Meeting the emotional needs of children with challenging behaviour and developmental disabilities

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LAURA DEBRA LEIGH HOWARD
(nee Buckley)

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ABSTRACT

Research on the utility of combining behavioural interventions with emotion-based components of intervention for children with developmental disability and challenging behaviour is limited. The current study aimed to gather empirical evidence identifying the importance of considering emotional and motivational needs in addressing behavioural difficulties in children with developmental disabilities. The four component model (Meyer & Evans, 1989) for intervening with challenging behaviour was utilised as the theoretical framework for this study, with each component being addressed in four single case designs. The four children and their families involved in this study were; Simon (aged 12), William (aged 5), Lily (aged 5) and Hohepa (aged 15). Results across baseline, intervention, and three- and six-month follow-up assessments indicated the difficulty in determining which component was most significant in creating change in challenging behaviours. However, the results consistently indicated benefits for each child through involvement in this study. Interviews with parents at three- and six-month follow-up also provided information on the benefits of this study, including improvements in their child's behaviour and benefits for themselves as parents. This research provides support for the four component model and implies the utility of adding an emotion-based component to behavioural interventions when working with such children. Future research would benefit from increased sample size and time periods to continue to document the utility, or otherwise, of this mode of intervention.

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FOREWORD

Ever since I was a child, I have wanted to work with other children. I remember being one of those kids, known as a 'teacher's pet', who always finished my work early in order to help someone else in the class. This passion developed as I grew, and resulted in the decision to study to become a teacher when I finished high school. However, after consultation with a careers advisor, I found out I could do a degree in Psychology first, and then do a one year Diploma in Education to teach children. This career path appealed to me, as although requiring an extra year, it would enable me to also obtain some insight into the whole process of human development. I began this journey with vivid passion and vowing to do something within my academic study that would be beneficial to children.

After completing the Bachelor of Arts in Psychology and Sociology, I continued to be drawn to the discipline of Psychology. I learnt a lot about human development and was intrigued to know more. Therefore, instead of enrolling in the Diploma of Education, I completed Honours in Psychology in 2007. After this, I knew I wanted to continue my study primarily within psychology. My passion for working with children had developed further to wanting to work with children who were disabled or having difficulties emotionally, behaviourally, and intellectually to help them improve their quality of life. From this realisation, I thought it would be useful to look at how I could actually achieve this. I encountered various theoretical models outlining different aspects of treatment and therapy for children with various behavioural, intellectual, emotional and social difficulties that were currently utilised. I decided to look further into an existing model, 'the four component model', which addresses challenging behaviour in children.

The four component model, proposed in 1989 by Evans and Meyer, has not yet been formally validated with children who have developmental disabilities as well as challenging behaviour. However, it holds potential for these children. It focuses on identifying and rectifying behavioural difficulties through methods of expression and communication, and the use of emotion rather than simply attempting to remedy the behavioural problem through external controls. This particular model continued to grow in appeal as I began to ask around and speak to families who had a child with a

developmental disability and challenging behaviour. After speaking to one mother, it become overwhelmingly clear that she believed her child was frustrated, which was why her child was displaying challenging behaviour. The frustration was not only specific to their disability, but this mother believed it to be related to her child's inability to comprehensively communicate ideas, needs and desires. I knew, without a doubt, that I wanted to do my best to try and help families like theirs to achieve a more functional and socially appropriate method of communication for their child whilst remedying their child's apparent current form of communication: their challenging behaviour. I believed that the four component model was the best fit for me to use to try and achieve this goal.

Hence, the aim of this study was to address the deficiency in the research literature surrounding the four component model as it relates to children with developmental disabilities. However, its primary and most important aim was to endeavour to make a difference in the lives of four children for whom challenging behaviour could be viewed as the most functional tool they have for expressing themselves. My idea was straightforward: what could I learn that would be useful in helping children with developmental disabilities and challenging behaviour communicate more appropriately and develop an increased quality of life?

Chapter One begins with a succinct summary of the need for this research and continues by providing a selective review of the current literature available in this area. Beginning with an overview of emotional knowledge, needs and their importance, this chapter emphasises the need to include these in interventions. The four component model is described as the model of choice for this study, with rationale for its selection. The components of this model are: changes needed in the environment, what behaviour or aspects of the behaviour are being reinforced, skills replacement, and the importance of emotional and motivational needs. Next, challenging behaviour, which is a common and normal occurrence in the lives of many young children, is outlined. This chapter will take the reader on an informative journey to develop a background understanding of the current study. The chapter then outlines development and developmental disability and an integration of these two broad topics. For children with developmental disabilities their challenging behaviour, although occurring in many instances for all children, can become more regular and occur beyond developmental milestones. This behaviour may form the methods of communication and expression that a child utilises. The latter part of this

chapter progresses into models and research which highlight and critique how work with children in this area has historically been done.

The focus of Chapter Two is the methodology utilised within this study. This chapter introduces the participants, and outlines the overall phases of the study. This is followed by an exploration of the process of data analysis and ends with an outline of ethical issues and procedure.

Chapters Three, Four, Five and Six allow one chapter to be dedicated to the four children involved in the study, and their families. All names and identifying details have been changed to protect their privacy. Lily, aged five at the beginning of this study has Angleman's syndrome. William, also aged five, experienced hypoglycaemia at a very young age, when he was just under one week old. For William, this meant continued difficulties with brain development impacting on factors such as cognitive development, ambulation and vision. Simon, aged 12, has Asperger's Syndrome and ADHD. Unlike the previous two children, Simon's difficulties were only diagnosed a year prior to the commencement of this study. Hohepa, aged 15, has Smith Magenis Syndrome. The chapters include further detail on the child's diagnoses, family background, and their current functioning. Following this, the child's individualised intervention plan is outlined as well as the changes that were achieved.

The final chapter, Chapter Seven, discusses the overall study and its outcomes. These outcomes are explored on both an individual family and entire study basis. The achievements of each family are emphasised within this section whilst also discussing the utility of the four component model in working with these families. The limitations of the study are then addressed and implications for further research are identified.

CHAPTER ONE: INTRODUCTION

Current Study

Overview

Children with developmental disabilities and challenging behaviour are the focus of increasing study. However, these children's ability to regulate and understand emotion has been explored in relatively few research efforts (Gottman, Guralnick, Wilson, Swanson, & Murray, 1997; Kopp, Krakow, & Johnson, 1983; Piling, McGill, & Cooper, 2007; Wilson, 1999; Wilson, Fernandes-Richards, Aarskog, Osborn, & Capetillo, 2007), despite the importance of emotions in understanding a child's behaviour (Crick & Dodge, 1994; Elias et al., 1997; Lewis & Haviland, 1993; Pithouse & Lowe, 2008; Van Nieuwenhuijzen, De Castro, Wijnroks, Vermeer, & Matthys, 2004; Wilson et al., 2007; Zins, Elias, Greenberg, & Weissberg, 2000). Addressing this relative gap in studies is crucially important for families, guardians, teachers, psychologists and everyone else who interact with these children; most of all for the children themselves. This information is necessary in order to treat all children and their families appropriately and respectfully through adapting interactions and interventions to their developmentally appropriate needs.

Aims

The current clinical study aimed to gather further empirical evidence identifying the importance of addressing behaviour, emotional and motivational needs underlying behaviour (emotional behaviour) in therapy for children with developmental disabilities and challenging behaviour. The literature identifies that behavioural techniques, emotional needs and knowledge are essential in enhancing positive behaviours and reducing negative or challenging behaviours in children who have developmental disability. Based on this previous research, the need for a holistic approach has arisen, including all of these factors along with an emphasis on the importance of family and culture. Specifically, the purpose of this thesis is to examine whether there are advantages in a model, known as the four component model (Meyer & Evans, 1989), that specifically addresses the theoretical and practical needs outlined by previous research, and that

incorporates both behavioural and emotional components. This model, on which the current study was based, was developed as a planning strategy for intervening in behavioural difficulties with children who have a developmental disability.

Each family involved in this study provided information on key behaviours requiring change (either enhancing or decreasing), which were operationally defined, and subjected to a functional assessment prior to intervention. The study aimed to remedy the most challenging of these behaviours, whilst focussing on enhancing emotional understanding and expression concurrently, as determined by parents and observed by the researcher. This was done through adapting environments, changing consequences, teaching replacement skills, and in a general sense targeting the emotional/motivational needs of the children (the four components of the Meyer-Evans model). This final component and its inclusion are in keeping with research identifying its need despite previous over-looking of such a component, and is therefore the major innovative feature of the study (Meyer & Evans, 1989). Each intervention was developed using this theory (each goal is outlined as being related to a different component of the model) as a series of single case studies. This approach was chosen to highlight the different needs of each child and their family and the importance of all of the identified components of intervention through both qualitative and quantitative data. My study therefore addresses what therapy and outcomes may look like for this population of children when along with behavioural intervention, emotional antecedents and functions of behaviour are also addressed.

It was hypothesised that each child and family involved in this study would benefit in some capacity from doing so. General literature from child development highlights the importance of emotional knowledge and behavioural interventions for remediating behavioural difficulties and this study evaluated whether the addition of the emotion-based component to behavioural interventions would be useful for all of the children involved.

The research objectives of this study can be summarised as follows:

Research Objectives:

1. Examine the research related to the current usage of emotion-based techniques for intervention with children who have developmental disabilities and challenging behaviour

2. Explore the importance of emotional knowledge and emotion based techniques for behaviour change

3. Using a series of four case study designs, evaluate the four-component model (emphasising emotion-based skills and understanding) as a planning strategy for reducing the destructive behaviour in each child.

This chapter outlines and summarises the literature relevant to the current study, focussing on children who have both a developmental disability and challenging behaviour, ultimately demonstrating the need for this research. It is divided into sections/themes most relevant to the thesis topic. The nature and importance of emotional knowledge is outlined first, concluded with an outline of the model used for this study. Following this, both challenging behaviour and developmental disabilities are discussed. A review of the progression of intervention designs for this population follows. This chapter is concluded by emphasising the shifts that have occurred within behavioural interventions outlining the need for the current research.

Importance of Emotional Knowledge

Research is increasingly identifying that problem behaviour needs to be seen as having an underlying function in emotion and/or as being used as a means of communication (Moyes, 2002; Repp & Karsh, 1994; Stephenson, & Dowrick, 2005). In order to illustrate the extent of the importance of emotional understanding and knowledge, the process of emotional development is outlined before moving to identify how emotions are increasingly being incorporated into therapy.

A child's emotional needs and knowledge develop from a very early age (Denham & Kochanoff, 2002). They continue to develop and change quite regularly as a child ages

(Pons, Harris, & de Rosnay, 2004). For a developmentally appropriate kindergarten-aged child, emotions are already an integral part of their lives. Children have learnt important skills such as how to manage and use their emotions in play. A child who chooses not to throw a tantrum and instead reflect and talk about what is upsetting them is also benefiting from emotional knowledge. At the most basic level, children are able to express and label emotions during social interactions. Important differences apparent in negative and positive interactions can be discerned, often based upon the context. This means that young children are also interpreting emotional responses that are appropriate in different situations. This knowledge leads into the child's development of an understanding of what causes emotions and its purpose, as well as the realisation that emotions can have consequences (Denham & Kochanoff, 2002). This cause and effect understanding begins with basic emotions such as happiness, sadness and fear and, once at school, this understanding develops around more complex emotions (Harris & Saarni, 1989). For example, a three-year-old who cries may come to expect that the consequence of this emotional action is someone giving him/her a cuddle. The most difficult part of emotional knowledge is being able to interpret the emotions of others. This may develop a little later, but still begins to become evident before a child begins school (Denham & Kochanoff, 2002). Imagine the onset of a developmental disability at or before this stage, which would in many cases effectively inhibit this process from occurring properly, if at all.

This initial emotional development without the presence of developmental disability then continues in a developmentally appropriate pattern throughout the early years of primary school. As the child ages their emotional skills and knowledge surrounding emotions become further refined. The child also adds to their emotional repertoire factors such as cultural influence, the ability to hide or mask emotions, as well as social pressures and expectations around what is expected emotionally in different situations (Denham & Kochanoff, 2002). It is a difficult task to obtain information about emotions that allow them to be grouped and identified in different situations. Despite this apparent difficulty, children learn how to identify emotions and also how to experience and understand more than one emotion at once during their school years (Harris & Saarni, 1989).

By about age six, children are learning to combine all of their emotional information. They are beginning to understand more complex emotions such as shame and guilt,

enabling them to begin utilising such emotions appropriately themselves (Denham & Kochanoff, 2002). At around age seven children can also connect emotions to desires and beliefs (Pons et al., 2004). However, it is argued that, because of a child's limited cognitive ability at this age, the experiencing and understanding of combined and complex emotions is not as fully developed as that of an adult's at this stage (Harter & Whitesell, 1989). Furthermore, although more complex emotions are developing at age six, a child may not understand them until they have experienced them for themselves, such as pride and shame (Harter & Whitsell, 1989). This also highlights the importance of social situations in shaping the development of emotional knowledge (Harter & Whitesell, 1989; Saarni, 1989). However, it has been found that by about age nine, children are able to reflect and view situations from various viewpoints and thereby understand associated emotions of different views (Pons et al. 2004). Neurophysiological systems are also critically involved in the development of emotional knowledge and regulation. The related neurocircuitry develops and reorganises understanding of emotions well into adolescence (Giedd et al., 1999).

Emotional knowledge is therefore vitally important in a child's development for a variety of reasons. A child who can describe and understand their own emotions is a step closer to understanding those of others. For children who are unable to understand, express or explain their own emotions, related negative emotions and behaviours may begin to develop out of confusion or frustration (Hyson, 2004). In challenging situations, appropriate understanding of emotion allows relevant and appropriate emotional and behavioural responses. Comparatively, inappropriate understanding of emotions fosters the opposite response, that is, potentially negative and inappropriate behavioural and emotional responses (Denham, 1998; Kopp, Krakow, & Johnson, 1983; Wilson, 1999). The examples described represent exactly how emotion works to shape and control behaviour. In children with developmental disability and challenging behaviour, these emotions may often take the negative form, shaping and maintaining behavioural difficulties.

Parents as a mechanism for providing emotional knowledge

Parents and peers provide the basic opportunities for socialisation and learning about emotions. Research shows the importance of the early years in shaping affect regulation

and emotional development (Eisenberg & Fabes, 1992; Evans, Meyer, & Buckley, 2008; Shields & Cicchetti, 1997). As a child progresses through middle childhood, appropriate affect regulation along with the development of increasingly significant regulatory capacities see children developing some competence in behavioural and social regulation (Lewis & Haviland, 1993). Children learn from their parents and those around them what is appropriate and how to display how they feel (Denham & Kochanoff, 2002; O'Kearney & Dadds, 2005). Wareham and Salmon (2006) identified that parents who discuss emotions when reminiscing about events have children who are more likely to do so. This research also shows the crucial role a parent, in particular a mother, whose style of emotional expression a child tends to internalise, has in guiding how their children represent their emotional experiences. Therefore, through modelling, a parent can show personalised causes and functions of emotions, particularly those relevant in a family context (Denham & Kochanoff, 2002). This form of reminiscing or elaborating on experiences is found to be associated with a child's more advanced emotion knowledge as well as both cognitive and socio-emotional development (Wareham & Salmon, 2006). These experiences give the emotion more meaning for a child as they learn that the same emotion has many purposes. Verbally coaching children about the meanings of emotions is also something a parent can do to help enhance their child's knowledge (Denham & Kochanoff, 2002).

Not dissimilar to a parent being able to foster the development of appropriate emotional regulation and expression, parental emotions and reactions can also impede a child's ability to develop appropriate emotional knowledge and regulation (Eisenberg, Cumberland, & Spinrad, 1998; Evans, Meyer, & Buckley, 2008). If a parent is punitive or dismissing, a child may not be able to appropriately understand emotional events and may come to view their emotions as frightening (Eisenberg, Cumberland, & Spinrad, 1998). This negative emotion modelling and related feelings can mean children avoid challenging or emotional situations, limiting their ability to learn from others how to respond appropriately (Eisenberg et al., 1998).

Due to the importance of parents in working with children it is essential to also address their needs. Parents can create environments for children that foster growth and emotional development, but can also foster a deficit environment whereby children learn to cope with things inappropriately. Parents, and siblings, therefore can benefit from appropriate

skills training in working alongside their children and also from an outlet or place to share their own experiences (Evans, Meyer, & Buckley, 2008; Hudson et al., 2003; Morris & Hawkins, 1999; Roberts, Mazzucchelli, Studman, & Sanders, 2004; Roberts, Mazzucchelli, Taylor, & Reid, 2003).

Family Therapy

The impacts on families with a child who has developmental disability and challenging behaviour are widespread and varied. These will be outlined in more detail later in this chapter. In particular, having a child with a developmental disability presents parents with a potentially stressful situation (Hastings, 2002). Parents and siblings can benefit from skills training in how to cope with their child and help them with their needs (Evans, Meyer, & Buckley, 2008; Hudson et al., 2003; Morris & Hawkins, 1999; Roberts, Mazzucchelli, Studman, & Sanders, 2004; Roberts, Mazzucchelli, Taylor, & Reid, 2003). However, it is evident that generalised parent skills training are not sufficient for many parents and instead an individualised training programme suited to the developmental needs of their child is recommended (Baker & Brightman, 1984; Hornby & Singh, 1984). McLaughlin and Carr (2005) highlight the importance of the caregiver relationship with the child as a factor which mediates problem behaviour. More specifically, when the rapport in the relationship is high, the problem behaviour levels decrease, emphasising the crucial importance of the caregiver in reducing behavioural difficulties (McLaughlin & Carr, 2005; Malins, 1997). Research by Couch and Evans (2010) explains this importance further. In summary, they found through developing this relationship by techniques such as individualised mindfulness strategies, teaching of emotional skills, and the use of rewards the relationship is enhanced and problem behaviours are reduced (Couch & Evans, 2010).

A study carried out by Allen, Hawkins, and Cooper (2006) identified that parental physical interventions were used commonly to manage challenging behaviour. However, parent training in appropriate interventions was uncommon, particularly surrounding the physical interventions used. They found that physical interventions had been used by 87.5% of their sample of 72 parents, whilst only 25% had received training on how to restrain safely (Allen et al., 2006). These results highlight the imminent need for research advocating appropriate and validated methods of managing challenging behaviour.

Parents can learn appropriate interventions, including safe physical holds, whilst also learning to address the motivational and emotional needs of their child. The current study aimed to reflect this literature highlighting the importance of parental involvement in therapy progress. This did take different forms, based on the needs of the child and the family, but the importance of both parents and siblings was recognized within the study as it is in the literature.

Aside from training to help their child, parents can also benefit from individualised therapy or couple therapy (Hayes, Luoma, Bond, Masuda, & Lillis, 2006; Morris & Hawkins, 1999). For example, acceptance and commitment therapy (ACT) based on behavioural therapy, but with the idea that cognitive processes distort and enhance unpleasant emotions and give rise to problematic behaviour as a means of avoidance or diminishing such emotions. It involves six core processes including: acceptance, cognitive defusion (attempts to alter undesirable functions of thoughts), being present (learning to experience the world more directly), self as context (being aware of own experiences), values and committed action. Parents can utilise therapy models such as ACT to help with their own stress levels and well-being (Hayes et al., 2006). Similarly, Couch and Evans (2010), stipulate the importance of enhancing 'balance' through the use of child and parent-specific mindfulness techniques. This allows the importance of the relationship to be enhanced whilst looking to reduce behavioural difficulties.

Siblings are also identified in the literature as being important and respected role models for many children. Because of this these children, and whole families, can and should be involved where possible and safe in interventions as outlined in the inclusion section of this chapter. However, these children also have needs that are diverse based on their situation with their disabled sibling. For example they may be being bullied at school, be experiencing significant worry about their disabled sibling, and/or displaying difficult behaviour themselves (Evans, Jones, & Mansell, 2001).

Emotional knowledge is therefore important for children, with parents playing an integral role here in transfer of knowledge to their children. As identified, therapy for parents is also important when working with children with developmental disability and challenging behaviour to ensure the needs of their children are met.

Emotional Needs: Inclusion in Therapy

Emotional knowledge and development are vitally important in a child's growth. Research has started to identify the vital nature of emotional knowledge and how deficits in knowledge and having needs met is commonly observed in children who have challenging behaviour and developmental disability. Broadly, emotional needs include the need for autonomy, love and control (Meyer & Evans, 2006). Reiss (2000) outlined that humans have 16 basic desires (needs) which drive our behaviour and shape our personalities. These are: power, independence, curiosity, acceptance, order, saving, honour, idealism, social contact, family, status, vengeance, romance, eating, physical activity and tranquillity (see Reiss, 2000 for more specific details of these desires). Reiss (2000) specified these needs arise automatically and we act accordingly to satisfy them, once satisfied another need becomes apparent. It has long been understood that emotions cause behaviour; however, it has not always been well defined. Emotions (e.g., anger, sadness) may underlie communicative intent (e.g., frustration is expressed as aggression) of our overt behaviour (e.g., aggression is shown in behaviour - hitting, kicking). However, communication can also occur without identifiable emotional underpinnings, behaviour can simply also be instrumental (a way of getting what is required).

It is within this understanding of emotion that the following information is presented outlining its need for inclusion in therapy. Behavioural support for children with developmental disability and challenging behaviour needs to involve much more than simply remedying the identifiable overt behaviour (Horner & Carr, 1997). Furthermore, educators and psychologists are increasingly becoming aware of the importance of promoting emotional learning (Elias et al., 1997). Researchers began to explore strategies for use with one study identifying the potential usefulness of highlighting emotively the negative consequences and functions of certain behaviours (Steiben et al., 2007). It appears that children with challenging behaviours are not as affected by environmental responses to their behaviour, as they do not adequately monitor their actions and associated feedback. This also implies that these children lack the ability to predict social outcomes which could be limiting their sense of personal control. The understanding of emotions and their role in creating observable behaviour would allow children to develop more appropriate responses and pay closer attention to their actions (Steiben et al., 2007; Wilson et al., 2007).

As well as creating and maintaining other behaviour, emotions can be altered or impacted through the developmental disability itself. Sometimes emotional difficulties/ behaviour may be part of the disability and, in other cases; the disability may limit interaction with others, also affecting emotional development, or both (e.g. when a young person with Autism lacks emotional awareness this may be due to their disability directly, but may also link to their lack of socialisation opportunities with others due to their disability). Therefore, knowledge about emotions (and awareness of this as behaviour in itself, i.e. anger, frustration) is not only important for the child, but is important for their families and those who work with them, as these people can be aware of a child's emotional needs and subsequently meet these needs (Hyson, 2004). Difficulties with emotion can be particularly hard for children who are unable to articulate what they need or feel as adequately as others. Without emotional knowledge and support, children with disabilities may develop challenging behaviour uncharacteristic of their disability and find themselves isolated and frustrated (Hyson, 2004; Kaiser & Rasminsky, 2007; Wilson et al., 2007). These and other emotional behaviours can then begin to act as reinforcers, enhancing and maintaining the overt challenging behaviour. Studies have found that the inability to regulate emotion is related to psychopathological outcomes, including anxiety and aggression partly because children have not learned how to appropriately monitor and utilise their emotions (Lewis, Granic, & Lamn, 2006; Wilson et al., 2007).

Another important reason why emotion needs to be addressed in this study is that numerous studies have identified emotional difficulties and deficits for these children. Children with developmental disabilities have been found to have deficient social and emotional skills (Van Nieuwenhuijzen, De Castro, Wijnroks, Vermeer, & Matthys, 2004). Those with developmental disabilities, even at mild levels, show fewer assertive responses in varied situations than children without intellectual disability (Van Nieuwenhuijzen, De Castro, Wijnroks, Vermeer, & Matthys, 2004). These inadequate emotion processing abilities are also related to development of explicit behavioural difficulties (Crick & Dodge, 1994). Wilson et al. (2007) found that, in boys with developmental delays, their emotional regulation abilities played a significant role in their social problems. More specifically it was identified that the lower their ability to regulate emotion, the greater the social difficulties (Wilson et al., 2007). Therefore, a child who is unable to express their needs may benefit from some help with identifying what their

needs and emotions are, how these underlie behaviours, and how they can be appropriately expressed through other behaviour.

Adams and Allen (2001) found aggression to be one of the most prevalent types of challenging behaviour exhibited in children with intellectual disability. Their study found four forms of aggression as being the most serious: "aggression towards siblings and other children, environmental damage, behaviours which were dangerous to the child themselves and aggression towards adults" (Adams & Allen, 2001, p. 339). Aggression has been found to be linked to emotional regulation, as children who cannot regulate their affect in challenging situations exhibit more aggressive responses (Ramsden & Hubbard, 2002; Shields, Ryan, & Cicchetti, 2001). These behaviours have a negative impact on a child's ability to fit in and interact with their peers (Evans, Meyer, & Buckley, 2008). Similarly, these children may tend to see others and situations in a negative light, viewing action by others as hostile, and aggression as a favourable and appropriate option (Dodge, Murphy, & Buchsbaum, 1984; Dodge & Somberg, 1987; Waldman, 1996). Comparatively, children who are able to better calm themselves when upset and experience fewer changes in their emotional states are found to exhibit less anxious and aggressive behaviour (Miller et al., 2006). These studies specifically show the importance of understanding and addressing emotional needs in attempting to ameliorate aggressive behavioural problems (Zigler, 1971). The studies also highlight the importance of emotional needs and knowledge in working with children, particularly those with developmental disability and challenging behaviour, is becoming abundantly clear (Crick & Dodge, 1994; Elias et al., 1997; Lewis & Haviland, 1993; Van Nieuwenhuijzen, De Castro, Wijnroks, Vermeer, & Matthys, 2004; Wilson, Fernandes-Richards, Aarskog, Osborn, & Capetillo, 2007; Zins, Elias, Greenberg, & Weissberg, 2000).

Cultural Considerations

The research identified so far has increasingly raised the importance of considering emotions and motivations in behaviour and taking a more holistic approach in therapeutic interventions. A holistic approach also needs to consider culture (Evans, Meyer, & Buckley, 2008). Our culture creates the framework within which we live our lives. We learn our culture from our families and community, and it shapes our own personal identity.

It is important to consider the behaviour of other family members in order to truly understand the behaviour of one member, as families are social systems (Evans, Meyer, & Buckley, 2008; Parke & Buriel, 1998). Ethnicity is just a part of culture, which includes other factors such as the rules and norms of society, the clothes we wear and the types of food we eat. Culture differs greatly throughout the world and even throughout small societies and family groupings. Therefore, both developmental disabilities and challenging behaviour need to be understood from the point of view of the culture that the child has grown up in or relates to. Different behaviours will be deemed acceptable and challenging, as partially determined by a child's disability. However, the understanding of someone's culture is also an important step toward understanding what is acceptable and what is challenging (Kaiser & Rasminsky, 2007).

Different settings also have their own culture. For example, the school or kindergarten culture may be significantly different to playground or home culture. The cultural context or situation therefore also has an influence on the perception of disability, as well as the nature of behaviour, its development and maintenance. Ethnic differences such as language difficulties may also make behaviour appear challenging. For example, a child who is learning a second language may find this frustrating and play alone or react aggressively, or the meaning of a word or action may be interpreted incorrectly by someone who is not knowledgeable of the child's culture. All of these different factors make up a person's culture, shaping who they are in different situations and contexts, and must be considered in understanding challenging behaviour (Kaiser & Rasminsky, 2007).

The Interaction of Culture and Emotional Needs

Not unlike the four component model, cultural models in New Zealand represent the necessity of considering a broader concept of the individual in considering their therapeutic needs. Models such as Te Whare Tapa Whā (Durie, 1994) address te taha whānau (family/ social health), te taha wairua (spiritual/ emotional health), te taha tinana (physical health) and te taha hinengaro (psychological health). These broad factors emphasise the importance of considering all of the parts of a person that interact in shaping who they are. Gordon (1989) points out that culture also plays a role in the emotional development of children. This is evident within his social constructionist perspective on development (Gordon, 1989). Many theorists assume that emotional

development and milestones are universal. However, Gordon (1989) comments on the importance of varied experiences and upbringings that also shape the milestones children achieve and understand emotionally. A child's experience within their culture allows them to make links between emotional concepts as they experience them, as opposed to at a certain chronological or developmental age. Although these developments may still occur around similar ages, culture inevitably impacts on a child's exposure to different situations based on differing cultural practices, economic resources and environments (Gordon, 1989).

Combined with emotional factors, cultural factors identify a strong and apparent need for therapeutic interventions to be holistic, to incorporate behaviour and emotions as well as the culture and family the child belongs to.

The Four Component Model

As identified there is a need to incorporate various determinants of challenging behaviour in interventions; especially to consider emotions. Around the time that research was increasingly reflecting the importance of emotions in intervention, Meyer and Evans (1989) proposed that a good intervention for remedying challenging behaviour needs to encompass four components. This model stood out for me as although research was occurring and advocating for emotional factors to be included in treatment, there was very little that actually encompassed emotion based intervention techniques within behavioural interventions.

The first three components of this model are derived from traditional applied behaviour analysis with an additional fourth component. The model posits that in order to change challenging behaviour, interventions must be aimed at addressing multiple levels of causality, seeking out and remedying all possible causes, and not just aimed at reducing the behaviour itself (Meyer & Evans, 1989).

Behaviour must be understood before it can be adequately and completely modified, and this is emphasised within the four component model (Evans, 1989; 1999; Meyer & Evans, 2006). The components of this model are outlined next, not in any particular order. First component of this model involves manipulating the stimulus conditions or the ecology in

which behaviour is more or less likely. The environment is therefore the first point of intervention and change in understanding and addressing challenging behaviour. Ecology or environmental change addresses the context in which a child develops and draws on the work of Bronfenbrenner identifying that this can occur at various levels of context (e.g. microsystem, macrosystem; Lynch & Cicchetti, 1998). McLaughlin and Carr's (2005) work on the importance of setting events is also relevant as this outlines further specific social factors, such as relationships, as providing the context for which behaviour occurs, and as such being a context which can be modified through intervention.

Secondly, the consequences of the behaviour need to be modified by identifying what reinforcers are currently in place and adapting/changing them as identified by contingency analysis. Thirdly, a more appropriate alternative to the current challenging behaviour needs to be taught (Evans, 1989; 2000, Harvey et al., 2009; Meyer & Evans, 1989). These alternatives are determined based on the needs of the child and the identified purpose and reinforcers of the current behaviour. The final component stands in contrast to traditional behavioural interventions in that it stipulates the need to regulate the motivational and emotional needs of a person that are compelling them to seek out certain consequences (Evans 1989, 2000; Meyer & Evans, 1989). In other words, the causal mechanisms of behaviour need to be understood and incorporated in treatment, including emotional causes, in order for the treatment to be beneficial in the long-term.

Challenging behaviours are described by this research as often having a communicative function driven by emotional needs. This behaviour is hypothesised to reflect some aspect of a child's needs not being met or recognised by others. Behaviours likely developed to express appropriate emotion, e.g. crying to show pain, have at some point adjusted to also express the inability to be understood (Evans & Meyer, 1989). Through changing environments and contingencies, teaching alternative appropriate behaviours, and encouraging emotional understanding and expression it is hypothesised that these inappropriate behaviours will reduce.

The four component model has identified strengths in terms of addressing the literature outlining the importance of both behavioural and emotional components in interventions for children with developmental disability and challenging behaviour (Meyer & Evans, 2006). However, the importance of parents and culture as highlighted in previous sections

would fit in as part of the environmental component but this is not outlined specifically by this model. For the purposes of this study, these factors will be understood and included as important factors of the environment of each child and their family as outlined by relevant research on ecological factors (Lynch & Cicchetti, 1998; McLaughlin & Carr, 2005).

Emotional knowledge literature advocates for the inclusion of concepts within behavioural intervention designs which reflect the crucial nature of such knowledge. In order to examine if this has occurred this literature is reviewed later in this chapter. Before this is possible however, an outline of challenging behaviour and developmental disabilities is necessary to describe the population for which these concepts are advocated for.

Challenging Behaviour: An Outline

This section outlines the nature of challenging behaviour, its varied definitions, classifications and prevalence. Challenging behaviour is a relatively new term and is defined in the following ways. It can be described as any behaviour that is identified to interfere with learning and development, is harmful to the child, harmful to another child or adult, or is a behaviour that puts a child at high risk for later social problems or school failure (Kaiser & Rasminksy, 2007). Denial of access to ordinary community facilities is also a component identified and used as a criterion to define this type of behaviour (Emerson, 1995). The behaviour must also be determined to be excessive, culturally abnormal, or socially inappropriate in order to be considered challenging (Kaiser & Rasminsky, 2007; Roberts, Mazzucchelli, Taylor, & Reid, 2003).

Behaviour can be viewed as challenging in a variety of ways and for a variety of reasons. For example, a challenging behaviour can be threatening, provocative and simulating all at once or it can comprise just one of these factors (Kaiser & Rasminksy, 2007; O'Regan, 2006). Examples of challenging behaviour include physical attacks on others, deliberate soiling, and deliberate mirroring of seizure-like activity, self-injurious behaviour, shouting, swearing, screaming, distractibility and hyperactivity (Imray, 2008). Although much of the research pertaining to challenging behaviour is carried out overseas, the only New Zealand prevalence study indicates that these behaviours are also evident here

(Church, 1996). It was found that 4.7% of children in Year 1 had noncompliant or antisocial behaviour, 6.7% in Year 4 and 6.5% in Year 7. Furthermore, 85% of those identified with these behavioural difficulties were boys (Church, 1996). These behaviours included moving around in an inappropriate manner, interrupting, ignoring, blaming others, failing to follow rules, failing to honour established commitments, failing to show appreciation, and failing to behave sympathetically towards others (Church, 1996). Consequences of such behaviour for a child may involve exclusion, seclusion, being situated in impoverished living conditions, being abused by carers and severe tissue damage as a result of self-injury (Allen, Lowe, Moore, & Brophy, 2007).

These diverse types of behaviour are also challenging in different ways for different people. The behaviour is challenging to the child who is put into a situation in which he or she is in danger of failing to learn or interact in appropriate ways in school, home and play environments. However, the behaviour is furthermore a challenge for those involved with the child, which is evident in Imray's (2008) explanation of challenging behaviour. Challenging behaviour is also defined as such because it creates a challenge to solve for those working with a child (Imray, 2008). The challenge is evident to the child's friends, family, teachers, classmates, support workers and countless others who come into contact with him/her, and can be immensely difficult and tiring. However, it is for the safety and well-being of the child involved that someone must attempt to meet the challenge of the child's behaviour (Kaiser & Rasminsky, 2007).

Developmental Appropriateness of Challenging Behaviour

Challenging behaviour has many definitions and forms, affects as many as 6.7% of children in New Zealand in any one year group (Church, 1996), and also impacts on others. However, challenging behaviour can also be developmentally appropriate and often expected early in life. Many children develop an understanding of the use of aggression and other such physical behaviours from a very young age. Aggression may be utilised by children as a means of controlling possessions and obtaining from those around them what they want. From the age of 30 months, these behaviours tend to reduce as children begin to explore and understand their feelings and emotions (Kaiser & Rasminsky, 2007). With the guidance of their family and others around them, young children gradually acquire other strategies that are socially accepted means of expressing

their needs and reaching their goals (Benedict, Horner, & Squires, 2007). However, it is also expected that such behaviours, including those that are physically aggressive, may continue to be used once in a while throughout life. Although developmentally appropriate at times, the recurrent use of challenging behaviour may remain evident in some children as a means of expression (Berotti & Durand, 1999).

