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The Evaluation of the Transformers Programme:

An Emotion Regulation Programme for People who have an Intellectual Disability.

A thesis presented in partial fulfilment of the requirements for the degree of

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New Zealand.

Jenna Louise McWilliams

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Abstract

It is widely accepted that emotion regulation difficulties are common in people who have an intellectual disability. Not being able to manage their distressing emotions can lead to challenging behaviour such as verbal and physical violence and property destruction and can lead to injury, alienation, poor-self-esteem, and legal problems. Growing research suggests that people who have an intellectual disability have the ability to engage in and benefit from interventions that address their emotion regulation problems. The current thesis consists of four papers—a systematic literature review, programme description, a study regarding emotional identification, and a study about emotion regulation. The main aim of the research was to evaluate an emotion regulation programme known as Transformers that is being implemented at an intellectual disability service. Transformers is a group-based treatment programme that is run over a six-month period. Five participants with mild to moderate intellectual disability (aged 17-42 years) attended the Transformers programme and took part in the studies along with their caregivers. A single-case design was chosen to evaluate the effectiveness of the programme. Participants completed emotion recognition tasks and self-report measures of emotion regulation before, during, and after their involvement in the programme. Caregivers also rated the frequency of participants' use of emotion regulation skills and incident reports provided insight into their ongoing behaviour. While the results showed that the Transformers programme was not effective in improving participants' abilities to recognise emotion nonetheless participants did increase in their ability to use appropriate emotion regulation strategies and reduced the number of incidents of challenging behaviour. Overall, these preliminary findings suggest that the Transformers programme is a viable treatment option for people who have an intellectual disability who have difficulty managing their own emotions. While

the findings are encouraging, it is recommended that further research be carried out using larger sample sizes and longer follow up periods to establish the effectiveness of the programme.

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Chapter 1: Thesis Overview

Rationale

The current thesis resulted from a request from clinical psychologists in the Wellington region who wanted to assess the programme they developed. The Transformers programme is a group-based programme to enhance emotion regulation skills for people who have an intellectual disability (ID) and emotion regulation difficulties. The psychologists believed the programme to be effective due to the positive feedback from clients and staff who had been involved in the group. However, they were seeking a scientific evaluation of the programme to support its use in clinical practice. After speaking with the programme facilitators and reviewing the emotion regulation literature, the current thesis was developed to address the needs of the ID service while contributing to the broader literature on ID.

The primary objective of the current thesis is to evaluate the effectiveness of the Transformers programme. The research questions relating to this objective are to determine whether the Transformers programme (a) increased participants' abilities to recognise emotions in other people, and (b) increased participants' abilities to use appropriate emotion regulation strategies, which in turn reduced their challenging behaviour.

The term *intellectual disability* has been used throughout this thesis. Mental retardation may be a more familiar term to many people given that it is the term used in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR; American Psychiatric Association, 2000). However, names change over time particularly when they become associated with stigma and are no longer acceptable. In the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013), the term intellectual developmental disorder replaces

mental retardation. The name change is in keeping with the terminology used by World Health Organization's International Classification of Diseases and organisations such as the American Association on Intellectual and Developmental Disabilities. At present, intellectual disability is the preferred term in New Zealand and is used in policy, between professionals, and by people who have an intellectual disability (Bray, 2003).

Overview

As an introduction to the research, a literature review of emotion regulation and ID is presented in Chapter 2. Chapter 3 describes the Transformers programme that is evaluated. In Chapter 4, ethical and methodological issues relevant to the current studies are discussed. Chapters 5 and 6 present quantitative results on the effectiveness of the transformers programme. Chapter 5 focuses on improvements in participants' emotion recognition abilities whereas Chapter 6 focuses on improvements in participants' emotion regulation abilities. Both of these chapters utilise data collected within a single-case design. Finally, Chapter 7 concludes the thesis with a general discussion of the findings of the research project, the limitations of the research, suggestions for future research, implications, and personal reflections.

This dissertation is in the form of a thesis by publication. Chapters 2, 3, 5, and 6 are written in the form of manuscripts for submission for consideration for publication in peer-reviewed journals. For readability, references for the manuscripts have been placed at the end of the thesis. Appendices are also referred to in-text for the purpose of this thesis but are removed from manuscripts that are submitted to journals. While efforts have been made to minimise repetition of material, the thesis does contain some repetition, particularly in the introductions to the different manuscripts and in the

discussion chapter. Additional chapters introduce and conclude the research and discuss some issues that have not been addressed in detail in the manuscripts.

Paper one. Although the literature commonly states that people who have an ID have emotion regulation deficits, finding an article that supported this notion proved to be a difficult task. The dearth of research formed the impetus for a systematic literature review—“a succinct description of the methodological and deliberate survey and assessment of a body of evidence” (Cullinan, 2005, p. 47). A systematic literature review was chosen to provide an unbiased, comprehensive, and reliable overview of the relevant literature and to shed light on gaps in the knowledge. Systematic reviews have been argued to be more rigorous than traditional literature reviews because they seek to identify all the available material relevant to a particular question and provide an explicit method that can be replicated (Petticrew & Roberts, 2008). Paper One describes the research questions and the process used to conduct the present review and evaluates the results of various qualitative and quantitative studies.

Paper two. Despite the limited literature on emotion regulation and ID, professionals who work with people who have an ID acknowledge that emotion regulation difficulties commonly exist (Oxnam & Gardner, 2011; Watson & Malcolm, 2011). Studies have reported successful outcomes after the psychological treatment of men and women who have an ID and emotion regulation problems (King, Lancaster, Wynne, Nettleton, & Davis, 1999; Lindsay et al., 2004; Rose, 1996; Willner & Tomlinson, 2007). Paper Two provides a description of the Transformers programme—a specific intervention designed for people who have an ID and emotion regulation difficulties. The treatment manual could not be included in this thesis as it belongs to the individuals who developed the programme and should only be used by health

professionals under the guidance of a clinician who has knowledge of complex therapeutic issues. However, a thorough description of the rationale, theoretical foundations, key components, and implementation of the programme that is being evaluated are provided.

Paper three. Emotion recognition is one component that is covered early in the Transformers programme. Individuals need to be capable of recognising emotions in themselves and others before they are able to find appropriate ways to regulate their emotions (Contugno, 2011). Researchers have found that people who have an ID generally have more difficulty identifying emotions than people without an ID (Gray, Fraser, & Leudar, 1983; McAlpine, Kendall, & Singh, 1991; Weisman & Brosgole, 1994). During the Transformers programme, individuals are taught how to acknowledge and label different emotions. Paper Three aims to provide details of one of the current studies, which looked at the impact of the Transformers programme on individuals' abilities to recognise emotions.

Paper four. Paper Four focuses on emotion regulation—an important skill related to emotion recognition (Contugno, 2011). As well as finding it more difficult to recognise emotions, people who have an ID appear to have difficulty regulating their emotions (McClure, Halpern, Wolper, & Donahue, 2009). Thus, emotion regulation is a key component covered during the Transformers programme. Various strategies are introduced to individuals to help them regulate their emotions in keeping with the situation they are experiencing them in. Paper Four aims to discuss the effectiveness of the Transformers programme in developing individuals' abilities to modulate their emotion and maintain regulation using more appropriate strategies.



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**STATEMENT OF CONTRIBUTION
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(To appear at the end of each thesis chapter/section/appendix submitted as an article/paper or collected as an appendix at the end of the thesis)

We, the candidate and the candidate's Principal Supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the candidate's contribution as indicated below in the *Statement of Originality*.

Name of Candidate: Jenna McWilliams

Name/Title of Principal Supervisor: Ian de Terte

Name of Published Research Output and full reference:
Emotion Regulation in Intellectual Disability: A Review of the Evidence

In which Chapter is the Published Work: Chapter 2

Please indicate either:

- The percentage of the Published Work that was contributed by the candidate:
and / or
- Describe the contribution that the candidate has made to the Published Work:
The candidate is responsible for the work put into this manuscript (e.g., design, analysis, and write-up). The supervisors have contributed to the manuscript in the same way that they have contributed to the usual chapters in this thesis: by providing guidance and feedback.

Jenna McWilliams Digitally signed by Jenna McWilliams
DN: cn=Jenna McWilliams, o=ou,
email=jenna.mcwilliams@massey.ac.nz, c=nz
Date: 2014.04.28 12:34:27 +12'00'

Candidate's Signature

28.04.14

Date

Ian de Terte Digitally signed by Ian de Terte
DN: cn=Ian de Terte, ou=Massey University,
ou=School of Psychology,
email=ian.deterte@massey.ac.nz, c=nz
Date: 2014.04.28 14:02:04 +12'00'

Principal Supervisor's signature

28-Apr-2014

Date

**Chapter 2: Emotion Regulation in Intellectual Disability: A Review of the
Evidence**

Jenna L. McWilliams, Ian de Terte, and Janet Leathem

School of Psychology, Massey University, Wellington, New Zealand

Author Note

Correspondence concerning this article should be addressed to Ian de Terte, School of Psychology, PO Box 756, Wellington 6140, New Zealand. E-mail: i.deterter@massey.ac.nz

Abstract

People who have an intellectual disability are assumed to have emotion regulation difficulties. This paper provides a critical review of the existing literature pertaining to emotion regulation in intellectual disability. A systematic literature review using defined inclusion criteria produced 32 articles for review. Articles included qualitative, quantitative, and mixed model methodologies which focused on emotion regulation in adults who have an intellectual disability. The methodology used in the studies reviewed varied and no attempts were made to operationalise the term emotion regulation. The majority of studies provided evaluations of interventions targeted at developing emotion regulation skills with few studies focused on the nature of the skills themselves. None of the studies compared the emotion regulation skills of people who have an intellectual disability with wider populations. There is limited research which looks at emotion regulation difficulties in adults with an intellectual disability. Further research is needed in order to advance the literature and guide interventions for this population.

Keywords: emotion, emotion regulation, intellectual disability, adaptive strategies

Emotion Regulation in Intellectual Disability: A Review of the Evidence

Researchers and mental health professionals have long claimed emotion regulation difficulties as a prevalent problem in people who have an intellectual disability (ID). The failure of people who have an ID to regulate emotions such as anger is considered a core element of their challenging behaviour (Black, Cullen, & Novaco, 1997). Challenging behaviours such as verbal aggression, physical violence, and property destruction may have consequences not only for the individuals involved (e.g., alienation, poor self-esteem, and legal problems), but for the people who care for them (e.g., physical and psychological injury, time off work, and diminished job satisfaction). The various consequences that can stem from poor emotion control provide rationale to explore the regulation of emotion in people who have an ID. If, according to the scientific literature, emotion regulation deficits do exist in this population then treatment programmes may be a useful way for people who have an ID to develop emotion regulation abilities.

Defining Important Terms: Emotion and Emotion Regulation

A discussion of emotion regulation requires a definition of emotion. Emotions are relatively brief episodes elicited by events that are important to an individual (Gross & Thompson, 2007). If attended to, these events can trigger a series of interrelated changes across experiential, behavioural, and physiological response systems that are directed toward an object (e.g., jealousy is directed towards a rival; Mulligan & Scherer, 2012; Rottenberg & Gross, 2007). While emotions prepare an individual to take appropriate action (Scherer, 2005), there are many different ways an individual can respond and the course of action that one takes is determined by how they regulate their emotions.

The terms emotion regulation, affect regulation, mood regulation, and coping have all been used to refer to the process of regulating emotions (Gross & Thompson, 2007). Although the terms emotion, affect, and mood are often used interchangeably, previous authors have provided a useful explanation of the terms and the ways in which they are distinct (Gross & Thompson, 2007). According to Gross and Thompson (2007), emotion regulation, mood regulation, and coping can all be considered subtypes of affect regulation because each process is used to try to control an affective experience, but the type of affective experience they are trying to control differs (i.e., stress, mood, emotion). Coping is one form of affect regulation that refers to an individual's efforts in response to a stressful situation that is taxing or exceeding their resources and threatening their well-being (Lazarus & Folkman, 1984). While coping and emotion regulation are related, coping tends to be concerned with much larger periods of time (e.g., bereavement). Coping also includes actions taken to achieve nonemotional goals (e.g., studying to pass an exam), while emotion regulation pertains solely to processes associated with modulating emotions (Scheier, Weintraub, Carver, 1986). Mood regulation on the other hand involves attempts to influence affective responses that are of longer duration (e.g., lasting for days or weeks), less intense, and less likely to be triggered by a specific object or situation than emotions (Gross & Thompson, 2007). Finally, emotion regulation refers to "the processes by which we influence which emotions we have, when we have them, and how we experience and express them" (Gross, 1998, p. 275). This paper will concentrate on emotion regulation. The focus here will be on the conscious regulation of negative emotions due to the array of problems they cause for individuals and society.

Emotion Regulation Strategies

There are many different emotion regulation strategies that an individual can use to alter their negative emotional experiences and the strategy that they choose may or may not be useful (Gross, 1998). Researchers have identified some strategies that are more effective at decreasing the experiential and physiological aspects of negative emotions, for example, acceptance, problem solving (Aldao, Nolen-Hoeksema, & Schweizer, 2010), reappraisal (Aldao et al., 2010), breathing exercises (Arch & Craske, 2006), and relaxation (Rausch, Gramling, & Auerbach, 2006). These strategies are considered to be adaptive across a range of contexts.

Some strategies are less effective for alleviating emotional distress and tend to be associated with maladaptive outcomes. These include rumination (Nolen-Hoeksema & Aldao, 2011), avoidance (Aldao et al., 2010), and suppression (Ehring, Tuschen-Caffier, Schnulle, Fischer, & Gross, 2010). People may also turn to unhealthy practices including misuse of alcohol (Cooper, 1994) or food in an effort to modify their emotional experience (Bekker, van de Meerendonk, & Mollerus, 2004; Polivy, Herman, & McFarlane, 1994).

Emotion Regulation and Psychopathology

There is a link between emotion regulation and psychological disorders. For example, generalized anxiety disorder (Salters-Pedneault, Roemer, Tull, Rucker, & Mennin, 2006), depression (Gross & Levenson, 1997), and borderline personality disorder (Glenn & Klonsky, 2009) are often viewed as the result of emotion regulation difficulties. Emotion regulation difficulties are implicated in over half of the Axis I disorders and all of the Axis II personality disorders listed in the Fourth Edition, Text Revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR;

American Psychiatric Association [APA], 2000; Gross & Levenson, 1997). Evidence suggests that emotion regulation difficulties play a significant role in the development and maintenance of psychopathology.

Emotion Regulation and ID

ID is defined in the DSM-IV-TR (APA, 2000) as significant impairments in intellectual functioning and marked limitations in adaptive functioning, both of which must be present before 18 years of age. Categories are used to describe the four severities of ID: Mild (IQ level of 50-55 to approximately 70), moderate (IQ level 35-40 to 50-55), severe (IQ level 20-25 to 35-40), and profound (IQ level below 20 or 25; APA, 2000). The categories reflect the individual's level of intellectual functioning as defined by scores on standard intelligence tests. A fifth category, severity unspecified, can be used when it appears that a person has an ID, but they cannot be assessed using standard intelligence tests (APA, 2000). Borderline intellectual functioning, that is, an IQ in the 71-84 range, may also be a focus for some researchers (APA, 2000).

Understanding emotion regulation in people who have an ID is especially pertinent for a number of reasons. First, anger commonly precedes aggression and aggression is associated with emotion regulation difficulties (Novaco, 2007) and rates of both anger and aggression are high in this population (Smith, Branford, Collacott, Cooper, & McGrother, 1996). Second, emotion regulation may be a core element of other types of challenging behaviour (Black et al., 1997) and challenging behaviours are also highly prevalent in this population. A large study in Sweden found that 12% of adults who have an ID displayed behaviours such as self-injury, attacking others, inappropriate sexual behaviour, or property destruction (Lundqvist, 2013). Third, people who have an ID experience similar rates of stress as the general population, but stress

from negative interpersonal relationships is greater in people who have an ID than the general population (Bramston, Fogarty, & Cummins, 1999). Finally, difficulty managing emotional experiences in people who have an ID may be exacerbated by a number of factors such as communication difficulties (Salovey & Mayer, 1989-90).

Oxnam and Gardner (2011) reported that all of the clients at their ID service had difficulty regulating their emotions. Furthermore, McClure, Halper, Wolper, and Donahue (2009) pointed out that the regulation of their clients' emotions was an issue that was repeatedly raised during group supervision at their service. Practitioners' interest in emotion regulation provides further indication that emotion regulation deficits are a common issue amongst people who have an ID.

Despite the growing literature on emotion and emotion regulation, there has been little research that has concentrated on these constructs with adults who have an ID. McClure et al. (2009) carried out a search of the PsycINFO database using the term ID which returned over 2,000 articles published since 2004. The number of articles was reduced to zero when they added the term emotion regulation to their search. A few more were identified when the authors searched using common variations of the term ID such as mental retardation. Their findings draw attention to the inconsistency between the amount of literature on emotion regulation or ID and that which examines the two constructs together.

While professional opinion is invaluable, the scientist-practitioner model is an integrated approach to science and practice. In accordance with the scientist-practitioner model, the notion that people who have an ID have emotion regulation difficulties should be based on empirical evidence, rather than relying on expert opinions (e.g., Oxnam & Gardner, 2011). The empirical literature should also be used to inform

treatment ideas and protocols. Thus, a review is necessary to formally evaluate the current state of the literature regarding emotion regulation in people who have an ID and highlight any need for further research.

The purpose of the current review is not to compare and contrast the results of previous studies on emotion regulation in people who have an ID nor is it to evaluate the effectiveness of psychotherapeutic interventions in the treatment of emotion regulation difficulties. Rather, the aim is to provide the reader with an overview of the available literature on emotion regulation in people who have an ID. The following key questions were used to guide the review: (a) what is the research evidence that people who have an ID are unable to regulate their emotions? And (b) how have emotion regulation difficulties in people who have an ID been measured?

Method

A search of the literature was conducted using the electronic databases; PsycINFO, Scopus, Web of Knowledge, and Academic Search Premiere. The databases were searched using two sets of keywords. The first set related to the population of interest: ID, intellectual handicap, learning disabilities, mental handicap, and mental retardation. The second set included emotion regulation, coping, anger-management, emotional control, affect regulation, and emotion management. Although emotion regulation is central to this review, the related terms were included because of the conceptual confusion and overlap around this topic (Gross & Thompson, 2007). Terms from the first set were combined with terms from the second set using the Boolean Operator AND to ensure that all combinations were utilised. Truncation enabled the search for singular and plural variations of the same word (e.g., disability, disabilities, disabled). No limit was placed on the time period covered. Books, book reviews,

conference abstracts and dissertations were excluded from the search results. This electronic database search generated over 1,000 potential articles. The titles and abstracts of these articles were closely read and the pool of relevant articles was reduced to 58 based on the following inclusion criteria: (a) the studies were quantitative or qualitative findings from English language studies investigating (with a specific focus on) emotion regulation in adults who have an ID; (b) the studies included participants who had comorbid diagnoses (due to the high prevalence of psychological disorders among adults who have an ID; Morgan, Leonard, Bourke, & Jablensky, 2008); (c) the studies focussed on emotion regulation in response to stress or emotions as the two concepts are interrelated (Lazarus, 1999).

Articles were excluded on the basis that they: (a) were not relevant to the research question; (b) focused on children or adolescents who have an ID rather than adults; (c) did not provide some form of data to support their findings; and (d) did not exclusively include participants who have an ID and/or focused solely on emotion, recognising emotion or emotional problems (i.e., did not address emotion regulation strategies).

The 58 remaining studies were then read in their entirety to ensure that they met the required criteria. Further studies were excluded because they did not meet the inclusion criteria and/or met the exclusion criteria and subsequently 29 studies were selected for inclusion in this review. The reference lists for these 29 papers were reviewed and three more articles were identified. The studies chosen for this review are summarised in Table 1.

Findings and Discussion

Limited Research

Although the current literature search initially identified a much larger number of articles in this area than other authors (i.e., McClure et al., 2009), closer inspection of the titles and abstracts made it clear that many of these studies investigated coping and emotion regulation strategies of parents, caregivers, teachers, and siblings of individuals with ID as opposed to the strategies of the individuals who have an ID. This observation is in line with a statement made by Arthur (2003), that “the emotional lives of people with an ID are much neglected” (p. 25). Similar criticisms have been made by various authors (e.g., Adams & Oliver, 2011; Benson & Ivins, 1992). The current review suggested that in spite of calls for further research regarding ID and in particular, emotion regulation, there remains limited research in this area. The review identified the following areas for potential research: (a) definitional issues, (b) sampling issues, (c) measures used to assess emotion regulation, and (d) evidence of emotion regulation difficulties in people who have an ID.

Table 1

Characteristics of selected studies addressing emotion regulation in people who have an intellectual disability (ID)

Author	Description ^a	Participants	Key findings
1. Allen, Lindsay, MacLeod, & Smith (2001)	<ul style="list-style-type: none"> • Single-case research • Measures completed by participants 	<ul style="list-style-type: none"> • <i>N</i> = 5 females • Aged 18-44 • Borderline intelligence or mild ID 	Relaxation treatment seemed to have little value. Any reductions in anger were not evident until cognitive aspects of treatment implemented. Progress was not uniform but there were reductions in assessment scores for participants at completion of treatment.
2. Benson & Fuchs (1999)	<ul style="list-style-type: none"> • Qualitative research • Structured interview carried out with participants 	<ul style="list-style-type: none"> • <i>N</i> = 68 (38 males) • Aged 19-59 • Borderline intelligence to moderate ID 	Interpersonal situations at work and home were a common source of anger. The responses of men and women were similar. Participants reported using a variety of coping responses.
3. Benson, Rice, & Miranti (1986)	<ul style="list-style-type: none"> • Quantitative research • Control group • Measures completed by participants and third-party 	<ul style="list-style-type: none"> • <i>N</i> = 54 (37 males) • Aged 17-57 • Mild/moderate ID 	Participants displayed decreases in aggressive responding following treatment. Three different interventions were used and no significant between-group differences were found.
4. Burns, Bird, Leach, & Higgins (2003)	<ul style="list-style-type: none"> • Single-case research • Measures completed by participants and third-party 	<ul style="list-style-type: none"> • <i>N</i> = 3 males • Aged 33-37 • Borderline intelligence or mild ID 	Some improvement following anger-management training but variation in the extent to which participants benefited from the anger-management training.

Author	Description ^a	Participants	Key findings
5. Chapman, Shedlack, & France (2006)	<ul style="list-style-type: none"> • Single-case research • Measures completed by participants and third-party; third-party observations; participant self-reports 	<ul style="list-style-type: none"> • <i>N</i> = 3 (2 males) • Aged 32-67 • Mild ID 	For all participants, scores on scales related to anger decreased following treatment.
6. Didden, Embregts, van der Toom, & Laarhoven (2009)	<ul style="list-style-type: none"> • Quantitative research • Measures completed using file notes and third-party knowledge 	<ul style="list-style-type: none"> • Borderline intellectual functioning or mild ID • With substance abuse: <ul style="list-style-type: none"> ◦ <i>N</i> = 18 ◦ Aged 21-46 • Without substance abuse: <ul style="list-style-type: none"> ◦ <i>N</i> = 21 (13 males) ◦ Aged 19-51 	Participants who engaged in substance abuse used more palliative coping strategies (e.g., relaxation, smoking, or drinking alcohol) and had more severe behavioural and emotional problems than those without substance abuse issues.
7. Douglas, Palmer, & O'Connor (2007)	<ul style="list-style-type: none"> • Quantitative research • Measures completed by participants and third-party 	<ul style="list-style-type: none"> • <i>N</i> = 6 (2 males) • Aged 22-65 • Borderline intellectual functioning or moderate/mild ID 	Two group members showed a clinically significant reduction in self-reported levels of anxiety. Qualitative reports suggested all participants developed coping strategies.
8. Duperouzel & Fish (2010)	<ul style="list-style-type: none"> • Qualitative research • Multiple interviews with participants 	<ul style="list-style-type: none"> • <i>N</i> = 9 (4 males) • Aged 24-36 • Mild/moderate ID 	Participants described utilising self-injury as an effective coping strategy that could provide relief from distressing emotional states.

Author	Description ^a	Participants	Key findings
9. Fuchs & Benson (1995)	<ul style="list-style-type: none"> • Quantitative research • Measures completed by participants and third-party 	<ul style="list-style-type: none"> • Aggressive group <ul style="list-style-type: none"> ◦ <i>N</i> = 16 ◦ Aged 23-60 • Nonaggressive group <ul style="list-style-type: none"> ◦ <i>N</i> = 19 ◦ aged 25-80 • Borderline intellectual functioning or mild/moderate ID 	<p>Both groups were able to produce a number of different solutions to situations. Participants in the aggressive group most often gave an aggressive response as their first response and were more likely to provide aggressive solutions than nonaggressive participants. All participants tended to correctly identified hostile situations as aggressive.</p>
10. Hartley & Maclean (2005)	<ul style="list-style-type: none"> • Quantitative research • Measures completed by participants 	<ul style="list-style-type: none"> • <i>N</i> = 88 (52 males) • Aged 22-71 • Mild ID 	<p>The most frequent stressful events experienced by participants were negative interpersonal relations and coping stressors. Participants reported using more active coping strategies than distraction or avoidant strategies, especially when events were perceived as controllable. Active coping strategies were associated with less psychological distress than other coping strategies.</p>
11. Hartley & Maclean (2008)	<ul style="list-style-type: none"> • Quantitative research • Measures completed by participants 	<ul style="list-style-type: none"> • <i>N</i> = 114 (60 males) • Aged 19-65 • Mild ID 	<p>Participants were more likely to use problem-focused coping strategies when faced with stressful social interactions. Problem-focused coping was negatively related to psychological distress.</p>
12. Howells, Rogers, & Wilcock (2000)	<ul style="list-style-type: none"> • Single-case research • Unclear who completed measures 	<ul style="list-style-type: none"> • <i>N</i> = 5 (3 males) • Aged 25-49 • Mild/moderate ID 	<p>Qualitative findings revealed that all participants felt more in control of their anger. The quantitative data was difficult to draw conclusions from.</p>

Author	Description ^a	Participants	Key findings
13. Jahoda, Pert, Squire, & Trower (1998)	<ul style="list-style-type: none"> • Mixed research • Measures and semi-structured interview completed by participants 	<ul style="list-style-type: none"> • Borderline functioning or mild/moderate ID • Study 1: <ul style="list-style-type: none"> ◦ $N = 44$ ◦ aggressive group aged 17-64 ◦ nonaggressive group aged 21-65 years • Study 2: <ul style="list-style-type: none"> ◦ $N = 19$ ◦ aggressive group aged 17-64 ◦ nonaggressive group aged 21-47 	<p>The aggressive group showed a greater proportion of aggressive responses for coping with stressful situations than the nonaggressive group. The nonaggressive group produced more assertive responses than the aggressive group. Male participants provided more aggressive responses than females.</p>
14. King, Lancaster, Wynne, Nettleton, & Davis (1999)	<ul style="list-style-type: none"> • Quantitative research • Measures completed by participants and third-party 	<ul style="list-style-type: none"> • $N = 11$ (7 males) • Aged 17-48 • Mild ID 	<p>The majority of participants displayed improvements in anger control following treatment and all participants displayed improvements in anger control at follow-up. Improvements in anger control were related to improvements in self-esteem.</p>
15. Lindsay, Allan, MacLeod, Smart, & Smith (2003)	<ul style="list-style-type: none"> • Single-case research • Measures completed by participants; information gathered from third-parties 	<ul style="list-style-type: none"> • 6 males • Aged 18-42 • Mild ID. 	<p>There was a general reduction in scores on measures of anger following treatment although this was not uniform across participants. After treatment, participants responded to the role-plays with less anger than at baseline and early in the treatment. No further assault-related offenses for any of the participants.</p>

Author	Description ^a	Participants	Key findings
16. Lindsay et al., (2004)	<ul style="list-style-type: none"> • Quantitative research • Control group • Measures completed by participants 	<ul style="list-style-type: none"> • Experimental group: <ul style="list-style-type: none"> ◦ <i>N</i> = 33 (25% female) ◦ <i>M</i> age = 28.4 ◦ <i>M</i> IQ = 65.4 • Control group: <ul style="list-style-type: none"> ◦ <i>N</i> = 14 (43% female) ◦ <i>M</i> age = 23.9 ◦ <i>M</i> IQ = 66.2 	<p>Participants demonstrated significant improvements in anger control on all measures. While there were significant within subjects improvement on the provocation inventory, participants in the treatment condition did not show significant improvement compared to participants in the control group at post-treatment. Participants in the control group were involved in a significantly greater number of aggressive incidents.</p>
17. Lindsay, Overend, Allan, Williams, & Black (1998)	<ul style="list-style-type: none"> • Single-case research • Measures completed by participants and third-party 	<ul style="list-style-type: none"> • <i>N</i> = 3 males • Aged 28-58 	<p>Positive changes on various methods of assessment for each participant following individualised treatment.</p>
18. Moore, Adams, Elsworth, & Lewis (1997)	<ul style="list-style-type: none"> • Quantitative research • Measures completed by participants and third-party 	<ul style="list-style-type: none"> • <i>N</i> = 6 (2 males) • Aged 20-58 • Mild/moderate ID. 	<p>The majority of participants reported being in control of their anger 'most of the time' while others reported being in control of their anger 'some of the time' following treatment. Participants were involved in fewer aggressive incidents after treatment. Feedback from staff members was mixed.</p>
19. Nezu, Nezu, & Arean (1991)	<ul style="list-style-type: none"> • Quantitative research • Measures completed by participants and third-party 	<ul style="list-style-type: none"> • <i>N</i> = 28 (18 males) • Aged 22-53 • Mild ID. 	<p>Participants demonstrated improvements on measures of psychological symptoms, distress, and adaptive functioning following treatment.</p>

Author	Description ^a	Participants	Key findings
20. Rose (1996)	<ul style="list-style-type: none"> • Single-case research • Record of aggressive incidents kept by third-party 	<ul style="list-style-type: none"> • <i>N</i> = 5 (3 male) • Aged 21-43 • Moderate/severe ID. 	Participants achieved very low scores on facial expression recognition both before and after the group. Staff reported fewer aggressive incidents and noted an increase in time between trigger and response following treatment.
21. Rose (2010)	<ul style="list-style-type: none"> • Quantitative research • Wait-list control group • Measures completed by third-party 	<ul style="list-style-type: none"> • Mild/moderate ID • Experimental group: <ul style="list-style-type: none"> ◦ <i>N</i> = 37 (26 males) ◦ Aged 18-66 • Control group: <ul style="list-style-type: none"> ◦ <i>N</i> = 19 (16 males) ◦ Aged 17-66 	Caregivers reported greater reductions in participant's anger following an intervention when they had accompanied participants to the intervention or attributed participant's behaviour to emotional causes.
22. Rose, Loftus, Flint, & Carey (2005)	<ul style="list-style-type: none"> • Quantitative research • Wait-list control group • Measure completed by participants 	<ul style="list-style-type: none"> • <i>N</i> = 50 (40 male) • Age not reported • Mild ID. 	There was a decrease in anger intensity scores, for some participants, following the intervention. Participants whose caregivers accompanied them to the intervention and those with higher vocabulary scores were more likely to show a reduction in anger intensity scores immediately after group.
23. Rose & West (1999)	<ul style="list-style-type: none"> • Single-case research • Measures completed by participants; record of aggressive incidents kept by third-party 	<ul style="list-style-type: none"> • <i>N</i> = 5 (5 male) • Aged 25-46 • Severity of ID not reported 	A significant association was found between anger intensity scores and records of challenging behaviour. Changes on the measures often coincided with external events such as moving residence.

