Using Positive Behavioural Supports with Fragile X Syndrome:
A Consultative Approach

by

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Abstract

This applied thesis focuses on accelerating the ability of an adult female with Fragile X Syndrome (FXS) to effectively identify and express feelings, and use coping strategies to increase frustration tolerance while decreasing anxiety-prompted behaviours. Both direct and indirect functional assessment procedures were utilized to identify the participant’s target behaviours and gather a baseline frequency for the behaviours. Due to the low frequency of the aggressive behaviour, data collected focused on setting events and antecedents, and the frequency of anxiety-prompted behaviours. The data were obtained through direct observation across a number of community settings, a scatter plot data collection chart, and the use of a sequence Antecedent, Behaviour, and Consequence (ABC) analysis. Also a Functional Assessment Interview, a Functional Analysis Checklist, and a formal file review from clinical records were conducted. Using the information and data obtained from the functional and baseline assessments, recommendations and strategies were made based on best practices interventions and designed to individually suit the participant’s needs. Using the PBS approach and a mediator consultative model, recommendations and strategies were formed as intervention.
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Chapter I: Introduction

Background

Aggressive behaviours are commonly seen in the field of developmental disabilities and may be described as violent and unpredictable. Although quite common, they are often misunderstood (Braden, 1997). In order to identify a behavioural remedy; it is important to understand the function the behaviour plays in each incident (Braden).

This applied thesis will take the form of a case conceptualization that focuses on a single subject, an adult female with Fragile X Syndrome (FXS). The participant has a low frustration tolerance and is having aggressive outbursts that are described as high intensity and destructive and could possibly escalate to be physically dangerous to the participant and/or others in the environment. An intake assessment report reveals that these behaviours are out of the norm for the participant. Aggression is not generally a related characteristic of FXS. Research suggests that certain genetic syndromes, such as Down’s syndrome and Fragile X syndrome (FXS), may be associated with lower rates of aggression than other forms of intellectual disabilities (Sturmey, 1996).

FXS is a relatively new area of study, it was only recently been discovered in the 1970’s, and has only appeared in educational research for a decade (Richards & Hoge, 1999). Reiss and Hall (2007) reported Fragile X incidences as 1 in 3600 males and 1 in 4000 – 6000 females. Further discussed is the research conducted regarding a diagnosis of Fragile X syndrome and related behavioural phenotypes including poor communication, and poor sequential thinking skills, as well as anxiety produced by change and inability to regulate arousal (Reiss & Freund, 1992).

Positive Behavioural Support (PBS) is the approach used in this case consultation. PBS is an applied science that uses educational and systems change methods to redesign an individual’s living environment to achieve an enhanced quality of life and to minimize problem behaviour (Koegel, Koegel, & Dunlap, 1996). As part of PBS, a functional assessment was conducted to gain detailed information regarding the participant’s case. Both direct and indirect assessment procedures were used to gather this information. The functional assessment results found in Chapter Three of this applied thesis will show that the aggressive behaviours were said to be related to a skill deficit in her ability to identify, express, and appropriately cope with how she is feeling.

Rationale

The following is a case conceptualization that will explore the case of a single subject participant, an adult female with Fragile X syndrome with social skill deficits displaying newly developed aggressive behaviour. The objective is to prevent aggressive outbursts from surfacing in the community and to avert them from occurring at home and to equip the participant with the skills that would help her regulate her emotions and act appropriately when interacting with others. The purpose of the case consultation was to make relevant
recommendations to target and accelerate the participant’s skills deficits to reduce and ultimately eliminate low frequency aggressive behaviour.

**Hypothesis**

Using a case conceptualization, appropriate intervention strategies and recommendations have been identified for the participant of the study. By accelerating the participant’s ability to effectively identify and express what she is feeling, she will be provided with the appropriate skills needed to prevent future aggressive outbursts. As a result, the participant will learn an alternative method of releasing built up feelings such as anger and/or frustrations. In addition coping strategies are recommended that will help to effectively increase the participant’s frustration tolerance, while decreasing her anxiety prompted behaviours.

**Overview**

This thesis examines the literature and its significance in the areas of Fragile X, aggression, and PBS; relevant assessment and treatment designs are also critically reviewed. Additional information regarding the participant and related behavioural phenotypes is included; as well as all assessment procedures and their results are reviewed. Recommendations and strategies are described in detail and appendices will show all intervention tools designed for the participant.
Chapter II: Literature Review

The thesis examines the existing literature and critically reviews the relevant research for this case conceptualization, and details specific information supported by the literature regarding Fragile X syndrome, aggressive behaviours, positive behavioural support, prevention and coping strategies, emotional regulation, and social skill building.

**Fragile X Syndrome**

Fragile X syndrome is a hereditary condition associated with learning disabilities in both males and females. Like all developmental disabilities, FXS is found in all races and at all socio-economic levels. The latest study by Reiss and Hall (2007) indicated that 1 in 3,600 males and 1 in 4,000 – 6,000 females are affected and that approximately 1 in 260 females are carriers. FXS is the leading cause of inherited neurodevelopmental disability (Richards & Hoge, 1999). It is an X-linked genetic disorder in which the mother is usually the contributing parent. A fragile site on the long arm of the X chromosome is the cause of the syndrome; with the abnormality causing the tip of the long arm to become narrowed (Harris-Schmidt & Fast, 2004). Fragile X can be identified with a DNA blood test.

Harris-Schmidt and Fast (2004) provided a comprehensive explanation of the inheritance of FXS. Inherited characteristics are carried from one generation to the next by chromosomes. Most individuals have 23 pairs (46) chromosomes. The sex chromosome pair determines the sex of an individual. Females have two X chromosomes and males have one X and one Y, the name of the syndrome comes from the location on the X chromosome (Harris-Schmidt & Fast).

These chromosomes are made up of DNA sequences or genes, which act as the templates for making proteins with specific functions (Harris-Schmidt & Fast, 2004). A change in a gene is called a mutation. Some mutations have no effect, but others, such as in the FMR-1 gene, cause changes on the structure or functions of one’s body (Harris-Schmidt & Fast). The FMR-1 gene is the DNA sequence called the ‘CGG’. According to Harris-Schmidt and Fast, this sequence is normally repeated between 6 and 50 times. In some people, this sequence is repeated between 50 and 200 times and is called a permutation that generally causes few or no symptoms of FXS. “In women with the permutation, the size can expand to over 200 repeats when that X chromosome is passed onto her egg. This is called a full mutation” (Harris-Schmidt & Fast, 2004 p.124). In the full mutation, the gene FMR-1 switches off and no protein is produced. Fragile X syndrome is the result (Harris-Schmidt & Fast).

Reiss and Hall (2007) described the behavioural characteristics of individuals with Fragile X syndrome. Characteristics of FXS include global developmental delays, speech and communication problems, anxiety, poor concentration, hyperactivity, and autistic like behaviours such as an unusual fixed interest and dislike of change in routine. Anxiety can manifest itself in various ways, and individuals with FXS may become worried about changes in routine or upcoming stressful events. Tantrums are in many cases the result of anxiety.
and/or a feeling of being overwhelmed. Strong reactions to changes in environment and heightened anxiety can compound behavioural difficulties. Sensitivity to the environment and anxiety produced by change makes it difficult to screen out stimuli such as noise, lights, and odours. This in turn, may provoke emotional outburst or tantrums (Reiss & Hall).

Moon et al. (2006) agreed that this impairment could range from learning disabilities to more severe cognitive or intellectual disabilities. FXS is commonly related to autism and share "autistic-like" behaviours. They described symptoms, which include characteristic physical and behavioural features and delays in speech and language development (Moon et al). Sabaratnam and Tony (2002) wrote that individuals with FXS have good functional life skills once they are acquired. Their weaknesses are poor auditory memory, poor sequential processing, and abstract thinking. Intervention must be devised to optimize the stronger characteristics without ignoring those that may be problematic.

**Behavioural Phenotypes of Fragile X syndrome**

When building strategies for intervention recommendations, it was relevant to understand the behavioural and emotional effects of Fragile X and the behavioural phenotypes that are characteristic of the syndrome. Behavioural phenotypes are patterns of behaviour that present in syndromes caused by chromosomal or genetic disorders. They have both physiological and behavioural implications, which can present in externalized behaviours dependent on social and environmental influences (Barnard, Pearson, Rippon, & O’ Brien 2002). Almost all individuals with Fragile X have trouble self-regulating their behaviour, difficulties in controlling their emotions, and difficulties concentrating (Reiss & Freund 1992). They may also have fixed interests in objects or activities and can strongly dislike any changes in their routines, thriving on consistency and being able to rely on and predict what will be happening next. Females with Fragile X often lack social skills and may even avoid social contact/interacting with others when under stress and anxious. Due to poor communication skills and receptive language deficits, individuals may also have difficulties communicating to others what is upsetting them and/or may have misunderstood what has been said to them (Reiss & Freund).

**Aggression**

The *Dictionary of Psychology* (Reber & Reber, 2001) defines aggression as “an extremely general term used for a wide variety of acts that involve attack and hostility; that typically, aggression is used for such acts can be assumed to be motivated by any of the following: a fear or frustration; a desire to produce fear or flight in others; or a tendency to push forward one’s own ideas or interest” (p.17). While this will do as a loose but acceptable definition, it barely touches on the extent of usage in psychological literature. There is no single widely accepted definition of aggression. The term ‘aggression’ may refer to a whole range of behaviours from throwing objects across the room to actual bodily harm to another person (Tyrer et al., 2006).
The research showed a prevalence of aggression among people with intellectual disabilities that ranges from 9-31 percent, and the median reported is 20 percent. Also, a higher rate of aggression is found in institutional settings; up to 45 percent in some studies. However, many schools, families, community residential and vocational settings now have a significant minority of participants with aggressive behaviours (Sturmey, 1996).

Aggressive behaviours in whatever form they are displayed may have many serious consequences for both the individual displaying the behaviour and for the people around them. The individual is often socially rejected and stigmatized. There is also the risk of retaliation from peers. More importantly is that the individual may lose opportunities for integrated community activities, integrated education, and living settings.

Foxx and Meindl (2007) stated that aggression may be an acquired behaviour or set of behaviours. This means that the individual has learned that a desired outcome can be achieved by aggression. Desired outcomes usually are either to gain attention from the victim or bystander, or to escape or avoid an unpleasant situation or demand. Foxx and Meindl emphasized that aggression is a learned behaviour and results may be desirable consequences for the aggressor, and there can be antecedents or precipitating factors that increase the probability that behaviour will occur. These factors can be environmental, physiological, emotional, and/or social changes.

