rail so her toe could reach the bottom of the pool. It became evident that Claire was
too anxious to let go of the rail. The parent and I discussed the problem and collectively
decided that she needed something else to hold on to when she let go of the rail. Claire
did not want to hold my hand or her mother’s hand, perhaps due to anxiety that we might
physically prompt her to go further into the pool than she wanted. Thus, we brought a
plastic pool chair into the swimming pool. The arm rests of the chair were at the right height and allowed Claire to let go of the rail and hold on to the chair. With the chair in the water, Claire was more willing to lean forward and put her toe on the bottom of the pool. Once, during training, Claire put her entire foot on the bottom of the pool, took her foot back out, and put her other foot on the pool floor. These accommodations allowed Claire to continue to make progress along the 16 steps in the anxiety hierarchy. Instead of a prescribed intervention, the intervention procedures were constantly evaluated and contextualized to suit both the parent and the child (Moes & Frea, 2000). As stated by Hieneman and Dunlap (2000) the need to understand the capacity of the individual and his or her unique characteristics is crucial in designing effective plans.

**Going the Family’s Pace**

Researchers should anticipate that when working with children with ASD and anxiety disorders and parents who also have mental health issues, the time and effort required to promote meaningful change will most likely increase. Researchers should be prepared to commit to the family for as long as it takes for progress to be made. Furthermore, the researcher must also be prepared to be open-minded and flexible in regard to making accommodations so that the parent with an anxiety disorder feels respected as a partner in the clinical support process (Lucyshyn et al., 2002). However, the commitment required to achieve meaningful outcomes with this population of children and families should not deter researchers from pursuing research with families who have additional challenges. Durand and Rost (2005) make the case that, too often, studies involve families that are highly motivated and reliable, which leaves researchers
wondering whether the intervention would have been as effective and efficient with a wider population of families who are in need of behavioral support services.

**Necessity of a Psychologist’s Expertise**

Special educators typically lack the skill-set to work with adults with anxiety disorders. Thus, it is crucial that a counseling or clinical psychologist with expertise in treating mental illness in children and adults is involved at every step of the therapeutic process. In this study, I benefited from the expertise of a counseling psychologist at the University of British Columbia. She directed me to key pieces of literature on conducting exposure exercises with children as well as to the Anxiety BC website and advised me during the development of the anxiety hierarchy. However, it may also have been beneficial if the parent’s psychologist was involved in the study. Although the mother’s psychologist was informed of the study and supported the parent’s participation in the study, the mother’s psychologist was not directly involved in the assessment and support process. Given that the parent received counseling from this psychologist for a number of years, the parent’s psychologist may have been able to provide additional information to help me ensure that the PBS plan was appropriate given the mother’s history of anxiety. Moreover, the efficacy of the PBS approach may have been enhanced if I more closely integrated the PBS services that I provided with the psychologist’s counseling services. For example, the psychologist, during her counseling session with the mother, might have contributed to teaching the mother to engage in brave talk and to decrease anxious talk.

Lucyshyn et al. (2009), in a recent longitudinal study of a family centered PBS approach, worked collaboratively with a parent with an anxiety disorder to improve the behavior and participation of a young boy with autism in three valued routines in the home. From
the very inception of the study, the researchers recognized the necessity of a psychologist’s expertise. Concurrent with the delivery of family-centered PBS services to the family, a counseling psychologist provided cognitive behavior therapy treatment with the parent. The authors viewed the inclusion of counseling for the parent as essential to the parent’s success in the three family routines with her son (Lucyshyn et al., 2009). Thus, expertise from a counseling or clinical psychologist is advised when working with parents with mental illness.

**Cautions**

Given the results of the study and its limitations, two additional cautions are recommended for consideration by future researchers.

**Ratings of Parent’s Level of Anxiety**

In addition to the expertise of a psychologist, it may be beneficial to include not only parent reported levels of the child’s anxiety but also parent reported levels of *parent* anxiety. The purpose of such an additional measure would be to alert the interventionist when the parent begins to experience a high level of anxiety during implementation support. Thus alerted, the interventionist could more immediately, in collaboration with the parent, make adjustments in the support process in regard to scheduling, amount of time, and training and support procedures. These adjustments would be aimed at ensuring that during the next training session, the mother would be less likely to experience a high level of anxiety. Procedurally, this would involve: (a) creating a one-item, self-report measure of the parent’s level of anxiety, using a Likert-type scale (i.e., 1 = no anxiety; 10 = high anxiety); (b) establishing with the parent an intolerable level of parent anxiety
during a training and support session; and (c) the parent self-evaluating his/her anxiety level after the training session was completed.

**Positive Behavior Support Strategies for the Entire Routine**

Finally, when conducting research in valued routines, the entire routine must be considered. In this study, I focused on going down the steps into the pool. Because this was the core problem related to the child’s anxiety, I overlooked the necessity of planning strategies to help Claire successfully walk up to the pool and exit the pool to the changing room. When families are initially describing the envisioned routine and how it would look like if it were successful, researchers need to be cognisant of each part of the activity setting and ensure that PBS strategies address all of the steps in the routine.

**Recommendations for Future Research**

There are three main considerations for future researchers. First, more research in this area is needed. This study and its preliminary results are the first to investigate the question as to whether a family centered, positive behavior support approach may be effective, feasible, and acceptable for a family with a child with ASD and an anxiety disorder. Given the inconclusive nature of the results of this study, replication of an intervention like this is necessary to provide empirical evidence of the internal validity of the approach. The study demonstrated two stepwise changes consistent with the changing criterion design. However, in its incomplete state, the study offers insufficient data to establish a functional relationship between the PBS approach and improvement in child behavior and participation in the swimming routine.

Replication of an intervention like the one in this study also is needed to establish the external validity of the PBS approach. External validity would be enhanced if the
approach was replicated with children of different ages, children with ASD and different levels of functioning, children with different types of anxiety disorders, families with different challenging issues (i.e., low SES, single-parent, different mental health problems) and families of different cultures. External validity also would be strengthened if the approach was shown to be effective in a variety of different home and community settings. In general, more research needs to involve families that are not necessarily “easy” families with whom to work. This is how researchers utilizing a PBS approach can clarify the conditions under which it works best, discover conditions when it is less effective, and can help PBS progress and evolve (Durand & Rost, 2005).

Second, research is required to investigate the efficiency of the approach. The current study employed a changing criterion design focused only a single routine. Future research should employ a multiple-baseline design across three or four routines and document the number of hours spent directly training the parent. It is not yet known if the time required to train parents would decrease from the first routine to the third or fourth routine. The essence of PBS is its ability to empower parents, and so it is important that future research investigates the extent to which the approach successfully helps parents acquire the skills necessary to increase child participation in all of the routines of family and community life that provoke anxiety-related problem behavior.

Third, future research should investigate the extent to which the family-centered PBS approach, implemented across two to three valued anxiety-provoking routines promotes generalization to other non-trained anxiety provoking routines (Stokes & Baer, 1977). To do this, procedurally, future research should employ a multiple-baseline design across two or three routines and simultaneously gather generalization probe data in other
non-trained routines in the home and/or community that are associated with anxiety-related problem behavior. In addition to gathering data within the multiple baseline design across targeted routines in baseline and intervention conditions, generalization probe data could be less frequently gathered in the non-trained routines across baseline and intervention conditions. Improvements in child behavior in non-trained routines during generalization probes during the intervention phase would offer preliminary evidence of the approaches efficacy for promoting generalization of improvements in child anxiety-related problem behavior.

**Conclusion**

The study investigated five main questions: (a) is there a functional relationship between a family-centered PBS approach and improvement in participation in a community-based, swimming routine by a child with an ASD and an anxiety disorder; (b) is there a correlation between a family-centered PBS approach and improvements in child behavior and participation in the community-based routine for a child with an ASD and an anxiety disorder; (c) is there a correlation between a family-centered PBS approach and a sustained decrease in the child’s level of anxiety, six weeks following termination of the implementation support; (d) is the approach socially valid from the parent’s perspective; and (e) is the PBS plan contextually appropriate from the parent’s perspective.