Author	Description ^a	Participants	Key findings
24. Rose, West, & Clifford (2000)	<ul style="list-style-type: none"> • Quantitative research • Wait-list control group • Measures completed by participants and third-party 	<ul style="list-style-type: none"> • Mild/moderate ID • Experimental group: <ul style="list-style-type: none"> ◦ <i>N</i> = 25 (23 males) ◦ Aged 25-62 • Wait-list control group: <ul style="list-style-type: none"> ◦ <i>N</i> = 19 (16 males) ◦ Aged 20-45 	There was a reduction in levels of reported anger and depression for the experimental group following treatment compared to the wait-list control group.
25. Sakdalan, Shaw, & Collier (2010)	<ul style="list-style-type: none"> • Quantitative research • Measured completed by third-party 	<ul style="list-style-type: none"> • <i>N</i> = 6 (5 males) • Aged 23-29 • Mild/moderate ID 	Participants displayed improvements on all outcome measures following treatment.
26. Singh et al., (2007)	<ul style="list-style-type: none"> • Single-case research • Record of aggressive incidents kept by third-party 	<ul style="list-style-type: none"> • <i>N</i> = 3 (2 males) • Aged 27-43 • Moderate ID 	Aggressive behaviours decreased for all participants following treatment.
27. Singh et al., (2011)	<ul style="list-style-type: none"> • Single-case research • Measures completed by participants 	<ul style="list-style-type: none"> • <i>N</i> = 3 males • Aged 28-32 • Mild ID 	Incidences of anger and aggressive behaviour decreased following the intervention.
28. Singh, Wahler, Adkins, Myers, & The Mindfulness Research Group (2003)	<ul style="list-style-type: none"> • Single-case research • Retrospective data from records; prospective records kept by participant and third-parties 	<ul style="list-style-type: none"> • <i>N</i> = 1 male • Aged 27 • Mild ID 	During and after treatment there was a decrease in incidents, physical and verbal aggression, PRN medication, physical restraints, and staff and resident injuries.

Author	Description ^a	Participants	Key findings
29. Taylor, Novaco, Gillmer, & Thorne (2002)	<ul style="list-style-type: none"> • Quantitative research • Randomised control group • Measures completed by participants and third-party 	<ul style="list-style-type: none"> • 19 males • Mild ID 	<p>Self-reported anger intensity reduced following treatment for the experimental group compared with the control group. Some participants showed decreased anger intensity according to staff-ratings but these differences were not statistically significant.</p>
30. Willner, Brace, & Phillips (2005)	<ul style="list-style-type: none"> • Mixed research • Measures completed by participants and third-party 	<ul style="list-style-type: none"> • <i>N</i> = 11 (6 males) • Aged 25-50 	<p>Participants experienced a decrease in anger and increase in coping skills following treatment compared to the control group. The measure of anger coping skills has acceptable reliability and it is preferable to use the same respondent if used repeatedly.</p>
31. Willner, Jones, Tams, & Green (2002)	<ul style="list-style-type: none"> • Quantitative research • Randomised control group • Measures completed by participants and third-party 	<ul style="list-style-type: none"> • Experimental group: <ul style="list-style-type: none"> ◦ <i>N</i> = 7 (4 male) ◦ Aged 18-57 ◦ <i>M IQ</i> = 63.9 • Control group: <ul style="list-style-type: none"> ◦ <i>N</i> = 7 (5 male) ◦ Aged 19-55 ◦ <i>M IQ</i> = 65.3 	<p>Anger ratings in the experimental group decreased following treatment compared to the control group.</p>

Author	Description ^a	Participants	Key findings
32. Willner & Tomlinson (2007)	<ul style="list-style-type: none"> • Quantitative research • Control group • Measures completed by participants and third-party 	<ul style="list-style-type: none"> • Severity of ID not reported • Experimental group: <ul style="list-style-type: none"> ◦ $N = 8$ (5 males) ◦ Aged 25-59 • Control group: <ul style="list-style-type: none"> ◦ $N = 9$ (7 males) ◦ Aged 20-24 	Participant's scores on measures of anger expression decreased and coping skills increased following treatment. Participants used different coping skills across different environments. The effects of the intervention appeared to transfer from the day service to the home setting.

Note. Participants' ages are reported in years. Table sorted alphabetically according to authors surname.

^aCategorisation of study design based on Coolican (2009).

Operational Definitions

The use of operational definitions to define constructs in ways that can be observed and measured is important in all research, including the area of ID as it provides information that will allow other researchers to understand and replicate the study. This review revealed considerable variation in the definition of ID. Some authors (e.g., Chapman, Shedlack, & France, 2006) gave a very clear operational definition of ID as “having a testable IQ in the range of 55 to 70, along with adaptive deficits and early onset of the condition” (p. 205) and others reported participants’ IQ scores, made reference to the particular IQ test or classification system used, or a combination of the three. Three studies (Rose & West, 1999; Willner, Brace, & Phillips, 2005; Willner & Tomlinson, 2007), did not provide any information on diagnoses beyond stating that participants had an ID. It is important that researchers outline the criteria they are using to define ID.

An operational definition of ID could also help with the use of inconsistent terminology. Numerous terms have been used to define ID such as mental retardation and learning disability. Willner and Tomlinson (2007) used two different terms—ID and learning disability—interchangeably in the same paper without explanation. Contributing to the inconsistent use of terminology is the use of different terms over time and across countries. This change in language is reflected in the change of terminology used by the same authors across different articles (Hartley & MacLean, 2005, 2008). Inconsistent terminology creates confusion about what is being studied and makes it difficult to accumulate and compare knowledge on ID to advance understanding in this area.

The review also revealed that emotion regulation as a construct lacked operational definition. This may be because many of the studies included were concerned with a single emotion and the variable of interest tended to be defined as the results on some measure of emotion, without an explicit definition being provided. An exception was, Singh et al. (2011) who defined anger as “a self-detected emotional arousal that included increased heart rate, facial flushing, furrowed brows, tightening of lips, and the hot feeling that results when an individual feels slighted, wronged, unable to cope with the demands, or is negatively provoked” (p. 2692). Other researchers should address this limitation by providing carefully constructed operational definitions as it would enable future researchers to better understand and compare results.

Sampling

The DSM-IV-TR identifies four different degrees of severity of ID: mild, moderate, severe, and profound (APA, 2000). Participants with mild and moderate ID were more often included in studies (22 and 11 studies respectively) than those with a severe ID (1 study) or borderline intellectual functioning (6 studies). No studies included participants with profound ID. Eight papers were excluded from this finding because the authors did not state the degree of participant’s ID using any of these categories (Benson & Fuchs, 1999; Kruger & Rosema, 2010; Lindsay et al., 2004; Lindsay, Overend, Allan, Williams, & Black, 1998; Rose & West, 1999; Rose, West, & Clifford, 2000; Willner et al., 2005; Willner & Tomlinson, 2007). Since mild ID is more common (85%) than moderate severity, it is not surprising that the majority of research is conducted with those with mild ID (Sadock & Sadock, 2007).

An issue arises when group methodology is used to examine average performance across varying levels of intellectual impairment. Intellectual and adaptive

functioning varies greatly across the different severities and research that combines participants with different severities of ID may not reflect such heterogeneity and limit the conclusions that can be drawn from the results. For example, people who have borderline ID do not necessarily need assistance from special educators, ID services, or mental health services due to their level of functioning (Baller, Charles, & Miller, 1966). In contrast, individuals with a diagnosis of profound ID generally have difficulty communicating, struggle to take care of their own needs and require support for most aspects of daily living (World Health Organisation, 1992).

Measurement of Emotion Regulation

Numerous measures were used across the studies to assess the intensity of emotions such as the Anger Inventory (Benson & Ivins, 1992). Previous research has found a relationship between self-reported anger as measured by the Anger Inventory and the number of incidents of challenging behaviour exhibited by people who have an ID (Rose & West, 1999). However, fewer measures are available which assess the emotion regulation strategies that individuals have knowledge of or use when necessary. The Utrecht Coping List (Schreurs, van de Willige, Brosschot, Telegen, & Graus, 1993) has been adapted for this purpose, but was not designed for people who have an ID. Willner et al. (2005) focused on the development of a measure, the Profile of Anger Coping Skills (PACS) which could assess the strategies that people who have an ID use to regulate negative emotions on a daily basis. It was used with caregivers of individuals involved in an anger-management programme. Their findings suggested that reliable and valid measures of emotion regulation strategies can be achieved for use with people who have an ID.

There is debate about whether individuals who have an ID can provide reliable accounts of their own emotions. In 16 studies, researchers used information provided by third-parties to corroborate individual's self-report information. Caregivers, family members, and nursing staff attended interviews and completed measures as a means of providing information about participants' abilities to regulate their emotions. Such studies are plagued by their own methodological issues. For example, research has shown that staff may not be able to reliably identify emotional states in their clients (Clark, Reed, & Sturmey, 1991). Although third-party reports are not an adequate substitute for individuals' accounts of their own emotional experience, a measure of emotion regulation provided by proxy can supply valuable information.

Another widely used approach to the measurement of emotion regulation has been to record and compare participants' incidences of inappropriate or challenging behaviour before, during, and after an intervention. In seven studies, participants monitored their own behaviour. In most cases, reports of inappropriate behaviour were kept by staff. This type of reporting can be easy to use as it is often produced routinely by the service caring for the individual and provides quantifiable data. However, incident reports only depict a fraction of incidents that occur and the reporting of incidents can be influenced by factors like the length of the reporting form, how busy staff are, and their perception of aggression (Bowers, 1999). Therefore, incident reports do not constitute an objective measure of rates of inappropriate or challenging behaviour and should be used to supplement information collected from participants or third-parties.

It is clear that there are a number of different instruments (e.g., Anger Inventory, Utrecht Coping List, PACS, etc.) and data-collection methods (e.g., self-report, third-

party report, incident reporting, etc.) that researchers have used to assess emotion regulation in people who have an ID. Each method has unique strengths and weaknesses and there is ongoing debate within the literature as to the most appropriate method to use to research the emotion regulation strategies of people who have an ID. Continued research efforts are needed to provide sound psychometric measures of emotion regulation skills that are appropriate for use with this population. Moreover, a combination of the data-collection strategies may be the most useful approach to research with people who have an ID (Mactavish, Mahon, Lutfiyya, 2000).

When describing the research design, researchers should clearly outline the process by which the data was collected (American Psychological Association, 2010). Gaps in the methodology around operational definitions, sampling, and measurement make it difficult to draw valid conclusions, compare the results of similar studies, or generalise the findings. In some cases it was unclear whether measures were completed by staff, participants, or the researchers themselves (e.g., Howells, Rogers, & Wilcock, 2000) or how long a particular intervention was run for. Other times, the sample was not described sufficiently with demographic characteristics such as ethnicity, co-morbid psychiatric disorders, and the severity of ID not always included. Without a full and logical description of the steps taken to obtain data, other researchers will struggle to replicate the study and validate the findings.

Evidence of Emotion Regulation Difficulties

Within the identified literature, the majority of articles focused on the description or outcome of emotion regulation programmes. However, the following seven studies expand on the construct of emotion regulation. Benson and Fuchs (1999) identified situations that made participants angry at work and home, how they reacted in

those situations, and what they did to calm down or relax. The types of strategies used to cope with emotional experiences are not always adaptive. Duperouzel and Fish (2010) found that participants in their study described self-injury as an effective strategy to alleviate emotional distress. On the other hand, participants also reported that they experienced feelings of guilt and shame following self-injury which could increase their emotional distress. Didden, Embregts, van der Toorn and Laarhoven (2009) hypothesised that there would be a difference in emotion regulation strategies used between people with and without substance abuse issues. However, there was little difference between the two groups except that clients who used substances demonstrated more frequent use of palliative reaction patterns (e.g., trying to relax, engaging in other activities). Fuchs and Benson (1995) and Jahoda, Pert, Squire and Trower (1998) demonstrated that participants with anger management difficulties tended to provide an aggressive response as their first solution to a hypothetical conflict situation and provide more aggressive responses in general compared to their nonaggressive counterparts. Hartley and MacLean (2005) demonstrated that people who have an ID utilised different types of coping strategies for different situations such as negative social interactions. According to Hartley and MacLean (2008), problem-focused coping strategies were used more frequently than emotion-focused coping strategies when dealing with negative social interactions. These studies are significant in that they contribute to a greater understanding of the nature of emotion regulation difficulties that are reportedly prevalent in people who have an ID.

The existing research has not addressed the emotion regulation abilities of adults who have an ID compared to their typically developing peers. In order to demonstrate a specific impairment, researchers need to determine that individuals who have an ID are

impaired in emotion regulation relative to control groups of typically developing individuals matched for comparable mental and chronological age. While some evidence suggests that people who have an ID have difficulty regulating their emotions, the same is true for people without an ID who also use many different emotion regulation strategies and some more healthier and effective than others (John & Gross, 2004). Hence, comparisons with other samples would likely provide much needed empirical evidence of the limited emotion-regulation skills of people who have an ID.

Given that the evidence about emotion regulation difficulties in people who have an ID is limited, it may be useful to draw upon other research such as that conducted on stress and coping. When appraising whether a stressful situation is controllable individuals rely on personal beliefs, social support, and previous experience (Lazarus & Folkman, 1984). Research has revealed that individuals with ID experience: a) a wider range of stressful events (Patti, Amble, & Flory, 2005); b) lower perceived self-confidence (Prout, Marcal, & Marcal, 1992); c) smaller amounts of social support (Forrester-Jones et al., 2006); and d) negative coping experiences (Hastings, Hatton, Taylor, & Maddison, 2004; Owen et al., 2004). Taken together, these findings suggest that when faced with a stressful situation, people who have an ID will be more likely to view the event as uncontrollable and subsequently experience stress in a more frequent and intense manner.

Anger and aggression research carried out with people without an ID has established that emotion regulation difficulties are associated with aggression (Robertson, Daffern, & Bucks, 2012). Individuals who have difficulty regulating their anger may be more likely to display aggressive behaviour. In support of this notion, levels of physical aggression were found to be higher among adolescents that reported

lower levels of emotion regulation skills (Sullivan, Helms, Kliewer, & Goodman, 2010). Likewise, males who admitted finding it difficult to manage their emotions were more likely to abuse their female partners (Tager, Good, & Brammer, 2010). Similar to people without an ID, emotion regulation difficulties may manifest as aggressive behaviour in people who have an ID.

Research has illustrated that children and adults who have an ID are less accurate in their recognition of facial emotion than typically developing individuals matched on mental age and gender (McAlpine, Singh, Kendall, & Ellis, 1992). The ability to recognise emotions in other people is believed to be connected to the ability to regulate one's own emotions (Keltner & Kring, 1998). Research with various other populations who commonly display emotion recognition deficits (e.g., women who have anorexia nervosa, individuals who have schizophrenia, etc.) has supported the notion that people who have difficulties recognising emotions also tend to have difficulty modulating their emotions (Harrison, Sullivan, Tchanturia, & Treasure, 2009; Kee et al., 2009). If indeed the two aspects of emotional functioning—emotion recognition and emotion regulation—are interrelated skill sets then we would also expect that people who have an ID who have emotion recognition difficulties would display emotion regulation difficulties.

Conclusions

The conclusions reached by studies in the related literature combined with clinical accounts provide some evidence that people who have an ID are limited in their use of effective strategies for coping with negative emotional experiences. However, there remains many unanswered questions: Do people who have an ID use cognitive and/or behavioural emotion regulation strategies? Do the particular emotion regulation

strategies used vary depending on severity of ID or type of stressor? Do people who have an ID utilise similar strategies to those utilised by people without an ID? Until research attempts to answer these and other pertinent questions and comparisons are made with other groups in the population, we will be forced to rely on the broader literature to inform practice.

From this review, it is clear that there is an important gap in the literature. There is limited research that has evaluated the ability of people who have an ID to modify their emotional experiences. Perhaps the limited research in this area is due to the complexities involved in working with people who have an ID. Further research in this domain will help to integrate current professional understanding, practice, and evidence based knowledge.

While identification of the effectiveness of various emotion regulation interventions is important, such research does not adequately address emotion regulation in people who have an ID. Notable efforts have been made by a small number of authors to gain a better understanding of emotion regulation and evidence from related areas of research suggests that adults who have an ID may be more likely to have difficulty regulating their emotions than typically developing individuals. Nevertheless, the general conclusion from this review is that, at present, there is no convincing evidence that people who have an ID are more limited in their ability to regulate their own emotions than the wider population.

Suggestions for future research projects in the area of emotion regulation and ID include using: a) explicit operational definitions; b) reliable and valid measures for people who have an ID; c) comparison groups; and d) carefully described methodologies. Given the dearth of available literature in this area and increasing

number of emotion regulation interventions, it is timely for further research which takes into account these suggestions.



MASSEY UNIVERSITY
GRADUATE RESEARCH SCHOOL

**STATEMENT OF CONTRIBUTION
TO DOCTORAL THESIS CONTAINING PUBLICATIONS**

(To appear at the end of each thesis chapter/section/appendix submitted as an article/paper or collected as an appendix at the end of the thesis)

We, the candidate and the candidate's Principal Supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the candidate's contribution as indicated below in the *Statement of Originality*.

Name of Candidate: Jenna McWilliams

Name/Title of Principal Supervisor: Ian de Terte

Name of Published Research Output and full reference:

Transformers: An Emotion Regulation Programme for People who have an Intellectual Disability

In which Chapter is the Published Work: Chapter 3

Please indicate either:

- The percentage of the Published Work that was contributed by the candidate:
and / or
- Describe the contribution that the candidate has made to the Published Work:
The candidate is responsible for the work put into this manuscript (e.g., design, analysis, and write-up). The supervisors have contributed to the manuscript in the same way that they have contributed to the usual chapters in this thesis: by providing guidance and feedback.

Jenna McWilliams Digitally signed by Jenna McWilliams
DN: cn=Jenna McWilliams, o=ou,
email=jenna.mcwilliams@hotmail.co.nz, c=nz
Date: 2014.04.28 12:34:27 +12'00'

Candidate's Signature

28.04.14

Date

Ian de Terte Digitally signed by Ian de Terte
DN: cn=Ian de Terte, ou=Massey University,
ou=School of Psychology,
email=ian.deterte@massey.ac.nz, c=NZ
Date: 2014.04.28 14:01:26 +12'00'

Principal Supervisor's signature

28-Apr-2014

Date

**Chapter 3: Transformers: An Emotion Regulation Programme for People who
have an Intellectual Disability**

Jenna McWilliams, Ian de Terte, and Janet Leathem

Massey University

Sandra Malcolm and Jared Watson

Te Korowai Whariki

Author Note

Correspondence concerning this article should be addressed to Ian de Terte, School of Psychology, PO Box 756, Wellington 6140, New Zealand. E-mail:
i.deterte@massey.ac.nz

Abstract

This article presents the rationale, developmental history, and description of a specific approach to the treatment of emotion regulation difficulties in people who have an intellectual disability (ID). The Transformers programme was adapted from the Stepping Stones programme (Oxnam & Gardner, 2011)—an emotion regulation programme for people who have an ID who live in an inpatient setting. The programme has shown theoretical and clinical promise, but has not been formally evaluated. The Transformers programme is delivered in weekly sessions over a 6-month period in a group format to individuals who have an ID and are residing in the community. The focus is on helping group members to develop skills in recognising and understanding negative emotions and to develop skills to cope effectively with such emotions. Treatment covers a variety of modules including relaxation, goal setting, chain analysis, emotion recognition, and emotion regulation. Specific strategies that are used to teach the material include role-plays, DVDs, and quizzes.

Keywords: Intellectual disabilities, learning disabilities, Transformers, emotion regulation, cognitive-behaviour therapy, challenging behaviour, anger management, group treatment

Transformers: An Emotion Regulation Programme for People who have an Intellectual Disability

There are many definitions for emotion regulation, but the most widely accepted is “the processes by which individuals influence which emotions they have, when they have them, and how they experience and express these emotions” (Gross, 1998, p. 275). This definition suggests that individuals use behavioural or cognitive strategies to regulate their emotions. In order for people to regulate emotions they need to be able to identify and recognise their emotions (Linehan, 1993). Given that people use cognitive and behavioural strategies to manage their emotions, it is perhaps unsurprising that people who have an intellectual disability (ID) display deficits in recognising and regulating their emotions. Evidence shows that people who have an ID have access to a limited range of coping strategies and the types of strategies that they use to regulate their emotions are not always effective (Benson & Fuchs, 1999; Jahromi, Gulsrud, & Kasari, 2008). Clinical evidence has suggested that people who have an ID have emotional regulation difficulties which lead to aggressive behaviour or other unwanted consequences. An emotion regulation programme for people who have an ID seems an important adjunct to the treatment of this population.

The impetus for developing this programme was the clinical observation that a significant proportion of clients at a community-based ID service demonstrated emotion regulation difficulties, commonly related to anger. Furthermore, some clients were diagnostically very complex, had serious offending issues, and did not appear to benefit from individual psychological treatment. Oxnam and Gardener (2011) developed the Stepping Stones emotion regulation programme to address the needs of individuals with ID who have committed an imprisonable offence and who have behaviour which poses

a serious risk to themselves or others. The programme was predicated on an evidence-based anger management treatment for individuals who have an ID (i.e., Lindsay et al., 2004), and was delivered in an inpatient setting at a secure facility over a 42-week period. The Stepping Stones programme was adapted for people who have an ID and had high and complex behavioural needs, but were living in the community. The adapted version of the programme became known as Transformers.

The Transformers programme is designed to run over 22 weeks to accommodate clients who are available for a shorter period of time due to legal requirements. Although most of the clients who have been involved in the Transformers programme have offending histories and have been subsequently placed under compulsory care orders, the care orders of these clients have typically been shorter than those who participated in Stepping Stones. The duration of the programme is similar to other programmes that have been run with people with an intellectual disability (e.g., Rose, 1996; Taylor, Novaco, Gillmer, & Thorne, 2002). The number of sessions allows time for participants to come together and function collectively as a group and provides adequate time for repetition of key information and practice of the material to facilitate learning (Jackson & Gentile, 2012). The Transformers programme also includes fewer core components than the Stepping Stones programme and only those components that directly addressed emotion recognition and emotion regulation were included. The overall aim of the programme is to (a) increase individuals' abilities to recognise emotions, and (b) develop individuals' strategies for managing their emotions. It was envisaged that addressing these core components would reduce the challenging behaviour of this population.

Principles of the Treatment Programme

The course content is designed to be delivered in a group format of up to seven members to facilitate group cohesion and effective learning (Yalom & Leszcz, 2005). The course of the treatment is delivered once a week for two-hour sessions. For some clients, individual therapy is carried out on an ongoing basis to maintain their engagement in the group. Individual therapy can also be used to discuss issues that are not appropriate for a group discussion, beyond the scope of the group, or to address personalised mental health concerns. The Transformers group is a closed group rather than an open one which means that once the programme begins, no new members are added (Corey, 2011). This type of membership provides a stable context for continual development and enhances cohesion among group members (Corey, 2011). However, some clients may not complete the programme for various reasons (e.g., deterioration in mental health).

Selection Process

The main inclusion criterion for entry into the programme is that individuals present with emotion regulation difficulties. If it appears that an individual has difficulty managing their emotions, care managers from the ID service or care coordinators from the Regional ID Care Agency can refer that person for the programme. Service leaders use judgement about who might benefit from the group and programme facilitators rely on their clinical judgment to make the final decision about who will take part. Consideration is given to the mix of people within the group and their level of understanding. Potential participants are also prioritised in terms of their legislative requirements. Participants are not excluded on the basis of co-morbid mental health issues or literacy skills. Once the programme facilitators have identified potential

participants for the group, they meet with them to provide broad information about the programme, collect verbal consent, and carry out a clinical assessment. The assessment provides additional information about a client's emotion recognition and regulation skills and appropriateness for the group. Participation in the group is voluntary.

Staffing

The Transformers programme is delivered by at least two (and a maximum of four) facilitators at each session. When more than two facilitators are in attendance, two facilitators lead the session while the other facilitators observe and assist the participants and caregivers. Facilitators can be any combination of staff from ID services including clinical psychologists, nurses, social workers, care managers, and other health professionals. The programme was developed as a professional resource that can be facilitated by a range of health professionals, but it is imperative that someone that comprehends complex therapeutic issues is involved (Willner & Tomlinson, 2007).