**Aggression in Fragile X Syndrome**

Some studies have found that more males than females exhibit aggression. Further, aggressive behaviour is exhibited more frequently or more intensely in adolescents and young adults (Sturmey, 1996). Research into behavioural phenotypes has suggested that certain genetic syndromes, including Fragile X, may be associated with a lower rate of aggression in other forms of intellectual disabilities (Sturmey).

Similar to Foxx and Meindl (2007), Braden (1997) stated that most behaviour serves a purpose and that the aggressive behaviours for the individual with FXS may provide an escape from something that is frightening or threatening. Individuals with FXS learn quickly that the aggressive behaviour is a powerful way to signal a desire to be left alone, move away, or take a time out. Also Braden described that if one wants to escape a situation and lacks the ability to communicate that need, they may become aggressive.

Hagerman (1999) wrote that aggression is a relatively common problem in children and adults with Fragile X that it is related to problems with impulsivity, overreactivity to stimuli, and mood instability. Hagerman also stated that aggression occurs in approximately 20 percent of individuals with FXS. Hormonal change can sometimes exacerbate aggressive outburst. Typically an individual can become agitated or fearful with a change in activity or a new situation, a rapid change in mood can lead to hitting, throwing, or destructive behaviour. It is important to prepare an individual for change both verbally and visually to aid with the transition (Hagerman). Although Hagerman’s article presents useful information regarding prevalence and cause of aggression in individuals with FXS, his solution to the behaviour appears to consider
only medication, as the article goes on to describe certain medications that are useful with individuals with FXS who are aggressive.

Generally speaking, aggression is a recognized problem in the field of developmental disabilities. Individuals with developmental disabilities often have communication difficulties and struggle to self report any aggressive feelings or communicate using behaviours. Therefore, the identification of emotions is often dependent on caregivers’ perception of the problem, which is influenced by their own abilities to cope (Tyrer et al. 2006).

Specifically, aggression as displayed in the diagnosis of Fragile X Syndrome also serves a purpose (Braden, 1997). With individuals with FXS, the events that lead up to the actual behavioural episode (the antecedents) are the most important to consider for remediating the behaviour because the individual with FXS is often unable to verbalize or clearly explain what has precipitated the behaviour. The behavioural intervention should always be developed using proactive strategies to reduce the frequency of the problem behaviour (Braden).

A variety of emotions are said to possibly trigger an aggressive reaction in individuals with FXS. To name a few, agitation, fear, anxiety, impulsivity, and emotional release are possible causes for aggressive behaviours. In addition, situations or environmental conditions can prompt confusion and uncertainty resulting in agitation or fear (Braden, 1997). Also Braden clearly stated that aggressive behaviours are exacerbated by poor impulse and emotional control, which are behavioural phenotypes of FXS. The reaction is simply a response to a situation that has become overwhelming. Intervening as a preventative measure and teaching to address skill deficits can effectively reduce and ultimately eliminate the aggressive behaviour (Braden, 2007). Lastly Braden emphasized the consideration of a proactive approach, increasing prosocial behaviours, while reducing maladaptive behaviour as the ultimate goal.

Anxiety

Anxiety is a physiological state characterized by cognitive, somatic, emotional, and behavioural components (Seligman, Walker, & Rosenhan, 2001). These components combined create the feelings that we typically recognize as fear, apprehension, or worry. All persons experience anxiety. Anxiety is expected and normal at specific times in development. For those with developmental disabilities, anxiety can be frequent and persistent. However difficult to recognize, significant anxiety may be reflected as a somatic illness, i.e., a stomach aches or headaches, and might present with emotional side effects such as frustration or sadness (Reiss, 1994).

Anxiety in Fragile X Syndrome

Anxiety disorders may underlie many of the behavioural characteristics of individuals with Fragile X. Both males and females present many characteristics of anxiety and may need intervention in order for them to cope with the demands of daily living. Hypervigilance has been tied to anxiety issues for individuals with FXS and it may be one of the most common
underlying emotional features (Harris-Schmidt & Fast, 2004). Sensitivity to environmental features and changes in routines cause great worry in individuals with FXS. They worry about upcoming events, including positive activities to which they look forward. Anxiety appears to be persistent throughout life for many affected people (Harris-Schmidt & Fast).

Poor eye contact, tendency to turn away during handshakes, and difficulties in social situations all relate to anxiety. Continuous worry about their competence, performance, and acceptability are also related to anxiety (Harris-Schmidt & Fast, 2004). The difficulty comes with being able to identify anxiety in individuals with FXS. Communication and other deficits related to the diagnosis interfere with the ability to inform others that they are anxious, as well as provide rationales for the reason anxiety was being produced.

Anxiety may escalate into outbursts or tantrums. An inability to filter sensory information seems to cause a rise in emotions that may result in an emotional display. Anxiety is seen in a number of physical signs, some of which serve as cues or prompts to caregivers that that person is feeling anxious and/or is about to have an outburst (Harris-Schmidt & Fast, 2004). Anxiety-prompted behaviours such as raised volume or escalated aggressive outbursts are examples of anxiety-prompted behaviours that individuals with FXS may display. Anxiety-prompted behaviours may be triggered by intense, demanding, or overwhelming experiences, including load situations, transition, crowded conditions, requests or instructions to perform a difficult or undesirable task (Harris-Schmidt & Fast).

**Frustration**

Frustration is an emotion that occurs in situations where one is blocked from reaching a personal goal. The more important the goal, the greater the frustration; can be comparable to anger. Sources of frustration may be internal and external. Internal sources of frustration involve personal deficiencies such as a lack of confidence or fear of social situations that prevent one from reaching a goal. Conflict can also be an internal source of frustration when on has competing goals that interfere with one another (Reber & Reber, 2001). Frustration may also be contributed to negative social interactions, or stress from demand or request situations. How much frustration tolerance a person has contributes to the likeliness of resulting in aggressive outbursts. Difficulties with frustration tolerance include challenges coping with upsetting events and/or difficult tasks in which individuals will avoid. Individuals displaying low frustration tolerance may also escape specific situations and become anxious versus addressing how the situation makes the individual feel. Low Frustration tolerance may include staying mad and/or upset with themselves or others for a prolonged period of time, resulting in lower levels of frustration tolerance, which hinder the ability to cope leading to verbal and physical aggressive outbursts.

**Emotional Regulation**

Emotional liability can be caused by anxiety and/or sensory overload. Individuals with FXS may express extreme reluctance to go to events and carry out activities, even when they
have looked forward to them. Problems in self-regulation affect a number of areas, including calming and control of emotions. It is often that behavioural outbursts occur as a result of skill deficits in identifying, expressing, and coping with emotions (Harris-Schmidt & Fast, 2004).

According to Gross (2001), regulation processes should have a different profile of consequences than natural processes such as suppression. Gross describes regulation processes as a consistent change in the way a situation is constructed so as to decrease an emotional impact, and suppression as a consistent process of inhibiting the outward signs of inner feelings. Gross found that experimental and individual-difference studies revealed that regulating is often more effective than suppression when addressing social consequences and behaviour (Gross, 2001).

One important aspect of emotional development is the ability to regulate one's emotions. Emotion regulation consists of both intrinsic and extrinsic processes that are responsible for learning to recognize, monitor, evaluate, and modify emotional reactions (Thompson, 1994). Emotional reactions include strategies to maintain, enhance, subdue, and/or inhibit emotions in attempting to accomplish goals (Denham, 1998). Regulating emotions is crucial in maintaining a connection with ongoing perceptual processes, having access to a greater number of adaptive responses, and enhancing flexible and appropriate responses. Lacking the ability to regulate emotions can result in deleterious emotional arousal and the misidentification and misdirection of emotions, thereby hindering the ability to function adaptively and appropriately (Fox, 1994).

According to Braden (1997), almost all people with FXS have trouble self-regulating their behaviour and emotions. This could cause bystanders to misinterpret aggression and intentional acts of violence; however, for the person with FXS, it is a release of built-up of tension. Reese and Challenner (2006) define emotional regulation as referring to the “factors by which emotional arousal is redirected, controlled, modulated, and modified to enable an individual to function adaptively” (p.9).

Positive Behavioural Supports

Applied Behaviour Analysis (ABA) is the systematic extension of the principles of operant psychology to problems and issues of social importance (Baer, Wolf, & Risley, 1968). ABA is the design, implementation, and evaluation of environmental modifications to produce socially appropriate human behaviour. The objective is to demonstrate that the intervention employed is responsible for the change in behaviour (Sulzer-Azaroff & Mayer, 1991). According to Carr et al. (2002), ABA has made two major contributions to the applied science of Positive Behavioural Supports. First, it has provided a conceptual framework relevant to behaviour change and, secondly, it has provided a number of assessment and intervention strategies. “With respect to theories, PBS is indebted to ABA for the concepts such as three-term contingencies, setting events, establishing operations, stimulus control, generalization and maintenance” (Miltenberger, 2004 p. 67). It is true that PBS has not only incorporated the elements of Applied Behaviour Analysis, but it has also evolved beyond the parent discipline to assume its own identity. PBS’s identity is strongly influenced by the realities of conducting research and intervention in natural community settings that “necessitate changes in assessment
methods, intervention strategies and the definition of what constitutes a successful outcome” (Carr et al., 2002 p. 9).

Based on assessment results, the current intervention is designed using a Positive Behavioural Supports (PBS) approach. An increasingly popular alternative to traditional practices is the use of PBS, which recognizes the broad set of relevant variables that can affect a person’s behaviour (Safran & Oswald, 2003). Carr and Sidener (2002) describe PBS as the current zeitgeist of providing positive behavioural interventions.

Positive Behavioural Support is an applied science that uses educational and systems change methods (environmental redesign) to enhance quality of life and minimize problem behaviour (Carr et al., 2002). PBS builds on a long history of behavioural research, but is guided by human values and real life problems confronting families and professionals. This approach is concerned not only with the problem behaviour but also with the strengths and life-style of the individual (Lucyshyn, Horner, & Ben, 1996). PBS initially evolved within the field of developmental disabilities and has emerged from three major sources: applied behaviour analysis, the inclusion movement, and person-centred values. The primary goal of PBS is to help the individual change their lifestyle in a direction that gives opportunity to perceive and to enjoy an improved quality of life. “An important, but secondary goal of PBS is to render problem behaviour irrelevant, inefficient, and ineffective by helping an individual achieve his/her goals in a socially acceptable manner, thus reducing, or eliminating episodes of problem behaviour” (Carr et al., 2002, p. 5).