Based on the results of the study, no firm conclusions can be offered; all that can be said, when viewing the observed and anecdotal findings in total, is that a family-centered PBS approach appears to be promising. The results collected before the parent’s conditional withdrawal from the study indicated that following intervention, Claire made
progress on the steps in the anxiety hierarchy (i.e., from step 2 in the baseline phase to step 6 in the intervention phase). Claire’s progress on the anxiety hierarchy also was consistent with the stepwise criterion changes in the changing criterion design. However, a functional relationship was not demonstrated due to the absence of a sufficient number of controlled changes in child behavior along the steps in the anxiety hierarchy. Visual analysis of percentage of intervals of problem behavior also indicated a modest association between the PBS approach and a decrease in problem behavior in the swimming routine from baseline to intervention. Social validity ratings and the goodness of fit index indicated that the parent viewed the behavior support approach as important and acceptable in regard to goals, procedures and outcomes, and that she viewed the behavior support plan as possessing a good contextual fit with the family’s goals, expectations, resources, and abilities. Nevertheless, due to the parent’s conditional withdrawal from the study, a clear conclusion about the effectiveness and acceptability of the family-centered PBS approach with the child and parent in a valued family activity setting in the community cannot be made. The study, despite its incomplete data, may be a springboard for the further advancement of effective, feasible, and acceptable intervention for children with an ASD and anxiety-related problem behavior in natural family contexts with parents as collaborative partners in the assessment and intervention process.
References


Appendix A

**BREB Certificate of Approval**

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The University of British Columbia  
Office of Research Services  
Behavioural Research Ethics Board  
Suite 102, 6120 Agronomy Road, Vancouver, B.C. V6T 1Z3

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### CERTIFICATE OF APPROVAL - FULL BOARD

**PRINCIPAL INVESTIGATOR:** Joseph M. Lustyshyn  
**INSTITUTION / DEPARTMENT:** UBC/BREB Certificate of Approval  
**UBC BREB NUMBER:** H09-00367  
**Psychology, and Special Education**

**INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:**
- UBC  
- Vancouver (excludes UBC Hospital)

**Other locations where the research will be conducted:**
Subjects' home; Assessment and intervention activities related to problem behavior in home contexts will be conducted within the family's home (the family will reside in the Lower Mainland) UBC Lab in Faculty of Education; in Dr. Joseph Lustyshyn's lab at UBC, videotaped data will be downloaded onto a computer and observed and coded using a computer monitor.

**CO-INVESTIGATOR(S):**
N/A

**SPONSORING AGENCIES:**
N/A

**PROJECT TITLE:** A FAMILY-CENTERED, POSITIVE BEHAVIORAL SUPPORT APPROACH TO ANXIETY-RELATED PROBLEM BEHAVIOR IN A CHILD WITH AUTISM

**REB MEETING DATE:** May 28, 2009  
**CERTIFICATE EXPIRY DATE:** May 28, 2010

**DOCUMENTS INCLUDED IN THIS APPROVAL:**

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The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

Approval is issued on behalf of the Behavioural Research Ethics Board and signed electronically by one of the following:

Dr. M. Judith Lynam, Chair  
Dr. Ken Craig, Chair  
Dr. Jim Roper, Associate Chair  
Dr. Laurie Ford, Associate Chair  
Dr. Anita Ho, Associate Chair
Appendix B

Letter of Initial Contact

The purpose of this letter is to inform you of an opportunity to participate in a research study whose purpose is to help a family with a child with autism who engages in anxiety-related problem behavior in the home and community. The study is entitled, “A family centered positive behavior support approach for a child with autism and an anxiety disorder.” The study will be conducted by the University of British Columbia. The Principal Investigator of this study is Dr. Joseph Lucyshyn, an Associate Professor in the Faculty of Education of the University of British Columbia. I am graduate student researcher and a Masters student at the University of British Columbia. The research study is for the fulfillment of a degree requirement for the Masters of Arts degree.

The purpose of the study is to examine the acceptability and effectiveness of a family-centered, positive behavioral support (PBS) approach to behavior support with a family with a child with autism and anxiety-related problem behavior. The approach is based on best practice in PBS with families of children with developmental disabilities. The approach emphasizes the development of a collaborative partnership with family members and the design of positive behavior supports that are both effective and a good fit with family life. The study will evaluate the extent to which the approach:

1. improves child behavior in a valued routine that are currently unsuccessfully due to anxiety-related problem behavior (e.g., child’s fear of dogs limits family outings to places where there could be dogs; child’s fear of the dark causes the bedtime routine to be difficult)
2. promotes the child’s successful participation in the targeted routine;
3. helps family members successfully support the child with autism, and improves the quality of life of the child with autism and the family as a whole

Participation in the study would involve you and your family collaborating with members of the research team in four steps of the family support process, and in four research activities. The steps of the family support process are:

1. comprehensive assessment of child problem behaviour and family ecology;
2. collaborative development of positive behaviour support plans;
3. implementation support to help families use behaviour supports in family routines; and
4. follow-up support for up to one month.

Form version 05-14-09
Research activities include:
1. preliminary assessment to identify routines and to confirm child problem behaviour;
2. videotaped observations in family routines, under conditions that may produce problem behaviour; to confirm the purpose of problem behaviour;
3. videotaped observations in two family routines;
4. assessment of family quality of life
5. assessment of parents accuracy in implementing support strategies

Because we are interested in promoting long-term improvements in child behaviour and the quality of parent-child relationships, we plan to work with families for five to six months. During the five to six months, the family will be involved in support and research activities in the home and/or community for approximately 2 to 4 hours per week. During the final month of the study, the family will be involved in support and research activities for approximately 1-2 hours every two weeks. Support activities will include conducting assessments, collaboratively designing behaviour support plans, and helping families implement plans in a valued home and community routine. All activities will be scheduled on a day and at a time that is convenient for family members.

The family chosen to participate in the study may experience five benefits. First, the child's anxiety-related problem behaviour may decrease to near zero levels in the targeted routine. Second, the child may develop new behaviours and skills that help him or her participate in the routine. Third, family members may enhance their parenting skills. A potential fourth benefit is that other families who have children with autism may be helped through the sharing of knowledge gained in this study.

If you are interested in participating in the study, or learning more about the study, please contact me (Vanessa Neufeld). My telephone number is [redacted]. My email address is [redacted]. Alternatively, you also may contact the agency representative who gave or sent to you this introductory letter. At that time, if you give the agency representative permission to release your name and phone number, I will contact you by telephone to answer any questions that you may have. In any event, thank you for your time and consideration.

Sincerely,

Vanessa Neufeld, Graduate student (Masters)
Student Researcher
Faculty of Education
University of British Columbia
Appendix C

Initial Screening Interview

Parent name: ___________________________ Phone #: __________________________
Date contacted: __________________________

This 5-6 month research project designed to investigate an approach to behavioral family intervention that seeks to decrease anxiety-related problem behavior in valued family routines.

The study is recruiting families that meet the following criteria:

• Have a child with a formal diagnosis of ASD (i.e., autistic disorder, Asperger’s syndrome, Rett’s disorder, childhood disintegrative syndrome, PDD-NOS)
• Focus child is between four and seven years old and lives in a two parent household
• Both parents/guardians speak English proficiently
• Focus child engages in observable problem behavior in at least one typical home or community routines (i.e., anxiety about unexpected visitors, anxiety about going to bed alone, specific phobia of water, riding a bike, dogs etc.)
• Parents do not perceive themselves to be in a “crisis” due to the child’s behavior or other family problems
• Parents/guardians agree to have an observer videotape child-parent interactions in typical routines in the home and community
• Mother or father is willing to act as an interventionist with their child
• Family is willing to participate in the study for 5-6 months
• Family is planning to stay in the Lower Mainland at least until December 2009 with no extended vacations lasting over 1 month

Do you have questions about these criteria? Does your child and family meet the criteria I’ve described?

I’d like to ask some questions about your child, your family and your reasons for wanting to participate in this study

Please describe your child: age, ASD diagnosis, school program or other services
Please describe your family: members, occupations, ability to participate in a study

Does your child engaged in anxiety-related problem behavior? Briefly describe behaviors that your child engages in that are anxiety-driven.

What are daily activities that are affected by your child’s problem behavior.

Are there home or community related routines that you don’t do anymore because of your child’s anxiety-related problem behavior?

Tell us about any questions or concerns you have about participating in a study

Because doing research is quite time-consuming and adds a bit of stress to the family, it’s important that your family is not in a state of “crisis” so I just wanted ask if you and your family is experiencing any major life stressors other than the problem behavior associated with your child with autism (e.g., other siblings, health, marriage).

The next step is screening; screening involves a researcher making an appointment to visit your home, obtain your consent to conduct interviews and observations that will help us confirm that your child and family are eligible candidates for participation in the study.
Following screening, one family will be selected to participate in the study.