Caregivers regularly accompany individuals to the group and in doing so are invited to participate in the activities (e.g., role-plays) so that participants feel supported. The number of caregivers can rise above two if necessary, in keeping with the service safety requirements (i.e., managed on a weekly basis dependent on the staff available to support needs of the clients at that time). This results in a high staff ratio which means that any difficulties that occur during the session can be dealt with effectively outside of the group. Evidence also indicates that the involvement of caregivers in the group therapy process can be useful therapeutically (Willner, Jones, Tams, & Green, 2002). Caregivers who attend the group may be able to help with homework completion and encourage participants to apply the skills they have learned in the group to real-life settings (Willner et al., 2002). Despite the large number of staff

involved in the programme, facilitators and caregivers attending a particular session should not outnumber participants because of group therapy processes (Yalom & Leszcz, 2005).

Theoretical Framework

The approach to the treatment of emotion regulation difficulties was drawn from the literature on cognitive-behaviour therapy (CBT; Beck, 1995), dialectical behaviour therapy (DBT; Linehan, 1993), and group therapy (Yalom & Leszcz, 2005). CBT is an evidence-based psychotherapeutic approach that aims to help individuals “analyse and ‘reality test’ existing patterns of thinking, emotional reactions and behaviour identified via an assessment of current difficulties, and to try out new approaches in a stepwise fashion, monitoring and evaluating effects, in all three areas” (Sheldon, 2011, p. 3). It is becoming a more widely used treatment approach with people who have an ID (Taylor, Lindsay, & Willner, 2008). Several controlled studies have demonstrated significant reductions in levels of anger and depression following the use of CBT for people who have an ID (Hagiliassis, Gulbenkoglou, Di Marco, Young, & Hudson, 2005; McCabe, McGillivray, & Newton, 2006; Rose, Loftus, Flint, & Carey, 2005). Willner (2007) concluded that although the evidence base is small, CBT interventions could provide effective treatment for this population. For this reason, the development of the emotion regulation programme was based largely on a cognitive-behavioural approach, which incorporated some DBT principles and techniques.

DBT is a modification of CBT that incorporates acceptance-based strategies along with cognitive and behaviour change strategies (Linehan, 1993). Originally developed for the treatment of women with borderline personality disorder, DBT is a structured, time-limited treatment approach that seeks to teach individuals to be aware

of and accept negative emotions while helping them to develop new, effective emotion regulation skills (Linehan, 1993). In particular, the DBT concept of *wise mind* (a balance between emotional experience and logical thought) has been simplified for use with people who have an ID and throughout the programme there is a strong emphasis on validation and the philosophy of building a life worth living (Linehan, 1993). DBT has been used to treat a variety of psychopathologies characterised by emotion regulation difficulties such as depression (Lynch, Morse, Mendelson, & Robins, 2003), eating disorders (Bankoff, Karpel, Forbes, & Pantalone, 2012), and personality disorders (Linehan et al., 2006; Turner, 2000). Furthermore, it has been adapted for people who have an ID (Verhoeven, 2010). Recently, Sakdalan, Shaw, and Collier (2010) employed a DBT training programme with a group of violent offenders who have an ID and reported improvements in individuals' level of risk, strengths, and global functioning. Lew, Matta, Tripp-Tebo, and Watts (2006) also reported data that individuals who have an ID showed a significant reduction in risky behaviours following DBT treatment. These results suggest that DBT can benefit people who have an ID.

There are numerous potential benefits to providing treatment in a group setting. Yalom and Leszcz (2005) argued that the delivery of therapy in a group format has the advantage of facilitating social learning. Furthermore, they postulated that group members are able to practice new skills and engage with others in not only receiving valuable feedback and insight, but also in providing it. They noted that groups provide the opportunity for individuals to identify with, and observe others with comparable issues. Finally, they suggested that as well as offering relief that other people have similar experiences, groups can provide support, encouragement, and acceptance.

Content of Group Therapy Sessions

Initial sessions focus on helping the clients get to know each other and establishing group boundaries. Activities have been chosen with the goal of enhancing participants' motivation, encouraging group cohesion, and allowing clients to become comfortable talking in front of others. Although the introduction formally spans two sessions, relationship building is an on-going process. Following the introduction, sessions concentrate on the nature and functions of different emotions along with the physiological symptoms that accompany them. Subsequent sessions introduce various skills that can be used to regulate negative emotions. Latter sessions prepare the individuals for the conclusion of group treatment and include the development of individualised relapse prevention plans. The final session is devoted to a celebration which acknowledges the effort and progress individuals have made throughout the programme. The celebration is attended by service leaders and group members receive certificates of completion. An outline of the programme structure is provided in Table 2.

The main content covered across sessions includes: relaxation, chain analysis, "A good life" (Ward & Gannon, 2006), emotion recognition, and emotion regulation. Relaxation and chain analysis are cognitive and behavioural strategies that individuals can use to manage their emotions. An explanation of each of these components follows.

Relaxation

Negative emotions such as anger, sadness, and worry, may be marked by heightened physiological arousal (e.g., increased heart rate and blood pressure; Kreibig, 2010; Park et al., 2013). Relaxation can be a quick and effective way for individuals to decrease their emotional and physiological arousal (Deffenbacher, 2011). In turn, the

Table 2

Theoretical components of each session

Session	Topic	Content
<i>Assessment 1, 2, and 3 completed</i>		
1	Introduction to programme	Welcome Information about group Group rules
2	Getting to know each other	Exercise to help clients get to know each other Introduction to relaxation
3	“A Good life”	Introduction to “A good life” Exercise to illustrate “A good life”
4	Chain analysis	Introduction to chain analysis
5, 6, 7	Emotion recognition (anger)	Brainstorm about anger Discussion about the concept of anger What makes people angry How anger feels Anger versus aggression Personal consequences of anger
8, 9	Emotion recognition (sadness and worry)	What makes people sad/worried How people look, think, feel, and behave when sad/worried
<i>Assessment 4 completed</i>		
10	Quiz	Quiz to recap material covered in sessions 1-9
11, 12, 13	Coping skills	Introduction to coping skills Wise mind versus feeling mind Breathing exercises Taking yourself away Exercise Distraction Doing something fun
14	Tool boxes	Developing individualised tool boxes
<i>Assessment 5 completed</i>		
15	Coping skills	Practicing coping skills through role-play
16	Quiz	Quiz to recap material covered in sessions 11-15
17, 18, 19	Relapse prevention	Recap material covered in all previous sessions Developing strength profiles

20, 21	Coping skills	Practicing coping skills through role-play <i>Assessment 6 completed</i>
22	Celebration	Certificate <i>Assessment 7, 8, 9, and 10 completed</i>

individual may be in a better position to apply other emotion regulation skills (Deffenbacher, 2011). As part of the programme, all participants are trained in relaxation. The introduction to relaxation involves a group discussion about the purpose of relaxation, different ways to relax, strategies that participants have tried in the past, and whether or not those strategies were useful. Various relaxation methods taught throughout the programme include visualisation, breathing exercises, listening to music, progressive muscle relaxation and a *Soles of the Feet* mindfulness exercise (Singh, Wahler, Adkins, Myers, & The Mindfulness Research Group, 2003). These methods are practiced at the end of each session. As the programme progresses, participants come to play a larger role in facilitating the group relaxation exercises.

A Good Life

This module was informed by philosophies from the strength-based *Good Lives Model* of offender rehabilitation (Ward & Gannon, 2006; Ward & Stewart, 2003). An underlying assumption of this model is that all individuals have similar aspirations and needs and that criminal behaviour occurs when individuals do not have the necessary prosocial means to meet their needs (Ward & Gannon, 2006). Thus, the role of rehabilitation is to motivate individuals to lead better lives by drawing on the things that are most important to them and equipping offenders with the capabilities they will need to satisfy their own life values (Purvis, Ward, & Willis, 2011). For the purpose of *Transformers*, *A Good Life* is the term used to refer to the kind of life that each member

wants to lead. This segment is introduced in an early session, with the aim of helping individuals uncover their motivation for attending the programme and developing their emotion regulation skills. Each group member identifies important goals in their lives and the steps that could be taken to achieve these goals. Facilitators assist group members to develop goals that are realistic and achievable. For example, a group member may consider the following goals important: moving to a farm, working outside in the garden, having contact with his/her dad, and playing soccer in a social team. Some of the steps on the pathway to achieving this goal could include the group member developing an understanding of why he/she gets angry, going to the Transformers group, learning to manage his/her anger, and getting on with people. A visual model of a pathway, taken from the Stepping Stones programme, is used to illustrate and help group members remember the *Good Life* concept.

Chain Analysis

The chain analysis is a tool used to influence behaviour change in DBT. It involves a detailed description of the challenging behaviour, events leading up to the challenging behaviour, consequences of the challenging behaviour, and alternative solutions to the challenging behaviour. The development of a chain analysis may lessen shame around the challenging behaviour and facilitate problem solving in an individual (Lynch, Chapman, Rosenthal, Kuo, & Linehan, 2006). Furthermore, a chain analysis may improve memory of an event. Enhanced memory of the event can help individuals to identify patterns and warning signs that precede the challenging behaviour and increase the likelihood that they will use a more effective behaviour next time (Lynch et al., 2006). Chain analyses have been modified for use with people who have an ID and incorporated into treatment programmes (Lew et al., 2006). All group members in the

Transformers programme are trained in completing a chain analysis. In the introduction to chain analyses, one facilitator guides another facilitator to explore a challenging behaviour with input from group members. Group members are then required to complete an individual chain analysis for homework between each session to address their challenging behaviours and develop and reinforce new skills that they learn. Caregivers assist group members to complete their chain analyses using questions such as: What was happening right before the problem? What was going through your head? And, how did your body feel? Between one and three members of the group can volunteer to present their chain analysis to the rest of the group at the beginning of each session.

Emotion Recognition

The ability to differentiate between facial expressions of emotion is essential for regulating one's own emotions (Linehan, 1993). Emotion recognition is also an important interpersonal skill that is necessary to accurately identify how others are feeling and provide an empathic response (Keltner & Kring, 1998). In turn, an individual who is unable to correctly identify facial emotions may react inappropriately in situations or towards others (Rydin-Orwin, Drake, & Bratt, 1999). People who have an ID experience problems recognising the facial expressions of emotion in others (McAlpine, Kendall, & Singh, 1991). However, their ability to recognise emotion in themselves and others can be enhanced through group training (McKenzie, Matheson, McKaskie, Hamilton, & Murray, 2000). To develop a better understanding of emotions and enhance emotion recognition skills, group members are asked to brainstorm different emotions. After identifying a range of emotions, they are shown pictures of faces depicting various emotions and asked to name the emotions in the picture. Then,

the group is asked to focus on several commonly experienced emotions: anger, sadness, and worry. For each of these emotions, the group identifies: the concept, what makes them feel that way, any physical symptoms associated with the emotion, and possible consequences. When discussing anger, the distinction between anger (the emotion) and aggression (the behaviour) is explored. Group members are taught that anger is a normal emotion and can be helpful, but aggression can have negative consequences.

Emotion Regulation

There are many different ways that people can regulate their emotions, for example distraction and breathing exercises (Aldao, Nolen-Hoeksema, & Schweizer, 2010; Arch & Craske, 2006). People who have an ID may have access to limited emotion regulation strategies (Fuchs & Benson, 1995; Wehmeyer & Kelchner, 1994). However, treatment programmes that have required individuals who have an ID to learn effective skills for managing their anger have reported successful outcomes (Taylor et al., 2002; Willner, Jones, Tams, & Green, 2002). In this module, participants learn more helpful strategies for dealing with their emotions. Strategies include: wise mind, distraction, taking yourself away, exercise, doing something fun, and breathing exercises (see Table 3). Each strategy is discussed in detail and group members are asked to provide examples of each strategy and when it might and might not be useful. The different emotion regulation strategies are likened to tools that can be used when fixing problems. If one strategy does not work in a particular situation, group members are encouraged to try a different emotion regulation tool. In keeping with this analogy, group members are asked to create a tool box poster with information about each tool

that they could share with the other members. During sessions, emotion regulation strategies are rehearsed using scenarios that cover a variety of situations and emotions.

Table 3

Description of each emotion regulation strategy as provided to group members

Emotion regulation strategy	Description
Relaxation	The act of using relaxation skills to reduce anger (e.g., progressive muscle relaxation, stretching, Soles of the Feet exercise).
Doing a Chain	Using a chain analysis worksheet to think about the problem situation in more detail (the lead-up, the situation, consequences, and next steps) and learn from this.
Wise mind	Making wise decisions and thinking about the consequences of your actions for others and yourself.
Breathing exercises	Slowing your breathing to make you feel calmer and more relaxed.
Taking yourself away	Taking yourself away from a distressing situation to avoid an aggressive confrontation.
Exercise	Changing your negative feelings by exercising and changing how you feel in your body.
Distraction	Doing something to take your mind off your problem or the thing that is making you angry, sad, or worried.
Doing something fun	Doing something enjoyable to change your negative feelings.

Relapse Prevention

Relapse refers to an increase in challenging behaviour following an initial improvement and is a common occurrence when individuals are trying to change their behaviour (Witkiewitz & Marlatt, 2007). Relapse prevention involves helping individuals to identify high-risk situations that could cause them to resort back to the

challenging behaviour (Witkiewitz & Marlatt, 2007). Once high-risk situations have been identified, the focus is on the assistance of individuals to develop and rehearse strategies to deal with future difficult situations (Witkiewitz & Marlatt, 2007). Relapse prevention has been found to be a useful adjunct to the psychological treatment of alcohol and drug problems (Witkiewitz, Marlatt, & Walker, 2005), depression (Bockting et al., 2005), and bipolar disorder (Lam et al., 2003). Moreover, relapse prevention has been included in treatment programmes for people who have an ID (Ayland & West, 2006; Taylor, Robertson, Thorne, Belshaw, & Watson, 2006).

This module is devoted to relapse prevention which focuses on ways that the group members can identify future triggers and continue to develop their emotion regulation strategies. Each group member is assisted by the rest of the group to create a *Strength Profile* made up of the following segments: (a) situations that they find upsetting, (b) ways that they can show they are upset, (c) things that they can do to help themselves, and (d) things that others can do to help them. The aim of the strength profile is to encourage clients to identify and document the key points that they learn about themselves during the programme and to acknowledge the development of strengths to manage difficult situations. The strength profiles will also assist clients to recognise the things they need to work on in order to maintain their wellbeing and continue to make progress. Each group member receives a copy of their strength profile, so they can remind themselves of what it is they must do to prevent relapse. A copy is also given to key support staff, and participants are encouraged to identify other important people they want to share the information with. Relapse prevention serves to bring together and reinforce information that participants learn throughout the programme.

Programme Delivery

The core components of the programme are delivered to participants through psychoeducation, self-monitoring, group discussion, DVDs, and role-plays. Activities such as role-plays, DVDs, and quizzes are utilised across sessions to consolidate learning and maximise group engagement. Role-plays are particularly useful when teaching group members to discriminate between inappropriate and appropriate responses and practicing effective responses to emotion-provoking situations. Group members frequently provide the scenarios to be role-played. They can also choose to direct or act in the role-plays while picking staff or other clients to act alongside them. Quizzes are designed to test group members' knowledge of the concepts they have learned while ensuring that each member has a reasonable chance of being able to answer the questions correctly. Small prizes for quizzes include toiletries, a deck of cards, games, or art supplies. Prizes are chosen that will enhance reintegration into the community and encourage clients to participate in activities of daily living. The DVDs that are shown to the group are relevant to the course material and generally depict individuals that have difficulty managing their negative emotions. After watching the DVD, group members are given the opportunity to identify the emotion that the actor is feeling, any signs that the actor is feeling that way, consequences of the actor's behaviour, and anything the actor could do differently in the situation. All group members are required to complete homework assignments between the weekly sessions to consolidate treatment material. A regular homework session takes place each week and clients receive assistance from caregivers to complete the work.

Session Structure

Each session follows a similar structure and begins with a welcome or karakia (a Māori prayer) followed by a recap of the previous session and outline of the current session. Next, group members are given the opportunity to share their homework. After a short recess, the theory component is introduced. Sessions conclude with a relaxation exercise and the opportunity to ask questions or provide feedback. Group members are also invited to formally close the session with an inspirational phrase, prayer, or karakia.

Conclusion

The Transformers programme involves the application of CBT and DBT paradigms to the treatment of emotion regulation difficulties. The approach aims to build the skills and competencies of people who have an ID to regulate their own negative emotions in a more effective manner. Since the commencement of the Transformers programme in 2010 eight groups have been run. Over 20 participants have completed the programme with some taking part multiple times. More recently, the programme has been implemented in other services, including with youth who have an ID. The feedback from participants who have taken part in the Transformers programme is positive and encouraging. Furthermore, staff at the regional ID service report some improvement in clients following their involvement in the programme. Although the programme shows promise, there is limited evidence regarding its effectiveness and many questions remain unexamined such as: What effect does involvement in the programme have on participants' abilities to recognise and regulate emotional experiences in the short-term? Are these effects maintained in the long-term? What components of the programme are most critical in producing change? Can the

programme be effective with ID populations residing outside of the New Zealand context?

The programme has continued to evolve and expand since its development, with a greater number of participants taking part in the programme. This will provide an opportunity for future researchers to conduct a thorough evaluation of the Transformers programme and demonstrate its value in reducing challenging behaviour and increasing participants' abilities to identify emotions and use appropriate coping strategies. The evaluation of this programme has the opportunity to bridge the gap between science and clinical practice.

Chapter 4: Research with People who have an Intellectual Disability

Studies that have attempted to answer some of the questions raised in Chapter 3 are reported in subsequent chapters. More specifically, the Transformers programme will be evaluated to see whether it can improve participants' abilities to recognise and regulate emotions and, in turn, reduce their challenging behaviour. In planning the studies, it was important to consider some wider issues related to research with people who have an intellectual disability (ID).

The need for careful consideration of ethical and methodological issues of working with individuals who have an ID was highlighted by Beecher (1966) in an early article on ethics and clinical research. Beecher drew attention to an experiment conducted at New York's Willowbrook State School in the 1950s. Willowbrook was an institution for people who had a severe ID. As part of the experiment, researchers infected children at the school with the hepatitis virus without their knowledge and consent. When controversy arose, the researchers argued that the children would have developed hepatitis anyway due to the poor conditions at Willowbrook. Although the importance of the research has never been questioned, Beecher and other researchers (e.g., Faden & Beauchamp, 1986; Ramsey, 1970) condemned the study for its serious breaches of research ethics.

Although the Willowbrook experiment is an extreme example of unethical research, it serves to highlight the important issue of protection of the rights of human research participants, particularly those who are vulnerable. Vulnerable populations include children, older adults, and people who have a mental illness or an ID (Stanley, Sieber, & Melton, 1996). People who have an ID are considered a vulnerable population because of their cognitive difficulties and life circumstances (Griffin & Balandin, 2004).

Such limitations can mean that people who have an ID lack the capacity to provide informed consent in research projects and are prone to being coerced into research (Rae & Sullivan, 2008).

Historically, people who have an ID have been excluded from research projects or included without consent. However, a shift over recent years has seen a drive to include this population in research projects in more positive ways. Researchers have come to recognise that people who have an ID can provide accurate and valuable information about their own experiences rather than having caregivers or family members provide partial accounts on their behalf (T. A. Booth & W. Booth, 1994; Goodley, 1996). As well as including people who have an ID in research projects, some researchers have invited people who have an ID to be involved in the design and implementation of research studies (Chappell, 2000; Walmsley, 1998).

Due to the Willowbrook experiment, ethical guidelines have been developed and provide direction for researchers. Ethical guidelines protect the rights of people who have an ID and are involved in research studies. A growing body of literature focuses on ways that researchers can apply these guidelines to their practice (Ward & Simons, 1998). For example, in 1998 a special issue of the *British Journal of Learning Disabilities* adopted research ethics as its theme. Articles in this issue addressed matters such as the research relationship, consent, confidentiality, and anonymity (W. Booth, 1998; McCarthy, 1998). The discussion of atypical ethical and procedural issues in research with this vulnerable population is helpful in advising researchers in the field of ID.

In an effort to carry out ethically sound research, consideration was given to salient ethical and methodological issues that could affect the participants, their

families, and support staff involved in the studies. The purpose of this chapter is to highlight and briefly discuss the key issues involved in the current studies: study design, data collection, research alliance, and informed consent and assent.

Study Design

During the development of both studies, consideration was given to the use of a control group or wait list control group to compare the effects of treatment versus no treatment. However, control groups were not feasible because there were insufficient numbers of people in the service, who had not taken part in an emotion regulation treatment programme, to form the group. Even if a sufficient number of individuals were available, it is likely that there would have been group differences such as varying etiologies and different behavioural phenotypes which would have made it difficult to compare the treatment and control groups (Hodapp & Dykens, 2001).

Based on previous research, it was hypothesised that a training programme such as that being evaluated would improve the emotion regulation difficulties of people who have an ID (Oxnam & Gardner, 2011; Willner et al., 2013). Thus, the withholding of treatment to a control group was considered unethical and could have had adverse effects for research participants. Instead, the single-case design was chosen for use in the current studies. Single-case refers to a methodology that can be applied when the sample size is one or when a number of individuals are considered as one group (Kazi, 1996). Using this method, the individuals served as their own control.

Further issues relating to the studies designs were the number of assessments to be conducted and the length of the studies. Dalton and McVilly (2004) suggested that researchers use the least invasive methods to address their research question. In total, 10 assessments were carried out with each participant. This number permitted the

recommended number of three assessments to be taken in each phase (Kratochwill et al., 2010; Perdices & Tate, 2009; Tate et al., 2008). There are three phases: pretreatment, treatment, and posttreatment. Each assessment took approximately 30 minutes and consisted of a self-report measure administered verbally by the interviewer and two short tasks administered using a computer. The assessments were brief and spread over approximately 12 months to minimise the burden to participants.

The length of the data collection spanned six weeks either side of the intervention period. The 10 assessments would have been conducted at regular intervals, but there were time restrictions because of when the Transformers programme was due to commence and to delay the commencement of the programme would have been unethical. To establish a baseline three assessments were completed, these had to be completed at a fortnightly interval because there were only 6 weeks available to complete these assessments before the commencement of the programme. To establish some continuity the posttreatment assessments were conducted at the same interval period as the pretreatment assessments.

A single follow-up assessment was carried out 3 months after the treatment programme had ended. From the researcher's perspective, three follow-up assessments would have been preferable to evaluate whether treatment gains were maintained. However, the treatment programme is run multiple times per year and the next Transformers group was due to begin which included the same participants. The programme facilitators hoped that repetition of the programme would support the development of appropriate emotion regulation skills. Thus, further treatment with its potential benefits for the participants was chosen in favour of a more rigorous design.

Data Collection

There were concerns around the use of self-report measures. One concern was that the participants would have difficulty understanding and answering the questions. Another major concern was response bias, particularly the tendency for people who have an ID to answer questions in the affirmative or respond in socially desirable ways (Finlay & Lyons, 2001; Hartley & MacLean, 2006). Response biases such as these can be exacerbated by sensitive topics and face-to-face interviews like in the current studies (Finlay & Lyons, 2001; Hartley & MacLean, 2006). However, speaking with people in person has advantages over other research formats (i.e., telephone, post, internet, etc.) including more ability to establish rapport and the opportunity to use visual aids and language that the participant can relate to (Clark-Carter, 2004; Visser, Krosnick, & Lavrakas, 2000). Furthermore, researchers can spot hesitation or possible confusion and answer questions as they arise (Dantzker & Hunter, 2006).

Importantly, not all people who have an ID have difficulty answering self-report questionnaires and previous researchers have offered suggestions as to ways that potential problems can be avoided or reduced (e.g., Finlay & Lyons, 2001). A number of methods were employed to enhance the validity of the assessments in the current studies. When participants had difficulty understanding a question, the question was paraphrased and/or expanded on. To reduce the impact of sensitive questions, individuals were explicitly assured at the beginning of each interview that they would not be punished on the basis of any material they shared. Precautions such as these have the potential to reduce response bias in people who have an ID and subsequently provide more accurate data (Finlay & Lyons, 2001; Hartley & MacLean, 2006).

Attention problems (i.e., reduced ability to ignore irrelevant stimuli and attend to relevant stimuli) are common with people who have an ID (Alevriadou & Grouios, 2007). People who have an ID can also have difficulty remembering long questions and take longer to process questions and provide a response (D'Eath, 2005). Given the attention, memory, and processing difficulties that can be present in ID, additional time was allowed for each assessment so that participants could be given sufficient time to complete the task (D'Eath, 2005). Participants in the current studies were often distracted by the thought of objects (e.g., cigarettes), events (e.g., upcoming personal shopping trips), or people (e.g., what other clients were doing) unrelated to the interview. Dealing with these practicalities required flexibility and sensitivity to requirements of the participants as well as additional time and patience.

Research Alliance

Previous researchers have posited that communication challenges can either be exacerbated or reduced depending on the willingness of participants to share their experiences with the researcher and the ability of the researcher to be open to understanding the participants experiences (T. A. Booth & W. Booth, 1996). In the current studies, it was necessary to establish good rapport and a trusting relationship with the participants, especially due to the sensitive nature of the topics for discussion. Greeting participants warmly, treating them with dignity and respect, and taking the time to engage in friendly conversation helped to develop the relationship. It was hoped that in the context of a good research relationship participants would feel more comfortable opting out of the research at any time. Not only would the participants feel that they could withdraw from the research if they chose to, but those who continued to

participate may have been more inclined to disclose information. Thus, rapport in the research relationship likely facilitated the collection of valid data (Ryen, 2002).

Hardy, Bukowski, and Sippola (2002) argued that there is a difference between being friendly and the establishment of a friendship. A friendship has been defined as a mutual and voluntary relationship between two people (Hardy et al., 2002). Previous authors (e.g., T. A. Booth & W. Booth, 1994; Stalker, 1998) have suggested that the research relationship may hold more importance in participants' lives than researchers can imagine and it is possible that people who have an ID will expect friendship from a researcher. Their smaller social networks made up of family, staff, and other people in the ID service rather than friends could make people who have an ID more vulnerable to expectations of continuing friendship than people who do not have an ID (Pockney, 2006). Thus, it was important to consider what the relationship meant and felt like from the perspective of the participants and balance rapport building with monitoring and maintaining appropriate boundaries.

Informed Consent and Assent

Research with people who have an ID often involves negotiation with “gatekeepers” (people whose job it is to safeguard the rights and interests of people who have an ID) before the potential participants can be approached. Before proceeding, permission was obtained from the clinical leader at the ID service to carry out research with the individuals who had been selected to be involved in the treatment programme. In some cases, the informed consent of a legally appointed welfare guardian was also required. A welfare guardian is someone who can make decisions for an individual for all aspects of their personal care if that individual cannot make decisions for themselves (Ministry of Justice, n.d.). A phone call was made to each welfare guardian to explain

the purpose and process of the studies and obtain verbal consent for the individual to participate. Following the phone call, a letter and information sheet about the studies was sent to the two welfare guardians (see Appendix 1). When it occurred, this process was documented by the researcher (see Appendix 2).

The consent of the individuals themselves was also required. Even when a welfare guardian provided proxy consent, the individual still needed to provide assent, that is, agree to take part in the studies (Griffin & Balandin, 2004; Sachs et al., 1994). A two-step procedure was chosen for this process and increased time was allowed to obtain informed consent (Cameron & Murphy, 2006; Taylor, Novaco, Gillmer, & Thorne, 2002). The research project was explained to participants and they were given time to think about whether or not they would like to be involved in the studies before they met with the researcher again. Before agreeing to take part in the research project, individuals were invited to consult with family members, friends, or staff at the ID service.

During the consent process, care was taken to ensure that the individuals understood the information they received. The researcher used appropriate language to interact with participants (see Appendix 3). On occasions, participants were asked questions or to repeat back to the researcher, what the research was about, to gauge their understanding of the research (Arscott, Dagnan, & Kroese, 1998). Participants were provided with ample opportunity to make comments or ask questions and their queries were addressed. Their right to withdraw from the studies at any time was emphasised and participants were assured that if they chose not to take part in the studies they could still be involved in the Transformers programme. Although a standard procedure was

developed, the consent process was adapted depending on the needs or the capacity of each individual.