PBS has evolved into a science that respects the realities of conducting research in complex community settings while at the same time incorporating the fruits of research conducted within the traditional practices represented by formal experimentation. The PBS definition of acceptable data includes qualitative measures, ratings, interviews, questionnaires, logs, and self-reports in addition to direct observation. The type of data may vary but the expectation remains that a systematic data source will be used to evaluate and guide intervention (Carr et al., 2002).

In the ONTABA Analyst, a newsletter that is produced and distributed to members of the Ontario Association for Behaviour Analysis, Anderson and Freeman (2000) described PBS as operating from a person-centered value base that recognizes the individuality of each person and seeks to produce meaningful outcomes, as well as view comprehensive assessments and multifaceted intervention. The ONTABA Analyst (Carr & Sidener, 2002) further describe PBS as operating with a focus on the environment, meaningful outcomes, a focus on ecological validity, and systems-level interventions.

In sum, PBS is an approach to intervention that integrates technical features of ABA with person-centered values. It offers a process for designing individualized approaches to support people experiencing behavioural difficulties in school, home, and community environments. PBS incorporates functional behavioural assessment and leads the behavioural intervention plans that are positive (i.e., proactive, educative, and functional) in nature. When using PBS to intervene,
the objective is to equip the individual with the skills needed by ensuring that the proper skills are taught in place of deficits, to enhance quality of life, and enjoyment of everyday enjoyments (Carr et al., 2002).

**Intervention Strategies**

**Social Skills**

It has been demonstrated that increasing one behaviour will positively affect another behaviour. O’Conner et al (2006) described how to teach social skills using behavioural techniques to young children with Fetal Alcohol Spectrum Disorder (FASD). The efficacy of child friendship training (CFT) versus delayed treatment control (DTC) was assessed for 100 children ages 6 to 12 years with FASD. Children in the CFT group showed clear evidence of improvement in their knowledge of appropriate social behaviour, and according to parent report. Also, the CFT group resulted in improved social skills and fewer problem behaviours compared with DTC. Gains were maintained at 3-month follow-up (O’Conner et. al). Teaching appropriate social behaviours and/or skills to adults with similar deficits would follow a similar route to enhance desired appropriate behaviours.

Modeling is another effective intervention tool used to demonstrate to the learner the desirable behaviours or skills. Bandura (1986) uses his Social learning theory to provide the foundation for behaviour modeling. Bandura asserts that most behaviours are learned by observation and modeling. It is recommended that the mediators model the skills for the participant that she will need to acquire (i.e., appropriate way to respond to stressful and anxiety provoked situations) and it is just as important to not assume that she has previously learned the skills she needs. Individuals with FXS can be taught how to appropriately interact socially through the use of modeling, social scripts, or power cards, as well as how to respond to natural consequences and how to use visual tools.

Social scripts are a well-publicized social facilitation intervention designed for children with autism spectrum disorder (Quilty, 2004). Social scripts were developed to address the difficulties that some with autism may have in reading, understanding, and formulating appropriate responses to social situations (Quilty). Additionally individual power cards are used to motivate individuals and provide an always-available coping tool. Power cards use some of the same principles as social scripts, but also engage the individual’s interest by having a favourite character as the motivator. Stories and summaries are on the cards and the individual’s favourite character tells them how important it is to accomplish certain tasks (Gagnon, 1994). Social stories and power cards are only two of many options that have been considered when teaching appropriate social interactions. Other options include teaching interactions. Dowd and Tierney (1992) provide simple step-by-step instructions on how to teach and apply social skills to youths. This systematic approach may be applied to the developmentally delayed population. Using the Boys Town social skills training manual by Dowd and Tierney as a guide, the participant is taught one at a time, a new social skill that will increase appropriate social interactions with staff and peers. Each new social skill is taught during one-to-one sessions,
practiced and applied in a social context with peers. The social skills are taught using teaching interaction techniques described by Blase and Fixen (1987).

**Coping Strategies**

Coping strategies refer to the specific efforts, both behavioural and psychological, that people employ to master, tolerate, reduce, or minimize stressful events. Two general coping strategies have been distinguished: problem-solving strategies are efforts to do something active to alleviate stressful circumstances, whereas emotion-focused coping strategies involve efforts to regulate the emotional consequences of stressful or potentially stressful events. Research indicates that people use both types of strategies to combat most stressful events (Folkman & Lazarus, 1980). There is also a distinction between active and avoidant coping strategies. Active coping strategies are either behavioural or psychological responses designed to change the nature of the stressor itself or how one thinks about it, whereas avoidant coping strategies lead people into activities (internalizing feelings) or mental states (anger/frustrations) that keep them from directly addressing stressful events. Generally speaking, active coping strategies, whether behavioural or emotional, are thought to be better ways to deal with stressful events, and avoidant coping strategies appear to be a psychological risk factor or marker for adverse responses to stressful life events (Holahan & Moos, 1987). Techniques of identifying, communicating and coping with feeling, may include tools such as social scripts, power cards, and a choice menu that are coping strategies and may be effective learning tools to use with many individuals with developmental disabilities.

This case study combines the Applied Behaviour Analysis (ABA) design with the Positive Behavioural Supports (PBS) person centered style. The participant’s aggressive behaviour is low in frequency, therefore the proactive strategies will include prevention, coping, and emotional regulation paired with social skills training to reduce the aggression being displayed. All techniques derived from the literature and reviewed here will help in providing the participant with the skills needed to successfully increase her appropriate social interactions.

Literature Review Word Count: 4,168
Chapter III: Method

Participant

The participant was selected for this case consultation during a wait list review meeting held in August of 2007. The supervising psychologist and coordinator of the Community Behavioural Services selected this participant for student involvement and the case was allocated to the fourth year Behavioural Psychology student in September of 2007. The participant is a twenty-eight (28) year old female who lives at home with her mother and her younger brother. The participant received a diagnosis of Fragile X syndrome confirmed by a DNA analysis completed at a Cytogenetic and DNA research lab.

The referral was made by the participant’s mother for Community Behavioural Services (CBS). The mother requested involvement to facilitate social skill development, as well as to address the newly observed behaviours described as aggressive outbursts. The participant’s mother described aggressive outbursts as verbal refusal to complete tasks and/or follow directions, which can escalate into destruction of participant’s valued personal property and throwing objects. The mother was concerned that these outbursts might escalate into physical aggression towards her or others. Consent was obtained from the participant for student involvement with a St. Lawrence College B.A.A. Behavioural Psychology student (Appendix A).

The participant’s mother indicated that the participant is currently taking two medications: Alesse 21, a contraceptive tablet administered daily, which primarily inhibits the action of ovulation only allowing the participant to menstruate every three months. The second medication is the PRN Olanzapine HCL, an anti-psychotic. This medication is taken only when the participant is extremely agitated, and only in half dosage (2.5mg).

The participant attends a day program, where she is involved in developing vocational skills with the support of her vocational counsellor; she also participates in three placements within her community. The participant appeared to be quite independent and actively involved in her community, participating in several sporting groups and the Special Olympic events throughout the year. She is described as being a social and enjoyable person. The aggressive outbursts are said to include verbal refusal and the destruction of valued personal property. They occurred in the home setting, with the exception of an isolated aggressive incident at the participant’s day program, which included a negative social interaction with a peer and resulted in the participant locking herself in her locker and refusing staff when she was instructed to come out. Given the participant’s involvement in the community, participation in her day program and involvement with the community behavioural services, a number of individuals have been in contact with the participant and therefore were included in the holistic approach to assessment.

Informed Consent

Obtaining consent from the participant included providing an explanation of the consent form and the purpose of consent. This process was an important one, as the participant is over the age of 16 and has the right to make her own decisions. It was crucial to ensure that the
participant was acting voluntarily, without coercion or undue influence and that she has had reasonable opportunity to obtain independent advice. The participant’s mother served as co-signer to the consents obtained at the request of the participant (Consent form - Appendix A).

Assessment Methods

Both direct and indirect functional assessment procedures were utilized to obtain results and other detailed information. Due to the low frequency of the aggressive behaviour, data collected focused more towards setting events and possible antecedents obtained through direct observation across a number of community settings, a scatter plot data collection chart, and the use of a sequence Antecedent, Behaviour, and Consequence (ABC) analysis. These methods allowed for the determination of any relationship(s) between events in the participant’s environment and the occurrence of the problem behaviour (Garner, Cole, Davison, & Karan, 1986). However, frustration tolerance and anxiety-prompted behaviours were of great concern for the person who referred the participant, therefore indirect assessment procedures such as the Functional Assessment Interview, Functional Analysis Checklist, and a formal file review from clinical records were conducted. Information was obtained from individuals who were familiar with the participant and her target behaviours.

Measures

Functional Assessment Procedures

The Functional Assessment Checklist (Van Houten, Rolider & Ickowitz, 1989) was completed in order to gain some preliminary information about the occurrence of the aggressive behaviour and anxiety-prompted behaviours, as well as what was reinforcing the behaviours. The participant’s mother and the participant’s Vocational counsellor from her day program provided responses given to items on the checklist. The Functional Analysis Checklist (Appendix B) is an interview-based questionnaire with forty-one (41) "yes" or "no" questions. The purpose of this tool is to identify possible functions of behaviour and possible factors that might be associated with behaviour problems, (i.e., biological and physical environment related factors, communication and escape demand related factors, elicited or adjunctive behaviours related factors or transition and positive reinforcement related factors).

The participant’s mother also completed the Functional Assessment Interview (FAI) (Appendix C) form O’Neill, Horner, Albin, Sprague, Storey & Newton (1997). The purpose of this tool is to prioritize behaviours for intervention, identify possible functions of behaviour, as well as define events and situations that predict the occurrence of target behaviours. A number of informant interviews were also conducted with a number of mediators across settings.

Sequence Antecedent-Behaviour-Consequence (ABC) Analysis (Appendix D) was completed by the participant’s mother. Data were collected using a chart that included, setting events, antecedents, behaviours, and consequences. An ABC contingency chart was given to the participant’s mother to record and provide descriptive information about the participant’s
behaviour in the home setting over a two-week time period. The mother was given explicit direction on how to collect and record data.