Factors Associated with Challenging Behaviour

Challenging behaviour is widespread and at times developmentally appropriate. However, for those challenging behaviours which are pervasive and developmentally inappropriate, there are many factors that contribute to their development. Nature and nurture factors are inextricably entangled in the production of all aspects of human development (Kaiser & Rasminsky, 2007; O'Regan, 2006). The development of challenging behaviour is no different. Therefore, reasons or risk factors for the development of challenging behaviour are explained by two broad categories: biological risk factors and environmental risk factors. However, because of the entanglement of these factors, definition and explanation of challenging behaviour overlap.

Biological Risk Factors

Biological risk factors include inherited characteristics that can enhance the development of challenging behaviours. Genes interact with the child's environment, and this interplay works to establish the presence or absence of a characteristic detailed by the inherited gene (Berk, 2002). Children are also born with their own unique temperament, which encompasses their particular way of being and doing things. The environment then comes to interact with the child's temperament, as it did with their genes. Although these biological aspects are evident before the environmental interaction, they do not stand alone in shaping identity and behaviour. Pregnancy and birth complications can also enhance the risk of developing challenging behaviours. For example, the use of heroin throughout pregnancy can enhance the likelihood of a premature birth and low birth weight, which puts these children at risk for the development of problems such as attention and developmental difficulties. Malnutrition, both during pregnancy and as a young child, may also contribute to the development of challenging behaviours (Kaiser & Rasminsky, 2007). Iron deficiency often accompanies malnutrition and creates risk for

such developmental delays as shortened attention, irritability and cognitive impairment (Shonkoff & Marshall, 2000). Gender has been found to play a role in the development of one type of challenging behaviour: aggression, as boys are at greater risk for the development of this behaviour than girls (Berk, 2000; O'Regan, 2006). One study identified that boys are 12 times more likely to shout out or make a lot of noise than girls, and four to five times more likely to have learning or behavioural difficulties (O'Regan, 2006).

Environmental Risk Factors

Although biological factors play a role for many children in the development of their challenging behaviour, environmental factors and the interaction between the two also play a contributory role for many. Varied environmental factors can impact on a child's development and whether they develop challenging behaviour. Broadly, diverse family factors can put a child at risk for developing challenging behaviour/s (Kaiser & Rasminksy, 2007; O'Regan, 2006; Smith et al., 2003). Life circumstances such as lack of education, young pregnancy, parental mental illness, large family size and parental criminality or aggressive behaviour are all factors that can hinder a parent's own well-being and/or their ability to effectively parent their child. Poverty, can impact on a child's behavioural development, it can mean a lack of financial support for sufficient prenatal and postnatal care, as well as high levels of stress for parents, making it more difficult for them to attend to the needs of their child or children (O'Regan, 2006). Violence in society, viewed first hand, through participation in a peer group (Smith et al., 2003), the media, or within the family can also impact on a child. Children exposed to violence may subsequently be learning that violent behaviour is an accepted and sometimes frequent response to situations (Smith et al., 2003). Lack of time with family or supportive others can also impact on a child's development of challenging behaviour. Child care is a part of daily life for many children; however this is not a choice that they make themselves. Children who find that their schedule changes regularly can find this frustrating, or on the other hand this lack of structure may lead to an increase in their feelings of anxiety and timid behaviour. All of these factors have the potential to interact with biological factors and other associated environmental factors in the development of challenging behaviours (Kaiser & Rasminksy, 2007).

Protective Factors

The number of identified risk factors for the development of challenging behaviour may seem overwhelming. However, it is not inevitable that a child will develop challenging behaviour given the interplay of some of these risks in their lives. Resilient children can be described as extremely affectionate and responsive to those around them, despite their biological and environmental predisposition. Protective factors evident within a resilient child fall into three categories: factors within the individual, the family, and the community (Kaiser & Rasminksy, 2007; O'Regan, 2006).

Individual Resilience

There are specific factors that exist within a child that contribute to their resilience. Social competence, problem-solving skills, autonomy and self-esteem as well as a sense of purpose and future are all identified to contribute to resilience (Copley, 2006; O'Regan, 2006). In particular, secure early relationships, good communication skills, humour and the capacity to reflect (O'Regan, 2006), as well as, good health and social skills also contribute to individual resilience (Smith, et al., 2003). Some of these factors are likely to be evident in many children (Kaiser & Rasminksy, 2007).

Family Factors and their Contribution to Resilience

Families can often provide an environment which fosters the growth of resiliency in an individual. The most important protective factor to avoid the development of challenging behaviour is having someone who cares and is committed to the health and well-being of the child (O'Regan, 2006; Smith et al., 2003). This bond does not need to be with a parent or relation, but must be an open, loving and trustworthy relationship, involving another person who is available and easily accessible in a child's life (O'Regan, 2006; Smith et al., 2003). It is also useful if a family has high but realistic expectations for their child and helps them to strive to fulfil such expectations with their full support (Kaiser & Rasminksy, 2007).

Community Factors and their Contribution to Resilience

Support from outside of the family allows a child to become connected to their community and develop a broader sense of resilience. Schools can be a form of

community, and are often crucial in advancing social and emotional skills (Rogers, 2004). Schools with strong academic, sporting, social and music opportunities as well as a generally positive attitude may provide an environment that fosters this resilience (O'Regan, 2006). A teacher may be one of the most secure and stable people that a child interacts with and the child may see their teacher more regularly than family members or caregivers. Thus, the teacher has the important role of facilitating the supportive environment required in a class setting and ensuring that a child feels understood and important, promoting the development of resilience (Finger, 2004; Rogers, 2004; Smart, West, & Curtain, 2004).

Developmental Disability: An Outline

One source of challenging behaviour is that associated with developmental disability. These types of behaviours are often part of the syndrome or disability a child has. However, these specific behaviours are not the target of this study. It is the challenging behaviours, as identified above that are distinct from disability that is focussed on within this study.

The following information and its subsequent integration later in the chapter will identify and cement the links between developmental disability and challenging behaviour. This section begins with an outline of human development and is followed by theories of development.

Human Development

Before delving into the topic of developmental disability specifically, it is important to have an understanding of how development itself progresses.

Human development occurs as a person grows and changes as they age. Child development makes up a component of this process, spanning from conception to adolescence. Different theorists adhering to different developmental paradigms argue that there are varied important milestones and that the attainment of particular characteristics ensures appropriate development. Each of these views emphasise to varied extents the

roles of nature and nurture. These theories also vary between the view that development is continuous or discontinuous (Berk, 2002).

Continuous views of development identify that growth and change is constantly occurring as we age and interact with our environment (Berk, 2002). Behaviourism and social learning theory advocate that child development occurs through different forms of conditioning and learning. Development in these views is constructed through our experiences as we learn from ourselves and other people around us. Piaget's cognitive-developmental theory stipulates that children are active agents who construct knowledge as they experience and manipulate their world. Vygotsky's socio-cultural theory of development emphasises both culture and social interaction as important factors which shape development. Theories of information-processing identify that children gradually develop their vital cognitive and perceptual skills (Berk, 2002). In contrast, bio-theorists advocate the importance of biologically pre-determined factors in shaping a person's development (Berk, 2002; Smith et al., 2003).

The discontinuous view of child development emphasises stages through which a child must proceed to achieve age-appropriate growth. Freud's psychosexual theory is an early stage-based approach to child development, established in the 1930s. Freud believed that children experience five stages of development during which the three portions of personality, id, ego and superego develop. Erikson extended Freud's theories and began to emphasise that development must also be considered in relation to a child's culture (Berk, 2002).

Other views emphasise both continuous and discontinuous development. Ethology identifies that development is continual, however, there are critical periods during which distinct capacities develop (Berk, 2002). Development as identified by Bronfenbrenner in 1979 highlights the importance of an individual's micro system (their immediate context), mesosystem (their links between contexts and settings), exosystem (indirect influences which affect them) and macrosystem which involves the social policies and operations existing in society (Smith et al., 2003). Research shows that these varied theoretical views offer insight into the development of a child (Berk, 2002). Therefore, a person, their behaviour and identity develop through an interaction of nature and nurture, through

continuous and discontinuous processes, as well as the culture and the systems they are part of (Smith et al., 2003).

Developmental Disability

Although the developmental changes and processes described occur without difficulty for many children, this is not the case for every child. There are numerous points in time and sources of interruption to development that result in some children having disrupted development, generally known collectively as a developmental disability. Disruptions can occur in utero or throughout the stages of development from newborn to adulthood. Factors creating deviation from 'normal' development include chromosomal deletions or incomplete coding, genetic problems, in utero or delivery problems, toxins, and birth defects (Berk, 2002). Developmental disability is often also termed intellectual disability and/or mental retardation, dependent on the origin of the research. For the purposes of this research, the predominant term used will be 'developmental disability'.

Specific Developmental Disorders

The disabilities outlined here are only those relevant to the participants of this study, and provide information on what these disorders/syndromes/difficulties encompass. There are many other disabilities that would be relevant to this literature; however, these are not covered in this study. Although for these diagnoses there may be behavioural difficulties outlined as part of the disability, the purpose of this research was to address additional behavioural difficulties, beyond those of the disorder. Much of the literature focuses on the scientific and medical aspects of disabilities mostly for the individual; however, the impacts on the family are also important and are addressed later in this chapter.

Asperger's Syndrome

Asperger's Syndrome (AS) is a pervasive developmental disorder. The focus for diagnosis is on impairment in social interaction and restricted or repetitive behaviours (American Psychiatric Association, 2000). A core factor evident in children with Asperger's Syndrome is a lack of emotional skills and difficulty with social relationships. However, these children do not lack the ability to care for themselves and others, but rather, can be confused by emotions and have difficulty expressing their feelings around

such concepts (Attwood, 1998; Lovecky, 2004). People with Asperger's Syndrome are thought to exhibit a desire to interact with and understand others but their ability to do so is impaired. In one account of a five-year-old girl with Asperger's Syndrome, her therapist describes her as feeling lonely and isolated and being extremely angry but unable to communicate such feelings. She wanted help, but could not find the right way to ask for it, or the right person to ask, as she did not know who would or could understand (Nesic-Vuckovic, 2004).

Attention Deficit Hyperactivity Disorder

Attention Deficit Hyperactivity Disorder (ADHD) is a developmental executive function disorder. The core categories of behaviour in ADHD are hyperactivity or inattention and a diagnosis relies on at least six features of either being identified in two or more contexts (APA, 2000). The level and complexity of these symptoms can change over time, for example, at a young age, a child may be more hyperactive than inattentive, and at a later age this pattern may reverse (Lovecky, 2004). The Diagnostic and Statistical Manual – Fourth Edition – Text Revision (DSM-IV-TR) stipulates that ADHD can be diagnosed prior to age seven, and at least some symptoms must be present before this age, although in some cases it is diagnosed later in life (APA, 2000). One researcher suggests that deficits in emotional awareness and expression, especially around concepts of empathy and compassion, can also be evident in some children with ADHD. This may be because some children with ADHD require intense stimulation and are so driven to achieve this stimulation that they do not notice the needs of others (Lovecky, 2004).

Developmental Delay/Disability caused by Hypoglycaemia

Hypoglycaemia is caused by low blood sugar levels and is the limiting factor in diabetes mellitus (Cryer, 1999). When unmanaged, hypoglycaemia has the potential to produce brain damage through energy failure (Auer & Siesjo, 2004). Paediatricians may find it hard to determine if hypoglycaemia is evident in infants as symptoms are described as nonspecific (e.g., lethargy, irritability, feeding difficulties) making it unclear if a complete assessment to rule this out is required (Lteif & Schwenk, 2005). However, in severe cases, hypoglycaemia in newborn babies can cause coma and convulsions (Neligan, Robson, & Watson, 1968). In older infants, children and adults, more specific symptoms

are evident including sweating, anxiety, tachycardia, seizure, coma and weakness (Lteif & Schwenk, 2005).

Angelman Syndrome

Angelman Syndrome is a neurodevelopmental disorder that results from incomplete imprinting of chromosome 15 and is therefore similar to Prader-Willi Syndrome. Although both sharing the cytogenetic deletion of 15q11q13 (Clayton-Smith & Laan, 2003; Knoll et al., 1989), the difference between the two syndromes is based on maternal inheritance for Angelman Syndrome, and paternal inheritance for Prader-Willi Syndrome (Knoll et al., 1989). Clayton-Smith and Laan (2003) also identify more specifically that it is the UEB3A gene within this chromosome that has deletions or small mutations creating the syndrome. Features of this syndrome include ataxic-like movements, and frequent, unprovoked and prolonged bouts of laughter (Clayton-Smith & Laan, 2003; Magenis et al., 1987). More specifically, Angelman Syndrome is characterised by a generally happy disposition, a seizure disorder, subtle facial features and sometimes jerky behavioural movements (Clayton-Smith & Laan, 2003).

Smith Magenis Syndrome

Smith Magenis Syndrome is a neurogenetic disorder that is usually accompanied by intellectual disability and is characterised by behavioural abnormalities, including self-injurious behaviours, sleep disturbance, and distinct craniofacial and skeletal anomalies (Girirajan, Elsas, Devriendt & Elsea, 2005; Smith, Dykens, & Greenberg, 1998). Other features include a hoarse deep voice, speech delay and signs of peripheral neuropathy (Smith et al., 1998). The facial features are distinct and include a broad square face shape with wide full lips and eyes that appear to be close and deep (Allanson, Greenberg, & Smith, 1999). Incomplete chromosomal encoding is the cause of this syndrome, specifically deletion on chromosome 17p11.2 (Girirajan et al., 2005; Smith, Dykens & Greenberg, 1998). This syndrome is estimated to occur in 1 in 25 000 births (Girirajan et al., 2005).

Emotional Deficits in Developmental Disabilities

As identified when discussing the emotional knowledge literature, emotional and behavioural deficits beyond the scope of a diagnosis may be apparent. Although emotional deficits are criteria for disorders such as Asperger's Syndrome, for the others mentioned the emotional difficulties may not be as clear. These difficulties, which may be expressed in challenging behaviour (Moyes, 2002; Repp & Karsh, 1994; Stephenson, & Dowrick, 2005), may occur because of a lack of cognitive development allowing for understanding of emotion (Blair & Diamond, 2008). The link between cognitive development and emotional capacities is evidenced by the necessity of cognitive abilities to self-regulate (Blair & Diamond, 2008). However, it may also be due to lack of opportunities for appropriate socialisation and understanding of interactions (Harter & Whitesell, 1989; Saarni, 1989). Thus, the behavioural difficulties may also represent these deficits, with a child struggling to communicate or understand others, not only specific aspects of the disabilities. Further, with developmental disability, language difficulties may occur. Many techniques suggest the use of verbal coaching to enhance emotional abilities (Denham & Kochanoff, 2002; Wareham & Salmon, 2006), and if communication of needs is primarily understood by the use of words, then a child's management of affective expression may also be hindered by this.

Family Impact

As identified when outlining the importance of family in intervention, it is also important to note the impact that having a child with a developmental disability has on the family as well as the individual. The previous descriptions have focussed specifically on the characteristics and impact on the individual while the developmental disability and specific family impacts are addressed in each case chapter (Chapters Three to Six). However, it is also worthwhile to describe here some of the general impacts these difficulties/disabilities may have on the family.

For families, the diagnosis of a developmental disability for one of their children can result in an array of changes impacting on both parents and siblings, and at times extended families. For some, a child with developmental disability may create an emotional crisis. For others, although often viewed as unfortunate and/or difficult, it can also be seen as an opportunity for growth within the family. These emotional response

differences are often based upon how a family appraises the situation. If tension arises, this can place considerable stress on the marital relationship as well as family dynamics overall (Trute & Hiebert-Murphy, 2002). Specifically, one study identified that families with a child who has a developmental disability had lower rates of employment, lower rates of social participation and larger family size. However, there are also areas where the impact of a developmentally disabled child may not affect family functioning; marital status, physical health and psychological well-being. If the child had a significant psychological problem, families were more likely to experience psychological difficulties and physical symptoms (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2000). Families also provide crucial support for children, their importance and involvement in therapy is further emphasised as this chapter progresses.

As identified developmental disabilities have broad impacts on the individual themselves and their families, and there are a multitude of factors which contribute to the onset and maintenance of such difficulties which will now be explored.

Factors Associated with Developmental Disability

Factors that influence the establishment and growth of developmental disability are similar in many ways to those of challenging behaviour in that both environmental and biological risk factors can play a contributing role.

Factors that influence developmental disability

There are different factors which interact and contribute to the onset of developmental disability. The occurrence of one risk factor also increases the threat for the occurrence of another, in turn enhancing the overall risk. Some children are born with birth defects that cause developmental disability. One study found that in 9,142 children born with birth defects, 657 (7.2%) also had serious developmental disabilities compared to 0.9% of children without a birth defect (Decouflé, Boyle, Paulozzi, & Lary, 2001). For others, disability onset is later in life through environmental experiences (Aber, Jones, & Cohen, 2000). Poverty is a highly researched factor, which affects child development. Bronfenbrenner's developmental framework can be utilised to identify mechanisms

through which poverty acts as a risk factor that hinders development in very young children (Aber, Jones, & Cohen, 2000).

Poverty has varied potential impacts on cognitive, emotional and social development. For example, parenting behaviours can be negatively affected by the stress of poverty, which can lead to a lack of time spent with children and a child's subsequent inability to develop appropriate thinking patterns, social skills and attachment (Aber, Jones, & Cohen, 2000; Lyons-Ruth, Alpern, & Repacholi, 1993; Lyons-Ruth, Easterbrooks, & Cibelli, 1997). Poverty and lifestyle factors have also been found to be correlated with brain development. Factors such as lower socio-economic status, low occupational status and crowded neighbourhoods are seen to be associated with neural tube defects (Wasserman, Shaw, Selvin, Gould, & Syme, 1998). The impacts of negative experiences, such as poverty, on an infant have also been identified to impact cortisol levels in the brain (Aber, Jones, & Cohen, 2000; Watson, Kirby, Kelleher, & Bradley, 1996). Researchers have found higher cortisol levels to be related to poor attention and poor self control (Gunnar, Tout, deHann, Pierce, & Stansbury, 1997) and the use of avoidant or disorganised attachment strategies in infancy and toddlerhood (Dawson, Klingerm Pangiotides, Spieker, & Frey, 1992; Nachmias, Gunnar, Mangelsdorf, & Parritz, 1996; Spangler & Grossman, 1993). These higher cortisol levels can be due to environmental stressors such as low home stimulation (Watson et al., 1996), as well as, punishment, neglect (McLoyd, 1998; Pianta & Egeland, 1990) and violence in the home and community environment (Aber, 1994; Coulton, Korbin, Su, & Chow, 1995). Therefore, poverty and its associated factors, which include low socioeconomic status, impact in various ways on the developing brain (Aber, Jones, & Cohen, 2000).

Less economically developed countries have higher rates of developmental disabilities with approximately 5 per 1000 children affected. In these countries, not unlike developed countries, risk factors include specific genetic disorders, a higher frequency of births to older mothers, consanguinity, specific micronutrient deficiencies, infections, trauma and toxic exposures (Durkin, 2002). One study indicated the importance of varied vitamins and nutrients in development, both cognitively and physically (Wasantwisut, 1997). Iron and iodine in particular have implications for growth and development in infants (Wasantwisut, 1997). These findings appear to provide more evidence for the increasingly researched factors of poverty and socioeconomic status (and their related

factors, such as poor nutrition and lack of medical care) as causal factors in developmental disabilities.

Links between Challenging Behaviour and Developmental Disability

The presence of challenging behaviour, evident in various forms, in children who have a developmental or intellectual disability is apparent throughout the literature (Adams & Allen, 2001; Allen et al., 2007; Einfeld & Tonge, 1996; Emerson, 2003; Goodman & Linn, 2003; Hastings, 2002; Kopp, 1990; McWilliam & Bailey, 1995; Mundy & Kasari, 1990; Quine, 1986; Roberts, Mazzucchelli, Studman, & Sanders, 2006; Roberts, Mazzucchelli, Taylor, & Reid, 2003; Tomporowski & Hager, 1992; Van Nieuwenhuijzen, De Castro, Wijnroks, Vermeer, & Matthys, 2004). For example, Allen et al. (2007) identified that challenging behaviours are evident in 10-17% of people with intellectual disabilities. McCarthy (2007) also acknowledged the heightened prevalence of behavioural disorders in those with intellectual and developmental disability, which appears to be more evident in children than adults. For example, Einfeld and Tonge (1996) found that challenging behaviours of an emotional or behavioural nature were evident in four out of ten (40%) children with intellectual disabilities. Quine (1986) identified that 64% of children aged 3-5 with developmental disability exhibit challenging behaviour. Other studies have found that 45 and 50% of children with developmental disabilities demonstrate challenging behaviour or a behavioural disorder (Corbett, 1985; Rutter, Tizard, Yule, Graham, & Whitmore, 1976).

Research has also identified the variety of challenging behaviours in children with developmental disabilities. In a sample of children with intellectual disabilities and challenging behaviour, 75% exhibited aggressive behaviours that were rated as moderate or severe. Threats to the safety of the child or someone else were identified in 87% of families as the most serious behaviour they had dealt with (Allen, Hawkins, & Cooper, 2006). A child's challenging behaviours can also be multiple and varied based on their situation. For example, Pithouse and Lowe (2008) found an average of 21 challenging behaviours for children. Piling, McGill, and Cooper (2007) reported that on average, children with intellectual disabilities attending residential day schools, displayed 10.8 various types of challenging behaviours (Piling, McGill, & Cooper, 2007). Challenging

behaviours such as self-injury and stereotyped behaviour are the two most commonly researched behaviours evident in those with developmental disabilities (Bodfish, 2007).

Theorists offer varied explanations for this significant correlation between developmental disability and challenging behaviour. For children with behavioural, social and emotional difficulties, even small things easily tolerated by the majority of children can provoke anxiety and result in the production of inappropriate outbursts or behaviours (Howarth, 2008). Thus having a disability or existing difficulty of a social, emotional or behavioural kind may work to lower tolerance levels and enhance inappropriate behavioural responses (Roberts, Mazzucchelli, Taylor, & Reid, 2003). Imray (2008) and Gallico, Burns, and Grob (1988) offer an explanation for this correlation in proposing that a lot of people with learning difficulties have problems expressing their needs. It is hard enough for a child with a learning disability and communication issues to address their basic needs such as asking for food when hungry, let alone expressing and understanding their emotional state appropriately. Frustration begins to build up, and a child begins to feel increasingly isolated, as if they are not achieving and do not belong (Gallico, Burns, & Grob, 1988). Imray (2008) points out that it is likely that the more severe the communication impairment or inability to get needs met, the greater the likelihood for the development of challenging behaviour. Learning difficulties may also reduce self-esteem and limit reflection on such things as emotional states and behaviour. Because of this, there is potential for less understanding and tolerance for others' behaviours and emotions (Imray, 2008).

An emotional perspective on the correlation between challenging behaviour and developmental disability is also described in the literature. For example, some authors note a frequent experience of failure and rejection, which children use in a repetitive, maladaptive sequence to problem solve (Zigler, 1999). One study found that 40% of children with developmental disabilities engaged in a form of destructive challenging behaviour at least once every day (Dunlap, Robbins, & Darrow, 1994). Challenging behaviour in children with developmental disabilities has been found to serve two social purposes: social attention-seeking and social avoidance (Taylor & Carr, 1992). These children may be constantly put in situations in which their frustration at being given tasks which are not suited to their developmental level becomes apparent through their behaviour. In fact these 'challenging' behaviours may actually be viewed as adaptive

responses to a world that is difficult to adapt too (Goodman & Linn, 2003). Conditions of poverty also appear to be related to the onset of both developmental disability and challenging behaviours through exposure to undesirable environmental conditions. Exposure to the metal lead in the environment and subsequent elevated blood lead levels has an impact on the development of children. This impact is evident in brain (Boivin & Giordani, 1995) and, cognitive development (Tong, 1998) as well as lower emotional regulation, destructive behaviours and withdrawn tendencies (Mendelsohn, Dreyer, Fierman, Rosen, Legano et al., 1998; Wasserman, Staghezza-Jaramillo, Shrout, Popovac, & Graziano, 1998).

Although research has clearly identified many links between challenging behaviour and developmental disability, this does not imply that if a child has one difficulty they also have the other, as often this is not the case. Also these correlations do not necessarily suggest that when a child does have these difficulties (developmental disability and challenging behaviour), research and treatment for this population integrates both difficulties. Traditionally, the disorder-specific behaviour or additional challenging behaviours have been focussed upon neglecting other components of a child's presentation, such as emotional factors underlying behaviour. Therefore, a review of traditional approaches and the progression toward new theory solidifies the need for the current study.

Conventional methods for Intervention

This section highlights the treatment methods which have been conventionally used for working with children who have developmental disability and challenging behaviour, although, the majority of the available literature is based on one or the other with little overt integration in treatment. Despite this, both when working with children with developmental disability and challenging behaviour, the focus in traditional behaviour approaches is changing the behaviour.

Early Intervention

Before describing the therapeutic interventions used, there are a few key principles identified by previous research considered to be crucial in any intervention. The first of

these is early intervention; which involves intervening prior to the development of significant difficulties where possible. Research shows strong support for early intervention in treating developmental disabilities (Carr et al., 1999; Guralnick, 2007; Harris, 2007; National Research Council and Institute of Medicine, 2000) and challenging behaviour (Benedict, Horner, & Squires, 2007; McIntosh, Horner, Chard, Boland, & Good III, 2006). Early intervention is also useful when both developmental disability and behavioural problems co-occur (Emerson, 1995; Roberts, Mazzucchelli, Taylor, & Reid, 2003). Benedict, Horner and Squires (2007) specifically emphasise the importance of working with children at a young age to identify risk factors for challenging behaviour. Research undertaken by O'Regan (2006) in 2001 found that many parents appear to be most interested and willing to be involved with their children and their education whilst the child is as young as possible, which also provides support for early interventions. Some children who have pervasive developmental disorders have been able to enter a regular school programme from age five after treatment in their preschool years. However, through behavioural interventions, older adolescents have also been able to exhibit marked improvement (Harris, 2007).

Inclusion

Inclusion is the second of the key components emphasised in the literature for therapeutic interventions with these children. One of the specific core components in treatment models for developmental disabilities is promoting inclusion, which involves working with a child in their natural environments to facilitate continued involvement in their context (Guralnick, 2007; Meyer & Bevan-Brown, 2005). This has led to increased service provision in natural environments, involving both families and the community. Inclusion focuses on helping children to feel as though they belong not only with other children who have developmental disabilities, but also with other children without disability. The developmental inclusive framework is also structured around the importance of having the family at the centre of any form of treatment (Guralnick, 2007).

Necessity of Widespread Involvement in Treatment

The necessity of widespread involvement in treatment is another key factor that has been long identified as useful in therapeutic interventions. The most beneficial approach for a child is a multidisciplinary team with multiple components and supportive factors (Meyer

& Evans, 2006). Parents, family, schools, community and health professionals have varied roles to play in working with children who have developmental disabilities and challenging behaviour (Evans, Meyer & Buckley, 2008). Each person involved with the child has the potential to develop uniquely supportive and important relationships that are essential for progress. These relationships may in themselves be useful in minimising challenging behaviour through their effects on more positive affect regulation, particularly if a child is previously lacking a secure attachment relationship. Children without secure attachment relationships are more likely to develop maladaptive ways for regulating their emotions and stress (Sterkenberg, Janssen, & Schnuegel, 2008).

Parents have a great influence on their children. Therefore, parents and families should be involved, where possible and safe, in the therapy and treatment provided for their child (O'Regan, 2006; Sterkenberg, Janssen, & Schnuegel, 2008). Families are required to adjust in many ways to accommodate a child with disability, often causing significant strain and stress on the family (Roberts, Mazzucchelli, Taylor, & Reid, 2003; Woolfson, 2004). Despite this, many parents and families are able to adequately adjust to the requirements of their child and be useful and supportive in therapy. A collaborative relationship involving health workers, teachers, and parents is shown to have the greatest positive effect on helping children with their difficulties (O'Regan, 2006; Webster-Stratton, 1999). Parents and families are also responsible for ensuring that treatment principles are maintained at home throughout and after therapy, which is an integral part of many treatment programmes (Harris, 2007; Olson, Platt, & Dieker, 2008). These factors highlight the importance of early intervention for children with developmental disabilities and challenging behaviour that involve both the child and their family.

Pre-school, school and the wider community should also be involved in therapeutic interventions where appropriate, possible and safe. Teachers can sometimes connect with students in a spontaneous or planned manner that allows them to develop a relationship with the child. This reciprocal and respectful relationship has been found to be essential in working with children (Finger, 2004; Smart, West, & Curtain, 2004). The modelling of positive relationships, through the teacher and peers, can also help children to make appropriate and respectful relationships with their peers, and peers can also become involved in behaviour management (Evans, Meyer, & Buckley, 2008; Price, 2004) especially if peers are accepting of behavioural difficulties of others from the outset

(Evans, Meyer, & Buckley, 2008). When teachers are working to implement behaviour management plans, involvement and collaboration with the parents still remains important and often crucial (Finger, 2004; Meyer & Bevan-Brown, 2005; Rogers, 2003). The community provides a wider support network for a child and an opportunity to belong to something larger than their family network. Communities involve people of varied ages including a child's peers from whom they can learn, and have rules, and roles and inclusion in these areas can also foster the development of a more secure identity (O'Regan, 2006).

Behavioural Methods and Models

The traditional models used with children who have developmental disability and/or challenging behaviour are behavioural methods of treatment (Roberts, Mazzucchelli, Taylor, & Reid, 2003), with a focus on functional assessment (Bodfish, 2007) which have been researched to show various success rates (Bodfish, 2007; Harvey, Boer, Meyers & Evans, 2009; Roberts, Mazzuchelli, Taylor, & Reid, 2003). There are many specific methods within this treatment paradigm to both prevent and eliminate challenging behaviour. These methods include operant and classical conditioning, modelling, fading, shaping, punishment, positive reinforcement, tokens and charts, and extinction which are all utilised to eliminate inappropriate behaviours and/or teach appropriate skills (Martin & Pear, 2003).

Functional Assessment and Positive Behavior support

Functional assessment is an assessment process and positive behavior support is a method of behavioural intervention utilised for managing challenging behaviour in children who have developmental disabilities. Both challenging behaviours and developmental disabilities have varied causal influences, and functional assessment allows for these behavioural variables to be identified and incorporated in treatment. Positive behavior support involves all children with intervention beginning at a school-wide level whilst also focussing on children with specific behavioural difficulties.

A functional assessment focuses on determining the functions of behaviour. Developed in the behavioural paradigm, an A-B-C analysis can help to distinguish the function of behaviour by identifying its antecedents and consequences (Berotti & Durand, 1999;

Morris & Hawkins, 1999). In this method of identifying behavioural functions, A stands for antecedents and involves anything that happens immediately prior to the behaviour. B is the behaviour itself, which needs to be outlined clearly and concisely. C outlines consequences, that is, what happens after the child acts in a certain way (Copley, 2006; Kaiser & Rasminsky, 2007; Myles, 2005). Data to complete a functional assessment is not based on observation alone and also involves the collection of collaborative data from sources such as family members, teachers and school records. There are three possible functions posited by functional assessment to be causing challenging behaviour: the child gets something, the child avoids or escapes from something or the child changes the level of stimulation. Because of these functions undoubtedly, challenging behaviour can be an important tool for gaining what one requires. The pay-offs are often quick and enjoyable, such as increased attention (Berotti & Durand, 1999; Imray, 2008). It is important to remember that although the function of the challenging behaviour may fit comfortably into one of these categories, the individual reasons that make up each category are numerous and varied (Berotti & Durand, 1999). It must not be assumed that challenging behaviour always serves the same purpose between children or even within the same child. In addition to this, in this research, the functions of behaviour are extended to consider the crucial importance of emotions in behaviour.

Originally developed within the field of developmental disabilities, positive behavior support incorporates a more ecological approach to managing challenging behaviour (Carr et al., 2002). It encompasses lifestyle issues and has less focus on the specific problem behaviour, moving away from pathology-based interventions where focus is solely on the individual. The parent or caregiver has a primary role in implementing the treatment which is provided in a naturalistic manner. The model of positive behavior support stresses the importance of multi-component interventions combining skills, environmental changes, and modification of consequences (Keen & Knox, 2004). The context and environment is considered to be the primary level of intervention. The importance of providing an environment that focuses on positive relationships is emphasised for all children regardless of whether they have a developmental disability and exhibit challenging behaviour. This is seen to be an efficient way of reducing problem behaviour in schools (McIntosh et al., 2006; Scott, 2001). The secondary level of intervention involves working with children in small groups who are exhibiting some problems with behaviour or social skills. The tertiary level involves individualised

interventions for children who are exhibiting challenging behaviours (Benedict, Horner, & Squires, 2007; Hagan-Burke et al., 2005). This behaviour is reduced and maintained within the environment of the child and the family system, emphasising working in conjunction with families (Bernheimer, Gallimore, & Weisner, 1990; Fox, Vaughn, Dunlap, & Bucy, 1997; Lucyshyn, Albin, & Nixon, 1997; Vaughn, Dunlap, Fox, Clarke & Bucy, 1997). Many of these researched techniques are used in schools to manage challenging behaviour. Despite these useful advances in behavioural approaches, of which I utilise many facets in this research, this model still does not advocate or incorporate the fundamental importance of emotions as both antecedents to and functions of behaviour.

Specific Behavioural Intervention Techniques

Components or techniques of established behavioural frameworks are used to manage challenging behaviours in children with social, emotional, developmental and behavioural difficulties. In managing challenging behaviour, an adult can identify what is appropriate, and model the behaviour to the child (Blance 2004; Rogers, 2003). For example, the classroom teacher may be seen as a role model from whom children can learn appropriate behaviours and patterns of interaction. The teacher can utilise positive, reinforcing strategies so that the child can learn to make better choices (Blance, 2004; Repp & Karsh, 1994; Webster-Stratton, 1999). Positive reinforcers have been found to be particularly useful for children with developmental disabilities and tantrum behaviours in school settings (Repp & Karsh, 1994). Reinforcers and rewards are most effective if they are particularly meaningful to the child, emphasising how it is important to have a relationship with the child and to understand what is important to them (Moyes, 2002). Picture cards or cues can also be used to avoid verbally interrupting the class and become reminders for the child or class of what they are meant to be doing (Miller, 2004; Rogers, 2003; Webster-Stratton, 1999). The cues are important for non-verbal children as well, and can be used as a means of communication that does not put pressure on the child to try to explain things in a way they cannot (Bogdashina, 2005).

Consequences and rules as therapeutic methods are most useful when established in conjunction with the child (Moyes, 2002). The technique of ignoring a child is also useful with some children. Serious behavioural problems should not be ignored, but that

strategic ignoring is appropriate for some minor misbehaviour. However, attention should always be given to the child as soon as appropriate behaviour has resumed, as a means of reinforcing positive alternatives (Webster-Stratton, 1999). Brown et al., (2008) outlines the shift in perceptions of those practising from both ABA (applied behaviour analysis) and PBS (positive behaviour support) orientations away from decelerative consequence-based behavioural procedures (Linscheid et al., 1990). Punishment based techniques such as electric shock and physical punishment (Larzelere & Kuhn, 2005), were identified as being increasingly less used, and in contrast, the use of redirection and extinction used by 100% of those involved in this study (Brown et al., 2008). This was, for varied percentages amongst each group, identified to be because of ethical reasons, new research advocating better alternatives and perceived ineffectiveness of strategies. Overall, both groups advocate the importance of ethics and empirical research in shaping practice when targeting problem behaviour (Brown et al., 2008; LaVigna & Donnellan 1986).