The research activities will consist of the following:

- A comprehensive functional assessment of the focus child’s problem behavior will be conducted.
- An assessment of problematic family routines will be conducted. Family members will be asked to describe important family routines that are currently not going well, but which they would like to improve. One routine will be targeted for intervention.
- I will work with family members to develop a behavioral support plan, and will train family members to implement the plan.
- I will videotape the problematic routines before and after the behavior support plan is implemented and will collect other data about how the plan is working. (only the researchers will view the videotapes and they will be stored in a secure location, no confidential information will be shared with anyone outside the research team)
- Behavior support plans will be updated and improved as needed.
- A benefit of participation in this study is that families will receive behavioral consultation and support in each of two problematic routines they identify.

Do you have any questions?

Are you interested in participating in the screening process?

Thank you for participating in this pre-screening interview. I will contact you within the next few days.
Appendix D

Preliminary Consent Form

A Family-Centered, Positive Behavior Support Approach for a Child with Autism and an Anxiety Disorder

Principal Investigator: Joseph M. Lucyshyn, Ph.D.
Faculty of Education
University of British Columbia
2125 Main Mall
Vancouver, BC V6T 1Z4

Student Researcher: Vanessa Neufeld, Graduate Student (Masters)
Faculty of Education
University of British Columbia
2125 Main Mall
Vancouver, BC V6T 1Z4

Dear Parent/Guardian:

The purpose of this form is to request consent for you, for your child with autism, and for other family members’ (focus child’s brother or sister) participation in a screening process for a research study. The study will be conducted in the Faculty of Education of the University of British Columbia. The study will be conducted in the Faculty of Education of the University of British Columbia. Joseph Lucyshyn is the Principal Investigator. The graduate student researcher is Vanessa Neufeld of the University of British Columbia. The research study is for the fulfillment of degree requirement for the Masters of Arts degree. I am inviting your family to participate in the screening process because a representative of a local social service agency has recommended your child and family’s participation. After reading the consent form, if you have any questions, I will be happy to answer them to ensure that the screening procedures are fully understood.

PURPOSE OF STUDY

The purpose of this study is to examine the acceptability, effectiveness, and sustainability of a family-centered, positive behavioral support (PBS) approach to behavioral support with families of children with ASD and anxiety-related problem behavior. The approach is based on best practice in PBS with families. It emphasizes a collaborative process in which family members and a behavioral consultant work together in equal partnership to improve the behaviors of the child with a disability and the quality of life of the family as a whole. The study will evaluate the extent to which positive behavior support plans:

Form version 05-14-09 Page 1 of 7
1. Improve child behaviour and parent-child interaction in a valued family routine;
2. Promote your child’s successful participation in the chosen routine;
3. Empower you and other family members to successfully support the child
4. Enhance the quality of life of your child and family.

SUMMARY OF FAMILY SUPPORT AND RESEARCH ACTIVITIES
Participation in the project will involve you and your family collaborating with members of the research team in four family support activities and in four research activities. The four family support activities are:

1. Comprehensive assessment
2. Development of positive behaviour support plans
3. Implementation support to help you implement the behaviour support plans
4. Follow-up support for up to one month.

The four research activities are:

1. Preliminary assessments to define routines and verify problem behaviour in the chosen routine
2. Videotaped observations in the chosen family routine, under conditions that may produce problem behaviour, to confirm the purpose of problem behaviour
3. Videotaped observations in the chosen family routine to measure child and family outcomes.

Participation in the project will involve you and your family collaborating with the student researcher in family support and research activities. Research and family support activities will occur over a 3-6 month period. During the first 4-5 months, your child and family will be involved in support or research activities approximately 2 to 4 hours per week. During the final month of the study, the family would be involved in support and research activities for approximately 1-2 hours.

CRITERIA FOR PARTICIPATION IN STUDY

Before a family can participate in the study, we first need to confirm that your child and your family meet the criteria for participation. These criteria are: (a) your child is between the ages of 4 and 7 years old; (b) your child has an autism spectrum diagnosis; (c) your child is able to speak English; (d) your child is currently exhibiting anxiety-related problem behaviors in at least one home-based or community-based routines (e.g., anxiety about going to bed alone or specific phobia of water, dogs, bikes); (e) your child and family is residing in the Lower Mainland at least the next six months, with no extended vacations lasting over one month.
SCREENING PROCESS

We have developed a screening process to find out if your child and family are eligible to participate in the study. We will first contact you by telephone, review the criteria for participation, and answer any questions you may have. We will then decide together whether to proceed with the screening process. The specific steps in the process are described below.

1. **Telephone pre-screening interview.** We will first have a brief telephone interview where we will review the criteria for participation in the study and ask some questions about your child, your family, and specifically about routines that are difficult to do because of your child's anxiety-related problem behaviors. The telephone interview will take approximately 30 minutes.

2. **Preschool Language Scale assessment.** If the telephone interview indicates that your child is a good fit for the study, then we will request permission to access his records to assure that your child has a receptive understanding of at least 3 years of age. If there is no record of this assessment in the past, then we will request permission to conduct this assessment. This will take approximately one hour.

3. **Anxiety Disorder Interview Schedule for Children- Parent Version.** If the preschool language scale assessment indicates your child does have a receptive understanding of at least 3 years of age, then we will request permission for a clinician to administer the anxiety-disorder interview schedule. A clinician will meet with you and ask you questions regarding your child's anxiety. The interview will take approximately one hour.

4. **Family Routine Assessment.** After the Anxiety Disorder Interview, we would request permission to meet with you, in your home, at the time that is convenient for you to further discuss the routines that your family values but are currently unsuccessfully due to anxiety-related problem behaviors. We will also gather information on how the chosen routine would look if it were successful, the steps and sequence of the routine, and the goals and values that would be reflected in the routine. The interview will take approximately one hour.

5. **Preliminary observations.** If the interview indicates that your child is a good fit for the study, then we will request permission to conduct observations in the home and/or community. With your permission, the student researcher will observe you and your child during the home and/or community routine in which anxiety-related problem behaviours regularly occur. During the observation, the student-researcher will use an observation form to gather data about child problem behaviours. A minimum of 2 to 4 observations will be conducted. Each observation will last between 3 and 15 minutes.
6. **Informed consent for study participation.** If the observations confirm the presence of anxiety-related problem behaviours in at least one family routine in the home and/or community, then we will invite you to participate in the study. At that time, we will ask you to read and sign an informed consent letter for participation.

**POTENTIAL RISKS AND SAFEGUARDS**

If you agree to participate and permit your child and family to participate, you will need to consider four potential risks: (1) physical, (2) psychological, (3) legal, and (4) loss of confidentiality.

1. **Physical Risk** Because your child engages in problem behaviour, there is more than a minimal risk that you, your child, or another family member may experience a physical injury during the study. Every precaution will be taken to minimize this risk:
   
   a. Members of the research team have extensive experience working with children who engage in problem behaviour in home and community settings.
   b. Observations will be terminated if your child begins to engage in medium or high intensity problem behavior.
   c. As needed, the student researcher will be available to assist you, your child, and other family members during observations.

2. **Psychological Risk** Because your family will be observed during home and community routines and will participate in training and support activities, you, your child, or other family members may experience psychological risk. That is, you, your child, or other family members may feel some discomfort or stress during these activities. Several steps will be taken to guard against this risk:

   a. During observation sessions, the observer will maintain a low profile and not call attention to herself.
   b. You or other family members can terminate an observation session at any time.
   c. Preliminary interviews will be conducted at a time and place that is convenient for you and your family.

3. **Legal Risk** A potential but minimal risk relates to the legal requirements around reporting abuse if it is witnessed. If members of the research team witness any abuse of the focus person by any person, they will have to report it to the appropriate provincial authorities. This risk will be guarded against in the following ways:

   a. If abuse is observed, you will be informed and invited to participate in reporting the incident. The research team also will offer your family counseling support.

4. **Loss of Confidentiality** There is a risk that you, your child, or another family member may experience a loss of confidentiality. To guard against this risk:

   - (Continued on next page...)
a. change the names of all persons, places, and programs described in the study;
b. allow access to information only to members of the research team;
c. keep all data, notes, and videotapes in a locked file in a secure office;
d. destroy all data, collected solely for the purpose of screening, 5 years after the study is completed

POTENTIAL BENEFITS

By participating in the study, you, your child with ASD and other family members may experience two potential benefits. These are listed below.