**Baseline Assessment Procedures**

Baseline assessment procedures included direct observations’ scatter plot assessment, as well as a non-compliance (verbal refusal) tracking form. The direct observations were conducted across several community settings. Observations were also conducted at the participant’s day program on several occasions between October 11, 2007 and November 20, 2007; each observation session was for one hour or one and a half hour intervals conducted at different times throughout the day.

In the day program it was observed that the participant socially interacted with staff and peers consistently throughout the day. Although aggressive outbursts were not observed in this setting, several instances of identified anxiety-prompted behaviours were observed; the frequency of these target behaviours was recorded using event recording.

A scatter plot chart (Appendix E) was sent home with the participant’s mother as an assessment tool to determine if there was a correlation between the participant’s menstruation cycle and her aggressive and verbal outbursts. Also the scatter plot was designed to determine if challenging behaviours occur at specific times in the day, which ones occurred more often and if they are occur in relation to specific tasks, routines or requests made of the participant in the home setting. The participant’s mother was asked to collect data on verbal outbursts, physical aggression, and any aggressive attempt made.

**Target Behaviours**

The identified target behaviours were determined and operationally defined based on assessment results found in the results chapter of this applied thesis. The first target behaviour identified was a low level of frustration tolerance, which hinders the ability to cope leading to verbal and physical aggressive outbursts. Low Frustration Tolerance for the participant included difficulties coping with upsetting events and/or difficult tasks in which she avoids certain situations and becomes anxious versus addressing how the situations makes her feel. Also included staying mad or upset for a prolonged period of time. Low frustration tolerance is observed when the participant displays inappropriate coping behaviours such as engaging in aggressive verbal outbursts. Anxiety may be defined as a physiological state characterized by cognitive, somatic, emotional and behavioural components (Seligman, Walker & Rosenhan, 2001). These components may be combined to create the feelings of fear, apprehension, anger, and worry. Unable to observe the physiological state of anxiety, the second target behaviours identified was Anxiety-prompted behaviours. Anxiety-prompted behaviours have been defined as repeating the words of others, using a raised voice level when speaking, verbally saying “Oh no, I’m in trouble” when approached by a staff or care provider, and displaying a blank facial expression. The rationale to increase her frustration tolerance and decrease anxiety is to increase
the ability to effectively communicate to others how she is feeling. This will enable the participant to rely less on aggressive outbursts to communicate.

**Objectives**

For this applied thesis, the goals were to increase the participant’s low frustration tolerance and to decrease the incidents of anxiety-prompted behaviours. Using the recommendations and strategies, the objective is to equip the participant with the ability to identify, communicate, and effectively cope with feelings and prevent aggressive and verbal outbursts from occurring. To obtain this goal, the intervention must focus towards increasing coping behaviours and decreasing anxiety-prompted behaviours that have been identified. It is also essential to provide recommendations to mediators who were to support the participant during the intervention. Objectively, the results of increasing frustration tolerance and coping behaviours, as well as decreasing anxiety and prompted behaviours will aid the participant in not having to rely on aggressive and verbal outbursts of behaviour.

**Procedures**

Using the information and data obtained from the functional and baseline assessments, recommendations and strategies were researched and designed to individually suit the participant’s needs. Using the PBS approach and a mediator consultative model, recommendations and strategies were formed as intervention. Intervention consisted of combination of verbal and visual tools that mediators were given and taught to use with the participant during intervention phrase. Mediators were provided with written mediator instructions and were given the visual tools with written step-by-step instructions on how to implement each tool. Also during a number of meetings with mediators, verbal instructions were given on how to implement the other intervention strategies and recommendations.
Chapter IV: Results

Functional Assessment Results

Informant interviews were conducted with the participant’s mother and vocational counsellor to gain a comprehensive review of the participant’s presenting behaviours in each setting. The participant’s mother discussed that presently there have been no recent incidents of aggressive or verbal outbursts to report. However, it was reported that the participant continues to be non-compliant and verbally refuse stating “No!” or “I don’t want to” (non-compliance) when a request is made of her to complete tasks (such as showing her mother how much money she has left or to change her clothes when they are dirty). The aggressive outbursts were described as non-compliance to complete tasks and/or follow directions which can escalate into destruction of the participant’s valued personal property and throwing objects. It was reported during the intake assessment that these behaviours started in late spring 2007. Since that time there have only been three occurrences of aggressive outbursts triggered by non-compliance with the mother and a verbal dispute with a peer at the day program. The participant’s mother reported that these aggressive episodes are uncommon behaviours for the participant and was concerned that it can escalate into aggression towards her or others.

The participant’s mother stated that she believed that her daughter might also experience pre-menstrual syndrome (PMS) and that the participant’s hormones during those times may be a contributing factor to the aggressive and verbal outbursts. Other contributing factors that the participant’s mother identified were her daughter’s social interactions with other people. The participant reportedly interacts well with adults and is easily frustrated with individuals who are “lower functioning”, for example other participants from her vocational program whom she may not understand when they are talking to her.

The Vocational Counsellor identified that the participant will display “warning signs” when she is becoming upset, frustrated, and/or anxious. These were described as, repeating words of others, using a raised voice level when speaking, and presenting with a blank facial expression. These occur when requests to complete an undesirable task are made, there is an unexpected change in her regular routine, when she is introduced to a new task, a difficult task or request is made, and/or when a peer says or does something that bothers or upsets her. These findings suggest that environmental stimuli (i.e., negative peer interactions etc.) may be contributing factors influencing the participant’s ability to cope in stressful situations and anxiety-prompted settings.

The Functional Analysis Checklist (FAC) (Van Houten, Rolider & Ickowitz, 1989) was completed by the participant’s mother and Vocational Counsellor. Responses given on the checklist reveal that the participant’s mother believes that her daughter’s challenging behaviour (i.e., non compliance/verbal refusal, aggressive and verbal outbursts) tends to occur more often just prior to the participant’s menstrual period or when an attempt to initiate self-care routines occurs. For example, the participant’s mother indicates that sometimes the participant may not want to shower when she is asked to, or may not want to wear what the participant’s mother
wants her to wear (based on the weather). It was also noted that there are possible communication factors which can trigger challenging behaviour, such as the inability to communicate a need and/or make an appropriate request, and a misunderstanding has occurred in regards to requests or instructions given to her. Other antecedents noted that trigger behaviour are unexpected and expected changes in her regular routine, for example, if a regular activity is cancelled or if it is raining outside and she is not allowed (by mother) to walk to her vocational program. Changes in routine are upsetting to the participant, and transitions, such as, change in activities, preferred to non-preferred, in both the home and vocational setting.

The participant’s Vocational Counsellor also completed the Functional Analysis Checklist. Although the vocational counsellor does not report any recent instances of aggression, she does report a level of anxiety that the participant appears to demonstrate during demand related times, such as, being taught a new skill or when the difficulty of a task has increased. The vocational counsellor also stated that when she is asked to have a one-on-one discussion with a staff, she will show signs of anxiety and state “Oh no, I’m in trouble”. The vocational counsellor identified that the participant will repeat the words of others, use a raised tone of voice, and will have a blank facial expression to indicate that she is becoming upset, anxious, and/or frustrated. It was reported that the participant appears to have difficulties independently expressing to staff and peers that she is becoming frustrated and/or upset, especially when interacting with peers who are “bothering” her.

The participant’s mother also completed the Functional Assessment Interview (FAI) form (O’Neill, Horner, Albin, Sprague, Storey, & Newton, 1997). The purpose of this tool is to prioritize behaviours for intervention, identify possible functions of behaviour, as well as define events and situations that predict the occurrence of target behaviours. The participant’s mother stated that the aggressive behaviour, when it does occur, includes yelling (at home, sometimes while out socially), non-compliance (won’t/doesn’t want to do what is asked of her), throwing objects, and destruction of property. It is noted that the non-compliance and yelling behaviours are reported to occur more often than the throwing of objects and destruction of property. It said to be the result of specific interactions with the participant’s mother. The FAI revealed that the participant’s schedule is predictable for her as each morning her mother describes how the participant’s day will unfold, and that her daily choices usually include what food is packed in her lunch, and what clothes she can wear. This is only a problem for the participant’s mother when the participant wants to wear dirty clothes (which are a personal care and hygiene issue) or if the clothing that she chooses is inappropriate for the weather. These disagreements between the participant and her mother trigger power struggles and argumentative behaviour that can escalate into non-compliance and/or aggressive or verbal outbursts.

The participant’s mother also reports that because she is the primary disciplinary person in her daughter’s life, many of the disputes and behaviours are a result of specific interactions. Behaviours are most likely to occur in the morning, at home, with the participant’s mother asking her to do something that she doesn’t want to do, for example, change her dirty shirt, or drive to work instead of walking. Also, if she is asked to “hurry up”, the participant may become upset and exhibit challenging behaviours, such as, becoming upset and displaying verbal
outbursts. These behaviours are least likely to occur in the evening before bedtime, while at job placement or with people she works with in the community.

The participant’s mother agreed to collect Antecedent-Behaviour-Consequence (ABC) data using a chart that included setting events, antecedents, behaviours, and consequences. An ABC contingency chart was provided to the participant’s mother to record and provide descriptive information about the participant’s challenging behaviour in the home setting over a two-week time. This assessment method was inconclusive, as there were no instances of aggressive and/or verbal outbursts recorded by the participant’s mother.

**Baseline Assessment Results**

Direct observations were completed by the researcher and were conducted across settings. Observations in the community began at the hockey arena where the participant volunteers. The participant independently prepares the Hockey books and brochures that are distributed at hockey games. Once she is completed this task, the participant sits with her supervisor in his office and waits for her mother to pick her up. There were zero incidents of aggressive outbursts observed in this setting or that have been reported by the staff. Continuing across settings the second hand clothing and thrift shop where the participant also volunteers was also visited by the researcher. There the participant follows a regular routine; at the start of her shift she locates her supervisor, signs in, retrieves her vest, and then is assigned an area to straighten or tidy up on the sales floor. The participant works independently completing the first task until 1200 hrs when she breaks for lunch and, at 1300 hrs, she works in the back room hanging clothes until 1530 hrs. At the completion of her shift, she signs out and then walks home. There were zero incidents of aggressive outbursts observed in this setting.

To get a better picture of the participant’s interaction with her mother and in a social setting, direct observations were conducted at the bowling lanes. The participant and her mother participate in Special Olympics bowling. There appeared to be little or no social interaction between the participant and her mother as they play on separate teams and the participant spends her time with her own team and coach. The participant interacted well with her peers and coach and is very encouraging of her teammates. There were zero incidents of aggressive outbursts observed in this setting.