Information and consent forms used in the current studies also needed to be adapted for people who have an ID (see Appendix 4 and Appendix 5). The forms were developed by the principal researcher in collaboration with professionals who have experience in working with people who have an ID. The information was bullet-pointed and simplified language, free from jargon, was utilised to make it easier for participants to understand (Cameron & Murphy, 2006; Griffin & Balandin, 2004). Visual cues were also included on the consent form as an additional way to communicate the information to the prospective participant. In the case that a participant was able to provide informed consent or assent, but was unable to read and sign or mark a consent form, oral consent was acceptable. Where oral consent was provided, this was documented on the consent form.

Consent was viewed as an ongoing process. Throughout the studies the researcher who carried out the assessments was aware of any non-verbal indicators that might suggest that participants did not understand what was required of them or did not want to take part in the research project. For instance, declining to stay in the room, failing to engage, or falling asleep during an interview can be an indirect way of refusing to participate in research (Rodgers, 1999). Other non-verbal indicators like overt signs of anxiety and discomfort could also be signs that a participant does not want to continue an assessment.

Conclusions

The single-case design used in the current studies with people who have an ID raised methodological and ethical issues. This chapter has described some of the issues

that were considered relevant to the current studies and briefly described some of the methods used to ensure best practice. It is hoped that discussions of this nature will serve as a starting point for careful planning for others embarking on research with people who have an ID.

The following chapters will introduce two studies, each conducted using the same group of participants. The first study focuses specifically on the effectiveness of the emotion recognition training component of the Transformers programme. The second study evaluates the Transformers programme and its impact on emotion regulation (as rated by participants and their caregivers) and challenging behaviour.



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**STATEMENT OF CONTRIBUTION
TO DOCTORAL THESIS CONTAINING PUBLICATIONS**

(To appear at the end of each thesis chapter/section/appendix submitted as an article/paper or collected as an appendix at the end of the thesis)

We, the candidate and the candidate's Principal Supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the candidate's contribution as indicated below in the *Statement of Originality*.

Name of Candidate: Jenna McWilliams

Name/Title of Principal Supervisor: Ian de Terte

Name of Published Research Output and full reference:

Recognition of Emotion in Faces and Stories: The Effects of Group Training for People who have an Intellectual Disability

In which Chapter is the Published Work: Chapter 5

Please indicate either:

- The percentage of the Published Work that was contributed by the candidate:
and / or
- Describe the contribution that the candidate has made to the Published Work:
The candidate is responsible for the work put into this manuscript (e.g., design, analysis, and write-up). The supervisors have contributed to the manuscript in the same way that they have contributed to the usual chapters in this thesis: by providing guidance and feedback.

Jenna McWilliams
Digitally signed by Jenna McWilliams
 DN: cn=Jenna McWilliams, o=pw,
 email=jenna.mcmw@massey.ac.nz, c=nz
 Date: 2014.04.28 12:34:27 +12'00'

 Candidate's Signature

28.04.14

 Date

Ian de Terte
Digitally signed by Ian de Terte
 DN: cn=Ian de Terte, ou=Massey University,
 ou=School of Psychology,
 email=i.deTerte@massey.ac.nz, c=NZ
 Date: 2014.04.28 14:02:55 +12'00'

 Principal Supervisor's signature

28-Apr-2014

 Date

**Chapter 5: Recognition of Emotion in Faces and Stories: The Effects of Group
Training for People who have an Intellectual Disability**

Jenna McWilliams, Ian de Terte, and Janet Leathem

Massey University, Wellington, New Zealand

Author Note

Correspondence concerning this article should be addressed to Ian de Terte, School of Psychology, PO Box 756, Wellington 6140, New Zealand. E-mail: i.deterte@massey.ac.nz

Abstract

The ability to accurately recognise emotions is essential for adaptive emotion regulation and social interaction. People who have an intellectual disability have difficulty accurately recognising emotion and this is linked to difficulty with emotion regulation. As part of a larger programme, five participants with mild to moderate intellectual disability received group training in an attempt to enhance their ability to recognise different emotions. Participants were assessed before, during, and after training using a recognition of emotion in faces task and a recognition of emotion in stories task. The results indicated that some participants improved in their ability to identify emotion in stories, but not emotion in faces. The reverse was also found. One participant demonstrated no change in their ability on either emotion recognition task. In general, improvements were minimal and the treatment did not appear to be effective. However, this finding may be due to limitations of the current study.

Keywords: Intellectual disabilities, Transformers programme, emotion recognition, emotion regulation, cognitive-behaviour therapy, challenging behaviour, group treatment

Recognition of Emotion in Faces and Stories: The Effects of Group Training for People who have an Intellectual Disability

Emotion recognition refers to the ability to perceive emotions in oneself and in other people (Riquelme & Montero, 2013). The ability to recognise one's own emotions is necessary for emotion regulation (Caruso, 2008). Research suggests that when people are aware of their emotions, they are more able to consider the cause of the emotion and socially acceptable responses (Robertson, Daffern, & Bucks, 2012). For example, a person who identifies that they are feeling angry may resist the urge to shout at a work colleague that they want to maintain a good relationship with. On the other hand, a person who can only identify that they feel "bad" might behave aggressively towards their colleague. The inability to recognise an emotion can make it difficult for an individual to know how to react in that situation. Instead of demonstrating self-control and engaging in more helpful behaviour they may be more likely to use problematic behaviours to cope with the difficult emotion (Robertson et al., 2012). Thus, emotion recognition can have implications for other aspects of emotional functioning.

The ability to identify emotions in other people is important in interpersonal contexts (Matsumoto, Keltner, Shiota, O'Sullivan, & Frank, 2008). Verbal cues (e.g., voice pitch) and nonverbal cues (e.g., facial expression, body movement) can be used to infer how another person is feeling (Banse & Scherer, 1996; Burgoon, Jensen, Meservy, Kruse, & Nunamaker, 2005). In particular, facial expressions of emotions provide information about one's feelings and behavioural intentions (Matsumoto et al., 2008). The ability to accurately recognise emotions in others using various cues is vital to understand how others are feeling and react appropriately in social situations. Whereas the inability to correctly identify facial expressions of emotion may cause an individual

to miss important social cues, respond inappropriately, or withdraw from social situations (Walker, 1981).

Emotion recognition deficits have been implicated in people who have an intellectual disability (ID; Gray, Fraser, & Leudar, 1983; McAlpine, Kendall, & Singh, 1991; Weisman & Brosgole, 1994). McAlpine, Kendall, and Singh (1991) reported that adults and children who had an ID were less accurate at identifying facial expressions of emotion when compared with children without an ID who had been matched by mental age. Weisman and Brosgole (1994) showed that adults who had an ID were impaired in their ability to recognise emotion in short stories compared with children without an ID. In a study of children and adults with mild and moderate ID, Gray et al. (1983) found that performance on emotion recognition tasks was worse for people who had an ID than people without an ID. Moreover, Gray et al. (1983) showed that performance on the emotion recognition tasks was related to intelligence. Thus, a consistent finding in the research is that people who have an ID have deficits in recognising emotions across contexts.

Research studies have already investigated the impact of training on emotion recognition in people who have an ID. For example, McAlpine, Singh, Ellis, Kendall, and Hampton (1992) trained participants to recognise emotion using a discrimination training procedure, directed rehearsal, and sets of photographs displayed over a reducing time period. Seven participants were involved in the training which took place over 70 sessions. Participants' abilities to recognise facial expressions of emotion improved following treatment and improvements were maintained at 9-month follow-up. Rydin-Orwin, Drake, and Bratt (1999) used a less time-intensive form of training where 15 adults who had an ID took part in two group-training sessions. They reported

that participants who received training significantly improved on tasks of emotion recognition compared with a control group who did not receive training. These results were replicated by McKenzie, Matheson, McKaskie, Hamilton, and Murray (2000). Their findings showed that training enhanced the participants' abilities to identify facial expressions of emotions in photographs and line drawings. These findings have suggested that training can improve the ability of people who have an ID to recognise emotions.

The Transformers programme is a community-based treatment programme that aims to improve the emotion recognition and emotion regulation abilities of people who have an ID (see McWilliams, de Terte, Leathem, Malcolm, & Watson, 2014 for a description). Emotion recognition was the focus of five consecutive weekly sessions which lasted for 120 minutes each. During these group sessions, participants were shown pictures of faces and asked to identify which emotions were depicted. Four emotions were covered in detail: anger, sadness, worry, and happiness. Participants were encouraged to identify any situations, thoughts, physiological sensations, and behaviours associated with each emotion. This information was reviewed and expanded in the following sessions. The aim of the present study was to explore the effects of the Transformers programme on the ability of adults who have an ID to recognise emotion. Specifically, it was hypothesised that training would increase participants' abilities to accurately recognise and identify emotions.

Method

Design

This study was based on a single-case design (Barker, Pistrang, & Elliott, 2002; Tate et al., 2008). Repeated measures were used to assess emotion recognition in

participants and treatment efficacy was evaluated by comparing individual's scores on the outcome measures across assessment points. The single-case research design was used to capture the features of the participants and was appropriate given the applied research setting (Morgan & Morgan, 2003). Data was also analysed at a group level.

Participants

The participants were three males and three females aged between 17 and 42 years ($M = 29$), who had a mild to moderate ID (American Psychiatric Association, 2000). Some participants had additional diagnoses of learning, attention deficit, anxiety, attachment, or impulse control disorders. Four participants identified as New Zealand European/Pakeha while the remaining two participants identified as New Zealand Māori. Participants undertook emotional recognition training as part of the wider Transformers programme (McWilliams et al., 2014). Six participants started the study, but due to personal circumstances (i.e., mental health problems) one participant withdrew. The study received ethical approval from the Health and Disability Ethics Committee, New Zealand.

Consent

Consent to take part in the study was obtained using a two-stage process that was tailored to the participant's level of understanding. The research was explained to each participant in the company of a staff member from the ID service who was present for support. Participants were informed that participation was voluntary and that they could withdraw their consent at any time without it affecting their right to participate in the Transformers programme. The participant was allowed time to consider whether or not they would like to take part in the research study or discuss it with a caregiver (i.e., a paid staff member who supports the person with their daily activities). After

approximately 30 minutes, the researcher met with the participants and if they had decided to participate in the study the researcher proceeded to gain their consent. Where the participants had welfare guardians, the guardians were contacted by phone prior to meeting with the participants. Welfare guardians were made aware of their freedom to decline to consent or withdraw their consent by contacting the researcher at any stage. Both welfare guardians provided verbal consent and were sent written information about the research.

Materials

Recognition of facial emotion. Thirty-six photographs were used (see Appendix 6 for examples of the photographs included in the task). There were six photographs of professional actors depicting each of the expressions; anger, fear, sadness, happiness, disgust, and surprise. The photographs used in the current study were taken from the NimStim Face Stimulus Set (Tottenham et al., 2009). The set is large in number, multiracial, and has a variety of expressions modelled by contemporary looking actors. The stimuli have been shown to have high test-retest reliability (mean proportion agreement 0.84) and high validity (overall mean proportion correct 0.79; Tottenham et al., 2009). Based on past research (Tottenham et al., 2009), only those photographs from the set that had high recognition rates (over 80%) were used in the current study. This was to ensure that participants were only shown photographs with less dispute about the the target emotion.

A colour photograph of each actor's head was presented on a white background. Randomisation was used to sort the photographs into six sets of 12 photographs and decide the order in which they would be presented to the participant across assessment points. Each set consisted of the following: two each of the six basic emotions, six male

and six female actors, and three European and three non-European actors. Participants viewed the photographs on a computer screen. Prior to each photograph, a fixation cross appeared on the screen for 1.5 seconds. At the beginning of each set, a practice photograph was presented to check participants understanding of the task. One point was awarded for each subsequent trial in which the participant correctly identified the target emotion verbally or by pointing to it on the prompt card. The range of scores was 0 to 12.

The emotions portrayed in the photographs were the same basic emotions identified by Ekman and Friesen (1971) as being universal in nature. The emotions, anger and sadness, were both discussed during the Transformers programme. The Transformers programme also looked at worry. Worry or anxiety is a secondary emotion that is activated by fear (Herrmann & Greenberg, 2007). Thus, the emotion recognition tasks were designed to test participants' knowledge of fear instead of worry. Happiness, disgust, and surprise were included to make the task more difficult.

Recognition of emotion in stories. Thirty-six brief story lines were used. See Appendix 7 for a full list of the stories used. Each story had been designed to represent one of the six basic emotions and was adapted from previous research studies (Owen, Browning, & Jones, 2001; Ribordy, Camras, Stefani, & Spaccarelli, 1988; Widen & Russell, 2010). For some stories the language was simplified, or changes were made so that the stories were appropriate for use with adults who have an ID living in New Zealand. For example, "Johnny/Susie was walking in the woods and met a hungry bear who liked to eat little children" was changed to "You were at the zoo and a bear escaped from its cage." Participants were shown a different set of stories at each assessment. The order of the stories in each set and the order that the sets were presented to participants

was randomised. Each set consisted of 12 stories and contained two each of the six emotions. Stories were presented on a computer screen using black, Microsoft Sans Serif, 25.8-point font, on a white background. Each story was also read aloud to participants. At the beginning of the trial, a practice sentence was presented to participants to check their understanding of the task. A response was considered to be correct if the participant named the target emotion out loud or pointed to it on the prompt card. Each correct response earned one point. The range of scores was 0 to 12. The small sample size precluded reliable calculation of Cronbach's alpha (Duhachek, Coughlan, & Iacobucci, 2005).

Pilot Experiment

The measures were initially presented to a small sample of five individuals who did not have an ID to ensure that the instructions and item wording was correct. Then, the same tasks were carried out with individuals who have an ID who were involved in the same ID service as the participants and had previously completed an emotion regulation programme. The purpose of piloting the measures with people who have an ID was (a) to ensure that the instructions and item wording was correct and understandable, and (b) to provide information about baseline levels of responding and whether there were likely to be floor or ceiling effects. The pilot study demonstrated that the task and its instructions were appropriate for use with people who have an ID. Furthermore, the scores of the individuals who have an ID varied and it did not appear that they found the task too easy or too difficult. Five individuals who have an ID completed the tasks and their scores ranged from 7 to 31 ($M = 19.4$) with a maximum possible score of 36 on the emotion recognition in faces task. On the emotion recognition in stories task, the individuals scores ranged from 7 to 33 ($M = 20.6$) with

maximum possible score of 36. Due to the variation in scores amongst people who have an ID, no changes were made to the task. Individuals involved in the pilot stage did not take part in the research project.

Procedure

In a single assessment, each of the six emotions was presented twice during the recognition of facial emotion task and twice during the recognition of emotion in stories task. Five participants were shown each target emotion a total of six times during a phase (i.e., pretreatment or posttreatment) for both tasks. Therefore, there were 30 possible opportunities for each emotion to be correctly identified by the group per phase.

Participants completed the assessment individually in a quiet room at their residence or day centre to avoid distraction and caregivers were present during some testing sessions. Participants were seated approximately 60 cm away from a 15.4 in. laptop computer screen so that they could clearly see the stimuli. In the recognition of facial emotion task, participants were shown the photographs, one at a time. A prompt card listing the six emotions was placed in front of each participant to remind them of the different emotions they could select (see Appendix 8). Using a forced-choice response format, participants were asked to choose the emotion that was depicted in the photographic stimuli (see Appendix 9 for full task instructions). Once participants had made their response, it was recorded (see Appendix 10), and they were shown the next photograph. Next, participants were read a series of 12 short stories sequentially. The participants were asked to choose the emotion, using the same prompt card, that they would feel if the story happened to them and their responses were recorded (see Appendix 11 for full task instructions). There was no time limit and no verbal feedback

provided in either task. Both measures were administered a total of 10 times: three assessments prior to the programme at fortnightly intervals, three assessments during the programme at two-monthly intervals, three assessments after the programme at fortnightly intervals, and one follow-up assessment 3 months after the programme.

Data Analyses

Individual data were graphed using Microsoft Excel and then analysed using visual analysis. Trendlines were added to assist in describing the data set. In addition to visual analysis, effect size was obtained using the *Percentage of Nonoverlapping Data* (PND) statistic (Scruggs, Mastropieri, & Casto, 1987). The PND statistic was calculated by identifying the highest point of the baseline data and drawing a horizontal line that extended from this point, into the treatment, post-treatment, and follow-up phases. The number of points that fell above the line were counted, divided by the total number of assessment points, and multiplied by 100. This yielded the percentage of data points that were not overlapping with the extreme baseline data point. PND scores below 50% suggest ineffective treatment, scores between 50% and 70% suggest that treatment effectiveness is questionable, scores between 70% and 90% suggest effective treatment, and scores over 90% suggest very effective treatment (Scruggs & Mastropieri, 1998).

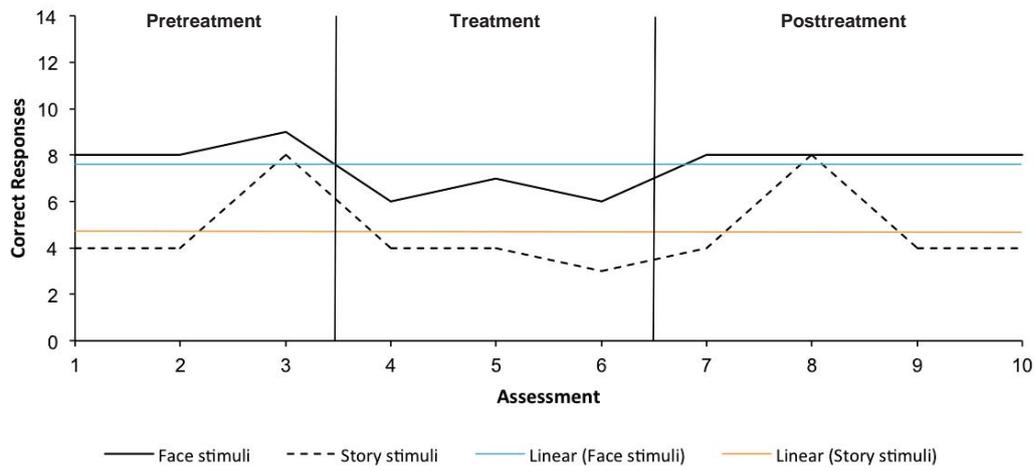
Change among individual participants was also illustrated using Brinley Plots comparing pre- and posttreatment results. A Brinley plot is a type of scatter plot that can be used to display data from two groups of participants (i.e., mean reaction times of one group can be plotted on the X-axis and the mean reaction times of another group can be plotted on the Y-axis; Brinley, 1965; Rucklidge & Blampied, 2011; Sobell, Sobell, & Gavin, 1995). Each data point represents the average performance of each individual in each condition. If the data points rest on the diagonal line this indicates that there has

been no change in participants' abilities to accurately identify emotions following treatment. If the data points rest above or below the line this indicates that there is a considerable difference in participants' abilities to identify emotions following treatment: above the line indicates that there has been an increase in ability to recognise emotions whereas below the line indicates that there has been a decrease. Brinley Plots are useful for detecting any changes as a result of interventions especially with a small sample as in the current study.

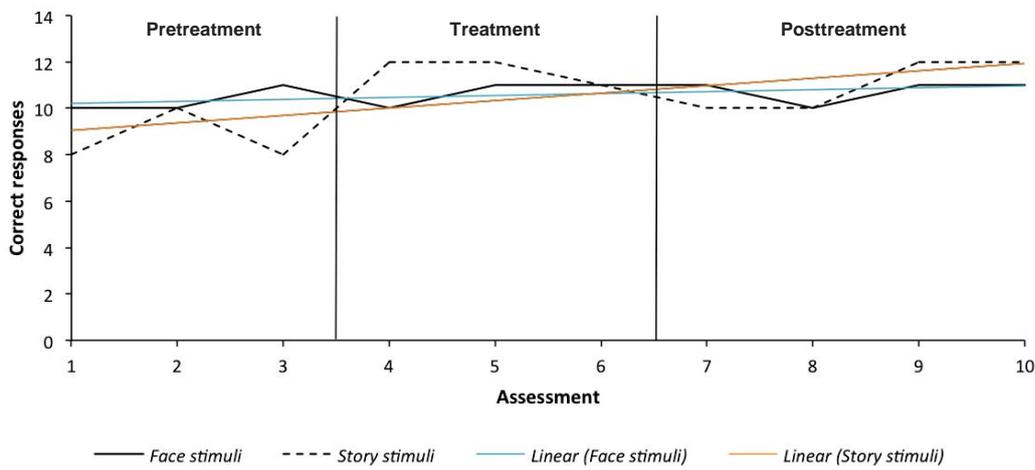
Results

The number of facial expressions correctly labelled by all five participants before, during, and after their involvement in the Transformers programme is illustrated in Figure 1. Based on visual inspection of the data, it appears that there was a slight upward trend in accuracy for emotion recognition in faces in participant 2 (P.2), participant 3 (P.3), and participant 4 (P.4). For P.2 and P.4, the improvements seem to be maintained at short-term follow-up. However, for participant 5 (P.5), there was a decrease in accuracy. There is also an upward trend in accuracy for emotion recognition in stories for P.2 and P.5. These changes were maintained at follow-up. In the case of P.3 and P.4, a decrease in accuracy for emotion recognition in stories was observed. For participant 1 (P.1) there appeared to be no change in accuracy for either emotion recognition task following treatment.

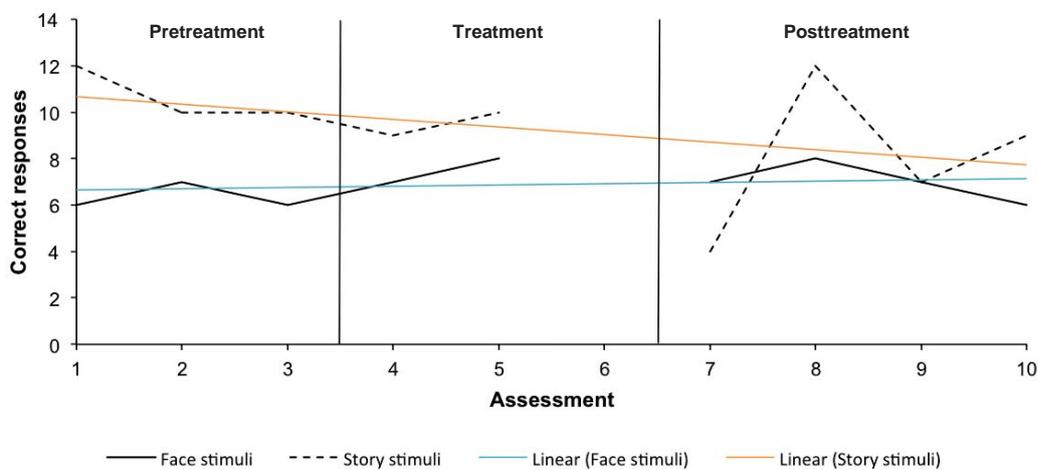
P.1



P.2



P.3



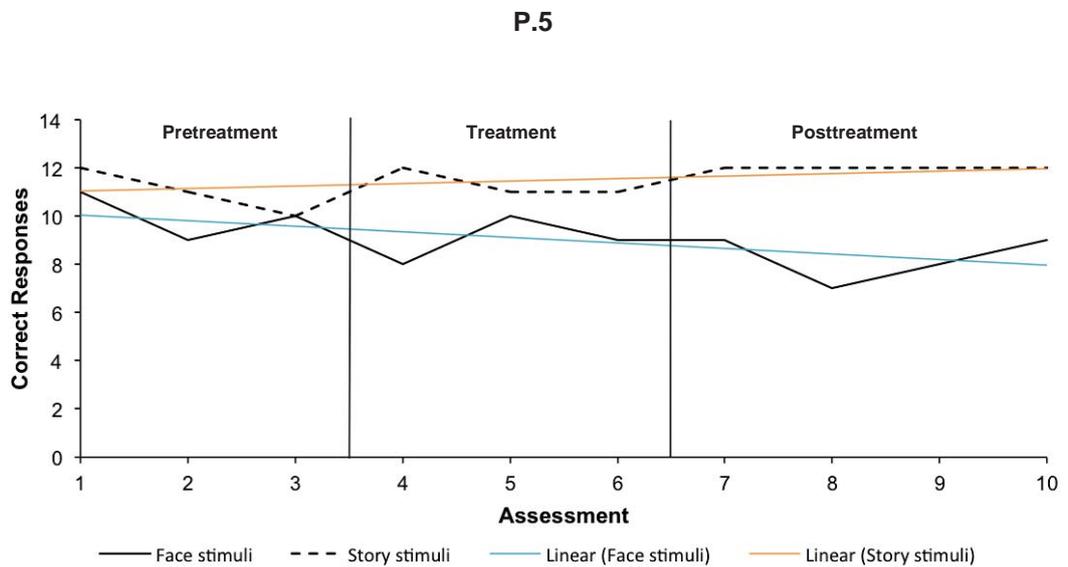
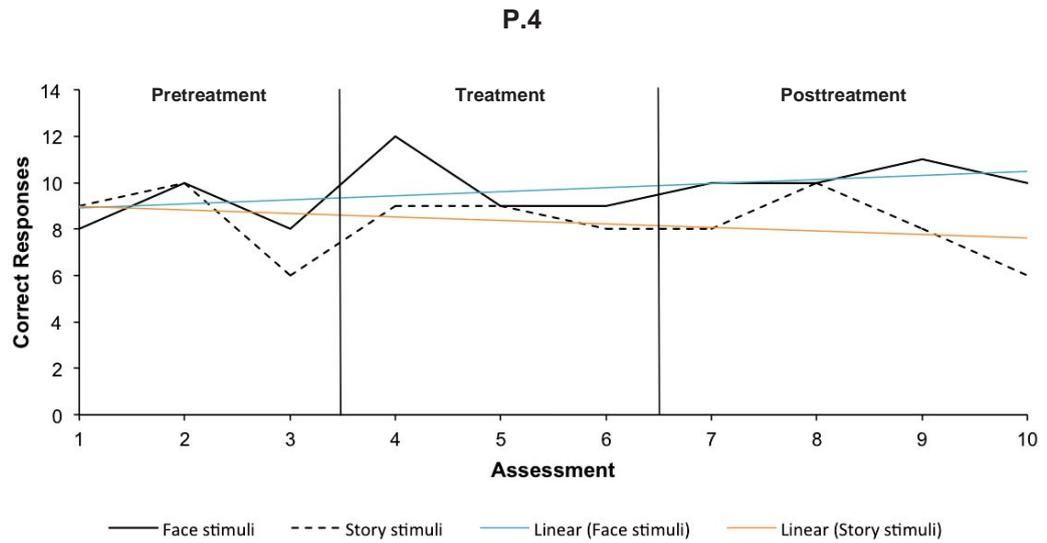


Figure 1. Number of correct responses in the recognition of facial expressions of emotion and emotion recognition in stories for each participant prior to, during, and following their involvement in an emotion regulation programme. The graph includes a linear trend line for each emotion recognition task.

The PND statistics for the emotion recognition in faces task were 0% for P.1, 0% for P.2, 71% for P.3, 29% for P.4, and 0% for P.5. The PND statistics for P.1, P.2, P.4, and P.5 indicate ineffective treatment. On the other hand, the PND statistic for P.3 indicates

effective treatment. The PND statistics for the recognition of emotion in stories task were 0% for P.1, 71% for P.2, 29% for P.3, 0% for P.4, and 0% for P.5. The PND statistics for P.1, P.3, P.4, and P.5 represent ineffective treatment. However, the PND statistic for P.2 indicates effective treatment.

Figure 2 shows the Brinley plots comparing participants' average number of correct responses on the recognition of facial emotion task (A) and recognition of emotion in stories task (B). Each data point represents the participant's performance on the tasks pre- and posttreatment (excluding the 3-month follow-up). Brinley plot A demonstrates that two participants, P.3 and P.4, improved on the recognition of facial emotion task. P.2's performance remained the same despite treatment. Brinley plot B shows that three participants (P.2, P.4, and P.5) improved on the recognition of emotion in stories task following treatment. P.1's performance remained consistent before and after treatment. Across emotion recognition tasks it appears that any improvements made following treatment were minimal. P.4 was the only participant to accurately recall more emotions on both tasks after treatment.