1. Participation in a family-centered PBS research study. If the screening process indicates that your child is a good fit for the family-centered PBS study, you will be invited to participate in the research study. There are three specific benefits of participation:
   a. Five-six months of family-centered positive behavioral support (PBS) services, for an average of 1-2 hours per week, aimed at improving the success of a valued family routine in the home and/or community;
   b. Improvement in your child’s behavior and participation in the chosen routine
   c. Contributions to knowledge about how to durably and meaningfully improve your child’s behavior in a valued family routine.

However, because behavioral and quality of life improvements cannot be assured, it is possible that you and your family may not experience all of the benefits listed above.

2. Assessment report and recommendations. If the screening process does not indicate that your child is a good fit for the study, then we will provide you with three benefits:
   a. summary of the preliminary interview and/or observations
   b. recommendations for behavior support that are based on the interview and/or observations, and referral to appropriate, alternative sources for family and behavioral support in your community.

ALTERNATIVES

If during the screening process, you choose not to participate in the study, we will refer you to appropriate, alternative sources for family and behavioral support in your community.
RIGHTS AS A RESEARCH PARTICIPANT

Your participation and that of your child and other family members in the preliminary screening process is voluntary. Your decision whether or not to participate and to allow your child and other family members to participate will not have any affect on your child’s education, the provision of support from a community agency, or future opportunities for behavior consultation and support. If you agree to participate and allow your child and other family members to participate, you are free to withdraw consent and refuse to continue your participation and that of your child and family. You may do so at any time without penalty or loss of benefits to which you, your child, or other family members are otherwise entitled. By signing the consent form, you do not waive any of your legal rights. If you have any questions, please contact Dr. Joseph Lucyshyn, Faculty of Education, University of British Columbia, 2125 Main Mall, Vancouver, B.C., V6T 1Z4, (604) 822-1904 or Vanessa Neufeld . If you have any concerns about your rights or treatment as a research participant, you may contact the Research Subject Information Line in the UBC Office of Research Services at (604) 822-8598. Your signature below indicates that you have received a copy of this consent form for your records. Your signature indicates that you consent to your, your child with autism and other family members (i.e., siblings) participation in the preliminary screening process.

Sincerely,

Vanessa Neufeld, Graduate Student (Masters)  
Student researcher  
Faculty of Education  
University of British Columbia

Joseph, M. Lucyshyn, Ph.D.  
Principal Investigator  
Associate Professor  
Faculty of Education  
University of British Columbia
CONSENT FORM FOR PRELIMINARY SCREENING ACTIVITIES

Study Title: A Family-Centered Positive Behavior Approach for a Child with Autism and an Anxiety Disorder
Principal Investigator: Joseph Lucysyn, Ph.D., Faculty of Education, University of British Columbia
Student researcher: Vanessa Neufeld, Masters Student (Graduate), Faculty of Education, University of British Columbia

Consent: I have read the attached letter and am interested in learning if my child and family is eligible to participate in the study entitled, “A Family-Centered Positive Behavior Approach for a Child with Autism and an Anxiety Disorder.” I consent to completion of pre-screening activities (i.e., home observations, assessment of my child’s receptive language skills, parent-rated questionnaire regarding child’s anxiety and a interview regarding anxiety-related problem routines). I understand that all information will be kept confidential and that my participation and that of my child and other family members (i.e., focus child’s brother and/or sister) is entirely voluntary and that I, my child, or other family members may withdraw consent and refuse to participate at any time without any penalty or loss of benefits to which my family is otherwise entitled, and that I am not waiving any legal claims, rights, or remedies. I also understand that I will receive a copy of this letter of request for consent for my own records. I understand that if results from the preliminary screening activities indicate that my child and family is eligible to participate, I will be given a more detailed letter about the timeline and procedures of the study and I will have the opportunity to decide whether or not I would like to participate in the study. My decision regarding my consent, that of my child with autism, and that of other family members is indicated below.

_________ YES, I consent to participate and give permission for my child with a disability and other family members (i.e., focus child’s brother and/or sister) to participate in preliminary screening activities.

_________ NO, I do not consent to participate, and my child with a disability and other family members do not have my permission to participate in preliminary screening activities.

Focus Child’s Name:______________________________

Parent/Guardian Signature:_________________________ Date:____________________

Parent/Guardian Signature:_________________________ Date:____________________

Witness:_________________________________________ Date:____________________

PLEASE RETURN THIS PAGE TO:
Vanessa Neufeld, Masters Student (Graduate)
UBC Faculty of Education
2125 Main Mall
Vancouver, BC, Canada V6T 1Z4

Form version 05/14/09
Appendix E

Preschool Anxiety Scale

PRESCHOOL ANXIETY SCALE
( Parent Report )

Your Name: ____________________________ Date: ____________________________

Your Child’s Name: ____________________________

Below is a list of items that describe children. For each item please circle the response that best describes your child. Please circle the 4 if the item is very often true, 3 if the item is quite often true, 2 if the item is sometimes true, 1 if the item is seldom true or if it is not true at all circle the 0. Please answer all the items as well as you can, even if some do not seem to apply to your child.

<table>
<thead>
<tr>
<th>Item</th>
<th>Not True at All</th>
<th>Seldom True</th>
<th>Sometimes True</th>
<th>Quite Often True</th>
<th>Very Often True</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>2.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>3.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>4.</td>
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<td>4</td>
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<td>5.</td>
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<td>6.</td>
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<td>2</td>
<td>3</td>
<td>4</td>
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<td>7.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>9.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>10.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>11.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>12.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>14.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>15.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>16.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>17.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Not True at All</td>
<td>Seldom True</td>
<td>Sometimes True</td>
<td>Quite Often True</td>
<td>Very Often True</td>
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</tr>
<tr>
<td>18</td>
<td>Has to have things in exactly the right order or position to stop bad things from happening</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>19</td>
<td>Worries that he/she will do something embarrassing in front of other people</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>20</td>
<td>Is afraid of insects and/or spiders</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>21</td>
<td>Has bad or silly thoughts or images that keep coming back over and over</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>22</td>
<td>Becomes distressed about your leaving him/her at preschool/school or with a babysitter</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>23</td>
<td>Is afraid to go up to group of children and join their activities</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>24</td>
<td>Is frightened of dogs</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>25</td>
<td>Has nightmares about being apart from you</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>26</td>
<td>Is afraid of the dark</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>27</td>
<td>Has to keep thinking special thoughts (e.g., numbers or words) to stop bad things from happening</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>28</td>
<td>Asks for reassurance when it doesn’t seem necessary</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>29</td>
<td>Has your child ever experienced anything really bad or traumatic (e.g., severe accident, death of a family member/friend, assault, robbery, disaster)</td>
<td><strong>YES</strong></td>
<td><strong>NO</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please briefly describe the event that your child experienced...

If you answered NO to question 29, please do not answer questions 30-34. If you answered YES, please DO answer the following questions.

Do the following statements describe your child’s behaviour since the event?

<table>
<thead>
<tr>
<th></th>
<th>Not True at All</th>
<th>Seldom True</th>
<th>Sometimes True</th>
<th>Quite Often True</th>
<th>Very Often True</th>
</tr>
</thead>
<tbody>
<tr>
<td>30</td>
<td>Has bad dreams or nightmares about the event</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>31</td>
<td>Remembers the event and becomes distressed</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<td>32</td>
<td>Becomes distressed when reminded of the event</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>33</td>
<td>Suddenly behaves as if he/she is reliving the bad experience</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>34</td>
<td>Shows bodily signs of fear (e.g., sweating, shaking or racing heart) when reminded of the event</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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</tbody>
</table>

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Family Routine Assessment

Identifying and defining activity settings

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Topography</th>
<th>Frequency</th>
<th>Duration</th>
<th>Intensity</th>
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<tbody>
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</table>
**Predictors**

Time of day (When)

2. Setting (Where)

3. People (With whom)

4. Activity (What activity)

**Possible Functions of Behavior**

<table>
<thead>
<tr>
<th>Behavior</th>
<th>What does s/he get?</th>
<th>What does s/he avoid?</th>
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<tbody>
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</table>
D. Child’s typical schedule of daily activities (home routines and community activities)

<table>
<thead>
<tr>
<th>Time</th>
<th>Day</th>
<th>Weekday</th>
<th>Weekend</th>
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<tbody>
<tr>
<td>Morning</td>
<td></td>
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<tr>
<td>Mid day</td>
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<td>Afternoon</td>
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<tr>
<td>Evening</td>
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E. Home routines in which anxiety-related problem behaviors typically occur, and your priorities for improvement.