The numbers of instances of anxiety-prompted behaviours were recorded using event recording across settings. These data were collected in several community settings and at the participant’s vocational program. In the day program setting it was observed that the participant socially interacted and engaged with staff and peers consistently and appropriately throughout the day. Although aggressive and verbal outbursts were not observed in her vocational setting, anxiety-prompted behaviours, as identified by her Vocational Counsellor were observed (see Table 1).
Table 1
Baseline Data – Anxiety-promoted and Coping Behaviours

<table>
<thead>
<tr>
<th>Date(s)</th>
<th>Time</th>
<th>Behaviour 1</th>
<th>Behaviour 2</th>
<th>Behaviour 3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Repeating Words</td>
<td>Raised Voice</td>
<td>Coping Behaviours</td>
</tr>
<tr>
<td>07-10-11</td>
<td>1000 to 1100hrs</td>
<td>5</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>07-10-12</td>
<td>1100 to 1200hrs</td>
<td>5</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>07-10-16</td>
<td>0900 to 1000hrs</td>
<td>6</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>07-10-17</td>
<td>1300 to 1400hrs</td>
<td>5</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>07-11-15</td>
<td>1200 to 1300hrs</td>
<td>5</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>07-11-20</td>
<td>0900 to 1000hrs</td>
<td>5</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>

The raw baseline data (see Table 1) and the visual representation (see Figure 1) of the data show a steady level of two anxiety prompted behaviours and coping behaviours (defined as approaching staff) displayed by the participant in her vocational day program, a highly social environment. Data was collected on several dates at a range of different times.

Fig. 1 Baseline Data – Anxiety-promoted and Coping Behaviours (Graph with Trend lines – Appendix F).
Table 2

Descriptive Data

<table>
<thead>
<tr>
<th>Descriptive Data</th>
<th>Behaviour 1</th>
<th>Behaviour 2</th>
<th>Behaviour 3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Repeating Words</td>
<td>Raised Voice</td>
<td>Coping Behaviours</td>
</tr>
<tr>
<td>Mean</td>
<td>5.3</td>
<td>5.5</td>
<td>5</td>
</tr>
<tr>
<td>Median</td>
<td>4.6</td>
<td>4.5</td>
<td>5</td>
</tr>
<tr>
<td>Mode</td>
<td>2.3</td>
<td>2.5</td>
<td>2</td>
</tr>
</tbody>
</table>

The raw baseline data was converted using descriptive data to better illustrate the results of baseline observations. Table 2 shows that the anxiety-prompted behaviour repeating words occurred a mean of 5.3 times per observation interval and raised voice occurred a mean of 5.5 times per observation interval. The third behaviour displayed in Table 2 is the coping behaviour that was observation. The participant approached a staff member for assistance a mean of 5 times per observation interval, a relatively high number of occurrences. This finding demonstrates the participant’s ability to effectively cope.

A scatter plot chart was sent home with the participant’s mother as an assessment tool to determine if there was a relationship between the participant’s menstruation cycle and her aggressive and verbal outbursts, if challenging behaviours occur at specific times of the day, which ones occurred more often, and if they are occur in relation to specific tasks, routines or requests made of the participant in the home setting. The participant’s mother was asked to collect data on verbal outbursts, physical aggression, and any aggressive attempt made. This assessment method was inconclusive, as there were no instances of aggressive and/or verbal behaviours recorded over a two-week period in the home setting. Data was recorded over a two-week period at which time the menstrual cycle and related hormones were set to occur.

**Intervention**

Apart from the participant’s diagnosis of Fragile X several behavioural phenotypes characteristic of the syndrome have been identified as being specific to the participant. These characteristics include: poor communication skills and receptive language difficulties, poor sequential thinking, the inability to self-regulate arousal and her emotions, social skill deficits and having difficulties responding to change which produce anxiety-prompted behaviours. It was hypothesized that the function of verbal refusal/non compliance, verbal, and aggressive outbursts may be to escape and/or avoid situations that are stressful to her.

It was further hypothesized that the participant may internalize her feelings over a prolonged period of time and has limited adaptive coping skills to assist her in stressful situations. The inability to appropriately express herself may have created a low frustration tolerance, specific interactions with her mother. It is suggested then, that by developing her ability to effectively identify and communicate what she is feeling in relation to the situation that provoked an emotional response, she will engage in less inappropriate behaviour as a response to
her stress and anxiety. Also, by teaching her more appropriate ways to cope and think through a situation (sequential thinking), the participant will gain the appropriate social skills needed to prevent future aggressive and verbal outbursts from occurring.

Strategies and recommendations are based on the results of data collection (interviews and observations). The strategies and recommendations are specific to the identified Fragile X syndrome behavioural phenotypes related to the participant. Recommendations and strategies include the following:

**Intervention Strategies**

It has been identified that the participant has poor receptive language and has difficulties expressing feelings in relation to the situation that provokes anxiety-prompted behaviours. The participant tends to internalize feelings over a prolonged period of time resulting in engaging in inappropriate behaviours, such as verbal refusal, non-compliance and verbal and physical aggression to get her needs met when she is upset, and/or frustrated. It will be important to teach the participant how to express herself more effectively.

**Systematic Learning**

To increase understanding for the participant when learning a new skill (social skills and coping strategies) it is recommended that mediators adopt a systematic learning approach. This approach is used in response to the participant’s sequential thinking deficits and difficulties processing newly acquired information. New skills are taught one at a time and broken down into manageable steps. Each skill will need to be achieved successfully before the next one is introduced. Skill acquisition should be supported visually, with pictures, where applicable (Dowd & Tierney, 1992).

**Coping Strategies**

Teach and reinforce adaptive coping skills to replace verbal and aggressive outbursts and improve her ability to self-regulate arousal (Folkman & Lazarus, 1980). Presently, the participant has limited adaptive coping skills and uses escape and avoidance motivated behaviours to relieve anxiety when faced with stressful situations. It will be important for mediators to become familiar with the "warning signs" that she is becoming upset, frustrated and/or angry, in order to provide the appropriate supports she will require. Intervening early in the presence of anxiety-prompted behaviours (i.e., elevated voice, repeating words and having a blank expression on her face) and providing the support she needs (i.e., giving her the opportunity to speak privately, allowing her to break from the situation and self calm in a quiet area) will prevent the occurrence of verbal and aggressive outbursts.

Coping strategies should be presented to the participant in visual format and visual strategies, such as, social scripts and power cards, individualized to the participant’s needs, could be implemented to teach her the skills she needs to manage and self regulate her stress and anxiety (Holahan & Moos, 1987).
Emotional Regulation

Emotional regulation is utilized to improve the participant’s ability to effectively communicate appropriately with others when upset, frustrated and/or anxious. To do so she will be provided with strategies that will help her to express and communicate how she is feeling more effectively and respond more appropriately to what she is feeling (Harris-Schmidt & Fast, 2004). That is, frequently discussing with the participant a variety of emotions, both positive and negative, will help her gain a better understanding of how to identify with her feelings, for example "Participant’s name you look sad, are you okay" or "Participant’s name you look mad, what happened?"

Visuals

Given the participant’s poor receptive language skills and poor sequential thinking skills, it will also be important for mediators, when giving instructions and/or making requests, to pair verbal instructions with pictures where appropriate. Pictures can be used to organize and sequence events and task analysis instructions. Also, when giving directions or when making requests of her, the participant should be given the time she needs to complete and process the requests made, this will further support her understanding of what is expected of her.

Modeling for the participant

In demand situations, mediators should be aware of and adjust their expectations accordingly to her ability to cope that day and build on her strengths. It will be important to offer more support with the things she has difficulties with, while watching for anxiety prompted behaviours. When verbal or physical aggression occurs, the mediator should model the behaviours and coping skills that should be used in place of outbursts (Bandura, 1986). For example, during arguments the mediator can model how to act and how to talk while remaining calm. Do not engage in behaviours that you do not wish to see her engage in, for example, yelling, and indicate to the participant that yelling is not appropriate. To do so the mediator is to incorporate social scripts and power cards during these opportunities for learning.

Social Scripts

Social scripts break down social situations into smaller steps and are supported visually with pictures or photographs. They can be used to visually demonstrate to the participant what to do when she is feeling anxious and/or angry by offering her alternate choices and responses, which are more appropriate than engaging in aggression to get her needs met. Social scripts can also open discussions about what she is feeling prior to an incident occurring and as a briefing tool (Dowd & Tierney, 1992). This tool is used frequently and in combination of other tools. Social scripts describing what to do in different situations should be individualized to the participant and reviewed with the participant when the situation calls for it, as well as during times when she is not engaged in aggressive behaviours. This tool can be generalized to a
For example:

Sometimes I feel upset
I may want to cry or yell or hit something
I need to calm down
I will take three deep breaths
I will ask someone to take a break
It’s okay to feel upset
I will stop feeling upset when I calm down

(Adapted from Harris-Schmidt & Fast, 2004)
(This would be supported with pictures)

(Visual Supports - Appendix G).

**Power Cards**

Individual power cards engage an individual’s interest by having a favourite person, character, or super star as the motivator, telling them how important it is to accomplish certain tasks. Short stories, statements, and summaries about correct responses and appropriate social behaviours are printed on the cards. This visual strategy could be used to motivate and provide the participant with an always-available coping tool (Harris-Schmidt & Fast, 2003). This tools is an alternative to the social scripts and can be used together to aid the participant in learning coping behaviours.

For example:

| Stop and take a breath |
| Ask someone if you can go to a quite area to have a break |
| Talk to someone, that will help you feel better |

(Adapted from Harris-Schmidt & Fast, 2004).

(This would be supported with pictures)
**Choice Menu**

Choice Menus could also be utilized to teach and reinforce appropriate responses. Choice menus provide a visual menu, paired with pictures, of options that the participant can choose from when she is feeling angry and/or upset.

For example:

<table>
<thead>
<tr>
<th>Say, ‘I am Angry</th>
<th>Take a Walk</th>
<th>Go to a quite area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Listen to Music</td>
<td>Take a Break</td>
<td>Go find someone to talk to</td>
</tr>
</tbody>
</table>

*(This would be supported with pictures)*

Use teachable moments to role-play and model appropriate responses when they occur in their natural environment (Harris-Schmidt & Fast, 2003).