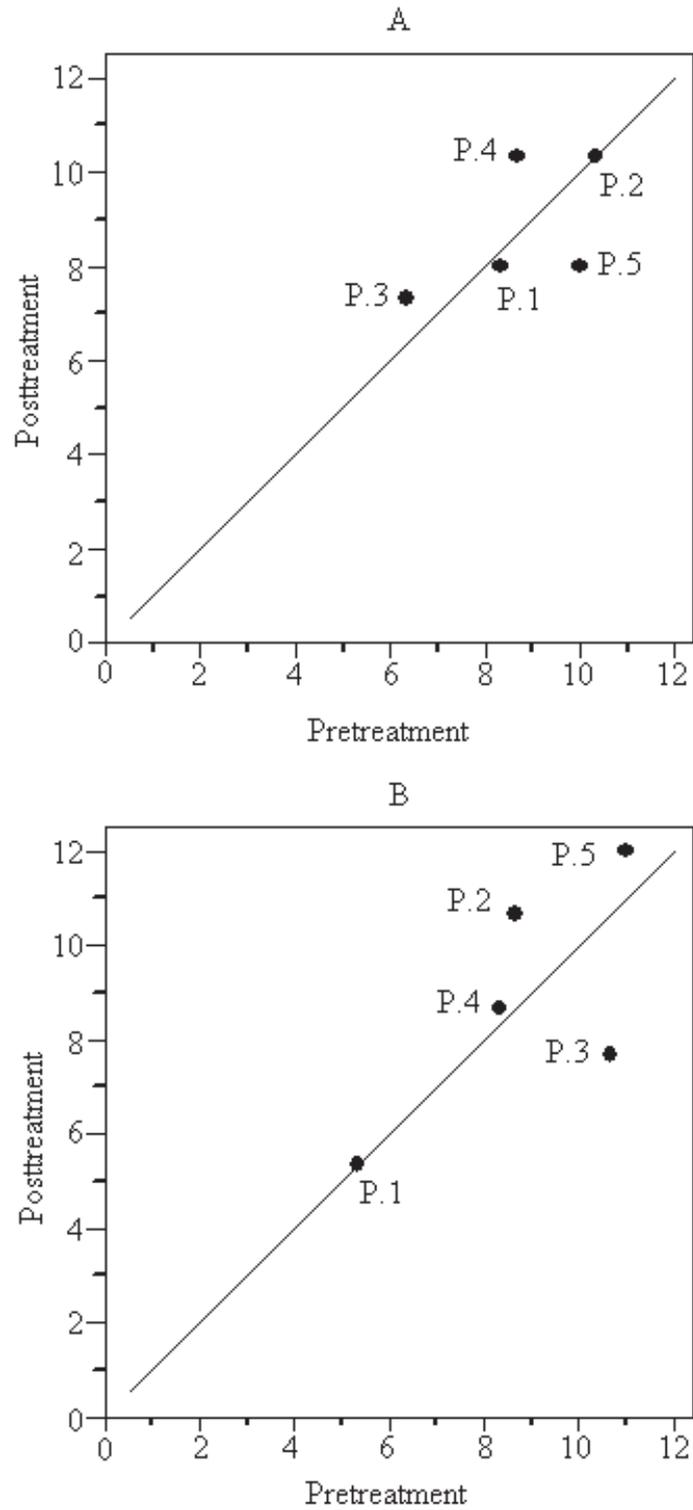


Figure 2. Brinley plots comparing the average of correct responses pre- and posttreatment (excluding follow-up) for each participant on two tasks: the recognition of emotion in faces task (A) and recognition of emotion in stories task (B).

The number of correct responses to each emotion was calculated for the facial expressions of emotion task and the emotion recognition in stories task across pre- and posttreatment assessments (excluding the 3-month follow-up) for all participants. Table 4 shows the number of correct responses for the individual emotions for all subjects on the recognition of facial emotion task before and after treatment. It would appear that the emotion most easily recognised was happiness. Participants accurately identified happiness on 97% of occasions before treatment and 93% of occasions after treatment. Disgust was the most difficult emotion for participants to identify on the recognition of facial emotion task during the pre- and posttreatment conditions (43% and 37%, respectively).

Table 4

Number of times each emotion word was selected in response to each target emotion for the pretreatment and posttreatment condition in the recognition of facial emotion task

Target Emotion	Response					
	Happiness	Surprise	Anger	Sadness	Fear	Disgust
Happiness	29/28	1/0	0/0	0/0	0/2	0/0
Surprise	0/0	23/23	0/0	0/0	6/6	1/1
Anger	0/1	3/0	22/25	0/0	2/2	3/2
Sadness	0/0	2/3	1/0	25/24	2/1	0/2
Fear	0/0	5/5	0/2	2/0	19/23	4/0
Disgust	1/0	3/4	8/7	4/2	1/6	13/11

Note. The number of times each target emotion was correctly identified is in bold. The number to the left of the forward slash is the pretreatment score and the number to the right of the forward slash is the posttreatment score. The total scores for each phase equal 30 per row. A possible 100% score for a target emotion would be 30.

Table 5 shows the number of correct responses for the individual emotions for all subjects on the recognition of emotion in stories task before and after treatment (excluding the 3-month follow-up). Similar to the facial expressions of emotion task, happiness was the easiest emotion to identify. Participants accurately identified happiness on 87% of occasions before treatment and 97% of occasions after treatment. Participants had the most difficulty identifying surprise before treatment. Surprise was only correctly identified on 50% of occasions. However, after treatment, participants did not recall fear correctly on any occasion.

Table 5

Number of times each emotion word was selected in response to each target emotion for the pretreatment and posttreatment condition in the recognition of emotion in stories task

Target Emotion	Response					
	Happiness	Surprise	Anger	Sadness	Fear	Disgust
Happiness	26/29	4/1	0/0	0/0	0/0	0/0
Surprise	7/3	15/19	3/1	1/0	4/6	0/1
Anger	1/0	0/0	23/23	1/4	0/0	5/3
Sadness	0/0	1/1	7/9	21/20	0/0	1/0
Fear	3/1	3/2	1/0	2/27	20/0	1/0
Disgust	0/0	2/1	3/3	3/2	0/5	22/19

Note. The number of times each target emotion was correctly identified is in bold. The number to the left of the forward slash is the pretreatment score and the number to the right of the forward slash is the posttreatment score. The total scores for each phase equal 30 per row. A possible 100% score for a target emotion would be 30.

Discussion

The results show that four individuals demonstrated improvement on either the recognition of emotion in faces task or the recognition of emotion in stories task. The finding that only some participants showed improvements in emotion recognition ability may be due to external factors such as P.1 having a moderate ID, whereas the other participants in the study had mild ID. As evident in the results, P.1 received the lowest posttreatment score out of all participants on any task. Individuals who have a mild ID tend to perform better on tasks of emotion recognition than individuals with more severe ID (Rojahn, Lederer, & Tassè, 1995).

An exploratory finding was that some individuals were better at identifying emotion in stories while others were better at identifying emotion in faces. This result might be related to the differential task demands. The recognition of emotion in faces task requires participants to visually process face stimuli whereas recognition of emotion in stories requires verbal comprehension of the stories. Although some participants made gains following treatment, any improvements were minimal and in some case participant's performance remained the same or even worsened; this does not support the hypothesis that emotion recognition training would improve participants' abilities to accurately identify emotion in stories and/or faces.

When the results were broken down according to the different emotions, happiness was correctly recognised most frequently. This finding is consistent with previous literature which shows that individuals who have an ID are better at identifying facial expressions of happiness than other emotions (Gray et al., 1983; McAlpine et al., 1991; McAlpine, Singh, Ellis, et al., 1992; Owen et al., 2001; Stewart & Singh, 1995). This finding is also true for emotion recognition in stories (Owen et al., 2001).

The scientific literature is less certain about which facial emotion is the most difficult to recognise. Previous research has identified surprise (McAlpine et al., 1991; McAlpine, Singh, Kendall, & Ellis, 1992), anger (Gray et al., 1983), and fear (Gray et al., 1983; McAlpine et al., 1991; Stewart & Singh, 1995) as the least frequently recognised emotions. The current study showed that people who have an ID demonstrated a deficit in their ability to identify facial displays of disgust. Although, these results differ from some research studies, they are partially consistent with those of Owen et al. (2001). Owen et al. (2001) also found that participants who have an ID had particular difficulty recognising disgust. However, in contrast to Owen et al. (2001) the current study also found that for the recognition of emotion in stories task, surprise was the least recognised emotion before treatment and fear was the least recognised emotion after treatment.

Possible environmental and neurological explanations have been proposed for the findings that people who have an ID have difficulty with fear and disgust recognition. At an environmental level, there is some evidence that caregivers of individuals who have an ID perceive them as youthful and compliant with pleasant and sociable personalities (Fidler & Hodapp, 1999). Caregivers use less negative emotional terms and facial expressions around people who have an ID that they believe have a positive disposition (Kasari, Freeman, & Hughes, 2001). Therefore, people who have an ID would have less opportunity to learn about emotions such as fear and disgust (Kasari et al., 2001).

At a neurological level, fear recognition is linked to the temporal limbic system and the amygdala (LeDoux, 1998). Research has found evidence of anomalies in the temporal limbic system in people with disorders such as Down syndrome and autism

that are commonly associated with ID (Krasuski, Alexander, Horwitz, Rapoport, & Schapiro, 2002; Pierce, Müller, Ambrose, Allen, & Courchesne, 2001; Sadock & Sadock, 2007). Thus, the anatomical abnormalities of people with ID may impact on their fear recognition skills. However, these explanations are tentative and require further investigation.

It is possible that findings of the current study lend support for the *emotion specificity hypothesis*, which is that individuals who have an ID are specifically impaired in their ability to recognise visually affective information (Rojahn, Rabold, & Schneider, 1995). Participants in the current study found it more difficult to recognise negative emotions such as disgust and fear compared to happiness. Alternatively, if emotion recognition deficits are a function of the more general cognitive impairment inherent in ID, then it would be expected that this would affect participants performance on the tasks more generally (e.g., participants would perform poorly irrespective of the type of emotion; Rojahn, Rabold, et al., 1995). Given that participants in the current study also displayed difficulty recognising negative emotions in stories, it may be that this specific deficit extends to verbal material as well as visual. However, without a control task it is impossible to discount the notion of a more general task deficit based on the findings of the current study (Moore, 2001; Rojahn, Lederer, et al., 1995).

Contrary to expectations, the general finding was that emotion recognition training did not improve the ability of people who have an ID to accurately perceive emotion. This result is in contrast to the findings reported in other emotion recognition training studies (e.g., McAlpine, Singh, Ellis, et al., 1992). A possible explanation for the results in the current study may be that five afternoon sessions were not sufficient for changes to occur. The main topics covered were: the concept of the emotion, what

made them feel that way, any physical symptoms associated with the emotion, and possible consequences. Given the more time-intensive training and narrower focus used in the studies by Stewart and Singh (1995) and McKenzie et al. (2000) and directed rehearsal procedures utilised by McAlpine et al. (1992) their participants would be expected to perform better than the participants in the current study.

Methodological limitations may also have contributed to the inconsistent findings between the current research and previous research in this area. Results of the current study were based on a small sample size. A larger sample size may have produced different results. In addition, while some participants showed an increase in their ability to accurately identify a range of emotions, it remains unclear whether this was due to the treatment itself or extraneous factors. Although the suggested three baseline measures were taken (Kratochwill et al., 2010; Perdices & Tate, 2009; Tate et al., 2008), participant's scores were variable and there was not a stable baseline. A stable baseline is one that is relatively flat and has little slope which indicates that there is only slight variability in the data (Parker, Cryer, & Byrns, 2006). Ideally, baseline data would have been collected using additional assessments spread over a longer period of time until a more narrowly defined pattern of data was evident (Kazdin, 2012). Another way to minimise this weakness could be the use of a multiple baseline design across participants (Kazdin, 2012). However, as an applied piece of research, these techniques were not feasible due to time restrictions involved in the current study and awareness around the number of assessments participants were asked to complete.

Finally, it was clear that there was a major limitation of the current measures. The majority of the participants reached ceiling level in their performance, indicating that the tasks were too easy. By piloting the measures this study did attempt to mitigate

potential ceiling effects and the tasks did not appear to suffer from ceiling effects so no alterations were made. Furthermore, incorporating photographs from the stimulus set that had lower recognition rates (i.e., less than 80%) in an effort to make the tasks more difficult may have resulted in using photographs in which there had been greater disagreement about the target emotion (Tottenham et al., 2009). Given the significant issues associated with the measures used in the current study, these results need to be interpreted with caution. It may well be that training did improve participants' abilities to recognise emotions, but the measures did not capture this change. Thus, it is recommended that future studies increase task difficulty by varying aspects of the presentation format (e.g., speed of presentation, subtlety of expression) to more closely match the more rapid, blended facial expressions of emotion that occur in real-life situations.

It must also be acknowledged that other factors may have impacted participants' performance on the emotion recognition tasks. Extraneous factors that were not controlled for include participants' abilities to concentrate during treatment or testing (they may have become tired or bored by repetitive testing), absences during the emotion recognition training sessions, and any co-morbid mental health disorders (e.g., anxiety, depression), or disruptions in daily life (e.g., changes in staff or living arrangements). According to previous research, people who have an ID who were exposed to significant life events such as staffing and residence changes exhibited greater incidences of aggressive behaviour (Owen et al., 2004). Research has also shown that disorders can differentially affect emotion recognition. For example, individuals with depression perform more poorly on tasks of emotion recognition than

individuals without depression (Langenecker et al., 2005). Thus, multiple extraneous factors could have affected the outcomes of the current study.

Despite these limitations, the present findings suggested a number of implications for current clinical practice. First, the discrepant findings between the current research and previous research suggest that more rigorous training may be necessary given the numerous topics covered in the Transformers programme (McWilliams et al., 2014). The programme could be extended or follow-up sessions could be provided to improve treatment gains. Second, it appears that people who have an ID have more difficulty recognising negative emotions and often confuse them. In addition to teaching people how to recognise emotions, the Transformers programme may need to demonstrate how to tell the difference between the emotions. Although the programme was targeted to individuals level of understanding, it may be that the programme needs to be adapted for people with moderate and severe ID. Due to the small number of participants, it was not possible to investigate the impact that severity of ID had on emotion recognition in the current study. However, previous research has indicated that ability to recognise emotion varies according to level of intellectual ability (Rojahn & Warren, 1997; Gray et al., 1983). That is, people with a mild ID are more accurate at identifying emotions than people with a moderate or severe ID (Rojahn & Warren, 1997; Gray et al., 1983).

The findings of the current study suggest that the Transformers programme is not an effective method for increasing the ability of people who have an ID to recognise emotion. Nevertheless, training which enhances the emotion recognition abilities of people who have an ID is especially pertinent given that emotion recognition is a

necessary skill for emotion regulation. Therefore, there is a need for further research and continued development of the Transformers programme to benefit people with ID.



MASSEY UNIVERSITY
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**STATEMENT OF CONTRIBUTION
TO DOCTORAL THESIS CONTAINING PUBLICATIONS**

(To appear at the end of each thesis chapter/section/appendix submitted as an article/paper or collected as an appendix at the end of the thesis)

We, the candidate and the candidate's Principal Supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the candidate's contribution as indicated below in the *Statement of Originality*.

Name of Candidate: Jenna McWilliams

Name/Title of Principal Supervisor: Ian de Terte

Name of Published Research Output and full reference:

An Evaluation of an Emotion Regulation Programme for People who have an Intellectual Disability

In which Chapter is the Published Work: Chapter 6

Please indicate either:

- The percentage of the Published Work that was contributed by the candidate:
and / or
- Describe the contribution that the candidate has made to the Published Work:
The candidate is responsible for the work put into this manuscript (e.g., design, analysis, and write-up). The supervisors have contributed to the manuscript in the same way that they have contributed to the usual chapters in this thesis: by providing guidance and feedback.

Jenna McWilliams Digitally signed by Jenna McWilliams
DN: cn=Jenna McWilliams, o=pz,
email=jenna.mcwilliams@hormail.co.nz, c=nz
Date: 2014.04.28 12:34:27 +12'00'

Candidate's Signature

28.04.14

Date

Ian de Terte Digitally signed by Ian de Terte
DN: cn=Ian de Terte, o=Massey University,
ou=School of Psychology,
email=i.coterre@massey.ac.nz, c=NZ
Date: 2014.04.28 14:01:28 +12'00'

Principal Supervisor's signature

28-Apr-2014

Date

**Chapter 6: An Evaluation of an Emotion Regulation Programme for People who
have an Intellectual Disability**

Jenna McWilliams, Ian de Terte, and Janet Leathem

Massey University, Wellington, New Zealand

Author Note

Correspondence concerning this article should be addressed to Ian de Terte, School of
Psychology, PO Box 756, Wellington 6140, New Zealand. E-mail:
i.deterter@massey.ac.nz

Abstract

The aim of the study was to examine the effectiveness of the Transformers programme on individuals' use of appropriate emotion regulation strategies. Five people who have an intellectual disability participated in the Transformers programme and took part in the current study. The intervention was evaluated using the Profile of Anger Coping Skills and incident reports. The Profile of Anger Coping Skills was completed by participants and their caregivers. The majority of participants demonstrated increases in self- and caregiver-reported use of appropriate emotion regulation strategies following their involvement in the Transformers programme. However, treatment gains were not always maintained at follow-up. Previous research has tended to examine the frequency of incident reports rather than the type of behaviour reported. In this study, incident reports were categorised according to the type of behaviour to determine whether there were increases or decreases in particular behaviours. Three of the participants also exhibited fewer incidents of challenging behaviour after taking part in the programme. Overall, the results provide preliminary support for the use of the Transformers programme with people who have an intellectual disability and have emotion regulation difficulties.

Keywords: Intellectual disabilities, learning disabilities, Transformers programme, emotion regulation, cognitive-behaviour therapy, challenging behaviour, anger management, group treatment

An Evaluation of an Emotion Regulation Programme for People who have an Intellectual Disability

Emotion regulation refers to “the processes by which we influence which emotions we have, when we have them, and how we experience and express them” (Gross, 1998, p. 275). The importance of emotion regulation in mental health is well recognised (Keltner & Lerner, 2010). The ability to sustain positive emotions and regulate difficult ones can help an individual to work productively, develop and maintain healthy interpersonal relationships, and to feel comfortable when alone (Gross & Muñoz, 1995). Emotion regulation also has direct and indirect effects on physical health (DeSteno, Gross, & Kubzansky, 2013). Direct effects include changes in the body’s physiology while indirect effects include delayed help-seeking behaviour and poor communication about problems (DeSteno et al., 2013).

Individuals who have an intellectual disability (ID) have difficulty regulating their emotions (McClure, Halpern, Wolper, & Donahue, 2009) and often display physical and verbal aggression and other challenging behaviours. Although prevalence rates of challenging behaviour are still debated, they range from 10% to 60% (Heyvaert, Maes, & Onghena, 2010; Janssen, Schuengel, & Stolk, 2002). Black, Cullen, and Novaco (1997), argued that aggressive and challenging behaviour is due to a failure to regulate emotions such as anger.

The failure to successfully regulate emotions may occur for a number of reasons. First, people who have an ID have limited strategies available for regulating their emotions (Benson & Fuchs, 1999; Hartley & MacLean, 2005). Second, the emotion regulation strategies that they use are not always effective (Duperouzel & Fish, 2010; Hartley & MacLean, 2008). Finally, even when they are able to generate adaptive

solutions, they can have trouble managing more immediate, impulsive responses to a situation (e.g., aggression; Jahoda, Pert, Squire, & Trower, 1998). Thus, people who have an ID may require help to cope more adaptively with difficult emotional experiences.

Numerous interventions have been specifically designed to develop emotion regulation skills in people who have an ID. Recent literature (e.g., Nicoll, Beail, & Saxon, 2013; Taylor, Lindsay, & Willner, 2008) has suggested that cognitive-behaviour therapy (CBT) can be an effective treatment modality with this people with mild and moderate ID. Treatment programmes have incorporated a range of CBT techniques such as self-monitoring, relaxation, and skills-training (Hagiliassis, Gulbenkolu, Di Marco, Young, & Hudson, 2005; J. Rose, 2010; Willner, Jones, Tams, & Green, 2002). Willner et al. (2013) argued that people who have an ID can learn to apply these techniques to respond more adaptively in emotion-provoking situations. In turn, interventions can reduce levels of anger and aggressive incidents (Hagiliassis et al., 2005; Lindsay et al., 2004).

Transformers is a group-based treatment programme for people who have an ID that is based on a cognitive-behavioural approach and includes dialectical-behaviour therapy principles and techniques. The programme seeks to increase participants' abilities to recognise emotions and develop strategies to regulate difficult emotions, particularly anger, sadness, and worry (McWilliams, de Terte, Leathem, Malcolm, & Watson, 2014). Sessions are held weekly, for 22 weeks, and last for 2 hours each. Content that is covered during the programme includes: relaxation, chain analysis, "A good life" (Ward & Gannon, 2006), emotion recognition, and emotion regulation. Sessions follow a similar format and begin with a karakia (a Māori prayer) and review

of homework followed by a short recess. After a break, the theory component is introduced. Sessions end with a relaxation exercise, opportunity for participants to provide feedback, and inspirational phrase, prayer, or karakia. To consolidate learning, homework is carried out between sessions. A range of staff are involved in the facilitation of this programme, such as clinical psychologists, nurses, and other health professionals with two or more attending each session. Where possible the same two core facilitators are utilised throughout the programme. Other facilitators may attend regular sessions to provide assistance and caregivers can also attend the sessions and participate in the activities. Although there was a high staff ratio, staff did not outnumber participants.

The current study investigated changes in the use of emotion regulation strategies over the course of the Transformers programme. It was hypothesised that taking part in the Transformers programme would lead to (a) an increase in participants' use of adaptive coping strategies, (b) a reduction in incidents of challenging behaviour, and (c) a change in the type of incidents reported. Specifically, physically aggressive behaviour was expected to decrease while less serious forms of challenging behaviour such as verbal aggression and other inappropriate emotion regulation behaviour were expected to increase.

Method

Design

The current study utilised a single-case research design with a series of people who have an ID combined with a group comparison method (Barker, Pistrang, & Elliott, 2002; Tate et al., 2008). The rationale for the single-case design was due to this being an initial study of a newly developed emotion regulation programme. The intention was

to carry out research in an applied setting in which the single-case design allowed flexibility. Single-case designs are useful with small numbers of participants and have the advantage of capturing the idiosyncratic features of the participants (Heppner, Kivlighan, & Wampold, 2008).

Participants

Six individuals at an ID service were identified as having emotion regulation difficulties and referred to the Transformers emotion regulation programme for treatment. These individuals were also invited to take part in the current research. One participant withdrew from the study due to personal circumstances (i.e., mental health problems). Five participants completed the programme and their data is reported here. The remaining participants consisted of three males and two females, who have a mild to moderate ID (American Psychiatric Association, 2000). Their ages ranged from 17 to 42 years with a mean of 29 years. Two participants were of New Zealand Māori descent and three participants were of New Zealand European descent. All participants lived in secure and supported housing. This study was approved by the Health and Disability Ethics Committee, New Zealand.

Consent

Consent was obtained using a two-stage process. First, individuals were provided with an explanation of the nature, purpose, and requirements of the study which was targeted at their level of understanding. They were advised that participation was voluntary and that they could decline to participate in the study or withdraw their consent at any time. Then, they were given time to consider whether they would like to take part in the study. After approximately 30 minutes, participants met with the primary researcher again to ask questions and provide consent (see Appendix 5). At this

point, they received an information sheet written in simplified language (see Appendix 4).

Two of the participants had welfare guardians. A welfare guardian may be legally appointed to make decisions for an individual if that individual is deemed unable to make or understand decisions about their care or welfare (Ministry of Justice, n.d.). In the current study, letter and information sheets were sent to welfare guardians. The welfare guardians were contacted by phone to gain informed consent. Two caregivers also provided their informed consent to be interviewed about the participants (see Appendix 12 and Appendix 13 for information and consent forms for caregivers).

Measures

Profile of Anger Coping Skills. Emotion regulation strategies were assessed using the Profile of Anger Coping Skills (Willner, Brace, & Phillips, 2005). The PACS measures the frequency that individuals who have an ID use cognitive and behavioural skills to regulate their anger. Two versions of the assessment are available; a service-user version for people who have an ID and a carer version for a staff member. A preliminary study showed good test-retest reliability (unspecified statistic = 0.78) and acceptable inter-rater reliability (unspecified statistic = 0.57) of the caregiver version of the PACS (Willner et al., 2005). A recent randomised-controlled trial demonstrated that service-user and caregiver ratings on the PACS were very similar and reflected sensitivity to change as ratings of participants use of coping strategies increased following an intervention (Willner et al., 2013). This suggests that, like the caregiver version, the service-user version of the PACS is a reliable measure of change.

Adaptations were made to the PACS for use in the current study. First, the original PACS focuses solely on anger whereas participants in the current study were

asked about coping with sadness and worry in addition to anger. The Transformers programme was designed to support participants to manage a range of upsetting emotions. Second, the original PACS was intended for use alongside the Provocation Inventory (PI; Taylor & Novaco, 2005) to help identify suitable situations where the client had been very angry. Caregivers involved in this study were asked to provide information about particular situations that caused the participants to become emotionally aroused. Finally, the original list of coping strategies (i.e., relax, count to ten, walk away, do something else, ask for help, rethink the situation, use humour, and being assertive) was changed. Instead, participants were asked about specific skills that were taught during the programme to cope with anger, sadness, and worry. The skills included: wise mind, distraction, taking yourself away, exercise, doing something fun, and breathing exercises (refer to pg. 49 for an explanation of the terms). A copy of the adapted version of the PACS is presented in Appendix 14.

The carer version was administered to caregivers before participants were assessed. For each participant, the same care manager completed the PACS at each time point to increase reliability of the PACS (Willner, Brace, & Phillips, 2005). The care manager was asked to identify situations where the participant had been angry, sad, or worried and then estimate how often different coping strategies were used by the participant in each situation. A brief description of each strategy was provided and frequency of use was indicated on a 4-point Likert scale ranging from 0 (*never*) to 3 (*always*). In the case that caregivers could not provide an example of a situation (e.g., losing at a boardgame, being called names, a planned outing being cancelled) in which the participant had been angry, sad, or worried, a score of 0 was given for the emotion for that assessment and the situation excluded from the analysis. Using the situations provided by the care manager, participants were also asked about their current use of

coping strategies. They could rate the frequency of use of the coping strategy on a simpler 3-point Likert scale ranging from 0 (*no*) to 2 (*always*). The PACS took approximately 15 minutes to administer to participants.

For a number of reasons to be discussed later in the paper there was a large amount of missing data for the PACS. Due to missing data at various time points, the data is analysed using mean scores instead of raw scores. Participants mean scores on the measure were calculated for each phase (i.e., pretreatment, treatment, and posttreatment). In each phase, the lowest mean score an individual participant could receive for strategies used for a particular emotion was 0.00 and the highest mean score anybody taking the test could receive was 24.00. The groups mean score on the measure was also calculated for each phase (i.e., pretreatment and posttreatment). In each phase, the lowest mean score the group could receive for their use of a particular strategy across emotions was 0.00 and the highest mean score the group could receive was 3.00.

Incident reports. Incident reports dating from January 2012 until June 2013 were collected from the ID service. Incidents were sorted into categories according to the type of behaviour: aggressive behaviour, nonaggressive sexualised behaviour, and other inappropriate emotion regulation behaviour. Aggressive behaviour was further defined as being towards others, towards property, towards self, or verbal. Categories were based on criteria for different types of problem behaviour outlined in the publication of the *Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation* (DC-LD; Royal College of Psychiatrists, 2001). The definitions of each category used in the current study are provided in Table 6. Numerous categories could be assigned to each incident report. Incident reports that

were not directly related to the behaviours of interest were excluded (e.g., medication errors, routine room searches).