Examining Recent Positive Behavioural Designs

Much of the early success using basic operant conditioning principles for reducing challenging behaviour came from single-case studies in which some sort of punishment contingency was imposed (Linscheid et al., 1990). These contingencies vary from relatively benign interventions, such as time out and overcorrection (Adams & Kelley, 1992), to much more aversive stimuli being used as the negative contingency (Larzelere & Kuhn, 2005). These included tabasco sauce in the mouth, slapping, electric shock with cattle prods, and electric shock with an automated device known as SIBIS (Self-injurious behaviour inhibiting system; Linscheid et al., 1990). While it was clear the use of aversive contingencies could be effective in controlling serious challenging behaviour such as aggression and self-injury, criticisms of the approach soon emerged, both from an ethical and from a practical stand-point (LaVigna & Donnellan 1986; Brown et al., 2008).

There were also a variety of concerns expressed by advocacy organisations, especially what was then known as The Association for People with Severe Handicaps (TASH). TASH, started in 1974, and developed a policy statement advocating the immediate cessation of all use of punitive interventions, or at least those based on highly aversive stimuli. Following this, various clinical researchers began to demonstrate that serious challenging behaviour could be addressed using positive intervention techniques (e.g.

Carr et al., 2002; Evans, Scotti, & Hawkins, 1999; Meyer & Evans, 2006; Harvey et al., 2009).

Very soon there was a widespread move within the field to eliminate punishment procedures and to focus on positive interventions. This move meant some separation from the traditional ABA approaches, even academic debates regarding the nature of scientific evidence. As identified, the key characteristics of the PBS movement involved a focus on addressing behavioural difficulties ecologically (Carr et al., 2002). This approach highlights the importance of challenging and changing contingencies and promoting alternative behaviours (Keen & Knox, 2004).

While PBS is now widely regarded as the appropriate strategy for managing challenging behaviour (Evans, Scotti, & Hawkins, 1999; Meyer & Evans, 2006; Harvey et al., 2009), there remain some limitations to this approach. In particular, Evans and Meyer (1989) questioned whether PBS's focus on function of the challenging behaviour provided a sufficient understanding of the child's emotional needs. The arguments were relatively simple: it might be established that the child's negative behaviour had the function of obtaining social attention. The reasoning was then that the child should be taught a more appropriate way of obtaining social attention, such as a communication skill. However it remains unclear that this satisfies the child's needs for love, acceptance, physical contact, emotional warmth, security, or any of the other features of typical children's emotional development. Perhaps interventions, Meyer and others argued, needed to consider the child's emotional and motivational needs, such as those outlined by Reiss (2000; Meyer & Evans, 2006).

Has this perspective been incorporated in positive behavioural designs as a general approach? To investigate this issue, recent articles within the positive behavioural tradition (and published in the Journal of Positive Behavior Intervention) were randomly selected and reviewed in order to ascertain the degree to which emotional development issues are specifically featured in the method or reported in the results (see Table 1 below).

Table 1. Positive behavioural interventions and emotion-based intervention techniques

Author, Design, N	Emotions addressed in intervention (interventions used)	Emotions (emotional needs) defined or communicative function specified.
Schneider & Goldstein (2010), Multiple-baseline case study, n = 3	Social stories (appropriate behaviours in social situations), visual schedule boards. **No specific emotion-based interventions mentioned.**	*Information not provided.*
Adolphson, Hawken, & Carroll (2010), AB experimental and survey design, N = 1049	Behavioural contracts, redirection/ prompting, assisting with on-track work completion. **No specific emotion-based interventions mentioned.**	*Information not provided.*
Simonsen, Britton, & Young (2010), Single-school case study, N = 53	Token economies (rewards systems), teaching social skills (through modelling, picture cues and board games – not described in detail), group skills sessions, problem solving skills, individual behavioural plans (details not disclosed). **No specific emotion-based interventions mentioned.**	*Information not provided.*
Kleeberger & Mirenda (2010), multiple baseline, case study, n = 1 (family)	Video modelling. Prompting/ fading and social reinforcement. **No specific emotion-based interventions mentioned.**	*Information not provided.*
Binnendyk & Lucysyn, (2009), case study, n = 1 (family)	Parental implementation of a hierarchy of successful eating steps. Included stimulus fading, use of contingent praise, and escape extinction procedures. **No specific emotion-based interventions mentioned.**	**Alluded too** (e.g. food refusal included crying or protesting and function of behaviour as child engaging in challenging behaviour to avoid situation).
Carlson, Luiselli, Slyman & Markowski (2008), multiple-baseline, case study, n = 2	Choice-making – opportunities provided for appropriate clothe changing at set intervals. Instructions to stop inappropriate behaviour. **No specific emotion-based interventions mentioned.**	**Outlined communication as a function of behaviour** (e.g. to gain new items).

Butler & Luiselli (2007), ABAB reversal design, case study, n = 1	Verbal direction, modelling, physical guidance. *No specific emotion-based interventions mentioned.*	**Outlined communication as a function of behaviour** (e.g. to escape demands/ situation).
Lucyshyn, Albin, Horner, Mann, Mann & Wadsworth (2007), Longitudinal, single-case, multiple-baseline experimental design, n = 1 (family)	Parent training. *No specific emotion-based interventions mentioned.*	**Outlined communication as a function of behaviour** (e.g. attention-seeking).

These studies illustrate that although positive interventions are developing and are beginning to address the communicative function of behaviour the emotional needs underlying these have not yet begun to be addressed specifically. Even when functional analyses were undertaken the emotional needs related to any of the disruptive behaviours indentified were either not identified or reported by the researchers.

Summary

Following from behavioural approaches and a long-held dominance in the field, the approach to working with children who have developmental disabilities and/or challenging behaviour has begun to change (Evans, Meyer & Buckley, 2008). There are, as identified, newly emerging holistic approaches which address functions (emotions/motivations, why does the child want attention? e.g., jealousy, hunger, pain) that underlie the overt and often focussed upon function of the behaviour itself (e.g., attention).

As late as the 1970s, the principles of behaviourism dominated the practice of psychology. Influential behaviourists working with children who have developmental disabilities and behavioural difficulties, such as Lovaas (1987), utilised applied behaviour analysis techniques. At this time, it was thought that one could only 'observe' and measure behaviour, and therefore, behaviour was the focus of study. However, the contribution of studying the environment with a focus on behaviour is as useful to this day as it was when the behaviourists focussed on it many years ago. Alongside this, a small but growing body of literature is starting to demonstrate the importance of incorporating emotional elements into intervention for challenging behaviour.

Although these researched approaches are useful in many respects, and groups within behavioural approaches are changing their views in-line with new research, they are not without their deficits (Brown et al., 2008; Evans, Meyer & Buckley, 2008). Emotions and their inextricably intertwined interplay with behaviour are neglected in traditional behavioural interventions (Brown et al., 2008). Without addressing all factors that an individual presents with (developmental disability and challenging behaviour), and the factors which are evident in creating and maintaining these behaviours (emotions), challenging behaviour cannot be expected to be corrected entirely through traditional behavioural programmes. In circumstances where it has been successful in reducing behaviour, it may be likely that a replacement behaviour driven by the same underlying emotions would be developed (Keen & Knox, 2004).

Research examples identify some success and efficacy in the use of these designs, however, the consideration of other developmentally appropriate and emotionally-based factors are becoming increasingly researched beyond the dominant behavioural paradigm. Research identifies that treatments based on principles of behaviour modification are effective in reducing challenging behaviour in individuals who have an intellectual disability (Bodfish, 2007; Chambless et al., 1996; Evans, Meyer & Buckley, 2008; Roberts, Mazzucchelli, Taylor, & Reid, 2003). However, some children with developmental disabilities may require additional or unique treatment components tailored to suit their developmental level of functioning (Evans, Meyer & Buckley, 2008; Imray, 2008; Myles, 2005; Reiss & Havercamp, 1997). For example, if a child is non-verbal, other methods of communication may need to be explored in order to implement a useful therapeutic intervention (Gerenser & Forman, 2007; Myles, 2005). Similarly, awareness of the communicative intent of many challenging behaviours in children with intellectual and developmental disabilities should also influence treatment options (Keen & Knox, 2004). For example, this is how the current study is advancing knowledge by attempting to address emotional and/or communicative functions of behaviours not primarily addressed in behavioural models.

It is also important to recognise that, for some children exhibiting both a developmental disability and challenging behaviour, complete cessation of inappropriate and/or challenging behaviour may be extremely difficult. For some children it may be beyond their abilities to function independently and be aware of their behaviour (Imray, 2008). In

these cases, it is not acceptable or ethical to try and teach behavioural treatment techniques that serve to completely eliminate behaviour and, in some cases, behavioural treatments may not be appropriate at all. Therefore, there is a need to explore and understand the function of the behaviour and what purpose it is serving for the child (Berotti & Durand, 1999; Evans, Meyer & Buckley, 2008; Morris & Hawkins, 1999) and to consider other treatment options which address different factors of the challenging behaviour in this population. Whilst this critique is necessary and valid in terms of addressing the need for the current research it is also important to be mindful of the fact that this research stems from behavioural theory and as such still consider behavioural theory to be crucially important in both research and practise.

This introductory chapter has broadly outlined the key topics of emotional knowledge and needs, challenging behaviour, developmental disability, traditional treatment and theoretical models as well as the importance of new approaches to treatment. Although behavioural approaches for working with children who have developmental disability and challenging behaviour has merits, more recent arguments have arisen addressing the need to include and consider emotional aspects of behavioural problems and to address them more explicitly. The four component model as the model of choice for this thesis, addresses this need, and was outlined in detail. The importance of utilising a holistic approach to working with children who have both developmental disability and challenging behaviour/s was emphasised, evident also in the importance of respecting and including culture in practise. This growing literature leads to the need for the current study utilising this model.

CHAPTER TWO: METHODOLOGY AND METHOD

Methodological Framework

Crotty (1996) recommends any research or thesis must clearly outline the epistemology, theoretical framework, methodology and methods used to carry out the study. This section will address the first three of these requirements, with the specific methods outlined throughout this chapter. The epistemology, or guiding principles, for this research have been presented in the literature review, addressing the importance of utilizing emotional and behavioural techniques for working with challenging behaviour. In its essence, this viewpoint is one of social learning theory, in that behaviour develops and is shaped by the environment, contingencies, lack of reinforced alternate behaviours and lack of communicative alternatives/ emotional skills and understanding.

This study employed a case study methodology to address the third research objective, which is to utilise the four component model with a focus on enhancing emotion based skills and understanding to reduce challenging behaviour. The model addresses the need, identified by the research, of employing a multi-component intervention for reducing challenging behaviour and it is on this theoretical framework the study is based (Meyer & Evans, 2006).

Case studies were chosen to provide much-needed examples of how the four-component model can be applied in practice. Meyer and Evans (2006) in their review of interventions for challenging behaviour highlighted the importance of case study methodology as it provides specific ideas that can be adapted and tried with other children in different contexts. Babbie (2004) also states that case studies provide idiographic detail of lives and events but can also work to re-inform theories on which they are based. Case studies utilise various methods, including observations, interviews and psychometric measures to gather comprehensive data. These methods, used for the present study, are outlined in further detail later in this chapter.

Given the richness case study data contributes, it was considered important to include both qualitative and quantitative data in these case studies. The use of either data source

alone would have made it difficult to address both the specific comments made by families and succinct effects of the study. The strength of qualitative data is evident in the depth of understanding of a situation that can be provided, while quantitative data allows analysis providing outputs which are directly comparable with other studies (Babbie, 2004). Therefore, this combined approach to data analysis provides full information and addresses the literature deficiency here, as outlined by the first and second research objectives.

Participants

Recruitment

The agencies Parent-to-Parent (a support group for parents of children with intellectual and/or developmental disabilities) and Autism New Zealand (an organization supporting those with Autism and their families) were provided with information summarising the project to distribute via their newsletters (see Appendix 1). Families interested in finding out more information and/or participating in the study were invited to contact me. Six families contacted the researcher at this stage, and following a telephone discussion, four of the families decided to set up an appointment to meet to discuss the study further. The two who chose not to proceed did so because they could not, at this stage, commit to a study that was of approximately one year's duration. Next, I met with and provided information to each family (Information Sheet, see Appendix 2). These initial meetings took a minimum of 1.5 hours, and on two occasions extended over two visits totaling more than 3 hours. This was to allow parents to get to know me and ask any questions and allowed the foundations of building rapport to occur. All four families who wished to participate were eligible for inclusion. The two exclusion criteria for this study were a current behavioural plan already being implemented and the presence of behavioural difficulties beyond those specific to the diagnosis/ syndrome the child had.

The rest of this section outlines each of the participants with identifying details changed to ensure anonymity and confidentiality. For further information on the disorders and syndromes outlined here please refer back to Chapter One under the heading of specific disorders. Following this section, the participants will be discussed in detail in separate

chapters, including their current challenges and family background, diagnosis, intervention plans, and results.

Simon

Simon is a twelve-year-old boy who has Attention Deficit Hyperactivity Disorder (ADHD; which is characterized by periods of inattention and/or hyperactivity), diagnosed only a year previously. He also has mild Asperger's Syndrome which is characterized by emotional impairment and/or repetitive behaviours. Simon communicates appropriately for his age but gets frustrated easily, particularly with his younger brother and only sibling. This can mean he is unkind to him and can hit him. He likes to keep his routine ordered, yet he has difficulty getting up and getting organised to go to school in the mornings as well as staying organised and focused after school to do his chores. His room is highly structured and organized and Simon is very competent at keeping it clean and tidy and putting things in set orders/locations. Simon enjoys drawing, Lego, playing on the computer, interactive gaming and carrying out activities on his own. He has a few friends in his neighbourhood whom he plays with at school.

William

William is a five-year-old boy who at three days after birth experienced hypoglycemia (caused by extremely low levels of blood glucose) causing brain injury. He has subsequently experienced various difficulties attributable to this, namely intellectual and developmental delays. William also has a seizure disorder and cortical visual impairments; he has glasses but does not enjoy wearing these and consequently on occasion will take time to notice others. He has a few sounds and words that he uses for communication and will use hand motions, pointing and squealing noises to communicate his other ideas and needs. He enjoys playing outside, on the swings and in the garden. When he plays outside he likes to hold things in his hands or move them from side to side. He also engages in this type of play when using objects inside. He watches DVDs (his mother identified that he has favourites and likes these to be shown regularly) and listens/dances to music. His challenging behaviour includes throwing stones at people and objects, hitting, kicking and difficulties with sharing, particularly sharing his mother with his younger brother and only sibling who is three years younger than him.

Lily

Lily is a five-year-old girl who has Angelman Syndrome. As identified in the introductory chapter, this is a neurodevelopmental disorder caused by improper imprinting of chromosome 15. Lily enjoys playing games and interacting with people older than her. She also has coeliac disease (an allergy to gluten), but despite this has a huge enjoyment and capacity for eating. In the second year of this study Lily was also diagnosed with a Seizure Disorder (epilepsy). Lily has about 30 words that she uses regularly to communicate and also a few signs. She will also gesture and point to communicate her intentions. Lily has two older siblings, with whom she likes to interact, especially when they will do what she wishes of them. She finds it much easier to play with children who are older and/or bigger than she is and prefers to engage with these children rather than smaller children. She enjoys playing on the swings, the trampoline, and with Playdough ©. The challenging behaviour she engages in includes spitting, hitting, yelling, kicking, and disobeying instructions.

Hohepa

Hohepa is a fifteen-year-old Māori youth who has Smith Magenis Syndrome. Smith Magenis Syndrome is a neurogenetic disorder characterised by such features as behavioural abnormalities, sleep disturbance and skeletal anomalies. Hohepa uses verbal communication effectively to communicate his needs. Some of his sentences are difficult to understand because they are muffled or incomplete, but he can and does use words to express himself. He will often echo a previous conversation or something he has heard elsewhere not necessarily to anyone. He tends to keep to himself and enjoys playing on the computer and watching "Spongebob Squarepants". He enjoys helping around the house and will often be found doing the washing or dishes or trying to help with the baby. He sometimes over-helps, for example, Hohepa may be found forcing the washing around in the washing machine so it will get clean faster, or bringing in washing off the line when it is still wet. His challenging behaviour involved physical aggression including hitting, kicking and acting out in other physical ways.

Measures and Procedure

Intervention Overview

Each intervention was designed based on the four component model to address the needs of each of the four children involved and their families. The four component model (Meyer & Evans, 1989) specifies the need to consider ecological influences (contextual; or setting variables), traditional contingency management (what behaviours are currently being reinforced), teaching more adaptive alternative skills (with the same function as the challenging behaviour), and finally the importance of meeting emotional and motivational needs. The literature outlining the importance of parents and siblings is also considered and wherever possible, families are included in the interventions for each child.

The new component of this research is the inclusion of the emotional and motivational needs in a behavioural intervention programme. The researcher at all times attempted to highlight the importance of emotion and focus on addressing emotions and motivations. However, the other three components are also crucial in each intervention. It would have been ideal to be able to separate out the effects of each specific component more, but it was found that each were a crucial component of a whole approach involving the child and their families. This does not mean that specific emotional techniques to address the fourth component cannot be identified, however. As described in chapter's three to six, all the children did have activities that targeted their emotions (i.e., emotion card sorts to teach emotion labeling and understanding). These targeted activities are derived from relevant writings on teaching emotional skills (e.g., Denham & Kochanoff, 2002; Wareham & Salmon, 2006). As Table 1 highlighted recent positive interventions are still lacking specific inclusion of this fourth component (emotions). Therefore, although there is a lack of definitive clarity here, as to which effects will be produced by which component, the definition of the contribution of emotions is a limitation of this research and the field as a whole at this stage (see Table 1). This study attempts to begin to look at how better to operationalise this concept and address it, as identified in the case study chapters.

Phases Outline

This study consisted of four single case designs and was divided into different phases as follows.

Phase One: Baseline assessment

This initial phase involved baseline behavioural observations, identified to provide insight into real-life situations and over time data on both variability and stability of behaviour (Babbie, 2004). Baseline data were collected from each family over ten hours. These ten hours were divided into five two-hour sessions. Each of these sessions focused on a different situation which were; routine (whatever the child would usually be doing on that day), materials/independent (child interacting either alone or with materials e.g. toys, games), adult one-on-one (interaction with an adult without other people), sibling/other child interaction (interaction with another child or the child's sibling/s), group/school interaction (interaction with 2+ others). These situations were chosen as I believed they represented five different common aspects of a child's environment and would allow me to gather broad contextual information on behaviours occurring. The behaviours coded differed for each child and the process for defining the behaviours to be coded is outlined in the section under data analysis later in this chapter. The ten hours of baseline observations were filmed in all instances other than at schools where additional consents from other people that could have been filmed would have been required. In these instances the researcher took detailed notes including time and duration of behaviours to ensure these data could also be used for baseline information. These same five situations were filmed/observed again at two later points (three and six month follow-ups).

Parents and caregivers were also invited to take notes of any additional behaviours occurring outside of the filmed sessions to provide extra information. Information provided included the environment in which behaviour was occurring, precipitants, actions, consequences, and alternatives engaged in or those which the parents believe the child should have engaged in. Data were also provided which involved the identification of positive behaviours that the child was engaging in.

The percentage of time that both challenging and positive behaviours were occurring was calculated, as well as what types (spitting, kicking, playing nicely etc) to compare with

observations made at both a 3 and 6 month follow-up. Those positives identified at baseline were integrated into each child's intervention sessions to encourage appropriate behaviour.

Following these observations and before the intervention began, parents completed the Child Behaviour Checklist (CBCL; Achenbach & Edelbrock, 1983). This allowed an additional measure of behaviours and was used after the intervention and at each of the follow-ups to identify if any change in behaviour was occurring. These data are analysed alongside the direct observational data in each of the child's case study chapters (Chapters 3-6). The properties of this measure are outlined in the next section.

Phase Two: Intervention

The second phase involved the introduction of individualised treatment programmes that were developed for each child alongside the families involved. The background information provided by families was incorporated at all times throughout the study. The specific tasks picked for each child were based on concepts derived from the four component model to target the specific behaviours of concern raised by each family. I was always aware of considering the importance of all four components and how I could best be of benefit to each of the children and their families. As the four components were all determined to be essential in therapy plans, it is difficult to discern them from each other as in fact all components were regularly addressed together through my interactions with each child and their family.

Interventions were also based upon behaviours observed to be occurring in the 10 hour baseline observations carried out with each family. Additional information provided by parents and obtained through the CBCL was also incorporated into therapy sessions by addressing these identified concerns and behaviours.

Each family had 12 hours of intervention sessions which were adjusted depending on what appeared to be useful for the child, according to their own identification and input from the parents/caregivers. Supervision was also sought during the interventions to ensure best treatment for the children involved in this study. The broad aim of these sessions was to reduce/eliminate behaviours that were determined as being challenging, through targeting the child's emotional difficulties, whilst enhancing positive behaviours

(e.g., increasing functional communication), modifying and managing contingencies and emotional knowledge/regulation. Each child also had specific goals for their therapy sessions, as will be discussed in their separate chapters. Family members were incorporated in sessions where possible. At all times, the researcher was the primary therapist, however in the case of Lily, her mother took over when it was evident that Lily responded better to this input. All ideas taught were shared with caregivers and siblings to ensure techniques continued to be used and also to recognise the huge importance the family plays in the life of a child.

Phase Three: Three-month follow-up

This phase involved a three-month follow-up which took observations in each of the five contexts (as with baseline – except this time only one hour per context). The CBCL was also administered at this stage. Also during this phase, the child's parents were interviewed (informally) to determine their views on the study and also to explore their own and their families' views on emotions.

Phase Four: Six-month follow-up

This phase involved a further follow-up at six months after the intervention ended (as with Phase three – total of ten hours across the follow-ups to compare with ten hours total baseline data). The CBCL was again administered at this stage. The same interview as at Phase three was carried out here in an informal unstructured manner to ensure that the views of the families had been correctly incorporated in the study. Interview data is presented in each child's chapter as qualitative data to outline family's perceptions and feelings surrounding this intervention.

The structure of these follow-up sessions allowed the comparison of current behaviours with baseline data to assess the degree of change that had occurred following the intervention.

Following this, families were provided with short manuals or booklets encompassing ideas from the intervention and results of this study. This allowed them to have a log of what ideas and techniques had been both useful and not useful. Throughout the intervention, visual journals were also kept of the tasks undertaken. These journals involved descriptions of the focus of each session and what was done during the time,

what materials were used and what strategies/techniques were engaged in. Photographs and pictures were added to give depth and detail to the journals. The journals were decorated with coloured paper, stickers and stamps and were left with families once all data were collected as a detailed document of what their child/ family and the researcher had engaged in during the intervention stage of this study (see examples Appendix 6).

Child Behaviour Checklist

The Child Behaviour Checklist (CBCL; Achenbach & Edelbrock, 1983) is a 112 item questionnaire completed by adult caregivers covering a range of social competencies and possible behaviours. It is widely used as an outcome measure in intervention studies and is believed to have excellent psychometric properties, although normative data for New Zealand children do not exist. This measure was normed with over 2,300 children and for the eight subscales, Cronbach's Alpha ranged from .62 to .92. Test-retest reliability ranged from .87 to .89. Validity for this measure is also high, with correlations with two other related measures ranging from .59 to .88 (Achenbach & Edelbrock, 1983).

The CBCL was completed by parents before and after the intervention sessions, and at the three and six month follow-ups. This measure was chosen for its ability to indicate different behavioural profiles and its common usage. As well as identifying factors of each of the eight profiles (Social Withdrawal, Somatic Complaints, Anxiety/Depression, Social Problems, Thought Problems, Attention Problems, Delinquent Behaviour, and Aggressive Behaviour), this measure also provides information on whether behavioural problems are internalising or externalising (Achenbach & Edelbrock, 1983).

Data Analysis

The observational data collected at baseline and at the three and six month follow-ups were coded based upon the goals devised for each child in their specific intervention plans. Intervention sessions were also coded using these codes identifying frequency of behaviours throughout this stage of the study. Codes were developed to ensure the key behaviours targeted through emotions were evident in each child's outcomes. This allowed for comparison between baseline and follow-up sessions to assess whether targeted behaviours had changed in any way. Codes were categorised into three meta-

categories: Pro-social behaviour, emotional understanding and aggressive behaviour. These were chosen based on the presence of behaviours in these areas for each child. Within each of these categories, each child had one to three codes which captured the target behaviour. The specific codes are defined and outlined in the following chapters dedicated to presenting the complete story of each child and their participation in this study.

In order to analyse behaviour using these codes, a computer based observational package called Interact, produced by Mangold, was used. A research assistant was employed to ensure there was no bias in coding as I felt that I could have interpreted behaviour more positively based on my involvement with the children and their families for over a year by this stage of the research. The research assistant was given the codes for each child (outlined in each child's chapter) and recorded the amount of time each of these codes occurred. A total of 50% of all data collected was coded by the research assistant. This was because behaviours were perceived to be relatively stable over time, children were often tired and losing interest by the end of the observations and at times, sessions and observations were finished early for varied reasons, meaning that complete data for a second hour or a full hour was not always able to be obtained. When analysed, totals of each code do not sum to equal 100 as at times no code was observed or codes overlapped. Results are represented by means which show the total percentage of time behaviour (each code) was engaged in.

These data were further analysed using two non-regression algorithms. The Standard Mean Difference (SMD) was used to calculate total effect size of each intervention for each child. This was calculated using the mean for all baseline and intervention data points, and is known as Standard Mean Difference all (SMDall; Busk & Sterlin, 1992; Olive & Smith, 2005). The SMDall was used as it outlines an overall change from baseline through intervention by incorporating all raw data in the form of means. The calculation provides an actual effect size and is simple to perform. However, the small effect sizes gained with this algorithm may be due to the inclusion of behaviours that were targeted to both increase and reduce; therefore this does not specify if behaviour increases or decreases were more evident overall (Busk & Serlin, 1992; Owen & Smith, 2005). The calculation for this is:

SMDall = baseline-treatment/ SD (Standard deviation) of baseline

Because of this the SMD has also been calculated for single behaviour categories (e.g. aggressive behaviour, empathy) across baseline and intervention to allow actual percentages of change per behaviour to be recorded, accounting for whether the behaviour was targeted to increase or decrease using the calculation:

SMD= treatment mean (specific behaviour; sb) – baseline mean (sb) / SD of baseline (sb)

Both of these calculations will utilise the ubiquitous criteria of the Cohen's d effect size, which is a statistic used to calculate the difference between means using standard deviation and is not dissimilar from SMD, to outline whether a result is small, medium or large. A small effect is that between 0.2 and 0.3, a medium effect is 0.4-0.7 and anything above 0.8 extending beyond 1.0 is a large or big effect (Cohen, 1988).

A second algorithm, Percent Zero Data (PZD; Harvey et al., 2009; Scotti, Evans, Meyer & Walker, 1991), was used to address changes in aggression for each child. This was utilised to identify any maintenance of elimination of this behaviour. The calculation for this involves selecting the first data point in an intervention phase to reach zero. Subsequent data points in that phase also reaching zero are divided by the total number of data points in that phase. This was calculated for the intervention phase, for follow-up (3 and 6 month combined) and for the phases as a whole (intervention through to 6 month follow up). The PZD was utilised to determine the extent of the effect of targeting aggressive behaviour in the study. It is useful for working with ratio scale data and is for the purpose of highlighting behaviour elimination. However, this algorithm is criticised as it only measures changes through zero data points and does not necessarily measure the magnitude of change (Scotti, Evans, Meyer, & Walker, 1991).

Further algorithms were considered but unable to be calculated with the current data. These were Percentage of Non-Overlapping Data (PND; Scruggs & Mastropieri, 1998; Scruggs, Mastropieri, & Casto, 1987), Percentage of ALL Non-overlapping Data (PAND; Parker, Hagan-Burke, & Vannest, 2007) and Owen White's Binominal test on extended phase A baseline (White & Haring, 1980). The PND was unable to be used for behaviour reduction (aggressive behaviours) as each child has at least one baseline score of zero and

behaviour could not be reduced beyond that. It was not able to be calculated for positive behaviours either as this would only have been possible through computing the raw scores into means and therefore change would only be evident based on this one score (rather than the different codes that make up positive behaviours). This calculation ignores all data except the one data point and as such can be subject to ceiling effects and at its best is sensitive to changes in level but ignores changes in slope (Scruggs & Mastropieri, 1998; Scruggs, Mastropieri, & Casto, 1987). PAND was not used in this study as it focuses on a baseline data point of one, making every calculation divisible by one and thereby producing very high, difficult to interpret, percentage outputs. It does not control for positive baseline shifts and requires 20 data points for calculation (Parker, Hagan-Burke, & Vannest, 2007). The final considered algorithm was Owen White's Binominal test on extended phase A baseline. This was not utilised as it has low sensitivity when interventions have fewer than 7 data points, has very low power, and is mainly used as a descriptive technique for studies with data sets that are longer and more stable (White & Haring 1980).

Data provided by the CBCL were compared across time periods as this was administered at four stages (baseline, end of intervention, 3-month follow-up and 6-month follow-up). This allowed insight into parent's perception of their child's repertoire and whether or not they identified any change (for better or worse) in their child's behaviour over the time they were involved in the research study.

Basic idea's about of topics to cover in the interview were also suggested to gain parents' perceptions of change; however, this did not take the form of a structured interview. Other than introducing topics, I provided parents an opportunity to share their thoughts surrounding any aspect of progress or change throughout the study for their child and family. Topic prompts included thoughts on their child's recent progress/changes, emotional understanding/usage, behaviour changes, and family relationships and how they envisaged life in five year's time for their child.

The results of all of these analyses are provided in the next four chapters about each of the participants.

Ethical Considerations and Procedure

Ethics Approval

The study was granted Ethics Approval from the Upper South B Health and Disability Ethics Committee in August 2008 (URB/08/08/036; See Appendix 3). The following sections outline informed consent, confidentiality and anonymity, and Māori and cultural issues.

Informed Consent

It was important to seek informed consent from all of the parents and guardians whose children were involved in this study. This process involved the parents or guardians agreeing that the study had been explained to an appropriate extent to their child. Explanations for children ranged from a basic outline of "I'm Laura and I'm going to be working with you" to more in-depth explanations of the study and what behaviours would be targeted, as appropriate to the child's developmental level. At any stage, if the child did not want to be involved or wished to ask questions, they were able to do so and their best interests were continually held paramount in this study. Explanations were based on discussion with parents and the child's levels of understanding. It was made clear that the family had the right to withdraw from the study at any stage. An Information Sheet (see Appendix 2) and Brochure (see Appendix 4) were provided to each family to make them aware of and fully informed about the nature and purpose of the current study. The accompanying Consent Form (see Appendix 5) was kept brief and straightforward to allow participants to respond by signing and returning it based on their understanding of the Information Sheet. The consent form outlined participation in the study, as well as whether families consented to be videoed throughout the sessions, if they required an interpreter at all, and if they wished the information gathered to be available to their medical doctor. There was also a field where the participating child could sign their name if they were able and wished to do so.

Confidentiality and Anonymity

It was important to ensure families involved in this study were able to keep their identities private. As this study was conducted over a long time period and involved many hours in

the families' homes, it was important that families felt confident and safe providing the researcher with information and engaging in the study. Therefore, this study has changed identifying details of the families to ensure their privacy. Participating families have all had the study and the process of publication fully explained to them. Families were also aware and happy with consultation and involvement of supervisors for this research to ensure ethical practice based on theory, in that the child and families' best interests were maintained throughout the study.

Māori and Cultural Issues

This study involved one family of Māori descent. The researcher sought cultural supervision from both the Kaumātua at the School of Psychology at Massey University Palmerston North and a Māori clinical psychologist who has experience in working with Māori clients. The researcher has Māori ancestry herself and has a beginners understanding of te reo as well as customs and beliefs that may be common in Māori families. The researcher had obtained two certificates in Te Ara Reo from Te Wānanga O Aotearoa at this time.

However, this family did not choose to speak in Māori constantly or require a translator for this study. The words (kupu) that were used were easily understood by the researcher and no difficulties in communication were evident.

CHAPTER THREE: SIMON

This chapter describes Simon, who was one of the participants in this study. It provides an overview of Simon's diagnoses, his background and current functioning and then details the 12 hours of intervention before presenting the data relevant to the case.

Diagnoses

Simon is a 12-year-old boy who had diagnoses of Attention Deficit Hyperactivity Disorder (ADHD), Asperger's Syndrome, asthma and hay fever. ADHD is a developmental executive function disorder in which the major areas of difficulty are hyperactivity and inattention, although difficulties with emotional awareness and expression can also occur (Lovecky, 2004). Asperger's Syndrome (AS) is a pervasive developmental disorder on the autistic spectrum, and is marked by emotional difficulties and often the collection of specific information (Simpson, 2004).

Family Background

Simon is English, was born in the United Kingdom, and lives with his parents and younger preschool sibling. Simon got on well with his parents and craves their attention and positive comments as reported by both himself and his parents. He interacts well with them but is easily offended if they discipline him for any reason or are attending to his younger brother, which may create anxiety for him around his own importance. Simon mostly gets on well with his young brother, but also finds him frustrating and at times thinks he is favoured. In general, Simon does not believe his brother is disciplined for anything and it is only him whoever gets into trouble. Simon finds that his little brother is very good at "winding" him up and he finds this difficult to walk away from or ignore, particularly when his younger brother has made a "stupid" or incorrect remark that Simon feels obligated to correct for him. When the boys disagree, arguing, shouting and occasional hitting occurs. Simon struggles to think about what will happen if he responds negatively toward his brother and is unaware of the varied consequences that his actions may have. Despite this, Simon's little brother always wants to play with Simon and, when they do interact, they both often appear to have a positive experience. Simon had no current or previous involvement in any behavioural intervention programme.

Current Functioning

Medication

Simon takes Rubifen (20mg every morning) to manage his ADHD which has side effects including decreased appetite, difficulty sleeping, and being worried about noises outside and in his room.

School

Simon attends a mainstream school with no teacher aide hours or special classes. Simon's school reports have shown consistent academic improvement since arriving in New Zealand a few years ago. Although Simon is sometimes seen as the "class clown", his academic abilities are in the average to above average range and he is able to participate well in all academic activities. He struggles with concentration at times and remembering to do his homework.

Home

Simon has difficulty remembering to do the tasks required of him at home and can be easily distracted. If reminded up to a few times, Simon will do the tasks required of him, such as putting his clothes in the washing basket, emptying his schoolbag and hanging up washing. He finds it difficult if his parents discipline him for this and would rather they all discussed it. He does not want them to be mad at him and worries about this. Simon's parents also identified they believe Simon lacked self-confidence and belief in anything that he wanted to do and would constantly seek reassurance from them even for small daily tasks.

Simon enjoys walking the dogs and playing with his friends and has groups of friends whom he interacts with on a regular basis. He also enjoys playing with Lego and any interactive games. Simon can at times play well with his younger brother (9 years younger) but will often have a short fuse with him, not understand why he has different rules and become anxious or jealous if his brother gets continual attention or time with his parents and he does not. Simon is identified to regularly crave the attention of his parents,

in particular his mother. Simon has a very limited appetite and eats few varieties of food and very little of these. He will often not eat his packed lunch at school.