**Consistency**

Coping skills and strategies will need to be reviewed with the participant by the Behaviour Therapist prior to implementation and then generalized to the home and vocational setting. Create consistency and reliability in routines, which are supported with visuals (pictures, checklists) to reduce anxiety-prompted behaviours caused by unexpected and expected changes (Crockett & Hagopian, 2006).

To respond to anxiety produced by change, unexpected and expected, and given that she has strong visual skills (has limited ability to read and write) reviewing her schedule with her, which reflects a pictorial representation of her day inclusive of all activities that she participates in, will enable her to predict what will happen and when. When changes do occur, it will be important to discuss these changes with her ahead of time and provide alternative activities, which are sensitive to what she wants, and alternatives are negotiated with her (i.e., ask vs. tell).

**Praise and Reinforcement**

In its common usage, praise is the act of making positive statements about a person, object or idea, either in public or privately. Praise is often contrasted with criticism. Reinforcement is an increase in the strength of a response following the change in environment immediately following a response (Reber & Reber, 2001). It will be just as important to recognize gains and compliance with praise and reinforcement. That is, when the participant responds appropriately to instructions, provision of praise will reinforce and motivate her to comply in similar situations. This intervention strategy should be used most frequently with the participant, as mediators should praise coping behaviours as well as alternative behaviours to aggression.
**Generalization and Maintenance**

All newly acquired skills (coping strategies) and implementation of strategies will need to be supported by a number of mediators. The mediators for the participant include a Behaviour Therapist, the participant’s mother, and the participant’s Vocational Counsellor. It will be important to implement these recommendations and strategies to mediators across settings (home and vocational placement). As such, this will further support and maintain newly acquired skills (i.e., learning to identify and communicate how she is feeling, in both positive and negative situations more promptly, learning how to self-regulate and appropriately respond to stressful and anxiety provoked situations). Mediator support, in both the home and vocational placement, will further result in increasing the participant’s frustration tolerance and will decrease her anxiety so she does engage in undesirable behaviour to get her needs met.

**In addition to these recommendation**

There should be a review of reasonable expectations which reflect both the participant’s limitations and strengths. This review, while respecting her desire to make personal choices versus making assumptions about what she should or should not do, will create a consistent and reliable approach for what is expected of her.

As such, given her age, the participant should also be provided with the opportunity to negotiate and make decisions for herself (as long as she is not putting herself or others at risk), also giving her the opportunity to learn from the natural consequences of the choices/decisions she makes. The participant is also more likely to make better choices in the future when she learns from experience. Not only will this foster respect and encourage independence it will also reduce argumentative and non-compliant behaviour. (Mediator Instructions – Appendix H).

**Monitoring Progress**

Lastly, it was strongly recommended that the assigned behaviour therapist closely observe the participant’s progress by utilizing the following strategy for monitoring the progress of intervention being implemented. An agenda/calendar was provided to the participant’s mother to record time and dates of meetings that the participant had with the community behavioural service involved. Also the mothers, as the primary mediator, were asked to track and record instances of verbal and aggressive outbursts and continue to receive information regarding the behaviour.
Chapter V. – Discussion

The purpose of this applied thesis was to use the results of an in-depth functional assessment to design intervention strategies using a consultative approach for mediators to implement with the participant as intervention. PBS as an approach incorporates a functional behavioural assessment and leads to a behavioural intervention plan that is positive (i.e., proactive, educative, and functional) in nature. Using PBS to design intervention recommendations and strategies, the objectives were to equip the participant with effective communication and coping skills needed by ensuring that the proper coping behaviours are taught.

Program Changes

Initially the participant was referred for aggressive outbursts in which occurred exclusively in the home setting. The outbursts were the target behaviour that was to be assessed and addressed during intervention. However the outbursts occurred in the home setting at such a low frequency that it was necessary to further investigate the function of the aggressive outbursts and identifying other target behaviours. Anxiety was identified as target behaviour for the participant and was to be assessed and decreased through intervention. Anxiety, as an emotion, is difficult to observe and measure, and the emotion was not easily expressed by the participant. The results of the functional assessment revealed that the aggressive outbursts were low frequency and were the consequence of low frustration tolerance. Low frustration tolerance was identifiable by anxiety-prompted behaviours such as repeating the words of others, using a raised voice level when speaking, verbally saying “Oh no, I’m in trouble” when approached by a staff or care provider, and displaying a blank facial expression. Anxiety-prompted behaviours were produced by the participant as a result of an environmental stimulus. These occur when requests to complete an undesirable task are made, there is an unexpected change in her regular routine, when the participant is introduced to a new task, a difficult task or request is made, and/or when a peer says or does something that bothers or upsets her. These findings suggest that environmental stimuli (i.e., negative peer interactions etc.) may be contributing factors influencing the participant’s ability to cope in stressful situations and anxiety-prompted settings.

Strengths

Strengths of this applied thesis include the thorough review of the literature as it examines all areas of study that were identified and relevant for the participant, including Fragile X Syndrome, aggression, anxiety, frustration, Positive Behavioural Supports, and several behavioural intervention strategies. An additional benefit is that the treatment of problems presented by the participant with Fragile X Syndrome using Positive Behavioural Supports is a relatively new area of study and are clearly described based on information obtained from empirical resources. Also the behavioural intervention strategies that were recommended are supported by the literature. The recommendations and strategies that were created for mediators to implement when working with the participant are individualized for the participant, and are directly the result of a complete functional assessment. Individualized instruction content, materials, and pace of learning are based upon the abilities and interests of the learner.
**Limitations**

There were a number of identified limitations to the implementation and completion of this applied thesis. The duration of time provided for the completion of the assessment and implementation of the applied thesis was fourteen weeks. It appears to be a considerably large amount of time, however the participant’s target behaviours and assessment proved to be more complicated than initially thought. Data on the effectiveness of the strategies and recommendations that were made were not collected due to the time constraints; as a result, the success rate of the procedures is not known. If more time was available, the intervention still would have utilized an AB design which is less robust than other designs such as an ABAB or multiple baselines.

The low frequency of behaviour was a major limitation of assessment and design of intervention. Low frequency behaviours are the most difficult to assess and change; aggression, the initial concern of the participant’s mother did not occur during the fourteen week time frame. Instead, other behaviours were defined and observed that were hypothesized to be contributing to the aggression.

**Multilevel Challenges to Services Implementation**

Clinical challenges occur at the margin of the treatment planning, programming and treatment intervention. A multisystem perspective examines four levels of analyses used to in the delivery of human services: client, program, organization, and societal.

At the client level low frequency of aggressive outbursts provided an opportunity for prevention as intervention. The aggression occurring infrequently meant that the behaviour would be difficult to observe and measure. The infrequent aggressive outbursts required further investigation into the function of the behaviour. It seems that other environmental incidents contributed to the anxiety-prompted behaviours which lead to the build up and ultimate release of anxiety in the form of aggression. Therefore anxiety-prompted behaviours were the focus of the intervention recommendations.

Challenges arose at the program level during the assessment and design of effective intervention. Due to time constraints, mediators did not receive full training on each of the behavioural strategies or recommendations that were made as intervention. Therefore it was not feasible to measure the effectiveness of the recommendation and strategies, nor was it possible to evaluate the accuracy of the implementation of the recommended interventions.

In the field of developmental disabilities, an individual can be involved with more than one organization; this is the case for the participant in this applied thesis. If was difficult to arrange time to work directly with the participant, and with her support team of mediators. The challenge arise from time constraints, high demand for services, and individual caseloads of the helping professionals. With consent, collaborating with other professionals and personal care providers for the participant was challenging as they experienced many of the same organizational challenges.
Although during the assessment and design phases of this applied thesis no societal challenges arouse, society still seems to have a low frustration tolerance for individuals with developmental disabilities or mental health issues when aggressive behaviours are demonstrated. Even though the behaviour may be low frequency, if not addressed, society may not be as accepting of the occurrence of the behaviour and therefore makes it more difficult to integrate the individual into the community.

**Recommendations for Future Research**

Since the discovery of the Fragile X gene in 1991, there has been tremendous progress in the understanding of this disorder. However, some affected families argue that not enough research is being conducted on the treatment of Fragile X. In response, experts explain that it is difficult to treat Fragile X without first understanding more about the biology of the condition and the meaning of the DNA expansions (Dura, Dunlap, Fox, Lentini & Clarke, 2004). Ongoing analysis of the FMR-1 gene and its protein product may help researchers understand the normal function of this protein and perhaps find a way to intervene when its functioning goes awry (Dura, Dunlap, Fox, Lentini & Clarke, 2004).

Although positive behavioural support (PBS) has been established as an effective approach for resolving the challenging behaviours of many populations, there is little research which has evaluated PBS with individuals with Fragile X syndrome. “PBS is unique in its focus on systems change and use of multi-component intervention guided by functional behaviour assessment” (Carr & Sidener, 2002, p. 249). Emphasis is placed on prevention, environmental redesign, and instruction. PBS has become the approach of choice for individuals with a range of diverse characteristics and circumstances and challenges in a variety of settings.

It is recommended for future research that both relatively new areas of study, Fragile X syndrome and Positive Behavioural Support in combination continue to be empirically investigated to address challenging behaviours for individuals of all ages and across settings. It is also recommended that future research use the behavioural interventions recommended in the applied thesis and evaluate the effectiveness of each strategy with FXS participants.

Thesis word count: 17,409
References


Dear [Name],

I am a student in the Bachelor’s Degree in Behavioural Psychology [BPSYC] program at St. Lawrence College. This four-year degree program is based on a behavioural framework, which has been proven to be effective in developing life skills with a wide range of clients in institutional and community settings. The behavioural approach increases the client’s desirable behaviours through teaching, practice and encouragement. This course focuses on the application of the basic principles of positive behavioural supports and applied behaviour analysis.

I am currently enrolled in an Applied Thesis course. An applied thesis is an intervention or project that includes a very detailed report. The development of the intervention/project will include on-going assessment procedures, direct observations, and an intervention plan. This client-focused intervention/project will be developed in collaboration with you, the agency’s staff, and team members.

The applied thesis project has been approved by [Name] and [Name] the supervising psychologist. [Name] is my College Supervisor.

The benefits of participating in the applied thesis include a thorough assessment and an empirically base intervention plan that is designed to benefit you specifically. There are no known risks of participating in the applied thesis.