F. Community activities in which anxiety-related problem behaviors typically occur and your priorities for improvement

G. Home or community routines that you have significantly altered or no longer do because of anxiety-related problem behavior, and your priorities for improvement.
<table>
<thead>
<tr>
<th>Time</th>
<th>Routine or Activity</th>
<th>Predictors</th>
<th>Problem Behavior(s)</th>
<th>Maintaining Consequence</th>
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Appendix G

Formal Consent Form

CONSENT FORM FOR PARTICIPATION IN STUDY
A Family-Centered Positive Behavior Support Approach for a Child with Autism and an Anxiety Disorder

Principal Investigator: Joseph M. Lucyshyn, Ph.D.
Faculty of Education
University of British Columbia
2125 Main Mall
Vancouver, BC V6T 1Z4

Student researcher: Vanessa Neufeld, Graduate Student (Masters)

Dear Parent/Guardian:

The purpose of this form is to request consent for your, for your child with ASD, and for other family members’ (i.e., focus child’s brother and/or sister) participation in a research study. The study will be conducted in the Faculty of Education of the University of British Columbia. Joseph Lucyshyn is the Principal Investigator. The student researcher is Vanessa Neufeld of the University of British Columbia. The research study is for the fulfillment of degree requirement for the Masters of Arts degree. I am inviting your family’s participation because a representative of a local social service agency has recommended your child and family’s participation. After reading the consent form, if you have any questions, I will be happy to answer them to ensure that the procedures are fully understood.

PURPOSE OF STUDY

The purpose of this study is to examine the acceptability, effectiveness, and sustainability of a comprehensive approach to behaviour support with families of children with ASD and anxiety-related problem behaviour. The approach is based on best practice in positive behaviour support with families. It emphasizes a collaborative process in which family members and a behavioural consultant work together in equal partnership to improve the behaviour of the child with a disability and the quality of life of the family as a whole. The study will evaluate the extent to which positive behaviour support plans:

1. Improve child behaviour and parent-child interaction in a valued family routine;
2. Promote your child’s successful participation in the chosen routine;
3. Empower you and other family members to successfully support the child
4. Enhance the quality of life of your child and family.
FAMILY SUPPORT AND RESEARCH ACTIVITIES

Participation in the project will involve you and your family collaborating with the student researcher in family support and research activities. Research and family support activities will occur over a 3-6 month period. During the first 4-5 months, your child and family will be involved in support or research activities approximately 2 to 4 hours per week. During the final month of the study, the family would be involved in support and research activities for approximately 1-2 hours. Research and family support activities are described below:

**Preliminary Assessment** Preliminary assessment activities will involve several activities: (a) completion of a telephone pre-screening interview; (b) assessment of your child’s receptive language level; (c) assessing whether your child has a classifiable anxiety disorder; and (d) an interview with you and other family members, which will be scheduled at a time and place of your convenience. These interviews will last approximately an hour. The purpose of the interviews is to identify valued routines in the home and community in which anxiety-related problem behaviour occurs, and to develop a preliminary understanding about problem behaviour. Following interviews, we will conduct two to three pilot observations in the identified routines. The purpose of these observations will be to verify the occurrence and purpose of the anxiety-related problem behaviour. Each observation will last up to 15-20 minutes.

**Comprehensive Assessment** If problem behaviours are confirmed, then preliminary assessment activities initiated during the first two meetings will be completed. First, a functional assessment interview will be completed. This will involve one meeting of 1 to 2 hours in length. This assessment will help us develop a comprehensive understanding of the conditions that predict problem behaviour and positive behaviour. This information will help us develop an effective support plan. Second, we will complete a family ecology assessment. This will involve one meeting of 1 to 2 hours in length in which we learn about your family’s strengths, social supports and resources, stressors, and goals for your child and family. This information will help us develop a plan that fits your family.

**Positive Behaviour Support Plan Design** Following assessment activities, we will collaborate with you to build a positive behaviour support plan for the anxiety-related problem routine. This will be done through a series of two meetings. Each meeting will last 1 to 2 hours. During a planning meeting, family members and the interventionist will review assessment information for a routine and build a support plan that fits well with the routine. The plan will include several positive behaviour support strategies. It will be designed to improve child behaviour and the success of the routine.

**Implementation Support** Training and support to help you and other family members implement the support plan in the routine will occur approximately twice per week and involve 1 to 2 hours. During these meetings, the student researcher will teach you and other family members how to implement support strategies with your child. Activities may include discussion of written instructions, role-play of strategies, and coaching in the routine.
Follow-up Support After you have succeeded in improving child behaviour in the routine, we will transition to a phase of research called follow-up support. During follow-up, we will provide training and support as needed for one additional month.

Videotaped Observations in Home and Community Routines Videotaped observations in routines will occur during three experimental phases of the study. These phases are baseline, intervention, and follow-up. Observation sessions will not occur on the same day as an implementation support meeting. During observation sessions, an observer will videotape your child and family’s participation in the selected routine. Each observation session will last between 20-30 minutes.

Level of Anxiety Rating You will also be asked to rate your child’s levels of anxiety at the end of each observation session. A simple 1-5 rating scale will assist you in making your estimations. Completing the rating form will take approximately 1 minute.

Assessment of Family Quality of Life Another research activity that will take place is an assessment of your family’s well being. This will occur at the beginning and end of the study. Completing the questionnaire will take approximately one hour.

POTENTIAL RISKS AND SAFEGUARDS

If you agree to participate and permit your child and family to participate, you will need to consider four potential risks: (1) physical; (2) psychological; (3) legal; and (4) loss of confidentiality.

1. Physical Risk Because your child engages in problem behaviour, there is more than a minimal risk that you, your child, or another family member may experience a physical injury during the study. Every precaution will be taken to minimize this risk:

   a. Members of the research team have extensive experience working with children who engage in problem behaviour in home and community settings.
   b. Behaviour support strategies will focus on preventing behaviour problems and on teaching positive behaviour that are designed to replace problem behaviour.
   c. Observation sessions and training and support activities will be terminated if your child begins to engage in medium or high intensity problem behaviour.

2. Psychological Risk Because your family will be observed during home and community routines and will participate in training and support activities, you, your child, or other family members may experience psychological risk. That is, you, your child, or other family members may feel some discomfort or stress during these activities. Several steps will be taken to guard against this risk:

   a. During observation sessions, the observer will maintain a low profile and not call attention to him or herself.
   b. You or other family members can terminate an observation session at any time.
c. "Family-friendly" features of the family support process should help to reduce stress associated with the study. Interviews will be conducted at a time and place that is convenient for you and your family. Support plans will be developed collaboratively with you and your family to ensure that plans fit well with your goals and routines.

3. **Legal Risk** A potential but minimal risk relates to the legal requirements around reporting abuse if it is witnessed. If members of the research team witness any abuse of the focus person by any person, they will have to report it to the appropriate provincial authorities. This risk will be guarded against in the following ways:

   a. The study focuses on providing family members with positive, non-punitive ways to prevent and manage child problem behavior. Family members who develop these skills are unlikely to engage in child maltreatment.
   b. If abuse is observed, you will be informed and invited to participate in reporting the incident. The research team also will offer your family counseling support.

4. **Loss of Confidentiality** There is a risk that you, your child, or another family member may experience a loss of confidentiality. To guard against this risk:

   a. change the names of all persons, places, and programs described in the study;
   b. allow access to information only to members of the research team;
   c. keep all data, notes, and videotapes in a locked file in a secure office.

**POTENTIAL BENEFITS**

By participating in the study, you, your child with autism and other family members may experience four direct benefits and one indirect benefit. These are listed below:

1. Your child's behavior problems may decrease to near zero levels in targeted routine.
2. Your child also may develop new skills that help him or her participate in the routine.
3. The quality of parent-child interaction may improve, and your knowledge and skills in supporting your child may be enhanced.
4. Through your participation, other families who have children with autism may also benefit. This will occur by describing project results in journals and at conferences.

However, because behavioral and quality of life improvements cannot be assured, it is possible that you and your family may not experience all of the benefits listed above.

**ALTERNATIVES**

If you choose not to participate in the study, we will refer you to appropriate, alternative sources of family and behavioral support in your community.
RIGHTS AS A RESEARCH PARTICIPANT

Your participation and that of your child and other family members is voluntary. Your decision whether or not to participate and to allow your child and other family members to participate will not have any affect on your child’s education, the provision of support from a community agency, or future opportunities for behavior consultation and support. If you agree to participate and allow your child and other family members to participate, you are free to withdraw consent and refuse to continue your participation and that of your child and family. You may do so at any time without penalty or loss of benefits to which you, your child, or other family members are otherwise entitled. By signing the consent form, you do not waive any of your legal rights. If you have any questions, please contact Dr. Joseph Lucyslyshyn, Faculty of Education, University of British Columbia, 2125 Main Mall, Vancouver, B.C., V6T 1Z4, (604) 822-1904 or Vanessa Neufeld.