Simon worries that he needs to be perfect and always do things right. He experiences feelings of loneliness and worries about a variety of things. He can find it difficult to get his mind off thoughts once he has started thinking of them and may ruminate on the same topics or issues for a long period of time. Simon can at times find it difficult to be places without his parents and may request to come home if in a social situation that he feels uncomfortable in, even if his family is also there.

In general, Simon engages well in independent play and also enjoys family games, particularly with his parents.

Formulation

Simon is a twelve year old boy who lives with his family. He is identified to have difficulties with understanding and expressing his emotions, feel wronged by his parents and anxious by their different treatment of him and his brother. It is likely his displays of aggression represent his misunderstanding of his brother's different needs, at least partially due to his Asperger's Syndrome, and is an effort to reduce his frustration and anxiety. Simon also has difficulties, which are likely indicative of his diagnoses of ADHD; he struggles to time manage, to follow things through and to concentrate on a particular task. It is proposed that Simon's family may have inadvertently reinforced these deficits, in that he has come to perceive his environment (e.g., his younger brother getting more attention from his parents) in a way that is consistent with his emotions (anxiety, frustration).

Simon's inability to understand and express his emotions appropriately is expected to be maintaining his difficulties. He has considerable feelings of being treated unfairly in contrast to his brother which are reinforced by his lack of understanding of the needs of others. He instead views his parents' extra attention to his younger brother as favouring him. His feelings of inequality and anxiety likely make it difficult for Simon to engage positively with his brother, as jealousy may lead him to feeling inferior at times, causing

him to act aggressively towards him. These emotional deficits and their resulting behaviour may also be continually reinforced by Simon's lack of other skills and environmental reinforcement for appropriate behaviours. Although Simon's skills deficits are likely related to his diagnosis of ADHD, he is in a situation where he is feeling less important than his brother. This may also render concentration difficult as this anxiety may be time-consuming mentally for him. Similarly, Simon's constant need for his parent's attention is likely maintained by this perceived inequality, in that he is attempting to alleviate the anxiety he experiences around feeling less important than his brother. In line with this, Simons view of discipline and its apparent confusion (in his mind) with withdrawal or lack of equal love will likely be maintained due to his lack of understanding of the difference between these concepts.

Simon is a young man who seems to be trying to understand his place in his family. With skills to manage, understand and name his emotions, as well as appropriate validation of these from his parents Simon will likely be able to better understand the dynamics of his family. When these are addressed it is hypothesised that Simon's destructive behaviour will no longer be required as he will have developed a new communication method for sharing and understanding his emotions. Similarly, he will be able to better focus and apply himself around the home and at school as his emotions will not be interfering with his mindset on a regular basis.

Intervention Outline

Simon's challenges were outlined from his parent's perspective. They identified Simon as having difficulty with getting his tasks done in a timely manner and with interacting with his brother. They found it difficult to get him motivated to do his tasks when required and were reminding him numerous times before he would do them. In terms of his brother, Simon was thought to be unable to "let go" of issues that disgruntled him, and would instead worry about them. From his parent's perspective, he picked at things his brother did without seeming to realise he was much younger than himself and had different needs. Simon would also get jealous when his brother would have the attention of his parents. His parents also identified that Simon lacked self-confidence and would seek reassurance in many aspects of his daily routine.

Thus, in terms of the four component model, Simon's intervention was designed to focus on the following:

Ecological Component	Contingency Changes	New Skills	Emotional Component
Family Support – use of family discussion here to allow Simon to learn the appropriateness of his emotions and understand the family dynamics (microsystem changes). Also to facilitate opportunities for his parents to see how to best support him.	**Rewards** (for doing tasks) **Positive reinforcement**, as opposed to only negative (when misbehaving)	**Organisation Chart** – Time management skills **Consequences Planning** – outcomes of actions Build **emotion labelling and understanding skills**	**Family session** for discussing emotions **Emotion naming** (brainstorming) **Consequences** chart – impact of behaviour on others (learning empathy) Building **self-confidence** and **reducing anxiety** through understanding emotions and task mastery

As identified in the literature review all of these four components are crucial and justified in the adequate intervention for the difficulties described. The specific techniques and discussions used to address these are described below in Simon's session outlines.

Session Number and Duration	Focus	Tasks Undertaken
1. Two hours.	Organisation/ Time Management	Chores Chart

The first session began with a discussion with Simon's family. I clarified what I would be working with Simon to do that day based on his parent's identification, that doing his tasks on time and without prompting was a priority for them. Simon and I discussed how we could make something together to help him with organisation – in particular, remembering his chores. Following this, Simon and I worked together to make a chores chart. Simon added lots of little things to the chart as well as stickers and sections for working out rewards.

2. Two hours.	***Organisation/ Time Management and Family***	Family Discussion – Emotion Naming

	Environment/Emotions

This session was planned to adjust Simon's chart, but for the most part this session was a family discussion with both Simon and his parents. Each of them took turns to express what had and had not worked with Simon's chart. This discussion took about 80 minutes. Discussion also involved exploring feelings and taking turns to reflect and explain the implications of household actions and interactions on each person in the family. Simon commented that he had enjoyed talking with his parents. I encouraged him to try using his chart more and he was going to do so over the next week. At the end of the session, Simon and I played a card game.

3. Two hours	***Organisation/ Time Management***	Chores Chart

After reviewing his chart again and finding it was not working, Simon and I made a new chart. Simon identified he had not been using this chart because he did not understand it and would forget about it. The new chart we made was much simpler and easy to follow. We also made a reminder to stick on his wall that he needed to check it every day. We discussed this with his parents and got them involved with tangible rewards that Simon could look forward to if he did all of his chores.

4. Two hours	***Emotion Exploration***	Brainstorms, Thought Charts – Emotion Naming

In this session, Simon's parents told me how well he had been using his chart. Simon was very pleased with himself and told me about the reward he had received for doing all of his jobs. Following this, we discussed emotions and Simon brainstormed all of the things he could think of around emotions and feelings. One of the things that arose was explored further (Simon getting upset and worried easily when disciplined) and then Simon shared this with his parents and we discussed them as a group. Simon's parents offered him feedback and ideas about how important he is to them and that discipline is just about an action (it does not mean they do not like him).

5. Two hours.	*Consequences/ Planning/ Thinking of others*	Sequencing charts and alternatives, Charts for likes and dislikes re swimming and soccer. Discussing emotions involved in actions for self and others.

Simon's parents reported at this stage that he was doing really well with his morning jobs but still needed some reminding in the afternoon. Simon wanted to quit swimming and his father wanted to know why and what he would like to do instead. Because of this, Simon and I discussed these ideas. We made charts showing the good and bad things about each sport for his parents to see. We also made charts that followed through sequences that happen at home when situations occur. The main one we explored was what happened when Simon argues or fights with his brother. We also explored what would be a better sequence (outcome for all involved) and how this could happen and shared these with his parents at the end of the session. When prompted, Simon was able to foresee consequences and sequences of events based on his previous experiences.

6. Two hours.	*Review and Consolidation.*	Discussion, Games

Simon and I discussed what we had done thus far. We talked about whether he needed any other reminders or help with his chart and he thought it was working well now. We played some games as we talked, including Xbox and a board game called Yahtzee. At the end of the session, for the last half hour we talked with his parents. Simon was able to tell them that he believes they are doing the right thing as parents and we talked about the importance of family discussions and sharing thoughts. Simon's father showed Simon a chart he had made that showed sequences for him and Simon was able to understand how things that he does impact on his father too. I gave Simon and the family the box of materials we have been using through the sessions and advised that I will check back in another month and that they can contact me with any thoughts or questions before then should any arise.

Results

Simon's specific codes and the results gathered from his intervention are as follows.

Organisation – **(Pro-Social)**

Simon is reminded to do tasks that he has already done. This code includes any time Simon is reminded to do something that he has already done and any time that he outlines having already done what he is supposed to have done. An increase in the evidence of this code would be a positive outcome.

Self-confidence – **(Pro-Social)**

This is coded any time that Simon is actively carrying out an activity without seeking reassurance, including sharing, turn-taking, or independent play. An increase in the presence of this code would be a positive outcome and indicate decreased anxiety.

Empathy – **(Emotional Understanding)**

Simon shows appropriate emotions if someone else is happy/sad. Simon apologises when he has hurt someone (this includes with prompting). An increase in the presence of this code would be a positive outcome.

Fighting with brother – **(Aggressive Behaviour)**

Simon is engaging aggressively (physical, verbal) with his brother, such as malicious teasing, hitting, kicking, yelling, and screaming. A decrease in the presence of this code would be a positive outcome.

Aggressive/ Violent Behaviour – **(Aggressive Behaviour)**

Simon hurts or attempts to hurt himself, an object or another person verbally or physically. This includes any property destruction (such as punching a wall) or interactions with people (hair-pulling, arguing, and yelling). This excludes instances of fighting with his brother. A decrease in the presence of this code would be a positive outcome.

The data provided, based on the above codes, are indicative of time spent (or total percentage of time) engaging in each type of behaviour in each observation. Table 2 and Figures 1 and 2 present the results obtained for Simon.

Table 2 *Simon's Baseline, Intervention and Follow-up coded behaviours (% of time)*

| | | Behaviour Type | | Emotional Understanding | Aggressive | |
| | | Pro-Social | | | | |
		Organisation	Self-Confidence	Empathy	Fighting Brother	Aggression
Baseline Situations	School/Group		38.38			
	Routine		98.54			
	Independent	0.27	31.17	0.64		
	Sibling		97.00		0.53	
	Adult	0.30	49.51			
Intervention Sessions	Session 1		75.47			
	Session 2					
	Session 3		20.73			
	Session 4		62.36			
	Session 5		52.66			
	Session 6		70.54			
3-month follow-up	School/Group		94.88			
	Routine		66.53			
	Independent		90.62			
	Sibling		68.92			
	Adult		49.63			
6-month follow-up	School/Group		87.17			
	Routine				0.68	
	Independent		87.56			
	Sibling		50.89			
	Adult		97.89			
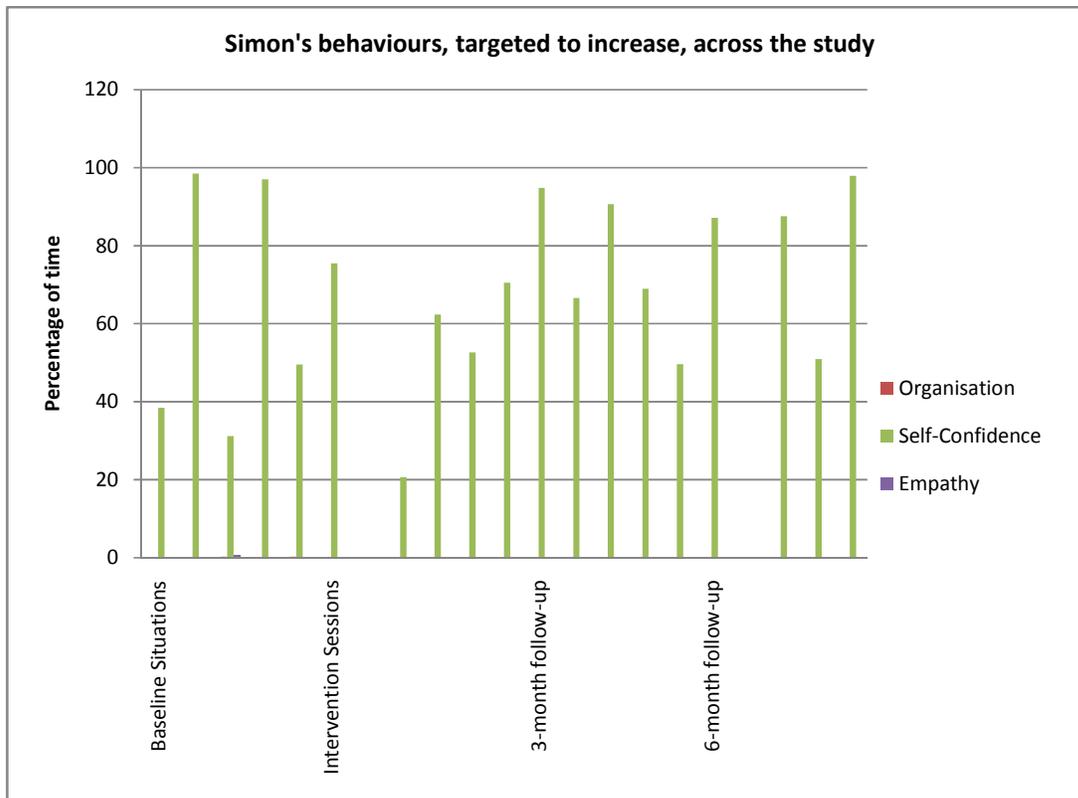
Figure 1 *Simon's behaviours, targeted to increase, across the study*

Figure 1 outlines the behaviours that were targeted for Simon to increase across the study. Simon's behaviours targeted to decrease are not graphed due to their incidence of occurrence being less than 1% at all times throughout the study.
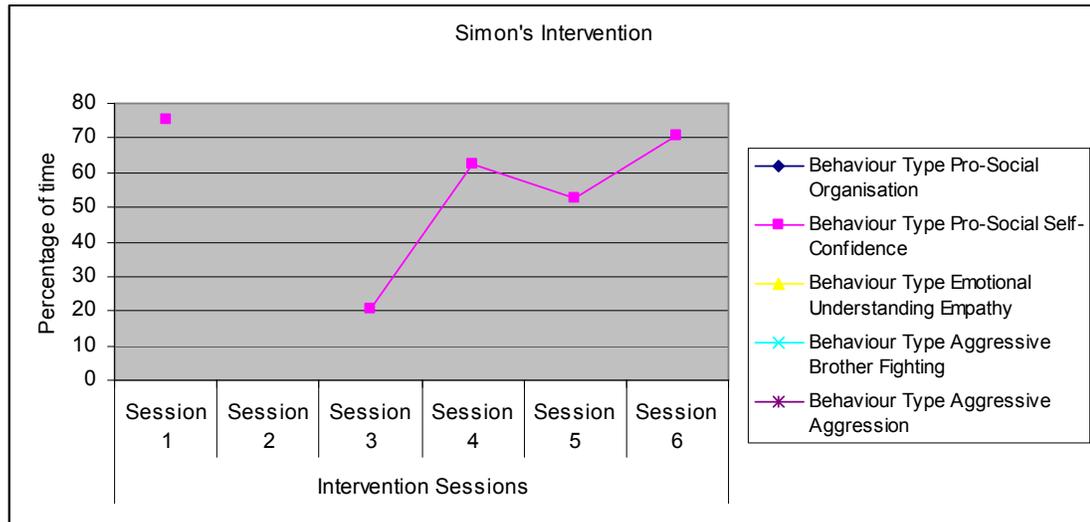
Figure 2 *Simon's intervention behaviour*

As evident from Table 2 at baseline, across all five situations, Simon showed levels of self-confidence, ranging from 38 – 98% of the time. Other identified behaviours for Simon were seldom recorded; Simon showed empathy when engaging in independent play (<1% of the time), organisation in independent play (<1% of the time) and adult interaction (<1% of the time) and demonstrated fighting behaviour (for <1% of the time) with his brother in sibling interaction. Simon was not observed at baseline to engage in any other form of aggressive behaviour in any of the situations.

Simon only demonstrated one type of behaviour during intervention observations, which were self-confident behaviour/interactions (see Table 2 and Figure 2). No target behaviours were evident in the family group session (Session Two).

At 3 and 6-month follow-up, Simon showed a continued pattern of self-confidence, which was evident 50-95% and 51-98% of the time. Again, no other target behaviours were observed at either follow-up point except in his Routine observation where Simon did not display self-confidence, his only coded behaviour for this situation was fighting with his brother, which was evident for less than 1% of the time.

Overall, Figure 1 details Simon's results throughout the study. It shows that self-confident behaviour was the only significant target behaviour observed, and was evident in all of the baseline situations, five of the intervention sessions, at all of the 3-month follow-up observations and at four of the 6-month follow-up observations. At baseline, Simon displayed some empathy and organisation; however, these were not evident for the rest of the observations. Fighting with his brother was observed to occur once at baseline and once at 6-month follow-up, but at no other stage.

 3 and Figure 3 displays the mean percentage of time Simon engaged in each of his target behaviours across the four stages of the study.

Table 3 *Simon's behaviour means, by target behaviour, across the study*

	Baseline	**Intervention**	**3-month**	**6-month**
Organisation	0.11	0.00	0.00	0.00
Self-Confidence	62.92	46.96	74.12	64.70
Empathy	0.13	0.00	0.00	0.00
Brother fighting	0.11	0.00	0.00	0.14
Aggression	0.00	0.00	0.00	0.00

Figure 3 *Simon's behaviour means, by target behaviour*

As evident in Figure 3, Simon consistently engaged in self-confident behaviour across the four stages of the study. The lowest peak of this behaviour was evident at baseline, and was highest at 3-month follow-up. Simon's other target behaviours were all evident across the study as being engaged in for a mean percentage of time of less than 1% each.

Utilising these data, two algorithms were calculated to determine the SMDall and PZD scores for Simon. Simon's mean difference (SMDall), utilising Cohen's criteria for statistical significance (Cohen, 1988) was very small (SMDall = -0.07). When calculating each behaviours effect size using SMD across baseline and intervention Simon's results were as follows. A small effect was evident in decrease of self-confidence, and all other effect sizes were not statistically significant. Organisation increased by 0.006, empathy decreased by 0.01 and fighting brother decreased by 0.0008. His reductions in aggressive behaviours using PZD were all 100% (Intervention, Follow-up and Total) as Simon never displayed aggressive behaviour throughout the study.

CBCL Results

Simon's parents filled in the Child Behaviour Checklist/ 6-18 Parent Form (CBCL 6-18) at all four stages of this study to provide information about Simon's competencies, emotional functioning and behaviour problems indicating their perception of Simon as having problem behaviours in some areas that were in the clinical range. Simon's scores on the Competence scales for Activities, Social, and School Competencies were all within the normal range at Baseline, Intervention, and follow-up. This indicated that Simon performs well across a variety of settings in a manner that is comparable to his age-matched peers. From these ratings, it appears that Simon is highly active, engages in a number of social activities and performs as expected at school.

Table 4 below reflects the categorisation of Simon's problem behaviours across the study. Problem behaviour scales can be in the normal, borderline or clinical range.

Table 4 *Simon's CBCL Problem Scale Categories across the study*

	Baseline	Intervention	3-Month	6-Month
Anxious/Depressed	Clinical	Clinical	Clinical	Normal
Withdrawn/Depressed	Clinical	Normal	Clinical	Normal
Somatic Complaints	Clinical	Normal	Borderline	Normal
Social Problems	Clinical	Clinical	Clinical	Borderline
Thought Problems	Clinical	Clinical	Clinical	Normal
Attention Problems	Clinical	Clinical	Clinical	Borderline
Rule-Breaking Behaviour	Normal	Normal	Normal	Normal
Aggressive Behaviour	Clinical	Normal	Borderline	Normal

Scores on the problem scales, as shown in Table 4, indicated varied levels of difficulty across the four time periods. At baseline, Simon was reportedly having difficulties with both internalizing and externalizing difficulties and was in the 'clinical' range for anxious/depressed behaviours, withdrawn/depressed behaviours, somatic complaints, social problems, thought problems, attention problems, and aggressive behaviour. Simon's overall score was elevated into the 'clinical' range, indicating global and often intrusive problem behaviours. These results indicate that it is likely at this time Simon was having difficulty managing his mood, social interactions and behaviour. The most significantly elevated scale at baseline for Simon was Attention Problems where his parents endorsed to the fullest extent all of the items in this category.

More specifically, it is likely that Simon was having difficulty with many facets of his life including being low in mood (highest endorsed items included feelings of worthlessness, talking of suicide, worried, crying a lot and being fearful) as well as experiencing a significant number of somatic complaints (highest endorsed items included nightmares, constipation, headaches, and stomach problems), social problems (highest endorsed items included loneliness, jealousy, feelings of others out to get him, accident prone, being teased, clumsy and a preference to interact with younger children), thought problems (highest endorsed items involved Simon having difficulty with getting his mind off thoughts, twitching, and having trouble sleeping), attention problems (all endorsed to the highest extent: acts young, fails to finish, cannot concentrate, cannot sit still, confused, daydream, impulsive, poor schoolwork, inattention and stares), as well as aggressive behaviour (highest endorsed behaviours included arguing a lot, demanding attention,

mood changes and being loud). Simon was in the normal range for rule-breaking behaviour.

At intervention, Simon's parents endorsed lower levels of all problem scales, except for thought problems which remained the same. Simon's profile was in the normal range for withdrawn/depressed behaviours, somatic complaints, rule-breaking behaviour and aggressive behaviour. Simon remained in the 'clinical' range for anxious/depressed behaviours, social problems, thought problems and attention problems. Social problems were now identified as Simon's most significant area of difficulty. Talking of suicide was no longer endorsed and feelings of worthlessness dropped to only being evident some of the time as opposed to often.

At the 3-month follow-up, Simon's problem scale scores were again for the most part lower than his baseline scores. However, his anxious/depressed behaviours and his rule-breaking behaviour were higher. Simon was reported to be in the 'clinical' range for anxious/depressed behaviours, withdrawn/depressed behaviours, social problems, thought problems and attention problems. Simon was in the borderline clinical range for aggressive behaviour and somatic complaints and in the normal range for rule-breaking behaviour. Simon was also identified to be talking of suicide again and feeling worthless often.

At his final follow-up, the ratings displayed a decrease in every area since his 3-month follow-up. Simon was in the borderline clinical range for social problems and attention problems. However, all of Simon's other scores were in the normal range (anxious/depressed behaviours, withdrawn/depressed behaviours, somatic complaints, thought problems, rule-breaking behaviour and aggressive behaviour). Simon was not reported to be engaging in any suicidal talk and feeling worthless sometimes. His attention problems were still his most significant area of difficulty, but had dropped by 35% and were now in the borderline clinical range as opposed to the clinical range as at all other ratings.

These results indicate that, by the end of data collection, Simon still exhibited difficulty with attention problems and social problems; however all of his difficulties were at a lower level than those identified at baseline by his parents. Based on these findings,

ongoing monitoring of Simon's mood and discussion with him about how he is feeling was recommended to his parents.

Interview Data

Simon's parents participated in a discussion at his follow-up. At the 3-month follow-up discussion, Simon was also present. The 3-month discussion was 96 minutes duration and at 6-months was 71 minutes.

Three-month follow-up

At the time of this interview, school holidays had recently passed. Simon's father commented on how Simon has been "a lot more mature" during this time period. They also discussed that Simon is continuing to not take his medication commenting that "If he's going to have an illness and take medication he needs to take responsibility for it… which he should be doing."

Relationships

The majority of conversation about family relationships centred on Simon's interactions with his younger brother. "Simon is allowed to do annoying noises if he wants to, but (brother) isn't" – was his father's viewpoint around Simon's beliefs on interacting with his little brother. They explained to Simon at this time that he needed to allow his brother to do whatever it was that he was also doing, i.e., making noises. Simon responded to this stating that when it came to his brother "I can't help it… he just gets on my nerves so much". When the boys argue, his mother explains that she has been telling the boys how she feels and trying to help Simon to let things go.

When asked about spending time with Simon, his father said "If he's doing his lego or anything like that I will spend time with him... I don't mind that"… followed by his mother who responded "I'm not interested in that at all." Despite this, his mother also explained that she did enjoy time with Simon, just not doing those kinds of activities. Simon's mother stipulated that Simon is starting to joke around with his parents and get a bit sarcastic ("We can have a joke now can't we, a little bit").

Emotions

Simon, his mother and father discussed when sympathy for Simon was appropriate and that this was perceived differently by each parent. His father believes his wife to be more overprotective than he is of the children. Simon outlined that he would rather talk to his mother, explaining further that "Although compared to dad, you would blurt it out… my mum I can talk to… my dad would keep it a secret" identifying the different benefits of talking to each parent.

Behaviour

When discussing behaviour with Simon and his parents, they asked him why he was different when I was around ("It's just you should know better about a lot of things… Laura's been here tonight and you've done those packed lunches… how long did it take you last night… about two hours… last night you were messing about)." Simon commented that he would listen to me or do things for me because I would not punish him and his parents tell him off. Simon explained that he "would rather be grounded than told off." Simon's parents steered the dialogue towards working together on things as a family ("Last couple of weeks you've been really good at yah jobs… we are all trying to work together… if you don't take your tablet…"). In response to this, Simon felt that when he does not take it (his tablet), he feels "really happy… but when I have it I have no worries at all… it's just boring…" His father summarised his behaviour that "If we could have him as he is now without taking the tablet, he would be the perfect child… does little bits to help out… he can be good with (brother)."

When asked what Simon had done in the last week that made them happy, both parents had different responses. "Probably, um the way he was with (brother)… um… yesterday the day before… you just were really… nice to your brother… seems to be very patient with him…" was his mother's explanation of Simon making her feel good and how this was good for her as she did not want to see the children bickering and arguing. His father responded that when Simon does his jobs, then he feels at ease because he knows he can do what he is asked.

Changes over the last year

"Since… a year… just over a year… he's got a year older… whether he has seen a different side to us cos you've explained it to him…" commented his father. Simon

outlined that over the last year what has changed for him is "she's like helped me with a lot of stuff… like that chart she helped us with, to do my jobs … helped me a lot… now sometimes I do them without being asked." Simon's mother summarised that perhaps it was helpful for him to understand how they saw things.

Five years time

Discussion around where Simon would be in five years time saw his parents outlining not only this topic but how much he had improved behaviourally. "I reckon he will be in the forces…" his mother commented and explained that she thought it would be good for him and that it would be his choice but they would also encourage it as a choice for him. "He's got the brains to be an accountant… he can't really think what he wants to do… ask me that question 6 months ago I would have said he would have been a very childish and immature 18 year old… he has improved drastically.... he's just improved so much… school reports… top of the class (in some areas)" was his father's response. He explained that they both could not see him as getting on the wrong side of the law, would not want to disappoint them or hurt anyone's feelings. These responses were both qualified with "it's his choice at the end of the day…"

Six month follow-up

Similar areas of discussion were covered in the final interview with Simon's parents. This discussion began with Simon's parents outlining how they discipline Simon, with his mother explaining needing to continue to ask him to do things and his father asking once, then raising his voice and getting the required response. They also outlined that Simon has not had as much of a temper. From their perspective, Simon has "come out of his shell drastically" regarding his fears and interactions with others, but also identified that "nothing is serious with him," identifying that he is seen as the "class clown." They outlined he would struggle with discipline now if he joined the army and that they are also finding him to be unmotivated with many things. Despite this, his father described this as "the best school holiday we've had" with Simon.

Relationships

In terms of attention and sibling rivalry, Simon's mother mentioned that "There's a bit of competition still going on isn't there." They both explained that they think Simon is still

"craving" their attention. However, his father also explained that Simon can be very good with interacting with his younger brother at times, and playing in his room with him. Both parents identified being closer to Simon's little brother than to Simon, because he was younger and needed more help with things. They also said that there are times when they, will have "a daddy night" with Simon.

Behaviour

Both of Simon's parents engaged in a discussion of Simon's ADHD. His mother identified treating him as though he did have ADHD (gives him "a bit more leeway"), and his father explained that he thinks the medication cancels it out and that's how he treats him. They jointly identified that Simon's friends act a lot more mature than he is and they would not want to leave Simon to babysit his little brother when he turns 14 next year because "he is too immature", but qualified this with outlining that they are pleased he has new friends who are more mature and that Simon is hanging out with them. They also think that going to High School next year will help him mature.

Emotions

There was less discussion around emotions specifically at this time, however Simon's father outlined that "He's happier … got friends… way more settled… wouldn't say he was more mature…."

Five years time

His parent's comments around where they saw Simon in five years time were similar to the 3-month interview in that they commented he was intelligent ("got the brains") and could do what he wanted.

Summary

Target behaviours for Simon were barely evident throughout the observational study, except for self-confidence. Simon's parents did identify improvements made by Simon over the period of the study evident in his CBCL profile and the interviews at follow-up. Because of this it appeared his behaviour was different throughout the study when I was not there to when I was. Simon himself also identified that he felt he had been helped with 'a lot of stuff'.

CHAPTER FOUR: WILLIAM

This chapter describes William who was one of the participants in the study. It provides an overview of William's diagnoses, his background and current functioning and details the 12 hours of intervention followed by the data related to this case.

Diagnoses

William, is a 5-year-old boy who suffered from hypoglycaemia at three days old. Hypoglycaemia is caused by extremely low blood sugar levels (Cryer, 1999). William has resulting complications of developmental and intellectual disabilities, seizure disorder and visual impairments. Medical information provided to William's parents indicated the impact of his damage was most significant in his parietal and occipital lobes.

Family Background

William is of New Zealand European descent and has one younger sibling. He lives with both of his parents and younger brother. William interacts with people by grabbing their hand or clothes, pushing gently or pointing, and often uses some noises to interact. William appears to regularly seek out his mother's attention and can struggle to share her when interacting with her and his younger brother. For example, he can become frustrated and shake his head or moan if his mother plays with his brother for too long. William is able to interact with his brother alone when he wishes to. For the most part, he prefers to play or interact independently. On occasion, he will spontaneously initiate interactions with his brother through activities such as pushing him on his bike or on the swings. In general, William is a happy boy who has a quick sense of humour and enjoys laughing.

William has numerous other health professionals who support him and his family. They have in the past suggested many ideas for behavioural management. These ideas have included the use of routine, a naughty chair, and the use of gold stars. William currently has a child psychologist conducting an assessment with him which has been going on for some time with them seeing William infrequently. At the time of intervention, William was not involved in any other intensive behavioural intervention programme but did continue to have the support of the other health professionals who work with him and his family.

Current Functioning

Medication

William currently takes the following medications: Lamotrigine - 110mg morning and at night = 220mg per day; Tegretol - 8ml morning, 8ml lunchtime and 8ml night = 24ml per day; and Stesolid -1 or 2, 5mg tubes given rectally when required only - for seizure control (to stop seizure). Lamotrigine is an anticonvulsant medication which works as a mood stabiliser and is used to treat seizure disorder. Tegretol is also an anticonvulsant and seizure control medication. Side effects of these may include nausea, vomiting, drowsiness and unsteadiness. William does not currently experience any of these symptoms.

School

William attends a special unit at a local primary school. His daily routine there consists of a lot of independent activity and some group activities such as singing. William always has a one-on-one teacher aide who will interact with him if he allows it. He does not appear to initiate any interaction with other children at school and prefers to engage in the same activities/toys. William has limited verbal words (3 – boo, poo and wow) and uses some physical gestures to communicate (pointing, head shaking).

Home

William engages in independent play regularly which involves activities such as moving rocks and leaves from side to side or throwing rocks at large objects such as the garage or the car. William likes to interact with the same toys and is seldom interested in new items unless they make noise or stimulate his senses in some way (e.g., if air comes out of them). William does not engage in any posting or putting-away behaviour and will simply discard or throw items away once he has finished with them. For example, usually when he has finished with his drink he will throw the cup to the ground or against the wall. There did not appear to be an antecedent to this behaviour, but could at times be evident to occur if William wanted attention as reinforcement for this appeared to be the noise or any attention he got as he would giggle at this.

William enjoys watching music DVDs, listening and dancing to songs and playing with water. In terms of DVDs and songs, he always insists on listening to or watching the same ones. He will demonstrate his frustration if the wrong one is played by moaning or shaking his head. These actions of frustration are evident if William is misunderstood in other contexts. On occasion, hitting or kicking will occur to demonstrate frustration/anger. William also struggles to follow some instructions and sit still for any length of time unless he is engaging in an activity of his liking and of an independent nature.

William will at times use pointing (most frequently) and head movements at home to indicate things he wants and knows where to go for basic needed items. For example, he will point to the fridge for a drink, or to the stereo for music. Clapping and laughing are explained to usually indicate correct or happy outcomes for William.

William has a great sense of humour and an understanding of other things that are funny if they are over-emphasised. He likes to laugh out loud when engaging in activities he enjoys and will also flap his hands in front of his body to show enjoyment and/or stimulation. William also taps his head and chews his hand at times – these behaviours appear to surround enjoyment or happiness and are self-stimulatory.

Formulation

William is a five-year-old boy who lives at home with his parents and younger brother. When William was only a few days old he suffered from low blood sugar resulting in severe complications of intellectual and developmental delays. Along with these complications, William's lack of ability to process his emotions appropriately has likely resulted in the development of his difficulties.

William currently interacts with others using predominantly non-verbal methods. He will gesture, point, or push gently to gain people's attention. Failing this, he will at times engage in hitting, kicking and screaming behaviours to get a response. Therefore, due to frustration, and perhaps anger, and a lack of ability to communicate with others in a way they understand William has likely begun to utilise aggressive behaviours as a

communication method for his underlying emotions. When playing, William appears to prefer to interact independently and can become frustrated or angered, evidenced by snatching, screaming, hitting and kicking if someone else enters his space unwanted. William does not regularly engage in sharing or turn-taking behaviour and appears to find it difficult to share the attention of his mother (evidenced by tantrumming behaviour). William receives inadvertent reinforcement (a contingent response, e.g., attention) from his environment, when engaging in undesirable behaviours. This will likely have seen these behaviours strengthen and develop and for him, rendered the need to develop other behaviours less necessary.

William's behaviours have developed a communicative function. For him, communication is more difficult due to his lack of verbal communication. However, teaching him more appropriate interactions, and modelling these communication techniques may enable William to adopt new methods, reducing his more destructive current behaviours. Given the important role of his environment and more specifically his family, William can then receive the reinforcement and stimulation he is seeking for positive behaviour with challenging behaviour being appropriately extinguished (e.g., with attention withdrawal) so he can discriminate between what is desirable and what is not.

Intervention Outline

William's problem or target behaviours for the study were identified by his mother. She outlined William as being aggressive at times. This aggression involved hitting and kicking others or tantrumming behaviour. She also explained that he had difficulty interacting with others and would choose independent activities on a regular basis. She was also concerned about his sharing and turn-taking abilities.

William's key intervention targets as identified by the four component model are as follows:

Ecological Component	Contingency Changes	New Skills	Emotional Component
Family Support – William's parents are encouraged to view and consider what is important to William and how to best reinforce his appropriate behaviours without giving undue attention to negative behaviours.	**Positive Reinforcement** for appropriate behaviour. **Withdrawal of negative reinforcement**, use of more appropriate discipline strategies (less time and attention given)	**Sharing and turn-taking behaviours.** **Communication techniques** – Yes/No head movements, reinforcement of use of pointing instead of aggression **Following Instructions**	Rapport – **Interactions with others**. William spent a lot of time independently and he was encouraged to engage with both the therapist and his family more.

All of these components, as identified by the literature, are crucial in intervening with William's challenging behaviour. The specific techniques and discussions used to address these are described below in William's session outlines.

William also has a support worker at the Sensory Resource Centre and many of the items used in his sessions were borrowed from her based on William's liking of items he knows well.

Session Number and Duration	Focus	Tasks Undertaken
1. Two hours.	*Relationship Building/ sharing experiences*	Toy play, DVD watching

William was hesitant to interact with me in this original session. I brought many different toys with me for him to look through and introduced them sequentially. He would look at some before throwing them away or moving them from side-to-side a couple of times. This interaction lasted only for a few minutes before he returned to his usual routine and wanted to watch a DVD. In order to continue to build a relationship with William, I went and watched this with him and took a couple of the toys with me. I played with them quietly whilst also dancing and interacting with him and the DVD. Increasingly, he began to look at me and took both of the items I was playing with at one stage and looked them

over again before discarding them to the floor. William's mother brought him some toys he is used to and before I left he showed me how he worked with these toys.