I would like your permission to implement the intervention/procedures described above. The intervention/project will be developed under the supervision of [Name] and [Name]. All information collected will be kept strictly confidential. Upon request, we will gladly share a copy of a brief report of the intervention.

If you agree to participate in the project, please complete the form at the bottom of this letter and return it to me as soon as possible. All information collected will be kept strictly confidential. Upon request, we will gladly share a copy of a brief report of the intervention. Participation in this project is voluntary and you may withdraw at anytime.

I sincerely appreciate your cooperation. If you would like to receive more information about the applied thesis or have additional questions or concerns, please contact my College Supervisor, [Name].

Sincerely,

[Name]

BPSYC Student
I understand and consent to the information on the previous page.

Name: ______________________

NOTE: all information identifying you will be removed from any reports to protect confidentiality

___√___ I consent ________________ to participate in the intervention/project conducted by ____________.

____ I do NOT consent ________________ to participate in the intervention/project conducted by ____________.

___√___ I consent for the data collected as part of this intervention/project to be put in a report in the college library.

___√___ I consent for the data collected as part of this intervention/project to be presented at a conference.

____ I consent for the data collected as part of this intervention/project to be published in a peer reviewed journal or professional publication.

Client/Guardian Signed:
Date:

Witness Signed:
Date:

BPSYC Student Signed:
Date:
Appendix B: Functional Analysis Checklist

The following is not the complete Functional Analysis Checklist (FAC), the following are the results of the FAC completed by the participant’s mother, received 2007-10-23

FUNCTIONAL ANALYSIS CHECKLIST

(Rolider, Van Houten, & Ickowitz, 1989).

**Biological Factor**

1. Does the behaviour occur more often just before the menstrual period?  
   YES / NO

**Alertness Related Factors**

16. Does the individual appear vague, puzzled, confused or baffled just prior, during or after a change (increase/decrease) of the behaviour?

If yes, please briefly describe,

The times where the participant does have a serious behaviour outburst, she becomes very quiet and withdrawn after the fast.

**Communication Related Factors**

20. Does the behaviour occur following the individual’s inability to communicate a need?  
   YES / NO
21. Is the behaviour occurs following the individual’s request or instructions by the caregiver?  
   YES / NO
22. Is the behaviour related to caregiver’s misunderstanding of the individual’s request?  
   YES / NO

**Escape Demand Related Factors**

23. Does the behaviour occur more often when you begin to teach a new skill?  
   YES / NO
24. Does the behaviour occur more when you attempt to initiate self-care routines?  
   YES / NO
25. Does the behaviour occur more when the difficulty of a task is increase?  
   YES / NO

   If yes, please briefly describe a task
Sometimes she may not want to shower when she is asked to, or may not want to wear what I want her to, but usually is not serious.

26. Does the behaviour occur more often when you increase the pace of a task or request?  
**YES / NO**

27. Does the behaviour occur when you are seated or standing close to the individual?  
**YES / NO**  
If yes, how close?  

*Within 10 feet (in the house or car) she is naturally slow and if asked to hurry she will sometimes get upset.*

28. Does the behaviour occur more often when a particular type of task is introduced?  
**YES / NO**  
If yes, what type of tasks?  

*She is set in a routine, if routine is broken she may get upset (for example, she likes to walk to day program, and if it’s raining she still wants to walk to day program).*

**Elicited or Adjunctive Behaviour Related Factors**

31. Is the behaviour often associated with the termination of specific activities?  
**YES / NO**  
If yes, briefly describe the activity?  

*Yes, more so if it is a regular routine activities.*

**Transition Related Factors**

34. Does the behaviour occur following a transition, regardless of the direction of the change  
**YES / NO**  
(i.e. as likely to following a shift from task A to task B from task B to task A).  

*Sometimes when we are getting ready to go out*
The following is not the complete Functional Analysis Checklist (FAC), the following are the results of the FAC completed by the participant’s vocational counsellor, received 2007-11-01

FUNCTIONAL ANALYSIS CHECKLIST

Biological Factors

7. Does the behaviour occur more often toward the end of a long, busy day, or following a prolonged activity?
   If yes, describe briefly,

   *Maybe some anxiety when questioned or asked to do something*

   YES/NO

Physical Environmental Related Factors

17. Does the behaviour occur more when the environment is noisy?
   YES/NO
   If yes, describe briefly,

   *She shows some yelling and repetitive behaviour when there is a lot of noise in the classroom setting*

19. Does the behaviour occur more in a crowded room
   YES/NO
   *Shows some anxiety during a crowded room.*

Communication Related Factors

20. Does the behaviour occur following the individual’s inability to communicate a need?
    YES / NO
21. Is the behaviour occurs following the individual’s request or instructions by the caregiver?
    YES / NO
22. Is the behaviour related to caregiver’s misunderstanding of the individual’s request?
    YES / NO

    *Shows anxiety during each of these situations.*

Escape Demand Related Factors
23. Does the behaviour occur more often when you begin to teach a new skill?
   YES / NO
24. Does the behaviour occur more when you attempt to initiate self care routines?
   YES / NO
25. Does the behaviour occur more when the difficulty of a task is increase?
   YES / NO
   If yes, please briefly describe a task

   Shows anxiety during each of these situations.
28. Does the behaviour occur more often when a particular type of task is introduced?
   YES/NO
   Is so, what type of task?

   She Shows anxiety

Transition Related Factor
34. Does the behaviour occur following a transition, regardless of the direction of the change?
   YES/NO
   (i.e. as likely to follow a shift from task A to task B as from task B to task A).
Appendix C: Functional Assessment Interview

The following is not the complete Functional Assessment Interview (FAI) the following are the results of the FAI completed by the participant’s mother, received 2007-10-23.

FUNCTIONAL ASSESSMENT INTERVIEW

(O’Neill, Horner, Albin, Sprague, Storey & Newton, 1997)

Person of concern: 
Date of interview: Received October 23, 2007
Responded: (mother)

A. DESCRIBE THE BEHAVIOURS

1. For each of the behaviours of concern, define the topography ((how it is performed), frequency (how often it occurs per day, week, or month), duration (how long it is performed), and intensity (how damaging or destructive the behaviours are when they occur).

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Topography</th>
<th>Frequency</th>
<th>Duration</th>
<th>Intensity</th>
</tr>
</thead>
<tbody>
<tr>
<td>a.</td>
<td>Throwing things</td>
<td>A couple of times</td>
<td>5 minutes</td>
<td>Breaking CD’s, hitting window with umbrella</td>
</tr>
<tr>
<td>b.</td>
<td>Screaming and yelling (at home and out socially)</td>
<td>One a month</td>
<td>Brief</td>
<td>Will go to her room until she calms down</td>
</tr>
<tr>
<td>c.</td>
<td>Refusal</td>
<td>Won’t/doesn’t want to do what is asked of her</td>
<td>Once a week</td>
<td>Brief</td>
</tr>
</tbody>
</table>

2. Which of the behaviours described above are likely to occur together in some way? Do they occur about the same time? In some kind of predictable sequence or “chain”? In response to the same type of situation?

Nothing predictable, severe outburst will include a. and b. and c. will include some of b.

B. DEFINE ECOLOGICAL EVENTS (SETTING EVENTS) THAT PREDICT OR SET UP THE PROBLEM BEHAVIOURS

5b. To what extent are the activities on the daily schedule predictable for the person, with regard to what will be happening, when it will occur, with whom, and for how long?

Her week is pretty much planned out, weekends can change, depending on what I work, going with her dad or her activities.
5c. to what extent does the person have the opportunity during the day to make choices about her activities and reinforcing events? (e.g., foods, clothing, social companies, leisure activities)

Some choice for food usually is not a problem, clothes more so if she wants to wear dirty clothes over again, and most of her social companies are at her day program. Leisure activities include her sports, not usually a problem.

7. What is the pattern of staffing support that the person received in home, school, work, and other settings? (e.g., 1:1, 2:1)? Do you believe that the number of staff, the training or staff, or their social interactions with the person after the problem behaviour?

Because I am the primary disciplinary person her life, we occasionally have difference. She is quite independent and does not require 1:1 staffing support.

C: DEFINE SPECIFIC IMMEDIATE ANTECEDENTS EVENTS THAT PREDICT WHEN THE BEHAVIOURS ARE LIKELY AND NOT LIKELY TO OCCUR.

1. Times of day: when are the behaviours most and least likely to happen?

Most likely: Mornings
Least likely: Bedtimes

2. Settings: where are the behaviours most and least likely to occur?

Most likely: Home
Least likely: Job placements

3. People: with whom are the behaviours most and least likely to happen?

Most likely: Mother
Least likely: People she works with in community

4. Activity: what activities are most and least likely to produce the behaviours?

Most likely: Asking her do to something that she doesn’t want to do (accept a drive to day program when it’s raining).
Least likely: Working at job placement

5. Are there particular or idiosyncratic situations or events not listed above that sometimes seen to “set off” the behaviours, such as particular demands, noises, lights, and clothing?

Sometimes when she is settled in her room with the TV or music going, she doesn’t want to do anything else.
6. What one thing could you do that would most likely make the undesirable behaviour occur?

*Insisting that she does something, and she doesn’t want to do it.*

7. Briefly describe how the person’s behaviour would be affected if…
   a. you asked her to perform a difficult task
      *Refusal*
   
   b. You interrupted a desired activity
      *Yelling, but would do it if you leave her for a while.*
   
   c. You unexpectedly changed her typical routine or schedule of activities
      *She might insist she is still going to do it but will settle on a good day, but can also get out of control.*
   
   d. she wanted something but wasn’t able to get it
      *Not a problem*
   
   e. you didn’t pay attention to the person or left her alone for a while
      *She would settle, might act like nothing happened*

F. WHAT FUNCTIONAL ALTERNATIVE BEHAVIOURS DOES THE PERSON ALREADY KNOW HOW TO DO?

1. What socially appropriate behaviours or skills can the person already performs that may generate the same outcomes or reinforcers produced by the problem behaviours?

*For the most past the participant is very easy going, very mush enjoys interacting with other (adults since a young age). Is very supportive of her fellow athletes*

G. WHAT IS THE PRIMARY WAYS THE PERSON COMMUNICATES WITH OTHER PEOPLE?

1. With regards to the person’s receptive communication, or ability to understand other persons…
   a. Does the person follow spoken request or instructions?