If you have any concerns about your rights or treatment as a research participant, you may contact the Research Subject Information Line in the UBC Office of Research Services at (604) 822-8598. Your signature below indicates that you have received a copy of this consent form for your records. Your signature indicates that you consent to your, your child with a disability and other family members (i.e., siblings) participation in the study.

Sincerely,

Vanessa Neufeld, Graduate Student (Masters)  
Student researcher  
Faculty of Education  
University of British Columbia

Joseph, M. Lucyslyshyn Ph.D  
Principal Investigator  
Associate Professor  
Faculty of Education  
University of British Columbia
CONSENT FORM FOR PARTICIPATION IN STUDY

Study Title: A Family-Centered Positive Behavior Support Approach for a Child with Autism and an Anxiety Disorder
Principal Investigator: Joseph Lucysyn, Ph.D., Faculty of Education, University of British Columbia
Student researcher: Vanessa Neufeld, Masters Student (Graduate), Faculty of Education, University of British Columbia

Consent: I have read and understood the attached letter of request to participate in the study entitled, “A Family-Centered Positive Behavior Support Approach for a Child with Autism and an Anxiety Disorder.” I also consent to and authorize the release of information from biographical records to document birth date, most recent IQ score and test, diagnostic information, and medical records. I understand that all information will be kept confidential and that my participation and that of my child and other family members (i.e., focus child’s brother and/or sister) is entirely voluntary and that I, my child, or other family members may withdraw consent and refuse to participate at any time without any penalty or loss of benefits to which my family is otherwise entitled, and that I am not waiving any legal claims, rights, or remedies. I also understand that I will receive a copy of this letter of request for consent for my own records. My decision regarding my participation, that of my child with a disability, and that of other family members is indicated below.

YES, I consent to participate and give permission for my child with a disability and other family members (i.e., focus child’s brother and/or sister) to participate.

NO, I do not consent to participate, and my child with a disability and other family members do not have my permission to participate.

Focus Child’s Name: __________________________

Sibling’s Name: __________________________

Parent/Guardian Signature: __________________________ Date: __________

Parent/Guardian Signature: __________________________ Date: __________

Witness: __________________________ Date: __________

PLEASE RETURN THIS PAGE TO:
Joseph M. Lucysyn, Ph.D.
Vanessa Neufeld, Masters Student (Graduate)
Faculty of Education, University of British Columbia
2125 Main Mall, Vancouver, BC
V6T 1Z4

Form version 05-14-09 Page 6 of 7
VIDEO TAPE CONSENT FORM

Study Title: A Family-Centered Positive Behavior Support Approach for a Child with Autism and Anxiety Disorders

Principal Investigator: Joseph Lucyszyn, Ph.D., Faculty of Education, University of British Columbia

Student Researcher: Vanessa Neufeld, Masters Student (Graduate), Faculty of Education, University of British Columbia

Consent: I understand that my participation in this study will involve videotaping of me, my child with autism, and other family members in our home and in community settings. I also understand that I may request that the researchers stop the videotaping at any time if I or a member of my family does not want to be videotaped. I also understand that all videotaped materials will be kept in a secure and locked location, and that only the researchers will have access to this material, unless I give my specific permission for it to be viewed by any other person.

My consent regarding the videotaping of my child’s participation and that of my family in this study is indicated below. I understand that I will receive a copy of this consent for my personal records.

______, Yes, I consent to the videotaping of my child and family.

______, No, I do not consent to the videotaping of my child and family.

Focus Child’s Name: __________________________

Sibling’s Name: __________________________

Parent Signature: ________________________ Date: ________

Parent Signature: ________________________ Date: ________

Witness: ________________________________ Date: ________

If I have questions or concerns about videotaping of my child or family, I may contact:

Vanessa Neufeld OR Joseph Lucyszyn
Faculty of Education
University of British Columbia
2125 Main Mall
Vancouver, B.C. V6T 1Z4
(604) 822-1904
joe.lucyszyn@ubc.ca
# Appendix H

## Partial-Interval Recording Form for Scoring Percentage of Intervals of Problem Behavior

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O: Occurrence of problem behavior; N/O= Non-occurrence of problem behavior
Appendix I

Parent Rated Levels of Child Anxiety

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<th>Date:</th>
<th>Person completing evaluation:</th>
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<thead>
<tr>
<th>How anxious do you perceive your child to be during this routine?</th>
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<tr>
<td>1 = not anxious 2 = a little anxious 3 = somewhat anxious 4 = noticeably anxious 5 = very anxious</td>
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Appendix J

Partial-Interval Recording Form for Scoring Parent Implementation Fidelity of PBS Plan

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<td>Time (Min: Sec)</td>
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<tr>
<td>Codes: Accurate (✓); Error (✗); Non occurrence (o)</td>
</tr>
</tbody>
</table>

- **Proactive, Preventative Strategies**
- Use of visual schedule
- + Contingency statement
- Safety signals

**Proactive pre-corrective prompts**
- Offer choice
- Model brave talk

**Teaching Strategies**
- Consequence map
- Gradual exposure

**Consequence Strategies**
- Contingent praise

Redirecting if problem behaviors occurred

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| Time (Min: Sec) | 4:30 | 5:00 | 5:30 | 6:00 | 6:30 | 7:00 | 7:30 | 8:00 |
|---------------------------------------------------------------|
| Codes: Accurate (✓); Error (✗); Non occurrence (o) |

- **Proactive, Preventative Strategies**
- Use of visual schedule
- + Contingency statement
- Safety signals

**Proactive pre-corrective prompts**
- Offer choice
- Model brave talk

**Teaching Strategies**
- Consequence map
- Gradual exposure

**Consequence Strategies**
- Contingent praise

Redirecting if problem behaviors occurred
# Appendix K

## Social Validity Questionnaire

Date: ____________

Family Member completing evaluation: ____________

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<td>1. The goals of the treatment plan are appropriate for my child</td>
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</tr>
<tr>
<td>2. The goals of the plan are consistent with my family’s goals, values and beliefs.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. The strategies and procedures used are difficult to carry out.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. The strategies and procedures are effective in improving my child’s behavior.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. The outcomes of the treatment effort are beneficial for my child.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. The outcomes of the treatment effort are beneficial to my family as a whole</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. The treatment effort has caused some anticipated problems in our family.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. Training activities have been well organized, clear and helpful.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. The person providing technical assistance has shown respect for our family’s values and beliefs.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. Overall, this treatment effort has strengthened our family.</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Appendix L

**Goodness of Fit Survey**

Date: __________

Family member completing evaluation: __________

<table>
<thead>
<tr>
<th>Question</th>
<th>Little</th>
<th>A lot</th>
<th>Can’t Tell</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Do you believe that the treatment plan takes into account your understanding of your child (e.g., reasons for your child’s anxiety-related problem behavior, strategies that encourage positive behavior, your child preferences?)</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2) Does the plan address your highest priority goals (i.e., routines that you value as a family but currently are unsuccessful due to problem behavior)</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3) Do you understand what you are expected to with this plan?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4) Are you comfortable with what you are expected to do?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5) Do you understand what others are expected to do (i.e., Vanessa, other family members)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6) Are you comfortable with what others are expected to do?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7) Does the anxiety-routine chosen reflect your highest priority routine?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8) Does the plan for the anxiety-eliciting routine disrupt the time of day to the point that stress and hardship will be created?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9) Does the plan recognize and build on your family’s strengths?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10) All things considered, how difficult will it be for you to use this treatment plan for the anxiety-eliciting routine?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11) Do you believe the treatment plan will be effective?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12) If the plan is effective, do you believe you can keep using the strategies for a long time (e.g., over one year) even though Vanessa will not be available as much? (little to no contact with Vanessa, some assistance by phone)</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Appendix M

Family Ecology Assessment

1. What would you characterize as the strengths of your family?

2. What might be some positive contributions that your child makes or has made to the family?

3. What formal or informal resources have you used to improve the situation? (e.g., respite care, participation in a parent support group, having other family members help with chores or childcare)

4. What are your sources of social support? (i.e., someone whom you discuss problems and find solutions; someone with whom you do leisure activities; someone who validates your worth as a person)

5. What are sources of stress in your family?
   a. What is the effect of your child’s problem behavior on your as a parent?
   b. What is the effect of your child’s problem behavior on the family as a whole?
   c. What are other sources of stress in the family?