Interrater reliability was assessed by having the primary researcher and two psychology students independently code all of the incident reports ($N = 860$) using the definitions provided. It was clear from the pattern of errors that one rater misunderstood the tasks instructions. Therefore, this rater's codings were excluded from the analysis and a third rater was used to code the incident reports. Agreement was defined as concordance of all raters on all categories assigned to each incident report. This process produced an interrater reliability of 88%, meaning that initially there was disagreement over 12% of the incident reports. Inter-rater reliability was calculated using a two-way mixed, single-measure model of intra-class correlation coefficient (Shrout & Fleiss, 1979). Inter-rater reliability was good ($r = .77$) and there was no significant statistical difference between raters. After independently coding the incidents, raters met to discuss those that were not agreed upon ($N = 107$). Final inter-rater reliability was reported to be 100%.

Procedure

The PACS was administered a total of 10 times: 3 assessments before, 3 during, 3 after the participants' involvement in the emotion regulation programme, and once at a 3-month follow-up. Table 2 provides an indication of points during the programme when assessments were conducted. Participants were assessed at their home or day programme in a quiet room to minimise distractions. Staff members were present on occasions, but were not permitted to advise participants or provide answers on their behalf. However, prompts were provided by the researcher when necessary to facilitate participants understanding of the question and visual aids (see Appendix 14) were used

Table 6

Definition and examples of behaviours as used to code incident reports

Behaviour	Definition	Examples
Aggressive behaviour, Physical	Towards others Towards property Towards self	Punching or throwing property at others, threatening with knife Slamming doors, breaking windows, throwing objects (not towards others)
Aggressive behaviour, Verbal	“Behaviours that harm or intend to harm others through physical force or the threat of physical force” (Anderson, 2007, p. 6). “Destroying or damaging an object, defacing the surface of an object, or altering an object such that it was no longer valuable or useful” (Schwebel, Tavares, Lucas, Bowling, & Hodgens, 2007, p. 147). “Destruction of body tissue without suicidal ideation and for purposes not socially sanctioned” (Klonsky & Muehlenkamp, 2007, p. 1045)	Burning or hitting the body, head banging, threatening to kill self
Nonaggressive sexualised behaviour	“Threatening another person with physical aggression or yelling and swearing angrily at another person” (Kettlewell & Kausch, 1983, p. 104). “A verbal or physical act of an explicit, or perceived, sexual nature, which is unacceptable within the social context in which it is carried out” (Johnson, Knight, & Alderman, 2006, p. 688).	Screaming, swearing, or threatening to kill others
Other inappropriate emotion regulation behaviour	Any verbal, physical, or nonverbal response that did not fit into the other categories yet was unacceptable in the context of the service.	Asking others to engage in sexual acts, touching others genitalia Running away, storming off, threatening to leave the property

to help with their response options. Follow-up questions were also used for clarification when necessary. Caregivers were interviewed by the primary researcher at their place of work.

Data Analysis

The analysis involved scoring and analysing individual data from the PACS and incident reports. Caregivers' ratings on the PACS were converted to a score in the range of 0 to 2 by combining *Sometimes* and *Always* responses, so that scores on the caregiver versions of the PACS could be compared to scores on the participant versions of the PACS. This was necessary because the caregiver version is a 4-point Likert scale while the participant version is a 3-point Likert scale. Data was then graphed so that it could be visually analysed: a useful and common method of analysis in single-case research (Lane & Gast, 2013).

Incident report data was also graphed. As participant 2 (P.2) joined the ID service in May 2012, there is missing data for early 2012. To ensure that data for P.2 could still be included and compared with the other participants, data was prorated for the missing months. To calculate the prorated data for the pretreatment phase, the total number of incidents for each category of behaviour for P.2 was divided by the length of time in the service prior to treatment ($n = 119$ days) and then multiplied by the number of days before treatment ($n = 200$). Results are reported using the prorated data.

In addition to analysing individual data, data was analysed at a group-level to provide further insight into treatment outcomes. Incident reports were further analysed using Standard Mean Difference All (SMDall) to test the efficacy of the Transformers programme on types of challenging behaviour. SMDall is an effect size calculation that

uses the mean for all baseline and treatment data points (Busk & Serlin, 1992; Olive & Smith, 2005). To calculate SMD_{all} the mean treatment is subtracted from the mean baseline and then divided by the standard deviation of baseline. Cohen (1988) argued that an effect size of 0.2 to 0.3 is small; an effect size of 0.4 to 0.7 is moderate; and an effect size greater than 0.8 is large.

Results

Effects of the Intervention on Emotion Regulation Strategies

Table 7 presents the groups mean score for each of the different emotion regulation strategies as measured by the PACS, at pre- and posttreatment. The results show that prior to treatment, participants rated exercise and taking yourself away as their most utilised strategies, whereas caregivers rated distraction and taking yourself away as participants' most commonly used strategies. Both participants and caregivers reported that the strategies wise mind and completing a chain analysis were rarely utilised pretreatment. In contrast to participant ratings, caregivers reported that breathing exercises were rarely used either.

Following treatment, caregivers reported an increase in the use of all strategies by participants, except breathing exercises and relaxation. While participants reported that their use of breathing exercises had increased, caregivers reported no change in the use of this strategy and still rated it the least commonly used strategy. Caregivers and participants rated the strategies taking yourself away and distraction as the most commonly utilised strategies posttreatment. Although caregivers and participants reported that the use of other strategies including exercise, relaxation, and wise mind increased following treatment, these strategies were still used infrequently.

Table 7

Self-reported and caregiver-reported PACS scores, by strategy, for the group across the pretreatment and posttreatment phase

Strategy	Pretreatment		Posttreatment ^a	
	Participant	Caregiver	Participant	Caregiver
Relaxation	0.38 ^b	0.18	0.72	0.13
Wise mind	0.06	0.00	0.75	0.30
Exercise	0.28	0.15	0.59	0.17
Doing something fun	0.28	0.29	0.78	0.53
Breathing exercises	0.69	0.03	0.78	0.03
Distraction	0.44	0.47	0.97	0.67
Taking yourself away	0.56	0.56	1.31	0.97
Doing a chain	0.00	0.03	0.28	0.07

Note. These scores represent the group mean scores across emotions. PACS = Profile of Anger Coping Skills.

^aPosttreatment includes data from assessments 7 to 9 but excludes follow-up data from assessment 10.

^bThe lowest mean score the group could receive for their use of a particular strategy across emotions in each phase was 0.00 and the highest mean score the group could receive was 3.00.

Table 8 displays average scores for each participant and the group on the PACS for the different emotions at assessments points (pretreatment, treatment, and posttreatment). Changes at an individual level are not discussed due to variability in data. The groups mean self-reported use of emotion regulation strategies for anger increased during treatment compared with before treatment, but then decreased slightly

after treatment. The groups mean self-reported use of strategies for worry also increased during treatment compared with pretreatment and these gains appeared to be maintained following treatment. The groups mean self-reported use of strategies for sadness could not be calculated due to the large amount of missing data. Visual inspection of the data suggests that caregivers' ratings of the groups' use of strategies for anger decreased slightly during treatment compared with before treatment, but increased following treatment, with their ratings consistently lower. Caregivers rating of the groups' use of strategies for worry also increased following treatment and these gains were maintained following treatment. Although caregivers did not rate participants' use of strategies for worry as highly as participants rated their own use of strategies, both the caregiver and participant ratings increased across conditions.

Table 8

Self-reported and caregiver-reported PACS scores for each participant across all phases

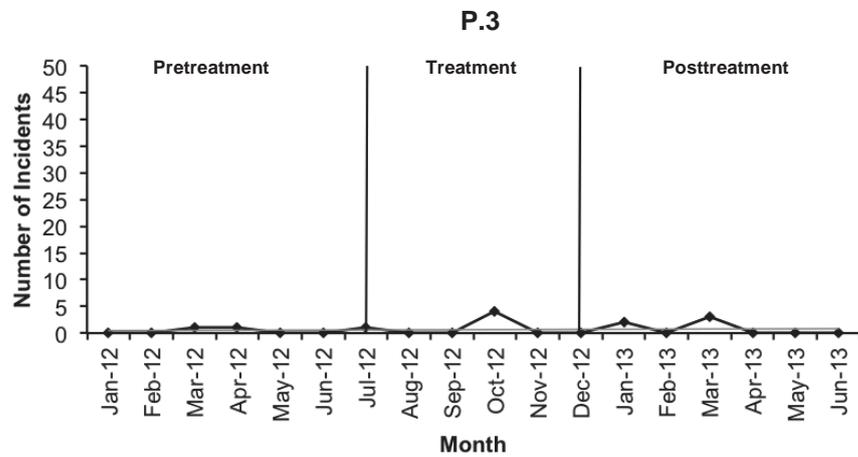
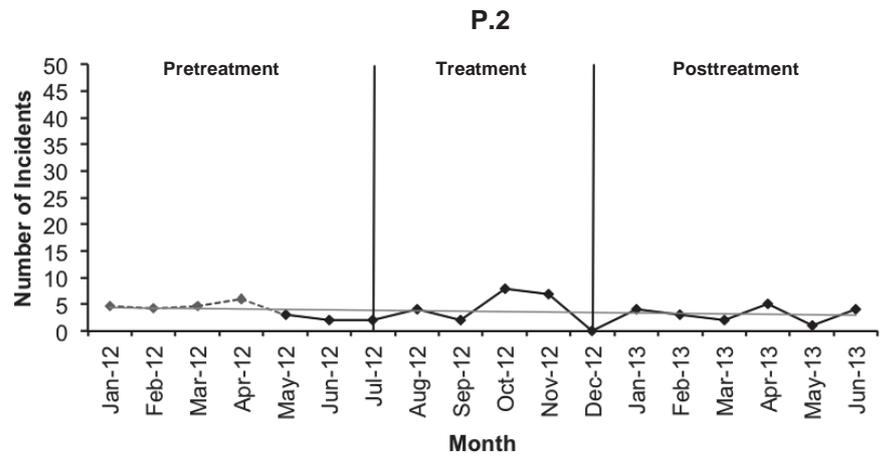
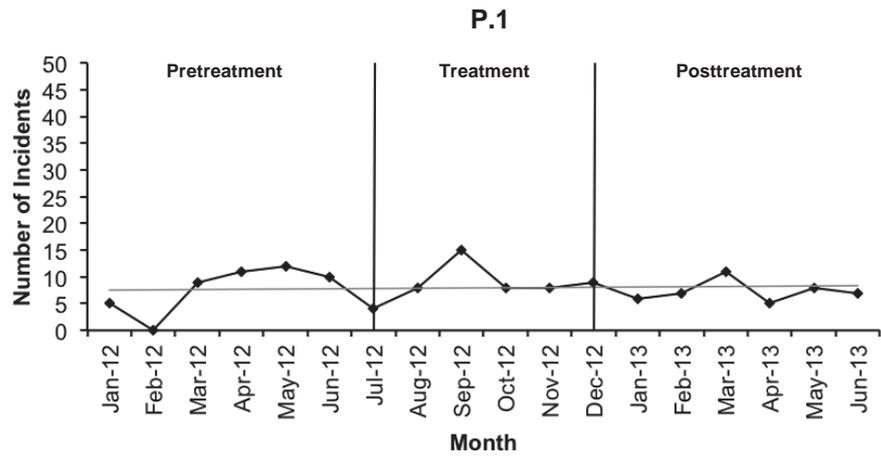
	Pretreatment		Treatment		Posttreatment ^a	
	Participant	Caregiver	Participant	Caregiver	Participant	Caregiver
Anger						
P.1	0.67	0.00	8.67	0.33	9.67	0.33
P.2	4.33	1.67	9.67	2.67	7.67	1.33
P.3	-	-	-	-	-	-
P.4	3.00	2.00	4.50	0.50	3.00	4.33
P.5	-	-	-	-	-	-
Group M	2.67	1.22	7.61	1.17	6.78	2.00
Sadness						
P.1	-	-	-	-	-	-
P.2	-	-	-	-	-	-
P.3	6.00	-	7.00	-	7.00	-
P.4	-	-	-	-	-	-
P.5	2.33	1.67	2.00	2.00	4.67	2.33
Group M						
Worry						
P.1	3.00	0.00	11.00	0.00	9.00	0.00
P.2	-	0.00	-	3.50	-	2.00
P.3	3.33	3.33	6.50	2.00	7.67	6.00
P.4	0.50	3.67	3.67	3.00	3.50	5.50
P.5	1.67	1.67	1.33	2.33	4.00	2.00
Group M	2.13	1.73	5.63	2.17	6.04	3.10

Note. Dashes indicate missing mean scores. That is, participants could not think of times when they were angry, sad, or worried or could not complete the assessments due to illness. Empty cells represent data that could not be calculated due to missing scores. The lowest mean score an individual participant could receive for strategies used for a particular emotion was 0.00 and the highest mean score an individual participant could receive was 24.00. PACS = Profile of Anger Coping Skills.

^aPosttreatment includes data from assessments 7 to 9 but excludes follow-up data from assessment 10.

Effects of the Intervention on Incident Reports

Figure 3 shows the total number of incidents of challenging behaviour for each participant by month as well as the total number of incidents for the group by month. Individual data suggested that the number of incidents of challenging behaviour was relatively low during baseline, with the exception of participant 1 and participant 5. Trendlines indicate a relatively horizontal trend in data for participant 1 (P.1), P.2, participant 3 (P.3), and participant 4 (P.4). However, participant 5 (P.5) demonstrated a sharp increase in incidents in July. Visual inspection of the group data suggests that the total number of incidents for the five participants decreased following treatment. There was a 31% decrease in the number of incidents which occurred posttreatment, compared to pretreatment.



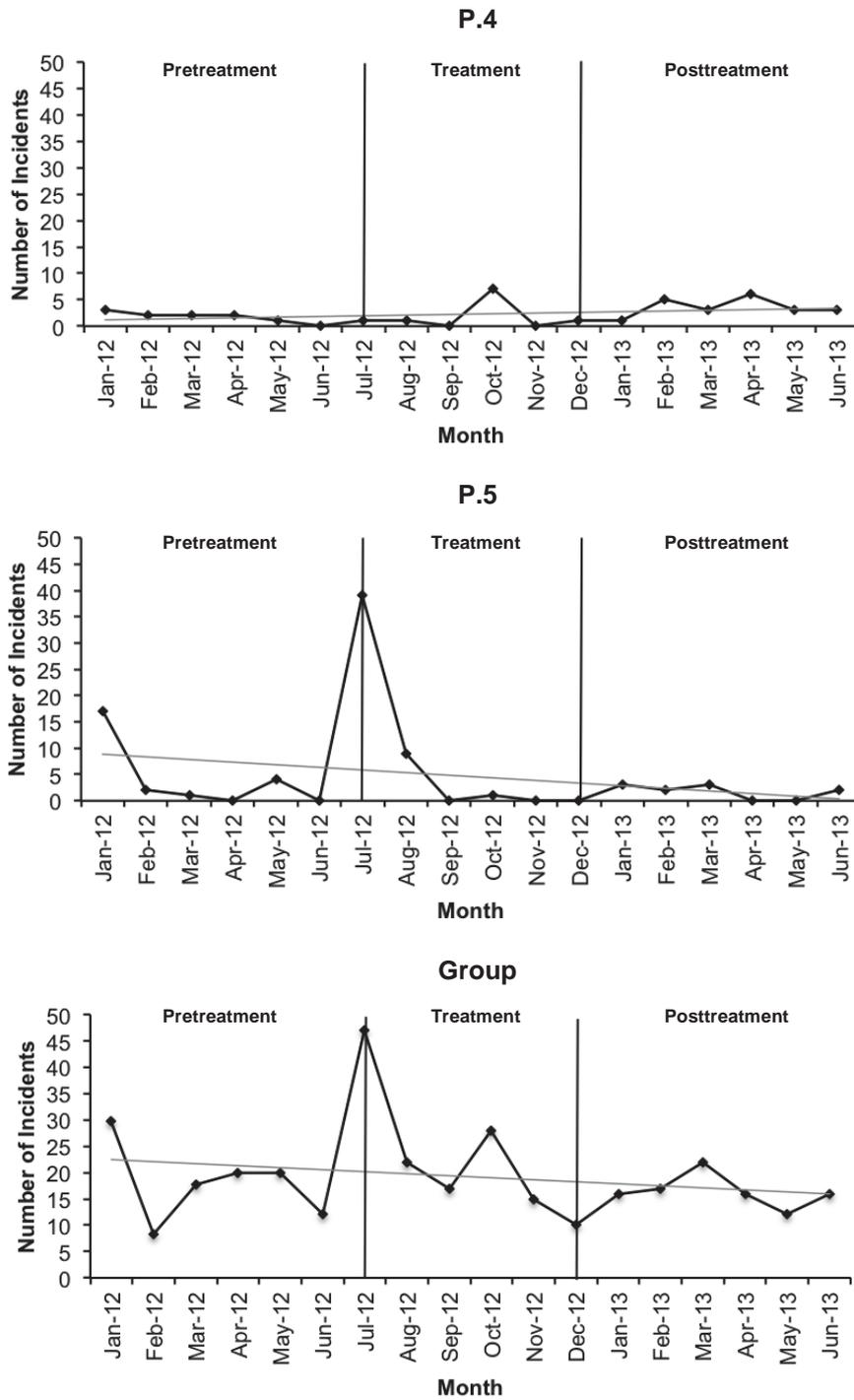


Figure 3. The total number of incidents for each participant and the group of participants by month. The dashed line for P.2 represents pro-rated data.

Table 9 displays the total number of incidents and descriptive statistics for the group according to the categories of challenging behaviour. Table 9 also presents the

SMDall effect sizes. The effect sizes for aggressive behaviour verbal and nonaggressive sexualised behaviour were within the small range. These results indicate a small reduction in nonaggressive sexualised behaviour posttreatment compared to pretreatment but a small increase in aggressive behaviour verbal posttreatment compared to pretreatment. Effect sizes for aggressive behaviour towards others, aggressive behaviour towards self, and other incidents of inappropriate emotion regulation behaviour were within the medium range. These results indicate a moderate reduction in aggressive behaviour towards others, aggressive behaviour towards self, and other inappropriate emotion regulation behaviour posttreatment compared to pretreatment. The effect size for aggressive behaviour towards property was found to exceed the Cohen's (1988) convention for a large effect. This result indicates a large reduction in aggressive behaviour towards property posttreatment compared with pretreatment.

Figure 4 shows the number of incidents for each participant pre- and posttreatment according to the type of challenging behaviour. Visual inspection of the data suggests that there was a reduction in aggressive behaviour towards others for P.1 and P.5 posttreatment, whereas, P.2 demonstrated an increase in aggressive behaviour towards others posttreatment. The majority of participants, P.1, P.2, P.4, and P.5, also demonstrated a decrease in aggressive behaviour towards property posttreatment. P.3 did not exhibit either behaviour pre- or posttreatment. While P.5 demonstrated a decrease in aggressive behaviour verbal and P.2 showed no change, all other participants demonstrated an increase in this behaviour posttreatment. There was also an

Table 9

The number of incidents, descriptive statistics, and SMDall for the group according to the category of behaviour pre- and posttreatment

Behaviour	Pretreatment			Posttreatment			SMDall
	No. of incidents	<i>M</i>	<i>SD</i>	No. of incidents	<i>M</i>	<i>SD</i>	
ABTO	36	7.20	9.20	19	3.80	4.49	0.37
ABV	56	11.20	13.75	68	13.60	14.54	-0.17
ABTP	53	10.60	7.64	19	3.80	3.90	0.89
ABTS	4	0.80	0.84	1	0.20	0.45	0.71
NASB	17	3.40	7.06	11	2.20	3.90	0.17
OIB	33	6.60	6.58	20	4.00	4.18	0.40

Note. SMDALL = Standard Mean Difference All. ABTO = Aggressive behaviour

towards others. ABV = Aggressive behaviour, verbal. ABTP = Aggressive behaviour

towards property. ABTS = Aggressive behaviour towards self. NASB = Nonaggressive

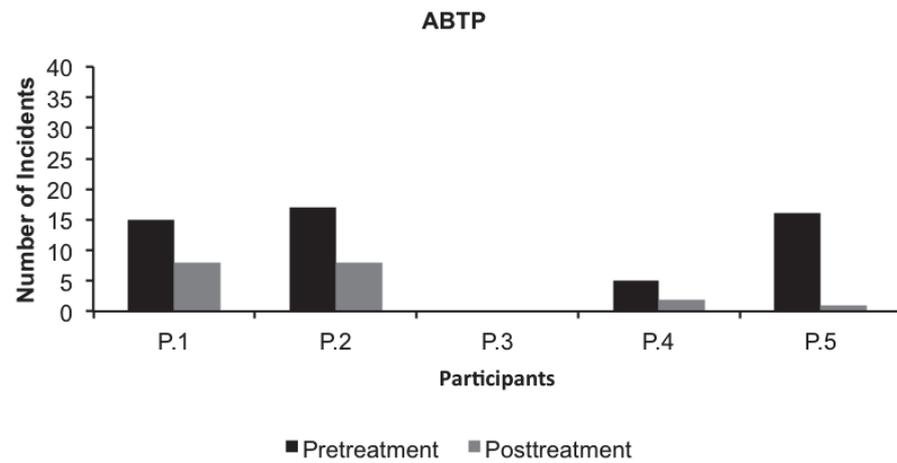
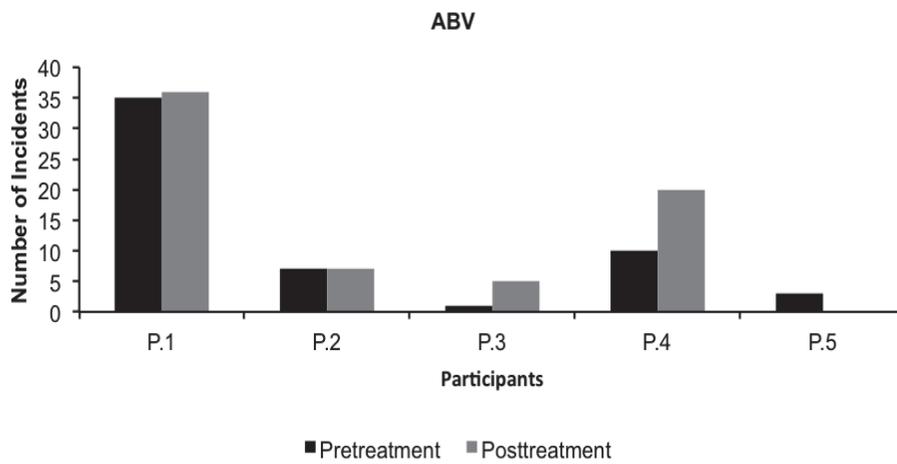
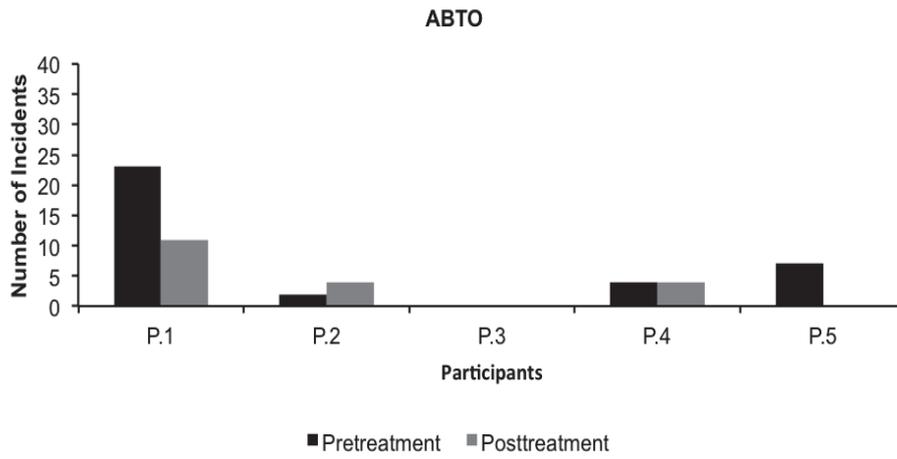
sexualised behaviour. OIB = Other inappropriate emotion regulation behaviour.

increase in the number of incidents of other inappropriate emotion regulation behaviour for P.2 and P.3. However, the remaining three participants demonstrated a reduction in incidents of other inappropriate emotion regulation behaviour. P.1, P.2, and P.3 were the only participants to display aggressive behaviour towards self at pretreatment and all showed a decrease posttreatment. P.1 and P.5 were the only participants to display nonaggressive sexualised behaviour at pretreatment. Although P.5 demonstrated a reduction in nonaggressive sexualised behaviour posttreatment, P.1's nonaggressive sexualised behaviour increased minimally.

P.1 was the participant who reported the greatest increase in use of emotion regulation strategies for anger and worry, during treatment and posttreatment, compared

with pretreatment. Before treatment, P.1 reported using the strategies doing something fun, breathing exercises, taking yourself away, distraction, or exercise and his use of these strategies was irregular. After treatment, P.1 reported making use of all the strategies, particularly doing something fun, breathing exercises, and wise mind. In contrast, his caregiver reported that he only used the strategy, taking yourself away, across the conditions. P.1 had the highest number of incidents of challenging behaviour at baseline which reduced by 23% following treatment. P.1 showed a reduction in all types of behaviour, with the exception of aggressive behaviour verbal and nonaggressive sexualised behaviour which increased by one incident each.

P.5 demonstrated an increase in the use of emotion regulation strategies. Prior to treatment, they reported using the following strategies to cope when feeling sad or worried: wise mind, relaxation, breathing exercises, distraction and taking yourself away. P.5 reported that their use of strategies decreased during treatment. Following treatment, P.5 reported using the same strategies more frequently than at baseline. P.5's caregiver confirmed that their use of coping strategies increased during treatment and these gains were maintained following treatment. However, the caregiver did not report that P.5 used the strategies breathing exercises or doing something fun. P.5 demonstrated the largest reduction in incident reports, of all participants. Results show that there was a reduction of 83% from baseline scores. P.5 showed a reduction in all types of challenging behaviour but the largest reductions can be seen in aggressive behaviour towards property and other incidents of inappropriate behaviour.