2. Two hours.	*Sharing experiences/ Interaction, Sharing, Turn-Taking*	Water Toys, Hide-n-Seek

William was able to engage with many of the water toys brought this session. William would move these from side to side and use them to splash me, his mother and his little brother. He got great delight in doing this. At times I was able to play in the water with him with these toys and he did not mind this. He would look at me from time to time and giggle. William figured out that if he threw items away I would pick them up. This turned into a useful interactive game where he would hide items, come back to me and push me in the right direction, laughing whilst I went off to look for it. We played hide and seek for about an hour in which we explored communication and turn-taking and he was able to use head signals to direct me which way I was supposed to run. His younger brother was included and we all took turns chasing each other, whilst explaining to William about and taking turns as we did this.

3. Two hours.	*Interaction, Sharing and Following Instructions*	Wooden Toys, Outside Play

In this session, William's mother and I first talked for about 45 minutes as it had been three weeks since I had last worked with William due to the family taking a holiday. During this time, I began to get out familiar toys for William to play with. His younger sibling came over and I began engaging him in turn-taking play. William got up from his DVD after about 35 minutes and came and joined in. The three of us were able to take turns with this toy and I would verbalise whose turn it was encouraging both boys to wait whilst the other had their turn. When outside, William was throwing rocks at the car and garage. Through continued instruction from both his mother and I and modelling of appropriate throwing, William was able to throw the stones into both the wheelbarrow and the washing basket. William was consistently praised for any on-task behaviour and

appropriate throwing was rewarded with cuddles and attention from his Mother. This was to meet William's apparent need for reinforcement and attention but used in a positive way to structure his behaviour towards more appropriate targets (e.g. the basket and wheelbarrow for stones).

4. Two hours.	*Imitation of Behaviour, Sharing and Yes/No (communication)*	In everyday situations

In this session, William was encouraged with Yes/No instruction (facial expression of smile or frown, head movement – vertical or horizontal and the word yes/no) where possible. We played both inside and outside and I encouraged him to interact with me and his little brother and take turns. When playing tag, I encouraged both boys to take turns and copy behaviour involved in chasing and playing (to learn appropriate interactive behaviour). I also encouraged William to use his head to direct me which way he wished me to go or to gently push me in the right direction rather than getting frustrated. I would respond quickly when he used an appropriate communication technique to reinforce this behaviour and wait patiently when he did not to allow time for this positive behaviour to occur.

5. Two hours.	*Imitation of Behaviour, Sharing, Interactive Play and Yes/No (communication)*	In everyday situations

In this session, William was encouraged to do many of the same interactions as in the previous session. Interactions were dictated by what he wished to do, but in all cases sharing and interaction were encouraged. Praise was given when instructions and actions were followed and this appeared to be occurring increasingly. William was also able to lead me in a basic follow-the-leader game where he would make a noise and I would copy it. At the end of the session, we played 'boo' in the garden. William attempted to echo me saying 'boo' and would do so with my encouragement, however, his parents were unsure if this word was 'poo' which he says regularly or 'boo'.

6. Two hours.	**Sharing, Following Instructions, Interactive Play, Use of words and Yes/No**	In everyday situations

William was able to recall the word we were using in our last session and with prompting and encouragement could say it to both me and his mother again in this session. When interacting with stones, William was encouraged to throw them into a wheelbarrow or basket. He could do this on most occasions and showed recognition of hearing and following instructions. Yes/No head nodding was also encouraged and praise was given to both William and his younger brother when they were interacting positively throughout the session. This was the final of William's 12 hours and we finished a little early because he was tired. Before I left, I gifted the box of resources to his mother for the boys to continue to use.

Results

William's specific behavioural codes and results from the intervention are as follows.

Sharing and turn-taking abilities – **(Pro-Social)**
William engages in behaviour that demonstrates turn-taking or sharing behaviour with someone else, including group interaction. This will be coded regardless of the nature of the activity and whether the activity/interaction is being carried out correctly. It will not be coded if William's behaviour is destructive or challenging toward himself, another person or materials.

Following instructions – **(Pro-Social)**
William is given instructions (verbal or through motions e.g., pointing). If this occurs coding will begin from when the instruction is given and cease when William responds or does something else/or if the person giving the instruction leaves the situation/ceases to reinforce the instructions given.

Empathy – **(Emotional Understanding)**

William shows appropriate emotions if someone else is happy/sad. William apologises (hugs, smiles at) when he has hurt someone (this includes with prompting).

Inappropriate Communication – **(Aggressive Behaviour)**

William uses screaming, crying (unless hurt or unwell) or physical (rough pushing, pinching, kicking/hitting) behaviours to communicate (a gentle push or nudge is not coded here).

Aggressive or Violent Behaviour – **(Aggressive Behaviour)**

William hurts or attempts to hurt himself, an object or another person verbally or physically. This includes any property destruction (such as punching a wall) or interactions with people (hair pulling, arguing, and yelling).

Independent Activity – Materials **(Pro-social)**

William is engaging in activities that he is doing successfully (not destructively – no ripping, biting, ruining or hurting himself/others). However, success is evident in the handling of materials and does not require the task to be carried out correctly. This also includes computer use, TV watching and any other independent activity.

Using the codes identified above the following results were obtained at baseline, intervention, and follow-up.

Baseline Data

Table 5 and Figures 4, 5 and 6 provide an outline of the percentage of time William spent engaging in these behaviours (identified by his behavioural codes).

Table 5 *William's Baseline, Intervention and Follow-up coded behaviours (% of time)*

		Behaviour Type					
		Aggressive		Emotional Understanding	Pro-Social		
		Inappropriate Communication	Aggression	Empathy	Sharing	Following Instructions	Materials
Baseline Situations	School/Group		1.00		31.0	3.00	65.0
	Routine		11.13		1.57		56.08
	Independent		13.69		5.45	2.06	61.79
	Sibling		17.66		3.59	0.41	18.46
	Adult		0.37			1.15	76.50
Intervention Sessions	Session 1		0.75			0.43	74.63
	Session 2		0.40		22.80		48.00
	Session 3				3.12		1.10
	Session 4				16.16		66.29
	Session 5		3.06		13.13		19.21
	Session 6		7.56		19.59	1.47	49.00
3-month follow-up	School/Group				33.34		36.67
	Routine				8.82		5.77
	Independent						63.65
	Sibling				3.17		67.36
	Adult				3.9		40.31
6-month follow-up	School/Group				33.34	3.34	33.34
	Routine				9.14		26.60
	Independent				39.26		39.26
	Sibling		0.57		17.03		69.49
	Adult				13.26		23.12
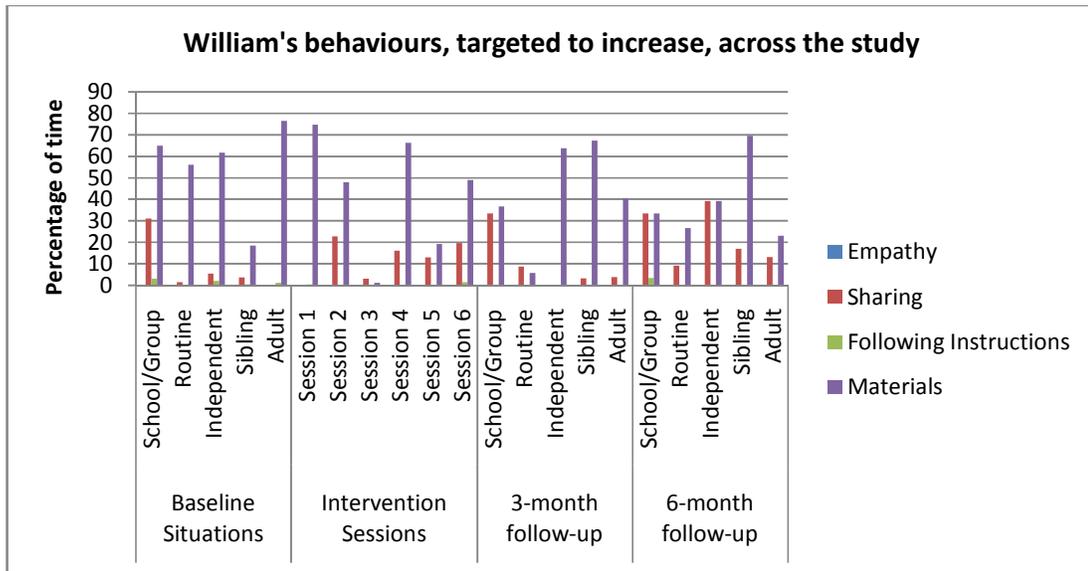
Figure 4 *William's behaviours, targeted to increase, across the study*
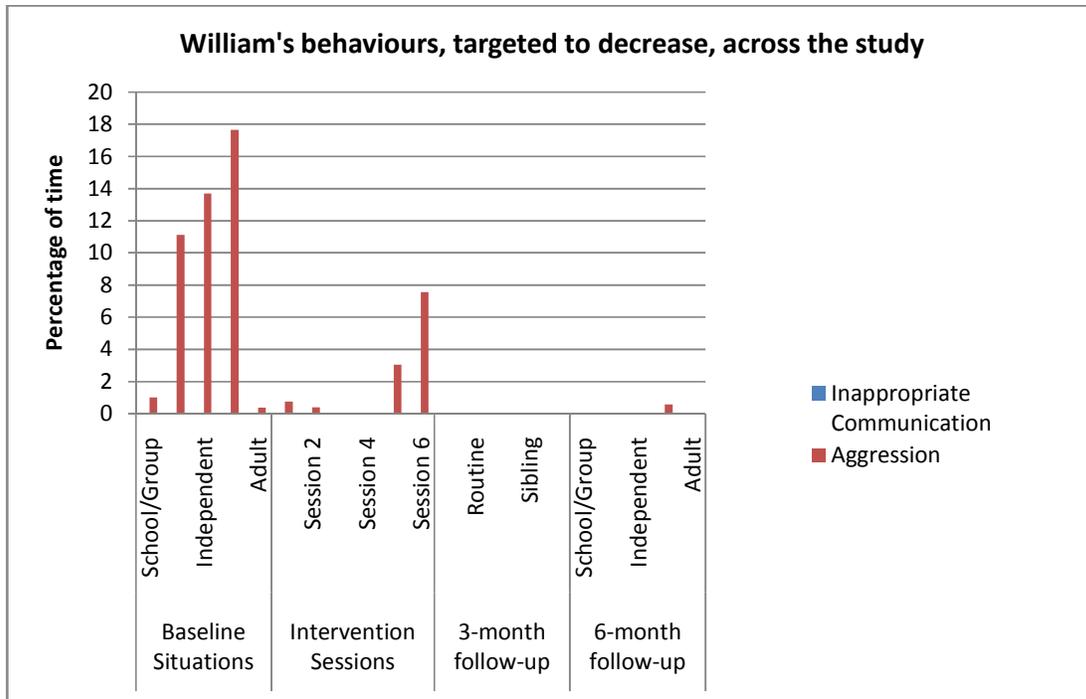
Figure 5 *William's behaviours, targeted to decrease, across the study*

William's target behaviours have been broken up into these two figures (4 and 5) to show those behaviours which were aimed to be increased and decreased separately.
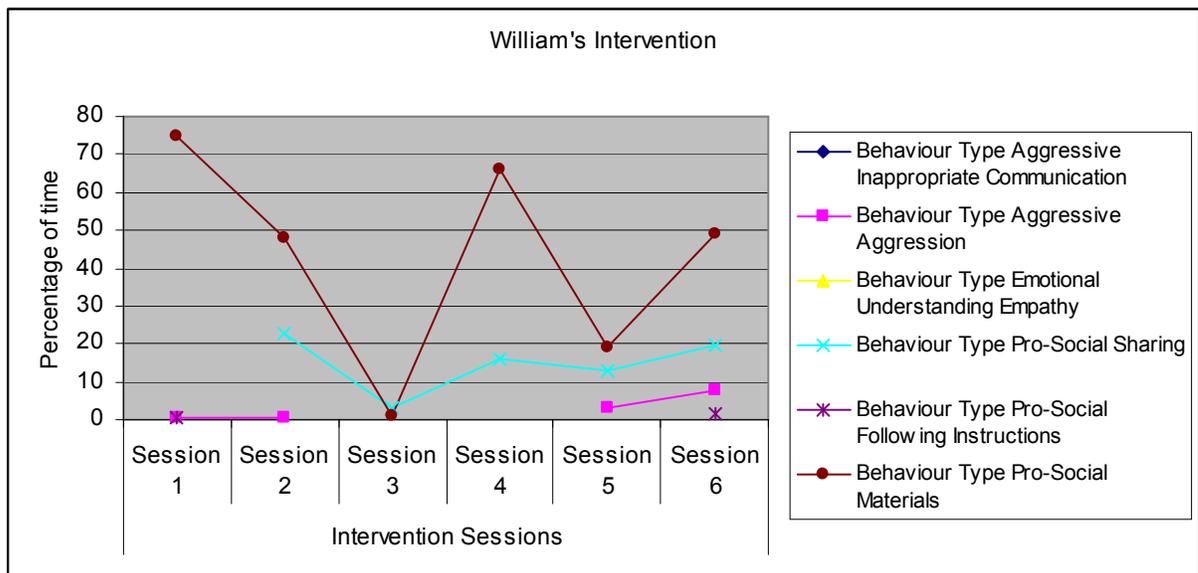
Figure 6 *William's intervention behaviour*

At baseline, William displayed aggression in every situation ranging from less than 1% to 18% of the time. William also displayed his ability to interact with materials in every

session ranging from 18% to 76.50% of the time. William's sharing abilities were evident in all situations other than in his interaction with an adult from 2% to 31% of the time. Following instructions was observed in every situation other than in William's normal routine ranging from less than 1% of the time to 3% of the time. Inappropriate communication and empathy were not observed for William at baseline.

William continued to present with some aggressive behaviour throughout the intervention sessions (See Figure 6) ranging from 0% of the time for Sessions 3 and 4 to almost 8% of the time in Session 6. William's sharing behaviour was evident across all intervention sessions after session 1 ranging from 3% to 23% of the time. It was only observed that William followed instructions in Sessions 1 and 6 for less than 1% and just over 1% of the time respectively. William's materials interactions ranged throughout the intervention from 1% to 75% of the time and were evident at each of the intervention sessions.

At the 3-month follow-up William engaged in no aggressive behaviour across all five situations. Inappropriate communication, following instructions and the use of empathy were also not coded at this follow-up. William consistently engaged with materials in each of the situations (ranging from 6% to 67% of the time) and displayed sharing behaviour in every situation other than independent play (ranging from 3% to 33% of the time).

At the 6-month follow-up William was most consistently observed to be engaging with materials (evident from 23% to 69% of the time). Also evident in every 6-month follow-up situation was William sharing with another person, this was evident to occur from 9% of the time to 39% of the time. At school William was also observed to be following instructions 3% of the time and when engaging with his brother William was observed to be fighting with him for less than 1% of the time.

Materials interactions have always been evident for William across all stages of data collection. Sharing behaviour has been evident at times throughout each stage of the study as well, evident in all of the final five 6-month follow-up observations. Aggression was much more evident at baseline than it was post-intervention for William and Inappropriate Communication and Empathy were not observed over the entire study.

Table 6 and Figure 7 display William's mean (percentage of time) behaviours, by target behaviour across the four stages of the study.

Table 6 *William's behaviour means, by target behaviour, across the study*

	Baseline	**Intervention**	**3-month**	**6-month**
Inappropriate Communication	0.00	0.00	0.00	0.00
Aggression	8.70	1.96	0.00	0.11
Empathy	0.00	0.00	0.00	0.00
Sharing	8.32	12.47	9.85	22.41
Following Instructions	1.32	0.32	0.00	0.67
Materials	55.57	43.04	42.75	38.36
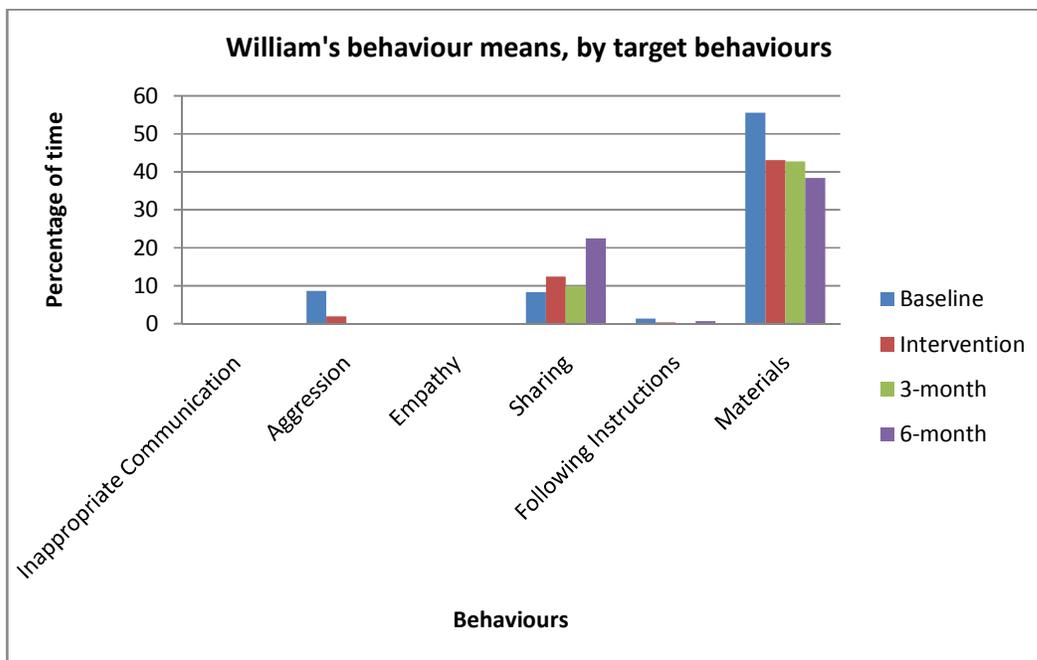
Figure 7 *William's behaviour means, by target behaviour*

William most consistently as evident in Figure 7, across all four stages of the study, engaged with materials. This behaviour was the peak for all of the stages of the study, with the highest peak being evident at baseline. Aggression also peaked at baseline. Sharing behaviours increased for William across the stages of the study, peaking at 6 months.

Two effect size calculations were carried out for William. His overall mean difference, using the SMDall algorithm was very small (SMDall = -0.12; based on Cohen's 1988 criteria). His SMD scores per behaviour between baseline and intervention are as follows.

A medium effect was evident with a 0.7 effect size decrease in aggressive behaviour, a small effect with a 0.28 increase in sharing and a 0.25 decrease in interacting with materials, and a statistically insignificant change of a 0.06 decrease in following instructions. Inappropriate communication and empathy were not observed for William throughout the study. His decreases in aggressive behaviour were evident in his PZD scores at intervention, follow-up and in total (33%, 90%, & 69% respectively) demonstrating that William's aggressive behaviour decreased an overall total of 69% throughout the study.

CBCL Results

William's parents filled in the Child Behaviour Checklist/ 6-18 Parent Form (CBCL 6-18) and the Child Behaviour Checklist 1 ½ - 5 Parent Form (CBCL 1½ – 5) were each filled in twice during this study as William was originally five years old and turned six part-way through. It is used to provide information about William's competencies, emotional functioning and behaviour problems. Because of the change in forms it is harder to profile William across the entire study and compare across all four stages.

Table 7 presents William's problem behaviour scores, which can be identified as being in the normal, borderline or clinical range, across the four stages of the study.

Table 7 *William's CBCL Problem Scale Categories across the study*

	Baseline	Intervention	3 Month	6 Month
CBCL 11/2 -5	Normal	Normal	Normal	Normal
CBCL 6-18	Normal	Normal	Normal	Normal

Both of these forms provide slightly different presentations of the results. The CBCL (1½ - 5) provides scores on DSM-Oriented Scales and Empirically Based Scales (similar to the problem scales of the CBCL 6-18). On the empirically based scales, William's parents identified different problem behaviour areas, however none of these when summed were determined to be in the clinical range at any stage (emotionally reactive, anxious/depressed, somatic complaints, withdrawn, sleep problems, attention problems, aggressive behaviours).

On the DSM-Oriented Scales at baseline, one scale was in the clinical range for William, this was the Pervasive Developmental Problems Scale (Note: This is not on the above table as it is not identified on the problem behaviour scales). All other Scales (affective problems, anxiety problems, attention deficit hyperactivity problems and oppositional defiant problems) were in the normal range. These results indicate that, at the time of reporting, in comparison to his age-matched peers William was interacting and engaging in a normal manner, with the only difference being the identification of Pervasive Developmental Problems.

The CBCL (6-18) identified that William was in the clinical range for engagement in activities and social interactions at intervention. At the 6-month follow-up, William was in the borderline clinical range for activities and remained in the clinical range for social interactions. This indicated that, in comparison to his age-matched peers, William was having difficulty with both social interactions and activities. His total competence score was unable to be calculated as the school-based questions were not answered (William does not attend school through the mainstream system). On the problem scales of this measure at both intervention and 6-month follow-up William was reported by his parents to, in all areas of the problem scales, be engaging in a normal range in comparison with his age-matched peers. The scores on all items were identical at intervention and 6-month follow-up with many items being determined as non-applicable. This means that these results on the CBCL 6-18 must be interpreted with caution as many responses were missing.

Despite missing data, these results indicate that William's difficulties lay in engaging with others and activities. The CBCL 1½-5 used at baseline and 3-month follow-up did not identify any significant difficulties for William other than those representative of Pervasive Developmental Difficulties. At no stage were items of talking about suicide or feelings of worthlessness endorsed by William's parents.

Interview Data

At both the 3 and 6 month interview/discussion, William's mother was present; his father was unable to attend. The first discussion took place for 50 minutes and at 6 month follow-up for 20 minutes.

<u>3-month follow-up</u>

Changes over time

Over the time I have been working with William, his mother identified that he has changed a lot behaviourally, with maturity and age. They have continued to make use of the Yes/No instructions I made up at home and have shared these with and encouraged their use with William at school.

Emotions

William's mother thought he probably used to share and express his emotions more than he does currently, but "in a bad way" because he was frustrated. She explained that she believed this to be because he could communicate better now and they (she and her husband) understood him better.

In terms of my interactions with William, his mother described that she thought "He really enjoyed having someone out there with him… I think he really enjoyed your company… when you'd gone sometimes he'd look a bit lonely…."

His mother outlined how she has many experiences of him making her feel happy lately. The most significant example she gave, was that William was doing riding for the disabled and had just made it up onto the horse and showed he was happy by smiling and making noises.

Behaviour

Overall, William's mother outlined that his turn-taking and sharing is improving.
She thought that, in the last few months, William has been communicating with gentle pushing and pointing more. She provided an example of this at school where he will get a teacher aide if he needs his nappy changed. He is also doing turn-taking at school with the car ramp and sharing the car with his teacher aides.

Relationships

His mother reported that William is probably closest to his father but qualified this by saying "It's funny it just depends." Whilst in hospital when William was born, his father

spent a lot of time with him to get to know him, and they spend time now "doing boy things", for example, playing on the ground. William's relationship with his younger brother is described by his mother as being "really nice", and also having "normal sibling stuff." "At times they can be a bit jealous of each other…" but William's mother described this as also being normal "sibling stuff".

Five years time

William's mother said that in 5 years time, she thought he would "always be my baby… always cuddle him… he will be eleven… in ten years time sixteen… I think I don't know, I imagine good things for him…." His mother went on to explain that she could imagine him sometimes "talking to her" and perhaps this would only be in a special way. She also added that she hoped he would be toilet trained by this time and wonders also about the stem cell research that is coming out and that she will continue to look for new ways to help him. "For us the big thing with him is happiness… maximising his potential…." and his mother explained that she would continue to involve as many people in his care as she could, but if he did not like something then they would stop it "we have to have lots of laughs" and "I want to live my life, I want to accept him for who he is… for him to be happy and for us to be happy."

Other Comments

If a child was critical of William his mother outlined that she would explain to them what life was like for him. If an adult was critical, she thought she would also let them know what she thought about this "It's my duty… it's a community problem… it could have been anybody's kid… people need to be far more giving… some people are brilliant but some people absolutely aren't…."

His mother also explained how talking to me had helped her "And just talking to you… just to say how I feel… it's good being able to talk… it absolutely does… I feel in control again…") in regards to how talking to mum helps the children also.

<u>6 month follow-up</u>

The 6 month interview was just after the last school holidays of 2009. William's mother was present but had another appointment and therefore the discussion was shorter than the first.

Changes over the last three months
William's mother commented "that he is kind of improving all the time" but that it is difficult to pinpoint exactly when changes are happening. She did identify that she thought even in the last three months he had shown improvement with communication and behaviour.

Emotions
William's parents are still working on Yes/No and he sometimes does this. His mother commented "I will keep plugging away" and keep working on this and encouraging him to communicate.

Behaviour
William's mother identified that he is continuing to show improvement over time. In comparison to last year's school holidays at the same time, she has found his behaviour to be much better "he was remarkable… he didn't once, really do anything destructive… his communication I think has got better."

Relationships
William's mother thought the relationships were similar to her response at three months. She commented that things are getting better too as William's little brother gets older and understands more.

Five year's time
William's mother commented when asked where she saw William in 5 years time "so he's eleven… I can see him mainstreaming, maybe not all of the time… I didn't think that would ever happen a year ago…." She recalled discussing this last time and added she still hoped he would be out of nappies ("that will happen I hope") and his communication "will have improved… I'd really like it if he started to make some words…."

Summary

Overall, William displayed a decrease in aggressive behaviours over time evident in the observations. He was also able to increase his frequency of sharing behaviours from baseline levels as identified in both his observations and effect size data. At no stage of the study was William observed to engage in target behaviours of inappropriate communication or empathy. William had missing results for much of his CBCL data, however, the results gained did not identify any significant or clinical areas of difficulty for William other than the presence of a pervasive developmental disability. Interview data outlined changes in William's behaviours from his mother's perspective including her view that as identified previously, through talking to me she was also able to benefit from the study.

CHAPTER FIVE: LILY

This chapter describes Lily, who was one of the participants in this study, based on discussion with her family. It provides an overview of Lily's diagnoses, her background and current functioning. Details of the 12 hour intervention and data are also presented related to this case.

Diagnoses

Lily is a 6-year-old girl who has Angelman Syndrome (aged 5 at the beginning of the study). Lily has seizure disorder, Coeliac disease and a Dissacharidase enzyme deficiency. Angelman Syndrome is a neurodevelopmental disorder that results from the incomplete imprinting of chromosome 15. Angelman Syndrome is characterised by four general attributes which are: a generally happy disposition, seizure disorder, subtle facial features and sometimes behavioural jerky movements (Clayton-Smith & Laan, 2003).

Family Background

Lily is of New Zealand European descent and has two older siblings (primary school-aged) whom she lives with along with her parents. Lily enjoys engaging with her siblings and her interactive skills are much better with older children (less aggression). With younger children, she can be a bit aggressive engaging in hitting, kicking or spitting behaviour. Lily can in general follow instructions and understand the basic consequences of behaviour (i.e., gets told off or put in time-out). Lily engages well with her parents and likes to have their attention. At times, she struggles with sharing and taking turns, but can interact for short periods of time in various activities without much difficulty.

Lily has not had any other interventions specifically targeting her behaviour. She has interventions in place for speech, cognition and the use of music. However, at school some of her Individual Education Plan (IEP) goals target her behaviour.

Current Functioning

Medication

During the intervention stage of this research, Lily was diagnosed with Seizure Disorder and is currently taking Epilim (2mls twice daily) and Lamotrigine, (5mgs twice daily). Epilim is used for suppressing the symptoms of epilepsy or seizure disorder. Lamotrigine is an anticonvulsant medication which works as a mood stabiliser and is also used to treat seizure disorder. Lily has responded to Lamotrigine with a rash and her parents were seeking alternative options for medication at the time of writing.

School

Lily is in a special needs class at a local school and has about 30-40 verbal words (often single) that she uses to communicate. She also knows various signs (about five without prompting and more with prompts) to indicate what she wants to express. Lily engages in classes appropriate for her age and has a teacher aide half-time. Lily has difficulty following instructions at school and interacting during class with other children. Lily can undertake basic counting and recognises pictures, colours and shapes. Lily takes some time to get used to new teacher aides and can be aggressive toward them until she is used to them.

Home

Lily enjoys playing with playdough, outside on the swings, drawing, and playing on the monkey bars. She also enjoys swimming and dancing. Lily can engage in activities with her siblings and they are very good at supporting her in doing what she wants.

At times Lily can become frustrated when interactions do not go her way. She will spit, kick, hit or scream and shout. Her parents have a time-out programme where Lily has to go until she apologises if she does not do so following her behaviour. Lily appears to understand this technique and, although she can become distressed in time-out, will eventually respond and apologise. At times, Lily can be distracted from whatever she is

doing that is unacceptable and will apologise immediately or change her behaviour. Lily is also very active, and finds it difficult to sit still and concentrate.

Lily is learning to be toilet-trained and has a sign that she uses to signal a need to use the toilet.

Lily has a passion for eating. However, because of her enzyme deficiency and Coeliac Disease, there are many things she cannot eat. Lily will overeat if given the opportunity and will get things from the kitchen if no one is watching. Consequently the fridge and freezer have locks on them and Lily's eating is monitored.

In general, Lily is described as being very loving and kind, and engages in lots of kissing and hugging behaviour with her family, particularly her parents. Lily is generally very happy and positive, but will at times laugh when others are hurt by her or through some other means. Lily struggles to grasp empathic concepts and has a limited understanding of the implications of her actions.

Formulation

Lily is a six-year-old girl with Angelman syndrome. This explains aspects of her difficulties in that she has limited verbal skills and is developmentally delayed. Lily is identified to use aggressive behaviours to communicate many of her needs. For example, when frustrated Lily may kick, hit, scream or shout. Similarly, if she does not get her own way and/or is angered. She does not always follow instructions or consider others, and can find it difficult to share/take turns with other people, particularly if they are new or younger than she is. In terms of Lily's ecology, Lily has a strong relationship with her parents, who may have inadvertently, through reinforcing Lily's efforts and providing attention when she is distressed maintained her difficulties.

Lily's behaviours have likely taken on the role of communication. She has some verbal words and uses these also but appears more likely, when frustrated or angered, to use physical expression to communicate. At times, Lily is able to manage these emotions better and will respond to others appropriately. Aspects of Lily's environment may be reinforcing her behaviours, for example, Lily's parent's use of time-out. Lily is able to

leave time out when she apologises which provides a reinforcing response as she can avoid her punishment (time out) at her own choice. Lily's lack of sharing skills may be evident as her parents can avoid her being put in situations in which she is required to make choices or share adequately, in order to reduce any aggressive behaviour that may follow. Through these contingencies, which provide reinforcement, Lily may have learnt her behaviours often get her what she wants reducing any need to develop other behaviours.

Lily is a positive and happy young girl who is generally easy to engage. She is able to imitate and understand some level of emotion and the behaviours of others. Lily could benefit from learning more about emotions, how they come about (i.e. through behaviours – kicking, hugging) and how to differentiate between behaviours which produce happy or sad outcomes. This would mean Lily could determine which type of behaviour to use when she wants to express herself and also consider others. Through practise Lily, who has a strong relationship with her parents, could also benefit from learning to interact appropriately with others. This, together with her increasing emotional knowledge will see her more able to share with her siblings and peers.

Intervention Outline

Lily's parents identified her problem behaviours to be mostly aggressive. Lily would lash out at other children she did not know in public areas and at school, taking the form of hitting, hair pulling, kicking and spitting. Lily would also on occasion engage in these behaviours with her family. She would at times not follow instructions or listen to what others said, and seemed to not be willing to apologise for her actions unless forced to do so. Lily was also identified, at times, to have difficulty with sharing and taking turns with others.

Based on the literature and this outline of Lily, the four-component model is used to address her difficulties with the following focus:

Ecological Component	Contingency Changes	New Skills	Emotional Component
Family Support – Lily has strong relationships with her family. This environment can be enhanced by appropriate reinforce of behaviours and modelling alternatives for Lily.	**Rewards** – marbles in her jar, treats, attention for the display of appropriate behaviour. **Appropriate reinforcement** – teach Lily's parents how to avoid providing Lily with opportunities to avoid things she dislikes, e.g. timeout.	**Turn-taking and sharing skills** – Lily can benefit from learning how to appropriately interact with others. **Emotional Skills** – Lily can learn how to understand and name emotions to better understand the consequences of her actions.	**Emotional knowledge** – Lily can learn to understand emotions through modelling and role play to show what behaviours create which emotions, also to build empathy. **Emotion Labelling** – Lily can learn to identify which emotions are good and bad on a basic level so as to better understand their meaning when shown to her.

The specific techniques and discussions used to address these are described below in Lily's session outlines.

Session Number and Duration	*Focus*	Tasks Undertaken
1. Two hours.	***Relationship Building/ Sharing***	Playdough, matching games, puzzle, follow the leader, passing a koosh ball, drawing on a colouring mat

In this initial session, Lily was open to playing and interacting with me. We engaged in lots of varied activities and Lily was encouraged to take turns in most cases. Her mother and siblings joined in with some of the games. If Lily got frustrated and spat, then I would say 'no' or 'don't' and move on quickly paying minimal attention to this behaviour.

2. Two hours.	***Sharing/ Imaginative Play***	Outside play, matching games, puzzle, colouring-in, imaginative games

Lily was very tired during this session and had been off school due to a recent diagnosis of seizure disorder. Despite this, she participated well in activities and was able to do some copying (imitation games – faces). Lily liked to direct this game and enjoyed watching me, her sister and mother copy her. She did not wish to imitate a sad face and would get mad or cry if I did one. She also got impatient in imitating other's actions but would do so for a shorter length of time before wanting it to be her turn again. Upon discussion with her mother, it was thought that perhaps she would not imitate the sad face

and got distressed by it because she thought she was in trouble. Lily had no trouble imitating other actions and happy expressions and this was used to encourage Lily to practise showing these emotions.

3. Half hour.	**Feelings Exploration**	Singing about feelings, Playdough

4. One and a half hours.	**Feelings Exploration**	Singing about feelings, Playdough

Lily's mother suggested we now do one hour sessions as Lily was still very tired. The sessions were two days apart and had the same focus. The first session was quite short as Lily was not in a good mood and was aggressive toward me. Lily apologised and in the second of these two sessions we played with playdough with her mother. Lily's mother and I talked about feelings and did faces encouraging Lily to copy them and she did whilst we played. We also sang a song that her mother had about feelings and pulled the faces that went with it. Lily joined in with humming and copied us pulling the faces she recognised. Lily's mother and I discussed her mother taking a more central role in sessions and I would feed ideas to her as Lily was clearly responded to her mum's introduction and modelling of emotions much more than my own.

5 & 6. One hour each.	**Distinguishing Emotions**	Games, Drawing

Following from the previous week, sessions remained as two one-hour sessions with the same focus. During these two sessions, we played a game of snakes and ladders with faces on it and pulled faces when we landed on different squares. Although not interested in playing the actual game, Lily could pull the faces and participated by rolling the dice. Lily also did some card-sorting based on whether she thought actions would make her happy or sad. Lily had to look at different actions (e.g., a child pinching, children fighting, children smiling) for this task and would show the appropriate emotion on her face as she sorted these. Lily preferred to stack and play with the cards than sort them; however, she did show the emotions they represented for her. After this, we went outside and drew faces with chalk on the concrete, and Lily could imitate them and identify which ones were happy and sad.