What are your goals for your child? What are you goals for yourself as a parent? What are your goals for the family as a whole?
Appendix N

Positive Behavior Support Plan

Positive Behavior Support Plan for Claire
Competing Pathways Diagram and Support Strategies

Claire’s anxiety disorder
Anxiety regarding new situations for parent
Parent model & reinforces fear

Setting Event(s)

Parent asks Claire to go in the pool

Antecedent Trigger(s)

Fearful talk
Verbal protest
Scream/cry
Physical resistance
Leave assigned area
Physical aggression
Tantrum

Problem Behaviour

Claire says, “I need a break” or “wait one minute”

Alternative Replacement Behaviour

Claire complies and goes into the pool

Desired Behaviour

Verbal praise
Preferred item (mermaid doll)
Walk around pool

Maintaining Consequence

Claire does not go into the pool
(avoid/escape)

Maintaining Consequence
### A. Positive Behaviour Support Plan

**Strategies that Make Problem Behaviours Irrelevant, Ineffective, and Inefficient**

<table>
<thead>
<tr>
<th>Setting Event Strategies</th>
<th>Preventative Strategies</th>
<th>Teaching Strategies</th>
<th>Consequence Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use gradual exposure to systematically expose Claire to the most anxiety provoking situation. Use anxiety hierarchy to guide training sessions. Do not move to the next step on hierarchy until Claire is displaying minimal or no anxiety at the current step.</td>
<td>Use the visual schedule to promote desired behavior and ensure predictability. Show Claire the visual schedule and review each step of the swimming routine with her before initiating the routine. Also, refer back to the schedule as each step of the routine is complete. Use positive contingency statements by telling Claire what to do and what she will get after doing the requested behavior (i.e., “after you go down to the first step, you can have the mermaid doll”). Use a safety signal to communicate to Claire how much more is expected before attaining the reinforcer (i.e., “just one more step and then you’re all done!”)</td>
<td>Use exposure technique and work on the targeted scenario until she is no longer anxious. Teach Claire to say, “I need a break” or “Wait one minute”. Teach Claire how regulate her anxiety (i.e., deep breathing and modified progressive muscle relaxation). Read the modified social story about going swimming. Role-play targeted step before going to the pool.</td>
<td>If Claire goes into the pool, give Claire specific praise for going into the pool and give her the reinforcer she had chosen (i.e., mermaid doll, Barbie) If Claire asks for a break or for one minute, give Claire specific praise for using her words. Allow her to sit/stand by the pool. Do not ask her to try the targeted step for 1 minute. If Claire engages in fearful talk, actively ignore and redirect to brave talk. If Claire starts to whine or protest (minor problem behavior), re-direct her to the contingency map and remind her of what she will receive if she completes the task. If Claire continues to whine or protest, redirect her to ask for a break.</td>
</tr>
<tr>
<td>Decrease parent anxiety by having graduate researcher, (Vanessa), provide initial instruction and gradually ease parent into intervention role. Teach parent to: (a) model “brave” talk (i.e., by modelling and prompting parent to make statements that the pool is safe); (b) refrain from reinforcing responding to fearful talk that is has no real basis (i.e., parent ignores anxious talk and redirects to brave talk) (c) model “calm” talk for fearful talk that does have a real basis (i.e., parent ignores anxious talk and reassures child she will be OK)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Use exposure technique and work on the targeted scenario until she is no longer anxious. Teach Claire to say, “I need a break” or “Wait one minute”. Teach Claire how regulate her anxiety (i.e., deep breathing and modified progressive muscle relaxation). Read the modified social story about going swimming. Role-play targeted step before going to the pool.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Setting Event Strategies</td>
<td>Preventative Strategies</td>
<td>Teaching Strategies</td>
<td>Consequence Strategies</td>
</tr>
<tr>
<td>-------------------------</td>
<td>------------------------</td>
<td>---------------------</td>
<td>-----------------------</td>
</tr>
<tr>
<td></td>
<td>Offer Claire choices of: (a) where she wants to enter in the pool (e.g., “do you want to go down the steps here or there?”) and (b) reinforcer (e.g., “do you want a chocolate chip or an M&amp;M?”) Use contingency map to teach Claire the positive consequences and negative consequences of following through with the instruction.</td>
<td>If Claire starts to tantrum or pinches (major problem behavior), implement crisis plan</td>
<td></td>
</tr>
</tbody>
</table>
Detailed description of behavior support strategies

Setting event strategies/ lifestyle enhancements

1. Decrease parent anxiety by having graduate researcher, (Vanessa), provide initial instruction and gradually ease parent into intervention role. To help ease the parent’s anxiety regarding the new routine, Vanessa will initially do the intervention and model the strategies and provide hands-on training with the child. At each step, Vanessa will initially work on that step (e.g., toes in water) until Claire is no longer anxious then transfer over to you. Then, Vanessa will gradually fade back her assistance and gradually ease the parent into the intervention role. When Claire is no longer anxious with both of us, Vanessa will work on the next step and again transfer over to Dana when Claire shows no/minimal anxiety with her.

2. Teach parent to: (a) model “brave” talk (i.e., by modelling and prompting parent to make statements that the pool is safe); (b) refrain from reinforcing responding to fearful talk that has no real basis (i.e., parent ignores anxious talk and redirects to brave talk) (c) model “calm” talk for anxious talk that does have a real basis (i.e., parent ignores anxious talk and reassures child she will be OK). Claire repeats a lot of things that she hears so it is important to model “brave” talk rather than anxious talk. You can model brave talk and encourage her to focus on the step on the anxiety hierarchy (e.g., “You can do it! Let’s go on the first step!”). You can model brave talk while she is enjoying her reinforcer at the pool (e.g., “isn’t the pool great? We’re safe and having fun at the pool!”). In the unlikely event that Claire gets hurt at the pool, you can model brave talk by reassuring her she will be OK (e.g., “It’s OK, you’re going to be just fine!”)

Antecedent/ preventive strategies

1. Gradual exposure to the most anxiety provoking situation. Use anxiety hierarchy to guide training sessions, do not move to the next step on hierarchy until Claire is displaying minimal or no anxiety at the current step. Just being at the pool is still a scary thing for Claire so we need to slowly ease her into the steps of the swimming routine. Each session we have at the pool, we will use the anxiety hierarchy to guide us. When Claire seems to show little or no anxiety at a step in the hierarchy, we will move to the next step. This helps set Claire up for success rather than failure.

2. Use the visual schedule to promote desired behavior and ensure predictability. Use the Boardmaker PCS to schedule the swimming routine and the exact step/scenario on the anxiety hierarchy that she is expected to complete so Claire knows exactly what is expected of her and also what preferred activity/item she gets after the swimming routine.

3. Use the visual schedule to promote desired behavior and ensure predictability. Show Claire the visual schedule and review each step of the swimming routine with her before initiating the routine. Also, refer back to the schedule as each step of the routine is complete. Use the visual schedule to show Claire the exact order of steps that will occur using either the Boardmaker PCS or the written version of “Today’s swim schedule.” Review with Claire the entire sequence of events while you are in the changing room and again when you are on the pool deck. You can refer back to the visual schedule as you
complete the steps in the routine. This helps build in predictability for Claire and may minimize the likelihood of problem behavior.

4. **Use positive contingency statements by telling Claire what to do and what she will get after doing the requested behavior.** A contingency statement involves the parent telling the child what to do and what the child will get after doing the requested behavior (i.e., “After you [do behavior], you can have [reinforcer]”). The reinforcer can be a preferred item (e.g., mermaid doll) or a preferred activity (e.g., singing together). It is important to use a positive contingency statement before a significant problem behavior occurs. For example, “go down to the 2nd step and then you can play with the mermaid doll.”

5. **Use a safety signal to communicate to Claire how much more is expected before attaining the reinforcer.** A safety signal is a verbal cue that communicates to the child when a mildly aversive event is terminated (e.g., going in the swimming pool). It is important to use a safety signal statement before problem behaviours occurs. For example, “after you put your toes at the edge of the first step, you can get out of the pool.”

6. **Use proactive, pre-corrective statements to remind Claire what to do if she wants a break (e.g., “Remember if you need a break, you can say to mommy, ‘I need a break’”).** A pre-corrective statement is a proactive reminder given to the child of what appropriate behavior is expected. It is important to use a pre-corrective statement before significant problem behavior occurs. For example on the first instance that Claire shows minor problem behavior (e.g., whines, verbal protest), say something like, “Remember, if you need a break, you can say to mommy ‘I need a break’ or ‘wait one minute’ and Mommy will give you a break.” This reminds her to escape from the task in an appropriate way.