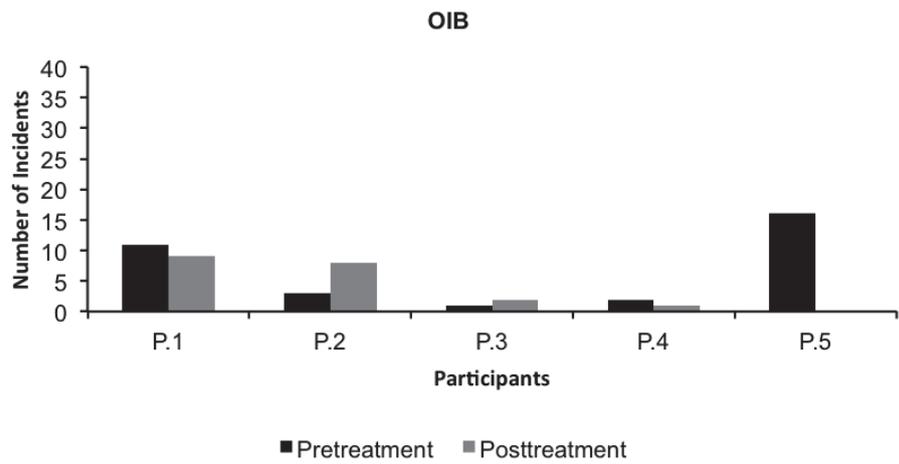
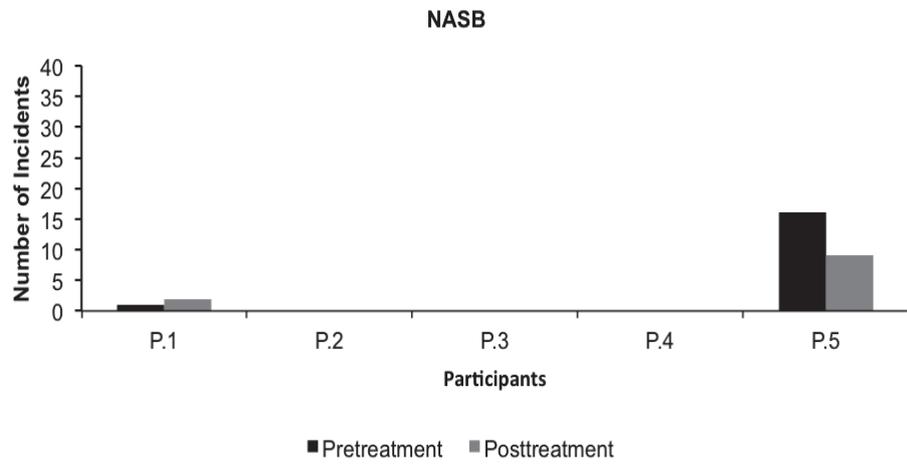
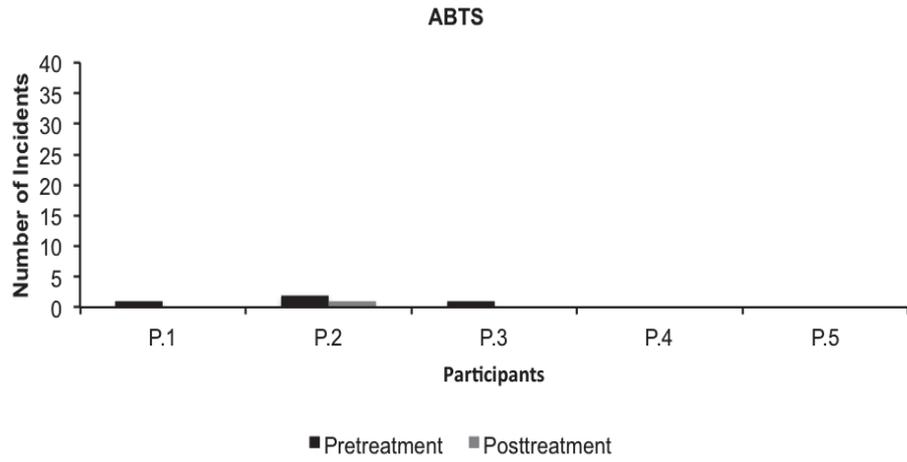


Figure 4. The total number of incidents of each type of behaviour carried out by participants pre- and posttreatment. ABTO = Aggressive behaviour towards others. ABV = Aggressive behaviour, verbal. ABTP = Aggressive behaviour towards property. ABTS = Aggressive behaviour towards self. NASB = Nonaggressive sexualised behaviour. OIB = Other inappropriate emotion regulation behaviour.

Discussion

Results from the current study supported the hypothesis that the Transformers programme would develop participants' strategies for managing their own distressing emotions. The majority of individuals who participated in the Transformers programme showed increases in self- and caregiver-rated use of emotion regulation strategies, compared to their own pretreatment ratings. However, gains observed during treatment were not always maintained at follow-up. Furthermore, some participants demonstrated larger improvements in their self-rated use of coping strategies than other participants.

As hypothesised, there was a general reduction in incidents of challenging behaviour. Three of the five participants involved in the Transformers programme exhibited fewer incidents of challenging behaviour following treatment. These results are consistent with recent research which shows that cognitive-behaviour therapy interventions can improve coping strategies and reduce challenging behaviour in people who have an ID (Douglass, Palmer, & O'Connor, 2007; Lindsay et al., 2004; Willner et al., 2005; Willner et al., 2013). Overall, this finding supported the hypothesis that involvement in the Transformers programme would lead to a reduction in incidents of challenging behaviour by the end of the group.

In contrast to earlier findings, caregivers generally rated participants' improvements in their use of emotion regulation strategies as being lower than participants' own ratings. Willner et al. (2013) reported that participant and caregiver

ratings on the PACS were significantly correlated. However, their findings also showed that participants reported better outcomes on the measure of anger coping skills than home carers. Thus, previous research also reported differential ratings for participants and third-party respondents (Willner et al., 2013). The difference between participant and caregiver ratings in the current study may be due to the participants responding in a socially desirable manner. Social desirability is a commonly observed response bias in people who have an ID (Hartley & MacLean, 2006; Heal & Sigelman, 1995). The tendency to choose the most positive response could explain why participants generally rate their use of emotion regulation strategies more favourably than caregivers. Problems with self-awareness could also help to explain the observed differences in caregiver and participant ratings. People who have an ID may have limited ability to reflect upon their behaviour which could influence their responses (Luckasson et al., 2002).

The results also indicated a reduction in incidents for all types of challenging behaviour, except aggressive behaviour verbal which increased. The slight increase in aggressive behaviour verbal could indicate that as well as a reduction in the total number of incidents for the group, there was a reduction in the seriousness of the incidents. After treatment, participants were less likely to engage in aggression towards others, towards property, towards themselves, or to exhibit other inappropriate emotion regulation behaviour and somewhat more inclined to react verbally when they were feeling angry, sad, or worried. Although verbal aggression is still considered to be a challenging behaviour that can have negative consequences, it may result in less physical consequences than some other challenging behaviours. It is possible that as participants become more practiced at implementing adaptive emotion regulation strategies, incidents of verbal aggression would also reduce. This finding supports the

hypothesis that involvement in the Transformers programme would produce a change in the type of incidents reported whereby there would be a reduction in physically aggressive behaviour and an increase in less serious forms of challenging behaviour.

Much of the research in this area has looked at whether a particular programme is effective in reducing anger (Hagiliassis et al., 2005; J. Rose, Dodd, & N. Rose, 2008), anxiety (Douglass et al., 2007), or aggressive behaviour (Lindsay et al., 2004).

However, few studies have investigated strategies that people who have an ID utilise to regulate their emotions (Willner et al., 2005; Willner et al., 2013). By identifying the emotion regulation strategies people who have an ID were most likely to employ, the current study also takes steps toward understanding which parts of the programme were the most useful. At a group level, behavioural and cognitive strategies such as distraction, taking yourself away, and doing something fun were most frequently used.

An explanation for this may be that these skills were more easily mastered by participants. Alternatively, staff at the ID service may have prompted participants to use these strategies more often than the other strategies when they noticed the participants becoming upset in daily-life.

On the other hand, strategies such as relaxation, exercise, and completing a chain analysis were rarely used. Previous research has also found that relaxation is not often used (Willner et al., 2005) and it may be that people who have an ID may find it difficult to tense and relax muscles (Rossiter, Hunnisett, & Pulsford, 1998). A chain analysis was also rarely completed by participants. During group sessions and homework groups, participants were usually assisted by caregivers to complete a chain analysis. Participants may have found this strategy difficult to carry out on their own or the process of discussing their challenging behaviour aversive (Lynch, Chapman, Rosenthal, Kuo, & Linehan, 2006). Exercise may have been utilised less often than it

could have been due to restrictions placed on participants, by the service, around leaving the immediate property.

When interpreting the results, it is important to consider the sudden increase in challenging behaviour at the beginning of the treatment phase for P.5. Although each participants' data was variable across the phases, the number of incidents reported for P.5 in July alone, exceeded the groups total number of incidents for the previous 6 months. It is possible that the increase in incidents is related to a change in personal circumstances that occurred for P.5 at that time. The increase is reflected in Figure 3 but because the Transformers programme started in mid-July, not all of the incidents for that month are included in the pre- and posttreatment comparisons. Therefore, the sudden increase in incidents is not expected to have impacted heavily on the data analyses.

The current study had a number of strengths. A large advantage of the study is the use of multiple sources of information. Self-report measures are an important source of information regarding an individual's own use of emotion regulation strategies in their daily life, whereas caregivers may be able to provide further information, a different view-point, and corroborate the information provided by the participants (Emerson et al., 2012). Moreover, incident reports can provide a clear record of progress (J. Rose & West, 1999). The use of multiple measures allowed the researchers of the current study to explore emotion regulation strategies from a number of directions. Another strength of this study is the use of the PACS as a measure of treatment effectiveness provides information about the mechanisms of change. A range of emotion regulation skills are taught during the Transformers programme and it is useful to determine the extent to which such skills are acquired and utilised in daily-life. A further strength of the study is that it was conducted in clinical settings with

participants of different ages, ethnicities, genders, and severities of ID. These factors contribute to the ecological validity of the study.

Despite these strengths, there are a number of factors which need to be considered in evaluating the findings of the current study. The main limitation of the study is the small sample size. For this reason, the findings may not generalise to people from the same population based on this study alone. However, this study was a pilot study and further research with a larger sample to replicate the findings of this study is necessary. Another limitation relates to the lack of a control group in the current study. There were a small number of people in the ID service at any one time and the remainder of the clients had either participated in the same programme or a different emotion regulation programme previously so were not appropriate to be included in a control group. Due to the small sample size and absence of a control group, it is difficult to determine whether or not other factors such as medication or concurrent treatments contributed to the observed changes.

Another important extraneous factor that may have influenced the findings was the presence of caregivers at the group sessions. It is unclear what impact caregiver attendance had as no objective data was collected on this. However, previous research suggests that the involvement of caregivers in the group therapy process can be useful therapeutically (Willner et al., 2002). Benefits of involving caregivers may include caregivers developing a better understanding of the function of participants challenging behaviour, helping participants with homework, and encouraging them to practice utilising their skills outside of the group (J. Rose, Loftus, Flint, & Carey, 2005; Willner et al., 2002).

There are also a number of methodological issues with this study. First, there is a limited amount of psychometric data around the measures used in the current study. While there is some research that reports on the psychometric properties of the caregiver version of the PACS, to the best of the authors knowledge, there is only one published article that provides support for the reliability and validity of the service-user version (Willner et al., 2005). Second, the PACS was not always completed consistently by participant and caregivers. There were occasions when participants could not identify an emotion-provoking situation that had occurred since the previous assessment. It may be that participants had difficulty recalling specific situations or that they did not want to talk about sensitive material (Lindsay et al., 2004). There were also occasions when participants disagreed with the emotion-provoking situations their caregivers had provided. These issues contributed to the bulk of the missing data. Third, there were low levels of each type of challenging behaviour during the pretreatment period which left little room for improvement. This could be due to aggression being a relatively infrequent behaviour (Singh, Wahler, Adkins, Myers, & The Mindfulness Research Group, 2003; Taylor, Novaco, Gillmer, & Thorne, 2002) or because some types of behaviour (e.g., verbal abuse) are under-reported (Foster, Bowers, & Nijman, 2007). Numerous factors influence whether or not staff members report incidents including not thinking it is serious enough to report and reporting procedures being too time consuming (Foster et al., 2007). Moreover, incidents are subject to staff interpretations of the event. To improve accuracy, researchers could devote time to training staff to fill out the incident reports correctly and cover operational definitions and examples of the relevant behaviour categories. Finally, only one follow-up assessment was carried out and this took place 3-months after treatment had ended. Ideally, multiple assessments would take place over a longer follow-up period until a pattern is established (Nestor &

Schutt, 2012). However, this was not possible due to time constraints involved in the current study. These limitations represent possible improvements and opportunities for future research.

To obtain more conclusive evidence for the effectiveness of the Transformers programme, further investigation could also look more closely at individuals with moderate or severe intellectual disabilities (determined by their IQ score and level of adaptive functioning) and determine in which ways the programme needs to be tailored to suit their needs. Other areas of future research that could be conducted include an investigation into which elements of the Transformers programme account for change. To conduct a component analysis of the Transformers programme, three groups of participants could be randomly assigned to one of three conditions: treatment as usual, treatment using only behavioural elements of the programme, and treatment using only cognitive elements of the programme. The current study has laid the foundation for this type of research by providing preliminary support for the effectiveness of the Transformers programme in treating people who have an ID and emotion regulation difficulties.

Future research should also consider the clinical and cost-effectiveness of group versus individual emotion regulation training. A comparison of the Transformers programme being delivered in both group and individual settings would help to determine whether meeting with a group of other people with ID who had emotion regulation difficulties offered greater benefits compared to individual treatment. Group treatment could allow for group emotional support and prove to be more efficient in terms of cost and resources. Merits such as these would provide further justification for the delivery of the Transformers programme in a group setting.

The findings of the current study have raised some important implications for clinical practice. Given the effective, but modest findings and the reduction in reported use of emotion regulation strategies posttreatment compared with during treatment for some participants, it may be beneficial to make the programme more intensive. A way to increase the intensiveness of the programme would be to make it longer and/or include maintenance sessions. Extending the length of the programme and revising and practicing the material could help to consolidate learning and maintain treatment gains (Paxon, 1995).

There is also practical importance for people who have an ID in evaluating treatment programmes for emotion regulation difficulties. Given the serious negative consequences associated with emotion regulation difficulties, involvement in an effective emotion regulation programme may enhance the quality of life of people who have an ID. Continued research in this area will allow for the development of emotion regulation programmes, and in particular the Transformers programme, to increase their efficacy.

In conclusion, the current study provides preliminary data which suggests that the Transformers programme has some value as a treatment programme for people who have an ID who have emotion regulation difficulties. More broadly, this study contributes to the expanding literature on the usefulness of cognitive-behaviour therapy for people who have an ID who display challenging behaviour and have difficulty regulating their own emotions.

Chapter 7: Conclusion

Overview of Findings

The intended aim of this thesis was to evaluate the effectiveness of the Transformers programme for people who have an intellectual disability (ID). Three hypotheses were related to the aims of the studies. First, it was hypothesised that taking part in the emotion recognition component of the Transformers programme would increase participants' abilities to recognise emotions. The results of the first study suggest that four out of five participants showed improvements in emotion recognition on at least one of the two tasks. Some participants became more accurate at identifying emotion in faces while others were more accurate at identifying emotion in stories. However, the improvements were minimal and one participant demonstrated no change in either task. In general, the programme did not appear to improve participants' abilities to accurately identify emotions. Though, this finding may be confounded by a ceiling effect, such that participants performed well on the emotion recognition tasks before treatment and there was little room to show improvement after treatment.

Second, it was hypothesised that participants' abilities to regulate their own emotions would improve following participation in the Transformers programme. As predicted, the results of the second study demonstrated that participants showed improvements in their emotion regulation abilities. The majority of participants and caregivers reported an increase in participants' use of emotion regulation strategies following their involvement in the programme. However, participants tended to report their use of emotion regulation strategies as more frequent than their caregivers. The observed treatment gains were not always maintained at follow-up.

Third, it was hypothesised that the Transformers programme would produce a reduction in incidents of challenging behaviour and a change in the type of incidents

reported. According to the second study, three out of the five participants demonstrated fewer incidences of challenging behaviour. Although two participants showed small increases in incidences of challenging behaviour, the total number of incidents for all participants decreased posttreatment compared to pretreatment. There was also a change in the type of incidents reported. A small increase in verbally aggressive behaviour suggested that there was a reduction in the seriousness of the incidents that were reported. Instead of reacting to distressing emotions using physically aggressive behaviour, participants were more inclined to use verbally aggressive behaviour. Overall, the Transformers programme demonstrated promise as an effective group treatment method for people who have an ID who have difficulty regulating their emotions.

Limitations

The integrity of these findings may be limited for a number of reasons. The sample size was small with only five participants completing the studies. The individuals were invited to participate in the research because they had already been chosen by staff at the ID service to take part in the Transformers programme. Due to the small number of people in the service who had not completed an emotion regulation programme and the applied nature of the research, random sampling for a larger number of participants would have been impractical.

A second potential limitation of the studies relates to the research design. A commonly cited issue related to the use of single-case design is the lack of generalisability. It is possible that the effects of treatment demonstrated in the small number of participants involved in the current studies may not generalise to others. Nevertheless, replication of the intervention effects across a wide range of individuals

who have an ID can provide further evidence for the effectiveness of the Transformers programme (Nock, Michel, & Photos, 2007).

Another limitation is that a control group was not included. Without a control group, comparisons cannot be made between people who have an ID that received the intervention and those people who have an ID that did not receive the intervention. However, the use of single case design does provide the opportunity for comparisons on an individual level between a participant's baseline performance and their performance during and after the programme.

Several other issues pertaining to the research design provide limitations to the current study. Previous research recommends the collection of baseline data until a stable baseline has been established (Kazdin, 2012). In this case, the researcher received short notice of the programme's start date (i.e., six weeks). There was a limited amount of time in which to collect baseline data and the intervention started before a stable baseline could be established. The rationale for not including more assessments during the six-week baseline phase was to minimise participant burden and retain participants. The short pre-treatment phase also precluded the use of a nonconcurrent multiple-baseline-across-subjects design. In a nonconcurrent multiple baseline design, the baseline for each participant begins at a different point in time and treatment is staggered across baselines of different lengths rather than across time (Carr, 2005). Given these limitations, changes in the dependent measure resulting from exposure to baseline conditions cannot be ruled out. Moreover, it is unclear whether changes in baseline functioning occurred as a result of treatment or extraneous variables.

Research also suggests a minimum of three assessments be carried out in each phase (Tate et al., 2008). Although this suggestion was adhered to for the pretreatment, treatment, and posttreatment phase, only one assessment was able to be carried out at

follow-up. The limited amount of follow-up data was due to the programme being run again, with the same participants, and the ethical issues of withholding treatment to collect further data. Therefore, follow-up data for the PACS could not be averaged and compared to data from other phases in Chapter 6. Without further follow-up data, it is not possible to determine whether any treatment gains were maintained over time.

Finally, the measures used in the current studies posed a number of limitations. They included ceiling effects and a limited amount of psychometric data. The participants scored highly on the emotion recognition tasks across conditions and did not have the opportunity to express further improvement beyond the items included in the tasks. The ceiling effects observed in the first study may have concealed differences between participants and prevented changes from being observed (Clark-Carter, 2004). In the second study, the PACS was used to assess changes in participants use of emotion regulation strategies. Previous research has indicated promising reliability and validity of the caregiver version of the PACS (Willner, Brace, & Phillips, 2005; Willner et al., 2013). However, further research is needed to examine certain psychometric properties including test-retest reliability of the service-user version. Limited psychometric properties of the measure used prevent definitive conclusions being drawn about the findings of the study.

There were also limitations in the ability to complete the self-report measures. This included disagreement between caregivers and participants and difficulty recalling situations where participants had become angry, sad, or worried. These issues resulted in missing data that made it difficult to compare the caregiver and participant reports.

Implications

The implications of these findings for people who have an ID are that taking part in the Transformers programme results in individuals getting support and learning

useful skills to self-regulate emotions and change their behaviour. Swapping inappropriate emotion regulation strategies such as physical and verbal aggression for more adaptive strategies like breathing exercises can reduce the negative consequences (e.g., injury, legal consequences) that are associated with inappropriate strategies. A reduction in challenging behaviour and the negative consequences that go with it may, in turn, enhance individuals' overall sense of well-being and quality of life.

The second study also employed a distinct way of examining incident reports. Instead of combining all of the incidences of challenging behaviour, the incidents are categorised according to the type of behaviour (i.e., verbal aggressive behaviour, aggressive behaviour towards property, etc.). To the best of this authors knowledge, very few, if any, studies concerned with the effectiveness of an intervention on challenging behaviour in adults who have an ID have looked at the different types of challenging behaviour. Research has shown that different types of behaviour can have a different prevalence rate and people may show more than one form of challenging behaviour (Emerson & Einfeld, 2011). Moreover, some types of challenging behaviour have the potential to elicit more serious, negative consequences (e.g., physical aggression can result in physical injury). By categorising incidences of challenging behaviour, the researchers could investigate whether the Transformers programme led to changes in the type and intensity of challenging behaviour as well as the rate.

These studies represents an initial step in exploring a new group-based therapy programme. The results provide preliminary evidence for the effectiveness of the intervention and rationale for a large-scale intervention study. A larger study could apply the methods and procedures used in the current studies with some modifications to refine and improve the research. The use of single-case design is appropriate given the applied nature of the research, but data collection tools used in the current studies

can be developed further to improve the data integrity. Thus, the outcomes of these studies can inform subsequent efforts to generate stronger evidence for the benefits of the Transformers programme.

While the implications of these findings support the continued use of the Transformers programme, the results also suggest areas for improvement. The results indicated that participants used particular strategies more than others. First, strategies that were rarely used could be removed from the programme leaving more time to focus on other material. Second, some participants demonstrated larger treatment gains than other participants and treatment gains were not always maintained at follow-up. It is possible that lengthening the programme would provide more time for repetition of material and practice of new skills which could help participants to retain the new information and apply the skills outside of the group (Paxon, 1995). Therefore, the findings of the current studies can be used to effect changes that can help to advance and refine the programme to provide optimal outcomes.

It is important that the justification for implementing the Transformers programme is based on scientific evidence as well as professional opinion. This evaluation attempted to bridge the gap between research and practice by scientifically investigating whether the Transformers programme was related to preferred outcomes for the individuals that completed it. On the basis of these studies results, it is reasonable to state that the Transformers programme improved participants' abilities to manage distress and reduced the frequency and severity of challenging behaviour.

As at October 6th, 2014, the manuscript titled *Transformers: An Emotion Regulation Programme for People who have an Intellectual Disability* (Chapter 3) has been accepted for publication in the Journal of Intellectual Disabilities and Offending Behaviour. The manuscript titled *An Evaluation of an Emotion Regulation Programme*

for People who have an Intellectual Disability (Chapter 6) has been published in the International Journal of Therapeutic Communities.

Future Research

Future research should use a controlled trial to provide further support for the effectiveness of the Transformers programme. While randomised controlled trials are considered the “gold standard” method for evaluating treatment outcomes (Hodgson, Bushe, & Hunter, 2007), ethical and practical issues can preclude their use with people who have an ID. A *treatment-as-usual* controlled condition—where participants receive usual care (e.g., individual psychotherapy)—would provide a suitable alternative to a randomised controlled trial and improve internal validity (Kring, Johnson, Davison, & Neale, 2010; Pignotti & Thyer, 2009). Treatment-as-usual controlled trials can also answer the question of whether the Transformers programme is more effective than the treatment individuals in the ID service would usually receive for the same problem (Pignotti & Thyer, 2009).

In terms of methodology, recommendations for future research include that modifications, revisions, and refinements be made to the measures used in the current studies. For instance, future research should increase the difficulty of the emotion recognition task to avoid ceiling effects. Further research is also needed to investigate the reliability and validity of both the caregiver and service-user versions of the Profile of Anger Coping Skills (PACS). Developing these measures and investigating their psychometric properties would improve the interpretability of results of studies that utilise them and support their continued use with people who have an ID.

The researchers also suggest that the use of self-report measures be followed up with interviews to incorporate qualitative and quantitative research techniques.

Researchers and programme facilitators need to know why participants tended to use

some strategies over others and qualitative methods can obtain this information.

Participant and caregiver accounts may also highlight any positive or negative unexpected outcomes of the group and barriers to change. Hence, qualitative methods are suggested as a useful adjunct to provide more in-depth, detailed information.

Further research should also begin a component analysis to identify which elements of the Transformers programme are responsible for behaviour change (Ward-Horner & Sturmey, 2010). To perform a component analysis, researchers must evaluate the independent effects of cognitive treatment and behavioural treatment and the effects of cognitive-behaviour treatment combined. If either of the components did not appear to be directly benefitting participants then it could be eliminated to enhance the social validity and efficiency of the programme.

Personal Reflections

Prior to embarking on this research journey, I had not been exposed to working with people who have an ID. The journey for this research sparked my interest in this area and taught me useful knowledge about the subtleties of working with individuals who have an ID. Although some changes need to be made to work effectively with people who have an ID, it is important to remember that these people are adults—with adult feelings, needs, and experiences and need to be treated accordingly. The knowledge, understanding, and skills I have developed through my interactions with people who have an ID are invaluable and will be directly transferrable to other populations that I will work with as a clinical psychologist.

This research proved to be very rewarding. I consider myself very lucky to have enjoyed the opportunity to work with the participants who were involved in this research and have fond memories of each of them. Their integrity and willingness to discuss sensitive topics with me was humbling and very much appreciated. It is hoped

that the participants' experiences of being involved in research were also positive and that they felt listened to and respected throughout the process.

Lastly, in years gone by there has been some disinterest and reluctance from psychologists to work with people who have an ID (Taylor, Lindsay, & Willner, 2008). However, the vulnerability of people who have an ID to mental health problems indicates a real need for mental health professionals with experience in this area who are willing to engage with them. It is hoped that writing this thesis will facilitate interest, further discussion, and enquiry into emotion regulation in people who have an ID and the broader area of ID research.

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Appendices

Appendix 1: Information sheet for Welfare Guardians



MASSEY UNIVERSITY
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TE KURA PŪKENGĀ TANGATA

An Evaluation of an Emotion Regulation Programme for People with an Intellectual Disability

Information Sheet for Welfare Guardians

The researcher

My name is Jenna McWilliams and I am a student enrolled in the Doctor of Clinical Psychology at Massey University of Wellington. As part of this programme I am carrying out a research project which will form my thesis. The supervisors for this project are Dr Ian de Terte and Professor Janet Leatham who are both from the School of Psychology, Massey University, Wellington.

The Research Project

The project I am undertaking is looking at emotion recognition and regulation in people with an intellectual disability. Emotion regulation difficulties can manifest as disruptive behaviours that can have consequences for the individuals involved. The purpose of this research is to evaluate the programme which provides strategies to help people with an intellectual disability cope with their emotions. If this programme is found to be effective then it could be introduced on a wider scale to help others.

I am inviting men and women with an intellectual disability to participate in this study. I will explain the study and what is involved to the potential participants and they will have time to discuss it with a Care Manager or Clinical Psychologist before deciding whether or not they would like to be involved. A Care Manager or Clinical Psychologist will be present when the participant gives their consent.

If the participants choose not to be involved in the study, they can still be part of the emotion regulation programme. The participants have been informed that they can change their mind about being involved in the study at any time without anything bad happening to them.

What is involved?

In the first task participants will be shown photos of a person displaying an emotion and asked which emotion they think the person is feeling. In another task the participants will be read a short story and asked how they would feel if the story happened to them. Participants will also be asked to answer questions about how they cope with negative emotions.

The participants will meet with me 10 different times over 9 months to complete the questionnaires. The questions will take about 30 minutes to answer each time. The interviews may be tiring for participants, but will not be physically harmful.



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What happens to the information?

The information collected will form the basis of my research project and will be reported on an anonymous basis. It will not be possible for participants to be identified personally. The information will be kept confidential and answers to the questions will not be seen by anyone other than me, and my supervisors. The data will be stored in a locked filing cabinet and will be kept for five years after the study has ended before being destroyed. It is anticipated that this research will provide the basis for articles submitted to academic journals and a copy of the completed thesis will be made available in the University Library.

Participant's Rights

Individuals are under no obligation to accept this invitation. If an individual decides to participate, they have the right to:

- decline to answer any particular question;
- withdraw from the study without question at any time, without explanation, before the data is analysed;
- ask any questions about the study at any time during participation;
- provide information on the understanding that their name will not be used unless they give permission to the researcher;
- be given access to a summary of the project findings when it is concluded.

This project has been reviewed and approved by the Health and Disability Ethics Committee: Application CEN/12/EXP/034

Contact Details

If you have any questions about the project, you are invited to contact me or my supervisor.

Researcher:
Jenna McWilliams
(04) 801 5799 ext. 62528
jenna.mcwilliams@hotmail.co.nz

Supervisor:
Dr Ian de Terte
School of Psychology, Massey University, Wellington
i.deterte@massey.ac.nz

Appendix 2: Consent form for Welfare Guardians



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Welfare Guardian Consent Form

Date:

Welfare Guardian Name:

Participant Name:

Contact phone number:

Address:
.....
.....

- The welfare guardian has received a copy of the information sheet
- The details of the study have been explained to the welfare guardian and any questions have been answered
- The welfare guardian has given their verbal consent for the participant to take part in the study

Appendix 3: Explanation of Information Sheet for Participants

An Evaluation of an Emotion Regulation Programme for People with an Intellectual Disability

Explanation of Information Sheet for Participants

I am carrying out a research project at University. I would like to invite you to take part in my research project. Before you decide whether or not you would like to take part in the project, I will tell you a bit about it.