7 & 8. One hour each.	*Understanding Emotions/ Consequences*	Face Ball, Games

In these two one-hour sessions, we used a ball that had a happy face drawn on one side and a sad face drawn on the other. When playing outside, Lily's mother and I would act out things like hitting, pinching, falling over and hugging and Lily had to choose which face matched the action. Eventually, Lily was able to do the acting and pull the appropriate face before we turned the ball around to indicate the correct face. She demonstrated multiple times without prompting that if she fell down it made her sad and to be helped up would make her happy.

9 & 10. One hour each.	*Appropriate emotions/ Summary*	Ball, Modelling, Imitation

In these last two hours, Lily was tired. Lily's father commented that she has been a bit moody for the last couple of weeks. This session was again separated into two one-hour blocks. The focus was to consolidate the emotional acting and use of the ball/correct facial expressions; however Lily was not in a good mood for these sessions. She took a bit of calming and cuddling from her mother to keep her from crying. In the first hour, Lily was not interested in interacting much but was able to spontaneously show a correct facial expression that matched one of her actions. It appeared that she was grasping what basic facial expressions (happy and sad) go with which actions and we all modelled this where possible. In the last hour on Sunday, Lily, her mother, her siblings and I all played outside for a while; however Lily was still quite unhappy and not interested in doing facial expressions or interacting with me. I discussed with her father what things we had tried and found useful throughout the 12 hours working together and at the end gifted the family the contents of the box of materials that we had used together.

Results

Lily's specific behavioural codes and her intervention results are as follows.

Empathy – **(Emotional Understanding)**

Lily shows appropriate emotions if someone else is happy/sad. Lily apologises when she has hurt someone (this includes with prompting).

Sharing skills – **(Pro-Social)**

Lily engages in turn-taking or sharing behaviour with someone else. This includes group interaction. This will be coded regardless of the nature of the activity and whether the activity/interaction is being carried out correctly. It will not be coded if Lily's behaviour is destructive or challenging toward herself, another person or materials.

Independent Activity – Materials **(Pro-social)**

Lily is engaging in activities that she is doing successfully (not destructively – no ripping, biting, ruining or hurting herself/others). However, success is evident in the handling of materials and does not require the task to be carried out correctly. This also includes computer playing, TV watching and any other independent activity.

Increasing understanding of basic emotions – **(Emotional Understanding)**

Lily identifies emotions and is able to name or imitate them when requested (or spontaneously). If prompted or asked, Lily can act out situations in which emotive responses (hugs, kisses) would be required and seek the appropriate reinforcement if these situations occur (e.g. fall over – go to someone for a hug, or others; if sibling falls over – go and give them a hug).

Aggressive/ Violent Behaviour – (**Aggressive Behaviour)**

Lily hurts or attempts to hurt herself, an object or another person verbally or physically. This includes any property destruction (such as punching a wall) or interactions with people (hair pulling, arguing, and yelling).

Using the codes identified above, the following results were obtained at baseline, intervention and follow-up. Table 8 and Figures 8, 9 and 10 display Lily's behaviours across the study.

Table 8 Lily's Baseline, Intervention and Follow-up coded behaviours (% of time)

		Behaviour Type				
		Pro-Social		Emotional Understanding		Aggressive
		Sharing	Materials	Empathy	Understanding Emotion	Aggressive Behaviour
Baseline Situations	School/Group	4.54	81.31		0.05	2.62
	Routine	52.02	6.13	0.86		1.70
	Independent	2.77	46.22	0.12		8.65
	Sibling	0.18	47.05			1.36
	Adult		51.17			0.09
Intervention Sessions	Session 1	88.37			0.34	
	Session 2	54.90	14.21		0.46	0.61
	Session 3	17.56	32.52	0.11	0.81	1.19
	Session 4	22.68	21.55	0.41	5.32	2.04
	Session 5	20.44	13.81	0.54	9.77	0.82
	Session 6	6.23	10.24	0.19		1.72
3-month follow-up	School/Group	8.90	49.59	0.80		6.81
	Routine	2.88	5.44			
	Independent	28.23	59.88			1.44
	Sibling		83.97			1.17
	Adult	44.17	27.30			1.29
6-month follow-up	School/Group	6.34	21.12			2.12
	Routine	30.94	61.82			
	Independent	9.54	39.54			2.44
	Sibling		44.81	2.46		6.12
	Adult	5.56	65.71			0.70
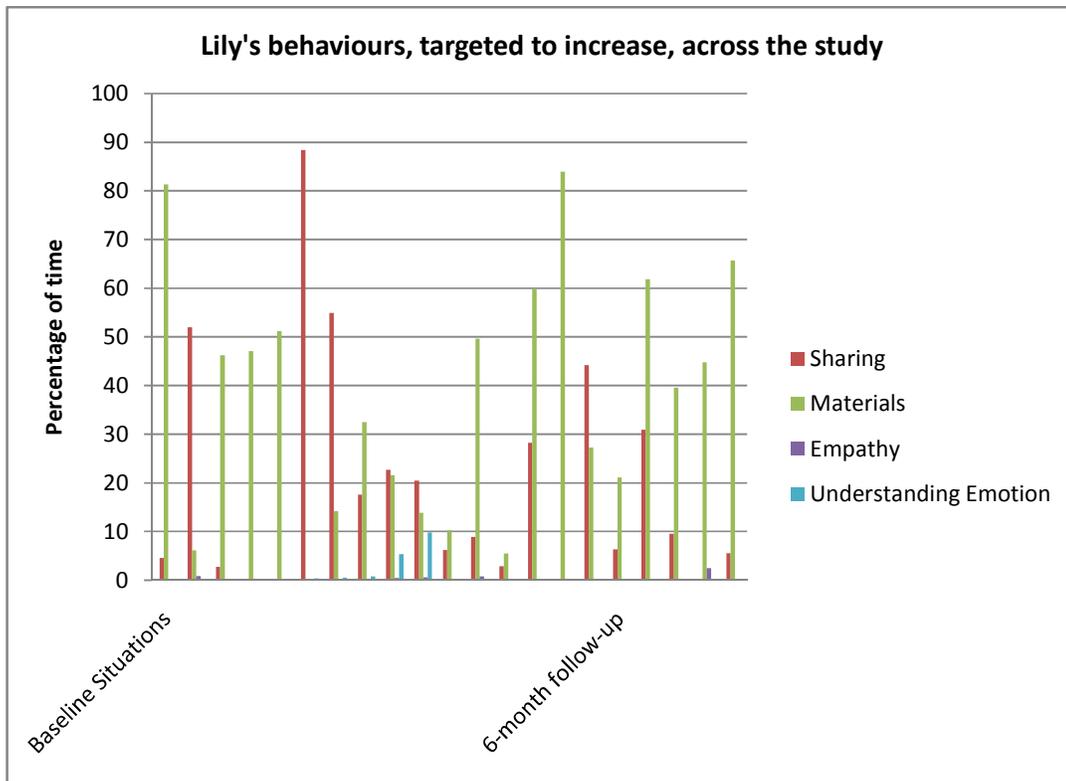
Figure 8 Lily's behaviours, targeted to increase, across the study
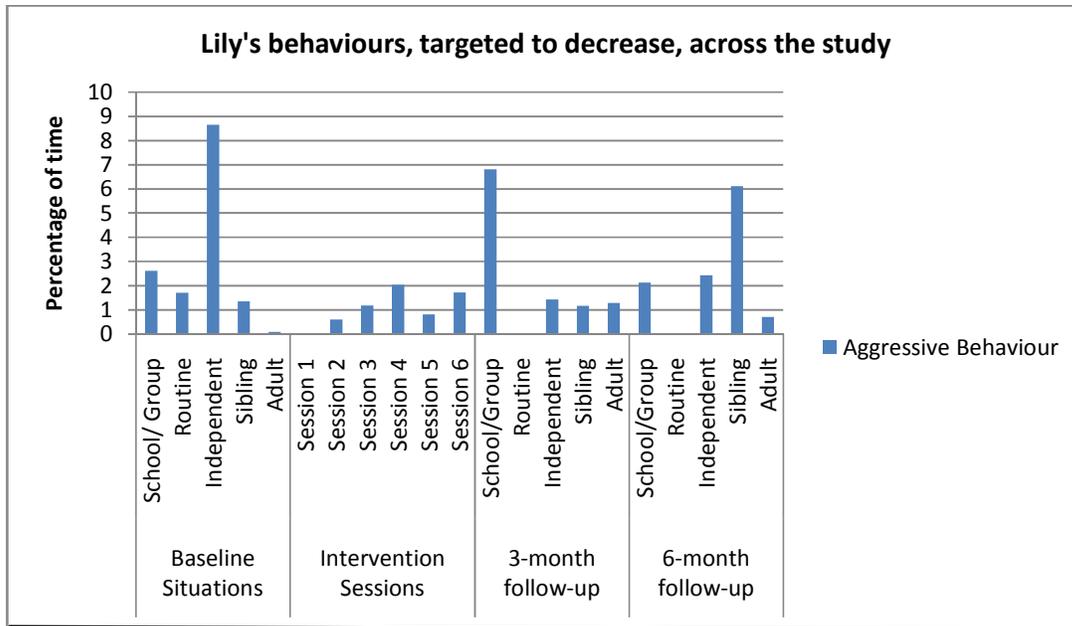
Figure 9 *Lily's behaviours, targeted to decrease, across the study*

Figure's 8 and 9 show Lily's targeted behaviours in terms of those targeted to increase or improve across the study and those to decrease.
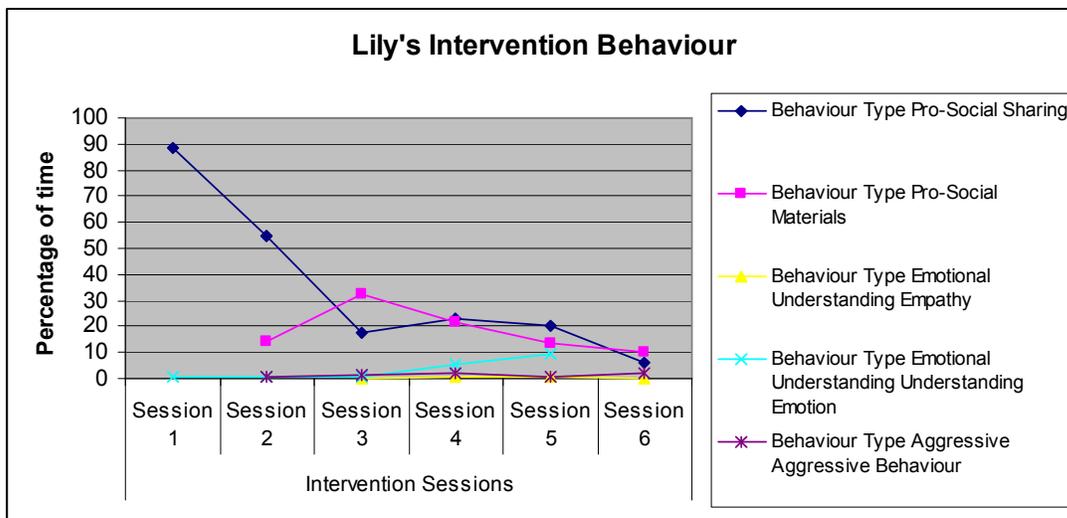
Figure 10 *Lily's intervention behaviour*

Lily displayed aggressive behaviour in every baseline observation ranging from being evident less than 1% to 9% of the time. Materials interactions were also evident for Lily in every baseline situation, ranging from 6% to 81% of the time. Empathy was observed for Lily in two situations; Independent and Routine, both of which were evident for less

than 1% of the time. Understanding emotion (or emotional understanding) was only observed for Lily in one baseline situation, that of independent play at less than 1% of the time. Sharing was evident for Lily in every situation other than in her interactions with an adult ranging from being evident less than 1 to 52% of the time.

Lily was observed to engage in all of the five behaviours coded for her throughout the intervention sessions (See Figure 10). Sharing behaviour was evident across all six intervention sessions ranging from 6% to 88% of the time. Materials interaction was observed for Lily in all except the first intervention session ranging from 10% to 33% of the time. Empathy was evident in Lily's behaviour in four of the six intervention sessions and was in all cases evident less than 1% of the time. Lily was observed to display behaviour indicative of understanding emotions in five sessions ranging from less than 1% to 10% of the time. Aggressive behaviour was evident for Lily in all of the sessions other than the first one and this ranged from being evident less than 1% to 2% of the time.

Sharing behaviour was evident across all six intervention sessions in contrast to at baseline where sharing behaviour was more sporadic (evident in four out of five observations). Similarly, Lily's materials interactions were more consistent across the intervention (evident in five sessions). Although this behaviour was evident across all baseline observations as well, it was much more sporadic (6% of the time to 81% of the time). Lily's emotional understanding showed a consistent rise throughout the intervention peaking at session 5 (10% of the time), in contrast to being evident only once at baseline observations for less than 1% of the time. Lily exhibited aggression across all baseline sessions peaking at 9% of the time as compared to intervention sessions were it was evident in five of the six sessions with a lower peak of 2% of the time. Empathy was evident in two of the baseline sessions and four of the intervention sessions with each occurrence being evident for less than 1% of the time with a high of 0.86% of the time in her routine observation.

Lily continued to consistently engage with materials at the 3-month follow-up ranging from 5% of the time to 84% of the time. Sharing behaviour was identified in four of the five follow-up situations, excluding sibling interaction (ranging from 3% of the time to 44% of the time). Empathy was observed once in a group situation evident at less than 1% of the time. Aggressive behaviour was observed in four of the five situations,

excluding Lily's routine and ranged from 1% of the time to 7% of the time. Understanding of emotions was not observed in Lily's 3-month follow-up observations.

Interaction with materials was evident at every situation at 6-month follow-up, ranging from being evident 21% of the time to 66% of the time. Sharing behaviour was observed in 4 of the 5 situations, excluding sibling interaction and ranged from being evident 6% of the time to 31% of the time. Empathy was observed once for Lily when engaging with her siblings at 2% of the time. Aggressive behaviour was observed in four of the five situations excluding Lily's routine and ranged from being evident less than 1% of the time to 6% of the time.

Lily consistently showed behaviours of sharing and interacting with materials. Understanding of emotion was evident only during intervention, whereas empathy was observed at least once across each stage, occurring most frequently (in four out of six) at intervention. Aggressive behaviour was also consistently evident across the different stages of the study; however, this behaviour was evident at every baseline situation and only in five out of six intervention sessions and four out of five of each of the follow-up situations.

Table 9 and Figure 11 below display Lily's mean levels (percentage of time) of behaviours across the four stages of the study.

Table 9 *Lily's behaviour means, by target behaviour, across the study*

	Baseline	Intervention	3-month	6-month
Sharing	11.90	35.03	16.84	10.48
Materials	46.38	15.39	45.24	46.60
Empathy	0.20	0.21	0.16	0.49
Understanding Emotion	0.01	2.78	0.00	0.00
Aggression	2.88	1.06	2.14	2.28
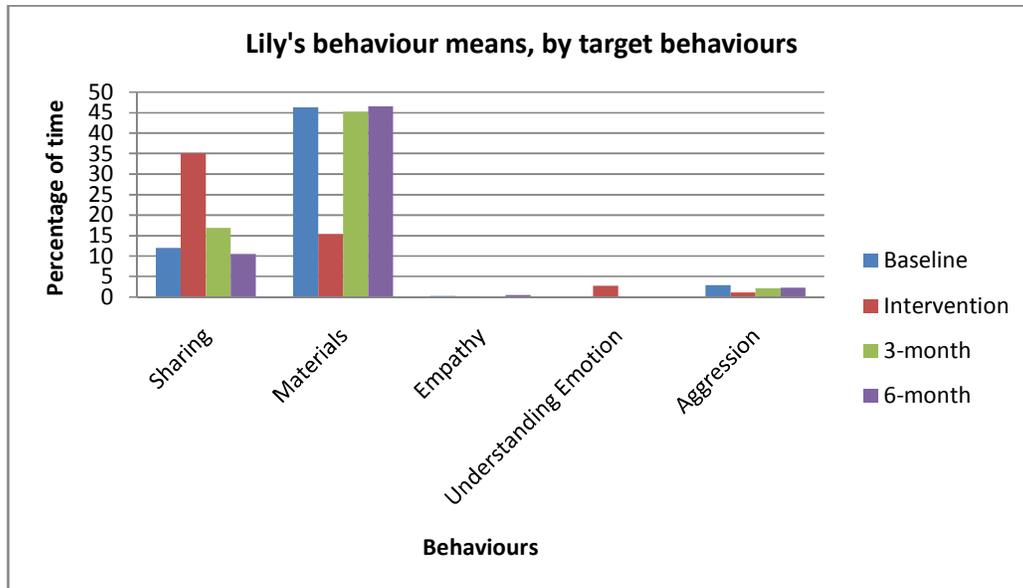
Figure 11 *Lily's behaviour means, by target behaviour*

Lily's mean percentage of time engaging in each behaviour (as shown in Figure 11) identify that her materials and sharing interactions were consistent across baseline and follow-up in terms of percentage of time spent engaging in each. During the intervention, Lily's sharing behaviours peaked and materials interactions decreased. Lily's empathy was always low throughout the study and her understanding of emotion was highest during the intervention. Lily's level of aggression was highest at baseline.

Lily's overall mean change in behaviour from baseline to intervention was very small (SMDall = -0.02). When calculating Lily's SMD for each specific behaviour independent of the others, the following effect sizes were obtained between baseline and intervention, explained based on Cohen's (1988) criteria for significance of effect sizes. A large effect was evident in sharing behaviour which increased by 0.9, a medium effect in materials interaction which decreased by 0.6, and a small effect in understanding of emotion which increased by 0.23 and the other two effect sizes although evident were of very small significance with empathy increasing by 0.007 and aggression decreasing by 0.06. Her aggressive behaviour effect sizes, utilising PZD, represent decreased behaviour at intervention, follow-up and overall (PZD = 17%, 20%, & 19% respectively). This outlines that overall, Lily's aggressive behaviour reduced by 19% throughout the period of the study.

CBCL Results

Lily's parents filled in the Child Behaviour Checklist/ 6-18 Parent Form (CBCL 6-18) at all four stages of this study to provide information about her competencies, emotional functioning and behaviour problems.

On the competence scales, Lily's scores were in the normal range across all four stages of the study for her activities interaction. For her social and school interactions, Lily was in the clinical range across all four stages of the study. This indicated that in contrast to her age-matched peers, Lily had no difficulties with activities but was unable to participate in the same way in social and school environments as her peers. Lily's total competence scores across all four stages place her in the clinical range.

Table 10 shows Lily's problem behaviour profiles, across the four stages of the study.

Table 10 *Lily's CBCL Problem Scale Categories across the study*

	Baseline	**Intervention**	**3-Month**	**6-Month**
Anxious/Depressed	Normal	Normal	Normal	Normal
Withdrawn/Depressed	Normal	Normal	Normal	Normal
Somatic Complaints	Normal	Normal	Borderline	Borderline
Social Problems	Borderline	Borderline	Normal	Clinical
Thought Problems	Normal	Borderline	Normal	Borderline
Attention Problems	Clinical	Clinical	Clinical	Clinical
Rule-Breaking Behaviour	Normal	Normal	Normal	Normal
Aggressive Behaviour	Borderline	Clinical	Clinical	Borderline

Scores on the CBCL 6-18 Problem Scales were similar for Lily across all four stages of the study. Lily's parents reported that, across all four stages Lily was in the normal range for anxious/depressed, withdrawn/depressed behaviours and rule-breaking behaviours. Somatic complaints were in the normal range at baseline and intervention but had increased to the borderline clinical range at both 3 and 6-month follow-ups (with an increase in skin problems and stomach difficulties). Social problems were in the borderline clinical range at baseline and intervention, dropping to the normal range at 3-month follow-up and increasing to the clinical range at 6-month follow-up. The

difference creating the change from normal to clinical range in Lily's parent's ratings was an increase of accident-prone behaviour and clumsiness. Thought problems were in the normal range for Lily at baseline and 3-month follow-up. For both the intervention and 6-month follow-up ratings, Lily's scores placed her in the borderline clinical range. This was evident due to an increase in skin picking, difficulties sleeping and getting mind off thoughts. Attention problems were consistently evident as being in the clinical range across all four stages. These appeared to increase across the stages with a peak at 3 and 6-month follow-ups. These peaks are indicative of more frequent recordings of difficulty with school work and impulsivity. The last scale, aggressive behaviour, was in the clinical range at intervention and 6-month follow-up and in the borderline clinical range at baseline and 3-month follow-up. The increase to clinical range is evident in increased scores of demanding attention, destroying things, being disobedient at school and attacking people.

Overall, these results indicate that attention problems are the most significant and consistent difficulty for Lily. Social problems and aggressive behaviour were both also at times identified as being in the clinical range when matched with Lily's peers. Talking of suicide or worthlessness was not endorsed by Lily's parents for her at any stage throughout the study.

Interview Data

Lily's parents were both present for her three month follow-up interview, and at 6-months I spoke with her mother. Interviews ranged in time with the first one being 20 minutes long and the second one 40 minutes.

3 month follow-up

The 3 month interview session was kept short as Lily had been hospitalised that day and her family were all very tired. At the 3 month interview, Lily's parents outlined that they have found it interesting having me involved and getting new ideas. Her mother commented that as I knew "Lily at the best of times takes a while to get to know people" and "Although it was every week, having those breaks may have made it difficult for her

to carry on with what she was doing with you." These comments were surrounding how they had found my involvement with Lily.

Emotions

Lily's mother outlined that she was aware I was working on emotions with Lily but that she thought Lily had found it difficult to concentrate and pay attention at times. Lily's mother described her emotions in the following way, "I've always known that she has the emotion, having her able to communicate them better is something we are always … trying to better in some way …. A lot of it was frustration originally, but now with more words coming, I think it's more about stubbornness …. She is showing a little more empathy, but it's not all the time... I guess we don't as often as we maybe could mention all of our emotions…."

Family relationships

When discussing family relationships Lily's mother replied that "Lily has I think equal legions with me and (Lily's father) … and if something isn't going her way and she is with dad, she wants me…." And when asked how Lily interacted with her siblings her mother responded "Lily is pretty good with both of them, how she feels about them, think she loves them both to bits." And in terms of how Lily's siblings interact with and see her she offered the following "There are times they go overboard but they are only kids, they are amazing" and that she thought Lily's siblings saw her as "a child with special needs, but, ah, a .. cheeky sister who is probably going to need extra protection…They know the opportunities for her aren't really the same… they are accepting of it… there may come a time they are less accepting of her… we hope that won't come…."

Behaviour

Lily's mother outlined that Lily makes them laugh/happy a lot. "Well she made us laugh at the hospital… she got (brother) to hop on the hospital bed…. and she pretended to saw off his bad knee" and in general Lily "cuddles and kisses… she sings." When asked about the last time Lily had made them feel sad, her mother outlined "I was upset tonight, just when she was not understanding what they were doing, they were trying to get the needle in…It's really sad that she doesn't understand." She explained this further by adding "I don't get angry with her or anything… generally it's um it's accepted as part of who she is and you just get on with it."

Lily's parents were asked how they would respond to criticism of Lily and responded "Depending on what frame of mind I'm in, if I can be bothered… I've often apologised if she's hit someone…. But um, generally I haven't said anything… just sort of, apologise… otherwise, I have thought of what I would say... Well Lily has Angelman syndrome if you'd like to have a little Google of it and understand you might not be so ignorant… just trying to be calm… just educate them."

Lily in 5 year's time

Lily's mother outlined her thoughts about her in 5 year's time "I see her happily in school, with a group of friends, buddies, … how old will she be, 11 – yeah… talking a lot more… just yeah being… hopefully with seizures and all of that under control and yeah just still being happy, happy with life – yep… we want her to do everything she can… don't look that far ahead really though… just happy I hope."

Other comments

Lily's parents offered some final feedback to me "Wish you well with it, pretty challenging thing to do, coming in to a family and yah know doing what you are doing and we are still parenting her 24-7 and we are still at losses sometimes about how to deal with things… sometimes it takes a different perspective… that's why we were open for it… the more hints we can get… you are a very likeable person… you just fit it in… I felt sometimes I wasn't really providing the right observations and thing but I thought you'd tell me…"

6 month follow-up

Lily's 6 month interview with her mother was just after the last school holidays for 2009.

General changes

Lily's mother began by explaining changes over the last 3 months for Lily, she commented that Lily is "On a new lot of drugs now and the absence seizures, I would have said up to about the last 3 days, were almost gone… we've got a specialist appointment next … Seizures seem to be controlled relatively successfully at the moment." She also identified that Lily is developing and learning more and that "the reaction to her knowing more is that she is going to try you know, more… try more out

on us." She also explained that Lily has "heaps more words, lots more attempts at it, very musical… following the tune and humming and keeping the rhythm and the length of sound… doing alright... trying the words… she'd have about 80-90 and the benchmark was 10-20" (words).

Emotion

When discussing emotions for Lily, her mother stated "no no I wouldn't think there is any improvement… if anything… possibly even worse… she just doesn't seem to understand… she's just learnt that word now too, to say sorry clearly… her being able to say sorry will probably help with that process …even though it might be a hollow sorry… it's still early days for it..."

Relationships and Behaviour

Lily's mother outlined the relationship Lily has with her siblings by stating she "Still just loves them to bits, but just goes a bit over the top… still, not quite so bad at playgrounds… probably in the last year… when I go out places I still think is it going to be busy there, well we won't go… there are a few we do go to… the incidences of her actually hurting a stranger are less, I think that's probably just cos I monitor it and plan it slightly better…It's just relentless really… if you've got little ones…." In relation to her and her husband and their relationship with Lily, she responded "She (Lily) seems to be favouring me (mum) a bit at the moment… it's nice for bonding, to have a little cuddle."

5 years time

Lily's mother discussed her thoughts on where Lily would be in 5 year's time and responded "I don't even really think of it, I see her probably… I guess... at school, doing her thing… hopefully still having a large people of involved… so hopefully we've got some good respite care, and she's happy really… and causing a little less stress. It's just sort of that terrible twos, is what she is doing at the moment… hopefully the drugs will be sorted… that's an up and down thing…I think she is pushing the boundaries of being one of the hardest with most aspects at the moment, refusing to move… I hope that improves, cos physically I don't know if I will be able to cope… verbally I think she will really take off… hopefully…."

Summary

Overall, Lily's results represent evidence of increased emotional understanding and empathy throughout the intervention stage of the study as evidenced by her observations and to a lesser extent her SMD statistics. Although aggressive behaviour continued to be evident for Lily throughout the study, the peak for this remained at baseline. Lily's SMD statistics also showed a large effect in her change in sharing behaviour (0.90) identifying this as a significant area of change for her. CBCL data indicated changes in behaviours for Lily across the study identifying attention problems as consistently the most significant area of difficulty for Lily. Interview data highlighted that Lily's parents found the new tips and ideas for behaviour management with Lily to be a helpful outcome of the study for them.

CHAPTER SIX: HOHEPA

This chapter describes Hohepa, who was one of the participants in this study. It provides an overview of Hohepa's diagnoses, his background and current functioning and the details the 12 hours of intervention, and then presents the data relate d to this case.

Diagnoses

Hohepa is a 15-year-old male who has Smith Magenis Syndrome and Attention Deficit Hyperactivity Disorder (ADHD). Smith Magenis Syndrome, as outlined in the introduction, is a neurogenetic disorder. This syndrome is characterised by features such as behavioural abnormalities, including self-injurious behaviours, sleep disturbance, and distinct craniofacial and skeletal anomalies (Girirajan, Elsas, Devriendt & Elsea, 2005; Smith, Dykens & Greenberg, 1998). Attention Deficit Hyperactivity Disorder (ADHD) is characterised by difficulties with inattention and/or hyperactivity as well as behavioural difficulties. Emotional deficits may also be evident (Lovecky, 2004).

Family Background

Hohepa is of Māori descent and has four siblings. Three of his siblings are younger than him and one is a year older. Hohepa lives mostly with his biological mother and three siblings. For three weekends of every four weeks, he stays with his biological father, stepmother and youngest sibling. Hohepa gets on well with everyone in his family. For the most part, he keeps to himself, however, when interacting with his siblings he can participate in activities such as drawing and games well. He will on occasion be angered by them and hit them, but this is occurring less and less frequently (according to his mother). Hohepa responds best to his eldest brother and father, followed by his mother. In general, Hohepa is well-behaved and cheeky, and when interacting with his family will show these traits. Hohepa's mother looks after two young children during the week. Hohepa loves to help with them, but can at times be a bit too demanding of them. For example, he may encourage the baby to take his bottle even when he is not hungry by pushing it against his mouth.

Hohepa's family has access to Tautoko Services, who provide information on behaviour management and also on his Smith Magenis Syndrome itself. Hohepa is not involved in any other behavioural therapy programme.

Current Functioning

Medication

Hohepa currently takes the following medications: 1.5mg of Risperidone (nocte), Monday to Friday and 10mg of Dextroamphetamine Monday to Friday (mane; 5mg at 8am and 5mg at 10.30am). Risperidone is an antipsychotic medication utilised for improving behaviour. Dextroamphetamine is used to increase behaviour and mood and is a psycho-stimulant known to have side effects of increased wakefulness and has many associated potential side effects including anxiety, euphoria, fever, diarrhoea, dry mouth and headache. These side effects were not identified for Hohepa.

School

Hohepa attends a special unit at high school. His classroom programme includes activities such as cooking, crafts and puzzles. He enjoys cooking and doing puzzles the most. At school, he is more aggressive and acts out physically at the teacher aides regularly if he disagrees with what they are asking of him. He does not always respond to instructions and can ignore people when they talk to him. He will attempt to run away from school and has to be cordoned off by a few teachers to get him to return. Hohepa can recognise and count numbers up to around 100 and recognise and spell basic words. Although sometimes unclear, he uses verbal communication reasonably effectively with complete sentences. Time-out seems to effectively calm him down for a period of time at school if he has acted violently.

Home

Hohepa enjoys playing on the computer, watching SpongeBob Squarepants, doing puzzles and helping with household chores (e.g., washing). He is at times impatient when helping at home and will carry out activities inappropriately. For example, he may bring the washing in when it is still wet or hang it out before the washing cycle has finished.

Hohepa is able to participate in family activities with little difficulty but needs to be monitored in many areas. For example, he will take the smaller children's food if they are not watching. He will also take food from the cupboards during the night and at times the cupboards and kitchen have had to be locked. He also struggles to concentrate and sit still to interact for long periods of time and may fail to complete tasks that he has begun. Following instructions is also difficult for him at times, although it is unclear if it is due to a lack of understanding or a desire not to do what is asked. This occurs much less frequently at home than at school.

Hohepa likes to do the same tasks regularly and takes time to warm up to new people and activities. When he has warmed to people, he is very affectionate and gives people handshakes and hugs when they arrive and leave. Every so often, he will act out at home, hitting or hurting somebody when he is angered or frustrated. He can also simply walk away if you are trying to engage or interact with him. Despite this, his behaviour at both homes is consistently better than it is at school and he creates minimal disruption here.

Hohepa has a sense of humour and will often try and trick or tease people when they are interacting with him. He is able to see the humour in things that others do. However, this can sometimes come across as immature behaviour.

Hohepa has a very high pain threshold and has in the past pushed holes through his bedroom walls and has many sores and skin surface injuries. He may be observed to do such things as put his head or hands in the oven without gloves to see what the food is doing without consideration of the heat and possibility of pain through touching things inside the oven.

Formulation

Hohepa is a 16-year-old male adolescent of māori descent. He shares his living time between his mothers and his father's homes. Hohepa has Smith Magenis Syndrome which accounts for some of his destructive and self-injurious behaviours. Although managing his anger is also a manifestation, in part, of his syndrome, Hohepa lacks the ability to communicate his feelings more appropriately (explaining or asking for what he requires) which may also contribute to his presentation. Hohepa, at times, appears to lack the

ability to think his actions through and understand their impact. Hohepa also has difficulty staying on task, completing activities, and listening to the directions of others. He appears to have a need for ongoing stimulation which for him is not met by persisting with tasks or activities. Unfortunately, people allowing him to stop these activities may also reinforce he is able to do as he wishes. Hohepa's environment may have contributed to his acting out behaviour as he has learnt particular behaviours provide him with stimulation and attention, or attention withdrawal e.g., his siblings being told to leave him alone (contingencies).

Hohepa's aggressive behaviours are evident across situations, but are most apparent at school. His frustration at being misunderstood, or not getting his own way, may activate inappropriate behaviour when others do not appear to respond as he intended, particularly when the person is unknown. Hohepa's high level of pain sensitivity may also be maintaining his physical behaviours as his environment does not provide a pain response upon impact (due to his high pain threshold). Hohepa's family are supportive, however at times his attempts to help and support them (i.e., care for baby, do the washing) are seen as being over-the-top (by his family) and not reinforced positively (Hohepa is told off, or asked not to help). This may mean he is struggling to identify how he is supposed to behave as both positive and aggressive behaviours receive attention. More confusingly, sometimes aggressive behaviours result in more caring (attention), if he has caused himself harm - further maintaining these as more useful than alternative behaviours.

Hohepa has a sense of humour and is able to respond to some societal cues. The use of modelling and shaping techniques to build positive behaviours, such as finishing tasks and interacting with others appropriately, will enable Hohepa to better understand behaviour. Through teaching emotion naming, modelling and consequences, Hohepa will also learn how to express his own emotions and understand those of others. Hohepa's relationships with his family will be beneficial in helping him to continue to shape more appropriate behaviour and receive appropriate reinforcement for doing so.

Intervention Outline

Hohepa's mother outlined the behaviour she wished to be targeted by this intervention. She highlighted that Hohepa has difficulty with controlling his anger and will hurt others

as well as himself. This involves hitting or kicking others, picking at his skin, putting his body parts into hot things without consideration or punching/ putting his head through the walls in his bedroom. He does not always listen to instructions given to him; however, this was identified to be most evident for him at school. Hohepa was reported to have difficulty with sticking to what he was doing and finishing things. He also liked to help at home but this could mean he would do things like make coffee when it was not wanted or hang out washing before it had finished the washing cycle.

Given this, in terms of the four component model, Hohepa's goals for intervention were as follows:

Ecological Component	Contingency Changes	New Skills	Emotional Component
Family Support – use of family support to help build Hohepa's knowledge of right and wrong and to appropriately reinforce behaviours. Also important for Hohepa's family to note his increasing capabilities and continue to encourage him to do more.	**Rewards** (for doing tasks) **Positive reinforcement**, - for on track behaviour and attempts (includes emotion naming) as opposed to negative (when misbehaving).	**Patience** – Hohepa to increasingly learn to see activities through and gain stimulation and confidence through mastery. **Interacting with others** – Hohepa to learn to engage with others rather than spend the majority of his time independently to meet his stimulation needs (rather than meet these through physical acts). Build **emotion labelling and understanding skills**	**Family session** for discussing emotions **Emotion naming** – use of cards to name emotion types **Emotion Sorting** – Build recognition of positive and negative impact of emotions. **Modelling behaviours** – to reinforce the place of emotions in actions. Building **confidence** through understanding emotions and task mastery

Based on the literature review undertaken and the emphasised utility of this model the specific techniques and discussions used to address these components are described below in Hohepa's session outlines.