7. **Offer Claire choices of: (a) where she wants to enter in the pool (e.g., “do you want to go down the steps here or there?”); and (b) reinforcer (e.g., “do you want a chocolate chip or an M&M?”).** A choice is when you allow Claire to make a decision during the swimming routine. For example, you may give Claire a choice of: (a) where she wants to enter in the pool (e.g., three different rails in the shallow end) and/or (b) a reinforcer (e.g., mermaid doll, chocolate chips). A choice does not necessarily require Claire to choose between two options (i.e., “Do you want [X] or [Y]?”). As long as Claire is aware of what her options are, you can use a more general question such as “What do you want to do?”

8. **Use contingency map to teach Claire the positive consequences and negative consequences of following through with the instruction.** A contingency map shows Claire the pathways of appropriate and inappropriate behavior and the consequences that will follow for appropriate and inappropriate behavior. Review this with her before significant problem behavior occurs to remind Claire of the consequences of appropriate and inappropriate behavior.

**Teaching strategies**

1. **Use the exposure technique and work on the targeted scenario until Claire is no longer anxious.** Use the anxiety hierarchy as a guide for sessions at the pool. Work on the targeted step on the anxiety hierarchy until Claire shows little or no anxiety at that step.
Move up the hierarchy one step at a time. Moving up the hierarchy at Claire’s pace will keep the swimming routine predictable and safe for Claire.

2. **Teach Claire to say, “I need a break” or “wait one minute.”** An alternative replacement behavior is a more appropriate behavior that is equally efficient in helping Claire meet her need (i.e., delaying going in the pool) but is more socially acceptable and appropriate. We will teach Claire to use her language and ask for a break instead of engaging in problem behavior. We will limit Claire to ask no more than 3 breaks during a session.

3. **Teach Claire how to regulate her anxiety.** Emotional regulation is an abstract concept, to make it more concrete and easier to understand for Claire, we will work on a modified progressive muscle relaxation program. Both you and the BIs can do this with Claire every day. On each page, read the text (e.g., “Squeeze your hands or a ball really tight. Hold it there. Squeeze. Squeeze. Squeeze”). At the same time, model for Claire the appropriate action (e.g., squeezing your hands into tight fists). Physically prompt Claire if necessary, it will take some time until Claire learns how to do this on her own.

4. **Read the modified social story about going swimming.** The modified social story is dynamic in that it is specific to the current targeted step in the anxiety hierarchy throughout intervention. One of the pages in the story describes the targeted step and this page will be changed as Claire progresses through the anxiety hierarchy. This is to help Claire predict the extent to which she is expected to enter the pool. There is also a page in the story that lists her “accomplishments” in the swimming routine. As Claire progresses through the steps in the hierarchy, these steps will be added to the page to highlight to Claire the progress she is making.

**Effective Consequences**

1. **If Claire goes into the pool, give Claire specific praise for going into the pool and give her the reinforcer she had chosen (i.e., mermaid doll, Barbie).** Specific praise means you let Claire know exactly why she is being praised and receiving the toy/activity that she wanted (e.g., “Good job going on the first step, here’s the mermaid doll!”)

2. **If Claire asks for a break or one minute, praise Claire for using her words. Allow her to sit/stand by the pool. Do not ask her to try the targeted step for 1 minute.** When Claire uses her words appropriately, say something like, “Nice telling me you need a break.” We will limit Claire to ask for no more than 3 breaks.

3. **If Claire starts to whine or protest (minor problem behavior), re-direct her to the contingency map and remind her of what she will receive if she completes the task.** Point to the contingency map and say something like, “Remember if you [do behavior] then you can have [reinforcer] but if you cry/scream then you won’t get the [reinforcer]”

4. **If Claire continues to whine or protest, redirect her to ask for a break.** Use a precorrect statement to remind Claire to ask for a break instead of engaging in problem behavior (e.g., “Remember if you want a break from trying to go in the pool, you can just say ‘I need a break’”).
5. If Claire continues to tantrum or pinches (major problem behavior), implement the crisis plan.

**Crisis Management Procedures**

Claire’s problem behavior usually follow a predictable chain from minor to severe (i.e., whine/verbal protest/physical resistance → scream/cry → flop down/tantrum/aggression). When Claire engages in major problem behavior (i.e., tantrum or pinch), in a firm but neutral tone say “no”, take her out of the pool and walk with her or carry her to the change room. Try to avoid talking with her or making eye contact and get her changed and take her home. Later, when she is calm, in a matter-of-fact and neutral tone of voice, say something like, “You didn’t get the [reinforcer] today, we will try again next time.”
Appendix O

Implementation Checklist for Swimming Routine

Date: ______________ Person Completing Checklist: ______________

Goal: Claire will go into the pool and play in the water with Dana for at least 15 minutes.

<table>
<thead>
<tr>
<th>Before you go to the pool</th>
<th>Not in Place...In Place</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Practiced deep breathing and modified relaxation exercises</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>2. Read story to Claire about going to the pool</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>3. Reviewed the consequence map</td>
<td>1 2 3 4 5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>At the pool</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Used gradual exposure and systematically expose Claire to the swimming routine gradually.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>2. Used visual schedule to promote desired behavior and ensure predictability</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>3. Used positive contingency statements (e.g., “If you….then you can have…)</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>4. Used safety signals (e.g., “Two more steps and you can get out of the pool”)</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>5. Use verbal correct strategy (e.g., “Remember if you need a break, you can tell mommy I need a break”)</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>6. Offered Claire a choice of:</td>
<td></td>
</tr>
<tr>
<td>(a) where she wants to enter the pool</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>(a) what she wants after completing the targeted step on the hierarchy</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>7. Used exposure technique and work on the targeted scenario until Claire is no longer feeling anxious.</td>
<td>1 2 3 4 5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reacting to behaviors</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. If Claire completed the targeted step, I gave praised Claire and gave her the reinforcer she had chosen (i.e., mermaid doll, treat)</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>2. If Claire asked for a break, I gave praise her for using her words and let her sit/stand by the pool for one minute before asking her to try again.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>3. If Claire started to whine or protest (minor problem behavior), I redirected her to the contingency map and reminded her of what she will receive if she completes the task.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>4. If Claire continued to whine or protest, I redirected her to ask for a break.</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>5. If Claire engaged in fearful talk, I ignored and modeled “brave talk”</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>6. If Claire started to tantrum or pinched, I implemented implement crisis plan.</td>
<td>1 2 3 4 5</td>
</tr>
</tbody>
</table>

Crisis Management Procedures

Claire’s problem behavior usually follow a predictable chain from minor to severe (i.e., whine/verbal protest/physical resistance → scream/cry→flop down/tantrum/aggression). When Claire engages in major problem behavior (i.e., tantrum or pinch), in a firm but neutral tone say “no”, take Claire out of the pool and walk with her or carry her to the change room. Try to avoid talking with her or making eye contact and get her changed and take her home. Later, when she is calm, you can say something like, “You didn’t get the mermaid doll today, we will try again next time.”

Steps complete in routine ____________ Yes No
<table>
<thead>
<tr>
<th>Steps complete in anxiety hierarchy</th>
<th>Yes</th>
<th>No</th>
<th>First trial</th>
<th>Last trial</th>
</tr>
</thead>
<tbody>
<tr>
<td>Toes in and out of water</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sit on edge of pool, put feet in water</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Go on 1st step, get back out of pool</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Go to the edge of the 1st step</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Go on 2nd step, get back up to 1st step</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Go to edge of 2nd step</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One foot tap clipboard immersed 1&quot; in water</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One foot tap clipboard immersed 3’ in water</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One toe tap bottom of pool</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One foot flat on bottom of pool</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Both feet on bottom of pool</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stand in pool and splash</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walk 3 steps to mom</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walk 5 steps to mom</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walk 10 steps to mom</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Splash and play in water for 15 minutes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Anxiety rating at last trial: _______________ (1= none; 2= some; 3= very noticeable)

Problem Behavior at the pool

1. Scream/Cry  
2. Verbal protest  
3. Leaving the assigned area  
4. Physical resistance  
5. Pinch/Hit  
6. Tantrum

Social Validity Check

<table>
<thead>
<tr>
<th>Disagree</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>The goals of the plan are appropriate for Claire</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>The strategies/procedures are effective in improving Claire’s behavior</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>The swimming routine was a success.</td>
<td>1 2 3 4 5</td>
</tr>
</tbody>
</table>