- The study is about emotions. We want to learn about how people understand and manage emotions.
- I have made up a test to find out about how people recognise emotions
- Before I use the questionnaire in my study, I need to
 - make sure people can understand the instructions that I give them *and*
 - find out how long it takes people to answer all of the questions
- If you want to take part in the research, I will ask you some questions. *If you find some of the questions hard, that is OK. I just want you to try your best. I will write down your answers to help me remember what you say.*
- It will take about 15 minutes.
- You might feel tired because you will have to think quite a bit when I ask you questions.
- It is up to you whether you want to take part in the research
 - You can say YES
 - You can say NO
- Even if you say YES now, you can stop being part of the study at any time. *If you decide not to take part in the study or pull out at any time, nothing bad will happen to you.*
- If you change your mind you can tell me
- *If you have any questions, you can ask me.*
- Any information we collect about you will be private. *If I need to talk with anyone about this information then I will try to talk to you first.*
- What is said in the questions and answers will be used for a report. *The report will tell people what I find out about emotion. Other people will be able to read the report but you will not be identified. That means your name will not be in the report and people will not know that the answers came from you.*

Do you have any questions?

If you do think of any questions, feel free to ask me.

Now that we have talked about the research project and you have had the chance to ask questions, it your chance to decide whether or not you would like to take part in the project.

This is a consent form. It says that:

- Jenna has talked to me to help me understand what the research is about.
- My questions about this research have been answered
- I do not have to do the research. It is my choice to take part.
- I can stop being in the research at any time without anything bad happening to me.

If you agree with these sentences and would like to take part in the study then tick this box (point to the appropriate box). If you do not want to take part in the study then tick this box (point to the appropriate box).

Note: *If the potential participant is unable to read then say something like “If you agree with these sentences and would like to take part in the study then say ‘I would like to take part in this study’. If you do not want to take part in the study then say ‘I do not want to take part in this study’.*

Appendix 4: Information sheet for Participants



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An Evaluation of an Emotion Regulation Programme for People with an Intellectual Disability

Information Sheet for Participants

- The study is about emotions. We want to learn about how people understand and manage emotions
- If you want to take part in the research, we will ask you some questions and we will write down your answers
- Each time we ask you questions it will take about 30 minutes
- I will need to visit with you about 10 different times to ask questions
- You might feel tired because you will have to think quite a bit when we ask you questions
- It is up to you whether you want to take part in the research
 - You can say YES
 - You can say NO
- Even if you say YES now, you can stop being part of the study at any time
- If you change your mind
 - You can tell Jenna
 - You can tell your care manager
- If you have any questions
 - you can phone Jenna
 - your care manager will help you
- We will need to collect some information about you from the services you have been involved with, but it will not identify you
- Any information we collect about you will be private. We will not talk to anyone about you without asking you first
- We will also ask your care manager some questions about how you are doing
- What is said in the questions and answers will be used for a report
- Jenna will visit after the research is finished and tell you what she found out about emotion

Appendix 5: Consent Form for Participants



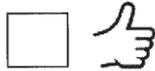
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An Evaluation of an Emotion Regulation Programme for People with an Intellectual Disability

Participant Consent Form

- Jenna has talked to me to help me understand what the research is about.
- I do not have to do the research. It is my choice to take part.
- I can stop being in the research at any time without anything bad happening to me.

My decision is:



I **DO** want to take part in the study



I **DO NOT** want to take part in the study

Signature:

Date:

Full Name (Printed):

The participant has given their verbal consent instead.

Statement of Investigator

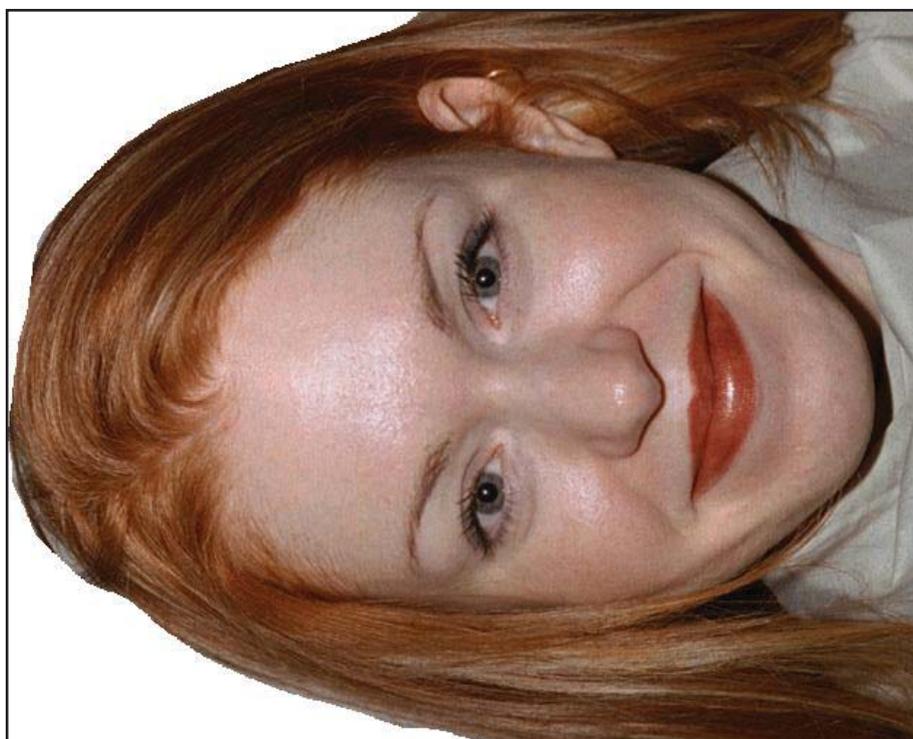
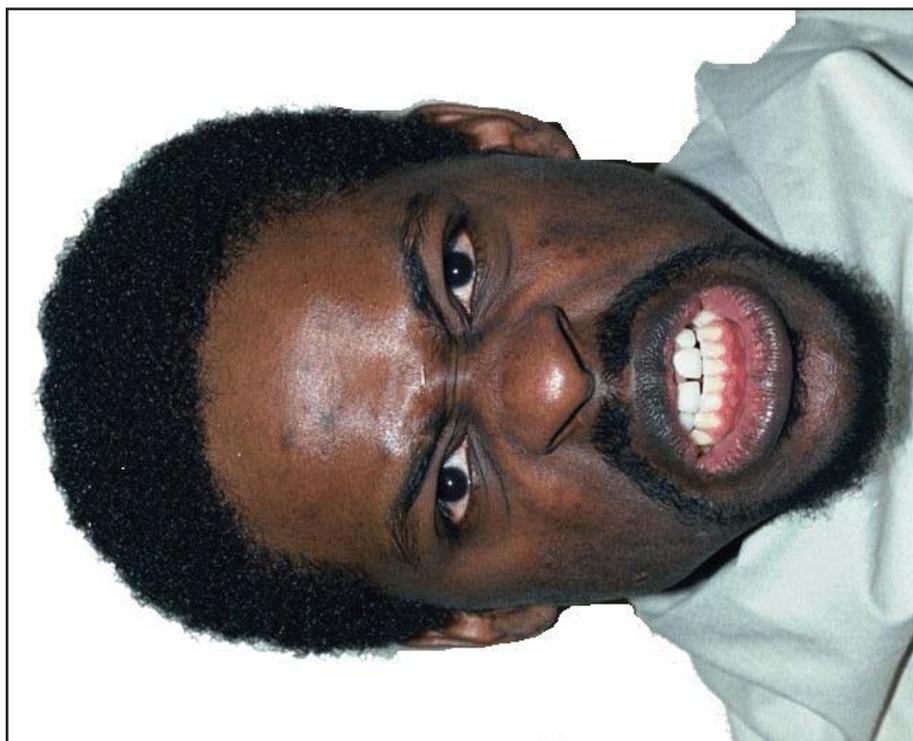
The research project has been carefully explained to the participant. The participant has been made aware of the benefits and demands of the research and has been given the opportunity to ask questions. All questions have been answered to the satisfaction of the participant. I certify that, to the best of my knowledge, the participant understands what is involved in this study.

Signature:

Date:

Full Name – Printed:

Appendix 6: Example of Photo Stimuli Used in Recognition of Emotion in Faces Task



Appendix 7: Story Stimuli used in Recognition of Emotion in Stories Task

Story Stimuli

Happy

1. You liked swimming and your friend told you that she was taking you swimming today.
2. Someone gave you a present that you had always wanted.
3. It was your birthday. You had nice food and got lots of presents.
4. You worked really hard on a picture and entered it in a competition. Your picture won a prize.
5. You haven't seen your friend in a long time. You invite your friend over and they come to your house.
6. You went shopping, and your friend brought you lunch.

Disgust

1. You met someone who smelled as if they hadn't had a wash for a couple of weeks.
2. You took a bite of a nice red apple and found that it was going rotten inside.
3. Someone threw up on you during lunch.
4. You went to a movie with a friend. In the movie, people were eating bugs and worms.
5. You took a bite of your sandwich and then saw that there was a fly in it.
6. You saw someone eating ice cream with tomato sauce and mustard on it.

Sadness

1. Your pet dog died.
2. Your best friend moved away to another town.
3. You lost your favourite jersey.
4. Everyone got presents on Christmas day, except you.
5. You spent a long time drawing a picture and then entered it in a competition. Your drawing didn't get picked for the prize.
6. You had a pet kitten. The kitten went missing and you couldn't find it anywhere.

Anger

1. You told someone not to do something but they went ahead and did it anyway.
2. You were trying to tell a friend about something exciting but someone kept interrupting.
3. You were waiting in line and a person cut in line in front of you without asking.
4. You like to play the Playstation but you can't play it anymore because someone broke it on purpose.
5. You were playing with a ball. You let someone join in and they threw the ball away over a very high fence.
6. You asked someone not to touch something, but they did and it broke.

Surprise

1. You opened a shoe box that you thought was empty and a bird flew out of it.

2. You were going for a walk and your friend jumped out from behind a tree and said “Boo!”
3. You went to bed in your own bed and when you woke up you were on the couch.
4. It was summertime, and when you went to bed, the weather was warm. When you woke up, it was snowing.
5. You saw your friend in the morning and they had brown hair. You saw your friend again in the afternoon and their hair was pink.
6. You walked past a dog and the dog talked to you.

Fear

1. You did not like the dark and one night when you were at home on your own all the lights suddenly went out.
2. You opened your back door and saw a big, fierce dog jumping up at you.
3. You were walking down the street when a big dog started growling and following you.
4. It was dark and you saw a shadow outside your house. It looked like a person with his hand about to come in through the window.
5. You had a bad dream and in it someone was chasing you.
6. You were at the zoo and a bear escaped from its cage.

Happy

Sad

Afraid

Angry

Disgusted

Surprised

Appendix 9: Task Instructions for Recognition of Facial Emotion Task

Recognition of Facial Emotion Task

Task Information

The primary aim of this task is to assess the recognition of facial emotion in people with an intellectual disability. The coloured photographs used in the task were taken from the NimStim set of Facial Expressions (Tottenham et al., 2009). Each photograph shows an actor displaying one of six basic emotions: happy, sad, afraid, angry, disgusted, and surprised (an example photograph is provided below). Eighteen different actors of varying age and race feature in the photos.

Administration Guidelines

- Photographs will be presented one at a time to participants using a computer screen
- Participants will be asked to identify which emotion the person in the photo is feeling
- The participant can give their answer verbally or indicate their answer using the prompt card provided
- The participant's caregiver may be present for the administration of this test. The caregiver will be asked to remain quiet and not to offer any form of help to the participant. The caregiver will be seated behind the participant so that they are out of the participant's field of vision.
- A prompt card listing the 6 basic emotions will be placed in front of the participant to remind them of the possible responses

Scoring Procedure

A score of 1 is awarded for each correct answer. No score is awarded for incorrect answers. The total score is calculated by adding the scores together. Total scores will range from 0-6.

Recognition of Facial Emotion Task

Instructions to Participants

- *“I am going to show you six different photographs, one at a time. They will be displayed on the computer screen in front of you. First you will see a cross appear on the screen. I would like you to look at this cross until a photo appears on the screen. The photographs show people feeling different emotions.*
- *I would like you to tell me if you think the person in the photograph is feeling happy, sad, afraid, angry, disgusted, or surprised. Please choose the one emotion that you think best describes how the person is feeling and say your answer out loud. These emotions are also listed on this card”*
- Pointing to the prompt sheet say *“You can use this card to help you remember the different emotions or you can ask me tell you them again”*
- *“You might find some emotions harder to identify than others. Just try your best. I will write down your answers to help me remember what you have said. Do you have any questions?”*
- *“Let’s try a practice one”. Display the sample photo. “What emotion is this person feeling?”*
- *“Okay let’s try another one.” Show the first photo and ask “How is this person feeling?”*
- Show each photograph from the set, in turn.
- Do not provide feedback. If the client asks for feedback say something like *“I can see you are trying very hard”*
- If the client asks for help, say *“Just try your best”*
- If the client interrupts during the story say something like *“Remember to wait until I have finished reading the story before you answer”*
- If the client provides two answers say *“Remember to choose the one answer that you think best describes the way the person is feeling”*

Appendix 10: Score Sheet for Emotion Recognition Tasks

Emotion Recognition Tasks

Stimuli Set A

Participant Name:

Assessment Point:

Date:

Recognition of Emotion in Faces Task

Item	Response						Score	
1	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1
2	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1
3	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1
4	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1
5	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1
6	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1
7	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1
8	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1
9	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1
10	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1
11	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1
12	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1
Total Score							/12	

Recognition of Emotion in Stories Task

Sample Item: Someone damaged your favourite coat.

1. You liked swimming and your friend told you that she was taking you swimming today.
2. You were trying to tell a friend about something exciting but someone kept interrupting.
3. You met someone who smelled as if they hadn't had a wash for a couple of weeks.
4. Your pet dog died.
5. It was dark and you saw a shadow outside your house. It looked like a person with his hand about to come in through the window.
6. You were going for a walk and your friend jumped out from behind a tree and said "Boo!"
7. You were waiting in line and a person cut in line in front of you without asking.
8. Your best friend moved away to another town.
9. Someone threw up on you during lunch.
10. Someone gave you a present that you had always wanted.
11. You went to bed in your own bed and when you woke up you were on the couch.
12. You were walking down the street when a big dog started growling and following you.

Item	Response							Score	
1	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1	
2	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1	
3	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1	
4	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1	
5	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1	
6	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1	
7	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1	
8	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1	
9	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1	
10	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1	
11	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1	
12	Happy	Sad	Afraid	Angry	Disgusted	Surprised	0	1	
Total Score							/12		

Appendix 11: Task Instructions for Recognition of Emotion in Stories Task

Recognition of Emotion in Stories

Task Information

The primary aim of this task is to assess the ability of people with intellectual disabilities to recognise emotion in affective stories. The emotional stories were taken from the Story stimuli developed by Owen, Browning, and Jones (2011). Each story describes a scenario that would elicit emotion in the person it happened to. The stories target the emotions: happy, sad, afraid, angry, disgusted, and surprised.

Administration Guidelines

- Stories will be read, one at a time, to participants
- Participants will be asked to identify which emotion they would feel if the story happened to them
- A prompt card listing the 6 emotions (happy, sad, afraid, angry, disgusted, and surprised) will be placed in front of the participant to remind them of the possible responses
- The participant can give their answer verbally
- Participant's answers can be recorded on the next page
- Each story can be repeated once. Repeat the story if the client asks for it to be repeated.
- If 15 seconds has passed and the client has not provided an answer or they say 'I don't know', remind them to try their best and ask if they would like the story to be repeated one more time
- The participant's caregiver may be present for the administration of this test. The caregiver will be asked to remain quiet and not to offer any form of help to the participant. The caregiver will be seated behind the participant, so that they are out of the participant's field of vision.

Scoring Procedure

A score of 1 is awarded for each correct answer. No score is awarded for incorrect answers. The total score is calculated by adding the scores together. Total scores will range from 0-6.

Recognition of Emotion in Stories

Instructions to Participants

- *“Next, I am going to show you six different stories, one at a time. They will be displayed on the computer screen in front of you. Like before, you will see a cross appear on the screen. I would like you to look at this cross until a short story appears on the screen. I will read the story out loud and when I have finished reading each story I will ask you to tell me how you would feel if the story happened to you.”*
- *“Would you feel happy, sad, afraid, angry, disgusted, or surprised? Please choose the one emotion that you think best describes how the person is feeling and say your answer out loud. These emotions are also listed on this card”* (indicate prompt card).
- Pointing to the prompt card say *“You can use this card to remind you of the different emotions or you can ask me to repeat the different emotions”*
- *You might find some emotions harder to identify than others. Just try your best. Do you have any questions?*
- *“Let’s try a practice one”*. Read the sample story. Do not provide feedback.
- *“Okay let’s try another one.”* Read the first story and then ask *“How would this make you feel?”*
- Read each story in turn.
- Do not provide feedback. If the client asks for feedback say something like *“I can see you are trying very hard”*
- If the client asks for help, say *“Just try your best”*
- If the client interrupts during the story say something like *“Remember to wait until I have finished reading the story before you answer”*
- If the client provides two answers say *“Remember to choose the one answer that you think best describes the way you would feel if the story happened to you”*

Appendix 12: Information Sheet for Caregivers



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An Evaluation of an Emotion Regulation Programme for People with an Intellectual Disability

Information Sheet for Care Managers/Caregivers

The researcher

My name is Jenna McWilliams and I am a student enrolled in the Doctor of Clinical Psychology at Massey University of Wellington. As part of this programme I am carrying out a research project which will form my thesis. The supervisors for this project are Dr Ian de Terte and Professor Janet Leatham who are both from the School of Psychology, Massey University, Wellington.

The Research Project

The project I am undertaking is looking at emotion recognition and regulation in people with an intellectual disability. I am inviting the Care Managers or Caregivers of men and women with an intellectual disability to participate in this study.

What is involved?

Participants will be asked to complete a questionnaire about how a particular client copes with emotions. If you agree to participate you will be asked to meet with me about ten different times to complete the questionnaire. The questionnaire will take about 15 minutes to complete each time.

What happens to the information?

The information collected will form the basis of my research project. It will not be possible for you to be identified personally and all identifiable information will be removed. The information will be kept confidential and your answers will not be seen by anyone other than me and my supervisors. The data will be stored in a locked filing cabinet and will be kept for five years after the study has ended before being destroyed. It is anticipated that this research will provide the basis for articles submitted to academic journals and a copy of the completed thesis will be made available in the University Library.

Participant's Rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study without question at any time, without explanation, before the data is analysed;
- ask any questions about the study at any time during participation;

Appendix 13: Consent Form for Caregivers



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An Evaluation of an Emotion Regulation Programme for People with an Intellectual Disability

Participant Consent Form for Caregivers

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

I agree to participate in this study under the conditions set out in the information sheet.

Signature: Date:

Full Name (Printed):

Appendix 14: Adapted Version of the Profile of Anger Coping Skills

The Profile of anger coping skills (PACS)

Guidelines for completing the PACS (Adapted Key Worker/Carer version)

The PACS should be completed in interviews with the Key Worker/Carer. The Key Worker/Carer must be assessed **before** the service user.

The purpose of this form is to obtain information relating to the client's use of coping strategies, before during, and after attending the group. In order to do this you must first identify three situations in which the client gets quite or very angry, sad, and worried on *at least a weekly basis*. You should identify suitable situations in discussion with the client's Key Worker/Carer. The reason for the emphasis on frequent situations is that, in order to assess the client's current use of coping strategies in particular situations, you need to ensure that the situation has occurred recently. Try to identify situations where the client has been rated as 'extremely angry', 'extremely sad', or 'extremely worried' (a score of 3), or if this is not possible, a rating of 'quite angry', 'quite sad', or 'quite worried' (a score of 2), and clarify with the person rating that the frequency with which each situation occurs is at least weekly. If it is not possible to identify situations that meet these criteria, then it is more important to use situations where anger, sadness, or worry occurs frequently even if these are not the situations where the emotion is most intense. Otherwise, when it comes to the post-group assessment, the behaviour you are assessing may be one that the informant has not seen recently – perhaps since before the group began.

If there is more than one situation that makes the client very angry, very sad, or very worried on a frequent basis, you will need to establish with the rater which of these situations is the most significant for the client. The three situations should then be entered onto the 'Profile of Anger Coping Skills' form.

Taking each situation in turn, ask the rater to estimate how often each of the coping strategies listed in the PACS is used by the client, placing the 'frequency scale' (below) in front of the rater as a reminder of the scoring system. Continually remind the rater of the specific situation they should be thinking about, to ensure they remain focused. Circle each answer that is given.

You will often need to explain the coping strategies in more detail. There are guidance notes later in this section to help you do this.

Add up the scores across the three situations (i.e. each row) to give a total score for the client's usage of each coping strategy. Determine the total score for each situation by adding all of the coping strategies together (i.e. add up each column). The overall PACS score is these three scores added together. These scores can be used to compare use of coping strategies before and after the group.

For repeat assessments, use the same scenarios as before. If one of the situations no longer occurs (eg. it relates to a specific person who is no longer present) then consider using a broadly similar situation (eg. a difficult relationship with a different individual).

Frequency scale for completion of Profile of Anger

Coping Skills

0 = Never

1 = Occasionally (= less than 50%)

2 = Usually (= more than 50%)

3 = Always

Explaining the PACS to key-workers and carers

Eliciting situations

The description of each anger-provoking situation should provide enough information to be clear to a different interviewer, in case the pre- and post-group assessments are conducted by different people. The situations selected should usually be specific, rather than generalised.

Coping terms require some explanation to clarify their meaning for respondents.

Relax

The act of using relaxation skills to reduce anger (e.g., progressive muscle relaxation, stretching, 'Sole of the Feet' exercise).

Wisemind

Making wise decisions and thinking about the consequences of our actions for others and ourselves.

Exercise

Changing your negative feelings by exercising and changing how you feel in your body.

Doing something fun

Doing something enjoyable to change our negative feelings.

Breathing

Slow your breathing to make you feel calmer and more relaxed.

Distraction

Do something to take your mind off your problem or the thing that is making you angry, sad, or worried.

Taking yourself away

Taking yourself away from a distressing situation to avoid an aggressive confrontation.

Doing a Chain

Using a chain analysis worksheet to think about the problem situation in more detail (the lead-up, the situation, consequences and next steps) and learn from this

Date:

Care Manager/Caregiver Name:

Participant Name:

PROFILE OF ANGER COPING SKILLS (Caregiver version)
Identify three situations where the client has difficulty managing his/her emotions. The situation should occur at least weekly.
Situation 1 – Anger (please specify)
Situation 2 – Sadness (please specify)
Situation 3 – Worry (please specify)

How often does the client use each of the following skills to cope successfully with each of these 3 situations?

		Never	Occasionally	Frequently	Always
Scenario 1	Relaxation	0	1	2	3
Angry	Wisemind	0	1	2	3
	Exercise	0	1	2	3
	Doing something fun	0	1	2	3
	Breathing	0	1	2	3
	Distraction	0	1	2	3
	Taking yourself away	0	1	2	3
	Doing a chain	0	1	2	3
Scenario 2	Relaxation	0	1	2	3
Sad	Wisemind	0	1	2	3
	Exercise	0	1	2	3
	Doing something fun	0	1	2	3
	Breathing	0	1	2	3
	Distraction	0	1	2	3
	Taking yourself away	0	1	2	3
	Doing a chain	0	1	2	3
Scenario 3	Relaxation	0	1	2	3
Worried	Wisemind	0	1	2	3
	Exercise	0	1	2	3
	Doing something fun	0	1	2	3
	Breathing	0	1	2	3
	Distraction	0	1	2	3
	Taking yourself away	0	1	2	3
	Doing a chain	0	1	2	3

Guidelines for completing the PACS (Service user version)

General

The service user version of the PACS is essential the same as the Key Worker/Carer version. The differences are:

- (a) The scenarios are provided rather than generated by the service user;
- (b) Each scenario is explored with the service user to engage attention to it;
- (c) A simpler 3-point rating scale is used
- (d) More care is needed to ensure that the service user understands the questions about coping skills.

Preparatory Considerations

You might find it is appropriate to illustrate the questions through varying means e.g. modelling. Whilst this is encouraged, caution should be taken not to compromise the central concept of the question.

Administration

a) The scenarios used are those provided by the service user's day service key-worker. Therefore, the service user's completion of the PACS must follow the Key Worker/Carers.

b) In preparing the respondent to complete the questions, initial work is needed around each of the three scenarios identified as inducing anger, sadness, or worry. Each scenario should be discussed in detail with the respondent in order for them to access the emotion experienced in this situation. To do this, questions may be asked about the last time the scenario arose. What happened, how it started, who was involved, and what happened next, could be explored in some detail.

Ask also:

"How angry did this make you feel?"

0 1 2

Not at all A little angry Very angry

These response options are presented on a horizontal page and show blocks of increasing size, together with their descriptors. Repeat this exercise for each scenario using the relevant emotion prior to asking about coping skills.

c) The rating scale for use of each coping skill is:

0 = No; 1 = Sometimes; 2 = Always.

Each question should be asked in two parts. First, the participant is asked to choose between a 'yes' and 'no' answer. If the answer is 'no' score 0 for that item. If the answer is 'yes' ask if that is 'sometimes' or 'always', and record the score as appropriate. Some respondents will be able to use the three-point scale from the start, others might learn the 'rules' as you proceed.

d) Use the prompts provided until you are fairly sure that the service user understands what you are getting at. Tick to record the prompts that were used.

Date:

Care Manager/Caregiver Name:

Participant Name:

PROFILE OF ANGER COPING SKILLS (Service user version)			
List the three situations identified by the service user's Key Worker/Carer where the client has difficulty managing his/her emotions.			
Situation 1 – Anger (please specify)			
How angry did this make you feel?	<i>0 = Not at all</i>	<i>1 = A little angry</i>	<i>2 = Very angry</i>
Situation 2 – Sadness (please specify)			
How sad did this make you feel?	<i>0 = Not at all</i>	<i>1 = A little sad</i>	<i>2 = Very sad</i>
Situation 3 - Worry (please specify)			
How worried did this make you feel?	<i>0 = Not at all</i>	<i>1 = A little worried</i>	<i>2 = Very worried</i>

	Anger			Sadness			Worry		
	N	S	A	N	S	A	N	S	A
When thinking about (situation 1/2/3) did you try to ...									
1. Relax <i>Did you try to calm your body by stretching your muscles? Did you listen to gentle/peaceful/comforting music? Did you imagine yourself somewhere different like on a beach? Did you try to calm yourself by staying still?</i>	0	1	2	0	1	2	0	1	2
2. Wisemind <i>Did you think about the consequences for yourself and others? Did you make a wise decision? Did you think before you acted? Did you go down the good path?</i>	0	1	2	0	1	2	0	1	2
3. Exercise <i>Did you change your feelings by doing some exercise? Did you do some exercise to feel better?</i>	0	1	2	0	1	2	0	1	2
4. Do Something fun <i>Did you take your mind off your feelings by doing something fun? Did you try to feel better by doing something you enjoy?</i>	0	1	2	0	1	2	0	1	2
5. Breathing <i>Did you slow down your breathing? Did you try to calm yourself with your breathing?</i>	0	1	2	0	1	2	0	1	2
6. Distraction <i>Did you try to take your mind off your feelings by doing something fun? Did you do something to take your mind off what was upsetting you?</i>	0	1	2	0	1	2	0	1	2
7. Taking yourself away <i>Did you take yourself away from the situation that was upsetting you?</i>	0	1	2	0	1	2	0	1	2
8. Doing a chain <i>Did you do a chain? Did you think carefully about the problem (what lead up to the problem, the problem itself, the consequences of the problem, and what steps to take next)?</i>	0	1	2	0	1	2	0	1	2

Very

A little

Not at all

Always

Sometimes

No