Session Number and Duration	Focus	Tasks Undertaken
1. One hour.	*Relationship Building*	Puzzles, Playdough, Drawing and Number Games.

In this initial session, Hohepa was hesitant to interact with me. He would stay seated for only a few minutes before walking off. At this stage, he did not respond to me when I

went to retrieve him and his mother or older brother would need to direct him back to me. Throughout this session and for each of the following sessions, I was careful to praise Hohepa whenever he engaged in on-task behaviour and whenever he would respond and stay seated with me.

2. One hour.	*Matching Items and Concentrated Play*	Matching Game, Puzzle and Drawing

In this session, I concentrated on encouraging Hohepa to engage with me using a new matching game. This matching game involved pairing together pictures of animals. He was able to do this for an increased length of time. Following this, we also did a puzzle and some colouring together. During this session, we were able to stay seated together at the table for a much longer period of time. It had become clear that around 50 minutes was enough time for a session for Hohepa as he was telling me at this stage that he had 'finished'. Because of this, his future sessions were of one hour's duration instead of attempting to do two hours each time.

3. One hour.	*Concentrated Play and Good/Bad Emotions*	Matching Game. Emotion Matching Task.

This session was at his father and stepmother's house. Hohepa sat with me for nearly the entire 50 minutes, only wandering away once. After 50 minutes, he told me he was finished and wanted to help with packing things up. In this session, we used the matching game he had liked from the previous session and also began looking at an emotion matching task. This task involved matching a series of pictures of activities and facial expressions to whether they would result in someone feeling good or bad.

4. One hour.	*Emotional Understanding/ Concentrated Play*	Same as Session 3.

In this session, Hohepa was increasingly showing his sense of humour. He attempted to trick me with the pairs he matched and watched for my response. Sometimes he would

giggle or smile when he gave incorrect pairs to me first. He was also engaging in self-reinforcing behaviour when he got pairs correct, clapping and praising himself. We were able to spend more time on sorting the situations into piles of good and bad emotional responses this session. Hohepa was able to identify what most of the pictures were but appears to be guessing sometimes as to where he places them (good or bad). This was evident as, if I questioned him on his placement, he just swapped the pile.

5. One hour.	*Emotional Understanding/ Concentrated Play*	This session involved the same activities as Sessions 3 and 4 with the addition of a more basic emotion card sort.

In this session, I introduced a new, more structured emotion sort game with fewer cards. The game has 10 cards, 5 are happy and 5 are sad – for example a sad card is someone kicking another person and a happy card is two people hugging. The sad cards in this set are all behaviours that he engaged in. The idea was for him to learn that things he does have the potential to make people both sad and happy. We discussed these cards as he looked at them and, if he sorted them incorrectly, I would tell him the correct response after questioning why it went there and if he was sure. I also introduced a timer this session and set it to 50 minutes (and continued to do this in further sessions). Hohepa enjoyed playing with it.

6. One hour.	*Emotional Understanding/ Concentrated Play/ Mastery*	Matching Game, 10 Card Sort, Puzzle.

We now always start our sessions together with the matching game (and continued to do so for all of the rest of the sessions) as it appears to be settling for Hohepa. This is evident as he will continue to do it, look at me and seek approval and then continue onto the next tasks. He can do this original task in around 20 minutes and this was also being used to build his sense of mastery. Following this, we focussed on the emotion (ten cards) sort and I discussed these with Hohepa. He was now getting around six correct out of the ten without prompting. However, I was always discussing these with him as sometimes he will continue to change the pile simply because I have questioned him on it. At the end of the session, I gave him a puzzle to do to attempt to build up his confidence again by getting something consistently correct (he can easily do this puzzle).

7. One hour.	*Emotional Understanding/ Concentrated Play/ Mastery*	Same as Session 6 (minus puzzle at end).

This session was at Hohepa's father and stepmother's home. He was a bit distracted during this session with his matching game taking closer to 40 minutes. We still engaged in the 10 card emotion sort but did not have time to finish with the puzzle. Despite being distracted, Hohepa did not leave where we were working until we had been doing so for at least 50 minutes.

8 & 9. One hour each.	*Emotional Understanding/ Concentrated Play/ Modelling/ Mastery*	Same tasks as Sessions 6 and 7

These two sessions had the same focus as previously (sessions 6 and 7) with increased emphasis on the emotional sorting cards. I began in these sessions to act or show on my face the types of things that the cards show, for example, if the card is of hair pulling I will pull my own hair gently and say 'ow'. Hohepa can copy these actions and could by session 9 show me what the actions would look like if he was doing them (i.e., pulling his own hair, pretending to spit – or actually spitting). In session 8, Hohepa took some coaxing by his mother at the start to come and sit with me as he had been violent that morning (putting his head and fist through the wall), but once sitting down he sat with me for the entire session. Session 9 involved him being a bit more distracted than recent sessions and he got up halfway through and took a few minutes for me to get him back to settle (but I was able to do this unaided). He was increasingly joking and interacting with me, however, it was difficult to encourage him to be serious at times and subsequently was difficult to tell if he was tricking or believes the answers he is telling me.

10. One hour.	*Imitation of Emotions associated with actions/ Emotional Understanding/ Concentrated*	Matching game, Emotion card sort

	Play/ Mastery

In this session, Hohepa continued to imitate my actions associated with the cards and scenarios. He could also act many of the cards himself. He was still trying to trick me with some of his responses and finds it funny when I tell him not to do this. I worked on being more serious myself in the session so he could concentrate more. Hohepa sat with me for only about 45 minutes in this session.

11. One hour.	*Same as Session 10.*	Same as Session 10.

Hohepa, in this session, sat for only about 40 minutes but was very productive in this time. He was able to show his mother how he gets almost the entire card sort correct now. He can use extra words and actions to describe the cards and will say things like 'poor boy' and 'he hit me' to indicate his understanding of the cards. He was also increasingly doing his puzzle and matching game much more efficiently, showing signs of memory of the tasks increasing (requires very little instruction) and was also self-reinforcing a lot more with phrases like 'you did it' and 'well done" to praise himself. In terms of memory involved in the matching game, Hohepa would increasingly scan for a card that he previously had held in the correct area of the table to identify a pair. He was also trying to trick me much less and I was reinforcing this as much as possible to accompany his own self-praise.

12. One hour.	*Imitation of Emotions associated with actions/ Emotional Understanding - Extended/ Concentrated Play*	Matching game, Puzzle, Emotion card sort – extra 7 cards

Hohepa and I followed our established routine of the last few sessions and began with the matching game. Following this, we worked with the emotion sorting cards and I added in 7 extra cards. Hohepa had no problem sorting these and aside from trying to trick me repeatedly with these extra cards, he could sort them all properly and well. He can now describe all of the cards and do some modelling without prompting of what the cards

represent. When prompted, he could also imitate other actions. He could consistently and easily do the puzzle now as well and will praise himself when doing some of the tasks. I gifted the family all of the resources we have been using and his mother commented on wanting to continue to use the emotion sort and is going to share this with the school.

Results

The results of Hohepa's data are provided below following an outline of the specific behavioural codes defined.

Mastery and confidence – Materials (**Pro-Social**)
Hohepa is engaging in activities that he is doing successfully (not destructively – no ripping, no biting, no ruining or hurting himself/others). However, success is evident in the handling of materials and does not require the task to be carried out correctly. This includes computer playing, TV watching and any other independent activity.

Mastery and confidence – Interactions **(Pro-Social)**
Hohepa is engaging in activities that he is doing successfully (not destructively – no ripping, no biting, no ruining or hurting himself/others). However, success is evident in his ability to engage in interactions and does not require that this involves correct sentence use/pronunciation.

These codes refer to confidence and mastery rather than attention as Hohepa will be demonstrating not only spending time in one place but also skill (lack of destruction/frustration) in doing so.

Emotional Understanding – **(Emotional Understanding)**
Hohepa identifies emotions and is able to name or imitate them when requested (or spontaneously). Hohepa can name situations where certain emotions would occur and demonstrate actions of these (e.g., act out hair pulling – gently) and name the emotion it would evoke for the person being hurt (e.g., sad, grumpy). In everyday interactions this will involve any emotional identification that Hohepa makes.

Empathy – **(Emotional Understanding)**

Hohepa shows appropriate emotions if someone else is happy/sad. Hohepa apologises when he has hurt someone (this includes with prompting).

Aggressive/ Violent Behaviour – **(Aggressive Behaviour)**

Hohepa hurts or attempts to hurt himself, an object or another person verbally or physically. This includes any property destruction (such as punching a wall) or interactions with people (hair pulling, arguing, and yelling).

Using the codes identified above, the following results were obtained at baseline, intervention and follow-up. Table 11 and Figures 12, 13 and 14 outline the results for Hohepa.

Table 11 *Hohepa's Baseline, Intervention and Follow-up coded behaviours (% of time)*

		Behaviour Type				
		Pro-Social		Emotional Understanding		Aggressive
		Interactions	Materials	Empathy	Understanding Emotion	Aggressive Behaviour
Baseline Situations	School/Group	10	70			20
	Routine	6.49	79.65			
	Independent	12.21	84.94			
	Sibling	8.84	32.08			
	Adult	3.34	18.09			
Intervention Sessions	Session 1	10.91	40.96			
	Session 2	30.96	78.27			
	Session 3	28.74	61.98		18.99	
	Session 4	38.95	75.04	1.02	17.87	
	Session 5	32.14	63.71	0.47	26.98	1.60
	Session 6	46.74	97.67	2.38	35.08	
3-month follow-up	School/Group	50.00	20.00			3.33
	Routine	17.21	57.62			1.17
	Independent	6.10	35.96			
	Sibling	20.90	12.25			
	Adult	14.82	58.00	0.47		1.30
6-month follow-up	School/Group	46.67	20.00			
	Routine	17.80	0.52	0.21		2.66
	Independent	1.62				
	Sibling	22.96	15.38	0.67		
	Adult	40.71	39.96			
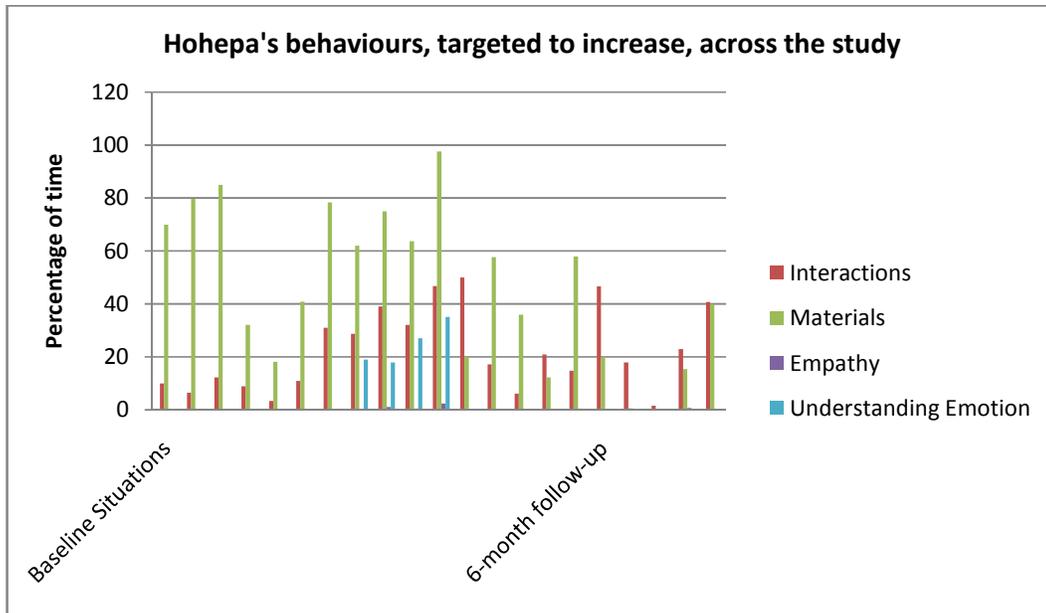
Figure 12 *Hohepa's behaviours, targeted to increase, across the study*
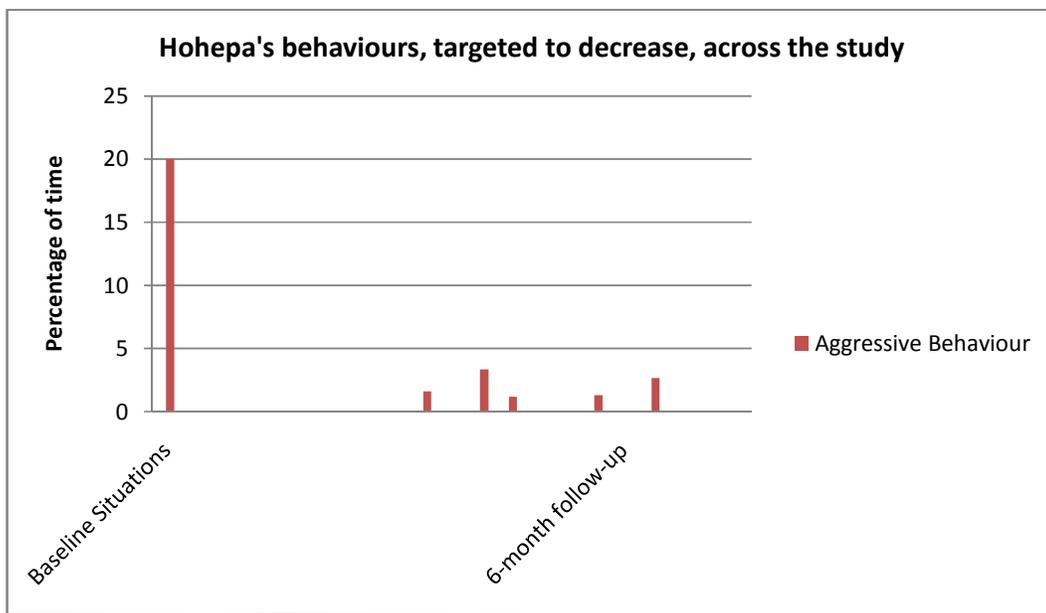
Figure 13 *Hohepa's behaviours, targeted to decrease, across the study*

Figure's 12 and 13 portray Hohepa's target behaviours across the study in terms of whether they were targeted as behaviours to increase or decrease.
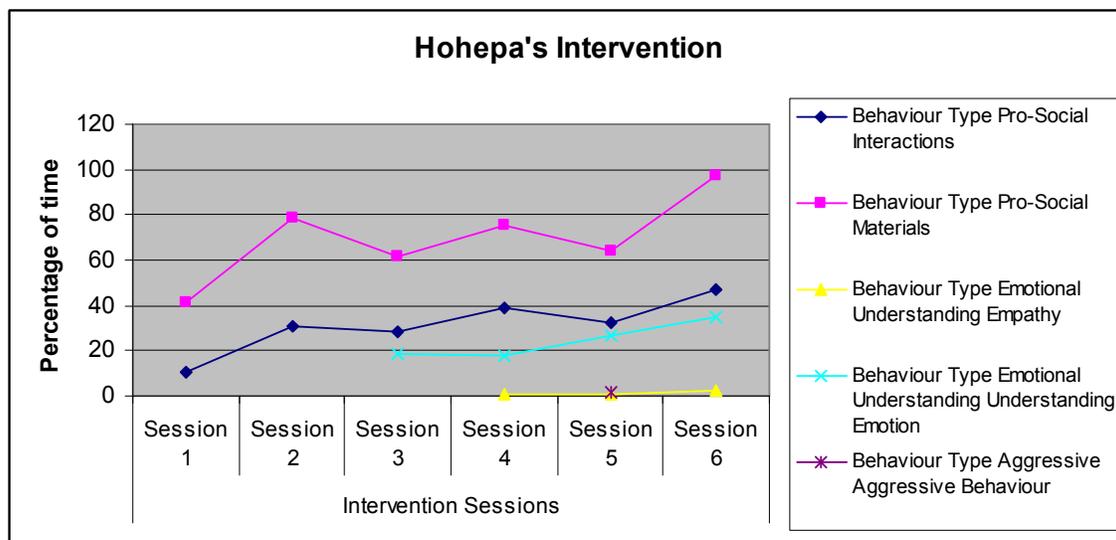
Figure 14 *Hohepa's intervention behaviour*

Hohepa engaged in aggressive behaviour in one situation at baseline and this was school/ group 20% of the time. Hohepa displayed no empathy or understanding of emotion at baseline observations. His interactions ranged from occurring 3% to 12% of the time. Materials interaction was evident for Hohepa between 18% and 85% of the time in baseline situations.

During intervention sessions (see Figure 14), Hohepa engaged in two new behaviours not evident at baseline observations. He displayed empathy in three sessions ranging from less than 1% to 2% of the time. He was observed to be displaying an understanding of emotion in four of the six sessions, ranging from 18% to 35% of the time. His aggressive behaviour was only evident in one of the intervention sessions for a total of 2% of time for that session. Hohepa engaged in interactions in each session ranging from 11% to 47% of the time. His interactions with materials were also evident in all six of the sessions ranging from 41% to 98% of the time.

Hohepa's materials interactions were consistently evident throughout baseline and intervention sessions. At baseline Hohepa spent the majority of his time interacting independently with materials (70% to 93% of the time) in contrast to intervention where although still popular as a behavioural choice for Hohepa, other behaviours such as, his interactions with others, understanding of emotions and empathy all also increased. Understanding of emotions and empathy were not evident at all at any of the baseline

sessions. At the intervention stage across the last four sessions, Hohepa demonstrated an understanding of emotion which peaked at being evident 35% of the time, his peak for empathy evident in three intervention sessions was 2% of the time. Hohepa displayed one instance of aggression at baseline for 20% of his school observation and one in session five of the intervention for 2% of the time, identifying a drop in aggressive behaviour between baseline and intervention.

At Hohepa's 3-month follow-up, he continued to consistently show behaviours of materials (ranging from 12% of the time to 58% of the time) and people interactions (ranging from 6% of the time to 50% of the time). Hohepa was observed to display empathy once in his interaction with an adult, evident less than 1% of the time. Hohepa also displayed aggressive behaviour at school, in his routine and with an adult (3%, 1% and 1% of the time respectively). Hohepa was not observed to display behaviours indicative of understanding of emotion at his 3-month follow-up observations.

At his 6-month follow-up Hohepa displayed consistently interactions across all five situations (ranging from 2% of the time to 47% of the time). He was observed to engage with materials in all situations other than independent activity. This behaviour was evident ranging from less than 1% of the time to 40% of the time. Empathy was also observed twice at this stage of the study for Hohepa during sibling and routine interactions, less than 1% of the time each. Aggression was observed in one situation for Hohepa, during his routine, at 3% of the time.

For Hohepa, the most consistently evident behaviour across all four stages of this study was interactions with others, seen at each session. Materials interactions were apparent at every session other than Hohepa's final observation in independent activity. Empathy was observed at three stages of the intervention and again three more times since then, once at the 3-month follow-up and twice at the 6-month follow-up. Hohepa's aggressive behaviour was sporadic and evident in every stage of the study but at the most only 3 out of 5 sessions at his 3-month follow-up. His aggressive behaviour never reached as high again in his observations as at his first school observation. Understanding of emotion was observed only during the intervention.

Table 12 and Figure 15 below detail the means of all of Hohepa's data by target behaviour, across the four stages of the study.

Table 12 *Hohepa's behaviour means, by target behaviour, across the study*

	Baseline	**Intervention**	**3-month**	**6-month**
Interactions	8.18	31.41	21.81	25.95
Materials	56.95	69.61	36.77	15.17
Empathy	0.00	0.65	0.09	0.18
Understanding Emotion	0.00	16.49	0.00	0.00
Aggression	4.00	0.27	1.16	0.53
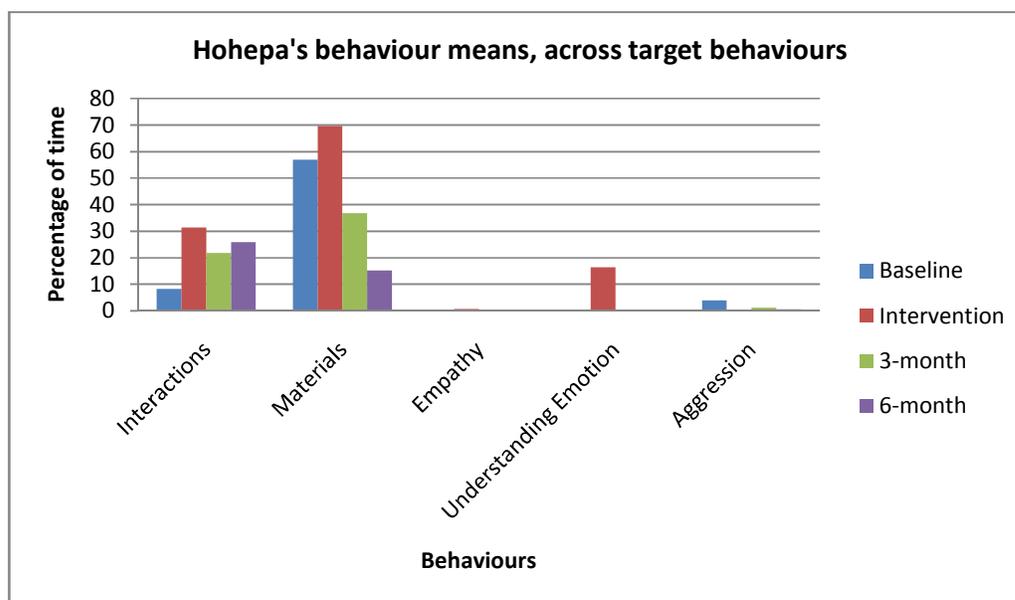
Figure 15 *Hohepa's behaviour means, by target behaviour*

Hohepa's mean behaviours, as shown in Figure 15, (percentage of time engaged in behaviour) identify that per target behaviour across the study there was little evidence of empathy and aggression. Aggression peaked at baseline but all mean scores were under 10%. Hohepa's interactions and understanding of emotion peaked during the intervention stage of the study, as did his interaction with materials.

Overall, the mean difference in Hohepa's behaviours throughout the study was very small (SMDall = 0.27; based on Cohen's criteria, 1988). His specific behaviour effect sizes using SMD are as follows across baseline and intervention. A large effect was evident in interactions with an increased effect size of 3.24, a medium effect in decreasing aggressive behaviour (0.60) and a very small effect size with interaction with materials

increasing by 0.05. This calculation was unable to be performed for empathy and understanding of emotion as these behaviours were not evident at baseline, however in intervention empathy was evident 0.65% of the time and understanding of emotion 16.48% of the time. His reductions in aggressive behaviour were calculated at intervention, follow-up and in total with the following effect sizes noted (PZD = 83.33%, 60%, & 62.5% respectively) outlining that overall from baseline Hohepa's aggressive behaviour reduced 62.5%.

CBCL Results

Hohepa's mother filled in the Child Behaviour Checklist/ 6-18 Parent Form (CBCL 6-18) at all four stages of this study to provide information about Hohepa's competencies, emotional functioning and behaviour problems.

Hohepa's scores on the competence scales indicated that at baseline, Hohepa was in the borderline clinical range for engagement in activities and the clinical range for social interactions. At intervention, Hohepa was in the normal range for activities interaction and the clinical range for social interactions. At both the 3 and 6-month follow-ups, Hohepa was reported by his mother to be in the clinical range for activities and social interactions. This indicated that Hohepa struggles with social interactions in comparison with his age-matched peers and can at times engage in activities at a level comparable to his peers but also has difficulties with this. Scores for school competence were not provided as Hohepa does not engage in mainstream curriculum subjects and therefore a total competence score was not able to be calculated at any stage for Hohepa.

Table 13 below outlines Hohepa's problem behaviour scales across the four stages of the study.

Table 13 *Hohepa's CBCL Problem Scale Categories across the study*

	Baseline	Intervention	3-Month	6-Month
Anxious/Depressed	Normal	Normal	Normal	Normal
Withdrawn/Depressed	Normal	Normal	Normal	Normal
Somatic Complaints	Normal	Normal	Normal	Normal
Social Problems	Normal	Normal	Normal	Normal
Thought Problems	Clinical	Borderline	Normal	Normal
Attention Problems	Clinical	Normal	Normal	Normal
Rule-Breaking Behaviour	Normal	Normal	Normal	Normal
Aggressive Behaviour	Clinical	Clinical	Normal	Normal

On the problem scales, Hohepa's mother's ratings placed him in the normal range across all four stages of the study for anxious/depressed behaviours, withdrawn/depressed behaviours, somatic complaints, social problems and rule-breaking behaviour. Thought problems were rated initially at baseline as being in the clinical range, and dropped to borderline clinical range at intervention and both follow-up ratings placed Hohepa in the normal range. The decrease in these ratings were evident in a decrease of self-harm, decreased difficulty in getting thoughts of his mind and decrease in repetitive acts. Attention problems were in the clinical range for Hohepa at baseline but all other ratings place him in the normal range with decreases most evident in acting young, concentrating problems, and impulsivity and increases in sitting still and attention. Aggressive behaviour also followed this trend; they were in the clinical range at both baseline and intervention and had dropped to the normal range by both 3 and 6-month follow-ups. Decreases in aggressive behaviour were most evident in less arguing, destruction of property, disobedience, screaming, sulking and teasing. None of Hohepa's ratings were consistently in the borderline clinical range or the clinical range. Feelings of worthlessness or talking of suicide were at no point endorsed for Hohepa by his mother.

Specifically, it appears that Hohepa's most significant difficulties were with thought problems, attention problems and aggression. However, none of the follow-up ratings for these or any of the other scales remained in either the borderline clinical or clinical ranges indicated decreases in all of these difficulties over time.

Interview Data

Interview/discussion was carried out with Hohepa's birth mother following his three and six-month follow-up observations. At both stages, his mother was the only adult present. The first discussion with Hohepa's mother was 48 minutes and the second at six-months post intervention was 67 minutes.

3 month follow-up

Changes over time

Hohepa's mother outlined that Hohepa is currently focussed at school, "during the holidays… away on respite… he rung home… we had a brief conversation" and this was his first use of the phone properly. This was also an identified example for his mother of her being really proud and pleased of him. She outlined that she believes Hohepa to be improving over the last year "I think he has become more aware that other people have feelings… he is trying to actually control himself in some ways… he is starting to verbalise stuff about what he wants… yeah things like that."

Emotions

In relation to the cards I used with Hohepa, his mother outlined "I found them really good" and she encouraged the school to use them and commented that "He does need to learn that his actions have consequences for other people… yeah."

Behaviour

Hohepa has been using language to avoid hitting or fighting with people, like 'get away, don't like it, don't bully' based on his mother's report. She would then explain to the other children if they did not respond and got hurt that "he (Hohepa) told you and you didn't listen." His mother outlined that a particular example of Hohepa's behaviour that is persisting is his desire to make coffee, once the cycle has started (making coffee) "it's a cycle I can't distract him from" and he also tries to help a lot with the washing and will get it in and out of the washing machine. For Hohepa, his mother is pleased that he is now being more involved in family things, like board games and explained that "he will throw the dice." She also explained that he has started playing on the computers again "he just keeps going back and going back… yeah so he will punch the keyboard" and that she was

not sure why this behaviour had come back as he had stopped being interested in computers.

Relationships

In terms of relationships, his mother did not think Hohepa was closer to anyone in particular in the family. When asked who was more tolerant with Hohepa, his mother responded "They all are, everybody is" (in the family). She also commented that "there are a lot of family members who want to get to know him better" but that Hohepa is not interested in this and commented "he has got to be with someone he knows." His mother did outline he is probably most comfortable with her though. In terms of her relationship with all of the children, she thought "Hohepa is a bit more dependent… I feel like I'm on all the time… even when I'm sleeping… we've still got the mother son relationship… some days he hates me, some days he loves me… but still there is that needy thing… it's the needs that come first." She believed that "I think I have more of a commitment to him than with the other children."

Five years time

Hohepa's mother outlined that, in five years time, when Hohepa would be 21 that "I think he will still be with me… hopefully he will be more aware… a bit more safety conscious… yeah… I want him to have more of his own social circle… but at this stage I can't see that happening… with the way he interacts with people." She also thought he would still be at school, because he could stay there until he was 21. Behaviourally, she thought he "has made some good steps, just in the last couple of years." She outlined that ideally "would want him to have some form of some life, that didn't revolve around me… want him to have his own stuff, with help… not with me so much in the decision-making role… around friends and things… just have options outside of his mother."

6 month follow-up

Changes over time

Hohepa's mother explained that he is still trying to self-manage his behaviour "he is trying to you know… get a bit of control… you know, to a certain extent." She also said that he has been "a bit more eager to join in… to participate in the things we are doing… whereas before he wouldn't… you wouldn't see him near the pen and the paper." Hohepa

is also back into swimming at school and "he loves the water" based on his mother's account.

Behaviour

Hohepa has been able to engage in more activities with others, and has been more willing to do so, based on his mother's perception of his behaviour. His family made a cart and Hohepa was observed to "have a good go at hammering" when he was with his father. His mother reported that he has "a great sense of humour" and that "it seems a lot easier…I don't feel like I am running around after him like a headless chicken."

Relationships

His mother explained that his younger sister is currently "horrendous" with interacting with Hohepa, she wakes up and is at him straight away and his mother thinks "maybe it's her age… she's ten, only just ten – it's not like she's twelve or thirteen" and that his younger brother is learning more about his (Hohepa's) behaviour and has "eased off a little bit… not as aggressive… I think that was kind of a learned thing… he learned the protection thing… he doesn't seem as aggressive with him… he is actually starting to talk to him a little bit more, and he's started to try and reason with Hohepa… that's a new one for him." His mother asked her daughter what would happen if they were all out and someone did something to Hohepa, and she replied that she would stick up for him "only I'm allowed to pick on him", their mother replied "you're still not allowed to pick on him."

Five years time

When asked where Hohepa would be in 5 years time, his mother outlined the following: "he will be finished school… I think he will still be with me… I want him to have his own life and his own friends… um, yah know have a job… have a life other than mine, his own interests, yeah… his own social network… I don't think that will happen in that time span, but I think it will happen."

Summary

Hohepa's results from this study show decreased intensity of aggressive behaviour evident in his observations and in further analysis of data (SMD 0.60). Hohepa displayed behaviours indicative of emotional understanding and empathy during the intervention

and empathy at three stages after this. Hohepa engaged throughout the intervention with me and his interactions with others increased from baseline and remained higher than this original level for the rest of the study (SMD for difference following intervention was a huge 3.24). His CBCL results saw the entire set of problem behaviour scales dropping to the normal range by the end of the study. In the interviews, Hohepa's mother identified increased insight and self-control for Hohepa in terms of his emotions and behaviour.

CHAPTER SEVEN: DISCUSSION

The present study aimed to gather information utilising a behavioural and emotion-based model for therapy with children, who have both developmental disability and challenging behaviour.

The first research objective of this study emphasised the need to establish the current use of emotion-based techniques for working with behavioural difficulties in children with developmental disabilities. To summarise this, research has identified that behavioural frameworks provide a solid foundation for working with children who have developmental disability and challenging behaviour. However, through the limitations of these models of treatment, new research and theory began to arise out of the identified need to form a more holistic approach. At the same time, the importance of emotional knowledge and its value in therapy was being explored, researched and emphasised with robust study outcomes showing emotion as a cause underlying and maintaining behaviour (Moyes, 2002; Repp & Karsh, 1994; Stephenson, & Dowrick, 2005). Research further highlights how emotional knowledge and the emotional developmental stage of the child also needs to be considered in therapy (Crick & Dodge, 1994; Elias et al., 1997; Lewis & Haviland, 1993; Van Nieuwenhuijzen, De Castro, Wijnroks, Vermeer, & Matthys, 2004; Wilson, Fernandes-Richards, Aarskog, Osborn, & Capetillo, 2007; Zins, Elias, Greenberg, & Weissberg, 2000), as factors such as a lack of emotional understanding may create and/or enhance problem behaviours (Denham, 1998; Kopp, Krakow, & Johnson, 1983; Wilson, 1999). This demonstrates the crucial nature of the second research objective, in that this area of research is advancing, necessitating the concomitant advance of designs and interventions for working with this population. Within this framework of development in the literature, behaviourism and its offshoots are increasingly broadening their approaches. Positive models of intervention are beginning to address these deficiencies, with Positive Behavior Support identifying key components of intervention. However, these models, when described in research designs, do not explicitly identify the research advocating the explicit incorporation of emotional needs in intervention and research reflects the inherent difficulty with defining and understanding these concepts (see Table 1).

 Through this development and based in a strong behavioural framework, the four component model was established (Meyer & Evans, 1989). This model was selected based on its identified meeting of the first two research objectives, in that it addressed the behavioural literature and the importance of emotional needs. This model, addresses adaptation of environments, challenging and changing consequences of behaviour, enhancing and modelling adaptive alternative behaviours and the consideration of emotions, is the framework on which the current study was based. Research also highlights the importance of culture in emotional development of children (Gordon, 1989). Cultural models (e.g., Te Whare Tapa Whā; Durie, 1994) in New Zealand highlight the importance of a holistic approach and so too does the four component model chosen for this study which emphasises a child's entire context as important in understanding and working with them (Evans, Meyer, & Buckley, 2008; Meyer & Evans, 1989).

Specifically, this model was utilised to address behavioural difficulties through behavioural and emotion based techniques with four children and their families. Behaviours that were targeted for intervention, utilising this model, were determined based upon observation, interaction and discussion with the families involved and were developed on an individual basis for each child. Through the use of this model with children and their families, these interventions attempted to address the deficiency in literature surrounding such a model or form of practice with this population of children.

Discussion of Results

The third objective of this study involved using a series of four case study designs to reflect the advances in literature for best practise when working with children who have developmental disabilities and challenging behaviour. Four children, Simon, William, Lily and Hohepa, participated in this study, based on the theoretical four component model (Meyer & Evans, 1989), over a period of approximately one year with their families. Although the theoretical framework was the same, the techniques required and used for each child were different as the needs of each child were diverse and therefore the intervention design needed to reflect the differences that each child had, (Kaiser & Rasminksy, 2007; O'Regan, 2006) as well as considering the different functions or purposes of their evident behaviours (Berotti & Durand, 1999; Imray, 2008; Kaiser &

Rasminsky, 2007; Myles, 2005). Through multiple data collection methods each child was identified to benefit from this study in some way.

Simon

For Simon, the combination of results from the CBCL data and the interviews provides a description of a child who struggled a lot in varied areas in comparison to his age-matched peers at the beginning of the study. These findings were not evident in my observations, but were noted consistently across the CBCL's and at interviews by Simon's parents. Despite the lack of difficult behaviour Simon engaged in during the study, he himself was able to comment in the 3-month follow-up interview how he had benefited from participating in this study (as outlined in his chapter). In contrast, Simon's coded results did not identify him as benefiting emotionally.

When reflecting on Simon's changes through the theoretical framework of the four-component model it is evident that the emotional components could be separated. Simon's formulation identified key emotional difficulties for him (e.g., anxiety and frustration, and lack of understanding of developmental needs of others) which could be addressed by his intervention. For Simon, this meant learning about the consequences of his behaviour and developing an understanding of appropriate emotions and needs at different developmental stages. Simon was able to express himself in his family session identifying the importance of sharing and modelling appropriate emotions. His parents validated they understood Simon's view and also expressed their own concerns and feelings. Simon articulated feeling this was worthwhile. It is through these specific techniques for Simon that the emotional changes are evident. Through these changes it is likely his behaviour will continue to modify, as identified by his parents and his CBCL scores, which all reflected reduced behavioural difficulties by the end of the study.