*Yes but the instructions and request need to be kept simple. Might seem like she understands but when she tried to follow through and tell others, she wont have it correct.*
Appendix D: Antecedent Behaviour Consequence (ABC) Data Collection Form

(Sample of form provided to Participant’s Mother)

<table>
<thead>
<tr>
<th>DATE (D/M/Y)</th>
<th>TIME</th>
<th>SETTING EVENT</th>
<th>ANTECEDENT (what come before the behaviour)</th>
<th>BEHAVIOUR (full description of the behaviour)</th>
<th>CONSEQUENCE (what happened as a result of the behaviour and what ended the behaviour)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Name of participant:

Definition of Behaviour:
Appendix E: Scatter Plot Assessment Form  
(Sample of form provided to Participant’s Mother)

Client: 

Date: 

Legend:  
- √ = at least one occurrence of behaviour within that ½ hour block  
- 0 = an instance of this behaviour did not occur within this ½ hour block  
- / = if you were unable to record behaviour for any reason

<table>
<thead>
<tr>
<th>Where is participant?</th>
<th>What’s going on?</th>
<th>Time in 30 min intervals</th>
<th>Verbal Outburst</th>
<th>Physical Aggression</th>
<th>Attempts of Aggression</th>
<th>Responses to Behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>AM 7:00-7:30</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>7:30-8:00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>8:00-8:30</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>8:30-9:00</td>
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<tr>
<td></td>
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<td>9:00-9:30</td>
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</tr>
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<td></td>
<td></td>
<td>9:30-10:00</td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td>10:00-10:30</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td>10:30-11:00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>11:00-11:30</td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>11:30-12:00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>PM 12:00-12:30</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>12:30-1:00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Definitions of Behaviour:

**Verbal Outburst includes:** raised voice level with a negative intonation, name-calling, inappropriate remarks, swearing, and/or yelling.

**Physical Aggression includes:** hits, slaps, punches, bites, scratches, pokes, kicks, shoves or throws objects at another person with sufficient intensity to inflict immediate pain and/or injury to another person. Also includes destruction of property.

**Attempts of Aggression include:** any attempt that the participant has made to engage in the behaviours described above, but are prevented or miss.
Appendix F: Graph with trends lines

Anxiety Prompted and Coping Behaviours

Number of Occurrences of Behaviour

Sessions

Baseline

Treatment

- Repeating Words
- Raised Voice Level
- Coping (approaching staff)
- Linear (Repeating Words)
- Linear (Raised Voice Level)
- Linear (Coping (approaching staff))
Social Scripts break down a task or social situation into small steps. The participant is a strong visual learner, as she is unable to read or write. Social Scripts will be used to visually demonstrate to the participant what to do when she is feeling happy, sad, tired, or angry. Using social scripts when discussing emotions also used to visually reinforce the skill that is being taught to the participant.

**Feeling Upset**

Sometimes I feel upset.

I may want to cry or yell or hit something.

I need to calm down.

I will take three deep breaths.

I will ask ________ to take a break.

It is okay. I will stop feeling upset when I calm down.

Adapted from Harris-Schmidt & Fast, 2004
Choice menu, providing a visual menu of options that the participant can choose from when she is feeling upset or angry.

**Anger Choice Sheet**

<table>
<thead>
<tr>
<th>I'm angry.</th>
<th>Go to a quiet area.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Say, “I’m angry!”</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Listen to music.</th>
<th>Take deep breaths.</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Take a walk.</th>
</tr>
</thead>
</table>

Adapted from Harris-Schmidt & Fast, 2003
Appendix H: Mediator Instructions

Mediator Instructions For Intervention Procedures

CLIENT NAME:
PROCEDURE: Coping Behaviours

MEDIATOR (S):
LOCATION: Across Settings

TARGET BEHAVIOUR (S) (operational definitions):

1. **Coping behaviours (accelerate)**, the participant is said to increase her coping behaviours when she has learned and is using the recommendations and strategies provided, which include:
   
   • Communicating with a staff/other persons (verbally or visually)
   • Walking away from situations
   • Taking a break
   • Does NOT escalating into verbal or aggressive outbursts

   The participant is engaged in coping behaviours when is faced with a stressful situation and displays one or more of the coping behaviours, this does not include ignoring or internalizing her feelings as a result of the situation.

2. **Anxiety prompted behaviours (decelerate)**, anxiety is a physiological state characterized by cognitive, somatic, emotional and behavioural components. These components combine to create the feelings of fear, apprehension, anger, and worry. Anxiety prompted behaviours are characteristic of females diagnosed with Fragile X and for the participant these include the following:

   • Repeating words of others
   • Using a raise voice level when speaking
   • Verbally saying “oh no I’m in trouble
   • A blank facial expression

Using a **positive behavioural support** approach, strategies will then include the following:

The participant tends to internalize feelings over a prolonged period of time resulting in the reliance on inappropriate behaviours, such as avoidance, escape, and aggression to get her needs met when she is upset, and/or frustrated. It will be important to teach the participant how to express herself more effectively

1. Poor Communication

   - **Identifying and responding to emotions appropriately**, an example of responding to an emotion is "you are smiling, you must feel happy".
   - Recognize and share others emotions with the participant, for example, "Look at Pete, Pete is laughing, he must feel happy".
   - Over exaggerate facial expressions and share her how you are felling, for example, “look I am smiling, and I feel happy today".
| 2. inability to regulate arousal | - Frequently discuss a variety of emotions with the participant, and look for both positive and negative emotions, for example “you look sad, are you okay” or “you look mad, do you want to tell me what happened?”
  - **Pairing Verbal instruction with visual support**
  - Incorporate pictures to support verbal instructions and/or directions.
  - Use visual supports to organize a sequence of events, enhancing her ability to understand, anticipate and participate in events
  - Be consistent with use of visuals, if they are successful

  This will help the participant to express and communicate how she is feeling without causing a build of emotion resulting in low frustration tolerance, and

  Eventually releasing her frustrations through aggressive and verbal outbursts. |

| 3. poor sequential thinking: | - **Identify anxiety prompted behaviours (warning signs) and triggers**, Observe and learn triggers that effect emotions for the participant, for example another individual is bothering her by repeating her name over and over.
  - Intervene early when the anxiety prompted behaviours are displayed (warning signs) and reassure the participant that she is not in trouble.
  - Encourage her to talk about what is going on and describe the situations
  - Provide a private and supportive opportunity to talk (the participant does not like to be the center of attention).

  - **In demand situations**, adjust expectations and demands, daily, accordingly to her ability to cope.
  - Model the skills you want to teach the participant, and give her the skills needed (do not assume that she has previously learned them and practice skills within the natural environment).
  - Build on her strengths, and offer more support with the things she has difficulties with and watch for anxiety prompted behaviours. |

|  | - **Task analysis**, break down a whole task into a series of small components, which are taught individually and later performed together as a whole task
  - **A systematic learning approach** will be implemented, where she will be taught one step at a time. Each skill will be broken down into manageable steps and will need to be achieved |
successfully before the next step is introduced.

- **Be clear and specific with request and directions**, be direct and firm while using a calm tone of voice and provide the participant with the time needed to process and complete the request that you have made. Also increase the amount of support that is providing in completing the task.

- When applicable, provide visual support with request or directions.

- **Be clear with expectations**: provide the participant with a clear and simple explanation, instruction and/or direction so that she knows exactly what is expected of her.

- Break down larger tasks down into small and clear steps to be completed on at a time.

- Have appropriate expectations (don’t set the bar to high) and work with her strengths, requests things that you know she knows how to do and help her with new or difficult tasks (given the participant’s age is will be important that she is asked versus assumptions that she needs help).

- **Provide choices for the participant**, to avoid a power struggle, or to de-escalate from a power struggle, asks the participant to something versus telling her to do something. Provide her with two options for completing the tasks and be open to negotiation alternatives.

- Provide examples of choices that are available to her versus forcing her to do something that is undesirable.

- Let her make her own decisions, however make it clear for the participant that if her decision is in any way dangerous or is at risk to cause harm to her or another person then she will not be able to follow threw with her choice.

- **Recognize compliance with praise and reinforcement**, when the participant responds appropriately to instructions; provide her with praise that will reinforce her for complying with a similar/future direction/request. Praise and reinforce for every instance of compliance.

- **Modeling**, during arguments, model of the participant how to act and how to talk while remaining calm. Do not engage in behaviours that you do not wish to see her engage in, for example, yelling, do not yell during arguments, and indicate to the participant that yelling is not appropriate.

- **Learning from Natural Consequences**, natural consequences are situations that are not controlled by anyone. Individuals learn through natural consequences as they can be used as teaching points. For example, when the participant makes the decision to walk to her day program in the rain/snow and refuses to be driven by her mother, she will learn naturally that when she walks to the day program in the rain/snow that she will get wet/cold and that it is not enjoyable.
### 4. Anxiety produced by change:

- Review the participant’s schedule, continue to provide her with verbal instructions on how each day will unfold, pair verbal instructions with a picture schedule that visually shows the activities that the participant will participate in throughout each day. Discuss possible changes and alternatives to activities and provide verbal (paired with a picture symbol) of choices of alternative activities. (Changes in the schedule might be signalled with a special coloured insert).
- Coping Tools, the follow tools can be individualized to the participant and used as a teaching method, as well as coping tools to help reduce anxiety produced by change.

**Social Scripts** Social Scripts break down a task or social situation into small steps. Pictures or photographs will play a vital role in Social Scripts, as the participant is a strong visual learner, as she is unable to read or write. Social Scripts will be used to visually demonstrate to the participant what to do when she is feeling happy, sad, tired, or angry. Using social scripts when discussing emotions also used to visually reinforce the skill that is being taught to the participant.

**Power Cards** Use of individual power cards to motivate the participant and that provide her with an always-available coping tool. Power cards use some of the same principles as social scripts, but also engage the individual’s interest by having a favourite person, character, or super star as the motivator; in short stories and summaries are on cards and the individuals favourite character tell them how important it is to accomplish certain tasks.

**Choice Menu** Providing a visual choice menu of options that the participant can choose from when she is feeling angry or upset.

Encourage and praise her when she engage in these activities and model and discuss (using the visuals) all the steps involved.

The participant is very agreeable by nature, and her mother reports that her daughter may shake her head in understanding without actually taking in and knowing what was said, this is consistent with Fragile X syndrome.

*It will be important to confirm understanding both visually and verbally when working towards achieving the goals and objectives for the participant.*

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### 5. Additional Recommendations

*However it must be clear that learning from natural consequences if fine as long as it is not in any way dangerous or is at risk to cause harm to herself or another person.*