William

When combining all of William's data it is complex to identify specific benefits for William from this study. Overall, sharing behaviour increased during the intervention and aggressive behaviour decreased with these benefits evident at both of his follow-ups. SMD statistics for each behaviour identified these changes as being evident between

baseline and intervention with William's sharing behaviour increasing by 0.28 and aggressive behaviour decreasing by 0.7. William's mother found many of the CBCL items to be non applicable to William and his data provided by this measure was therefore incomplete. However, the sections that were complete highlighted the presence of a Pervasive Developmental Disorder for William. Interview data provided most insight into changes for William over the period of the study. William's mother saw William as improving all the time and began to imagine things for him, like mainstreaming at school, that she wouldn't have thought possible a year earlier. She also noted the benefit this study had for her in providing her someone to talk too about her experiences with her son. This finding emphasised the importance of familial inclusion and consideration of their needs, as research showed that family also benefit from strategies to cope with their own stresses as well as how to interact and help their child/ sibling, (Evans, Meyer, & Buckley, 2008; Hudson et al., 2003; Morris & Hawkins, 1999; Roberts, Mazzucchelli, Studman, & Sanders, 2004; Roberts, Mazzucchelli, Taylor, & Reid, 2003) and in turn their child or sibling also benefits from an enhanced positive environment.

For William, the use of the four-component model as a method of intervention had many implications. His formulation showed the use of aggressive behaviours had developed as a means of expressing himself in various ways. This rendered alternate behaviours less useful for him. His intervention therefore addressed the deficits of alternate communicative behaviours. William was able to develop more communication skills which reduced his frustration at his previous lack of ability to communicate adequately. His mother was able to share her emotions and as a family the importance of appropriate reinforcement and praise were emphasised. Based on the literature articulating the importance of parental and caregiver relationships, William may have benefitted from his mother being involved in the study in the intervention stages. This may have increased the likelihood of his skills generalising to the home environment and have seen them easier to develop through the relationship he already had with his mother. This is based on theory which outlines that a positive, significant relationship often decreases problematic behaviour (McLaughlin & Carr, 2005).

Lily

Overall, Lily's benefit from being involved in this study was evident throughout the intervention with her behavioural changes and increase in emotional understanding as well as in her parent's responses. Four of Lily's behavioural changes were significant as calculated by SMD for each behaviour with sharing increasing by 0.9, empathy increasing by 0.007, understanding of emotion increasing by 0.23 and aggression decreasing by 0.06 when comparing intervention data with that of baseline. Lily's mother's final response highlighted how they had found the study "Wish you well with it, pretty challenging thing to do, coming in to a family and yah know doing what you are doing and we are still parenting her 24-7 and we are still at losses sometimes about how to deal with things… sometimes it takes a different perspective… that's why we were open for it… the more hints we can get… you are a very likeable person… you just fit it in". This alerts to the fact of how an intervention can and should consider each person holistically (Evans, Meyer, & Buckley; 2008; Gordon, 1989; Kaiser & Rasminsky, 2007; Meyer & Evans, 1989; Parke & Buriel, 1998).Through considering Lily holistically and using this approach this study allowed for work to be done with Lily alone and also for the provision of useful ideas to her parents that Lily herself may not have been able to pick up on or be interested in. Thus it ultimately had an impact on her through her parent's learning, which again emphasised the research highlighting the importance of including families in intervention (Evans, Meyer, & Buckley, 2008; Hudson et al., 2003; Morris & Hawkins, 1999; Roberts, Mazzucchelli, Studman, & Sanders, 2004; Roberts, Mazzucchelli, Taylor, & Reid, 2003).

In line with the four component model and relevant literature (e.g. McLaughlin & Carr, 2005), it is evident that Lily, like William, could have benefitted from the more considered involvement of her parents in the intervention part of the study. Her formulation identified Lily's skills deficits but, also the key relationship she had with her mother in particular, and her willingness to follow what her mother modelled or asked was apparent. Involving her mother earlier in the study may have enhanced Lily's outcomes as she struggled at times to interact with me, as with other new people. Teaching her parents skills rather than attempting to work directly with Lily may also have further minimised difficulties with her intervention. Lily was also often sick during the period of the study and this likely impacted on her ability to interact with someone

new. It would have been useful for her involvement in the study to be discussed in more detail with her parents during the times she was ill, and adapted further to make it easier for her. Although sessions were shortened and changed, more involvement of the family at this point should have been sought by the researcher, to best consider Lily's needs. Nevertheless, through the four-component model and her involvement in this study, Lily could identify different emotions and behaviours related to these (behaviours which produced happy and sad outcomes), which likely will continue to help her to understand this connection.

Hohepa

When combining these results, all of the data shows shifts for Hohepa with decreases in destructive and aggressive behaviour as well as an increased emphasis on controlling his own behaviour and understanding consequences and others emotions. The SMD statistic showing effect size of each behaviour between baseline and intervention showed Hohepa gaining in interacting with others (3.24), and decreasing in aggressive behaviour (0.60). Of particular relevance for Hohepa is research emphasising the negative impact aggression has on a young person's ability to interact with others (Adams & Allen, 2001; Dodge, Murphy, & Buchsbaum, 1984; Dodge & Somberg, 1987; Waldman, 1996; Wilson et al., 2007).Therefore with his reductions in this area coupled with his increasing abilities to interact with others there are potential benefits for Hohepa in terms of his continued interactions with others. It appears that Hohepa benefited from being involved in the study, was able to identify and demonstrate emotions and over time decreased his challenging behaviours. In particular, Hohepa's mother valued the usefulness of the emotion sort cards used during the intervention for him.

The four-component model, for Hohepa meant that he was able to develop many emotion-based skills. His formulation highlighted a young man who struggled to express what he required of others, or elicit the reinforcement he was seeking when attempting to engage appropriately (e.g., help around the house). Because of this, his intervention focussed on enhancing communication and developing alternate skills based on new understanding of emotions. He could, by the end of the study, match pictures of behaviours with whether they produced happy or sad emotions/outcomes. Hohepa could also model and imitate behaviours and their resulting emotions with little prompting. He

came to be able to explain to others how he was feeling with limited words. Following this study his maturity and ability to interact with others was outlined as being enhanced (by his mother). Hohepa showed changes throughout the intervention in terms of his ability to grasp and use his new emotion-based skills. This model appears to have served Hohepa well in addressing his communicative deficits, not only did he learn to express emotion but he also learnt the implications of his actions for others.

These results show, in varied outputs or outcomes, that there is evidence for each child in the value of exploring and including their emotions in a behavioural intervention for challenging behaviour. At times this was evident in the intervention, for example, Hohepa showing emotional understanding and decreased aggression or Lily showing increased understanding of emotion. The interviews also provided more examples of the efficacy of this study. Simon's parents outlined how he had benefited from seeing their point of view and Simon himself expressed the value of having someone to talk to. Lily's mother outlined that they appreciated all of the new ideas and William's mother explained how she had benefited herself from having someone to talk to about everything. CBCL profiles also indicate changes and improvements, for example, by the end of the study all of Hohepa's problem behaviour scales were in the normal range.

On this note, it is evident that the use of both qualitative and quantitative data was able to provide this study with the information that as identified above could highlight different aspects of a child's progress and change. Observations allowed a real time view into what the child's environments were like. The CBCLs outline the thoughts of the children's parents, distinct from what was observed and provided a different source of information. Finally, the interviews allowed parents and families to ask questions, and have their say about the study and their child. Specifically, this perspective allowed parents to explain their thoughts and provide insights about how they had found the study. The extent of the therapeutic relationship with each child and their family also plays a role in the success of this research with each family.

In terms of comparison amongst the children, although not the intended purpose of the study, the codes at their meta-levels: Pro-Social, Emotional Understanding and Aggressive Behaviours identify how each child's therapeutic intervention was aligned to each other and to the four component model. At all times, through each child's specific

therapy goals, the study aimed to increase pro-social and emotional understanding behaviours and decrease behaviours of aggression. It is not possible to determine if one child or family benefited more than the other. However, through these meta-codes and the shared research orientation as well as theoretical model, it is evident that similar factors were incorporated and targeted for each child and family involved as outlined in their individual chapters.

Limitations

Overall

When reviewing the results gathered for each child involved in this study, it is difficult to entirely attribute their successes to their involvement in this study as this section will continue to outline. As well as the factors detailed below it is important to consider that all of the children aged and moved through different stages of their lives throughout the study as would participants in any long term study and this is likely to have impacted on their results also. However, the results speak for themselves outlining the array of the benefits each child and their family did experience from the input of this research. The therapist's role was to change ecologies, teach alternative skills, change contingencies, and focus attention on emotions. Perhaps this way of doing research is comparatively/relatively new that its results are harder to quantify than previous, often strictly behavioural, research studies with similar populations. This research poses new thoughts and ideas surrounding the importance of emotion identifying that the centrality of emotional behaviour within all overt behaviours cannot be ignored (Meyer & Evans, 1989; Evans, Meyer, & Buckley, 2008).

More specifically, this research has shown there is difficulty in highlighting the specific advantages of each of the components of intervention on their own. However, it has identified that with this combined approach, with techniques utilised to address each component, changes are evidenced overall. Given this understanding, this research advocates that all of the four-components need to be included as a comprehensive approach essential to working with this population.

Generalisability

The data gathered by this study is not intended, nor is it able, to be generalised to all children who have developmental disability and challenging behaviour. As a single case design with four participants, this was never the intent of the research. The case study approach was chosen as it allowed exploration of the theoretical four component model, addressing emotions in the children involved and observing their behaviour over a long period of time. Despite the limit of generalisability, single case designs allow benefits in terms of allowing effect to be shown through implementing a particular approach (Evans, Scotti, & Hawkins, 1999), more specifically it showed the importance of considering emotional underpinnings of behaviours in working with children who have developmental disability and challenging behaviour.

Another limitation of this study is based around not only the number size of the study, but the characteristics of the families who chose to participate. The small sample of participants involved were all children from families whose parents sought out extra ideas by asking to participate in this study. Although this is a limit in terms of determining the usefulness of the actual intervention, this is a huge strength for the child and the family's themselves as evidenced by literature showing the importance of the involvement and support of families (Evans, Meyer, & Buckley, 2008; Fox, Vaughn, Dunlap, & Bucy, 1997; Harris, 2007; Lucyshyn, Albin, & Nixon, 1997; Olson, Platt, & Dieker, 2008; Sterkenberg, Janssen, & Schnuegel, 2008; Vaughn, Dunlap, Fox, Clarke & Bucy, 1997). This study offered no financial incentive and the study required a large time commitment over a period of approximately one year. There were originally two other interested families but they terminated their interest in the study before an initial meeting could be set up. It is likely that the families involved were already immensely invested in their child's care and as such are highly motivated families who wish their children to succeed. This is not to say that those families who pulled out did not or that other families also do not have these abilities and inclinations. However, despite the huge utility of family's involvement and support for their child, this is still another potentially limiting factor in the generalisability of these results to other families who perhaps did not have the time or inclination to participate in such a study, but have children with the same difficulties as those in this study.

Structure

Two of the children involved in the study had school observations as their group setting and two did not, based on their parents' choice. Subsequently this also means that the data for each participant is gathered from different sources. Although this would be inevitable as each child is from a different family, it could also mean that if the children who were observed at school or in another area in a group situation were observed in the opposite situation (school or a group elsewhere) that their behaviours could have been different. However, in general this is the case with every observation in this study, as if observations had taken place earlier or later on any given day, there is the potential that what was observed then would have been different to the observations and the data obtained. Babbie (2004) outlines this as a characteristic of observational research, as it, like other research provides a snapshot of what is happening, and in fact, observations are useful for the real-life data they do collect which over a period of observations shows variation and change as well as some evidence of patterns and structure.

My emotional involvement with these families was also a factor for me arising from the structure of the study. I worked with and got to know the families in this study for over a year, through e-mailing, phone-calls and visits. I found that I developed an investment in seeing each child improve and I wanted the family as a whole to benefit from their participation in the study. Babbie (2004) outlines that researchers may become involved in studies that are observational and qualitative in nature, beyond the scope of other research designs, and that this involvement can change the researcher's views on issues or ideas relevant to the study. Due to this, the data was coded by a research assistant not involved in the study but employed in a similar field and aware of the literature. This meant I could not unintentionally attribute any bias to the coding of results. However, this is still a potential limiting factor as although I developed the codes for the study, it is difficult to tell if my research assistant understood these in exactly the same way as I did. Also, it is unclear if the same results would have been obtained if I had actually coded them myself.

The different codes and targeted behaviours for each child and my descriptions of these also showed how each intervention was completely different, although based on the same theoretical model. It would be difficult to replicate these exactly as due to the individual

nature of the studies there is no manual of treatment. Therefore, as much detail as possible has been integrated into my outlines, in each child's chapter, of what was done in every session. It is also not intended however, that the particular adaptations of ideas and techniques that were useful for each of the children in my study would be beneficial to others unless their situations were identical.

Implications for Research and Practice

The current study highlights the importance of utilising both behavioural and emotional techniques when working with children who have developmental disability and challenging behaviour. This is evident in the literature combined and provided in this thesis as well as the data this study has presented.

Overall, my view of the literature after reviewing it did not change significantly. The part of my thinking that changed surrounded the importance of emotions. As I engaged this literature and then began to work with families, I found abundant evidence of the importance of emotions. I could not look at behaviour without thinking of the possible emotional causes and the variability of these. Emotional concepts are more difficult to define and are not yet as readily measured or observed, as previous research designs within the behavioural paradigm demonstrate (e.g. see Table 1). However, it is evident, based on this research and the work of notable others already mentioned, that there are varying possible emotional interpretations and reasons for overt behaviour. Emotional functions and techniques are specific, measurable and observable, but they are intertwined within what will become, in this author's opinion, the comprehensive and best model of practise for this population. The ability to define and outline these concepts was identified in each child's formulation and also the components specified for their interventions. Also, I think that emotional factors, motivators and responses are varied in any given situation dependent on whose eyes you look through, at which age, during what day of the week and at what time. Although we genetically share the ability to have many common emotions as members of the human species, our ways of presenting, understanding and using them are inevitably going to be different in the very same way as we ourselves as human beings are different. The research summarised in Chapter One does not highlight this knowledge enough, and this is a key learning from this review of literature and my study as a whole.

In terms of future research, it would be useful to have therapeutic models and standardised manuals of techniques made available. These would incorporate key aspects of behavioural designs as well as considering and incorporating the importance of emotional development and knowledge. The following are suggestions for a method of how best to extend this model and its use in research and clinical practise. In terms of emotional knowledge, specific techniques and ideas for teaching emotions, such as those used in this study, like the use of picture cards or role-play, could be outlined in greater detail in articles conceptualising this model. This would allow an array of basic ideas to be further adapted by researchers and clinicians alike utilising this model in the future. Further, instructions for what to ask children to determine their knowledge base surrounding emotions and their behaviours, and how to ensure techniques are appropriate for age and developmental level would also add to this model. Descriptions of developmental stages, adapted to include developmental disability literature and adjusted milestones, would likely enhance the ability of future researchers to adjust techniques accordingly. For alternate behaviours, research shows that children can be taught how to communicate their needs in appropriate ways despite developmental disabilities. This will likely render aggression and behavioural difficulties as only one of the available communication techniques a child can access, which can be emphasised further in further studies.

In terms of extending on the whole theory, as identified in the literature section of this study, the four-component model could benefit from further detailing the importance of family and culture in intervention. It highlights the importance of a supportive environment, but does not specifically detail how this could be enhanced. The literature reviewed emphasises when working alongside families the home environment can be shaped to support behaviour appropriately whilst also enhancing the coping and management strategies of other family members. Beyond this, broader school, extended family and societal factors need to be considered, not dissimilar from the positive behaviour support literature. Case studies could include techniques used in school and descriptions of how the community, media and wider families are also inextricably involved in creating and maintaining behaviour. To summarise, the four component model, is consistent with the literature advances, and would remain as the theoretical underpinning for treatment. This model would be advanced by the provision of more

specific examples of what should/could be done for different behaviours and for children of different backgrounds whilst still emphasising the importance of adapting these to suit the individual.

This current study has gone some small way to fill this void by identifying specific techniques relevant to each component and showing how the combination of these crucial identified components, as an approach, benefitted each of the families involved. Research has made the importance of multi-component approaches abundantly clear and further articles and research, similar to that carried out in this study, will enhance the field by contributing to an increasing body of literature in this area. Another aspect to be made clearer is that the emotion-based component is not a distinct component of a four part model to be used alone, as it may be perceived when read theoretically, but rather that all four components of the model are inextricably connected and in therapy they must be considered as such. It is important to be clear here, that the components themselves are specific but they are inevitably intertwined, and work together to enhance a child's situation and that of their family. The nature of the components means that all should be used in any intervention.

As identified in the limitations of this study, other factors arose which could also be addressed in future research to provide more robust data. Although utilising single case designs, an increased number of participants would, in the future, add value to that which has already been researched here. However, as a case study methodology, this study articulates in detail what was achieved, and further research utilising case studies will increasingly contribute to the body of data on specific techniques, encompassing both behavioural and emotional concepts. In terms of the development phase of establishing codes, if an external research assistant was still to be employed for coding, there could be benefit in approaching this differently. Both the researcher and the research assistant could develop behavioural codes collaboratively so that there is a more definite shared understanding of the codes and their meanings. However, if the researcher was to choose to code data themselves, it would be advisable to seek inter-rater agreements on some of the film clips to ensure that shared understanding of concepts and behaviour is still captured by the research.

The emotional involvement of myself in this study was difficult to avoid, and in order to manage this better, future research could have another person filming across the entire

study. This would be useful to ensure that the researcher is not involved in every aspect of data collection themselves and could be less involved with the families when it came to intervention potentially rendering therapist variables as less significant in outcome. However, this is also not without its limits, as this could mean that the children may not respond as well to the researcher at intervention if they had not had a chance to get used to them and build a good rapport during the initial filming sessions. Both of these methods for obtaining data have their merits and should be considered in future research. Data could also be gathered from more sources in future research. This study attempted to have different viewpoints, namely focusing on that of the families involved being expressed. However, additional data from teachers and perhaps other family members and support workers could have added to the profiles of the children that were developed.

Although this research has limiting factors, it demonstrates a realistic approach to research. It is unrealistic to think that research could be carried out in any capacity without such a multitude of factors interplaying with the intervention and results. It is important to remember that this research involved real children and their families, each with their own unique and varied experiences. The study was not about the need to quantify the changes as much as it was about benefiting these children and their families, and doing this by concentrating on and highlighting emotions are an essential component of therapy. Perhaps these limitations and the complex data identify the search for new knowledge and show that good science can be about being interested in new theories and new ways of understanding.

It appears these new emotion-based methods may have been systematically ignored in previous literature and studies. The progressive literature highlighted throughout this thesis identifies that from a strict behavioural framework, this is often indeed the case. However, even if emotional factors are systematically ignored or controlled for in some capacity by other researchers, and their studies, I have learnt and believe in the need for stressing the key point of this research which identifies the centrality of emotion in everything we do and are. To control or exclude this in research is to control or exclude being human, and surely this makes human research itself invalid.

The current study has provided results that identify that both behavioural and emotional therapeutic techniques and their frameworks are important in working with children who

have developmental disabilities and challenging behaviour. This research proposes that a holistic model is most useful and that the absence of either addressing behaviour or emotion would not be as beneficial as the combination of the two. However, this study is not without its limitations and it is difficult to determine if any results obtained are attributable to the study entirely due to unavoidable factors such as development and maturity and other people being involved with the children. A larger study would be needed to further explore and validate the findings produced by this study taking into consideration it's limitations and recommendations for future research. Therefore, in order to best work with a child to address their behaviours of concern, the key finding and message of this study, is that the emotions underlying and driving these behaviours must also be addressed.

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APPENDICES

APPENDIX 1

<u>Children with developmental disabilities and challenging behaviour:</u>
<u>An Emotional Intervention</u>

My name is Laura Buckley. I am a postgraduate student enrolled in the Doctorate of Clinical Psychology at Massey University, Palmerston North, in the School of Psychology. I am currently undertaking research addressing the emotional needs of children with developmental disabilities and challenging behaviour in treatment. This research will be based upon the principles of an established intervention model, the four component model (Evans & Meyer, 1989) which considers four important components in working with children and their families. These components are: ecological influences (contextual or environmental variables), traditional contingency management (what behaviours are getting reinforced), teaching more adaptive alternative skills (replacing a challenging behaviour with a more appropriate alternative that serves the same purpose), and finally the importance of meeting emotional and motivational needs.

Interventions are expected to begin later this year (after considerable time spent getting to know children and families) and carry on into 2009 and would involve the child, their parents and siblings. This study would also involve two follow up sessions at 3 months and 6 months after completion of the intervention components. These (free) interventions will be flexible and individualised, developed to suit each child, with an aim of decreasing and eliminating challenging behaviour. I am hoping to work with five families with young children (primary school age or younger) who have both a developmental disability and the presence of challenging behaviour. I am interested in hearing from anyone who would like more information and/or is interested in participating in the study. Thank you.

Laura Buckley
lazarati@hotmail.com
60 Rennie Avenue, Palmerston North
(06) 354 9593

APPENDIX 2

Massey University
COLLEGE OF HUMANITIES AND SOCIAL SCIENCES
Te Kura Pūkenga Tangata

School of Psychology
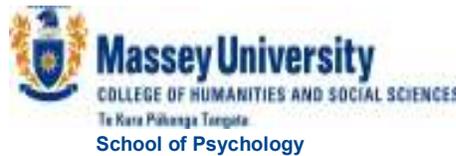
PARTICIPANT INFORMATION SHEET

1st July 2008

Ethics Approval Number: URB/08/08/036

Dear

My name is Laura Buckley and I am a doctoral student at Massey University Palmerston North. I am currently undertaking research addressing the emotional needs of children with developmental disabilities and challenging behaviour in treatment. I am supervised by Professor Ian Evans, Doctor Shane Harvey and Doctor Joanne Taylor. You are invited to take part in this research which will involve individual case studies. The aim of this study is to help with challenging behaviour in children who have developmental disabilities with the intervention based upon the principles of an established intervention model, the four component model (Evans & Meyer, 1989) which considers four important components in working with children and their families. This study will span approximately one year from September 2008 and is completely voluntary; you have the right to choose not to participate or to withdraw from the study at any stage without providing a reason.

This study is aiming to involve approximately 4 to 10 families. This number is selected based upon the need to do in depth and detailed work with each family. Participants will be recruited through local agencies, which will provide flyers outlining the study, no individual contact will be made by the

researcher unless contact is previously made by an interested participant. The initial stage of the study will be conducted at your home. This stage will involve observations and time spent to ascertain when behaviours are occurring (approximately 60-80 hours total). However, some of the intervention will be based in the Psychology Clinic at Massey University, Palmerston North (sessions of one to two hour duration once a week for approximately three months). During this part of the intervention sessions will also be videotaped. This is necessary to ensure appropriate supervision and the best intervention for each child and their family. If a participant is travelling from outside of this area travel reimbursement will be made available. No other reimbursement will be offered for participation in this study. If bullying is identified the researcher will discuss this first with you and your child. If bullying is deemed to be of a serious nature with risk of harm to either the child involved or another child the researcher will be required to inform the school after consultation with the family. Information will only be reported to the school if it is considered to involve risk of harm to any child or adult. This may result in some action being taken by the school to remedy this issue; this issue will not be remedied by the researcher.

There will be follow up stages in this study at both 3 and 6 months after completion of the intervention, this will each involve observations (approximately 15 hours each time) and an opportunity for families to ask any questions and provide feedback on the study. Although a lengthy therapeutic study there is no predicted harm or discomfort to families involved, however, should any difficulties arise please advise the researcher. Participation in this study will be stopped if any harmful effects should appear or if it is deemed that it is not in the participant's best interests to continue in the study.

You have the right to withdraw from this study at any time. In the event that you withdraw from this study all data samples collected up to the time of your withdrawal may be included in the study.

Data will be obtained by the researcher through observation and communication with family members and schools (where applicable). This data (both written and recorded) will be stored in a locked filing cabinet at Massey University for a period of ten years, or until the youngest participant in the study has turned 16, whichever is longest. Data will be presented as part of the Doctorate of Clinical Psychology but personal details (name and locality) will be altered to ensure anonymity. A summary of the findings will be provided to each family in printed or electronic form (both if requested) when the study is completed. A manual of techniques found to be useful in this study will also be provided to all participants upon the completion of the researcher's doctoral degree – December 2010.

If you have any questions about this project, please don't hesitate to contact me (or any of my supervisors) as per the details below. I look forward to working with you and your family in the future. Please sign the consent form in the presence of the researcher after asking any questions you may have if you are interested in participating.

If you have any questions or concerns about your rights as a participant in this research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act. Telephone 0800 555 050, fax 0800 2787 7678 or e-mail advocacy@hdc.org.nz.

This project has been approved by the Upper South B Ethics Regional Committee (URB/08/08/036).

Sincerely

Laura Buckley
Doctoral Candidate
60 Rennie Avenue
Palmerston North
lazarati@hotmail.com

Professor Ian Evans, I.M.Evans@massey.ac.nz, (04) 801 5799, ext 62125.
Doctor Shane Harvey, S.T.Harvey@massey.ac.nz, (06) 356 9099, ext 7171.
Doctor Joanne Taylor, J.E.Taylor@massey.ac.nz , (06) 356 9099, ext 2065.

APPENDIX 3

Upper South B Regional Ethics Committee
Ministry of Health
4th Floor, 250 Oxford Tce
PO Box 3877
Christchurch
Phone (03) 372 3018
Fax (03) 372 1015
Email: uppersouth_ethicscommittee@moh.govt.nz

15 September 2008

Laura Buckley
Massey University
50 Pencarrow Street
Palmerston North

Dear Ms Buckley

Ethics Reference Number: URB/08/08/036
Behavioural interventions for children with developmental disabilities and challenging behaviour: The effects of adding emotion-focused treatment elements
Investigators: Laura Buckley, Professor Ian Evans, Shane Harvey, Dr Joanne Taylor
Locality: Psychology Clinic at Massey University

The above study has been given ethical approval by the **Upper South B Regional Ethics Committee.**

Approved Documents
Information sheet dated 1 July 2008
Consent form dated 1 July 2008
Expected outcomes leaflet
Screening questionnaire revised 24 May 2007

Accreditation
The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Progress Reports
The study is approved until **31 December 2010**. The Committee will review the approved application annually and notify the Principal Investigator if it withdraws approval. It is the Principal Investigator's responsibility to forward a progress report covering all sites prior to ethical review of the project in **September 2009**. The report form is available at http://www.ethicscommittees.health.govt.nz. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

Amendments

It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

The Committee would like to take this opportunity to wish you all the best with your research.

Yours sincerely

Diana Passe
Upper South B Regional Ethics Committee Administrator
Email: diana_passe@moh.govt.nz

APPENDIX 4

EXPECTED OUTCOMES

1. For each child referred there will be an extended assessment report, a special assessment of emotional needs/development, an interim treatment plan, and eventually a full treatment plan emphasising the emotional component of the 4-component model.

2. Data will be gathered on the target behaviour or behaviours of concern and reported back in the child's teacher, their school and their family.

3. It is anticipated that there will be significant reductions in the behaviours of concern as a result of the intervention.

EXPECTED OUTCOMES CONTINUED...

4. The long term outcome is that there will be a series of rigorous individual case studies that will clearly demonstrate the role or otherwise of the emotion-focused intervention, the presentation of such data (appropriately made anonymous) at conferences or in journals and the involvement of RTLB (resource teacher of learning and behaviour—may be involved with children who have learning/behaviour difficulties) teachers, and school staff in such activities according to their interest and/or contributions.

5. Offering of a manual of suggested ideas and techniques.

Laura Buckley
60 Rennie Avenue
Palmerston North
Phone: 06 - 354 9593
Mobile: 027 419 7608

Massey University
COLLEGE OF HUMANITIES AND SOCIAL SCIENCES
Te Kura Pūkenga Tangata
School of Psychology

CHILDREN WITH DEVELOPMENTAL DISABILITIES AND CHALLENGING BEHAVIOUR: AN EMOTIONAL INTERVENTION
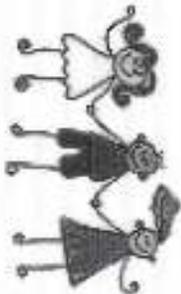
INTRODUCTION

My name is Laura Buckley. I am a postgraduate student at Massey University, Palmerston North, in the School of Psychology. I am undertaking the doctorate of clinical psychology and the information contained within this brochure outlines my proposed research for this degree. I have three supervisors: Professor Ian Evans, Doctor Shane Harvey and Doctor Joanne Taylor. The Massey University Psychology Clinic will provide support for me, however, there will be no fees charged for inclusion in this study.

BACKGROUND INFORMATION

Contemporary models for the behavioural management of challenging behaviour in young children with developmental disabilities tend to focus on multiple sources of influence. For example, the 4-component model of Evans and Meyer specifies the need to consider ecological influences (contextual; or setting variables), traditional contingency management (what behaviours are getting reinforced), teaching more adaptive alternative skills (with the same function as the challenging behaviour), and finally the importance of meeting emotional and motivational needs. Similarly the widely-accepted model of positive behaviour support emphasises social influence networks, enhanced choice and autonomy for the individual client, positive interactions with caregivers, and the acquisition of new skills. In both these models there is importance placed on the emotional needs of the child.

However, there is little formal research to demonstrate how this can be done or what the benefits really would be. The goal of this thesis research is to remedy this deficiency in the literature.

APPROACH

In order to investigate the role of emotional variables in effective management plans it is assumed that the best research paradigm at this stage of our knowledge is to use a series of single case research designs. At some stage in the design an emotion-focused intervention element would be introduced and the effects on the target behaviour of concern would be estimated, both in terms of absolute effect size, and in terms of relative contribution compared to the other elements. In order to fully evaluate one treatment model it is proposed to use the Evans and Meyer 4 component model, and the influence of the emotion-focused intervention would be compared to the influence of the other three components.
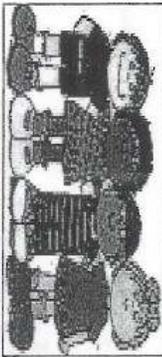
REQUIREMENTS FROM FAMILIES

Provide support for me in working with your child (Commit to helping and supporting the intervention with your child).

This intervention is expected to begin approximately in September 2008 and will have follow up sessions extending for most of 2009 (A year total). Families need to be able to commit to being involved for this time period.

Give permission for Ian, Jo and Shane as supervisors to participate, e.g. visit schools, visit home, talk to parents, receive reports, etc—all of which will be clarified in the research consent form.

PARTICIPANTS

Ideally it would be useful to focus on one age range, given that emotional development in children is highly influenced by their developmental stage. Thus the intervention would focus on preschool or early primary age. This study would like to involve children of any culture who have:

1. Significant developmental delay

2. Not already engaged in a full treatment plan through another agency

3. A cooperative family or caregivers (i.e. foster parent), school/preschool

4. Behaviour that is identified as challenging

5. Can provide consent to videotape whilst I am with the child, family, in class, this would be clarified appropriately on the consent form.

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APPENDIX 5

Massey University
COLLEGE OF HUMANITIES AND SOCIAL SCIENCES
Te Kura Pūkenga Tangata
School of Psychology
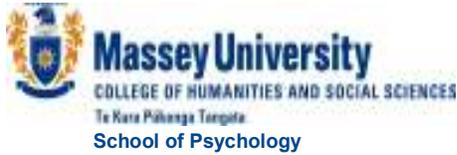
1 July 2008
Ethics Approval: URB/08/08/036

Emotional Intervention Study

PARTICIPANT CONSENT FORM
(Parent/ Care-giver Form)

This consent form will be held for a period of ten (10) years

I have read and understand the Information Sheet and have had any unclear details of the study explained to me. I have had the opportunity to utilize whanau support to ask any questions about the study. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I have had time to consider whether to take part in this study.

I understand that participation in this study is voluntary (my choice) and that I may withdraw from the study at any stage.

I understand that participation is confidential and no identifying personal information will be provided to other parties in reports or through other means.

I understand that the treatment will be stopped if it appears to be harmful to my child and I know who to contact if there are any side effects to the study.

I have witnessed the study being explained appropriately to my child.

I understand that oral consent will not be sought from my child.

I have had the study explained to me by _____.

I agree/do not agree to the intervention techniques being video taped.

I agree/do not agree to having the information obtained made accessible to my child's doctor.

I wish/ do not wish to have an interpreter.

I agree to have my information included in this study under the conditions set out in the Information Sheet. In the event that you withdraw from this study all data samples collected up to the time of your withdrawal may be included in the study.

Parent/Care-Giver

Signature: .... **Date:** ....

Full Name - printed ....

Child (if able to give written consent)
Signature: .... **Date:** ....

Full Name - printed ....

Laura Buckley
Doctorate of Clinical Psychology Candidate
School of Psychology
Massey University
Palmerston North
(06) 354 9593
lazarati@hotmail.com

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Laura came for one hour on Thursday and Friday this week. We used a ball with a happy and sad face drawn on it and practised making these faces.

Mum and Laura did some acting and I could choose what face matched what they were doing (e.g. pinching, hugging, falling over). I could also do things myself and pull the right face (fall over and frown and then smile when someone came to help). I am getting very good at using the ball as means of expressing my feelings.

On Friday we also played with snakes and ladders and tiddly winks.

In these sessions Laura and I have been using the emotions cards lots. I am getting really really good at these and I am tricking her less with my answers. When I concentrate and think about them I can get every card correct.
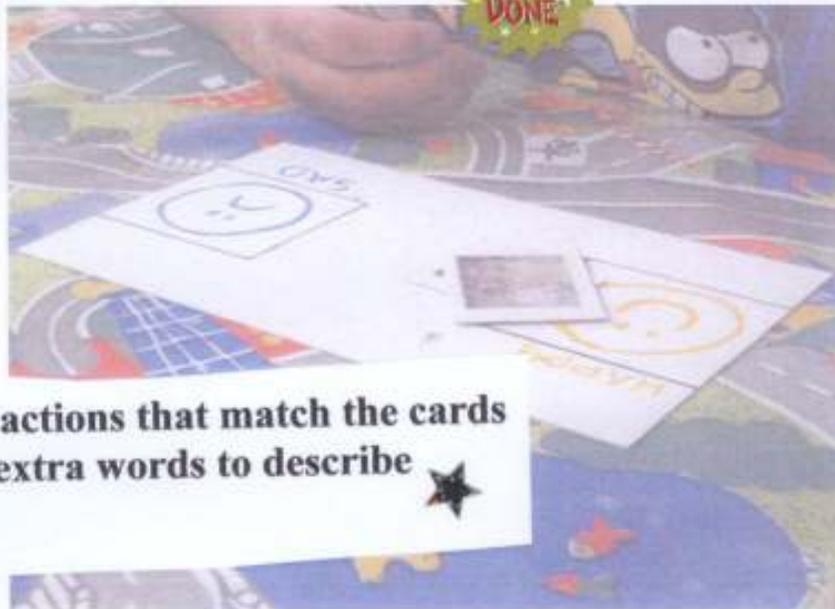
I can do actions that match the cards and use extra words to describe them.

I am also getting quicker at the matching game and my puzzle. I can remember sometimes where I last had a matching game card and go back to get it to give Laura a pair.